EXPLORING LEGAL CONSCIOUSNESS:
EXPERIENCES OF FAMILIES SEEKING FUNDING FOR ASSISTIVE
TECHNOLOGIES FOR CHILDREN WITH DISABILITIES

A dissertation presented

by

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ABSTRACT OF DISSERTATION

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Abstract

This exploratory study examined parents’ experiences with the law as they obtained funding for speech generating devices for their communicatively disabled children, either through public health insurance, private health insurance or a public school. The study explored how parents engaged with the law and how their experiences and perceptions about the law compared to the formal law. This research was based on sociolegal theory, particularly the concept of legal consciousness, which examines how people think and act in relation to the law as a consequence of social interactions, and analyzes how law in action compares with the formal law. Sociolegal theory broadens the definition of law to include “the meanings, sources of authority, and cultural practices” (Ewick and Silbey, 1998, p.22) as well as the formal law.

Similar to other sociolegal research, this study collected personal narratives of law using grounded theory methods to identify themes within those narratives. The narratives revealed that while parents expressed varieties of legal consciousness, there was one overarching theme: the law provided a framework for parents to envision rights, discuss rights and claim rights. While few parents invoked formal legal mechanisms to solve grievances, the law, its language and its intent were constantly negotiated in their everyday lives as they advocated for their children. Each parent persistently advocated for their children by interacting with a variety of people and most parents consistently interacted with other parents on multiple levels. These experiences shaped their perceptions about the law and influenced some very important decisions that parents made. Based on interactions with people, parents made decisions about whether to access their health insurance or the public school for funding speech generating devices, seek an independent assessment, ask the public school to pay for an independent assessment, obtain private therapy through
health insurance, apply for benefits through a public health insurance program, meet with teachers to discuss their child’s Individualized Education Program, or invoke the formal law. Therefore, the law created a rights consciousness among parents which empowered them to acknowledge and validate the notion of rights and entitlements.
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Introduction

Thesis and Research Questions

Families may face multiple challenges as they participate in the funding process for speech generating devices (SGDs) for their children whose speech is not functional for their daily living needs. These electronic devices offer synthesized and/or digitized speech output, enabling a person to communicate. While health and education laws and regulations establish the rights that children have for obtaining funding for SGDs for their children, these laws and regulations form a complex maze of policies and procedures which may be difficult for parents to navigate and have an impact on their ability to assert their rights as well as those of their children.

During the process of obtaining funding for SGDs, families will interact with many different people, within and across agencies. These individuals may have varying degrees of experience with assistive technologies. Moreover, they may have varying degrees of knowledge about health insurance and special education laws, different perceptions of a child’s assistive technology rights and entitlements and different perceptions of a child’s needs and skills. The process may be further complicated by differences in languages and cultural values among families and practitioners (Goldbart and Marshall, 2004; Huer and Parette, 2002; Kemp and Parette, 2000; Parette and Angelo, 1996). These challenges can lead to incomplete, inaccurate, or misinterpreted information, as well as disputes among parties. In turn, funding may be delayed or denied. This process can leave families feeling frustrated, disillusioned, and disempowered, and sometimes without access to helpful technology (Goldbart and Marshall, 2004; McCord and Soto, 2000; Parette and Angelo, 1996).
To examine people’s experience with the law, we need to move beyond the formal law to law in a social context. We need to shift our focus from law as a static process to law as a dynamic process which evolves as people experience and talk about the law in their daily lives, during commonplace interactions and within relationships. To explore law in a social context, many sociolegal scholars have analyzed personal narratives (Engel, 1991, Engel and Munger, 2003; Ewick and Silbey, 2003, 1999, 1998, 1995; Felsteiner et al., 1980-1981; Gerstmann, 1999; Greenhouse, 1994; Hull, 2003; Kostiner, 2003; Merry, 1990a,b; Munger, 2003; Nielsen, 2000; Sarat, 1990; Sarat and Kearns, 1998a,b; Seron and Munger, 1996; Yngvesson, 1988). Personal narratives of law are stories that illustrate everyday acts of resistance to power and inequality (Ewick and Sibley, 2003, 1998, 1995, 1992; Engel, 1993, 1991; Engel and Munger, 2003). They describe temporally ordered events and characters situated in the context of a struggle or opposition. Personal narratives are more than just chronicles of events and characters. They are stories that recount how as well as why events occurred. Moreover, narratives of law have a normative component. They describe a person’s beliefs about what they ought to do and how the law should act.

Narrative analysis is a qualitative research method that uses grounded theory principles and inductive analytic strategies (Charmaz, 2000; Glaser and Strauss, 1967). Grounded theory is a middle range theory that attempts to explain the ways that people act and construct meaning. Using grounded theory research strategies, data is collected, defined, coded, and categorized. To enhance understanding, data is compared. This is known as cross-case analysis. As the data is collected and analyzed, the researcher builds a conceptual framework about the phenomenon under study.
This exploratory study used the insights gained through narrative analysis to examine how families thought and acted in relation to the law and explored how their experiences and perceptions about the law compared, if they did, to the positive law. The study collected in-depth personal narratives of law among ten families who obtained funding for SGDS for their school aged, severely communicatively disabled children, 3-17 years of age in four states: Massachusetts, Rhode Island, Pennsylvania and Virginia. It also examined the Individuals with Disabilities Education Act (IDEA), state special education regulations and the types of Medicaid and private health insurance programs operating in these states. The analysis led to a conceptual model of how law on the “street” compared with law on the “books”.

This study explored the following questions: As families obtained funding for SGDs for their children, how did they think and act in relation to the law? What were their experiences and their perceptions about the law and how did they compare, if they did, to their rights and entitlements under the law? In addition, based on what we know about the funding process and the challenges that families may face, this research study explored several other questions to examine how families experienced the law.

- What were families’ perceptions of their legal entitlements? How did these perceptions compare to the positive law and did these perceptions influence their decisions? If so, how?
- How did families obtain their knowledge about the law?
- In what ways did the law help or hinder a family as they went through the funding process?
- Were there similarities and differences among the families in terms of strategies for achieving a positive outcome? What were the barriers? What people and groups were judged helpful (or unhelpful)?
• Were there similarities and differences among the families in terms of their perceptions of rights, how they obtained their knowledge, their experiences with people and institutions, and the outcomes? If so, what were they?
• Did families talk about whether ethnicity, economic status, level of education, gender, and/or primary language affected their experiences? If so, what role did the families perceive these factors played in their experiences? Were there any similarities and differences among families?
• What were the funding outcomes? How did the outcomes compare with the positive law and to the families’ perceptions of their entitlements under the law?

Significance to Law, Policy, and Society

In 1974 Marc Galanter published his seminal work on the contradictions in our legal system (Galanter, 1974). He illustrated the strategic advantages of some parties compared to others, in a system that aims to distribute justice. Since that time, sociolegal scholars have been exploring the gap between the formal institutions of law and the social construction of law – how law operates in everyday life and is embedded in social context. Through sociolegal research we have come to understand that the power of the law is derived not only from its authoritative institutions and rules, but also from how people experience the law, taking into account social and cultural factors. This research has improved our understanding of how people come to think about the law, how they make decisions based on this knowledge and how their perceptions may influence how they exercise their legal rights. This study contributes to sociolegal research by helping us understand the complex and variable interaction of law with culture. Furthermore, it helps us understand when and how the law penetrates everyday life.
Chapter 1

Augmentative and Alternative Communication (AAC) Systems: Meeting the Needs of Children with Communication Impairments

Augmentative and Alternative Communication (AAC) Defined

Augmentative and alternative communication (AAC) systems are modes of communication used by individuals whose speech and/or writing is not functional for their daily living needs.\(^1\) According to the American Speech-Language and Hearing Association (ASHA):

AAC is, foremost, a set of procedures and processes by which an individual's communication skills (i.e., production as well as comprehension) can be maximized for functional and effective communication. It involves supplementing or replacing natural speech and/or writing with aided (e.g., picture communication symbols, line drawings, Blissymbols, and tangible objects) and/or unaided symbols (e.g., manual signs, gestures, and finger spelling.) (ASHA, 2005)

AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication. (ASHA, 2005)

There are two major types of AAC systems: aided and unaided. Unaided systems consist of gestures and facial expressions as well as manual sign. In contrast, aided approaches require some external support and are divided into two groups: non-electronic and electronic. Non-electronic communication aids include communication boards and communication books with some type of graphic symbols, such as pictures or orthographic symbols (e.g. letters, words). Electronic devices offer synthetically produced speech or recorded, digitized speech. These devices are known as *speech generating devices* (SGDs) or *voice output communication aids* (VOCAs) (ASHA, 2005; Beukelman and Mirenda, 2005).

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\(^1\) There are a variety of medical conditions that can cause severe communication impairments. Some causes are congenital, with or without genetic factor(s), while others are acquired. Some are associated with a disease process. Also, traumatic brain injury, stroke, and brain tumors can cause severe communication impairments. For some children, the etiology is unclear. Among children, the two most common congenital conditions include cerebral palsy and autism and related disorders. (Beukelman and Mirenda, 2005; Blomberg and Johnson, 1990; Matas, et al., 1985).
Since 1983, the Food and Drug Administration has classified AAC devices as “powered communication systems” (21 C.F.R. §890.3710). These devices cost as little as $100.00 and as much as $25,000. The most commonly recommended devices range between $3,000-9,000.

An individual with a disability may access a SGD in two primary ways. S/he may directly select targets on a keyboard or touch screen using a part of their body. If the person does not have the motor control to directly select, s/he may use a switch (e.g. keyboard interface) or series of switches to advance a cursor on a screen. Given advancements in technology, an individual can directly access a communication device with their eyes or with even the slightest movement in a body part by using a switch or series of switches.

**AAC: Benefits to Children, Need and Use**

Children who do not acquire speech and language skills to allow them to communicate are at high risk for developing problems with social interaction, expressive language, and literacy (Lund and Light, 2007). Over the past ten years AAC systems have played a significant role in meeting the communicative needs of persons with severe communication impairments in educational settings as well as non-academic environments (Beukelman and Mirenda, 2005; Branson and Demchak, 2009; DiCarlo and Banajee, 2000; Hourcade et al., 2004; Light and Drager, 2007; Lund and Light, 2007; Reichle et al., 2002; Schlosser, Blishak and Koul, 2003). Results of AAC research indicate that individuals with complex communication needs use multiple modes of communication, either simultaneously or sequentially, depending on the child’s skills, the social context and task (Blackstone et al, 2003; Light, et al, 1985). These modes of communication may include electronic
communication systems as well as speech approximations, signs, communication boards, and gestures (Binger and Light, 2006; Light and Drager, 2005).

How many children need and use AAC systems? The National Census Bureau does not collect data on AAC device use and there is a paucity of published data and peer reviewed surveys examining the numbers and characteristics of children who need and use AAC systems. It is difficult to compare these studies due to variations in definitions, methodology, and response rates. Furthermore, studies that report the prevalence of people with severe speech impairments vary widely, depending on the country, age group, and type(s) of disability surveyed (Beukelman and Mirenda, 2005).

According to the National Survey of Children’ with Special Health Care Needs (CAHMI, 2005-2006)\(^2\), approximately 13.9% of children ages 0–17 years in the United States (10.2 million) have special health care needs\(^3\) and 22.6% percent (2,272,475 weighted estimate) have difficulty with speaking, communicating or being understood. In this survey, it was estimated that 2.2% of children under the age of 18 years needed communication aids or devices sometime during 2005. In this same study, when a parent or guardian was asked whether a child received all the communication aids or devices that s/he needed, 76.1% (158,605 weighted estimate) said “yes”, 6.1 (12,625 weighted estimate) said that the child received “some” of the needed aids or devices, and 17.8 % (37,163 weighted estimate) said “no” (CAHMI, 2005-2006). The survey did not report data on types of communication devices or information on funding.

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\(^2\) This survey included a total of 364,841 children from 192,083 households

\(^3\) The prevalence of children with special health care needs ranged from 10% to 18.5% across the 50 states and the District of Columbia. 1 in 5 households with children in the United States had at least one child with special health care needs. This translates into over 8.8 million households nationally. The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as: “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998)
Several state surveys have been conducted to determine the number of children who use augmentative communication systems. Again, it is difficult to compare these studies because of varying methods, ages of children, definitions and response rates. Moreover, these studies span 18 years. In a survey of special education agencies in Pennsylvania, Binger and Light (2003) found that over 11% of children enrolled in early intervention programs required AAC and 24.1% of children on speech-language pathologists’ caseloads required AAC. While a wide range of systems was used, approximately 15% of the children used SGDs. Another survey conducted in Pennsylvania found that 3-6% of preschool children enrolled in special education required AAC (Matas et al., in 1985). In contrast, a survey conducted in North Dakota in 1987 of all services providers, found that the prevalence rate of persons age 3-21 years who were non-speaking was 15.25% per 10,000. This survey did not report how many individuals used AAC systems (Burd et al., 1988).

**Speech-Language Pathologists and Children Who Use AAC Methods**

Surveys indicate that speech-language pathologists frequently work with students in public schools who cannot use speech as their primary mode of communication. It is somewhat difficult to compare these surveys because of variations in the definitions of non-speaking and differences in survey methodology. The most recent survey of speech-language pathologists in public school settings by the American Speech-Language and Hearing Association (ASHA, 2008a,b,c) revealed that 45% of 2,556 speech-language pathologists in public schools reported that they regularly served individuals who were non-speaking. Among this group, the mean number of non-speaking individuals served per month was 4. The average total caseload was 50, with a range between 2-290. The number of speech-language pathologists who served individuals who were non-speaking was the highest
among school speech pathologists who worked in day/residential and preschool programs – 63.1% and 57.1 percent, respectively\(^4\). ASHA defined non-speaking as speech that is not functional for daily living needs (ASHA, 2008a,b). The U. S. Department of Education (DOE) reported that 39.8% of speech-language pathologists in the public schools worked with students who were non-speaking during 1999-2001. The DOE’s definition of non-speaking included selective or elective mutism, total lack of speech in at least one situation, despite the ability to speak in other settings; or no verbal communication in any setting (DOE, 2001). The DOE did not report this data in subsequent annual reports. Neither the ASHA or DOE surveys reported the total number of non-speaking children served and/or the type(s) of communication systems they used.

In summary, speech generating devices may help a child communicate and function more independently. Some of these devices can be costly. The next chapter discusses whether and how these devices may be funded through the public school and health insurance.

\(^4\) The response rate was 64.0%. Analysis was limited to respondents who were employed full-time.
Chapter 2

Funding of Speech Generating Devices

Federal Laws and Health Benefit Programs

This chapter discusses the federal laws and health benefit programs which may provide access to and funding for speech generating devices. It also reviews case law that is relevant to funding of speech generating devices by the public school and health insurers.

Assistive Technology and Federal Laws

There are several federal laws that help ensure that children enrolled in the public school receive assistive technology devices and services. This section discusses the two most important laws – The Individual with Disabilities in Education Act and Section 504 of the Civil Rights Act.

Individual with Disabilities Education Act (IDEA)


IDEA is a comprehensive statute that guarantees that all children with disabilities, (as defined and enumerated by the law) regardless of severity, from 3-21, the right to receive a “free appropriate public education” (FAPE) as defined in 20 U.S.C. §1401(9). Children with disabilities who are between the ages of three through five are covered under Part B of IDEA, which also covers school-aged children. IDEA Part C covers children from birth through two years (20 U.S.C. §1431 et seq.; 34 C.F.R. Part 303). Part C is a federal grant program that assists participating states in operating early intervention programs for infants and toddlers with disabilities. The federal government gives states the funds to help cover the costs of meeting the educational needs of students with disabilities. In return, states
must abide by IDEA laws and regulations. IDEA is not a static law. It has a long history, which is beyond the scope of this research study. However, specific developments in IDEA and its regulations are discussed that are relevant to this research study.

**Key Provisions Under IDEA**

IDEA guarantees that all students with disabilities, as defined by the law, regardless of severity, aged 3-21, have the right to a “free appropriate public education” (FAPE) (20 U.S.C. §§1401(9), §1412 (a)(1)(A-C) and 1419(b)(2). The purpose of FAPE is to provide special education and related services (§1401(26)(A-B)) in order to meet the unique needs of the student (§1400(d)(1)(A)). Related services include: transportation services, other “supportive services”, such as speech-language pathology and audiology, occupational and physical therapies, interpreting services, psychological services, counseling services, recreation, social work services and school nurse services. While the definition also includes medical services, the school is not obligated to pay for medical devices and services, except for diagnostic purposes (§ 1401(1)(B)). All services must be at no cost to parents (§1401 (9)(A)). Furthermore, students who receive special education and related services must not be separated from non-disabled children, unless they cannot be successfully educated in a regular classroom, given supplementary aids and services. This provision is known as the least restrictive environment (LRE) (§1412(a)(5)A-B).

Based on IDEA, a free appropriate public education program must be based on the unique needs of the student and must consider the student’s intellectual potential. A student must

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5 Historically known as The Education for All Handicapped Children Act of 1975 (EHCA) (P.L.94-142), the law was passed in 1975 and became effective on September 1, 1978. This legislation passed both houses of Congress with near unanimous support. Amendments to EHCA occurred in 1983, in 1986 (adding Part H for infants and toddlers) and in 1990 the law was renamed IDEA.

6 The concept of an “appropriate education” is based on the landmark Rowley Case (458 U.S. 176 (1982). In Rowley the Supreme Court determined that FAPE does not mean a school must provide the “best” education or one
be benefiting from the education, making progress, and receiving more than minimal benefit. IDEA regulations specify that a FAPE is available to any child with a disability, even if the child is not failing or has not been retained (34 C.F.R. §300.101(c)(1)).

To qualify for services, a student must meet the definition of a “child with a disability” which is defined as

“(i) with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this chapter as “emotional disturbance”), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, needs special education and related services” (20 U.S.C §1401(3)(A)(i-ii))

For a child ages 3 through 9, the term “child with a disability” may include, at the discretion of the State and the local educational agency, a child:

“(i) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in 1 or more of the following areas: physical development; cognitive development; communication development; social or emotional development; or adaptive development; and (ii) who, by reason thereof, needs special education and related services. These include mental retardation, hearing impairments, (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance orthopedic impairments, autism, designed to maximize the student’s potential (Board of Ed. of the Hendrick Hudson Sch. Dist. v. Rowley, 458 U.S. 176 (1982)). The Rowley case was also important in another way: it acknowledged a collaborative relationship between the school and parents. In Rowley the Supreme Court noted that both the states and the family have important roles to play in the child’s educational program. “the primary responsibility for formulating the education to be accorded to (a child with a disability), and for choosing the education method most suitable to the child’s needs, was left by the Act to state and local educational agencies in cooperation with the parents.” (Rowley at 207).
traumatic brain injury, other health impairments, or specific learning disabilities.” (20 U.S.C §1401(3)(B)(i-ii)).

IDEA requires that special education programs must consider a child’s need for supplementary aids and services (20 U.S.C. 1414 (d)(1)(A)(i)(IV)) and assistive devices and services §1414(d)(3)(B)(v)). As defined by IDEA, “supplementary aids and services” include,

“aids, services, and other supports that are provided in regular education classes or other education-related settings to enable children with disabilities to be educated with non-disabled children to the maximum extent appropriate” (§1401(33)).

The definitions of assistive technology devices and services were adopted from the Technology-Related Assistance for Individuals with Disabilities Act of 1988 ("Tech Act") (P.L. 100-407) and added to IDEA by the Education of the Handicapped Act Amendments of 1990. These definitions have been retained in IDEA since this time. An assistive technology device (§1401(1)(A) is defined as:

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7 This act was reauthorized in 1994 (P.L. 103-218) and again in 1998 as the Assistive Technology Act of 1998 (P.L. 105-394) ("AT Act"). These two definitions were retained when Congress reauthorized The Tech Act of 1998 and amended it in 2004 (P.L. 108-364). The Tech Act provides discretionary grants to states to assist them in developing and implementing a variety of state assistive technology projects. The Tech Act is administered by the Rehabilitation Services Administration in collaboration with the National Institute on Disability and Rehabilitation Research, the Office of Special Education and Rehabilitation Services Administration of the U.S. Department of Education. The Rehabilitation Engineering Society of North America provides technical assistance to grantees. For information about state assistive technology programs go to http://www.resnaprojects.org/nattap/at/statecontacts.html

8 The definitions of assistive technology (AT) devices and services were added to the Education of All Handicapped Children Act Amendments of 1990. Congress included the amendments to:

“(1) clarify the broad range of assistive technology devices and related services that are available, and (2) to increase the awareness of assistive technology as an important component of meeting the special education and related service needs of many students with disabilities, and thus enable them to participate in and benefit from educational programs” (House Report No. 101-544, 1990 U.S. Code Cong. & Admin. News, p. 1730). Since 1990 Congress has underscored the importance of AT in the education of children with disabilities. The definitions of AT devices and services were retained when Congress passed IDEA and within each of its reauthorizations. IDEA ’97 stated that the need for AT must be considered for all students when developing the Individualized Education Program (IEP)(20 U.S.C. § 1414(d)(3)(B)(v)). In 1999, the IDEA regulations clearly stated that it is “mandatory for the IEP team to consider each child’s AT needs” (64 Fed. Reg.12590-91). On December 3, 2004 former President Bush signed into law the IDEA of 2004. This reauthorized IDEA and aligned it with the goals of No Child Left Behind. Following this reauthorization, the Department of Education, Office of Special Education

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“Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability.”

This term excludes surgically planted or replaced devices, such as cochlear implants (§ 1401(1)(B)). An assistive technology service (§1401(2)(A-F) is defined as:

“Any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device”.

AT services include evaluating, purchasing, leasing or acquiring AT; selecting and customizing AT, coordinating educational services associated with AT, training the child and the family to use the AT and training professionals to use AT. Each of these definitions would apply to speech generating devices. Speech generating devices are included under both supplementary aids and services and assistive technology category, based on IDEA’s definition of assistive technology.

**The Special Education Process Under IDEA**

How does a child qualify for IDEA? States are obligated to identify, locate and evaluate all children who may need special education and related services. States accomplish this through the “Child Find” process (20 U.S.C. 1412(a)(3)). This process involves several key elements: defining the target population, developing public awareness campaigns, establishing referral and intake procedures, screening of children who may be eligible, determining eligibility, tracking and interagency coordination.

IDEA is a highly procedural law. It involves multiple steps that educators and parents must follow in order for a child to be evaluated, to receive special education and related services, to measure progress and determine the need for continued services. A child must be first be
assessed in all areas of suspected disability (§1414 (b)(1-3)). The local educational agency is responsible for administering the assessments in order to determine a child’s unique needs. If the child is found eligible for special education and related services, the school system schedules a meeting to write the child’s Individualized Education Plan (IEP). The IEP is a written statement indicating the child’s present level of performance (§1414 (d)(1-7). It includes annual, measurable, goals; a statement of “special education and related services” and “supplementary aids and services” (§1414 (d)(1)(A)(IV)). The law states that the IEP must consider the communication needs of the child, including “whether the child needs assistive technology devices and services” (§1414 (d)(3)(B)(v)).

IDEA regulations state that an IEP Team develops the IEP. The IEP team includes the parent(s), at least one of the child’s regular education teachers, at least one special education teacher and a local educational agency representative, typically a special education administrator. It can also include the child if the child is not too young (34 C.F.R. § 300.321). IDEA regulations require that the child’s IEP team determine whether the child requires supplementary aids and services and assistive technology devices and services (34 C.F.R. §300.320, §300.324). The Supreme Court called the IEP the “centerpiece of the (IDEA’s) education delivery system” (Honig v Doe, 484 U.S. 305, 311 (1988)). For children under three years of age, the team writes an Individualized Family Service Plan (§1436 (a)-(e)). After the IEP is written the school is obligated to provide the special education and related services that are specified in the IEP (34 C.F.R. §300.323). At least once per year the child’s progress is reviewed with the IEP team (§300.324) and at least once every three years a child must be reevaluated (§300.303).

Parents and IDEA

Federal Register on August 14, 2006. These regulations retained the definitions of AT devices and AT services.
When IDEA was first enacted, it gave parents a critical role in the IEP process. As a member of the IEP team, the law mandates that the parent(s) be actively involved in development and implementation of the child’s IEP. When IDEA was reauthorized in 1997 the parental role was strengthened even further (Meade and Paige, 2008). The law stated that the school must consider “the concerns of the parents for enhancing their child’s education when developing the IEP” (§1414 (d)(3)(A)). The 1999 and 2006 IDEA regulations have retained the critical role that parents play in developing their child’s IEP.

According to IDEA, parents have rights in four areas: notice, consent, participation and challenge. Since the enactment of the Education of All Handicapped Children Act in 1975, these rights have been expanded (Mead and Paige, 2008). In terms of notice, parents have rights to receive written notice of the public school’s intent to evaluate their child and parents may grant or deny permission to have their child evaluated or to receive special education and related services. Parents have rights to be a member of their child’s Individualized Education Program and to participate in decisions about their child. Parents have access to all records and they have rights to have all evaluation results explained to them. They have rights to invite persons of their choosing to meetings called to discuss their child. Parents also have rights to obtain independent evaluations when they disagree with the school’s evaluation results and recommendations. In terms of complaint provisions, parents have rights to have mediation at the school’s expense, to challenge a school’s decision in the presence of an impartial hearing officer, to appeal the decision of the hearing officer in state court or federal district court and to receive reimbursement of attorney’s fees and educational costs if the school district fails to provide FAPE. While parents have these rights, the laws and regulations are complex and can be difficult for parents to understand and navigate. This may impact parents’ ability to invoke their rights and claim their children’s rights.
Public School Funding for SGDs

The IDEA regulations state that supplementary aids and services and assistive technology devices and services must be made available to a child with a disability in order for the child to receive a FAPE if required as “part of the child’s special education, related services or supplementary aids and services” (34 C.F.R. §300.105 (a-b)). The regulations extend this provision to public agencies that provide extracurricular activities and services (34 C.F.R. §300.117). Thus, a child with a communication disability must have the resources - the “supplementary aids and services” - to enable him or her to be educated in a regular classroom with non-disabled peers, as well as participate in extracurricular activities with non-disabled peers.

According to the IDEA the school is obligated to provide AT devices and services, including SGDs, if these devices and services are special education and related services or supplementary aids or services and necessary in order for the child to receive a FAPE. It is important to note that to achieve a FAPE, the public school is not obligated to provide state of the art assistive technologies for a child. The type of device selected for the child is determined by the child’s Individualized Education Program (IEP) team, which includes the parents. This determination is based on their assessment of the child’s unique needs and skills. As noted in Chapter 1, there are many assistive technologies available and some of these devices are costly. An assessment is needed to determine which device is appropriate (see Chapter 3 for a discussion concerning assessments). The law and regulations are more ambiguous concerning the funding for AT devices and services. One factor that complicates

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9 A public agency, as defined by IDEA, includes an educational service agency or any other public institution or agency that has administrative control and direction of a public elementary school or secondary school (§1401 (19)(B)).
this matter is the possible obligation of non-educational public and private agencies to provide AT devices and services to children in public schools.

**Non-educational Public Agencies - Responsibility for Providing Services**

According to IDEA, other non-educational public agencies, such as Medicaid or private insurers, who are obligated to provide special education and related services, including assistive technology devices and services and supplementary aids and services, under federal or State law, must precede the financial responsibility of the local education agency (§1412(12)(A)(i)). If the non-educational agency fails to provide the special education and related service, the local educational agency is responsible and must provide the necessary services (§1412(12)(B)(i)), though it may seek reimbursement for the services from the noneducational agency §1412 (12)(B)(ii). In terms of infants and toddlers, IDEA states that the state is the “payor of last resort”. This means that funds may not be used for services that would have been paid for by another public or private source, unless needed to prevent delay in providing necessary services (20 U.S.C.§ 1440 (a)). Furthermore, the law states that the agency with ultimate responsibility may be required to reimburse the state for services (§1440 (b)(2)(B)). According to Attorney Ronald Hager at the Assistive Technology Law Center, there is no known organization or database that collects information on funding of SGD by school districts. (Hager, 2006b).

**Access to Public or Private Health Insurance by the Public School**

IDEA regulations state that if the child or family is covered by public or private health insurance, the school is permitted to use these programs to assist the school in providing a FAPE to eligible children (34 C.F.R.§612 (a)(12)). In fact the 2006 regulations the regulators stated that “the public agency is encouraged to use the public benefits or insurance to the extent possible” (71 Fed. Reg. 46608). However, IDEA regulations specify
the conditions under which the public school may use the benefits. IDEA regulations state that a family must consent each time the school seeks access to the child’s or family’s public (§300.154 (d)(2)(iv)), or private health insurance (§ 300.154 (e)(1)). In addition, the family must not incur any out-of-pocket expenses, such as a deductible or co-pay (§300.154 (d)(2)(ii) and §300.154 (f)(2)). If so, the school may be obligated to pay these costs.

The regulations include other parental safeguards. For example, if the school uses the child’s or family's public or private health insurance, such action must not reduce the child’s or family’s insurance benefits in any way, increase premiums, or risk loss of eligibility for home and community-based waivers (§300.154(d)(2)(iii)). Moreover, if the parent refuses to allow the school to access the health benefits program, the school is not relieved of its responsibility. The school must provide the special education and related services and supplementary aids and services to ensure that the child receives a FAPE (§300.154(d)(2)(iv)(B)). The regulations also state that the school may not require a family to sign up or enroll in a public or private health insurance program in order for the child to receive a FAPE (§300.154(d)(2)(I)).

Section 504 of the Rehabilitation Act of 1973

Section 504 prohibits discrimination on the basis of disability in any program that receives federal funds and any program run by the U.S government. (29 U.S.C §794)\(^{10}\). Since public school districts receive federal funds, they must comply with Section 504. Section 504 also applies to private schools that receive federal funds. The Office of Civil Rights enforces Section 504 in programs and activities that receive federal financial assistance from the

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\(^{10}\) Section 504 was modeled after the Civil Rights Act of 1964. It also served as the foundation for the Americans with Disabilities Act (ADA).
Department of Education. A complete discussion of Section 504 is beyond the scope of this paper. Key provisions are discussed which relate to assistive technology devices and services.

**Section 504 Definitions**

The definition of disability within Section 504 differs from the definition within IDEA. On September 25, 2008, the President signed the Americans with Disabilities Act Amendments Act of 2008 (ADAAA).\(^\text{11}\) The ADAAA, which became effective January 1, 2009, broadened the interpretation of the definition of disability. Section 504 was amended so that it now incorporates the ADAAA by reference and applies to public school students under Section 504. Section 504 defines disability as:

Any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having an impairment (34 C.F.R. §104.3 (j))

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\(^{11}\) This is another law that provides assistive technology rights to individuals with disabilities, as defined by the law. Congress passed the ADAAA, in part, because it found that Supreme Court and the lower courts narrowed the definition of disability and found that people with “substantially limiting” disabilities were not considered disabled under the law (§12101(a)-(b)). The ADAAA regulations apply to all programs, services and activities provided or operated by states and local governments (§12131(1); §35.104). Title III DOJ regulations apply to all private schools (§12181(7)(j)); §36.104). Thus, the ADAAA extends further than Section 504 of the Rehabilitation Act, which applies only to programs or activities receiving federal funds. The law and regulations state that an individual with a disability who qualifies under the law cannot be excluded from participating and benefiting from programs, services or activities of any public entity. The regulations state that a public entity must ensure that it communicates with qualified individuals with disabilities as effectively as it communicates with non-disabled people (§35.160). This means the public entity must furnish auxiliary aids and services (§35.104). According to the regulations, the Department of Justice interprets auxiliary aids and services to mean

“those aids and services designed to provide effective communications, i.e., making aurally and visually delivered information available to persons with hearing, speech, and vision impairments.”

Auxiliary aids and service include: (1) Qualified interpreters, notetakers, transcription services, written materials, telephone handset amplifiers, assistive listening devices, assistive listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, telecommunications devices for deaf persons, videotext displays, or other effective methods of making aurally delivered materials available to individuals with hearing impairments; (2) Qualified readers, taped texts, audio recordings, Brailled materials, large print materials, or other effective methods of making visually delivered materials available to individuals with visual impairments; (3) Acquisition or modification of equipment or devices; and (4) Other similar services and actions. (§35.104).

According to the DOJ Title II and Title III Technical Assistance Manuals, auxiliary aids and services include speech synthesizers and communication boards, (II-7.000, III-4.3300) The DOJ has not published more recent manuals which address this topic.
The term “substantially limits” is also defined in the ADAAA and Section 504 conforms to this definition. The ADAAA describes the term “substantially limits” as follows:

a) An impairment that substantially limits one major need not limit another major life activity and it need not limit other major life activities in order to be considered a disability. b) An impairment that is episodic or in remission is a disability, if it would substantially limit a major life activity when active, and c) The determination of whether an impairment substantially limits a major life activity is made without regard to the ameliorative effects of mitigating measures such as medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies; use of assistive technology; reasonable accommodations or auxiliary aids or services; or learned behavior (Title 42 Ch. 126. Sec. 12102(4)(B-E)).

The term “major life activities” includes self-care activities such as walking, seeing, hearing, speaking, breathing, learning and working (34 C.F.R. §104.3(h)(2)(ii)).

Similar to IDEA, Section 504 guarantees that students with disabilities receive a Free Appropriate Public Education (FAPE) within the Least Restrictive Environment (LRE). Section 504 regulations define FAPE somewhat differently than IDEA. According to Section 504, FAPE is defined as “regular or special education and related services and aids and services that are designed to meet the individual educational needs of handicapped persons as adequately as the need of non-handicapped persons are met” (34 C.F.R. §104.33(b)(1)).

Like IDEA, Section 504 has procedures that schools must follow in order to ensure that a child with a disability has equal access to education. According to Section 504, schools must abide by specific referral and evaluation procedures (§104.35) and schools are responsible
for creating an “individual accommodation plan” for a student which specifies the accommodations or modifications that will be made to the child’s regular education program. Like IDEA, Section 504 also specifies procedural safeguards for parents, though these safeguards are much less extensive than those under the IDEA (§104.36).

**Accommodations and Modifications**

Section 504 covers students with less severe disabilities than the IDEA, though children with severe disabilities will be covered under Section 504 and under IDEA. Students with disabilities are eligible under Section 504, even if they do not receive any special education services under the IDEA. Section 504 regulations mandate that schools take all reasonable steps to ensure that students with disabilities have access to all programs and activities that nondisabled children do (§§104.4, 104.21, 104.22, 104.34, 104.37). Furthermore, Section 504 mandates that schools are responsible for modifying the academic requirements to ensure that the program does not discriminate on the basis of the child’s disability (§104.44).

Under Section 504 a student would be eligible for services under if only accommodations or modifications were made to his or her regular education program (34 C.F.R. § 104.33(b)(1)). An accommodation would allow the student to complete the same test or assignment as other students but with extended time or change in setting, such as a quiet environment. A modification would allow an adjustment to an assignment or a test. For example, the student may complete a part of a standard test or complete an alternate assignment. Modifications may also include complete assignments or tests using assistive
technologies, labeled as “auxiliary aids and services” (§104.44 (d)(2)). Auxiliary aids are defined as

“May include taped texts, interpreters or other effective methods of making orally delivered materials available to students with hearing impairments, readers in libraries for students with visual impairments, classroom equipment adapted for use by students with manual impairments, and other similar services and actions. Recipients needs not provide attendants, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature” (§104.44 (d)(2)).

Section 504 states that these auxiliary aids must be provided by the public school for individuals with sensory or manual impairments and impairments in speaking (§104.44 (d)). Unlike IDEA, Section 504 does not indicate whether a non-educational agency may be responsible for providing these aids.

Access to Assistive Technologies through Health Benefits Programs: Medicaid and Private Health Insurance

Health care benefit programs are another source of funding for SGDs. For children these programs may include Medicaid, the Children’s Health Insurance Program, and private health care insurers. These programs may cover and pay for SGDs. Unlike IDEA, health care benefit programs do not usually use the term assistive technology. These providers typically use the terms equipment, durable medical equipment (DME), prosthetic devices, and speech generating devices when referring to SGDs. This section includes a brief

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12 Many legal scholars believe that the Supreme Court’s interpretation of Section 504 in Southeastern Community College v. Davis (442 U.S. 397 (1979)) set the precedent for the reasonable accommodations requirement for all of the provisions of section 504 (Hager and Smith, 2003). In this case the Supreme Court agreed with Southeastern Community College that a student with a disability was not qualified for admission because the admission would require “substantial adjustments in existing programs beyond those necessary to eliminate discrimination against otherwise qualified individuals” (42 U.S.C. 397 (1979)).
overview of Medicaid, SCHIP, and private health insurance programs and discusses how these programs may cover SGDs. This section also includes a brief summary of trends in Medicaid and SCHIP that may impact children’s access to health care and therefore SGDs.

**The Medicaid Program – Title XIX of the Social Security Act** (42 U.S.C §§ 1396 et seq.)

Medicaid is a nationwide health care program for low-income people, jointly funded by the federal government and the states and the District of Columbia. Based on the latest estimates, in 2008 Medicaid provided health care for approximately 43.5 million people in 50 States, including the District of Columbia (Ellis, et al., 2009). Medicaid covers approximately 29 million children and 7 million in CHIP (KCMU, 2009b). This includes approximately 8 million people under the age of 65 years with severe disabilities. Among these 8 million people, 1.3 million are children and youth under 21 years of age (KCMU, 2009b). More than one of every five disabled child has Medicaid coverage and 7 out of 10 poor children with disabilities are covered by Medicaid (Williams and Tolbert, 2007).

According to the Medicaid statute, the purpose of Medicaid is to

“furnish rehabilitation and other services to help such families and individuals attain or retain capacity for independent of self care.” (42 U.S.C. §1396).

The courts have acknowledged “independence” and “self-care” as the purposes of the Medicaid Act\(^\text{13}\).

**Benefits and Eligibility:** If states choose to participate in the Medicaid program, they must administer their programs consistent with the Medicaid Act (42 U.S.C. §1396 a (b)).

\(^{13}\) (See Meyers v Reagen, 776 F2d 241, 243 (8th Cir. 1985); Skubel v. Sullivan, 925 F. Supp. 930, 941 (D.Conn 1996) (acknowledging independence and self-care as purposes of the Medicaid Act as a whole) **affirmed sub nom.** Skubel v Fuoroli, 113 F 3d 330 (2nd Cir. 1997).)
The Medicaid statute establishes broad eligibility and benefit guidelines. While some services are required, most are optional and states have considerable flexibility to define their benefits and eligibility guidelines. There is considerable variation across states in terms of income eligibility levels and covered services. Thus, Medicaid is a complex maze of federal and state laws.

In most states more than half of Medicaid beneficiaries are enrolled in Medicaid managed care programs (KSHF, 2008). As of June 2008, (the latest year for which data is available), 70.9% of Medicaid beneficiaries were enrolled in managed care programs (KSHF, 2008). States have been reluctant to mandate enrollment in managed care plans for individuals with disabilities and some states grant exceptions for children with special needs (Gold et al., 2004). Some policy experts express concern that managed plans are not familiar with the multiple and complex health care needs of individuals with disabilities. Very few states have developed managed programs to address these needs, such as care coordination and case management (Rosenbach and Young, 2000; Crowley and Elias, 2003). Managed Medicaid plans can be a complex maze of policies and procedures. No published study has examined the experiences of families who have children with disabilities as they navigate through these systems.

**Children and Medicaid: Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)** (42 U.S.C. 1396 a(a)10(A), 1396a(a)43, 1396d(a)(4)(B), 1396d(r))

Where children are concerned, the federal government imposes stricter standards on state Medicaid programs. States must establish higher eligibility thresholds and provide a range of mandated services. Children under age 21 years with disabilities are covered under a comprehensive set of services known as Medicaid’s Early and Periodic Screening, Diagnosis
and Treatment (EPSDT). This program opens the door to every optional service category under Medicaid and SGDs fit in several required benefit categories. Under the EPSDT program, states must provide a comprehensive range of services to children. The Medicaid statute stipulates that states must provide the:

“necessary healthcare, diagnostic services, treatment and other measures to correct or ameliorate defects and physical and mental illnesses and conditions.”

(42 U.S.C. §1396d(r)(5)).

**Medicaid Coverage for SGDs:** According to Lewis Golinker, Director of Assistive Technology Law Center, all health benefits programs, including Medicaid, have a 4-question test concerning SGDs (Golinker, 2006a):

1. Is the person “eligible”?  
2. Is the item or service “covered”?  
3. Is the item or service “medically necessary”?  
4. Does the request meet any special eligibility or coverage rules that may apply?

In most state Medicaid programs, speech generating devices fit into several benefit categories, under the term *equipment or durable medical equipment*. (Sheldon, 2004; Golinker, 2006a)\(^{14}\). The term *equipment* is included in several Medicaid coverage categories: home health care services, including medical supplies and equipment; optional home health services (e.g. physical, occupational, and speech therapies), rehabilitation services, speech, hearing and language therapy and prosthetic devices. While there is no federal definition of DME, most states define DME based on the following features:

- can withstand repeated use

\(^{14}\) Brief History of SGD Funding through Medicaid - In the late 1970s Washington State Medicaid program and New Jersey Medicaid were the first programs known to cover SGDs. In 1980 New York Medicaid was the first funding program to adopt criteria for SGD coverage. In 1982 New York Medicaid was the first Medicaid program known to be sued for denying coverage for a SGD. As of 2000, all Medicaid programs covered SGDs. More than 1,000
• primarily and customarily used to service a medical purpose
• generally not useful to a person in the absence of illness or injury, and
• is suitable for use in the home (O’Connell et al., 2004).

In addition to fitting within a Medicaid benefit category, Medicaid will not cover a SGD unless it is considered a medical necessity. This term is not defined by the federal Medicaid law or regulations. However, state definitions must be consistent with the broad purposes of the program (as stated above). A state’s definition of medical necessity is usually much broader than that used by private insurance companies (Golinker, 2006a). According to Golinker, (2006a), many states adopt the definition similar to the one used by New York Medicaid:

“to prevent, diagnose, correct, or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person’s capacity for normal activity, or threaten some significant handicap.”.

According to Lewis Golinker every state Medicaid program covers SGDs (Golinker, 2006a.) Therefore, if the individual qualifies for Medicaid and the item is considered medically necessary, a state Medicaid program may fund the device.

Under the EPSDT, SGDs are covered under one of several benefit categories: home health care services, including medical supplies and devices; prosthetic devices, rehabilitation services, preventative services, and SLP. The Medicaid definitions for these terms are noted below:

different insurers and health benefit plans have paid for SGDs. The first known Medicare approval of an SGD was in 1981 (Assistive Technology Law Center, 2006; Bristow, 2000).
-home health services: The purpose is to maintain independence and self-care, and to prevent institutionalization (42 U.S.C. §1396(d)(7)). It includes medical supplies, equipment and appliances. (42 C.F.R. §441.15 (a)(3)).

-prosthetic devices:
replacement, corrective, or supportive devices prescribed by a physician or other licensed practitioner of the healing arts within the scope of his practice as defined by state law, to (1) artificially replace a missing portion of the body; (2) prevent or correct physical deformity or malfunction; or (3) support a weak or deformed portion of the body (42 U.S.C. §1396d(a)(12); 42 C.F.R. § 440.120(c)).

-rehabilitation services:
services provided by a physician or other licensed practitioner of the healing arts within the scope of his practice as defined by state law, to (1) prevent disease, disability and other health conditions or their progression; (2) prolong life; and (3) promote physical and mental health and efficiency (42 U.S.C. §1396d(a)(13); 42 C.F.R. § 440. 130(c))

-physical, therapy, occupational therapy and speech-language pathology services are identified as a Medicaid service at 42 U.S.C. § 1396d(a)(11). The Medicaid definition of these three services clearly states that each service is a potential source of coverage for medical equipment - “any necessary supplies and equipment” (42 C.F.R §440.110(a)-(c)).

**Children’s Health Insurance Plan (CHIP) – Another Safety Net for Low-Income Children**
In 1997 Congress passed the Balanced Budget Act of 1997 and established the State Children’s Insurance Program (SCHIP) (42 U.S.C. §§1397aa-1397jj). SCHIP is block grant program which provides health coverage to low-income children in families who may not
meet the Medicaid income eligibility guidelines. In 2009 the 111th Congress passed legislation to reauthorize SCHIP and President Obama signed it into law on February 4, 2009. The Children’s Health Insurance Program Reauthorization Act (CHIPRA) of 2009 (P.L. No. 111-1) extends and expands SCHIP, now known at CHIP. Over the next four and a half years the federal government will add $33 billion in federal funds for children’s health coverage. CHIP is expected to cover 4.1 million children who would have been uninsured by 2013 (KCMU, 2009a).

What services are covered under CHIP? Under CHIP, states must provide benchmark-equivalent coverage. This means that CHIP benefits must be largely equal to the benefits provided by the following programs: the Federal Employee Health Benefits Program Blue Cross/Blue Shield Standard Option, a HMO plan with the largest commercial enrollment in the state, or a health benefits plan offered by the state to its employees. When states expand Medicaid coverage with CHIP plans, they must use the mandated Medicaid benefits package that includes EPSDT. Since SGDs are a covered benefit under state Medicaid programs and EPSDT, they may be a covered benefit under CHIP as well.

Latest estimates indicate that 7 million children are covered through the CHIP. Approximately 9 million children remain uninsured even though approximately two thirds qualify for Medicaid and CHIP (Ross and Marks, 2009). This translates to one in five poor children. Why is this so? Research indicates that either parents did not enroll their children or they were previously covered and parents did not re-enroll them. In 2005-2006 many states implemented programs to increase enrollment by educating families and simplifying enrollment procedures. Despite these efforts, parents reported they lacked information about Medicaid and did not know how to apply for SCHIP (Smith et al, 2008). Other obstacles may have hindered enrollment. In 2007 SCHIP was not reauthorized as
scheduled, though Congress passed a temporary extension that provided funds to states. During this time the federal government imposed Medicaid citizenship documentation requirements. Furthermore, the Centers for Medicaid and Medicare directed states to limit expansions (Ross and Marks, 2009).

**Trends in Medicaid and SCHIP That May Impact Children**

Based on recent 50-state survey of Medicaid and SCHIP programs by Ross and Marks, (2009) covering the period January, 2009 through December, 2009, some recent trends may positively impact enrollment and coverage. They found that other trends may cause barriers to enrollment and reductions in care. Results of this survey are noted below.

**Increasing Access:** Despite the economic downturn, nineteen states improved access to CHIP by either expanding coverage, reducing procedural barriers or reducing financial barriers. States are using several strategies to reduce procedural barriers by simplifying enrollment. These strategies include: no interview at application time, no interview at renewal time, no asset test, 12 month renewal period, 12 month continuous eligibility, presumptive eligibility in Medicaid and administrative verification. Some states are also experimenting with using technology to streamline the application and renewal processes.

**Restricting Access:** Ten states imposed at least one measure to restrict coverage. The most common measure was to establish premiums or increase premiums. Three states restricted eligibility by imposing waiting periods or cutting income eligibility. Rhode Island was one of three states that cut income eligibility for parents. Pennsylvania and Rhode Island, two states pertinent to this study, increased premiums. Rhode Island imposed a $45 premium per child, per month in families with income as low as 133 percent of the federal poverty line (FPL) ($23,467 for a family of three in 2008). The previous eligibility standard
was 150 percent of FPL. The premiums for other children range from $86 per month to $114 per month. For some families this represents a $29 per month increase.

**Increasing Outreach Efforts:** Several states (number unknown) increased budgets for outreach activities. In follow-up interviews some states reported cutting budgets and some states are concerned that budget shortfalls may impact the plans to go forward with the outreach activities.

**Expansions and Reductions through Medicaid Waivers:** Section 1115 of the Social Security Act gives the Secretary of Health and Human Services broad authority to waive statutory and regulatory provisions under the Social Security Act, including Medicaid and CHIP. Section 1115 waivers permit states to use federal funds to expand health care coverage to low-income populations\(^\text{15}\). Some waivers apply to specific services, such as family planning services, primary care services, and services for individuals with HIV. In 2001 the federal government granted CHIP waivers to expand coverage to parents using CHIP funds. In 2007 the federal government stopped renewing CHIP waivers covering adults and CHIPRA continues this trend. CHIPRA limits coverage for adults and prohibits new waivers for parent coverage.

Other waivers permit states to provide home and community-based services to people as an alternative to institutionalization for certain populations. These are known as Section 1915 Home and Community Based Service Waivers (HCBS). Some HCBS waivers cover children with complex medical needs and children with a diagnosis of mental retardation, developmental disability or autism. Eligibility requirements vary among the States. States

\(^{15}\) To finance expansions through waivers, states must demonstrate they can offset savings or redirect existing federal funds.
may offer a variety of services and equipment. HCBS waivers that include children may provide coverage and funding for speech generating devices.

Little is known about coverage for speech generating devices through waiver programs. Kitchener et al. (2008) collected data from State officials for each State waiver program providing assistive technology for the period 1999-2002. The study did not include managed care initiatives. In this study *assistive technology* (AT) was defined broadly, using the definition in the Assistive Technology Act of 1998 (29 U.S.C. §3001 et seq.)

Any item, piece of equipment, product system, whether acquired commercially, modified or customized that is used to increase maintain or improve functional capabilities of individuals with disabilities (§3002(4)).

The results by Kitchener et al., (2008) revealed that 47 of 52 States provided some form of assistive technology through a waiver program. There was a rise in the number of waivers providing AT, though there was wide variation among the States. In terms of the recipients, most of the spending for AT was for persons with developmental disabilities. These researchers did not provide specific information on the age of recipients or whether waivers provided funding for speech generating devices.

**Private Health Benefits Programs**

Some private health insurance programs cover SGDs. If SGDs are a covered benefit, they must fit into one or more covered benefit categories. SGDs are usually covered under the durable medical equipment (DME) category and they may also be categorized as prosthetic devices (Golinker, 2006a). As with the term DME, there is no universal definition of
“prosthetic device”. Most private benefit health plans define the term consistent with Medicaid’s definition (42 U.S.C. §1396d(a)(12)).

“replacement, corrective, or supportive devices prescribed by a physician or other licensed practitioner of the healing arts within the scope of his practice as defined by state law, to (1) artificially replace a missing portion of the body; (2) prevent or correct physical deformity or malfunction; or (3) support a weak or deformed portion of the body.” (42 C.F.R. §440.120(c)).

Many health plans have covered SGDs under the DME category - Aetna, many Blue Cross/Blue Shield Association plans, Care First Blue Cross of Maryland, Harvard Pilgrim Health Program, just to name a few (Golinker, 2006a,b). An approvals database is available at www.aacfundinghelp.com. This database indicates the names of insurers and health plans and the number of times each was reported to have approved an SGD. However, it is a partial list and it does not indicate how many times an insurer and health plan was asked to fund a SGD. Also, it does not include how many requests were denied (Assistive Technology Law Center, 2006). According to Lewis Golinker at the Assistive Technology Law Center, there is no database with this information (Golinker, 2006b).

Only one known published study has examined third party payment of SGDs. Beukelman, Yorkston and Smith (1985) examined third party payer response to requests for SGDs in Washington State in 1985. These investigators collected data by distributing questionnaires to professionals who worked with communicatively impaired individuals. Of a total of 250 questionnaires, 53 were returned. Results indicated that 70% of requests were approved. In terms of funding sources, 57% were made to Washington Medicaid, 28% to private insurance companies, and 17% to agencies. In terms of specific payers, private insurers paid for devices only 33% of the time (15 requests), Medicaid paid for devices 84% of the
time (29 requests) and other organizations paid for devices 81% of the time (9 requests). These included Division of Developmental Disabilities, Crippled Children’s Services, Division of Vocational Rehabilitation, Labor and Industry (Beukelman, Yorkston and Smith, 1985).16

**Speech Generating Devices: Covered vs. Funded**

As noted above, under IDEA and Section 504 schools must provide and fund speech generating devices as assistive technology or supplementary aids and services in order for a child to receive a FAPE. However, IDEA and Section 504 regulations do not specify the process for providing devices and services. This process is determined by local educational agencies, on a case-by-case basis. As discussed above, IDEA is not the primary payor when another non-education agency, private or public, is responsible for providing the funding under federal and state law and the public school may seek reimbursement from the non-educational agency. Again, IDEA regulations are rather vague concerning the circumstances under which public schools make these decisions. Moreover, under IDEA regulations public schools are not required to provide AT that is best or state of the art. While IDEA guarantees rights concerning AT devices and services in order for child to achieve a free appropriate public education (FAPE), the term “appropriate” is a rather ambiguous term, open to some interpretation by the IEP team and subject to review.17 Therefore, rights and entitlements concerning AT devices and services can be confusing and possibly discretionary and can lead to misunderstandings and disputes between families and the public school.

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16 It is quite possible that funding patterns and outcome have changed since this time.
17 The concept of an “appropriate education” is based on the landmark Rowley Case (458 U.S. 176 (1982). In Rowley the Supreme Court determined that FAPE does not mean a school must provide the “best” education or one designed to maximize the student’s potential (Board of Ed. of the Hendrick Hudson Sch. Dist. v. Rowley, 458 U.S. 176 (1982)). The Rowley case was also important in another way: it acknowledged a collaborative relationship between the school and parents. In Rowley the Supreme Court noted that both the States and the family have important roles to play in the child’s educational program.

“the primary responsibility for formulating the education to be accorded to (a child with a disability), and for choosing the education method most suitable to the child’s needs, was left by the Act to state and local educational agencies in cooperation with the parents.” (458 U.S. 176 (1982).
In terms of public and private health benefits plans, a covered benefit does not imply a device will be funded. The most common reason for denial is the DME criteria stating that the SGD must serve a medical purpose (Golinker, 2006a). Health benefit programs may conclude that the SGD does not serve a medical purpose. Golinker encourages AAC practitioners to make sure their documentation explicitly states that the SGD will be used to treat a severe communication disorder that interferes with meeting a person’s daily living needs.

How does a parent decide whether to access their health insurance to cover a SGD (if they have health insurance that covers it) or whether to obtain AT devices and services through the public school? This decision can be complicated if the public school and the parent(s) do not agree about whether a SGD is necessary for a child to receive a FAPE or do not agree on the type of device that is needed. The decision is further complicated if a health insurer and parent(s) do not agree that a SGD is a medical necessity. There is little formal law to guide parents and public schools, as discussed in the following section.

**Legal Precedent – Case Law**

**Health Insurance Coverage for Speech Generating Devices**

Few disputes concerning SGDs have reached the formal institutions of law. According to Lewis Golinker at the Assistive Technology Law Center (2006a), no private insurance provider has been brought to court for denying coverage for a SGD. Many cases brought to court have involved durable medical equipment. (Golinker, 2006a). However, only 6 cases have involved funding of a SGD. Each of these cases involved a state Medicaid program. Only one of these cases involved a child. See the table below for details.
Among the cases that have gone to court, the federal courts have ruled that speech generating devices can serve a medical necessity. The courts have held that state Medicaid programs must cover and provide AAC devices because the ability to speak is “vital” and that the loss of the ability to speak is the most devastating aspect of any disability (Fred C. v. Texas Health and Human Services Commission, 1996, 1997; Hunter v. Chiles, 1996.)
### Case Law Concerning Health Insurance and Speech Generating Devices

<table>
<thead>
<tr>
<th>Case Name</th>
<th>Citation</th>
<th>Age</th>
<th>Medical Diagnosis</th>
<th>Equipment</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fred C. v Texas Health &amp; Human Services Commission (I)</td>
<td>988 F. Supp. 1032 (W.D.Tex.1997), vacated and remanded per curiam, 117 F.3rd 1416 (5th Cir. 1997)</td>
<td>48 years</td>
<td>Traumatic brain injury at age 12 years resulting in speech impairment</td>
<td>SGD</td>
<td>Court ruled that the state Medicaid program had no rational basis for denying covering of the device to individuals older than 21 years</td>
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<tr>
<td>Fred C. v Texas Health and Human Services Commission (II)</td>
<td>988 F Supp. 1032 (W.D. Tx. 1997), affirmed, per curiam, 167 F.3d. 537 (5th Cir. 1998)</td>
<td></td>
<td></td>
<td>SGD</td>
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<tr>
<td>Hunter v. Chiles</td>
<td>944 F.Supp. 914 (SDFL) 1996</td>
<td>Powell - 22 years Hunter - 7 years</td>
<td>Cerebral palsy resulting in severe dysarthria Cerebral palsy resulting in severe dysarthria</td>
<td>SGD</td>
<td>1) Powell - Once a Medicate state program chooses to cover optional services - in this case home health- it is required to cover the device 2) device is covered under the EPSDT program. Court cited 42 U.S.C.S.§ 1396(c) - availability of special education funds cannot be used to deny medically necessary services under Medicaid</td>
</tr>
<tr>
<td>Lagowski v. Whalen</td>
<td>270 A.D.2d 827 (N.Y. App Div. 2000)</td>
<td>adult</td>
<td>CVA resulting in aphasia</td>
<td></td>
<td>Device was medically necessary and the most appropriate device for the person, based on the individual’s skills and needs. The other devices, though less costly, would be not optimize communication skills.</td>
</tr>
<tr>
<td>Case Name</td>
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<td>Age</td>
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<tr>
<td>Meyers v. Reagan</td>
<td>776 F.2d. 241 (8th Cir. 1985)</td>
<td>adult</td>
<td>Mental retardation, dysarthria</td>
<td>SGD</td>
<td>Once the state chose to cover therapies and related services it could not arbitrarily exclude AAC devices. Device was judged medically necessary for individual.</td>
</tr>
<tr>
<td>Myers v. State of Mississippi</td>
<td>3:94 CV-185-LN (S.D. Miss June 23, 1995)</td>
<td>3 individuals under 21 years</td>
<td>Cerebral palsy, dysarthria</td>
<td>SGD</td>
<td>The Court rejected the interpretation of medical need: a state employed physician contended that the state of Mississippi would not cover AAC devices unless the messages produced by the device were solely used to express medical needs. The court adopted a broader definition of AAC devices, “AAC devices are electronic and non-electronic devices that allow individuals to overcome, to the maximum extent possible, communication limitations that interfere with daily activities”. The court threw out the across-the-board exclusion of AAC devices.</td>
</tr>
</tbody>
</table>
IDEA Case Law: FAPE, LRE, and IEP standards have been the subject of much litigation (Hager and Smith, 2003). Many cases involved assistive technology evaluation, services, and devices (Hager, 2006; Hager and Smith, 2003). However, of these cases, only one case involved the school’s responsibility to provide a SGD. In this case the family prevailed, as noted below.

<table>
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<tr>
<th>Case Name</th>
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<th>Equipment</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>School Board of Independent School District No. 11, Anoka Hennepin, Plaintiff, v. Sarah Pachl, a minor and through her parents and legal guardians, Kevin and Suzanne Pachl</td>
<td>Civil No. 01-342 (SRN) May 2, 2002</td>
<td>10 years</td>
<td>Multiple disabilities, dysarthria</td>
<td>SGD</td>
<td>Court ruled FAPE was violated when school failed to conduct an AT evaluation and provide a SGD for child to use. Court ordered compensatory educational services until the SGD was provided by the school.</td>
</tr>
</tbody>
</table>
In summary, while education and health care laws and regulations establish a child’s rights and entitlements for speech generating devices/assistive technologies and parent’s rights to advocate for these rights, these are complex systems to understand and navigate. Some provisions of the laws and regulations are open to interpretation by those who implement them. Furthermore, determinations about what is educationally appropriate and what is medically necessary can be discretionary, which may lead to disagreements among parents, the public school and health insurers. As parents seek information about their funding options, they will interact with a variety of people and these interactions may influence whether and how they assert their children’s rights and their rights.

In addition to challenges associated with understanding the laws and regulations, parents may face other challenges when seeking a device for their child. These include difficulties with obtaining a referral, obtaining an evaluation and completing the prior approval process for health insurance. Furthermore, there may be cultural and language differences between parents and practitioners which may cause misunderstandings. These challenges are discussed in the next chapter.
Chapter 3

Access to Speech Generating Devices:

Challenges that Families May Face

As discussed in Chapter 2, families often interact with two complex systems when advocating for their child to receive a speech generating device. They may interact with the public school system and the health care system - each with its complex laws, regulations, policies and procedures. Furthermore, families seeking a device for their child may face additional challenges. These potential challenges involve obtaining a referral, seeking an evaluation, participating in an evaluation, participating in the funding process and the impact of culture and language and racial and ethnic health disparities. These issues are discussed below.

**Obtaining a Referral for an AAC Evaluation:** The referral process is one of the family’s earliest experiences with education and health care laws concerning speech generating devices (SGD). Families must obtain a referral for an augmentative and alternative communication (AAC) evaluation, either through the public school system or a health care provider. During this process families frequently make multiple decisions and may face many challenges. When considering the referral and the AAC evaluation, the family, school, and health care provider(s) will begin to discuss who has the resources to conduct an evaluation, reasons why the child may need an AAC system and in what environments the child may use the system. These discussions are critical because they influence who may conduct and fund the assessment. These discussions may also influence who pays for the SGD.
During the referral process, families will interact with a variety of people – health care providers, educators, friends, other families, and perhaps community members. Families will ask a variety of questions and confront multiple decisions along the way: How can I obtain the AAC evaluation referral? Who do I speak with? How much will the evaluation cost? Who will pay for the evaluation? Will I need to pay for the evaluation? If so, how much? Who is best qualified to conduct the AAC evaluation? Should I seek an independent evaluation? If so, will the school pay for it? Who conducts AAC assessments in my geographic area? What have other families done in these situations? What is best for my child? When asking many of these questions, families interact with a variety of professionals and non-professionals and these encounters may influence how the family thinks and acts in relation to the law. Thus, when considering an AAC evaluation referral, the family faces a complex process involving multiple stages and decision points. This complex process may launch s a bureaucratic maze and set the stage for who influences the family.

While health care benefit program policies and procedures vary considerably, in most cases, the physician will be responsible for writing the “doctor’s order” for the evaluation referral. After that, depending on the type of health benefits program, the parent may need to obtain authorization from their health insurance company for the referral, obtain a list of approved health care providers from their health insurance company, or seek a provider on their own. Though a physician may write the order, this does not ensure that the health benefits program will pay for the service. To process and expedite this referral, in most situations, the parent will make numerous telephone calls and talk with many different people, such as physicians, health insurance employees, allied health care professionals, other parents, and/or friends.
**Seeking an Evaluation**: Families may face several challenges when seeking an evaluation. Public schools need a team of specialists with knowledge and skills in assistive technology. Given their professional background, the speech-language pathologist typically assumes a primary role in augmentative communication evaluations (ASHA, 2005, 2002a, 2002b). The most recent survey of speech language pathologists who work in the public schools indicated that 27% thought they did not have adequate training in augmentative communication technologies (ASHA, 2008a,b,c). However, this percentage also included other areas of technology training and therefore it was difficult to determine the significance of this finding. In terms of teachers, a recent survey of teacher preparation programs indicated that AT training was limited. Only twenty five percent to one third of licensure programs provided coursework in assistive technology (Sims, 2009). Given the cost of assistive technologies, schools may not have an array of devices available to conduct a thorough assessment. Furthermore, there are few specialized assistive technology programs and therefore families may need to travel outside their geographic area to obtain services. Given demographic changes in this country, practitioners must also be trained to work with an increasing diverse group of children and families (ASHA, 2002b; Beukelman and Mirenda, 2005; Parette and Brotherson, 2004; Parette et al., 2001; DOE, 2009).

**The AAC Evaluation**: The goal of the assessment is to determine which AAC systems and strategies will improve a person’s ability to communicate as independently as possible. Families usually attend and participate in AAC evaluations. A multidisciplinary team of allied health professionals usually conducts the AAC assessment with the parent(s): speech-language pathologist, occupational therapist and physical therapist. If conducted in a school, the child’s IEP team is
involved. These individuals may have varying degrees of expertise with assistive technologies. Moreover, it is important to note that these individuals know the child and/or family from different perspectives. They may have different opinions about the child’s skills and needs. These factors – varying degrees of knowledge and expertise with assistive technologies and differing perspectives concerning the child’s skills and needs – can fuel disagreements among the team and the parents.

The evaluation typically begins with a needs and skills assessment. The family and others who are involved with the child often complete a questionnaire to determine the child’s needs and skills. The AAC team reviews this questionnaire as well as the child’s educational and medical records, as available. The AAC team interviews the various people who work with the child, as possible: family, caregivers, teachers, school administrators, and therapists (speech-language pathologist, occupational therapist, physical therapist). The evaluation may also include an appraisal of the perceptions and attitudes of the family toward an AAC system, including cultural values and beliefs. The AAC team will assess the child’s ability to use symbols to communicate. If appropriate, the child is evaluated using non-electronic and/or electronic communication devices. After the device trials, the team discusses the recommendations with the individual and family. After the evaluation, the team generates a written report. If a speech generating device is recommended, the written report must meet documentation guidelines established by the school and/or the health benefits program. Documentation guidelines are discussed below.

**The Funding Process:** The funding process involving multiple people and multiple procedures, which can be difficult for families and professionals to understand. Families may have two funding options: the public school and a health benefits
program (private or public). Children who use AAC systems often have multiple disabilities. Most are enrolled in special education programs within public schools, where they receive services mandated under the Individuals with Disabilities Education Act (IDEA) (20 U.S.C. §1400 et seq., 34 C.M.R. §300 et seq.). As discussed in Chapter 2, according to IDEA regulations, the school is obligated to provide an assistive technology device if it is necessary for the child to receive a Free Appropriate Public Education (FAPE) (34 C.M.R §300.5, §300.105). However, the public school is not the primary payor if there is a non-educational agency, pubic or private, that is responsible for funding the device, based on state and federal law (20 U.S.C. §1412 (12)(A)(i)).

In terms of health insurance, the child may be entitled to a speech generating device if it is a covered benefit under their private or public health insurance programs (Golinker, 2006a).

How does a family decide which option to pursue or which option is best? During the process of obtaining a device, the parent will likely speak with several members of the child’s educational team about the child’s needs as well as the child’s physician or other health care providers. Parents may also talk with other parents, professionals, friends and/or members of the community about their experiences obtaining funding for devices through the public school system and health care systems. Parents may also get information about assistive technologies, funding, laws and regulations from the Internet. The process may become more complicated under several possible circumstances: 1) The child had a previous evaluation at school and the parents want an updated assessment. 2) The child had a previous evaluation at school and the parents are seeking a second opinion, from an independent practitioner. 3) The
parents had an independent evaluation and the school disagreed with some or all of
the results and recommendations. 4) The parents and the school did not agree that
the evaluation was necessary. In order to resolve these situations, the parents and
the educational system must abide by complex health care regulations, complex
IDEA or Section 504 laws and regulations, as well as numerous local policies and
procedures.

**Submitting a Funding Request through Health Insurance:** The documentation
and procedures for submitting a funding request through a public or private health
benefits program involves multiple documents, multiple people and multiple steps.
The family and AAC evaluation team will need to work closely together to complete
the process. Most public and private health benefit plans have a prior approval
process that the parent and AAC team must follow when submitting a funding
request. The prior authorization process varies among health plans. In terms of
Medicaid, the prior authorization process varies among the states. Some states
require that the child receive a trial period of training with the device before
considering a funding request. Some states require that the child have trials with
competitor’s device. Some states require a copy of the child’s Individualized
Education Program. Most health benefit programs require that the AAC team provide
a written report detailing the child’s skills and needs. This written report is a very
important part of the funding process. It explains how the child’s current
communication needs are not being met by her/his communication skills and why the
SGD is a medical necessity. The report explains how the technology will impact the
child’s ability to function independently. When seeking funding from a health benefits
program, many AAC specialists use the Medicare documentation requirements for
SGDs\textsuperscript{18}. These requirements are available at http://www.aac-rerc.com/pages/medicare/RMRP.htm

While there are variations among plans, most health insurance programs also require written documentation from a physician to establish medical necessity. Some health benefit programs have an approved vendor list and the SGD must be purchased from a vendor on this list. If there is an approved vendor list, the AAC team must contact a vendor on this list. Often the vendor will work closely with AAC team. Some legal advocates suggest submitting additional letters of support from other individuals who know the child, such as physicians, therapists, a psychologist, school personnel, case managers, family members, personal care attendants, neighbors (Golinker, 2006a). The family will often assume responsibility for obtaining these letters of support.

After all the documentation is obtained, the vendor works directly with the insurance company to advance the funding process. The funding process is more complicated when more than one health insurer is involved. Some children have benefits though a Medicaid program as well as benefits from a private health insurer. In these cases, Medicaid is the payor of last resort (42 C.F.R § 433.139). If the private insurer does not cover speech generating devices, this information must be obtained in writing before Medicaid will consider the request. Many health benefit programs impose a cap on durable medical equipment, the category most commonly used for speech generating devices. In these cases, Medicaid may fund the amount that the private health insurer does not pay (Golinker, 2006a)

\textsuperscript{18} Effective 1/1/ 2001 Medicare began covering speech generating devices as durable medical equipment under §1861(n) of the Medicare Act. Details can be found at: http://www.cms.hhs.gov/manuals/pm_trans/R158CIM.pdf.
The Health Insurance Appeal Process: If the health benefits program denies the request, the family may have the opportunity to appeal. Some states have laws that provide some due process rights while other states do not. Moreover, it may depend on the plan as to whether such rights apply at all. There are many health insurance plans and many different procedures to follow. When health benefits programs deny a request, some will inform the applicant of the decision through a written notice. The written notice may include the reason(s) for the denying the request and specify the appeal process, if there is one. In terms of public health insurance programs, the federal Medicaid law requires that the beneficiary receive a reasonably prompt written notification of the denial. The notification must include the reasons for the action, the specific regulations supporting the action, and an explanation of the person’s right to request a hearing (42 C.F.R. §435.912). Medicaid due process protections include a fair hearing and the ability to be represented by an attorney or other representative. The beneficiary has the right to review the case file and all documents as well as call witnesses. Medicaid programs have been challenged in court for untimely notices, failure to provide a fair hearing or conduct proper fair hearing (O’Connell et al, 2004). The Assistive Technology Law Center recommends that families seek an advocate in every circumstance. (Golinker, 2006a).

Families and AAC Intervention: Research indicates that families play a vital role in supporting a child’s use of an AAC device (Angelo, 2000; Angelo et al, 1995; Bailey, et al., 2006; Binger, et al, 2008; Goldbart and Marshall, 2004; Hetzroni and Harris, 1996; Huer, 1997, McNaughton et al., 2008; Parette and Angelo, 1996; Parette, Brotherson, et al, 2000; Huer and Soto et al., 2006). Families are actively

This coverage decision was the result of intense lobbying by ASHA and others, submitted to Medicare on December 30, 1999. The formal request for national coverage of SGDs can be found at: [http://www](http://www)
involved in making decisions concerning AAC systems for their children and work collaboratively with AAC practitioners. Therefore, assistive technology specialists have long advocated a family-centered, team approach to AAC decision-making (Angelo, 2000; Beukelman and Mirenda, 2005; Grandlund et al., 2008; Hunt et al, 2002; Parette and Brotherson, 2004; Parette, Brotherson et al., 2000, McNaughton et al., 2008). This approach involves collaboration among family members and other specialists.

Research indicates that family involvement in training to use SGDs contributes to a positive outcome. This means that when parents receive adequate education and training, the child learns to use the device more effectively (Angelo, 2000; Bailey, et al., 2006; McNaughton et al, 2008; Parette et al., 2001). Under IDEA the public school system is obligated to provide any necessary training for the child, parents, and team of educators working with the child, to ensure that the child is making progress and benefiting from the educational program (34 C.F.R. §300.6(d)-(f)). Alternately, if the family and/or child has health insurance, this training may be a covered benefit. Some families may seek training within both the school and a specialized assistive technology program, if available in a family’s geographic area.

Studies indicate that family members are actively involved in many types of collaborative decision-making activities concerning implementation of SGDs. These include selecting vocabulary, programming the device, troubleshooting problems, daily maintenance of the device, implementing interventions, and developing opportunities for AAC users (Angelo, 2000; Angelo, et al., 1995; Bailey et al., 2006; McNaughton, et al, 2008; Parette, Brotherson, et al., 2000). In studying AAC

augcominc.com/whatsnew/medicare/html.
decision making among a group of ethnically diverse families, Parette, Brotherson, et al., (2000) found that families of all ethnic groups wanted to collaborate with professionals in the AAC decision making process. All families wanted more information, education, and training concerning the device. When a family was not involved in the decision making process, there was partial or complete abandonment of the AAC system in the home and community. When families collaborated with professionals, abandonment was minimized. McCord and Soto (2004) and Huer et al., (2001b) found that Mexican-American families supported the use of SGDs for their children at school but less so at home. In the home environment the families preferred other, more intimate forms of communication, such as eye contact, facial expressions and physical affection. In a survey of the needs of parents with children who use SGDs, Angelo et al., (1995) found that the mothers’ and fathers’ priorities differed. The mothers’ top three priorities were ensuring that children had opportunities to use the device in the community, with other users and non-disabled peers; developing community awareness and support, and increasing knowledge of devices. In contrast, the fathers’ top three priorities included increasing knowledge of AAC systems, knowing how to operate and maintain devices, and planning for the child’s future communication needs.

In some studies, families reported they were not satisfied with the AAC services they received. Families reported limited access to information about AAC devices and services. This problem was more prevalent among undeserved, minority groups (Bridges, 2004; Bridges and Midgette, 2000; Parette et al., 1996). Some families stated that professionals needed to better understand them and their culture (Parette, Brotherson and Huer, 2000). Other families reported much frustration with operating the SGD. In some cases this caused families to abandon them (Angelo, et
al, 1995; McCord and Soto, 2004; Parette and VanBiervliet et al., 2000). Among a group of parents involved in a focus group, the most commonly reported problem was lack of knowledge and experience among professionals. Parents thought that this resulted in delayed or inappropriate treatment interventions. (McNaughton, et al., 2008).

**Culture and Language:** Health care providers and educators work with an increasing number of families from culturally and linguistically diverse backgrounds who may have belief systems, values, and cultural assumptions that differ from their own. It is crucial that AAC specialists understand the social and cultural influences that may affect their practices. What are the cultural and demographic characteristics of families who have children with disabilities who attend public school and receive special education services, as defined by IDEA? This study examined this data from two sources: 1) the 24th-28th annual reports to Congress by the Department of Education, Office of Special Education and Rehabilitation Services (OSERS) on the implementation of IDEA, and 2) multicultural research in AAC, primarily case studies. Results are discussed below.

**OSERS Annual Reports to Congress:** These reports indicate that compared to the general population, children who receive special education and related services tend to come from households which are poorer, lives in households with parents who have lower educational levels and most children are from a racial/ethnic minority. According to the most recent report, the 28th annual report, (DOE, 2009), a greater percentage of poor students received special education and related services than did non-poor students in each grade. For children ages 3 through 21, American Indian/Alaska Native children and Black children were more likely to receive special
education services than all other racial groups combined. According to the 27th annual report (DOE, 2007), the percentage of the population receiving special education and related services was largest for American Indian/Alaska Native students (13.8 percent), followed by black (12.5), white (8.7 percent), Hispanic (8.2 percent) and Asian/Pacific Islander (4.5 percent). According to the 26th annual report (DOE, 2005), three-year-old children in poorest health were disproportionately from a racial/ethnic minority, lived in single parent homes and lived in households with limited income and without health insurance. Among older children there were significant differences between children with disabilities who received language arts instruction in special education classes vs. children with disabilities who received language arts instruction in regular classes. The children who received language arts instruction in special education classes were more likely than to be living with one parent or to be living in foster care, more likely to be from households headed by someone who was not a high school graduate and more likely to be from a household with another person with a disability. According to the 25th annual report to Congress (DOE, 2005) students with disabilities were more likely to be poor than students in the general population. Almost one-fourth of elementary and middle school students and one-fourth of high school students with disabilities lived in poverty compared with 20 percent of the general population. According to the 24th annual report (DOE, 2002), children receiving special education services were more likely to be living in households with incomes below $25,000 than children in the general population. However, that group had declined by almost 33 percentage points by 2001, compared with a 19 percentage point decline in the general population. At the same time, the proportion of students with disabilities living in households with incomes of more than $50,000 increased by 30 percentage points, similar to the increase among students in the general population. In terms of
education level of parents who had children enrolled in special education, one third of mothers of poor children in kindergarten did not finish high school, compared with 7% of mothers of non-poor children. In terms of family constellation, the number of children with disabilities who lived in households with no biological parent was more than twice that of students in the general population.

**Multicultural research in AAC:** Research has been examining the impact of culture and language on AAC outcomes. Results of these studies detail some variations among cultural groups with respect to perception of disability, child-rearing practices, value placed on education, value placed on rehabilitation, and family involvement in education and the rehabilitation process (Battle, 1993; Binger, et al., 2008; Ferguson, 2002; Harry, 2002; Harry et al., 1999; Huer et al., 2001a,b; McCord and Soto, 2004; Parette et al., 1998; Roseberry-McKibbin, 1997; and Salas-Provance et al., 2002). Some examples follow.

Salas-Provance et al., (2002) investigated the beliefs about disability in forty members of one Hispanic family (Spanish American). The researchers examined whether there were changes in beliefs systems over time and whether education, socioeconomic status, and/or language affected the beliefs. The investigators found that most family members believed that medically based problems, rather than folk beliefs, caused disabilities. There was little variation in beliefs based on age, gender, income or education. However, belief in folk causes and cures was significantly more prevalent among lower-income, less educated, and older people.

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19 Sheila Bridges (2004) reviews the challenges faced by researchers who conduct multicultural research in AAC.
McCord and Soto (2004) conducted an ethnographic study to investigate the experiences of Mexican-American families with school aged children who used SGDs. They found that family-centered decision-making concerning the SGD was lacking. Families reported they were not asked to participate in school meetings. When they were asked to participate, many families could not attend because of their work schedules. Furthermore, some meetings were held in English and families could not participate. In terms of the SGD, most family members stated that they supported the use of the device at school but less so at home. Families felt that using the SGD at home limited intimacy with their child. They preferred other modes of communication in the home environment, such as facial expressions, eye contact, and physical affection. Many family members reported they could not understand the speech synthesizers and the picture symbols used on the display. Many also reported that the programmed messages were not meaningful in the home environment.

Harry, Rueda and Kalyanpur (1999) conducted an ethnographic and participatory observation study of seven families who had children with moderate-severe disabilities. Among the families there were two African American families, one Trinidadian, two Hispanic (Dominican and Salvadoran), one Palestinian, and one mixed culture family, a Chinese-American father and Caucasian American mother. When describing their goals for the child, the parents frequently used the term “normal life”. The families gave examples, such as “go to school”, “have a job”, “have his own life”. The researchers also interpreted the term “normal life” to mean the parents desired their child to live independently. They soon realized that they misinterpreted what the families meant when they used this term. After they explored what the families meant, they realized that only one family - the mixed Chinese-American family - ever expected the child to live outside the biological
family. Most of the families expected the child to live with the parents as long as possible. Siblings were expected to care for the individual when the parents were no longer able to. Harry and colleagues also identified another theme. Most families felt the disabled child was unique and did not have to be compared to normal children. Based on this, some families rejected ideas from the educators to involve the child in activities with non-disabled peers.

Roseberry-McKibbin (1997) described the cultural beliefs and practices among Filipinos, an increasingly large group of people living in the U.S. She found several dominant cultural themes that are relevant to AAC practitioners. Among Filipinos, the family unit is of utmost importance. It is hierarchical, based on age. Grandparents have the greatest authority and power. Family members are expected to sacrifice for the good of the family. Older siblings, particularly girls, are expected to care for younger siblings. Children hold a special place in Filipino families and most families have several children. There is an emphasis on physical closeness and dependency. Interpersonal relationships are highly valued and group consensus is crucial. Thus, Filipinos typically avoid direct confrontation and do not publicly express their anger. While they may say “yes”, they may actually disagree. The Filipino culture has great respect for authority figures. While education is highly valued, this respect for authority figures can make it difficult for parents to advocate for their child or participate as equal partners in meetings. In the Philippines many families live in poverty and health care is scarce. Many tribal and rural Filipinos believe that witches cause illnesses. They seek folk healers for their medical problems. Many Filipinos do not discuss a child’s disability. A child with a disability causes the family to feel shame and the family may be stigmatized. The family may believe that God is punishing the child with a disability for the sins of the parents or their ancestors.
Parette, Huer and et al., (2002) examined African American families’ attitudes and beliefs concerning AAC practices and their disabled children. The researchers mentioned several cultural issues that may impact AAC practices and outcomes. In African American families the extended family plays a crucial role in caring for the disabled child. The extended family may include multiple family members as well as members of the community and church. The church is an important support network for many African American families. These investigators also found that African American families may have a degree of mistrust for professionals due to experiences with institutional racism and discrimination. Therefore, when interviewing families, practitioners need to be aware of this. Some African American families reported they were reluctant to use an AAC device in the community. Some families did not want to call unnecessary attention to the child. They feared that the stigma associated with the disability might be exacerbated by the child’s racial background. The investigators noted; however, that African American families expressed a strong desire for their child to be independent. They expressed a high degree of interest in learning how the AAC device would promote independence in the community.

These examples may illustrate some of the differences between Euro-American and non Euro-American cultural beliefs. Mainstream Western beliefs are deeply rooted in objectivity, individuality, personal choice, and equality. Western cultures emphasize independence and parental responsibility. Western cultures also emphasize individual achievement and parents are considered responsible for advocating for their child to obtain the services they need. These attitudes and beliefs are rooted in our healthcare and education laws. For example, parental involvement and rights are key
components of the Individual with Disabilities Education Act and have been strengthened in subsequent reauthorizations (Meade and Paige, 2008).

These studies underscore that AAC practitioners need to understand a family’s attitudes and cultural beliefs about augmentative communication in order to foster a positive outcome for the child. To achieve this Kalyanpur and Harry (1997) advocate a “posture of cultural reciprocity” when working with families of different cultures. This perspective focuses less on the individual and more on the culture of the individual. It emphasizes examining the cultural underpinnings of beliefs, theirs as well as the practitioners; and engaging in explicit dialogue with families to discuss the differences. In working with culturally diverse families, several AAC assessment models have been proposed. Most focus on determining the access and opportunity barriers a child may experience when using an AAC device (Parette, Huer and et al., 2002). In contrast Hertzoni and Harris (1996), Huer (1997) and Parette (1998) advocate assessment models that focus on examining cultural values and beliefs. Huer (1997) proposes a “Culturally Inclusive Assessment of AAC Model”. This model incorporates specific interview strategies to help practitioners self-assess their beliefs and assumptions, as well as methods for conducting a culturally sensitive needs assessment.

**Racial and Ethnic Health Disparities:** There are other factors to consider that may affect a family’s access to and quality of care. It concerns racial and ethnic health disparities in healthcare. Ever since the Institute of Medicine released its report revealing racial and ethnic disparities in healthcare (Smedley et al., 2003), there have been numerous reports documenting similar findings. Studies have found consistent and persistent disparities in treatment affecting African Americans and
Hispanic patients in particular and a disproportionate impact on women of color. Disparities have been documented in routine care as well as high technology treatments and only a small percentage of disparities were attributed to problems with health insurance (AHRQ, 2008, 2007; Beach, 2006; Betancourt et al., 2005; Mead et al., 2008; Sohler et al., 2003). No study has explored how race and ethnicity may influence access to augmentative communication devices and services by families and children.

We can see that families will interact with a variety of people as they seek assistive technology devices and services for their children, based on rights and entitlements under IDEA or through health insurance. Sociolegal scholars use the term *legal consciousness* to describe how people experience the law within a social context. To date no study has explored how families get involved in the referral, evaluation and funding processes and no study has explored how families learn and think about the law while involved in these activities. In the next section I define the term *legal consciousness* and review studies that have explored how the law has impacted the lives of ordinary people.
Chapter 4

Legal Consciousness and the Social Construction of Law

Legal Consciousness and Legality Defined

As discussed in Chapters 2 and 3, families interact with a variety of people and face multiple decisions concerning funding for assistive technology devices and services for their children. They may have disputes with public schools and health insurers concerning referrals, evaluations, funding and implementation of speech generating devices. How do families make these decisions and try to resolve these disputes? Since most disputes do not reach the formal institutions of law (Abel, 1995, 1991, 1984; and Munger, 2003; Ewick and Silbey, 1998; Felstiner, 1980-81, Galanter, 2006, 1974; Sarat, 1981) how do we study the dispute process?

Sociolegal scholars have discovered that most legal activity takes place outside the formal institutions of law, involving interactions among professionals and non-professionals during daily routines. These interactions take place within family, the workplace, within neighborhoods, schools, and the community (Ewick and Silbey, 1998; Engel, 1995, 1993, 1991; Felstiner, 1980-81; Merry, 1990a,b, Sarat, 1981; Yngvesson, 1988.). Therefore, to study how law impacts the lives of ordinary people, we must examine how people think and act in relation to the law as they go about their daily lives. Sociolegal scholars use the term legal consciousness to refer to how commonplace interactions may shape peoples’ perceptions of the law and consequently influence their actions. The study of legal consciousness builds on a

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To examine how people think and act in relation to the law, the definition of law must be broadened to include the social context within which law is experienced. Ewick and Silbey (1998) propose the term “legality” to capture this concept of law: “meanings, sources of authority, and cultural practices that are commonly recognized as legal, and associated with legal concepts and terms, regardless of who employs them and for what ends....even if the meanings are not associated with its formal institutional boundaries”. (p.22, 23)

In contrast, Ewick and Sibley (1998) define the term “law” as the formal legal actors and institutions. These terms and definitions have been adopted within this research study.

Some sociolegal scholars contend that the study of legal consciousness draws upon the constitutive perspective of law (Ewick and Silbey, 1998, 2003; Nielsen; 2000; Seron and Munger, 1996; Yngvesson, 1988). The constitutive perspective emphasizes that law is embedded in history, culture, and belief systems and therefore shapes ideas. In contrast to the institutional perspective of law, in which law is viewed as external to social relations and practices and functions primarily to regulate aspects of social life, the constitutive perspective focuses on how law influences meaning and shapes social practices. Those who adopt the constitutive perceptive stress the reciprocal relationship between law and social context. This

refers to the ways that law forms identity and experiences, how law permeates social life. Law is viewed as one component that constitutes the everyday practices and systems of meaning. These practices and meaning systems give form and meaning to the law. According to Sarat and Kearns (1998) law has “meaning-making power”. (p.28)

“Even when people are not familiar in detail with legal rules and doctrines, their habits or mind and social practices will tend to be highly legal in character.” (p.28).

Sarat and Kearns use the term “legal in character” to emphasize that the law is infused in social life and it is constructed and reconstructed in conversations and arguments. The law emerges as a feature of social relations rather than an external force imposed on social life. Furthermore, Sarat and Kearns describe the law as more “diffuse” (p. 28) than the formal legal mechanisms. It is shaped by more than formal legal factors. The law is shaped by people and institutions that are embedded within local cultures through cultural codes, vocabularies, values and conventions. Ewick and Silbey (1998) refer to this aspect of legality as cultural schemas. Cultures also produce and differentially distribute resources and human capacities, such as wealth, education, legal knowledge, political power and some schemas are dependent on resources to sustain it. Thus, legality consists of a culture of law, a culture comprised of people whose interactions and practices are shaped by complex and diverse cultural schemas and resources.

**Studying Legal Consciousness**

Studies that examine legal consciousness use interpretive research methods, specifically in-depth personal narratives, in order to understand the way people understand and use the law. Narratives are not simply descriptions of what
happened. In stories of law, narratives have a normative aspect. They describe a person’s beliefs about the way they should act and why the law should or should not be obeyed, resisted or mobilized.

Ewick and Silbey (1995, 2003) describe narratives of law as “subversive stories” and “hegemonic tales”. They claim that narratives of law often reveal the institutionalization of power and disparities in power among individuals. Disparities in power can influence how people think and act in relation to the law and influence whether and how people understand and claim their rights. Ewick and Silbey’s (2003, 1998, 1995) definition of a narrative was adopted in this research study. A narrative is a form of communication that has several structural components:

1. It includes past events and characters.
2. The events are temporally ordered; there is a beginning, middle and end.
3. Events and characters are related to each other, frequently based on a struggle or act of resistance.

According to Ewick and Silbey, resistance has three distinguishable features. Resistance involves the perception of having a less power within a relationship. Resistance also includes the perception of an opportunity to act to seek justice for an unfair situation. Lastly resistance involves a perception that the disparity in power involves a claim to seek justice and to attribute responsibility for an unfair situation (Ewick and Silbey, 2003).

Narrative research has discovered that people explain their actions to themselves and through stories (Bruner, 1990, Ewick and Silbey, 1995). Therefore, narratives

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provide a way to discover how law emerges as people recount experiences and
events. Furthermore, some authors argue that narratives can be a form of social
action. Through stories people not only reflect on their experiences but also relive
activities. This reconstruction of events and activities can influence future encounters
by sustaining meaning and also by creating new relations and meanings (Austin,

Several studies have analyzed narratives to determine how ordinary citizens
experience the law (Engel 1991; Engel and Munger, 2003, 2001; Ewick and Silbey,
1998; Greenhouse, 1994; Nielsen, 2000; Yngvesson, 1988). Some studies have
investigated how oppressed groups experience the law (Ewick and Silbey, 1992;
Other narrative research has examined how specific social groups experience the
law, such as social activists (Kostiner, 2003; McCann, 1994) and lawyers and their
clients (Sarat and Felstiner, 1988). Most of these studies affirmed the findings of a
research study conducted by Ewick and Silbey who interviewed a random sample of
430 adults in New Jersey, in the context of their everyday life (Ewick and Silbey,k
1998). Ewick and Silbey analyzed narratives to determine how individuals
experienced, interpreted and used the law. They identified 3 main forms of legal
consciousness that they described as “interpretive frames” (p. 1027). Each frame is
characterized by a set of normative claims, justification, and values. People invoke
these frames when interpreting their experiences with the law. Ewick and Silbey
labeled these frames “before the law”, “with the law” and “against the law”. In the
frame before the law individuals perceived the law as powerful and objective. People
frequently made reference to the formal institutions of the law, such as the

\[\text{(Ewick and Silbey's definition of a narrative incorporates concepts from Jerome Bruner, David Maines,}\]

\[\text{22}\]


impartiality of judges and conditions under which a person may or may not call the police or sue a neighbor. People were with the law when they perceived the law as a game whose rules could be manipulated. Individuals regard lawyers as the ultimate players in the game. In against the law people thought the law was arbitrary. They tended to distrust the law, and they regard themselves as “have nots”. They found ways to evade the law. Ewick and Silbey’s research revealed that these themes were context and temporally dependent. In other words the same individual expressed one or more of these views at different times and in different situations.

Few studies have examined the legal consciousness of people who have disabilities and even fewer have investigated how parents who have children with disabilities perceive IDEA. Research by Engel revealed that families of children with disabilities experienced the law during daily interactions with teachers and other school officials as part of the Individualized Education Plan (IEP) process (Engel, 1991, 1993). As described in Chapter 2, this highly procedural process involves an evaluation to determine a child’s eligibility for special education and related services, the development of the child’s IEP to determine needed services, and periodic updates to assess progress. Engel interviewed families of children with disabilities and educational officials to determine why and how the Education of All Handicapped Children Act (later renamed IDEA) differed from its stated goals. By examining the narratives of families and educational officials, he analyzed how interactions between these two groups shaped the process by which parents claimed their children’s rights and exercised their parental rights. While the law was intended to provide legal rights to children with disabilities and give parents rights to advocate for their children’s rights, Engel found that parents were conflicted about the law’s intent.

Haydn White and others. For details see Ewick and Silbey (1998) and Maines (1993).
They perceived that the law provided constraints and opportunities for their children. Furthermore, parent’s perceptions of the law were influenced by interactions they had with educators and these interactions influenced whether and how parents claimed their children’s rights and entitlements and asserted their parental rights. Here are a few examples:

- To qualify for services, a child must be considered disabled (20 U.S.C. §1401(3)) and therefore different from her/his peers. Some parents disliked what this term implied. They resisted having their children labeled “disabled” in order to qualify for services. Parent’s thought that this classification would be stigmatizing and stereotyping. They thought that this label could influence how educators interacted with their children and affect their expectations. Some parents preferred other terms, such as “speech impaired”.

- While the law established a cooperative decision making process between parents and educational staff, there were frequent disagreements among families and staff concerning the child’s skills and needs. Engel found that family’s narratives revealed that interactions and decisions were characterized by an imbalance of power between parents and professionals. Engel also discussed how parents and professionals viewed the children from different perspectives, which led to disagreements about the functional significance of the disability. For example, Engel talks about the “rigid dichotomization of parental and professional roles” and states, “because they perceived the child through different lenses, they tend to draw conflicting conclusions about the significance of the child’s disability”. (p.187).
- Most parents favored the intended benefits under IDEA. However, few parents understood the due process protections available under the law. Among those who expressed understanding, few were interested invoking these legal rights. Parents expressed concern that legal confrontation might jeopardize their relationship with school officials and their ability to obtain services for their children.

In another study, Engel and Munger interviewed individuals with disabilities to examine the impact the ADA had on their lives. The researchers examined how the ADA influenced people’s right’s consciousness and how the law influenced them in their career planning and jobs (Engel and Munger, 2003). In their analysis of narratives they found that the formal institutions of law played a minimal role for adults with disabilities. Engel and Munger state

“there was a complete absence of any attempt to invoke rights by lodging a formal claim or even by consulting a lawyer when confronted with behavior they perceived as unfair.” (p.96).

However, even when rights were not formally involved, the narratives reflected clear changes in individuals’ thoughts, language, and actions concerning their legal rights. Individuals’ perception of rights changed social interactions and their identity. Rights affected individuals work relationships and relationships with friends and family. For some individuals, their knowledge of rights empowered them to advance their education and careers. Thus, the law had indirect, yet powerful effects on these individuals. It increased their rights consciousness and thereby transformed their sense of self.
Engel and Munger identified several factors that influenced how individuals thought about their legal rights. These factors included: family, religion, community, education, class, race, and gender. When analyzing the narratives, Engel and Munger uncovered three shared discourses. They called these interpretive frames the discourse of racial justice, the discourse of the market, and the discourse of faith. Engel and Munger found that these discourses were widely discussed among the participants in the study and they were not mutually exclusive in any one narrative. In several narratives Engel and Munger found that two or more of these discourses were woven within a person’s life story, which is consistent with Ewick and Silbey’s work (1998).

Another sociolegal study examined the legal consciousness of a group of parents enrolled in an IDEA advocacy training program. In this study Barton (2004) analyzed the discourse among support group facilitators and primarily African American mothers. Barton found that group facilitators provided a relational perspective to advocacy rather than a rule-based perspective. Barton used the term relational to refer to how parents tended to advocate for their children based on their personal judgment and expertise - what parents believed their children needed or should have - rather than based on the application of the rules of law. While the advocacy curriculum cited specific IDEA regulations, the interpretation and dialogue between facilitators and mothers emphasized the regulations in relational terms. Moreover, Barton found that facilitators discouraged parents from pursuing their formal due process rights for two primary reasons – power and economics. Facilitators told parents that schools have institutional power over them and that invoking the law could be cost prohibitive. Barton argues that advocacy training should employ
relational and rule-based perspectives in order for parents to effectively advocate for their children under IDEA (Barton, 2004).

In conclusion, in order to study how people experience the law in their everyday lives, one must move beyond the formal institutions of law and study law in a social context. This research study was based on the theory of legal consciousness which examines how people think and act in relation to the law as a consequence of social interactions, and analyzes how law in action compares with the formal law. The next several chapters discuss the research methodology, based on these premises; followed by the results of the study and conclusions.
Chapter 5
Research Methodology and Design

Qualitative Research Methodology - Grounded Theory

In order to explore how law on the street compares with the formal law, we must examine law as a dynamic and variable process that is an integral part of social relations. Therefore we must examine what people do and say about the law as they go about their daily lives. Grounded theory is a middle range theory that uses qualitative research methods to explain the ways in which people construct meaning of their lives and is therefore well suited to examine the social construction of law.

Grounded theory methods, originally developed by Glaser and Strauss (1967), emphasize an analytic process. The methods involve “systematic inductive guidelines” (Charmaz, 2000) for collecting and analyzing data. This means that as data is collected, it is defined, coded, and categorized. The coding helps to further interpret the data. The coding leads to categories for explaining the data and to theory development. Grounded theory methods use analytic research strategies. Charmaz (2000) discusses 6 of these strategies which include: collecting and analyzing data, creating codes and developing categories, making comparisons, memo writing, refining emerging ideas through sampling, and integrating the theoretical framework. Making comparisons is a major technique in grounded theory. A researcher may compare people (e.g. their views, actions, etc) over a period of time, and compare data from the same person. Miles and Huberman (1994) describe cross-case analysis as analyzing individual cases and then comparing the analyses.
They contend that cross-case analysis enhances understanding and explanations. This type of analysis also helps ensure that processes are not wholly idiosyncratic.

Qualitative research methods are interpretive methods that examine personal experiences. These techniques focus on collecting data in natural contexts and examining how individuals construct meaning (Denzin and Lincoln, 2000). These methods enable the researcher to explore an issue from an individual’s perspective (Tetnowski and Franklin, 2003) and examine the constraints of everyday life (Denzin and Lincoln, 2000). This leads to an in-depth understanding and a rich description of phenomenon. Qualitative research methods were well suited for this study because it explored parents’ perceptions of the law which evolved and were constructed through their interactions with a variety of people.

**Objectivity and Subjectivity in Qualitative Research**

Some scholars have suggested that qualitative research methods permit the researcher to enter a field of inquiry in a relatively objective manner. For example, in the early stages of the research process, the researcher may adopt a rather broad focus of inquiry and may have a relatively loosely formed research question. Since qualitative methods focus on collecting data in natural contexts and exploring lived experiences, they capture the individual’s point of view and the constraints of the social world. Scholars have also noted that while the researcher tries to remain neutral, it is not possible to be completely detached from the process. The researcher has her/his own perceptions and convictions. Shulamit Reinharz (1997) argues that researchers not only “bring the self to the field... (we also) create the self in the field” (p.3). Guba and Lincoln (1981) discuss this concept when emphasizing the role of reflexivity in the research process. This refers to how researchers critically
reflect on the self, explore the multiple identities they bring to the process, and engage in self-discovery. Furthermore, most qualitative research methods are not passive processes. There is interaction between the interviewer and respondent. Miles and Huberman (1994) describe interviews as a “collaborated act” (p. 8). By that they mean that information is gathered by both the researcher and the subject. Ewick and Silbey (2003) refer to this collaboration when discussing how personal narratives are interactive. Narratives are told within a social context, specified by social norms. These social norms guide the rules of participation.

The researcher recognized that her role as researcher and her professional background could influence the research process. The researcher acknowledged that her interest in the subject, her expectations, knowledge of AAC, and thirty years experience in working with families to obtain funding for AAC devices could influence the process. The researcher recognized that families may inquire about her knowledge and experiences and this could influence their perceptions and their disclosures. It is also important to note that there are reason(s) why people tell stories. Ewick and Sibley note that people may tell stories to achieve some goal(s) – to persuade, entertain, instruct, obtain advice, etc (1995). Ewick and Silbey describe this as aspect of storytelling as “strategic” (1995, p. 208) and the strategic use of narratives can influence how narratives are constructed. Furthermore the researcher recognized that families may ask her opinion or advice. Therefore, to minimize this possible effect, early on, the researcher informed families that she could not give advice about the law, specific advice about funding, and could not prescribe assistive technology devices and interventions.

Research Methods: Data Collection and Analysis

Personal Narratives of Law
This study obtained personal narratives of law through in-depth interviews among families who obtained funding for speech generating devices or were in the process of obtaining funding for speech generating devices for their disabled children. As discussed in Chapter 4, this research study adopted Ewick and Silbey’s definition of a narrative (2003, 1998, 1995). According to these sociolegal scholars, a narrative is a form of communication that has several structural components. It includes past events and characters. The events are temporally ordered; there is a beginning, middle and end. The events and characters are related to each other, frequently based on a struggle or act of resistance. Narratives of law are more than descriptions of encounters with the law. They have a normative component. These stories describe people’s beliefs about the ways people should or should not act. They also tell about people’s decisions concerning the law, such as why they may mobilize, obey or resist the formal law, as well as their use of the law outside the formal legal settings (Ewick and Silbey, 1998).

By analyzing narratives of law, sociolegal scholars can learn how the law is interpreted in a social context, across time and space. This analysis can reveal how the perceptions of the law may differ from the formal law. Moreover, narrative analyses can help us understand why these gaps may exist and whether and how perceptions of the law ultimately influence rights under the formal law.

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23 Ewick and Silbey’s definition of a narrative incorporates concepts from Jerome Bruner, Irving Goffman, David Maines, Haydn White and others. For details, see Ewick and Silbey (1998), Maines (1993), and Maines and Bridger (1992).
Study Participants

This study was limited to families whose disabled children were between the ages 3-17 years. There were a total of twenty three interviews and ten of these were in-depth interviews to obtain personal narratives of law.

The study was conducted in two phases. Phase I involved preliminary telephone interviews with twenty three parents to obtain information about the funding source(s) for speech generating devices, the funding outcomes and the parents’ perceptions of the difficulty with funding versus implementation of the device. A four point rating scale was used for this purpose. During these preliminary interviews, basic sociodemographic data were collected including gender, ethnicity, profession, level of education and family income. These interviews were typically 20 minutes long. Based on these preliminary interviews, ten subjects were selected and asked to participate in Phase II which involved in-depth interviews to obtain personal narratives. These interviews were approximately two hours long. The participants in Phase II were from the states of Massachusetts, Pennsylvania, Rhode Island and Virginia. Initially the researcher planned to conduct the Phase II interviews in person and these parents were selected because they came from 4 different states and lived relatively close to the researcher. Due to personal circumstances the researcher could not travel and decided to conduct Phase II interviews on the telephone. No changes were made to the selection process because these parents had already agreed to participate in Phase II interviews.

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24 This study was approved by the Institutional Review Board, Office of Human Subject Research Protection, Northeastern University, Boston, MA. IRB#08-01-02.

25 The researcher discussed this issue with the IRB at Northeastern University. The IRB advised the researcher to maintain the initial selection process.
A two-phase process was chosen for several reasons. Firstly, it helped ensure that the size of the group was manageable for intensive study. Secondly, it enriched the study to have a group of participants who were from different states and who potentially varied in their degree of involvement with the law. While this research studied a similar process among participants (e.g. process for obtaining funding for speech generating devices), the researcher expected that individuals might conceptualize the problem differently. The researcher also expected that parents’ stories might be influenced by particular attitudes, beliefs, experiences and resources, which might generate different themes.\(^{26}\)

Why analyze whether and how ethnicity, socioeconomic status, gender, and level of education may be expressed in personal narratives of law? As discussed in Chapter V, few studies of legal consciousness have examined these factors. Among these few studies, researchers found that for some individuals these factors influenced their perceptions of the law and ultimately determined whether and how they exercised their rights (Ewick and Silbey, 1998; Engel and Munger, 2003; Nielsen, 2000). As discussed in Chapter 3, demographic factors are also important to consider because families who have children with disabilities enrolled in special education are poorer and less educated than families who have children enrolled regular education. Furthermore, based on research on ethnic and racial health care disparities (see Chapter 3), it is important to identify the participants’ ethnicity and explore whether and how they perceived this affected their experience with the law and the decisions they made. Since this project was exploratory and the research sample was small, there was no implication that the results would be generalizable. Rather, this study

\(^{26}\) My personal communication with Engel (2006) and Ewick (2006), each suggested this two phase method to enrich the study.
was interested in comparing families’ experiences concerning these factors and the meanings they attributed to them.

**Interview Format and Questions**

As noted above, the Phase I and Phase II participants were interviewed on the telephone. The Phase II interviews involved a semi-structured interview format. When interviewing families this format is suggested to help establish a rapport and acquire insights into a family’s views and perspectives (Westby, 1990). The interviews began with guide questions that were open-ended, “grand tour questions” or “experience questions (e.g. “Tell me about...”). This encouraged families to tell their stories. During the interviews the participants were asked open-ended questions for clarification or elaboration.

The interviews were designed to capture parent’s everyday experiences with legality. However, the researcher did not want to convey her own hypothesis about how legality is constructed. Thus, the interview was structured in three parts, similar to the design that Ewick and Silbey (1995) used. During the first part of the interview the researcher asked parents questions concerning when they first started thinking about getting a speech generating device for their children. This encouraged parents to talk about their interactions with a variety of people over time. After that, the researcher asked questions about what might have troubled the parents or bothered them, as well as what they thought went well. This encouraged parents to talk about particular people and events, their successes as well as disputes and grievances. The final part of the interview consisted of more closed ended questions. These questions addressed the parent’s formal legal knowledge, their formal legal experiences and
their perceptions of the effectiveness and legitimacy of legal procedures. Sample questions are noted in Appendix A.

**Analysis**

Interviews were tape-recorded for analysis. The researcher transcribed the transcripts verbatim. The data from the transcripts were analyzed using coding procedures, consistent with grounded theory, as described above. Each analysis culminated in a case study. Case studies are found in Appendix A. Each case study included quotes from the transcripts. These quotes preserved parent’s words. There was minimal editing. The editing involved eliminating some words that were unrelated to the meaning such as a series of “ums” and “you knows”.

There were three stages to the data analysis: early, interim and final. The early stage involved analyzing three cases and creating a preliminary list of categories and codes, using the research questions as a guide. The three cases were transcribed and coded and the list of categories and codes were revised to reflect emerging themes. The interim stage included a sequential analysis of case summaries, comparing and contrasting cases, entering codes on matrices and drawing conclusions about the data. The final stage of analysis involved completing case comparisons, drawing and verifying conclusions and creating a meta matrix.

**Recruitment**

The researcher contacted several organizations via telephone and/or email to determine whether they would agree to place a flier about this study in their service area. These organizations included assistive technology programs and parent advocacy programs. The researcher also contacted several on-line augmentative
communication user groups to request that they post a flier on the listservs. The following organizations and on-line groups agreed to participate in this manner.

**Assistive Technology Centers**

- Children’s Hospital, Communication Enhancement Center, Boston, MA.
- Rehabilitation Institute of Chicago, The Technology Center for the Environment and Communication, Chicago, IL
- The Woodrow Wilson Rehabilitation Center, Fishersville, VA.

**Organizations that Serve Families Who Have Children With Disabilities**

- Easter Seals
- United Cerebral Palsy

**State Assistive Technology Programs** (as described in Chapter 2)

**Augmentative Communication Listservs**

- AAC Special Interest Division of American Speech-Language and Hearing Association
- Augmentative Communication On-Line Users Group (ACOLUG)
- Promoting Augmentative Communication Together (PACT)
- Google Parents

**Parent Advocacy Groups**

- Family Voices, a national advocacy group for parents who have children with disabilities
- Alliance for Technology Access (ATA), a national and international network of technology resource centers, community-based organizations, agencies, individuals, and companies.
- Kids Together Inc., a non-profit information and resource center for children and adults with disabilities


**Background Legal Research**

This study included a comparison between federal IDEA regulations and special education regulations in each of the states where the Phase II families resided: Massachusetts, Pennsylvania, Rhode Island and Virginia. This comparison was conducted to determine the possible differences between federal and state regulations that could affect the evaluation process for speech generating devices (SGDs), funding of SGDs, implementation of the devices, children’s assistive technology rights and parents’ rights to advocate for their children. Since Medicaid is a primary funding source for speech generating devices for families (as discussed in Chapter 2), this study included a determination of the types of Medicaid plans within each of the four states and the criteria used to qualify children and families for Medicaid.

**Research Ethics**

While this was a low risk, exploratory study, the researcher recognized that some participants may be considered vulnerable. The participants in this study cared for severely disabled children, which can cause tremendous stress on families. The researcher also recognized that the participants may have experienced conflict, frustration, and disappointment when advocating for their children. Therefore, the researcher made efforts to ensure that families understood the consent form and the purpose of the study. The consent form indicated how to contact the researcher if the participant had questions. Also, after the participants received the consent form, the researcher contacted them to answer any questions they had and/or clarify information. When discussing the consent form and during the interviews, the researcher informed parents that they had the right to refuse to answer any
question. The researcher offered to discuss her results with the participants and provide them with a copy of the published dissertation.

The next two chapters discuss the results of the study and the conclusions.
Chapter 6

Results

The results of this study are discussed in three main sections:

I. Demographic Information
II. Funding Outcomes
III. Case Studies – Cross-Case Comparisons

I. Demographic Information

Table 1 illustrates the demographic characteristics of the participants.

Gender and Marital Status: There were a total of twenty-three participants in this study and all participants were mothers. All but two mothers are married and live with their husbands.

Geographic Area: The twenty-three mothers are from thirteen states. The ten mothers who participated in Phase II interviews are from the states of Massachusetts, Pennsylvania, Rhode Island and Virginia.

Education: Most of the twenty-three mothers in this study completed some college and ten of the mothers completed at least four years of college. Six of the twenty-three mothers completed an advanced degree. Five of the ten mothers in Phase II of the study completed at least four years of college and three of the ten had advanced degrees.
**Annual Income**: Among participants there was a wide range in reported annual family income, from no income to above $200,000. A total of five participants declined to provide this information. Among the Phase II families, annual incomes ranged from no reported income to $150,000. Three Phase II families declined to provide this information.

**II. Funding Outcomes**

**Health Insurance**

As seen in Table 1, health insurance funded speech generating devices in seventeen of the twenty-three cases. Among the twenty-three families, fourteen obtained funding for their children’s speech generating devices through a Medicaid program. A Medicaid program was the only payor for eight of these fourteen cases. A Medicaid program funded a device in combination with a private, employer-based health insurer in five of these fourteen cases.

Seven of the ten Phase II families decided to access their health insurance benefits to fund speech generating devices. Each had a positive outcome. In one of these cases the school purchased a device for the child but when the child got older, a different device was recommended and the parent decided to access her health insurance to fund this device. Among these seven parents, one received a denial through her private health insurance. This parent appealed the decision and won the appeal.

Among all ten Phase II families, a Medicaid program provided funding for five of the ten speech generating devices. In one of the five cases a Medicaid program was the only funding source. In two of the five cases, a Blue Cross/Blue Shield, employer-
based health insurance plan funded a portion of the cost and Medicaid paid the rest. In two cases, children received funding through a Medicaid waiver program. Based on Medicaid law, Medicaid waiver programs permit states to cover a broad range of services as an alternative to institutionalization for certain populations. These services may not be covered by a state’s Medicaid Plan or may extend coverage under the state’s plan. One child received funding through Section 1915(c) of the Social Security Act, home and community based services (HCBS) Medicaid waiver program. The 1915(c) HCBS waiver program provides services to individuals with a diagnosis of mental retardation who are medically qualified and are financially eligible based on their income and assets. One child received partial funding for a device through another Medicaid waiver program – the Kaileigh Mulligan Program (130 C.M.R. §519.007). This program provides health care services and equipment for children with complex medical needs.

The states of Massachusetts, Pennsylvania, Rhode Island and Virginia each have several state funded health insurance programs that cover children and may fund speech generating devices. Two of these Medicaid programs funded speech generating devices for children in this study. A brief description follows.

Massachusetts

The children in four of the Phase II families have Medicaid coverage through a MassHealth program. Three are covered under the CommonHealth program (130 C.M.R. §450.105 (E). This program provided funding for the childrens’ speech generating devices. CommonHealth provides Medicaid benefits to children and adults whose are disabled and whose incomes are too high to qualify for MassHealth Standard (130 C.M.R. §450.105 (A). In terms of eligibility, there is no income limit
for MassHealth CommonHealth. However, based on monthly income, a family may need to pay a premium or meet a one-time-only deductible, if their monthly income is above 100% of the federal poverty level. In this study, parents of the children who receive benefits under this program reported that while they paid a premium, they felt it was worth it because it paid for durable medical equipment. One parent reported she had significant difficulty applying for this program for her son. She was repeatedly told her child did not qualify.

One parent reported her child receives health care services through the Kaileigh Mulligan Home Care Program (130 C.M.R. §519.007). This waiver program provided partial funding for the speech generating device. This is a waiver program designed for children under the age of 18 years who have complex medical needs. As noted above, Medicaid waiver programs permit states to cover a broad range of services as an alternative to institutionalization for certain populations. This program aims to help severely disabled children remain at home. To qualify a child must be severely and permanently disabled, based on the Title XVI disability standards and definition in accordance with 130 C.M.R. 515.001. The child must require a level of care equivalent to that provided in a hospital or nursing care facility in accordance with 130 C.M.R. 519.007(A)(3) and (4). The child must have less than $2,000 in countable assets and $60 or less in countable-income. A family's assets and income are not considered.27

Pennsylvania
The speech generating devices for the two children from Pennsylvania were funded through the family's employer based health insurance coverage. However, the parent
reported that both children receive other health care services through Pennsylvania’s Consolidated Waiver Program, a Home and Community-Based Services (HCBS) waiver program. The Consolidated Waiver program is designed for individuals age three and older with a diagnosis of mental retardation. To qualify, the person must be recommended for an intermediate care facility based on a medical evaluation.\textsuperscript{28}

Rhode Island
While the speech generating device for the child from Rhode Island was provided and funded through the public school, the parent reported that the child receives health benefits through the Katie Beckett HCBS waiver program. This program provides health care services and medical equipment for children under the age of 19 years with long-term disabilities or complex medical needs who live at home. To be eligible, the child must need a level of care typically provided by a hospital, skilled nursing facility or institutional care facility as defined in 42 C.F.R §435.225 (b)(1), and meet the criteria for childhood disability as defined under Title XVI of the Social Security Act. Eligibility is also based only the child’s income and assets.\textsuperscript{29}

Virginia
In this study, one family from Virginia received funding for her child’s speech generating device through the The Mental Retardation/Intellectual Disability Waiver Program (MR Waiver) (12 VAC 30-120-213). This waiver program provides services

\textsuperscript{27} Additional information about these public programs can found at the Massachusetts Office of Health and Human Services website: \url{http://www.mass.gov/masshealth/}

\textsuperscript{28} Additional information about the state of Pennsylvania’s health insurance programs can be found at the Department of Public Welfare Office of Medical Assistance: \url{http://www.dpw.state.pa.us/OMAP/}

\textsuperscript{29} Additional information about this program and other public health insurance programs in the Providence of Rhode Island can be found at the Rhode Island Department of Human Services website: \url{http://www.dhs.ri.gov/dhs/famchild/dfcmap.htm}
and equipment to children and adults who have a diagnosis of mental retardation or are under 6 years old and at risk for a diagnosis of mental retardation. The individuals must also be at risk for placement in a public or private intermediate care facility (ICF) as defined in 42 C.F.R. §435.225. The most common diagnoses include cerebral palsy, epilepsy and autism. To qualify the individual’s income level must be 300% of the current Supplemental Security Income payment standard for one person. The Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (VDMAS) administers the program.\(^{30}\)

**Public School**

As seen on Table 1 the public school system provided funding for speech generating devices for four of the ten children in the Phase II group. Each of these four families had unique personal circumstances, which influenced this outcome.

The parent from Rhode Island pursued funding through the school because of resistance she encountered from individuals involved in the health insurance funding process. Her physician and the school speech-language pathologist refused to complete the paperwork required by child’s health insurance. While she considered pursuing the process, she changed her plans when the speech-language pathologist said she would withhold treatment in order to complete the paperwork. The parent then pursued funding through the public school. While she was successful, the process involved many disputes. She filed a formal complaint after the public school and the private school (recommended by the public school) could not agree about

\(^{30}\) Additional information about this and other programs may be found at the Virginia Department of Medical Assistance website. [http://www.dmas.virginia.gov/](http://www.dmas.virginia.gov/)
who was responsible for an augmentative communication evaluation and for funding the speech generating device. She prevailed but continued to have problems with implementation of the device at school.

One of the two parents from Virginia reported her health insurance excluded speech generating devices. She based this on written information she obtained from the plan and she did not pursue the matter. Over the years the public school system provided devices for her son to use, though she was highly dissatisfied with how the devices were implemented.

The parent from Massachusetts reported that over the years she purchased low technology devices for her son to use with her personal funds. The school also provided low technology devices for him to use. This parent reported she lived in a wealthy suburb and the school district had resources to fund some assistive technologies for the students. While she was confident her health insurance would provide funding, she indicated that she did not think her son was ready for a more sophisticated device. Thus, she did not pursue funding through health insurance.

The other parent reported that over the years her daughter had 3 different speech generating devices. Health insurance funded two devices and the public school funded the other device.
III. Case Studies and Cross-Case Analyses

The ten case studies are found in Appendix A. In analyzing the narratives, several themes were identified. These themes were categorized, coded and compared among the ten cases, as illustrated on the meta matrix found in Appendix B.

Themes from the narratives are discussed within the four following sections:

Part A: Parents’ Perceptions of the Funding Process Compared with the Funding Outcome

Part B: Parents’ Perceptions of IDEA

Part C: Parents’ Perceptions of Rights Under IDEA Compared to the Positive Law

Part D: Strategies Parents Used to Advocate

Part E: Strategies Parents Used to Obtain Knowledge About the Law
A. Perceptions of the Funding Process Compared with the Funding Outcome

Health Insurance Regulations: Empowered by an Orderly and Relatively Predictable Funding Process

As seen in Table 2, 16 of the 23 parents rated the funding process from “easy to slightly difficult”. Furthermore, based on the ten narratives, most parents regarded the funding process as something they could manage. This was because they perceived the process as relatively predictable and sequential. This perception evolved as they interacted with vendors, independent evaluators and other parents who helped them navigate the health insurance funding process. While parents reported some difficulties with the process, such as multiple steps, multiple documents, multiple people, and lost paperwork; few parents thought these issues were significant barriers. Rather, they described a process that was relatively structured and objective, with a sequence of steps that they could execute.

Nine of ten parents expressed confidence that their health insurance would provide funding for speech generating devices. It is important to note that all children in this group had multiple medical problems and most parents were familiar with health insurance benefits, particularly coverage for durable medical equipment. Most parents had prior experience with the process for obtaining medical equipment for their children through their insurance and each family had successfully obtained durable medical equipment for their children through health insurance. Based on the funding outcomes, the parents’ perceptions of their health insurance benefits were consistent with the funding results. Parents thought the process was orderly and manageable and each had positive outcome.
While few parents had knowledge of health insurance laws and regulations, the narratives revealed that this legal structure empowered them to pursue their children’s entitlements through this system. I use the term “empowered” to mean two things. The health insurance laws and regulations provided a legal framework for parents to envision justice and to challenge injustice. As a legal structure it empowered parents to assert their rights and to advocate for their children’s entitlements. In addition, parents also thought that the law had the potential to ensure their children could receive equal and fair treatment and parents were committed to this notion. The law was infused into their words and actions through everyday interactions.

**Factors that Influenced Parents’ Decision to Pursue Funding through Health Insurance**

The parents discussed two main factors that influenced their decision to access their health insurance to fund speech generating devices for their child. They explained that by accessing their health insurance for funding, rather than through the school system, they would own the device. They believed that ownership gave them control and autonomy over where and how the device was used. There was one other factor that influenced some parents’ decision to obtain funding through health insurance. Some parents did not have confidence that the school had the knowledge and resources to conduct an evaluation and determine the most appropriate device. Thus, they sought augmentative communication services outside the school system. Furthermore, most parents reported that the independent evaluators and vendors helped them with the funding process, which gave them confidence. In the following excerpts parents discussed these perceptions about the funding process.
**Ms. Blair** discusses an “organized funding packet” that she received from the vendor. She discussed factors that influenced her decision to access health insurance for funding: ease, confidence in benefits, ownership and concern that the school did not have the resources to provide the device.

When we applied—when we went through the process of purchasing the LEO, the people at assistive technologies had a very organized, thorough funding packet, which was very easy to—you know, they basically said, “Go to your doctor; have them copy this letter. Go to your state AAC clinician, and have them copy this letter. Make sure you have this, this, this, and this, and send it to us.” ....When she recommended the LEO, she included the Web site and a—you know, a photocopy of the information about how to contact the company to get a funding packet. So I assumed that that’s just—you know, was a very easy way to handle it, and it was.

...Since we could use it, and it would cover the whole thing, and we still want the autonomy to have our own device that we could use outside of—out of the public school setting, we—that’s why we decided to go for insurance.

And also, I didn’t—I couldn’t even imagine how much time it would take for them (the school) to figure out, you know, how to access—maybe the money for that school year’s budget is—maybe they—you know, if the money for that school year’s budget was already spent, where were they going to pay for a device for X to use in school? And where were they going to find it?

This parent, **Ms. Hall**, described going through a funding process, which was long but rather manageable. She had the knowledge and confidence, which she attributed, in part, to prior experience using her health insurance to fund other
medical equipment for her two sons. An independent evaluator assisted her with submitting the necessary documents and the physician was supportive and helpful. The next round was my deal, with the communication device. And so, I had learned enough from her (a physical therapist) to know that once I knew the papers were submitted, calling the insurance company quite often was going to be a good thing. So I called, like, every two weeks after I knew all the paperwork had been submitted.

I kept in touch with Dr. X (the independent evaluator). She told me when she had submitted what she needed to submit... She wrote up the eval. I had to take the paperwork to the family doctor to get the prescription needs to say. And then—I don’t think he had to write an actual letter of medical necessity. I think just the prescription and signing off on the paperwork from the speech therapist was enough...She wrote the report, and I think all the doctor had to do was sign off on her report and write the script. And our doctors basically said, “You know what? Whatever. Other people recommend whatever the OTs, PTs, and therapists think your kids need. If you’re cool with it, I’m signing the paperwork, because they know their field and I know mine, and I know your kids are pretty sharp.”

We submitted paperwork to them, and then I just kept calling them, saying, “Is there any other paperwork you need? What’s the progress on this thing? Let me know if there’s anything else I can do to make this happen.”....I just called their 800 number, and I just hung out on the phone however long I was on hold, until I talked to somebody and said, “This is what I’m calling about. This is what I want to know. Do you need anything else?”—you know, that good old “I’m attempting to be helpful, but I want to keep reminding you that it’s been thus
and so long and I haven’t heard anything yet.” So then—and we had a little glitch in that they approved rental of the device, but they didn’t approve purchasing it at first. And I called them back and said, “You know, this is weird to me, because we didn’t submit for rental of the device. We submitted to purchase a device. We don’t need to rent one in the meantime. We just need to get one.” “Oh, okay, we’ll get that squared away.” And then, a week later, they did. And we were official. So the funding process was long, but it wasn’t horrible.

This parent described how she took an active role in the funding process, which involved multiple documents and multiple steps. Like other parents, she gained confidence in managing the process as she gained experience. She stated that “I just do it all.” Like several of the other parents, she stated that the vendor’s website was helpful. **Ms. Klass** stated:

Basically, just getting everything together—getting all your paperwork, making copies of all of your paperwork, sending it certified mail, calling a week to ten days after you mailed it to ask if they’ve received it—just making sure that they knew that we were on top of things. I think that helps.

Well, with the Merc, it was much easier, because this is our third device and they have the great Web site. With the first device, I relied heavily on the Communication Clinic (independent evaluator). They did it all. You know, they know we need whatever, whatever, and I just got it and brought it in. But I think parents need to take an active role. You can’t—I think we—just happened that that situation—the first one just happened to work. But now we—I just do it all. Well, I found that the Assistive Technology—that’s the company that makes the Merc—their Web site was so useful. I could click on their Web site, and I knew that I needed to get this letter, this documentation—“Copy your health insurance
cards; fill out this form”—I felt in control. I felt like I had a clue of what was going on. So I think that was huge.

Ms. Dean discussed her response to the denial by her insurance company. She appealed the denial and prevailed. While she had to “fight” them, her perception of the process was that it was orderly. Like other parents, she thought the school might pay for a device, but she preferred to go through health insurance. She stated that she did not want to be “owned” by the school.

But I had to fight them. I called them, and I wrote them, and I sent them a 32-page fax of pictures of my son using it and showing how cute he was and smiled. And I called the guy who was doing my case every day for two weeks….you know, you have to write a letter. You have to—and then if they don’t—and if they don’t—they review it and then they still don’t appeal, you can go to an in-person hearing. But I didn’t have to go there—do that.

... I knew that the school could pay for it and has paid for them for other people, but philosophically, I’m not really sure the school’s always the best place to do all this stuff – you know, provide all those services. I don’t—it’s the only way that they’ve defined this nation, but I don’t think the delivery mechanism is really appropriate, either. So I didn’t want it to be owned by the school; I wanted it to be owned by me.

Like several other parents, this parent indicated that while the school might provide a device, she decided to go through her health insurance. Like the seven other parents, she indicated there were two reasons she accessed her health insurance: ownership, which would give her control; and ease. She described the “red tape” she might experience if she went through the school. Like several of the other parents,
she described how the funding process was “easy” and she mentioned that the forms and the process were accessible on the vendor’s website. Ms. O’Brien stated:

So anyway, once we had selected the Vantage Plus, then it was time to try to order it and figure out who was going to pay. And basically, we knew that I wanted to go through our own insurance. And there was never any question about whether the school district was going to pay or not. I wanted this device to be owned by us...I guess because I wanted to be able to have the device in the home when it wasn’t in the school. And not that there would be any question on that, but I was also thinking about—you know, when she ages out of the district at 22, were we going to have to start looking at getting another device or, you know, returning this one to the school at some point? And just knowing how school district budgets work, I just didn’t want the red tape to hold up my daughter getting a device. So I just felt this was an easier route to go.

...And the other thing that kind of influenced my decision is—you know, we purchased the device from PRC, and I went on their Web site, and they have a whole section on funding. And, you know, it’s even—it is so detailed that you can even click on your state, and it tells you exactly what the requirements are for insurance—you know, state insurance and private insurance and the process in order to get the device approved. And it seemed like a fairly easy process as long as, you know, we filled out the correct forms. And I thought, “Well, I think I’d rather go this way, you know, for a $7,000 device. It looks like it’s going to be easier than trying to get this approved through the school.” And then we would have ownership of it, and I just felt better that, if it’s my daughter’s device, you know, we actually have the finally say on what’s going to be—how it’s going to be programmed and that type of thing.
...Yeah. I mean, they—it seems like they have experience working with all of the Medicaid state agencies and most private insurances. So, you know, they have developed applications and forms to submit right to the insurance company and any backup, you know, as far as input from speech therapists and school staff and the parents and, you know, how to submit it so we get, you know, the funding.

Similar to several other parents, this mother stated two reasons for accessing her health insurance for funding rather than the public school: confidence in obtaining benefits and ownership. This parent expressed one other reason: if health insurance purchased the device, she could negotiate with the school for other services. **Ms. Smith** stated:

  We almost always use our insurance to purchase equipment for our son, for three reasons. First, we then own the equipment; second, our insurance will cover it. We have private insurance (Aetna HMO) with excellent DME coverage if you use their preferred providers and we have MassHealth as well. Between the two, just about everything is covered. Third, if our insurance will pay for it, it saves our school system dollars and gives us more leverage to ask for other things. They have purchased some necessary equipment for our son over the years without complaint.

Like **Ms. Smith**, this parent mentioned that if she accessed her health insurance, her daughter’s school may pay for other services. **Ms. O’Brien** stated:
And I just felt that if my insurance can pay for this—that I would rather use my daughter’s school funds for things that it will not pay for, so it—like transportation and, you know, job coaching and that sort of thing.

In this excerpt, this parent expressed confidence in obtaining benefits for her daughter through a Medicaid program. Like some other parents, she stated that it is “easier” than going through the school.

**Ms. Von:**

Because everything we pretty much do, we go through Medicaid, because we get it done faster. And I know you’re going to go, “What? Medicaid, you get it done faster?” Yes, they are faster than the school system. That doesn’t mean we got it, like, the next day.....when you have Medicaid—I have to be honest with you—there’s not a lot of paperwork you have to do. They pretty much—the doctors or the therapist do write it; you sign what you need to sign, and they put it through.....There’s really—when it comes to Medicaid, I know people frown upon it, but I’ll be honest with you: it’s a major headache in some areas, but in other areas, like doing the paperwork, what you have to do with them is follow up with them constantly.

**Medicaid (42 U.S.C. § 1396 et. seq.): Up Against the Law**

**Difficult to Navigate but Worth It**

While many parents expressed confidence in obtaining Medicaid benefits and benefits through state subsidized waiver programs for their children, these same parents reported that the system was bureaucratic and difficult to navigate. One parent thought the renewal process was meant to threaten and intimidate. Another parent reported that the application for Medicaid benefits was so complex that she delayed
applying for benefits. Several parents reported that they networked with other parents to obtain information about navigating these systems. I use the term “up against the law” to describe the parents’ perceptions of the law as they responded to challenges with Medicaid. I have adopted this term from Ewick and Silbey’s\textsuperscript{31} sociolegal research.

In the following excerpts parents talked about the challenges they faced when applying for Medicaid benefits and the problems they had with navigating the system. Despite these problems, the parents were satisfied with the benefits.

One parent described significant difficulty applying for Massachusetts Common Health. She learned about an event featuring the Director of Public Health from a listserv and decided to attend the event to tell her story. After she attended the event, people contacted her to help her with the application. It should be noted that this parent works as a professional fundraiser. This case is a good example of how a parent networked to obtain information to navigate the system, which ultimately resulted in a positive outcome: the child’s application to Common Health was approved.

\textbf{Ms. Brady:}

So I was having a nightmare getting it—we ended up getting Common Health, which is the supplemental disability insurance through the state—through Mass Health. And they kept denying us, and I’m like, "I don’t want MassHealth; I want Common Health. I’m going to pay you for this. I just want it for equipment for my son," because I knew he was going to need the chair and, for the future, he’s

\textsuperscript{31}Ewick and Silbey (1998) used this term to describe how some participants in their research study were
going to need more equipment. And my personal insurance, you know, DME, is—
covers only $895, and all this medical equipment is thousands and thousands and
thousands of dollars.....Right, and I—even though I filled everything out wrong, it
was just one thing. So I’m, like, getting annoyed. So I hear that the new Director
of Public Health—Depart—Director of the—or Department Head, whatever his
name—title is, X.....So I hear he’s going to perform—he’s going to be in
Worchester like, in—just south of Worchester. So I’d say, “All right.” I—it comes
on “Mass Family Voices,” which is a listserv and everything. So I hear—read this
thing, and I go to this meeting. I sign up, and I go to this meeting, and I drive
my little sorry self out to Worchester and I’m ready to do battle....And it’s a CHNA
meeting, C-H-N-A, Community Health Network Alliance or something like that,
for south-central Massachusetts. When I go, there’s got to be 40 people there,
because, you know, they’re meeting X right? He’s a good guy. I’m the last
person, oddly enough, to speak. I’m in the middle of the room; it shouldn’t
happen that way, but it did. And I—you know, at the—I said, “I’m a parent; I
didn’t know this was really a provider thing, so I apologize. And I’m from X,
Mass; I’m not even part of your district; I apologize. But I can’t get my son to get
approved for Common Health; nobody knows what the hell Common Health is.
And you know, I wanted to come meet you, because you’re the leader, and you
should know that this is ridiculous. And I’ve made 17 phone calls, and no one
knew—of the 17 phone calls, 16 did not know what the hell I was talking about.
And I’ve lost—my case is lost, and it’s been—I’ve been denied four times. And
finally, after I met X the next day I got four—I got two calls from two different
people [laugh], and then I got calls from those people until it got solved, which
was less than a week later [laugh].

cought up in the law and resisted the law in various ways.
In the next example, the parent reported that her case manager did not know that the waiver program might fund assistive technologies for her daughter. The parent told the case manager that she had a friend whose child obtained this benefit. The case manager then checked the benefits and helped her obtain a laptop computer for her daughter. This is a good example of how networking helped this parent obtain information to navigate the system and ultimately claim her daughter’s rights under the law. **Ms. Von** stated:

But anyway, so we came out here, and they didn’t actually have a case manager for her out here. So she was under the direct supervision of the supervisor for a while. So we didn’t get much done, because, you know, he could never manage to find time to come out and do the monthly—you know, whatever they do—kind of thing. So finally I find her a case manager—you know, a permanent case manager—and she started to come out very sweetly—she’s still with us today—very sweet lady, but not a clue about a lot of stuff that’s going on. So basically, we learned together. So I’ve mentioned stuff about, you know, a friend of mine whose child got equipment through the MR waiver, and how she did it. And I said, you know, “Can we do this for X?” And she’s like, “I don’t know,” but she’s, “what did she call it again?” And I told her, and she’s, “Well, let me go and look at up.” Well, she called me about two weeks later, and she said, “Oh, yeah, they do have some technology available—you know, funding available, and you have $5,000 a year.” You know, that’s a lot of money.

Another parent discussed her problems with the Medicaid program. She discussed problems with accessing information due to staff who gave conflicting information.
and a renewal process that she believed was meant to intimidate. Despite these challenges, she satisfied with the benefits. **Ms. Smith** stated:

If you never have to call them, you just stay away. They are so messed up, especially when you’ve been used to dealing with, like, Blue Cross, where they’re so good. And Aetna’s okay, but, oh, gosh, depends who you talk to there. They’ll (Medicaid) tell you totally different things. So I can honestly tell you, I probably haven’t talked to a person there in years... And we had to—I had to send in the paperwork that’s sent to me. They decide my premium; we also have premium assistance; they pay that. And, you know, I also get PCA hours. I get—but that hasn’t been a problem, either. They’ve covered everything that I’ve submitted, so there hasn’t been a problem...

...Oh, it’s daunting. Oh, yeah, they’re horrible, horrible—the first ones, I guess. But, you know, you’ve just got to get over that and just do it. And then they send you one every year, and it’s not so bad.....And that’s about once a year. Other than—they never call or anything; you just get threatening letters, you know. And besides, I haven’t gotten any threatening letters in a while. “Unless you reply, your services will be cut off,” you know. Oh, please. None of that happens, actually. It’s just—they send threatening letters....

... Yeah, you know, the pa—I get a lot of questions about MassHealth. You know, people are like, “Oh, really? Is it worth it?” If you have a child with any durable medical, it’s definitely worth it. I mean, his braces alone are $1,600 each, you know. So it’s definitely worth it. But if you have a child with autism or something and you don’t have that, yeah, you get PCA hours, but that’s going to cost as much as your insurance premium, you know. But in our case, it’s, you know—it’s
pretty much a requirement. How am I going to—I mean, his wheelchair costs as much as a car.

Another parent expressed similar thoughts— the application process was intimidating.

**Ms. Blair:**

Since X was born we’ve been meaning to apply for Mass Health supplemental insurance and I look at that form and I don’t want to start the process.

Another parent turned to her state Senator due to difficulty applying for benefits through a Medicaid waiver program. **Ms. Cole** stated:

We have private Blue Cross through my husband’s employer and what they don’t pay the state Medicaid waiver called Katie Beckett covers usually without question. We must apply yearly now for this waiver and am always made to feel like he won’t qualify from year to year....We were told about the Katie Beckett waiver from Early Intervention after X had his second hospitalization. I had no idea what it was all about but knew it was important the way our service coordinator delivered the info to us. It was so difficult to get a return phone call that I needed to contact our local Senator to finally get an appt. Senator X continues to be a great advocate for us when we need him.

This same, **Ms. Cole**, parent explained that she thought the yearly process for qualifying for benefits was difficult because of budget problems. She thought that some children were enrolled in this program who did not qualify and the state took action to remove them from the program. In terms of the qualifying process, the parent indicated she believed the assessment was somewhat arbitrary, “can be a matter of personal opinion.”
The state's budget is in dire straits and so cuts have been everywhere. Once upon a time, all kids who needed help were placed on Katie Beckett with the thought that helping them now would save money in the long run. X qualified for this program well before his diagnosis and only because he was significantly delayed in all areas and he was beginning to have medical issues around age 14 months. Now, it's all about saving money. More than half the kids were thrown off the waiver, and rightfully so for most, but it is the state's intention to keep as many kids off the program as possible. I am told yearly that medical needs do not qualify a child alone, that they must be institution level of care. And since there is no model for this here, picking and choosing a child at this level can be a matter of personal opinion. We are sent an extensive packet to fill out, which I usually just copy and use from year to year. Copies of updated reports and medical are required as well and a determination is then made as to whether the child qualifies. It's quite nerve racking.

**Medicaid - The Payor of Last Resort**

Most parents thought that if they had private insurance and Medicaid benefits, Medicaid would be the payor of last resort. This perception is consistent with Medicaid regulations *(42 C.F.R § 433.139)*.

**Ms. Blair:**

And I think—I mean, from what I think happened, from my understanding, is that the—MassHealth *(130 C.M.R. § 503.007)* requires the private insurance to pay the full amount of their—whatever their—whatever our policy specifies.

**Ms. Hall:**
We have Blue Shield, and the boys also have the Medical Access card. So... We have to start with the Blue Shield, and then, if they deny, then Medical Access picks up.

...Dr. X (the independent evaluator) told me, and I also knew that from the funding for the power chairs.

Ms. O’Brien:

I contacted PRC’s funding department, and they kind of walked me through what I needed to do from then. I printed out all the forms that we needed, and it was two sets, because one would first go to Blue Cross, and then the other would go to MassHealth. ...o I called both Blue Cross and MassHealth, and Blue Cross said that it had been approved and they were sending the paperwork out. And then I heard—and I can’t remember who from—if it was—geez, I don’t remember who told me, but they said, “You know, your primary insurance says that it’s approved, but it’s only approved for how much they want to pay.” So, you know, that could be only, like, a small portion of it. So I called MassHealth, and I just remember the gentleman being super. And he said, “It has been approved, or it’s on the verge of being approved in the next couple of days.” And I said, “Well, what does that mean? Is that everything that the insurance—Blue Cross is not paying for?” And he said “yes.”

In summary, most parents were empowered by the health care insurance laws and regulations, though they expressed challenges with navigating the systems. While no parent cited a specific statute or regulation, most parents had confidence that health insurance would fund speech generating devices for their children.
**B. Parents’ Perceptions of IDEA**

*Empowered by the Law*

Of all the varieties of legal consciousness that parents expressed about IDEA, the concept of empowerment was the most overarching theme. As described above, I use the term “empowered” to mean two things. IDEA provided a framework for parents to envision justice and to challenge injustice. As a legal structure it empowered parents to assert their rights and to advocate for their children’s entitlements. In addition, parents also thought that IDEA had the potential to ensure their children could receive equal and fair treatment and parents were committed to this notion. The law was part of their everyday lives. It was infused into their words and actions through everyday interactions.

While each parent reported problems with implementation of speech generating devices at school, all parents in this study persistently advocated for assistive technology services for their children. I use the term “against the law” to describe parents’ perceptions of the law as they reported struggling with the public school to obtain assistive technology devices and services. I have adopted this term from Ewick and Silbey’s sociolegal research (Ewick and Silbey, 1998). Even when parents felt up against the law, they were empowered by the legal structure of IDEA, which enabled them to think about rights and to advocate for their children.

The narratives revealed several themes associated with empowerment. These themes are discussed in the following sections.

-IDEA: Achieving its Purpose
Three of the ten parents expressed thoughts about whether IDEA was achieving its purpose as written and intended. All three of these parents expressed confidence that IDEA enabled their children to receive a range of special education and related services, though they also reported dissatisfaction about accessing some of the services and the quality of services.

Two parents expressed somewhat differing perceptions of whether IDEA was meeting its objectives, but when you analyzed the narratives closely, there were some similarities. **Ms. Smith** thought the law enabled a child like her son to receive special education and related services and since her son had significant disabilities, she was confident that he would consistently qualify for services under IDEA. Thus, she thought she had little need to be concerned about the rules and regulations. In general, the law was in the background for her, though she thought she could depend on it if necessary. **Ms. Smith** also believed that IDEA would provide her child with a range of special education and related services. She had another perception of IDEA. She thought that it may be more difficult to obtain rights under IDEA for children with less severe disabilities. She thought that parent’s who have children with less severe disabilities may need to use the formal law to assert their rights and claim their children’s rights. In contrast, **Ms. Glade** thought that IDEA may better meet the needs of children with less severe disabilities. She believed that IDEA has failed her son. She thought that the teachers and therapists did not know how to educate her son, due to the severity of his disabilities. However, like **Ms. Smith**, **Ms. Glade** was confident her son would consistently receive special education and related services. Like **Ms. Smith**, she was less concerned about the degree of services, than the quality of services. Another parent, **Ms. Klass**, also expressed confidence in the law. She thought that the law would provide her daughter with the
services she needed. However, she expressed another view of IDEA: while the laws were there, the laws may not be interpreted or enforced properly. Therefore, she thought it could be difficult to obtain rights and entitlements.

While Ms. Smith, Ms. Glade and Ms. Klass each expressed some confidence that the law was on their side, each parent also described disputes with the school about their child’s entitlements under IDEA. Moreover, each parent used IDEA rules and regulations to solve some of these disputes. As noted above, Ms. Smith reported problems with implementing her son’s device in the classroom and in the excerpt below she indicated that she could have invoked her rights but chose not to. She stated she was not sure why she did not pursue her rights and his rights. Ms. Klass reported that she has resolved some disputes with the school about her daughter’s rights by using informal advocacy methods. Therefore, these examples from the narratives reveal how the law simultaneously empowered parents and constrained them.

Ms. Smith stated:

Because my son has significant disabilities that are obvious, he uses a wheelchair,

no one has ever denied him services of any kind. Can I say, they are being executed to the best of their ability? I don’t know. But they are giving them at the best of their ability in the broadest coverage. I think if you had a child who has less significant disabilities, I think those parents have more of a challenge than I do. Um you know, the kids with learning disabilities. I have a friend battling her school system now. He does well in some areas but can’t read. You know that’s tougher and you might have to pull in more laws and regulations and
things…. I learned about IDEA from attending Federation workshops. It's a subject parents would never need to know about until they have to! While I believe it's important for parents to know about, it's something parents can fall back on in a litigious situation. I have never had to rely on it for support.

Denise: What about when you were trying to get AAC devices and strategies implemented throughout X’s day? Did the law give you any options?

**Ms. Smith:** I never pulled that string but perhaps I should have.

Denise: Why not?

**Ms. Smith:** I’m not sure.

Ms. **Klass** stated:

As a parent, I think—I know she has a right to a—what's it—free and adequate education. But she has never been denied something that I truly believed she’s needed, so I have never had to investigate that or take it to that level. You know, there—I’m not saying it’s been easy. Just this past September, I wanted her to be able to go to the library at the high school, because we just—you know, our taxes just renovated this wonderful library God knows how many millions of dollars. And I was told that she couldn’t, because there was some Code in Massachusetts that said that the building had to be evacuated in under three minutes, which bothers me….So it kind of got my dander up a little bit. So I called the Fire Prevention Officer in town and asked him what the ruling was, because I found it strange that they had just built this huge library and built these great new staircases with wells on the outside of the building, but neither one could get a wheelchair out, and there were four kids in the high school that are all in chairs. So—he wrote—he’s also—he’s an educator (her husband). So he wrote a letter to the principal, the Director of Special Education, X’s liaison, and
the superintendent, and I delivered the letter. And within 24 hours, we had a
meeting with the Director of Special Ed, the principal, the Fire Prevention
Officer—So we ended up putting together an evac team, practicing the evac
team, getting people comfortable that them carrying her down in those little evac
chairs is not going to hurt her in any way as she’s laughing hysterically going
down the—and I think they just needed to be educated. I don’t think that they
were denying her something because they didn’t want to have to deal with it. I
think no one had ever challenged it before. And she has a right to be up in the
library and taking classes on the second floor as much as any other kid. And once
we pulled the team together and they knew that we were looking to work with
them—we weren’t working against them—it all worked out in the end.

...It takes a long time to write X’s IEP. We’re never within the
regulations....Because she’s so multilayered. She’s so physically involved but so
cognitively appropriate, age-appropriate, that at times it’s just that we, school
and me and technology—I don’t think we’ve caught up with what she can do. So
it’s all a trial and error. And then you have to make sure everything’s
measurable. You know, you’ve got to follow the guidelines. And she doesn’t fit in
a little perfect box. Yeah, and I don’t think I’ve ever rejected a full IEP. I know
that I have accepted parts of it, and we’ve added parts or taken parts out or, you
know, whatever.

**Ms. Glade** stated:

You know, I think particularly the more challenged the child is—you know, I think
if you have a child with, you know, mild learning disabilities or something like
that, you know, fine, whatever. But, you know, if you’re—you know, the way the
system is set up, for a child like X it’s basically—gives them the right to just kind of write him off….It’s very challenging to determine what he knows. And the school system is very hung up, to use a kind word, on knowing what the kid knows before they will move on to something else. So if they can’t prove that he knows something, -they basically stick with teaching him the same thing over and over again.

He got loads of resources. They couldn’t throw enough resources at him. You know, they kept increasing his therapy times. You know, people complain about the school system wanting to decrease their times and decrease their resources. We never had that. They would always increase his times.

-IDEA: Potential to Resolve Grievances
Four parents discussed their perceptions of IDEA’s potential to resolve grievances. 
**Ms. Von** expressed confidence in the IEP process and in her due process rights, though she thought that parents should carefully consider other dispute resolution strategies before filing for due process. In this excerpt you can sense that the law has empowered this parent to obtain her daughter’s rights and entitlements, though she continues to have disputes with the public school. **Ms. Klass** also expressed confidence in the law to solve grievances. She thought that IDEA provided a structure for parents to advocate for their children’s rights. **Ms. Dean** and **Ms. Von** are two of the three parents who invoked the formal law. Of all the parents in this small group, **Ms. Dean** expressed the greatest knowledge of formal law. She stated she obtained this knowledge by attending advocacy classes and in the following excerpts she describes how she helped the attorney prepare her case. She seemed empowered by the law. **Ms. Smith** expressed some disillusionment with IDEA. She
thought the law could not help her get her son’s device implemented in the classroom. However, she is one parent who invoked the formal law and successfully obtained a device for her child through the public school.

**Ms. Von** stated:

I would not sign the IEP, because the IEP was not meeting her needs....They wrote an IEP that I did not agree with; I would not sign it. So they threatened to pull her out of that class and send her to another class that was even worse. I’m like, “Oh, no, no, no.” So I went through—back then it was called the Rights of Virginians with Disabilities...An organization that—and those are people that provide lawyers for people who are low-income like we were and still are. And now it’s called...and I can’t remember, but basically it’s the same thing; it’s just kind of changed over the years. I called the Department of Ed to file a complaint. And they were talking about—“You might need to go to due process,” you know, and I—“here’s the information,” and they sent me all this paperwork... information, and then that—listed “If you’re not able to, you know, attain a lawyer, you might contact these people. They might help.” And what they did is that they’d take it case by case, and if they thought your case warranted them stepping in, they would do it; they would find a lawyer. We didn’t have to go to due process. The lawyer came in, and we had a meeting with the school and their lawyers, and our lawyer made them look like fools, basically, and walked out of there with—and the school was hanging with their tail between their—you know, their legs, basically....They put her back in the class she was supposed to be in. But we still had problems with implementing the IEP. That has not changed to this day.
...What I would not recommend is that every time you have an issue to start threatening due process because after awhile it's no longer a threat and they just treat you as if you are running your mouth and that's all. So if you ask for an AT eval they have it put into the IEP so it has to be done, if a communication device is recommended then they have it put into the IEP so it has to be used and write goals for using it so it has to be done. Now of course we all know that even when it has to be done it isn't always done so then you start out (which I forgot that step) with going over your special ed director to their boss and work your way up the chain of command so that if you do end up in due process you don't lose because you didn't exhaust all other avenues first.

**Ms. Klass** thought that parents could and should solve disputes by learning to work within the system. She faulted some parents for seeking legal help before they tried to manage the problem themselves. However, you also sense from this excerpt that the parent recognized there were some circumstances when legal help may be needed, although she described these circumstances as “extreme”. **Ms. Klass** is one of two parents who discussed how she worked collaboratively with the public school. She mentioned several personal factors that she perceived helped her advocate for her daughter: her professional background, education, her family, and ties to her community.

You know, I know some families that would’ve called an attorney right away. That’s not going to get you anywhere. I think you’ve got to work within the system, and then, if something’s not right, then go to those extremes.... I think people are just jumping into getting attorneys and mediators and all this kind of stuff without even trying, and how are you going to learn the process if you never have to do it yourself?
**Ms. Dean** stated:

Yeah. My brother’s an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help X, and that he didn’t know them well enough, but there were lawyers that specialized in it. ...So we filed for due process, and I met with the lawyer again. And at this point, the lawyer’s—I’m writing all the letters, and she’s just saying, “Yeah, that’s okay,” because I was trying to save money, because my—this is—the lawyer fees were cutting out of my speech fund (fund her parents gave her.) Because the advocacy training—I did all the documentation, except the actual filing of the paperwork for due process. But I met with her, and I spelled it out—you know, what the issues were. In Massachusetts, you need to have a preconference hearing date. And to be honest with you, I could’ve went to mediation, but because the speech therapist was so poor in her quality of work with him, I could not give in on that. That was not a negotiable item for me.

**Ms. Smith** stated:

I just feel that he has a right to communicate, so I feel that they are obligated to purchase him something if he needs assistive technology. But to go beyond that, I feel like I’m in limbo.... I don’t feel that I have any options. In order to program? I would have to say no...IDEA is a great concept but if you are not putting any money or training behind it, what good is it.

**Problems with Implementation at School – Up Against the Law**

Table 2 reveals that fourteen of the twenty-three parents in this study indicated that implementation of the device in school was more difficult than obtaining funding for
the device. Of these fourteen parents, twelve parents rated implementation as “extremely difficult”. Among the Phase II participants, seven of the ten reported that getting the speech generating device implemented was more difficult than getting it funded and six of the ten Phase II participants rated implementation as extremely difficult.

In contrast to the parents’ perception of a relatively predictable and manageable funding process through health insurance, parents described persisting problems with implementation. These problems led to frequent disputes between parents and staff. Parents reported that the school system did not have the knowledge, expertise or resources to provide assistive technology devices and services. Parents expressed other perceptions of IDEA as they engaged with people who implemented the law. As parents interacted with educators, therapists and school administrators, they described IDEA as a complex set of rules and regulations. Moreover, they thought that teachers and therapists did not understand the law, which they believed caused problems with implementing the law. Some parents described the formal law as ambiguous and some referred to the arbitrary nature of the law.

Several parents discussed their relationships with people in charge with implementing the law. As they engaged with the law, some parents felt intimidated and disempowered because they believed teachers and administrators made most of the decisions. Several parents expressed distrust for staff. Some parents expressed fear that if they asserted their rights some teachers might retaliate, which they thought could have unintended consequences for their children. Also, some parents perceived that educators and therapists were resistant to their ideas.
As parents interacted with the school system, they persistently advocated for their rights and their children’s rights. Parents described attempts to challenge the school’s decisions, avoid the law, or just make do. Most parents responded to problems with services by advocating for these services within the school as well as going outside the school system. Three of the ten Phase II parents filed a formal complaint with their school departments due to problems with implementation.

Most parents responded to the complex nature of IDEA by networking with other parents. They obtained information about the law plus advice and support by networking with parents on multiple listservs. Some parents enrolled in advocacy classes to learn about the law and some reported that they read the state and federal regulations. Therefore, although parents expressed many struggles with the public school concerning implementation, the law empowered them to gain knowledge about the law, assert their rights and advocate for their children’s rights.

I use the term “up against the law” when discussing the parents’ perceptions of the law as they experienced problems with implementation. These perceptions are described and illustrated through excerpts from the narratives.

**Up Against the Law**

*-Inadequate Experience, Knowledge and Resources*

These excerpts illustrate that parents thought that the public school did not have the experience, knowledge and/or financial resources to conduct an augmentative communication evaluation or implement the device in the classroom.

**Ms. Blair:**
When the issue of technology has come up—I was in a—I remember being in a—it’s not even in an IEP meeting, just parent-teacher conference and one of the therapists was the speech therapist, and I said something about, you know—if we wanted to pursue technology, how would they go about getting it? And all—the director of the program, the classroom teacher, and the speech and language therapist, all of whom have been working in our town for at least a dozen years each, looked at each other just, like, totally puzzled, like they had never had a kid in their preschool who needed a piece of technology. And they said, “Well, we could try calling”—first they were just puzzled. ....And they said, "Well, there’s a boy in the high school who’s in a wheelchair, and he has a”—and I was like, “No, that’s not going to help me.”

...I mean, I read so many horror stories from other parents about things, you know, it makes me wonder, like, if these people are educated or—you know, why would school districts go about denying free and appropriate public education to students? Why would they try to, you know, warehouse all their students in the district in one school? Why would they not be modifying classroom lessons? Why would they not care to support the classroom teachers? And I have to think that they’re—nobody does it because they’re evil; they do it because they don’t have enough money. I hope, not an ignorance and a lack of knowledge and a lack of understanding. But for the most part, what I see as being—that the law is positive and should guarantee a lot of things for people, including X and our family, but that as an unfunded—unfunded mandate, it doesn’t really have much teeth.
Ms. Brady discussed that the school system does not have the knowledge and expertise to provide assistive technology services.

He's in school for several months before anyone at pre-school even thought about it...it was a total focus on verbal communication for him which, with his diagnosis and physical capabilities is really not appropriate. So I think my statement about this is that the local school district SLPs are not at all prepared to even consider/or are typically aware of AAC as an option. That's why I wound up at X’s (hospital) using my insurance rather than working with the school dept.

....I think what’s worse is that most of our providers—most of our therapists—most of my personal—X’s personal therapists and providers don’t know about this—didn’t know about this stuff before we found out about it and did it. So, like, I had one person, of all the different people, say that to me. Nobody else knew it. Like, I go to the school meeting—I was at the school meeting today, and X’s the first kid to use one in five years at our preschool. So it’s a whole new crop of therapists, teachers, and parents. So they don’t know what that—and, you know, speech—the speech department had a changed—you know, they’re outsourcing all of speech now and are working with an organization to help streamline therapy delivery. All that stuff has changed, and if they’re not—and it’s expensive, so the schools don’t want to buy it. So they’re not learning about this kind of stuff; they’re trying to—they’re not pushing the learning of that; you know what I mean? Sharing the info?.... In our district in particular, our therapists are really strapped and pushed hard which is really unfortunate, but special ed is the "red-headed stepchild" who is treated differently.

Here another parent discussed her frustration with the school system because her son was not receiving services she felt he needed. The child was enrolled in a private
preschool and this placement was recommended by the public school. However, neither school would take responsibility for providing assistive technology services and devices. This parent eventually filed a formal complaint with the Rhode Island Department of Education and prevailed. The public school funded the evaluation and the device. This is consistent with IDEA regulations in that the law states the public school is responsible for providing special education and related services to children with disabilities in private schools placed or referred by public agencies (34 C.F.R § 300.145-147). These regulations have been adopted within the Rhode Island special education regulations (RISER § 300.145-147). In terms of providing a device, the public school is not obligated to fund a device for child if there is a non-educational agency, such as private or public health insurance, which is obligated under federal and state law to provide the device (34 C.F.R. §300. 154(b)(1)(i)); RISER §300. 154(b)(1)(i)). However, the public school is required to provide a device if the non-educational agency fails to do so and may claim reimbursement from the non-educational agency (34 C.F.R. §300. 154(b)(2); RISER §300. 154(b)(2)). In this case, the child did have health insurance, which may have funded the device, but the school speech-language pathologist and the child’s physician refused to complete the necessary documentation required by the health insurer. Thus, parent could not pursue funding through the health insurer. Therefore, the school’s decision was likely consistent with the law.

Ms. Cole stated:

In March 2004 he was beyond this single symbol level and I was moving more toward a dynamic device for him. At school he was using a CheapTalk 4 and 8, purchased by the out-of-district program. The school was using a device that he had obviously outgrown, but no initiative was being taken to move beyond that. I tried to contact our local assistive technology center, Tech Access, prior to this
visit, only to be told they wouldn’t help me because of the conflict between placements. T at the hospital (the local augmentative communication (AAC) specialist), he didn’t like that and actually made a call to the woman I spoke to and gave her an earful right there on speakerphone. So X (the local AAC specialist) really emphasized the Rhode Island regs to us at this visit about the school purchasing the device. He told me to do whatever I had to do to get X a device and that meant filing a formal complaint. He was furious with the run around I was getting and made it well documented in his report. He made recommendations for the Dynavox MT-4, E-Talk Impact, MiniMerc and Speaking Dynamically Pro.

...He’s not getting the therapy that he needs. I’m meeting this week with X’s special ed teacher and the speech therapist to discuss the Dynavox use at school. So far, he opens it and turns it on. Usage is minimal and no new information has been added this year except for my changes to some of his pages such as new teachers. It seems the speech therapist has complained to the Director of Special Ed about having too large a caseload and no time to learn/program the device.

....IDEA is a great concept but if you are not putting any money or training behind it, what good is it.

Another parent reported that the school did not have the knowledge or skills to provide augmentative communication services. When asked why the parent thought the school had not conducted an augmentative evaluation, the parent, Ms. Glade, responded.

lack of training, coordination, and—I hesitate to use the word, but competence ..."I’m not sure they could do one....
This parent also reported that speech generating devices were provided by the school district but were not used effectively. The parent attributed this to lack of knowledge and expertise among the speech-language pathologists and lack of collaboration between the speech-language pathologists and the assistive technology department.

But I don’t think they were used terribly effectively. You know, that’s one of the things looking back, you know, in – I just don’t think that, you know the use of the devices was all that effective. You know, the assistive technology department sort of, at that time – I think they may be doing better now – you know brought devices into the preschools, and you know, they might have said, “Well you could let the kids, you know, choose a snack or do this or do that.” But it wasn’t that well integrated into what they were doing. And, you know, they – you know, so the kids weren’t really learning to communicate, and the parents were not being educated in that sort of thing at all.

...In the school system, you know, we have two separate departments. We have the assistive technology department, and we have the speech department, and never the twain should talk to each other in the past. They’re doing better now. But in the past, you know, there was not much crossover. We never had a speech therapist who knew anything about augmentative communication. In fact, my speech—my private speech therapist told me, in observing one of X’s speech therapists in school, that he—that she was committing child abuse by what she was doing with him [laugh].

Similar to Ms. Glade, in this excerpt, Ms. Hall, stated she did not have confidence that the school had the knowledge and expertise to provide an assistive technology
evaluation. She described funding for the speech generating device as “right” but had encountered so such resistance that she went outside of the school system for an evaluation.

I knew I had a right to ask the school to fund it, but to be quite honest, I didn’t want them involved at all in this part of the deal. I had no confidence whatsoever that they could do anything to help me. They’d already attempted to and hadn’t even understood what I was telling them about my kids, didn’t have a good handle on what the boys were already doing, and I didn’t want them in there in the eval. I didn’t want them messing with what was going on. I wanted a whole new take on it from somebody else who was going to see them fresh, start over, who at least understood what I was saying when I talked to them. And if they came out of the eval telling me that my kids really weren’t doing what I thought they were doing, I would’ve taken it. I would’ve said, “Well, at least you listened to me. At least you spent time with my kids and you looked at them from a perspective of ‘I want to evaluate what these kids can and can’t do,’ not from a perspective of ‘I want to think about what I’m comfortable doing in my setting to support these kids.’

Ms. Smith discussed the teacher’s lack of knowledge about assistive technology, which led to persisting problems with her son’s access to these technologies. Over the years the parent advocated for an assistive technology specialist who could help the speech-language pathologist. Eventually the school provided this person.

...And then there was always the compu—“Well, that computer was a Mac, and this printer’s this, and he needs a joystick,” you know. There’s always, like, one obstacle after another, which eventually got accomplished, but it took a long time, because the teachers themselves didn’t know how to do it. So he’s finally in
a classroom now where the teacher knows how to do a lot of these things. And I insisted that they get an assistive technology AAC person for the speech pathologist in that class, which they did, so—which they had in the collaborative; she just wasn’t working with X. So now we have a great one and a good teacher. And, you know, they’re doing a lot more computer-based activities, which he likes, and he can use a mouse or a joystick.

Ms. Von talked about interactions with public school staff who do not have the knowledge to work with her daughter’s speech generating devices and she encountered problems when she offered to train them how to use the device. She had persisting problems with implementation and she eventually filed a complaint with the Virginia Department of Education.

The speech pathologists at the local hospital trained me on how to use it, and then they told me “You can go in and you can train the teachers and the speech therapist how to use it.” So I went into school, and I took it in, and I explained to them this was her, you know, communication device and how to turn it on and how to check for the batteries—the whole nine yards—and how to make the sheets for it. And they’re like, “Oh, we can’t use that; we have to get our technician or whatever to come out and show us how to use it.” I said, “Do they know anything about communication devices?” “Well, I’m sure they do!”...So they set up an appointment with the technician to come out, and he comes out, and he goes, “I don’t know anything about this! This is not computers!” You know, “Why did you call me in on this?” They’re like, “Oh, well, then, you’re going to have to get somebody to come out and teach us how to use it.” I said, “I just told you. I can teach you how to use it. It’s not hard. You push a button—’Hello.’ You know, it’s easy.” So I called the hospital, and so the speech therapist wrote them
a letter saying how I had been trained, how I could show them how to use the
device, and it was very simple to use. So we went in; they go. They reluctantly
said “You can show us.” So I showed them. We discussed what, you know,
symbols and icons to put on that X might need starting out. And then they
proceeded to put it in the back of the room, nowhere near X—didn’t bring it over
for use, and it sat back there.

..Well, I kept going in, and I kept making programs for her to use, and I kept
telling them, “There’s programs; here’s how you access them.” They just weren’t
using it, so you just—at every IEP meeting, I kept asking for AT training. And we
still, by the way, have not got AT training yet.

In the following excerpt a parent reported that the school refused to include the
child’s device into his IEP. This parent hired private speech pathologists because the
school system was not providing the therapy she thought her son needed. She also
hired an attorney because she and her family anticipated problems with the school
district. Personal factors likely influenced her decision to hire private therapists and
hire an attorney. Her mother had a medical background and suggested that the
parent hire a private therapist. Her brother, an attorney, suggested she get legal
help. Her parents paid for the therapy and the legal fees. The parent’s older child
had learning problems and she had some problems obtaining services for him.
Furthermore, the parent had a self-reported learning disability. She recalled how her
mother advocated for her and this experience influenced how she advocated for her
son. **Ms. Dean stated:**

Well, it was a bad day in my life, so… it was—so we went in, and we wanted to
add the device on as a goal to the IEP. And essentially, they said no. The school
SLP said, "Absolutely not"; she would not support it. ...No one at the school supported it. My—both my private therapists, my husband, myself, my attorney—we all supported it. And never did I think it was going to be a huge ordeal.

I—we don’t have a whole lot of money, and at the time, money was extremely tight. And I didn’t have the $125 fee for an hour for a private speech therapist. So what my parents did was, they came in, and they gave me a huge lump sum of money and said, “Here, we want you to put this in an account and use it for X’s speech therapy.”

My mother’s also a nurse, so she knows that if you need something that has specialized...specialty, then you need to go get that specialty—that someone else not having the information firsthand is going to trickle down; it’s going to get watered down, maybe—and that really, he needed some of the—had that information firsthand....At my first IEP meeting, or qualification meeting, my parents paid for a lawyer to be present.

Yeah. My brother’s an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help X, and that he didn’t know them well enough, but there were lawyers that specialized in it.

I saw my mother—how my mother advocated for me. My mother, believe it or not, got extended school year services for me before Chapter 766 came in to being in Massachusetts.... You know, so she’s a strong advocate, and, you know,
I did learn through her: If something isn’t right or you don’t think something is right, you need to act upon it, because it’s not going to change on its own.

**IDEA Rules and Regulations: Complex, Ambiguous**

The following excerpts revealed that some parents thought IDEA was complex and ambiguous. Several parents discussed their frustration with this aspect of the law.

**Ms. Glade** explained that teachers and therapists do not seem to understand the law. She believed this affected their ability to write IEP goals and to implement the IEP.

"I think it’s frustrating, because so much of it is so jargony. You know, all the measurement things are so jargony that I don’t think even the teachers understand it half the time. You know, when you’re talking about, you know, doing something on four out of five—doing it four out of five times on three trials and, you know, three occasions or something [laugh]—Oh, yeah, you know, eighty percent of the time on three trials and [laugh]—consecutive trials you know. Thinks like that just, you know, kind of make my eyes glaze over.

In this excerpt this same parent thought that the school may have either misunderstood the regulations or the regulations had changed. She is frustrated because of the impact she thought this had on her son: He was not allowed to take a Standards of Learning test, which was written into his IEP. She stated “he got screwed”.

Oh, he was also supposed to take a Standards of Learning test, you know, the, you know, high-stakes test this year, because they figured out that he could take the social studies test. Well, in January, we put it in his IEP: He would take the
social studies SOL in January. They sent out a—the state sent out a memo: "If you take one SOL, you have to take them all." Well, of course he’s not on grade level on any of his courses, but, you know, it’s—in social studies, it’s close enough that they could teach him, you know, the basic curriculum in social studies. So he got screwed, so he can’t take the SOL—couldn’t take the SOL [laugh]….Yes, in January [laugh]! Or they may have realized that they should have had this all the—all year long—that this was the requirement of No Child Left Behind that they test everybody in everything [laugh].

Ms. Carter is one of three parents who filed a formal complaint with the school district because of series of disputes concerning assistive technology services and devices. As described above, her son was enrolled in a private, integrated preschool. The public school recommended this placement. The parent reported that the public and the private school could not agree on which school was responsible for the assistive technology evaluation, training and a device for her son. She eventually filed a formal complaint with the Rhode Island Department of Education. She described the paperwork as “intimidating”.

Then the school department claimed we were out of district so they weren’t responsible. The preschool said they are not responsible because we are out of district. We went back and forth back and forth until he was five and eventually I filed a formal complaint. One hand does not know what the other hand does. They are not on the same page in different departments.

…I had to put down the section of the law that I felt was not being fulfilled. How can any typical person understand the educational laws that well to be able to pick from the list to apply to their particular situation? Needless to say, this
particular part held up my application until I was told by a woman at the Dept. of Education that the department of Special Populations would help with that section and for me not to worry about it. And to be honest, the more I think about it, the more I’m realizing that the paperwork that was given to me on my rights was difficult to follow and was quite intimidating to me.

Ms. Blair described the law as a “little daunting” and said that some statutes were “vague”

I find the—you know, the legal stuff is a little daunting for me, but the Wright’s Law Web site and the Wright’s Law books have been very helpful to me.... Massachusetts has a very vague statute about—if parents purchase a piece of equipment that is required for use in the school, who is responsible for it? You know—or the other way around: If the school purchases something, can the parents have it—can the family have it at home when the child is not in school over the summer? And it basically says something like, “Each district and school has to find a—and family has to find a way to deal—to handle this their own selves.”

-Arbitrary

Two parents described the arbitrary nature of IDEA. They thought that the teachers and administrators interpreted and implemented the law in an inconsistent and discretionary manner.

Ms. Glade stated:

Sometimes they’ll write it into the IEP and sometimes they won’t. It’s very strange. It depends on who is doing it. But I think that they are – they seem-
they don't want to be obligated to do anything (laugh) which is very — seems very strange to me, you know, because you know you've got a kid who needs this device, and, you know, what are the choices? You're going to give him a device; you're not going to give him a device, you know (laugh)

Ms. Burke stated that administrators in her school did not abide by hiring rules, which she believed was not consistent with the law.

That's completely against the law. Everything's complete—the way that they're operating right now is completely against the law, but they get around it because, well, a, who knew the—but did you know that the principals hire the paraprofessionals so that any training that should be done for all the paraprofessionals gets roundabout, because the principals are hiring and they hire a permanent sub and say that the job is posted?

-Disparity In Power and Influence

In these excerpts the parents described interactions with people in the school system which suggested perceptions of disparity in power and influence. In some cases these perceptions caused parents to distrust people in charge with implementing the law.

Ms. Glade described feeling intimidated at IEP meetings and she responded by bringing a friend who was more knowledgeable about IDEA.

And so we've had many, many frustrating meetings with people. You know, I walk into an IEP meeting, and typically—not so much this year, but when he was in elementary school, there would be at least fifteen to twenty people in all of our IEP meetings. And finally, toward the end, I started taking one of my friends to a
couple of the meetings, just because I felt like my husband and I would go—for a long time, I went by myself, and then I started making my husband go. And then I started taking—I took to a couple of the meetings one of my friends, who is an expert in all the regs and that sort of thing and is actually the chair of the local advisory committee for students with disabilities, because I thought, “Well, at least she can back me up on what I’m saying and some—at least, you know, maybe kick me under the table if I’m starting to say something wrong or kick them [laugh], verbally or, you know, something if they’re—what—they’re saying things wrong, or at least glare at them.

In the next excerpt this same parent (Ms. Glade) described a confrontation with teachers because they would not allow her son’s device to be mounted on his wheelchair. The parent argued that unless it is mounted and available to him, he cannot learn to use it. They reported that the teachers told her that that the professionals make this decision. This illustrates that the parent sensed there were distinct and unequal roles between the professional and parent.

And I argued and argued and argued, and they said, “No, no, no, no, no. He uses it inappropriately, so he can’t use it.” And I said, “That doesn’t make sense. How can he learn to use it if he can’t have it? And, you know, it’s not right—it’s not good practice.” And they said, “We’re the experts.”

This next excerpt illustrates that this parent thought there may unintended consequences if she asserted her rights under the law to request an augmentative communication evaluation for her son.
No. No, in ten years of being in the school system [laugh]. I think I’m afraid if I ask for it, they’ll say, “Well, he obviously can’t use the DynaVox” [laugh]. Let’s go back to a Superhawk.”

When asked whether she thought the law was on her side, this parent expressed that the school had most of the decision-making power.

I think it’s a mixed bag. You know, I think, obviously, the—you know, there are some protections, but I think it is—I think, you know, the school system has most of the weight. The parent has, you know, very little weight. You know, I think particularly the more challenged the child is—you know, I think if you have a child with, you know, mild learning disabilities or something like that, you know, fine, whatever. But, you know, if you’re—you know, the way the system is set up, for a child like X, it’s basically—gives them the right to just kind of write him off.

Similar to Ms. Glade, this parent expressed fear that the teacher may retaliate if she asserted her rights under the law. The teacher took the child’s device away from him when he did not answer a question. The child became very upset and the parent eventually pulled him out of school. Ms. Hall stated:

He’s my kid, and I had a right to do whatever I wanted to. I had perfectly good rights to pull him out. I had perfectly good rights to file a complaint. I had perfectly good rights to do whatever I wanted to. I saw what happened as verging on child abuse. I could have pursued all kinds of things, I would think, against that teacher for that kind of behavior.
...There was some fear that she would retaliate, that she had already screwed up my kid enough and that she would be worse to him if she knew that something was pending. There was also the fact that we were going to get out of there, and I didn’t want to ever have to see her or talk to her again, including whether it was, you know, in a meeting to try to set things straight or whatever. I just didn’t want anything to do with her.

Similar to Ms. Glade, this excerpt illustrates that Ms. Hall perceived that parents and professionals had distinct and unequal roles.

The speech therapist at school was appalled when I talked to her about “The boys are starting to sign, and they’re inventing signs. We need to be teaching them, you know, some real signs, or you need to do something, because they’re inventing their own language”. And if they were speaking twins inventing their own language, you’d be pretty freaked out right now.” “Oh, well, we don’t teach kids sign language anymore; we—that just isn’t done.” “Well, what is done?” She kind of sputtered, and that was the end of the conversation. I was so mad. I called my sister, who’s a speech therapist in Minnesota and said, X where do I go from here to get my hands on somebody who knows something about those talking boxes that people use? Because these folks are idiots. They don’t listen to what I say. And I need somebody who’s at least going to understand that I’m communicating to them in English and be able to give me some answers about what should be done or why it can’t be done the way I think it should, aside from “That’s just not what we do here”.
Like Ms. Glade, Ms. Smith thought that the professionals may not appreciate that she had years of practical experience caring for her son. She also stated that the professionals may not appreciate that she had other family responsibilities.

The new EI providers need to know that, yeah, they just, you know, went to school for four, six, eight years, whatever it took them, but I lived it 24 hours a day. And it’s important for everyone to be realistic. You know, people come into the house for an hour, and they do their treatment, and then they expect me to do it seven days a week, three times a day. I’ve got two other kids. It’s not going to happen. And I think—we’re getting off topic, but I think that one of the other things providers need to learn is that when I go to—when they come to the house and I go to fold a load of laundry, that doesn’t mean that I don’t care what they’re doing and I have no interest in it. It just means I need 15 minutes to check out. So I think that’s what we do.

This excerpt illustrates that this parent, Ms. Cole, felt somewhat threatened by a professional. She described an interaction with the speech-language pathologist about completing paperwork for health insurance funding. The speech-language pathologist told the parent that she would withhold therapy if she had to take the time to complete the paperwork. Since this documentation was required, the parent had no choice but to terminate the funding process. Ms. Cole stated:

The speech therapist was worried about who would pay...who would pay for her time to fill it out and it would take away from her speech therapy. It was ridiculous. Like that’s not my issue. I was told that X’s speech time would be used to fill in paperwork and he could not receive any direct services due to the amount and time required.
This same parent discussed strategies she had used to guard against “intimidation”. She was highly organized, logged all phone calls and focused on conveying information in a factual manner, rather than getting emotional.

I still have issues. It’s just of matter of logging all my phone calls. It’s not intimidating when you have those logs in front of you with all the info you need. The hardest part is staying neutral and sticking to the facts. And of course, staying organized. I am still angry there is no assistive technology specialist to help him. They had him repeat kindergarten so staff could get use to the device.

In the next excerpt the parent, Ms. Von, expressed distrust of administrators who she believed were autocratic. The parent stated that she noticed a pattern: administrators fire the staff when they disagree with the administrators. This perception influenced her decision to take her daughter out of this school.

And what we’ve noticed is, whenever you get somebody good that advocates for the child’s needs, they get rid of them....But the thing is, what we notice as a pattern is, whenever you get somebody that works and advocates for the child’s needs and goes against the wishes of the administrator, they get sent off.

Several parents in this study expressed distrust of some people who implemented the law – teachers, therapists and administrators.

This excerpt revealed that Ms. Von perceived that her experiences with the law have helped her gain knowledge about the IEP process, although she thought her increased knowledge had fueled greater discord between herself and the public school. She stated:
Well, I—you start out talking with the teachers. And of course, to be honest with you, they’re like, “Oh, yes, we agree with you; you’re right; we agree.” But then you get to the IEP meeting, and then all of a sudden they become mute...Most of the time, we got nothing. They would be like, you know, “Well, we’ll get back to you.” With X, you learn that when they say they’ll get back to you—that, you know, “You know you’re not going to get back to me.” So now you start saying, “I want it written to the IEP in their prior written notes.” See, this is something that’s accumulated over the years. I didn’t know that the first three, four, six, seven, eight years. You know what I’m saying? I learned more and more. Well, thing is, once you learn more and more, the schools really fight you. They get really upset with you. They don’t want you there.

This parent believed she could not trust the staff to implement the technologies in the classroom and she monitored how staff used the device, in a rather covert manner.

... I was catching onto—“You people are not doing what you say you’re doing.” How did I catch onto that? I don’t know; just little—just, like, instincts. So I started popping in, sometimes almost daily, sometimes two or three times a week. And when I came in, they never knew what time I was coming in, so they didn’t have time to go pull the device out as if they were using it. So basically, when we fast-forward to today, guess what? We have the same issues, except I can’t pop into the school every day like I used to, so I used modern technology to put a monitoring system on her laptop to see if it’s being used. But this is basically what it’s been like.
This same parent, Ms. Von, discussed how she learned about IDEA and medical issues from interacting with other parents on-line. She indicated that parents shared information on–line, information that she believed some professionals withheld from parents.

...and to be honest with you, almost anything I’ve learned—most—unless it’s a medical—and even medical comes from parents. But I would say 90 to 95 percent of what I’ve learned is through this parent group....When we learn something new, we get on there; we share it with other people, you know, because it seems to be one of these things that—it’s “Don’t tell unless they ask.”

In this excerpt another parent expressed a sense of distrust of the school because she believed she could not predict its actions. This perception influenced her decision to obtain funding through her health insurance. Ms. Burke stated,

Initially, it was just stupidity or lack of knowledge that I could do it through them. And then when I found out, I already started, and then I started thinking about the—I just wanted to own it. I wanted to own it, because you never know what the schools are going to take from you [laugh]. And it would be hard-pressed to say that they would take a device from the kid, but you know what? They’ve oft—they’ve already—the wonderful speech therapist who has changed—you know, done a 180-degree turn on the device, has, on occasion, taken it to another place to show somebody else. And I’m like, “No, you bring X with you if you’re going to take it. It’s his device; it’s not your device.” So I understand the concept; it’s just easier to take—you know, “Let me just run this for 20 minutes.” Well, 20 minutes turns to 40 minutes, and 40 minutes—you know, it’s just too much time to be without your own voice.
Ms. Cole discussed how her distrust for teachers, therapists and administrators evolved over time, based on a series of interactions. As reported above, this parent eventually filed a formal complaint with the department of education. As she told the story, she read from logs, which documented the events. She documented all phone calls, in part, because of distrust.

As of May 24, 2004 – Unable to reach anyone by phone and no return calls received. By mid June 04 I was finally given verbal approval through the school dept. for an evaluation to be done through Tech Access. I was told the necessary paperwork was mailed ions ago but found out through multiple calls it was only received a day or two before. Needless to say, I freaked out and demanded an eval as soon as possible but had to wait for a letter to be received by all parties before an appointment could be made. This letter was received late June. In June 30 through July 14, 2009 X was evaluated through Tech Access and the report was sent to the Director of Special Services in early August, 2004. In order to get a copy for myself, I needed to contact the Director’s secretary since they paid for the evaluation. I made several requests throughout August only to be put off with varying excuses…..In early October 04 I called Child Outreach coordinator and was told to just sit back and wait. She told me the district speech supervisor had reports and will contact the school's speech therapist with any questions. She also told me the two had actually spoke about X the week before, but upon asking the school speech therapist. Not true. In Mid October 04 I spoke with RIDE (Rhode Island Department of Education), after lots of phone tag, to complain about non-compliance of the IEP. I was informed a complaint could be filed given the information I provided. She sent the forms in the mail: complaint form, RI regs and new family friendly regs. She also made phone calls to find out what's happening. I think at this point, I was so tired of being lied to by
administration. Then on October 27, 2004 the school department received a letter informing them of a complaint to RIDE. It said “Students IEP calls for an electronic augmentative communication device to be used as part of a total communication system. The parent reports no device has been purchased. The IEP was March 23, 2004. On November 1, 2004 I was notified that device was ordered today! I made many, many phone calls to follow up on this, just to be sure. The purchase order was NOT cut until mid Nov! See, I knew it! In Dec, 2004 the school dept. purchased the Dynavox MT-4 for X. When it arrived at administration building, it sat in the secretary’s office for TWO weeks before finally being delivered to school!

Like Ms. Von, Ms. Burke and Ms. Cole, this parent, Ms. Hall, also expressed distrust toward staff at her son’s school. Ms Hall described two encounters with the school speech-language pathologist. Each excerpt illustrates distrust.

The speech therapist never came to any of our IEP meetings in preschool. None. The only meeting she came to was the one that looked like World War III. So she showed me a device, how it was set up to put together sentences. I said, yes that’s what I have in mind because that’s what going to help them stop inventing language and start using real words. Well that’s what we talked about in the IEP draft. What came back in the IEP later and stupid me. I trusted them at this point in time and didn’t look at the second round. What had gone into the draft was mom wants more activities for the Tech Talk. Nothing about the other things that we talked about, nothing about building sentences, nothing about anything that was important. So when I came back I was fed up.
This parent uses the term “sabotage” to describe how she thought the speech pathologist was purposely interfering with the process of teaching the children to use the devices. The parent responded by insisting the school use the devices, per the recommendation of an independent evaluator. She also sought therapies outside the school at a local hospital. These services were funded through health insurance. Ms. Hall stated,

I just knew that she had done something awful to this device, and this wasn’t anything like the way it ran for X and T (her two children). Oh, she had also turned the predictive lights off, too, so that the lights didn’t disappear when you got closer to the word you were going to say. And I just sat there the whole time thinking, “Either this woman is a total idiot, or her goal is to sabotage the boys’ communication.” And by the end of the meeting, I was so mad I couldn’t say anything, because I couldn’t figure out—“Either she’s more of an idiot than I am on this device, or she’s purposely sabotaging my kids, and I’m not sure which approach to believe and which tack to take.” And I didn’t know enough about the device to know, “Oh, you have the activity row turned off. Here, let me help you.” I just knew that it wasn’t the way the boys were using it. I kept telling her, “This is not the way that the device looks when the boys are using it. When it comes to school”—because we—they scheduled the meeting on a day when the kids weren’t there—“when it comes back to school, you guys look at it, because it doesn’t look this way. There’s stuff that happens up here that isn’t here.”

…But anyway, so basically, I just kept saying, “You know what? I had a recommendation by somebody who understood what I was saying, and we spent a lot of time getting to know my boys and got a good feel for it. And I don’t see anything here that shows me that I should do something different than the
recommendation that I got from the expert. And I’m going with what I heard.” And they had to go with it.

...After we had the evaluation part of it, then we continued to do some intervention stuff. She (the independent evaluator) was working with the boys. Now I had HealthSouth working with the boys, now that I had this loaner at least secured through summer. And they were doing awesome at HealthSouth. They were going all over the hospital. They were talking to people everywhere....I had speech at HealthSouth, too, at this point—all three therapies, because I wanted to be able to document that it was working somewhere besides school. I knew that they either didn’t know what they were doing, or they were going to sabotage my kids. And I needed to know that as many other people as possible were seeing that it was working.

-Resistance

As some parents engaged with people in charge of implementing IDEA, they experienced resistance to their ideas – ideas about teaching methods, scope of services, and implementation of speech generating devices. Some disputes began when their children were in early intervention programs, before they thought about augmentative communication methods. Most parents responded to the resistance by challenging those in charge with implementing the law. Parents advocated through informal dispute resolution methods. Some parents turned to the formal law when these methods failed. Each parent successfully obtained services they felt their children needed by going outside IDEA and the school system and most accessed their health insurance to cover the cost. These disputes also influenced parents in another way: they were motivated to increase their knowledge about assistive
technologies. The law enabled these parents to advocate for their children’s rights and to assert their rights and, therefore, it empowered these parents by establishing their sense of entitlement.

In the following excerpts Ms. Cole and Ms. Dean described how they encountered resistance when advocating for their children to receive speech-language services within an early intervention program. The parents responded by obtaining services outside the school system, which were funded through health insurance.

Ms. Cole stated:

I had a really difficult time trying to get speech therapy for X in Early Intervention. She said he had so many issues and that that was—would just add to the list.

I was pretty upset about that, and so that got me to start taking workshops—local workshops whenever I saw something. I started taking a lot of workshops and educating myself. So by the time he was three, he was using pictures from magazines and boxes and I put them on the fridge. ....X started receiving private speech while in Early Intervention due to my persistence and complaints, because they felt it wasn't appropriate for him to receive this service in EI. They felt that he had too many other issues to resolve before speech got involved.

Ms. Dean described a similar dispute:

Originally what happened was, my EI provider was not providing me with a speech and language pathologist, and I thought my child needed some of that—had that expertise firsthand instead of going through, like, an educator that would talk to the speech and language pathologist...We did have a speech and language pathologist, and she left the EI agency that I was working with. And
that’s when they said that they could provide an educator in place of the SLP.
And I adamantly said no, and I called a person within my EI system, and I don’t
know exactly—she was on the state level—what her title was, but her name was
X.. I believe, off the record, someone at EI told me that that’s the next level I
could go to. And I couldn’t tell you who at EI did, but that’s, I believe—was
someone within the EI agency that said, “Well, you know, if you’re not satisfied,
you can appeal to the next—you know, to call this person, X. And it was—and it
might have been even the director, to be honest with you, because when they
weren’t going to give me an SLP, I had to speak all the way up to the director.

After several disputes with the school, this same parent researched information
about her child’s speech disorder and brought the information with her to an IEP
meeting. This parent eventually filed a formal complaint with the school department.

Ms. Dean stated:

I came in with data that—you know, I researched it and came in with concrete
research that showed it—that it was needed. I brought—the late-talker book was
one of the books that I brought in. The Children—Childhood Apraxia Speech
Association—I brought in their information off their Web site. I brought in, I
believe, a letter from my neurologist saying that he needed to have private, you
know, one-on-one speech therapy. I mean, I loaded my stuff with data.

In the next two excerpts two parents discussed disputes with the school about their
children’s diagnostic labels. The parents believed these labels were not justified.
Here the parent encountered resistance when she disagreed with the school about labeling her child “severely cognitively impaired”. You sense that the parent was cynical and disillusioned with the law. **Ms. Glade** stated,

> Oh, and then, in Virginia—and I don’t know if this is anywhere else or not, but to qualify for taking the alternative testing, the non-testing, you have to be declared to be significantly cognitively impaired, among other things. And yet X—I mean, they cheerfully checked this off for X, but he’s never been tested as significantly cognitively impaired. I don’t know how they can do that....Every time they want to do this, I say, “No! How can you do this?”

The parent indicated that she believed this decision was not justified.

Well, it has more to do with other stuff than with—I mean, it’s more than just intellectual disability” or something, you know....It’s his lack of cooperation. He’s significantly and cognitively impaired because he won’t cooperate with us” [laugh]. I mean, that’s practically—it’s practically the way it comes out....You know, “Because he’s not succeeding, that means he’s impaired,” you know [laugh]......You know, at some point, you just start thinking that it’s almost not worth it.

This parent perceived that a diagnostic label influenced the therapist’s perception of her son’s abilities. **Ms. Hall** stated:

> The assumption was that “We have walking, talking MR kids in here, and then we have these kids who have an MR label who can’t do anything physically. They must be more stupid than the rest of them. We can’t let them drive their power chairs.” Meanwhile, I took them alone to supplemental therapy at HealthSouth, let them out of the car in the parking lot one at a time—so somebody had to sit
in his power chair and not drive in the parking lot until I got brother unloaded—and drove them in—both of them drove themselves into the room. And the only time they didn’t drive is if there was misbehavior: “Boom, you’re done. You start messing around, I tell you to stop, and you drive in the parking lot—you’re done. I turn you off, I’m pushing you, and brother gets to control himself.” And they understood that.

This same parent encountered resistance from the school concerning assistive technology devices for her sons. After seeking an independent evaluation, she asked the school to help her obtain the devices through the State’s Assistive Technology Program lending program. The school refused. She persistently advocated by contacting school administrators with increasing levels of authority. She obtained information about who to contact from the independent evaluator and by reading information the school district gave her concerning her rights. Ms. Hall stated:

So the biggest hassle came when I talked to the school, because what we wanted to have happen between—the loaner device had to go back, and it was going to take us probably three or four months to get the insurance funding. We wanted them to provide us a long-term loan and to start using it in school....Even though we had been through an outside eval, and I wasn’t asking them to go back and pay for the eval that we had had. I wasn’t asking them to pay for anything. All I was asking them to do was to sign up for a loan for three or four months until we got our devices and to use the thing in the classroom... So they cut loose. They just lost it. And so I called the next person up, the assistive technology guru at the intermediate unit, and told her what was up. And she pretty much had a twenty-minute temper tantrum on the phone and told me what a bad parent I was, that I had gone outside of them to get help, and on and on and on about
how awful this was. I mean, I was just an idiot and didn’t care and—etc. And I just sat there thinking, “This is the most unprofessional thing I’ve ever witnessed.” And I knew that the best thing for me to do was to keep my mouth shut and, you know, hold the high ground so they couldn’t talk about “Oh, that parent, she just blah-blah-blah-blah-blah.” So I got off the phone with her and breathed deep for about half an hour and then called the head of the whole intermediate unit and told him, “Listen. This is the deal. This is what I put on the IEP in September. This is what they wrote down. They haven’t done anything to help my kids. I talked to you guys in September. It is March now. You wouldn’t help me, so I went and got my own eval. And I don’t care if you pay for that eval or not. I’m not asking you to do that. All I’m asking is that you support the professional who did this outside eval by providing my kids with the device that was recommended in the interim until my insurance covers it.”

When asked how she knew whom to contact, she referred to the independent evaluator and information on her rights that the school gave her.

..the next name up from the people at school, I got from Dr. X (the independent evaluator). The name after that, I just went right to the top. I just said, “You know what? This lady was just over-the-top unprofessional. I am calling her boss or her boss’s boss. I don’t care which. I’m just getting the first name I can get.”

...I went through, like, the procedural safeguards and all of that kind of stuff—paperwork, and I—that they had given us before—you know, all that junk that you might as well wallpaper your bathroom with, because you never look at it. Well, I dragged it back out. I looked for the person on there who was the top dog, and I called him. He said, “You weren’t supposed to have done this, but now
that you have and you’ve called me,” that he would talk to people and he would figure out what their problem was.

**C. Parents' Knowledge About Rights Under IDEA Compared to the Positive Law**

The narratives revealed that several parents discussed their rights or their children’s rights under IDEA by using some terminology from the law and regulations. Parents discussed their child’s right to have an assistive technology evaluation, to use a device to access the curriculum, the right to obtain an independent evaluation and a parent’s right to reject the IEP (Individualized Education Program). No parent was familiar enough with IDEA to cite specific regulations concerning their children’s rights concerning assistive technologies: assistive technology (AT) evaluation (34 C.F.R §300.6), AT device (34 C.F.R §300.5) AT training (34 C.F.R. §300.6), AT devices to meet FAPE (34 C.F.R. §105) and AT and the IEP (34 C.F.R. §§300.320, 300.324(a)(2)(v)).

How did parents learn about the law? Many parents obtained information about the law by networking with other parents. Most communicated with other parents via multiple listservs and other parents networked with families in their communities. These concepts are discussed and illustrated by comparing excerpts from narratives.

**Assistive Technology Services and Devices**

Based on the excerpts above, many parents thought that the school should provide an assistive technology evaluation, an assistive technology device and training for the child to use the device. In terms of an evaluation and training, the parents’ perceptions were consistent with federal regulations which have been adopted, by
reference, in each of the states where Phase II families reside (603 C.M.R. 2801; 022 Pa. Code 14.102, 103; RISER 300.5, 300.105; 8 VAC 20-81-10, 8 VAC 20-81.100 (F)(1), 8 VAC 20-18-110F (2)(g)). By law, the school is obligated to provide an assistive technology evaluation and device training to the child, parent and professionals who work with the child. Two parents indicated that school never conducted an assistive technology evaluation. One parent requested the evaluation and waited for 3 years before the process was initiated. As described above, this was the parent whose son was enrolled in a private school, which was recommended by the public school. If accurate, these findings would not be consistent with the law. The other parent did not request an evaluation because she feared the school might retaliate.

In terms of funding a device, IDEA states that non-educational public and private agencies, such as private insurers and Medicaid, are the primary payors when they are obligated to pay for these devices under federal or state laws (20 U.S.C. §1412 (12)(A)(i)). If the non-educational agency does not provide the necessary device, then the local educational agency (LEA) is responsible for providing it, (§1412 (12)(B)(i)), though the LEA may seek reimbursement from the non-educational agency (§1412 (12)(B)(ii)). This means that the public school is not the primary payor. Although no parent expressed knowledge of this aspect of the law, the parents’ decision to seek funding through health insurance may not have been a departure from IDEA. As noted above, parents did not pursue funding for a device through the school for several reasons. They were not confident in the school’s knowledge and expertise, they wanted to own the device and vendors helped the parents to navigate the health insurance regulations.
Excerpts from the narratives illustrate parents’ perceptions of their children’s assistive technology rights under IDEA.

**Ms. Cole** stated:

My first request went in May 2006-2007 and today is the first time I’ve met an assistive technology person. It was in the IEP to request an assistive technology eval. Because they didn’t have anybody-you know-the special ed. department in X was a mess for awhile, and it’s back—it’s coming back. They don’t have a specialist. The specialist kind of stuff gets thrown to the bottom of the list.

**Ms. Glade** feared that if she requested an assessment, the school might give her child a less sophisticated device. Thus, she did not advocate for her son’s rights under the law.

**Ms. Glade** stated:

No. No, in ten years of being in the school system [laugh]. I think I’m afraid if I ask for it, they’ll say, “Well, he obviously can’t use the DynaVox” [laugh]. Let’s go back to a Superhawk.”

In the next two excerpts, the parents indicated that they thought the school would provide a device for their children. However, these parents chose to access their health insurance because they wanted to “own” the device.

**Ms. O’Brien** stated:

Okay. ...once we had selected the Vantage Plus, then it was time to try to order it and figure out who was going to pay. And basically, we knew that I wanted to go through our own insurance. And there was never any question about whether the school district was going to pay or not. I wanted this device to be owned by us.
Ms. Smith stated:

Well, if they (parents) don’t have insurance that’s going to cover it, then they have to rely on the school system to pay for it, or pay for it themselves, but who’s going to pay for an $8,000 device themselves? I don’t—I haven’t known anyone who’s done that.

When asked if the parent thought the school would provide the device, this parent replied, “Oh, absolutely”.

Another parent discussed a similar thought: She believed the school was responsible for providing the device. However, like several other parents, she accessed her health insurance because she did not have confidence in the school’s knowledge and skills.

Ms. Hall stated:

And had our insurance not approved it, I would be fighting the school district through first grade, probably, to get the device....They should have provided it. They should have started out by listening to me as a parent when I said, “My kid’s inventing sign language and putting words together. Something needs to be done here.” But the speech therapist never even saw my kids alone. Basically, what she did the whole time they were in preschool was, she went into the preschool class and taught it for a half hour a week so that the teacher could go fill out her paperwork. She never had one-on-one time with any of those kids, so she never did any artic with anybody that needed that, never worked with any of
the Downs kids on word formation—certainly never worked with my guys on anything.

**Independent Evaluations**

Two parents thought they were entitled to have an independent evaluation paid for at public expense through the school district. The right to an independent evaluation is consistent with federal regulations, under specific conditions (34 C.F.R § 300.502), which have been adopted by each of the states where parents resided (603 C.M.R. 28.04 (5); 22 Pa. Code 14.102.103; RISER 300.502; 8 VAC 20-81-170(B)). These two parents did not state the specific conditions under which they could assert this right. While these parents had some knowledge of their rights under the law and may have succeeded in invoking their rights, they chose not to assert their rights. These two cases illustrate how interactions with people influenced their perceptions of the law which, in turn, influenced their actions.

**Ms. Hall** was one of the two parents who chose not to assert this right. After many disputes with the school, she stated she did not want them involved. The other parent, **Ms. Dean**, was concerned that the school might impose some restrictions on who could conduct the independent evaluation. This is consistent with federal regulations (34 C.F.R. §300.502(b)(2)(e) and Massachusetts’ special education regulations (603 C.M.R. §28.04(5)(a)). This parent also thought that the school district’s budget problems could limit her choices. She compared her situation to that of friend in another state, who obtained an independent evaluation at the expense of the public school

**Ms. Hall** stated:
I knew I had a right to ask the school to fund it, but to be quite honest, I didn’t want them involved at all in this part of the deal. I had no confidence whatsoever that they could do anything to help me.

**Ms. Dean** stated:

Unfortunately, in Massachusetts, I’m tied, because they pay so poorly. For me to find a competent professional that would accept their low payment—that it’s really hard in Massachusetts, in my opinion. I have a friend in New Jersey; she got an IEE for her child, and the school district paid $6,000+ for neuropsych and observation and everything. That would never fly in my State. They—you know, you have to find a provider that’s willing to accept the payment, which—it’s miniscule. I mean, it’s like—I don’t want to say pennies on the dollar, but—

**Access to a School Purchased Device Outside of School**

Six parents discussed concerns about whether a child may have access to a school purchased device outside of school. According to federal regulations, this decision is made on a case by case basis by the child’s IEP team (34 C.F.R §300.106(b)). This regulation has been adopted by each of the four states (603 C.M.R. 28.01; 22 Pa. Code 14.102; RISER §300.106(b); 8 VAC 20-81-100 F(1)). Three parents indicated that this issue influenced their decision to obtain funding through their health insurance.

**Ms. Dean** stated:

...you’re fighting so much for so many other things that it’s sometimes easier if you have private insurance to go through, because then you run into the other problem of—which doesn’t make sense to me at all—the school system will keep the device at the school, and they’re only entitled to use it between the hours of
8 and 3 when school—or not during the summer. If you own the device, they can’t tell you you have to leave it at school at 3 o’clock…. I would think that in my situation at the school district—that I had such a poor SLP that I think they probably would—she would’ve kept it at the classroom. But the new SLP that we got—I think she would advocate it for him to be able to take it home, without a doubt….

Ms. Brady stated:

I started thinking about the—I just wanted to own it. I wanted to own it, because you never know what the schools are going to take from you \[laugh\]

Ms. O’Brien:

I guess because I wanted to be able to have the device in the home when it wasn’t in the school. And not that there would be any question on that, but I was also thinking about—you know, when she ages out of the district at 22, were we going to have to start looking at getting another device or, you know, returning this one to the school at some point? And just knowing how school district budgets work, I just didn’t want the red tape to hold up my daughter getting a device. So I just felt this was an easier route to go.

Ms. Blair,

Massachusetts has a very vague statute about—if parents purchase a piece of equipment that is required for use in the school, who is responsible for it? You know—or the other way around: If the school purchases something, can the parents have it—can the family have it at home when the child is not in school over the summer? And it basically says something like, “Each district and school
has to find a—and family has to find a way to deal—to handle this their own
selves.”

As described in this chapter and noted in Table 1, in the public school provided
devices for four children in Phase II of this project. Two parents had disputes with
the school about the device coming home. One parent reported the school would not
allow the device to come home. The other parent indicated that the device was
allowed to come home once the school district and the parent resolved issues
concerning liability for the device.

**Ms. Glade:**

There was a little bit of an issue – just trying to remember. At one point, there
was an issue, because it-with a bus. There was an issue about taking it on the
bus, I remember. And we had to, for a while, actually take it back and forth to
school (laugh) which is weird. Yeah. And then they kind of realized-they decided
that it was okay to put it on the bus. You know, once they decided that the
transportation people were willing to, you know, have it on the bus- and I think it
was the transportation people that weren’t willing to have it or something
(laugh). That was the real stumbling block. Then they said, “Yeah, the device
can come home.” And then there was also, you know, the “Can it come home
over the summer?” issue, you know, like the first year (Laugh). You had to sign a
form that you’d send it back in the fall (laugh).

**Ms. Carter** stated:

At this meeting I was told the device he was using at school could not be sent
home because it was for school use only. I sent a letter to the Director of Special
Services describing my frustrations regarding the team decision to not allow the device to be sent home....I got no response.

**Content of the Individualized Education Program**

Two mothers stated that IEP’s must have measurable goals. This is consistent with federal regulations (34 C.F.R. §320(2)(i)) which have been adopted by the four states in which Phase II mothers reside (603 C.M.R. 28.05; 22 Pa. Code 1413 (a)ix(5); RISER §320(2)(i); 8 VAC 20-81-110G2).

This parent, **Ms. Glade**, did not have confidence that the measurable goals were written in a meaningful manner. She also questioned how her child’s progress toward the goals was measured.

“jargony” ... “I don’t think even the teachers understand it half the time... You know, when you’re talking about, you know, doing something on four out of five—doing it four out of five times on three trials and, you know, three occasions or something [laugh]— Thinks like that just, you know, kind of make my eyes glaze over.” [laugh].

..They put together some book describing how he’s doing wonderfully against these goals. And he’ll get a pass advance, but he’s making almost no progress against his IEP. He’s getting twos and threes on his IEP goals, which is—two is no progress, and three is sort of maybe progress. He’s got fours on his physical therapy—you know, physical, like—adapted PE goals [laugh]. So....

These two parents discussed how they learned about formulating measurable goals by networking with other parents and professionals.
Mr. Dean stated:

And then the IEP meeting occurred—we had one in June, before he turned three, the last day of school. But I rejected that IEP in totality. It wasn’t appropriate. It didn’t have measurable goals... I had—at the time, I didn’t know what I didn’t know about EI—about the school system, about IEPs. So I started researching it....Well, I didn’t know what an IEP was. And on a listserv that I was on—there’s actually a listserv in Massachusetts and New England, “Apraxia.” There was a woman on there that lived in my state who was kind enough to forward me her child’s IEP and told me, you know, “It’s very individualized.” And I didn’t get that then. I totally get it now, but I’d never even seen an IEP. So she shared her daughter’s with me, and one of the things that I looked at—it was—there—you could measure it. It was concrete; it was black and white; and at the end of three months or whatever, you could determine what the results should be...But I also, at that time, started taking—in Boston, there’s a Federation of Children with Special Needs, and they have advocacy workshops for parents.

Ms. Hall stated:

..I think she (the independent evaluator) may have mentioned to me X, and so I looked up X’s name on the Internet and found the X for Literacy and Disabilities—eventually got X’s name, and X offered to send me sample IEP goals that they had written for the deaf/blind classroom, which didn’t completely apply to my boys, but close enough. And I laugh when I’m talking to other parents. I say, ”It took me five years of IEPs before I finally figured this out—this whole goal-writing thing and how to make goals that are documentable and tight.” And now, when I share goals with professionals, they look at my goals and they just go, “Holy cow, my goals are not as tight as your goals,” because you can’t argue with them.
“Here’s what you’re going to do. Here’s how you’re going to document it.” There’s no flinch room. You either did it, or you didn’t do it. And it’s just really directed towards whatever the goal is supposed to be. And that’s just from, like I said, five years of trying to wrap my brain around this so that I could write better IEP goals.

**Access the Curriculum and Free Appropriate Public Education (FAPE)**

Two parents indicated that their children had a right to use their communication device to access the curriculum. This is consistent with federal regulations (34 C.F.R. §105), which have been adopted by the four states in which the parents reside (603 C.M.R. 28.02 (by reference); 22 Pa. Code 14.102 (by reference); RISER 300.105; 8 VAC 20-81-100F).

**Ms. Dean** stated:

Well, I know under social education laws, which—I mean, I—let’s see: IDEA, ADA, and then... under—if a child’s enrolled in school and they need to have access to the general curriculum, which is a law: everyone is entitled; it’s an entitlement; everyone’s entitled to have that. And they’re unable to access the general curriculum, because speaking is one of their disabilities and they’re not intelligible. So my thought is that if you can’t understand what a child’s saying, how do you actually know that they’re accessing the general curriculum?

**Ms. Blair** stated:

I think the primary underlying right for the parent and child is access to FAPE. Sometimes it’s hard to recognize the need for a communication device, since the student may be able to take in information that is taught in school - but w/o augmentative communication, the child cannot fully participate in all the facets of the classroom. A parent should think of a SGD as a tool for allowing their child
access to the education that is being provided - if a child were blind, that access would be guaranteed through Braille materials, or books on CD, or having a scribe for the child. If a child had a mobility issue, FAPE would be guaranteed through ramps and wide doorways and accessible toileting and playground facilities. Technology that gives children their voice is crucial to allowing them to access the free and appropriate public education which is their right.

**Right to Reject an IEP**

Two parents stated they had the right to reject part of all of an IEP and each asserted this right. This is consistent with federal regulations (34 C.F.R. §300.300(b)) which have been adopted by the four states in which the parents reside (603 C.M.R. 28.05(3)(b); 022 Pa. Code §14.102; RISER 300.300(b); 8VAC 20-81.110). Each of these parents eventually filed a formal complaint with the school district concerning implementation of the speech generating device.

**Ms. Dean** stated:

And then the IEP meeting occurred—we had one in June, before he turned three, the last day of school. But I rejected that IEP in totality. It wasn’t appropriate. It didn’t have measurable goals. The SLP from the school district was retiring that day...So she wrote up the goals, and they were half-assed, and I rejected them, and—I rejected everything. So I talked to the SPED director during the summer, because they don’t meet during the summer. And since preschool didn’t start until the second week of school starting—that she guaranteed that we could have another meeting the first week of school.
This parent discussed how she would not sign her daughter’s IEP and proceeded to file a formal complaint with the Virginia Department of Education. The case was resolved before she filed for due process.

**Ms. Von stated:**

I would not sign the IEP, because the IEP was not meeting her needs....They wrote an IEP that I did not agree with; I would not sign it. So they threatened to pull her out of that class and send her to another class that was even worse. I’m like, “Oh, no, no, no.” So I went through—back then it was called the Rights of Virginians with Disabilities...An organization that—and those are people that provide lawyers for people who are low-income like we were and still are. And now it’s called...and I can’t remember, but basically it’s the same thing; it’s just kind of changed over the years. I called the Department of Ed to file a complaint. And they were talking about—“You might need to go to due process,” you know, and I—“here’s the information,” and they sent me all this paperwork... information, and then that—listed “If you’re not able to, you know, attain a lawyer, you might contact these people. They might help.” And what they did is that they’d take it case by case, and if they thought your case warranted them stepping in, they would do it; they would find a lawyer. We didn’t have to go to due process. The lawyer came in, and we had a meeting with the school and their lawyers, and our lawyer made them look like fools, basically, and walked out of there with—and the school was hanging with their tail between their—you know, their legs, basically....They put her back in the class she was supposed to be in. But we still had problems with implementing the IEP. That has not changed to this day.
D. Strategies Parents Used to Advocate

-Advocating through a Relational Perspective

Most parents advocated for assistive technology devices and services based on their knowledge of their children and expertise as a parent, rather than the rules of law. Many parents thought that building relationships would help them achieve a positive outcome. I use the term “relational” to refer to this orientation to advocacy. I adopted this term from the sociolegal research conducted by Engel (1998) and Barton (2004).

Three of the parents stated that they engaged with legal actors (e.g. teachers, therapists, school administrators) in a purposely collaborative way. The narratives revealed that these mothers focused on building relationships and they believed that this approach helped them advocate for their children and achieve positive outcomes. While they reported some disputes with the school district, they believed IDEA was on their side. Two of the parents stated that they believed their children were never denied their rights under the law and they expressed confidence that the law would provide what their children needed.

One the parents, Ms. Klass, discussed some personal factors and circumstances that may have influenced her approach. Early on in the interview she reported that her professional background as a discharge planner prepared her to advocate for her daughter. She also discussed that her family had “resources” — they are well educated, her husband is a teacher, and as parents they work well together to solve problems. Furthermore, the parent believed that being part of the community for a long period time helped her advocate for her daughter. Another parent, Ms. O’Brien, discussed how she consistently educated herself about assistive
technologies, shared the information with the team and sought their input. She talked about how she was there to “help” and brought knowledge and resources to the team. She also discussed that her husband, a teacher, is on the school committee and in this position he had some knowledge about the school district’s fiscal problems. This knowledge influenced her decision to seek funding through health insurance, rather than ask the school.

**Ms. Klass** stated:

Okay. I think what we probably need to get on the record somewhere is, prior to staying home, I was a discharge planner/case manager. So I think my background helps...I think it helps in many reasons. One, it helps with the whole documentation piece. You know, as soon as I pick up the phone, I write a date on a piece of paper and ask the person their name. And I think it helps because if I find that I’m not being heard, I don’t have a problem asking to speak to a supervisor. This really hasn’t happened with an AT device, but just recently, I was trying to get X a piece of equipment covered, and I realized that the person I was talking to—and I had to spell every diagnosis and spell every med. It was a waste of my time, because they had no clinical background. So I had no problem saying, “Can I please speak to a nurse or a physician or a respiratory therapist or just someone so I’m not spelling ‘cerebral palsy’ every time?”

...X (her husband) and I are very well-educated, and we can work together, and we can sort out issues or obstacles—I feel sorry for the people that don’t have those resources....We are fortunate that we live in a great town. And I’m not saying that we haven’t had our differences, but X and I have both grown up in this town, and X’s been in public school since the day she turned three. And it’s
worked, for the most part. And I think that because we approach things as a
team—that she has a tendency... I can’t really think of any time she has been
denied something that I truly believe she’s needed....I think it is X’s right to have
whatever she needs to get through school, but I don’t start my IEP meeting
saying that. You know, I start my IEP meetings—hopefully, I have—that I thank
the people for what they’ve done, because I know it’s not easy—and hopefully
that I—everyone sitting around that table—I have an example of something that
they did that I think went above and beyond. And if they don’t, then they’re the
ones left out at the table.

This same parent asserted her rights when the school told her that her daughter
could not attend the school’s new public library. She responded by working
collaboratively with the school district and the city so that her daughter could access
the school’s public library. Ms. Klass stated:

As a parent, I think—I know she has a right to a—what’s it—free and adequate
education. But she has never been denied something that I truly believed she’s
needed, so I have never had to investigate that or take it to that level. You know,
there—I’m not saying it’s been easy. Just this past September, I wanted her to
be able to go to the library at the high school, because we just—you know, our
taxes just renovated this wonderful library God knows how many millions of
dollars. And I was told that she couldn’t, because there was some code in
Massachusetts that said that the building had to be evacuated in under three
minutes, which bothers me. So it kind of got my dander up a little bit. So I called
the Fire Prevention Officer in town and asked him what the ruling was, because I
found it strange that they had just built this huge library and built these great
new staircases with wells on the outside of the building, but neither one could get
a wheelchair out, and there were four kids in the high school that are all in chairs. So when all of this... then we wrote a letter. And I think the school system knows that if my husband X is involved—that it’s a big deal. I handle all the little stuff—I do my thing; I handle X’s stuff. He is very involved with her, but I handle the school and the Merc and that kind of stuff, and he handles the power chair, and we all have our little roles...But he wrote—he’s also—he’s an educator. So he wrote a letter to the principal, the Director of Special Education, X’s liaison, and the superintendent, and I delivered the letter. And within 24 hours, we had a meeting with the Director of Special Ed, the principal, the Fire Prevention Officer—

...So we ended up putting together an evac team, practicing the evac team, getting people comfortable that Maggie does all the rides at Disney, including Tower of Terror and Splash Mountain—that them carrying her down in those little evac chairs is not going to hurt her in any way as she’s laughing hysterically going down the—and I think they just needed to be educated. I don’t think that they were denying her something because they didn’t want to have to deal with it. I think no one had ever challenged it before. And she has a right to be up in the library and taking classes on the second floor as much as any other kid. And once we pulled the team together and they knew that we were looking to work with them—we weren’t working against them—it all worked out in the end. You know, I know some families that would’ve called an attorney right away. That’s not going to get you anywhere. I think you’ve got to work within the system, and then, if something’s not right, then go to those extremes. I think people are just jumping into getting attorneys and mediators and all this kind of stuff without
even trying, and how are you going to learn the process if you never have to do it yourself?

The other parent, **Ms. O’Brien** stated:

…I think you have to be involved, and I think you have to push, but I think you have to push with the knowledge that you’re going to be there to help out….I could have stood there and screamed. And you know, when they don’t know where to look or they don’t have anybody, you know, in the district that could help them, you know, that’s where I think the parent has to figure out, “Okay, I’m going to help and research and find out what I want for my daughter, and then I’m going to go to them and tell them about it and see what they think.”

You know, so—but I have to say that this support has been great. You know, the—we go to see the communication program at children’s every six months, and at least one staff from the school comes with us—either the consultant, her aide, or the classroom teacher. Recommendations are written up, and immediately the whole team comes back with those recommendations and implements them in the next six months. Or we do our best.

…I really didn’t know in the beginning that the school was following up on the recommendations from the CEC (independent evaluator), though I did know they were doing some of it through daily communication with them. Before the next follow up, I pulled out the summary that they sent us after the appt. and realized that the school had done everything! We did work together, but they were keeping better track of it than I was. After the first couple of times, I would check the recommendations a couple of months afterwards to make sure we
were addressing everything. Sometimes my help was required to get going on some of the things, but I knew that they were making every effort to prepare X for the next visit. I think communication is key after every session with the AAC school consultant which does happen twice a week - they write an update in X’s daily log...actually all the therapists do that. It’s a wonderful tool and I’m happy to say most are consistent.

This same parent described how she collaborated with the school to hire a reading specialist. Again, she independently obtained information to help advocate for her daughter. Ms. O’Brien stated:

...The focus lately has been on reading. It’s one of those things that just kind of fell through the cracks as we are focusing on her device. And we ordered the—some soft device for the—software for the device that was supposedly helping kids with devices learn to read. And it took us a year to realize that this was not going to work for X. So, you know, it—again, the school district was pretty great. You know, I looked up and said, “We’ve got to try something else,” and they looked up and said, “We just don’t know what.” And, you know, there’s a number of reading programs out there that we were looking at, and finally I—we hired a reading specialist with assistive technology background to look at this. And we’re in the process now of adapting the device for Wilson Reading Program.

In this next excerpt Ms. Klass discussed that she had knowledge about the school’s budget problems from her husband, who was on a school committee, and she stated that she was sensitive to its needs. She decided to submit a funding request through her health insurance, rather than ask the school to fund the device, because she thought this might help the school with its budget problems.
My husband has been on the school committee for eight years, so we have a lot of knowledge of what’s going on with the school budget and how tight things are. And I know, deep down inside, I should not let that influence, you know, what kind of services my daughter gets. But I felt that if our insurance could pay for this—that we’ve certainly given in $7,000 in co-pays—that, you know, this would make it easier on the school district.

Another parent, Ms. Brady, discussed that she focused on building relationships with people and “finding common ground”. In this excerpt, the parent stated at times she had become upset and then she would ask her husband to help her.

I think the—you get a lot more—I—honest to God, you get a lot more with honey than you do with vinegar. So always start off—you know, the key here for me is always, you know, being polite. And, you know, clearly I’m into making—developing rapport and relationships with people, no matter who I talk to, and finding the common ground before you move on in the conversation. So that’s where I usually try to, you know, relax, have fun, say—there’ve been only a couple of times where I’m at my breaking point and I’m—that’s when I need to have—talk to my husband and say, “You need to talk to them [laugh], because I’m going to start to swear or cry, and neither one is really productive”—although, when I was crying to the guy from Springfield [laugh], Mass, Health Office, things changed pretty quickly there [laugh].

Four parents discussed how they advocated for their children based on their personal knowledge and expertise – what they believed their children needed and should have. The following excerpts illustrate this theme.

Ms. Blair:
And he doesn’t need any—he doesn’t need signs; he doesn’t need PECS (picture exchange communication system); he doesn’t need technology to be a receptive learner. He needs all those techniques to be an ex—to express his knowledge....I know they’re very overwhelmed, to some degree. It’s nice that they are trying to figure out how to meet their needs in the classroom. And I think that—I’m hoping that it’s not an overwhelming amount of technology—that they’ll look at it as a tool. I mean, I really want him to be able to use it as an expressive language tool.

**Ms. Brady:**

Don’t do it just because you “have” to do it or they tell you to do it. Do it because it works for whatever the situation is. And I’m trying to do that, so that’s what I always try to encourage other parents to do.... Yeah. And you get caught up in that mentality of “Well, he deserves it!” or “She deserves it!” And it’s like, you know, that’s a little socialist for me.

**Ms. Dean:**

Originally what happened was, my EI provider was not providing me with a speech and language pathologist, and I thought my child needed some of that—he had that expertise firsthand and didn’t—needed the person that had the knowledge first at hand instead of going through, like, an educator that would talk to the speech and language pathologist... My kid needed this, and—so when they finally sent out someone, I think it was, like, the beginning in—I want to say... maybe the week before Christmas or January. They—she actually was coming out twice a week for two hours, and—you know, so I’d go from no SLP to twice a week. You know, so someone got the gist of the need—at least I think so.
But when all that was going on, my parents stepped in and said, “Look, you need to have a speech and language pathologist. You need to find someone.”

**Ms. Hall:**

The speech therapist at school was appalled when I talked to her about “The boys are starting to sign, and they’re inventing signs. We need to be teaching them, you know, some real signs, or you need to do something, because they’re inventing their own language. And if they were speaking twins inventing their own language, you’d be pretty freaked out right now.” “Oh, well, we don’t teach kids sign language anymore; we—that just isn’t done.” “Well, what is done?” [Sputter] She kind of sputtered, and that was the end of the conversation. Fairly quickly, they were stringing together signs to make sentences. This was all before they were four.

**Ms. Klass:**

And I also truly believe that if I believe she needs it, then she’s going to get it. I just have to figure out a way to do it.... And I think that because we approach things as a team... I can’t really think of any time she has been denied something that I truly believe she’s needed. ... As a parent, I think—I know she has a right to a—what’s it—free and adequate education. But she has never been denied something that I truly believed she’s needed, so I have never had to investigate that or take it to that level.

...You’ve got to be part of a team. You can’t always go in with your guns loaded and be angry...And it is X’s right to have whatever she needs to get through school, but I don’t start my IEP meeting saying that. You know, I start my IEP meetings—hopefully, I have—that I thank the people for what they’ve done,
because I know it’s not easy—and hopefully that I—everyone sitting around that
table—I have an example of something that they did that I think went above and
beyond. And if they don’t, then they’re the ones left out at the table

**Ms. O’Brien:**

You know, I looked up and said (to the IEP team), “We’ve got to try something
else,” and they looked up and said, “We just don’t know what.” And, you know,
there’s a number of reading programs out there that we were looking at, and
finally I—we hired a reading specialist with assistive technology background to
look at this. And we’re in the process now of adapting the device for Wilson
Reading Program.

**Denise:** And when you say “hired,” did the school hire it, or did you hire this
person?

**Ms. O’Brien:** I did.

Denise: Okay, so you’re paying this person?

**Ms. O’Brien:** Yes, yes, and again, you know, maybe I’m a sucker, but this
person was recommended by X who runs the assistive technology program at X.
So again, rather than go through the school and have them fight to pay for her
because she didn’t actually have credentials, I just wanted to get this going. And
because she was in school, her rates were extremely reasonable. And when—the
first time I talked to her on the phone, I thought, “This is the person we need. I
love her.”

**Ms. Von:**

Basically, it’s—that’s it. So in school from then on, I was always every year, you
know, advocating, “We need to get her sign language.” And I’ve been fighting
for—in fact—well, we won't go there, but we finally got a signing assistant this past year. ...Oh, I just kept advocating for her needs; I kept looking up information on the Internet, explaining to them why it was beneficial for a child with a disability, especially for a child with MR, to have sign language or, you know, be able to communicate... Yeah, and it's a lot—and this is over the years that—I mean, I've been fighting, like I said, for years. And now, I get her both—all of her communication devices have been received through her MR waiver or Medicaid.

-Advocating through a A Rule-Based Perspective

Three parents adopted a rights perspective and invoked the formal law to resolve grievances. I use the term rule-based to describe this orientation to advocacy, which I adopted from Barton’s sociolegal research (Barton, 2004). In each case these parents tried to resolve disputes through informal methods and they turned to the formal law when these methods failed. Each parent identified personal factors and/or social circumstances that influenced their decision.

**Ms. Cole** reported that she filed a formal complaint with the Department of Education after the school system did not provide her son with an assistive technology evaluation and a speech generating device, as promised. She stated she did not know which section of the law was violated and she felt this held up her application. She stated that the Department of Education helped her with this matter. She mentions that she is organized and "sticks to the facts" when advocating for her son. **Ms. Dean** filed a formal complaint after the school refused to incorporate the child’s speech generating device into his IEP. She hired an attorney after her brother, an attorney himself, suggested she do so because he thought the
law could help the parent obtain her son’s rights. **Ms. Von** filed a formal complaint and obtained legal help, after years of advocating through informal methods. She stated that she is “determined” and she lets people know that they should not underestimate her ability to obtain legal help, despite the fact that she has limited financial resources.

Excerpts from the narratives illustrate these themes.

**Ms. Cole:**

In Mid October 04 I spoke with RIDE (Rhode Island Department of Education), after lots of phone tag, to complain about non-compliance of the IEP. I was informed a complaint could be filed given the information I provided. She sent the forms in the mail: complaint form, RI regs and new family friendly regs. She also made phone calls to find out what’s happening. …I had to put down the section of the law that I felt was not being fulfilled. How can any typical person understand the educational laws that well to be able to pick from the list to apply to their particular situation? Needless to say, this particular part held up my application until I was told by a woman at the Dept. of Education that the department of Special Populations would help with that section and for me not to worry about it. And to be honest, the more I think about it, the more I’m realizing that the paperwork that was given to me on my rights was difficult to follow and was quite intimidating to me.

I think I’m able to move forward, although sometimes too slowly, with the school because of follow through on the issues….I try to log my phone calls with dates, request, comments, etc. so I have a timeline to follow. When I have extra time to review my notes and see nothing has moved forward, I make another round of
phone calls and set up meetings, and again log my calls, request, comments, etc. to remind me of what's happening. I usually lose my temper at this point in time and really have to stay focused on what's important and stick to the facts. I DO usually threaten at this point in time with filing non-compliance with the Dept. of Ed which always gets them moving, but not necessarily to completion of the request. I really only have to look in the blue pages of our phone book, find RI Dept of Ed, Special Services Division, and make a call. I'm transferred to someone familiar with my district and just tell my story using my logs. This person makes phone calls to confirm, sets a fire under their butt and gives me recommendations on what to do next. Really quite simple!!! It's not intimidating when you have those logs in front of you with all the info you need, the hardest part is staying neutral and sticking to the facts. And of course, staying organized!!

**Ms. Dean:**

My brother's an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help X, and that he didn't know them well enough, but there were lawyers that specialized in it.

...No one at the school supported it (the speech generating device). My—both my private therapists, my husband, myself, my attorney—we all supported it. And never did I think it was going to be a huge ordeal. They said, "Absolutely not," and that was his last day of preschool. We pulled him out. So I continued on doing the thing with our two private speech therapists. I continued on—the lawyer filed papers for due process hearing...Because I took the training at the
Federation. I knew that was the only recourse that I’m going to have, because they weren’t allowing my child to be who he needed to be and to access the curriculum. If he can’t speak, how do you know he’s accessing the curriculum? Also, I got a picture—this is one thing that makes me cry even today—of the preschool kids having their picture taken in the fall, and the PECS pictures exchange for feelings was hanging above all their heads. So even if my son was sad, he couldn’t go and pick that thing off, even if he stood on a chair.

...So we filed for due process, and I met with the lawyer again. And at this point, the lawyer’s—I’m writing all the letters, and she’s just saying, “Yeah, that’s okay,” because I was trying to save money, because my—this is—the lawyer fees were cutting out of my speech fund (fund her parents gave her.)

**Ms. Von:**

Well, I kept going in, and I kept making programs for her to use, and I kept telling them, “There’s programs; here’s how you access them.” They just weren’t using it, so you just—at every IEP meeting, I kept asking for AT training. And we still, by the way, have not got AT training yet. So I keep going back, and you know, I am not one that wants to go all full gun and go, “Okay, we’re not going to due process,” because, you know, sometimes that can harm more than help...So, you know, if I’m going to go to due process, it’s going to be the last resort of anything that I do. This is ‘9, so it’d be 2007, I believe—no, two thou—wait a minute; I’m trying to remember when I did it—2007. The lawyer came in, and we had a meeting with the school and their lawyers, and our lawyer made them look like fools, basically, and walked out of there with—and the school was hanging with their tail between their—you know, their legs, basically....They put
her back in the class she was supposed to be in. But we still had problems with implementing the IEP. That has not changed to this day.

...I wrote up a formal request again, handed it to them at the IEP meeting again, waited to see what they were going to do—give them enough time to set up something. They didn't do it. So in 2008, I filed a state complaint......You just call the Department of Ed. They send you the paperwork. Or actually, now you can download it off the Internet, off their Web site... So I did that, and I sent it in, and they thought it had enough merit. They contacted the school district and told them they had 10 days to get it rectified to the satisfaction of the parent, or they would have to come in. Now, I don't know what they mean by that, but evidently it's not a good thing, you know. And so, we worked on that; she—so they finally found some—actually, I found the person and contacted them. It was a person at the school for the deaf and blind—state school for the deaf and blind who was able to do that, because one of the—anything that I ask for now with X—the person needs to have sign language. So even though X may not be that great expressively with sign language, she's very good at—receptively—you know, receptively with sign language. So when you're talking to her, you need to be signing, because she can't hear all the different sounds. So finally, we got one set up.

... I never went to due process. No, didn't have to, because when I threatened to go and I told them I'm not playing—I said, "I don't care"—and you know, their attitude is, "Oh, these are poor people; they don't have money for a lawyer." I said, "Look, I got a lawyer before. I'll get a lawyer to come one way or the other. Don't worry about how I'm going to pay for the lawyer; that's not your concern."
I said, "Because I am determined," and I said, "You will meet her needs one way or the other." Then I got demanding, because I was mad then. So we did—they finally set up—and again, this is one of those things—I contacted another—an organization—a rehab organization for them—the state, and they told me who to contact for this and who could do that. And I took all these things, and I gave them to the special ed director, and I said, "Now"—because she kept telling me, "We can’t find anybody for this; we can’t find anybody for that.” So I took—I said, "Here, here’s the names. Call them.” So we finally got it set up to get the speech-language evaluation done. And we got that done, and it took two months to get the report back. So do you wonder how our kids get service to begin with [laugh]?

-Personal Resources and Social Circumstances

The narratives revealed that several parents thought their level of education, wealth, family, and professional background helped them advocate for their children. Two parents thought that personality characteristics influenced how they advocated. No parent mentioned that they perceived their race or ethnicity or a provider’s race or ethnicity impacted their experiences or decisions. As noted in the first section of this chapter, all Phase II parents in this study described themselves as Caucasian, which may have contributed to this finding.

Ms. Carter

I think I'm able to move forward, although sometimes too slowly, with the school because of follow through on the issues....I try to log my phone calls with dates, request, comments, etc. so I have a timeline to follow. When I have extra time to review my notes and see nothing has moved forward, I make another round of
phone calls and set up meetings, and again log my calls, request, comments, etc. to remind me of what’s happening.

**Ms. Hall**

I was just so convinced I was right. I just knew that my boys had more potential than what the school acknowledged. And I knew that if they were being successful at HealthSouth, they were being successful at Leader Clinic at Edinboro, they were being successful with me at home, there’s no reason why I should change what’s successful in three places to make it work for these people who were basically idiots as far as understanding the potential of my kids. And I don’t know; I think, because I’m just so stubborn, that when I’m convinced that I’m doing the right thing, I’m not going to change. That was the part of it that carried me through—was, “This is my kids, this is my babies, and I know for sure that this is the right thing to do. And if nobody else in the world believes me, that doesn’t make it any less right. This is what needs to happen.” And since then, X (her husband) has come around and began to understand why I would not budge.”

**Ms. Glade**

But, you know, I tend to be a person who takes people at their word and tries to hold them to their word. You know, if somebody tells me something, I expect them to live up to it, and I will go back to them and say, “But you told me....” And I’ll try to get it in writing—like, send them an email and expect to get an email back, or if you tell me this—and I’ll send you an email and say, “This is what I understand.”
In the next excerpt, Ms. Blair described how a group of parents started a faith-based organization to provide therapy for children with disabilities at the faith-based school. The parents started this organization due to problems that parents faced when they had to transport the children from the faith-based school to the public school for therapy.

**Parent:** For years and years, their parents would send them to private schools, go there at 11 o’clock, drive them across town, wait for half an hour, bring them back to the day school. So it was always a balance of—you know, was what they were getting from the half-an-hour therapy twice a week worth what they were missing in the day school? The—so it originally started out a collaborative—a couple of the day schools—the Jewish day schools in this area; parents got together and decided to just try to fund—I think at the time, it started out with a PT and an OT to go from school to school to service these kids, so they didn’t have to leave their private school settings and go to public school.

Denise: And who was paying for it?

**Parent:** Parents.

Denise: So the parents paid for all of this.

**Parent:** Yes, and parents fundraised, and parents hired the staff....

Denise: Congratulations! Oh, my.

**Parent:** Thank you. And then we found out that there was a similar organization doing a similar kind of thing, but only for supplementary school, like Sunday school, in—actually in X and X (cities). So five or six years ago—five years ago, the two organizations merged, and now they serve at a dozen schools in the greater Boston area. And they continue to run a Sunday program, a supplementary program, a program for teens....

Denise: Oh, wow! That’s so exciting!
**Parent:** Yeah, it is. And it—you know, it’s all—it all came out of a bunch of parents—I can’t honestly say we were among the founding parents. We were among the second generation.

**Ms. Dean**
You know, I—we don’t have a whole lot of money, and at the time, money was extremely tight. And I didn’t have the $125 fee for an hour for a private speech therapist. So what my parents did was, they came in, and they gave me a huge lump sum of money and said, “Here, we want you to put this in an account and use it for Xs speech therapy.” So they did that, and when they did that, then it took the pressure off of me to ask them permission every week

..My brother’s an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help Lee, and that he didn’t know them well enough, but there were lawyers that specialized in it.

I saw my mother—how my mother advocated for me. My mother, believe it or not, got extended school year services for me before Chapter 766 came in to be in Massachusetts.

Denise: And when you say you saw how your mother advocated—

**Parent:** Well, she—you know, what I—one of the things that happened to me in second grade in December was, our teacher—the teacher I had, Ms. X—if you didn’t finish a certain number of boards by 11 o’clock in the morning—I think it was three boards by 11—of work—that you had to sit in the corner, where [beeps]. Now, it happened to me in December—my recollection is it happened in December—and I came home crying and told my mom that, you know, this had
happened. And she was down to school that day. That’s my recollection; she tells me it wasn’t that day; she did call [laugh]. But the point of the matter is that—and I also got D’s on conduct, and the teacher said the reason why—because my mother asked me, “Are you yelling? Are you pushing in line? Are you talking out of turn?”, and I was like, “Nope, nope, nope.” The reason why was because every afternoon, I’d lay my head down on the desk and cry, and that’s why she gave me a D in conduct. So my mother said, “Don’t you think there’s a problem here? This is happening on a daily basis; what’s going on?” and, you know, etc. So, I mean, my mother advocated for pencils. They used to give you free pencils in school, and then they stopped it. I remember her writing a letter campaign. You know, so she’s a strong advocate, and, you know, I did learn through her: If something isn’t right or you don’t think something is right, you need to act upon it, because it’s not going to change on its own.

**Ms. Klass**

Okay. I think what we probably need to get on the record somewhere is, prior to staying home, I was a discharge planner/case manager. So I think my background helps....I think it helps in many reasons. One, it helps with the whole documentation piece. You know, as soon as I pick up the phone, I write a date on a piece of paper and ask the person their name. And I think it helps because if I find that I’m not being heard, I don’t have a problem asking to speak to a supervisor. This really hasn’t happened with an AT device, but just recently, I was trying to get Maggie a piece of equipment covered, and I realized that the person I was talking to—and I had to spell every diagnosis and spell every med. It was a waste of my time, because they had no clinical background. So I had no
problem saying, “Can I please speak to a nurse or a physician or a respiratory therapist or just someone so I’m not spelling ‘cerebral palsy’ every time?”

...We are fortunate that we live in a great town. And I’m not saying that we haven’t had our differences, but X (her husband) and I have both grown up in this town, and X’s been in public school since the day she turned three. And it’s worked, for the most part. And I think that because we approach things as a team—that she has a tendency... I can’t really think of any time she has been denied something that I truly believe she’s needed.

Ms. Smith

I’m perfectly comfortable letting my insurance go first, but I don’t think all people have that luxury of having that insurance that would pay for everything. I always use my insurance for—actually, that’s not true. The school system pays for X’s equipment. They pay for his stander and his—a walker and stuff, so they have bought him mobility equipment. They’ve bought that.... I live in a pretty nice suburb.

Ms. Von

..I think knowledge, the more I learned, because I have to be honest with you: I am a—I’m a rebel. So—and rebels not always—even when we have the best intentions, we’re not always sophisticated enough to do what we need to do in the right way. In other words, I don’t play their games. I don’t have time to play their games. So sometimes, that’s a drawback. So that’s what I’ve learned. You know, when people say, “What positive things have you learned?” you’ve got to learn about the negative things that you’ve learned. And one of my negatives is
the fact that I’m like a bull in a china shop. My intentions are good; I have good—the good point in my advocating is to have a lot of good knowledge that I’ve learned over the years. And I’ve learned where to go now to get more knowledge and who to ask and—you know what I’m saying?

...When I threatened to go (to due process) and I told them I’m not playing—I said, “I don’t care”—and you know, their attitude is, “Oh, these are poor people; they don’t have money for a lawyer.” I said, “Look, I got a lawyer before. I’ll get a lawyer to come one way or the other. Don’t worry about how I’m going to pay for the lawyer; that’s not your concern.” …Because I am determined,” and I said, “You will meet her needs one way or the other.”

E. Obtaining Knowledge About the Formal Law: Strategies Parents Used

**The Power of Networking and On-Line Communication**

Most parents obtained knowledge about the law by talking with other parents on listservs and many stated that they participated on multiple listservs. Some parents gained knowledge by talking with other parents in their community, with friends, and with health care professionals. Some parents reported they read the regulations on-line.

**Ms. Von:**

And to be honest with you, almost anything I’ve learned—most—unless it’s a medical—and even medical comes from parents. But I would say 90 to 95 percent of what I’ve learned is through this parent group....When we learn something new, we get on there; we share it with other people, you know, because it seems to be one of these things that—it’s “Don’t tell unless they ask.”
Ms. Brady discussed how a social worker helped her identify resources and told her about a local advocacy group that has a listserv. The parent stated that she gained much knowledge about services and providers from this listserv. She also reported that she joined another listserv by “surfing the net”.

Ms. Brady stated:

I learned about them from X from the Western Regional Consultation Program – a program for kids with more complicated care – medically that is. She was introduced to me by early intervention. She’s amazing. She’s really an amazing woman. She knows everybody, and she knows, like—you know, so when I got denied from Mass Health for the fifth time, before I got—gotten—she gave me the—you know, she hooked me up with the right person to get the local Springfield office head. And I called him up crying, and he fixed—you know, he started working on it—so, you know, like that kind of stuff. She knows everybody.

...They have a listserv that shares information between parents and providers. On it I get so much info about other services and organizations, and ideas for our situation. In addition, MFV (Massachusetts Family Voices) runs these really cool topical conference calls that you can listen in on live or play back after. I love them.

..I joined a Web site in the summertime; it’s a listserv for parents from YAK—I think is the group. Oh my God, it’s, like, so great, because everybody’s helpful. It shares info and talks you through, and—I don’t really talk online—I don’t really write to people, but I’m a lurker, as I like to refer to it. But it’s just been—I really
appreciate the sharing of this community....Surfing the net looking for information on talkers.

This same parent reported she gets most of her information about IDEA from other mothers and from a local advocacy group. She stated she was not knowledgeable about the formal law, though she had a link to it on her computer. This parent is the president of a parent’s advisory committee (PAC) in her school district. She interacts with other parents who may have questions about the law and she stated she is not always certain about the accuracy of the information she provided. Ms. Brady stated:

I get the bulk of my info from other moms. Or I apparently make it up the way I see it, which is really all about common sense. I also ask the director of Mass Family Voices for help because she’s a stickler to details and clearly knows and understands (emphasis) what IDEA states. I know that there is a law and I just presume that the things I want for X are included in it. So I'm embarrassed to say that I'm really not up to par on the actual law - although I do have a link to it on my favorites. And any other parent that comes to me with a question about it - if I don't think the request is outrageous or wrong - I absolutely tell them that it's the law - again not really knowing exactly if it is. I figure that if it's not actually part of the law, the school will know and fight back. Then I'll read it to find a way to make it what I want....

Ms. Blair stated that she obtained information from a website and by reading book. She described the formal law as “daunting”.

You know, the legal stuff is a little daunting for me, but the Wright’s Law Web site and the Wright’s Law books have been very helpful to me. They have a great
book for parents, called *From the Motions to Advocacy*, about how to use the system and how—what things to do and what things to kind of—and to avoid. Right, and, you know, anything on the Internet that’s reasonable, sounds reasonable has been helpful. I don’t have a lot of other parents with this particular need that I actually know in real life.

**Ms. O’Brien** is another parent who stated she learned some information about the formal law from reading posts on a listserv.

I’d have to say I’m not real good about reading all kinds of, you know, rights law and, you know, all kinds of state laws. Basically, I learned about it on the Yahoo! list.

…Basically, by, you know, the people on the Yahoo! list. You know, I mean, I take everything that’s said with a grain of salt, and—but you know, a lot of the people are—when they say something, they say, “This is where you can find out where it is,” and exactly what it says. And I think, you know, you have a responsibility to find out exactly what’s true and what’s not.....Yeah, I guess—you know, there was a time that someone brought up that they thought—I can’t remember. It was recently where they thought that a device was mentioned that they had a right—the kids had a right to take it home, if it was purchased by the school. And that was one of the first times I went to IDEA and looked up that section, just so I knew how it read. And it was indeed true that a child’s—you know, if a school district buys the device, the child has a right to use it wherever they are. Yes, and they actually said that they couldn’t remember where it was in IDEA, and they didn’t find it, so I—from my own knowledge, I wanted to know what it said. So I went to IDEA and figured out where it was.
Several parents reported that they learned about Medicaid waiver programs from care coordinators. Two parents learned about the programs when the children were in early intervention.

Ms. Von **stated:**

When she was born and went on Medicaid. So you have to have a case manager when you’re on Medicaid. So she had a really, really good case manager, X, up until we moved to the county here in 2000. So she had an excellent one; when she discovered about the MR waiver when it first came out, she came up to me and she—well, she called me; she says, “I need to come talk with you about some things.” So she came over, and she says, “New program. It’s called MR waiver. Would you like to put X on?” She said, “It’s really great.” And I said, “Yeah.” So we put X on it. Well, it was brand new, so even they didn’t know a lot about it at the time. They just knew that it’s one of those things you wanted to get on right then. So X got approved immediately back then. There was no waiting list back then; that—I mean, people didn’t know about it, so there was no waiting list; you know what I’m saying?

**Ms. Cole:**

We were told about the Katie Beckett waiver from Early Intervention after X had his second hospitalization. I had no idea what it was all about but knew it was important the way our service coordinator delivered the info to us. It was so difficult to get a return phone call that I needed to contact our local Senator to finally get an appt. Senator Reed continues to be a great advocate for us when we need him.

**Ms. Hall:**
The boys must have been not quite three, because we still had our in-home early intervention people there. And the coordinator for that had told us that we were going to have this test, because we needed it when we started the preschool. ...And it opened up the option to eventually be part of the waiver program.

**Summary**

This small exploratory study revealed that the law empowered parents to persistently advocate for their school aged children to receive assistive technology devices and services. Most parents advocated through informal dispute resolution processes and some invoked the formal law to assert their rights and claim their children’s rights under health insurance laws and IDEA.

The narratives revealed that the law was an integral part of parents’ daily lives. It was situated in diverse places such as families, neighborhoods, schools, workplaces, doctors’ offices, hospitals and on multiple listservs. Therefore, the meanings associated with the law extended beyond the formal legal institutions to include the culture of law. Sociolegal scholars refer to this broadened definition of the law as legality. Parents’ perceptions about legality, known as legal consciousness, evolved and were constructed through their experiences with a variety of people over time. Based on these perceptions, parents made decisions about their rights and their children’s rights. The ways in which parents thought and acted in relation to legality accounted for some of the differences between the formal law and the law in action. These findings now lead to a discussion of the concept of legality vs. law as an analytic framework and of legal consciousness as a way to describe how parents were engaged in the construction of legality. These concepts are analyzed and discussed in the next and final chapter of this dissertation. The final chapter also
discusses the policy implications of this study and some possible directions for future research.
Chapter 7

Discussion, Policy Implications and Directions for Future Research

Beyond the Boundary of the Formal Law

Families face many challenges as they advocate for their children’s assistive technology rights and entitlements. They will interact with two complex systems - the public school system and the health care system - each with its own complex laws, regulations, policies and procedures. During the process, they will engage with numerous people – educators, health care professionals, health insurers, vendors, their families and others parents. These individuals may differ in their degree of knowledge about the laws, perceptions about the child’s assistive technology rights and entitlements under the law, their expertise with assistive technologies and their perceptions about the child’s needs and skills. These differences may result in incomplete, inaccurate, or misinterpreted information, as well as disputes among parties.

This study focused on how parents’ perceptions of the law evolved as they interacted with a variety of people and how these perceptions influenced whether and how they asserted legal rights. Therefore, this study examined law in a social context. To study law in a social context, one must move beyond the boundaries of the formal law. We must shift the focus from the formal law to law in everyday life – to law as an integral part of social relations. This shift has methodological implications. To study the social construction of law, one must broaden the definition of law and study it as a dynamic, rather than a static process. Sociolegal scholars use the term “legality” when discussing the diffuse and dynamic nature of law. The word “legality”
refers not only to the formal institutions of law and its formal legal actors. It includes the social meanings of law, its cultural traditions and the sources of authority (Ewick and Silbey, 2005). Given this definition, legality can be found in diverse places – within families, neighborhoods, schools and various other places within a community – as well as formal institutional settings. The study of legality builds on a long tradition of sociolegal scholarship that examines the complex and variable character of law. Sociolegal research is also interested in exploring how the written law compares with law on the street. It examines how social networks, cultures, organizations and personal resources may shape how people perceive the law and how these factors may influence whether and how people assert their rights.

Many sociolegal scholars base their research on the theory of legal consciousness. They define legal consciousness as how people think and act in relation to the law in their daily lives (Ewick and Silbey, 1998; Engel and Munger, 2003). As discussed by Ewick and Silbey (1998), legal consciousness is a “collective construction” (p. 46). By that Ewick and Silbey mean that legal consciousness emerges and is expressed in the exchange of ideas which are shaped by cultural codes, language, norms, and institutional procedures. As discussed in Chapter 4, to study legal consciousness, sociolegal scholars often collect and analyze stories of ordinary citizens. According to Ewick and Silbey (1998), personal narratives are a “lens to study law in everyday life” (p. 29). Through stories people explain their actions to themselves and others. These stories are temporally-ordered accounts of events and relationships, known as personal narratives. Personal narratives of law are stories that describe a person’s beliefs about the way he or she should not act and why the law should or should not be obeyed, resisted or mobilized (Ewick and Silbey, 1998). Personal narratives were
well suited for this study because it focused on families’ accounts of law and their responses to the law as they interacted with a variety of people over time.

This research combined legal consciousness theory with a grounded theory research method to analyze parents’ experiences with the law. Grounded theory is a middle range theory which uses qualitative research methods to explain the ways in which people construct meaning of their lives (Glaser and Strauss, 1967). Grounded theory methods offer systematic inductive guidelines to collect, compare and interpret data, which then lead to development of a conceptual framework. Grounded theorists contend that data are narrative constructions (Glaser and Strauss, 1967; Maines, 1993). In other words, data are not the original experience but the reconstruction of experience. The data are rich and highly descriptive and the analysis is a comparative process; data are constantly compared across time. The researcher may compare data among people (their views, experiences, accounts) and/or data from the same individual, which may be contrasted at different points in time. Grounded theory strategies are well suited to study legal consciousness because these techniques can study a dynamic process, examine lived experiences and capture an individual’s point of view.

In this study, the researcher collected personal narratives of legality by interviewing parents about their experiences as they advocated for their children to receive assistive technology devices as services. These narratives were rich, thick descriptions of how parents experienced and constructed legality. Through these narratives parents recounted their experiences with legality. These experiences were embedded in social structures, such as family, friendships, community, education, and bureaucracies. The parents’ stories were infused with highly detailed descriptions
of past and present experiences and the relationships which developed among themselves, their children and the many people who they interacted with. Parents often told stories about when their child was first diagnosed with a disability and about encounters with physicians and numerous specialists. The stories often circled back and around many different interactions - trips to the hospital, school days, telephone calls with insurers, meetings with teachers and therapists, discussions with family and friends, and discussions with other parents. The stories were told with much emotion. Parents often talked about their struggles and the frustrations. They also talked about their hopes and aspirations for their children. Therefore, within these narratives parents interpreted their experiences using a variety of legal and non-legal concepts.

As discussed in Chapter 4, the narratives were coded, categorized and compared to determine how parents’ perceptions evolved and how their experiences of legality shaped their legal consciousness and influenced their decisions and actions. The narrative analyses examined whether and how parents claimed their children’s rights, asserted their rights as well as the reasons why they may have resisted or avoided the law. The study also compared how participants’ perceptions of the law compared with the positive law.

**Legal Consciousness As Revealed Through Narratives: Measuring the Role of Law in Everyday Life**

The stories that parents told revealed that they constructed legality as they interacted with a diverse group of people over a period of time. Such people included family members, friends, teachers, therapists, school administrators, health insurers, independent evaluators, vendors and attorneys. Moreover, parents regularly
interacted with other parents through electronic communication, on multiple listservs.

Parents’ legal consciousness emerged and was reconstructed from interactions and relationships with people. Their legal consciousness was reflected in what they said and what they did. Legality was infused within parent’s victories as well as their struggles. Parents described ways that the law provided opportunities to act and ways that the law constrained them. However, these forms of legal consciousness were not mutually exclusive. Rather, parents expressed several varieties of legal consciousness, depending on the context of their interactions and events. Therefore, the narratives revealed the variable and complex nature of legal consciousness.

**Empowered by the Law**

The narratives revealed one overarching theme: As an element of social life, legality was constructed and reconstructed in conversations and parents were empowered by it. I use the term empowered to mean two things. The law provided a framework for parents to think about rights, talk about rights and claim rights. The law became part of parents’ everyday speech, thoughts and actions. Furthermore, all parents were committed to the possibility that the law was a way for their children to receive equal and fair treatment. While parents expressed a sense of being caught up in the law, due to problems they had in obtaining some assistive technology rights, through the parents envisioned these rights for their children and they persistently advocated for them. Though few parents could cite specific laws and regulations, they talked about justice and injustice and spoke and behaved as if their children had rights. Moreover, their words and actions revealed that parents recognized that they had rights to advocate on behalf of their children. The law made it possible for parents to think
about assistive technology rights and entitlements and to think about challenging the law. It created a rights consciousness among parents without which parents may not have had a way to acknowledge and validate the notion of rights and entitlements. The law enabled parents to recognize that their children were entitled to assistive technology devices and services and therefore make legitimate claims to these rights.

The concept of legality provided a context for creating a rights consciousness among the parents. How was this achieved? Engel applies the concept of a domain to describe how legality can shape the rights consciousness of parents who have children with disabilities (Engel, 1995). The term domain refers to an arena where social interactions take place on a regular basis and these interactions are characterized by a common language. Within the domain are actors who come together within particular places and times and who interact around shared values, purpose and normative expectations. For parents in this study, the law provided a rather distinct arena within which parents engaged with a community of people, at particular times and in particular places. In this arena they shared a common language, though there was considerable variation among people concerning their notions about education, health insurance, the formal law, parental participation, authority and power. In this social domain there were children, who were classified by educators and therapists in order to qualify for services and devices. There were schools where parents and educators developed, reviewed and implemented the IEP at particular times, based on IDEA procedures. There were independent evaluators and vendors who helped parents navigate the health insurance process, a process that was highly procedural. There were parent advisory committees where parents talked with a community of parents and there were multiple listservs where
communities of parents routinely interacted. Legality was infused and constructed in this social domain and in this domain parents incorporated rights into their thoughts and actions.

This study revealed that rights can influence people in other ways, even when they choose not to invoke them formally. In this study three parents reported that they engaged in new opportunities during the process of advocating for their children. One parent became president of a public school parent advisory committee, one parent started her own business selling low technology augmentative communication products and a third parent assumed a leadership role with an augmentative communication website. This same parent carved a role for herself at her children’s school. She does all the programming on her children’s devices so the children can access the curriculum. Another parent described how she thought her son’s experience with his speech generating device at school indirectly helped other children. After the teachers and therapists became familiar with her son’s speech generating device, the school district purchased several devices for other children to use. These examples are consistent with Engel and Munger’s (2003) research which revealed that experiences with the law can shape a person’s sense of self and experiences with the law can enter social settings indirectly.

Exploring the Gap Between Law in Action and the Formal Law

In each of the narratives the parents discussed how the law provided opportunities and as well as constraints. While the law provided children and their parents with a set of rights, parents also discussed their frustrations and apprehensions with the law. Moreover, parents discussed their fears that by challenging decisions or by invoking the law, specifically IDEA, they may cause opposition and antagonism which
could cause greater harm than good. Many parents were conflicted by IDEA’s intent and its everyday meanings and this conflict contributed to the gap between the formal law and the law in everyday life. Therefore, while health and education laws and regulations establish the rights that children and their parents have for obtaining assistive technology devices and services, parents’ experiences of legality influenced whether and how they exercised certain rights.

As parents interacted with a people, their legal consciousness was experienced and constructed. Parents expressed varieties of legal consciousness, depending on the context. At times they were empowered by health insurance laws and regulations. At other times they were disempowered by it, due to its complexity and bureaucracy. In terms of IDEA, parents described how IDEA was meeting its obligations by providing a range of special education and related services to enable their children to learn. Some parents thought the law had the potential to resolve their grievances. In contrast, parents also felt caught up by the law and disempowered by the law. These perceptions evolved due to persisting disputes with the public school about implementing assistive technologies in the classroom and due to perceptions of inequality between themselves and schools. Most parents thought IDEA was not implemented as intended and some thought the law was complex, ambiguous or arbitrary. Despite these rather negative perceptions of IDEA, parents’ thoughts and actions revealed that the law enabled them to advocate for their children. In fact, all parents persistently advocated for their children to receive assistive technology services in the schools. Most advocated through informal dispute resolution strategies. Others asserted their rights under the formal law.
These types of legal consciousness accounted for some of the differences between law in action and the formal law. Based on interactions with people, parents made important decisions about exercising their rights and claiming their children’s rights. They made decisions about whether to access their health insurance rather than the public school for funding of speech generating devices, to seek an independent augmentative assessment, ask the public school to pay for an independent assessment, obtain private therapy funded through health insurance, apply for benefits through a public health insurance program, meet with teachers to discuss their child’s IEP, reject an IEP, obtain legal advice, invoke the formal law to obtain their due process rights under the law. Parents also made decisions not to act. In other words, at times some parents decided to avoid conflict or just make do.

To address their grievances, all parents used informal dispute resolution strategies and they employed a “relational” orientation, a term I adopted from Engel (1991) and Barton (2004). The term “relational” refers to how parents advocated based on what they thought their children needed and should have, versus their children’s rights; and how they focused on building relationships as part of the process. Three of the ten parents invoked the formal law. How and why did parents make these decisions and how did their circumstances compare? The narratives revealed some themes, which are discussed below.

-Mastering the Funding Process: Empowered by Stakeholders

While the IDEA and health insurance may each provide a means for funding speech generating devices, several parents decided to access their health insurance benefits rather than obtain the device from the public school. These parents thought the funding process was orderly, predictable and therefore manageable. Each of the six
parents that submitted a funding request to health insurance had a positive outcome. How did parents’ perceptions of the funding process evolve? The narratives revealed that perceptions were directly linked to interactions with vendors and independent evaluators. These individuals assisted the families by explaining the funding process and helping them navigate health insurance programs. Thus, these interactions influenced parents’ perceptions of their rights and consequently determined how parents asserted rights.

Over the past several years assistive technology vendors have focused their efforts on helping families master the highly procedural funding process. Manufacturers of speech generating devices have developed user-friendly websites with state-specific information to assist parents and professionals. Furthermore the major manufacturers have hired networks of people nationwide to provide training and technical support. Thus, it is possible that the vendors’ market force is having a significant impact on how children’s formal rights are actualized.

How did parents’ funding decisions compare with the positive law? Six parents opted to access health insurance benefits to fund speech generating devices rather than obtain the device through the public school. This finding may not be a departure from the positive law. The public school may not be obligated to provide a device. Under IDEA, the school is not responsible for providing a device if a non-educational agency, public or private, is obligated to do so under federal and state law (40 U.S.C. §1412 (12)(A)(i)). However, if the non-educational agency failed to provide a device, the public school would be responsible and must provide it (20 U.S.C §1412 (12)(B)(i)). Moreover, in such a case, the public school may seek reimbursement from the non-educational agency (40 U.S.C. §1412 (12)(B)(ii)).
Given the complexity of IDEA and health insurance regulations, there is the potential for disagreement among a parent, the public school and a health insurer concerning who is responsible for funding a device. Since each of the children in this study had severe communication impairments due to medical conditions, one could argue that speech generating devices are a medical necessity, as defined by many public and private health insurers. One could also argue that each of the children needed the device in order to receive a FAPE. No parent in this study described any dispute of this nature.

**-IDEA: Not Implemented as Intended**

In terms of assistive technologies and services, most parents thought that law was not implemented by schools as intended. They thought the public school did not have the knowledge and expertise to provide assistive technology devices and services. For most parents, this perception evolved over a period years, as they interacted with teachers and speech-language pathologists. Based on these interactions, parents did not have confidence that the public school would or could evaluate their children’s assistive technology needs.

In terms of the positive law, IDEA states that the public school is obligated to provide an assistive technology evaluation in order for the children to receive a FAPE (34 C.F.R. § 300.6, 300.105) and this regulation has been adopted within the special education regulations in each of the states where the children live. Thus, if the school could not or did not provide an evaluation, this would be a departure from the law. Most parents went outside the public school and had their children evaluated at local hospitals. These services were funded through health insurance.
Most parents expressed the greatest degree of dissatisfaction with how devices were implemented in the classroom. Parents thought that staff did not have the expertise to help the children learn to use the devices and therefore the devices were not used effectively. If accurate, this would be a departure from the law. IDEA regulations, which have been adopted within the special education regulations in each the states the children live in, entitles children, their parents and the professionals who work with them to receive training to use assistive technology devices in order for the child to receive a FAPE (34 C.F.R §300.6 (e-f)). How did parents respond? Most parents persistently advocated for training through the public school and some obtained training at local hospitals, funded through health insurance. Parents learned about these private services by networking with other parents in their community and on listservs. This illustrates how parents learned about the law and how interactions influenced their perception of their rights and their children’s rights.


There may have been other reasons why parents thought the law was not implemented as intended. This concerns the differences between the federal and state procedural provisions of IDEA and the substantive provisions of IDEA. The procedural provisions of IDEA are highly specific and detailed. In contrast, the substantive provisions of IDEA are relatively vague. The substantive provisions involve the standards and criteria used to develop a child’s Individualized Education Program (IEP). For example, the terms “individualized educational program” (34 C.F.R. §300.320) and “appropriate education” as in “free appropriate public education” (FAPE) (34 C.F.R. §300.101-113) are key rights under IDEA, though there are no substantive definitions for these terms and there are few guidelines for
a school district to use. Based on IDEA, the child’s multidisciplinary team is responsible for developing a program tailored to meet the unique needs of the child so that the child can benefit from special education and related services and receive a Free Appropriate Public Education (FAPE). The interpretation of “appropriate education” may be relevant in two cases in this study. Two parents reported that the school provided speech generating devices for the children but the parents disagreed with the school systems about the type of devices that was needed. The parents believed that the children needed more sophisticated devices. Under IDEA regulations the child is not entitled to a specific device and the school is not obligated to provide the best or state of the art equipment. If the school provided a device, the type of device is determined by the child’s IEP team, based on their evaluation. Furthermore, as noted above, the school is not obligated to provide a device if a non-educational agency is obligated to do so by federal and state law (20 U.S.C. § 1412 (12)(B)(i)). Thus, IDEA is explicit about children’s right to have assistive technology devices in order to receive a FAPE, but the school may not be obligated to pay for them.

There is another factor that may influence implementation of assistive technology services under IDEA. In terms of augmentative and alternative communication interventions, evidence based research is just emerging. When practitioners evaluate children’s assistive technologies needs and develop treatment programs, they have limited evidence-based information to guide them. While there are published case studies and some systematic reviews, evidence at higher levels is just emerging. These types of evidence include evidence-based practice journals, evidence-based databases, evidence-based textbooks and computerized decision-making protocols (Schlosser and Sigafoos, 2009)
Given rather vague substantive provisions and emerging evidence based research, the IEP process can be rather discretionary, which may influence and perpetuate problems with obtaining and implementing assistive technologies in the classroom.

**-IDEA and Parental Participation: Disparity in Power and Influence**

Many parents recognized their children’s rights and entitlements under IDEA. They recognized the school was obligated to provide an assistive technology evaluation and provide training to the child and the family. Parents recognized their right to participate in developing the child’s Individualized Education Program (IEP) and their right to reject part or all of the IEP. Most parents, however, did not know the specific procedures for obtaining these rights. When they had grievances, parents preferred to advocate through informal dispute resolution strategies rather than by invoking their formal legal rights. Why? The narratives revealed that parents often made this decision because they perceived there was a significant difference in power and influence between themselves and the public school. Parents reported that they thought educators did not value their knowledge or input. While parents thought they knew their children better than the “experts”, parents also recognized that the educators had specialized training which they did not have. Furthermore, parents thought that the professionals had greater knowledge of the law than they did. These factors caused parents to feel disempowered. Parents reported that at times they suppressed or avoided conflict because of this disparity in power and influence. Some parents reported they did not invoke the law because they feared that asserting their rights could foster an adversarial relationship between themselves and the public school, which could have intended consequences for their children. Thus, these perceptions of power and influence directly affected parents’ decisions and
consequently determined how they asserted their rights and claimed their children’s rights.

These findings concerning disparity of power and influence between parents and educators are consistent with sociolegal research conducted by David Engel (1991). As in this study, Engel interviewed parents to examine their perceptions of the Education for All Handicapped Children Act (EHCA), which was later renamed as IDEA\textsuperscript{32}. Engel’s subjects and the participants in this study expressed some similar perceptions of the law. Like subjects in this study, Engel found that his participants felt disempowered by the law, which made it difficult for them to assert their rights under the law. Participants felt disempowered due primarily to the unequal power and influence between themselves and school district personnel. Within the boundaries of IDEA, parents and professionals have separate and distinct roles - what Engel refers to as a “rigid dichotomization” (p. 191). Engel asserts that professionals have highly specialized knowledge and training, while, parents know the child better than the professionals but lack specialized knowledge and training. Furthermore, most parents do not understand the complex regulations and therefore cannot converse using the technical language of these regulations. Engel found that parents thought that educators did not value their input and that professionals made most of the decisions. Engel also found that parents felt vulnerable for another reason. Parents thought that if they asserted their rights it might increase the level of adversity between them and the professionals, which might lead to unintended consequences for their children. Thus, some parents avoided conflict and focused instead on maintaining and building relationships.
While IDEA as written gives parents specific rights to advocate for their children, in everyday life the power may rest with the public school. Sociolegal scholar Susan Silbey discusses how power becomes institutionalized and she asserts that legal hegemony helps explain how the law sustains its institutional power, despite its promises of equality (Silbey, 2005). By legal hegemony she means the ways that power within institutions produce transactions and how the transactions become repeated, patterned and stabilized within legal systems. She asserts that often these sources of power and subordination are not visible. This study demonstrated the impact of legal hegemony on the experiences of parents who advocated for their children under IDEA.

-Mothers as Advocates: Relational versus Rights Perspective

This study involved 10 mothers. As noted above, most of these mothers used a relational strategy to advocate for their rights or their children’s rights, rather than a rights strategy. Parents persistently and assertively advocated for their children through informal dispute resolution strategies, based on their personal judgment and expertise. In other words, parents frequently discussed what they believed their children needed and should have, rather than what they were entitled to have. Furthermore, when they discussed rights, they frequently talked about the importance of collaboration, fairness and equality, rather than specific rights under the law.

This finding supported Engel’s research concerning gender and rights consciousness among parents who have children with disabilities (Engel, 1991) and Barton’s research which examined the dialogue between parents and advocacy group.

32 Pub L. No. 94-142, 89 Stat. 773 (1975). In 1990 Congress changed the name of the law to "Individuals
facilitators (Barton, 2004). Engel found that mothers were more involved with school related issues than fathers and many of the mothers emphasized relationships rather than rights. In Engel’s group, many mothers emphasized the importance of cooperation and maintaining relationships. He found that some mothers suppressed conflict or compromised to maintain relationships, rather than assert their rights.

Barton (2004) analyzed the discourse among facilitators and a group of parents, primarily African American mothers, who were enrolled in an IDEA advocacy group for parents. Barton used the term “relational” to refer to how parents tended to advocate for their children based on their personal judgment and expertise - what parents believed their children needed or should have - rather than based on the application of the rules of law. They humanized the law making it specific to the individual needs of their children and within the parameters of their specific settings and resources. Moreover, Barton found that the group facilitators emphasized a relational perspective to advocacy rather than a rule-based orientation. While the curriculum cited specific provisions of the regulations, the interpretation and dialogue emphasized the regulations in relational terms. In addition, Barton found that facilitators discouraged parents from pursuing their formal due process rights for two primary reasons – power and economics. Parents were told that schools have institutional power over them and that invoking the law could be cost prohibitive.

While beyond the scope of this project, these findings are also consistent with a large body of research that confirms that that women are more likely than men to focus on reciprocity and building relationships rather than rights and entitlements under the law (Gilligan, 1982; Marcus et al., 1985; Traustadottir, R., 1993). Moreover, like some sociological feminist research (Kaufman, 20003, 1990), the women’s
narratives elucidated their experiences in everyday life and shed light on the social construction of gender and family. The stories also illustrated the interplay between interpersonal networks and more formal social structures.

-Effects of Social Circumstances and Personal Attributes on Legal Consciousness

Resources and social circumstances are some of the social structures of the law which may instill meaning, promote or constrain social action. This study revealed that some parents perceived that certain personal factors affected their thoughts and decisions. These factors included wealth, education, family, social relationships, community, and personal attributes. Some parents reported that their personal wealth enabled them to purchase low technology devices for their children and to obtain health insurance with good durable medical equipment benefits. One parent in this study seemed to be empowered by her lack of wealth. She explicitly stated that school district personnel should not underestimate her persistence and her ability to access resources in order to assert her rights, despite her socioeconomic status. Some parents reported that their education helped them understand the formal law, which they believed helped them participate in the IEP process. Several parents reported that their professional backgrounds prepared them to advocate for their children. Three parents used the term "persistent" to describe themselves and their ability to relentlessly advocate for their children. One parent reported that her family’s connection to the community helped them advocate for their daughter. No parent discussed whether they perceived that their race or ethnicity or a provider’s race or ethnicity influenced their experiences or decisions. However, all participants in this study were Caucasian, which may have accounted for this finding.
The influence of personal factors is consistent with other studies of legal consciousness (Engel and Munger, 2003; Ewick and Silbey, 1998; Marshall and Barclay, 2003; Nielsen, 2000). Engel and Munger (2003) describe these factors as “resources” which can influence the sense of self, how people think about the law and their discourse. These resources may be weaved together and can influence whether and how people exercise their rights.

The Mutually Constitutive Relationship of Legality

Sociolegal scholars talk about the mutually constitutive relationship between law and society. By that they mean that the relationship between law and society is reciprocal: law affects people and society and people and society affect the law (Engel and Munger, 2003; Ewick and Silbey, 1998; Sarat and Kearns, 1998; Yngvesson, 1988). The law’s normative element may direct us to behave in a certain way while the culture of law – its social structures – can influence how we understand it, which in turn can encourage or constrain social action. This research study revealed that parents’ perceptions of the law were shaped by their experiences with the law and their experiences influenced whether and how they claimed certain rights. For example, most parents in this study were able to master the process of submitting a funding request through their insurance and therefore they were able to assert their rights under the law. Thus, in a sense the process and their perceptions of the process influenced whether they exercised certain rights. Another example is that some parents were able to master aspects of the IEP process, such as rejecting an IEP and learning to write measurable goals. Their perceptions of these rights and their ability to master these procedures determined whether and how they exercised their formal rights. In terms of getting devices implemented in the classroom, most
parents faced many challenges when asserting their rights under the IDEA. Most parents persistently advocated for these rights through the public school. Several went outside the school system to obtain therapy services and they accessed their health insurance benefits to fund these services. Thus, the challenges parents faced with implementation affected their perceptions of rights and these perceptions influenced their decision to access their health insurance.

Policy Implications: The Results of this Study and Stakeholders

While the results of this study cannot be generalized to a large group, the findings may be useful to several groups of stakeholders – families, speech-language pathologists, educators, legal advocates, vendors, policymakers and researchers.

Families: Families may be empowered to determine their options for obtaining speech generating devices for their children. Some families may be encouraged to determine their health insurance benefits for speech-generating devices and to manage the funding process. The results of this study may also help families better understand some challenges they may face concerning implementation of the devices in the classroom and they may find a community of parents with whom to network on listservs.

Speech-Language Pathologists: This study may encourage some speech-language pathologists to advocate for a workload analysis framework versus a caseload analysis framework. A workload analysis framework recognizes that certain factors contribute to the complexity of work and these factors must be considered when determining the amount of work a person is assigned to do. We know that speech-language pathologists in the public schools work with a large number of
children who have augmentative communication needs - approximately 20% of caseloads include students in this category (ASHA, 2008). We know that children who use augmentative communication systems have complex communication needs and their care can significantly increase the workload of speech-language pathologists. In addition to direct service, speech-language pathologists who work with these children provide a range of vital, indirect services. These services include designing, maintaining and programming augmentative communication systems and training staff and parents to use the systems. The American Speech-Language and Hearing Association has recognized these challenges and developed standards and guidelines for establishing a workload analysis approach for speech language pathologists in the public schools.  The results of this study may encourage speech-language pathologist to advocate for changes in working conditions so that they can better serve the children and their families.

**Legal Advocates:** The results of this study may help legal advocates understand why the formal law differs from the law in action. This understanding may help advocates understand the challenges that some families may face when they seek funding for assistive technologies through health insurance and or public school systems and the challenges that some families may face in getting devices integrated into the child’s educational program. If advocates are more aware of the types of challenges that families face, they may be better equipped to tailor their advocacy to the parents’ actual experiences and to the specific needs of their clients.

**School Administrators:** Parents in this study reported that schools did not have the resources to adequately train teachers and therapists in using assistive

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33 For additional information on workload analysis see “A Workload Analysis Approach for Establishing
technologies. Again, this was a small group of parents who expressed their perceptions of a problem. While one cannot assume that a larger group of parents would have similar perceptions or that parents’ perceptions of the school’s competency were accurate, this study may encourage administrators to assess whether their staff think they have adequate training and resources to meet the assistive technology needs of children in their schools. School systems may want to examine what resources they do have and ensure that their staff utilize these resources. They may also want to examine the processes for accessing these resources. For example, some parents reported that the schools had assistive technology programs but that these programs did not coordinate their services with the teachers and therapists. Therefore, school districts may want to determine how various departments communicate their knowledge about assistive technologies.

**Policymakers:** This study may help policymakers understand why or how the formal law differs from the law on the street, which, in turn, may help policymakers determine when and how to focus their efforts. For example, in this study parents consistently reported that speech-language pathologists were not knowledgeable about augmentative communication devices. Again, this was a small group of parents who expressed their perceptions and results cannot be generalized to a larger group. However, the American Speech-Language and Hearing Association (ASHA) may want to examine whether its standards for certification and renewal in the area of augmentative communication are meeting the needs of its constituents. This would directly affect state licensure because most states tie licensure to ASHA certification and renewal standards. The results may also encourage school administrators and teacher certification boards to examine whether their standards

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Speech-Language Caseload Standards in the Schools: Guidelines” at www.asha.org
are meeting constituents’ needs. Moreover, the findings of this study may be also be useful to state assistive technology programs, which are funded and administered by the Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitation Services. These programs are mandated to have outreach programs and they have staff who are highly trained in the area of assistive technologies. These state programs may want to determine how teachers, therapists and parents gain access to the program’s knowledge and expertise and determine where there may be gaps in services.

**Sociolegal Scholars**: This study adds to and supports a body of research that explores law in a social context. However, there are few sociolegal studies that examine perceptions of disability rights. Even fewer studies examine perceptions of rights at the intersection between special education laws and regulations and health insurance laws. This study may encourage sociolegal scholars to explore these areas.

**Limitations of the Study**

This was a small, exploratory study that aimed to illuminate people’s experiences with the law. The study focused on a specific group of people – parents who obtained speech generating devices for their communicatively disabled children. Thus, by design, this research study included a purposive group, rather than a random sample. While the study did not aim for a representative group of parents, it was more difficult to recruit families than expected. No fathers responded to recruitment efforts. If the interviews were conducted in person some fathers or other family members, such as grandparents, may have participated.
The Phase II group was homogenous based on several other factors. Each parent in this group was actively involved in pursuing their child’s rights through health insurance and IDEA. Most parents were highly networked with other parents through on-line communications. In fact, each parent in this study contacted this researcher in response to a posting on a listserv. Parents in this group were similar based on another variable. Most parents had access to augmentative communication specialists in their geographic area who evaluated the children, recommended a device and assisted them with the funding process through health insurance. Furthermore, this study did not control for a potentially significant variable: parents in this study had varying levels of experience with submitting funding requests. The parents with more experience reported that this factor was an asset and they thought it affected their results.

As described in Chapter 6, many of these parents in this study conceptualized their challenges in a similar manner, which may have been influenced by their homogeneity. If the study included a more diverse group of participants the narratives may have revealed a greater variety of themes.

Reflecting on Objectivity and Subjectivity in Sociolegal Research

As discussed in Chapter 5 some scholars who conduct qualitative research discuss the strengths and the challenges associated with qualitative research methods. Qualitative research methods focus on collecting data in natural contexts about a phenomenon in question and examine how participants construct meaning in their lives. This leads to data that are rich, filled with detailed descriptions and introspection about a wide range of experiences. These methods are strategies which add depth to an inquiry. However, the researcher must recognize that the knowledge
obtained through qualitative research methods does not capture literal representations of reality. The data are reconstructions of experiences, not the original experiences. Furthermore, with qualitative research, the researcher is known to be part of the process of creating as well as interpreting data. The narratives do not unfold objectively. The researcher asks questions and responds to questions. The researcher brings personal experience, knowledge and perceptions to the process. Moreover, the researcher has an interpretive role in constructing meaning. While some researchers are critical of some of the interpretive features of qualitative research, these features also distinguish it as field of inquiry that is well suited to study the social construction of meaning by capturing an person’s perspective about everyday life.34

In conducting this study I had to remind myself that the narratives reflected parents’ perceptions not the original experience. I had to recognize that parent’s perceptions were not universal or immutable. Parent’s words and actions reflected one image of their reality. At times this was difficult to do. Parents spoke passionately about their experiences. At times it seemed as if they focused on the challenges they faced rather than how the law helped them. Therefore, I found that it was necessary to analyze more than overt statements about the law. I also had to consider what parents did not say and whether they perceived legality is less explicit ways. This analysis helped ensure that I captured the nuances of the text. For example, while no parent stated that she was empowered by the law, parent’s words and actions suggested otherwise. One parent stated she has “never had to use the law” but her words and actions revealed the law was a part of her everyday life.

34 See Denzin and Lincoln (2000) for a discussion about the history and practice of qualitative research
Throughout the research process I was mindful of critically reflecting on why I brought myself to the research process and how I might contribute to it through my questions and responses. The stories that unfolded were the consequence of my interaction with the parents. Furthermore, my questions and comments were influenced by personal perceptions and convictions. I was not neutral or detached. I often empathized with parents. I talked with parents about my background and interests and why I chose to do this research project. However, I did not infuse the narratives with personal experiences and advice.

I describe this research process as collaboration between ten parents and a researcher. Parents told me their stories and from their stories, I constructed my story. I recognized that parents told me their stories for their purposes. Parents may have told their stories to relate facts, to share their victories and their disappointments and to persuade me that they were right and someone else was wrong. In analyzing the narratives, I focused on retaining the parent’s voices while writing my own story of legal consciousness.

**Directions for Future Research**

This research study looked at how parents gave meaning to the law, how this meaning emerged and was reconstructed through the culture of the law. It offered a hypothesis and concepts that other researchers may use to study similar research problems. The results of this study may help define areas of future research. These areas are discussed below

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and the tensions between some qualitative and quantitative researchers.
Sample Characteristics and Interview Process

This study points to a need to explore the legal consciousness of a more diverse group of parents and compare those results with this study. It would be valuable to interview and compare groups of parents based on how active they are in advocating for their children, such as, parents who are minimally, moderately and highly active in asserting their rights or their children’s rights. It would also be useful to interview parents multiple times, over a several year period of time. This may reveal how their perceptions and decisions about rights may change over time. It would also instructive to interview parents who did not succeed in getting funding to determine more about their experiences with the law and their perceptions of factors that influenced the outcome.

Perceptions of Stakeholders Concerning the Funding Process

Future research should explore the perceptions of other stakeholders who are involved in the funding process, such as teachers, therapists, school administrators, insurance providers, vendors, physicians, lawyers and parent advocates. It would be useful to know how various stakeholders’ perceptions of the funding process compared with the families’ perceptions. Surveys and/or focus groups could be used for this purpose.

Electronic Communication Among Parents

Recent research indicates that an increasing number of people are obtaining health information on the Internet35. Parents in this study gained information about the law

35 A recent survey published by Manhattan Research found that more than 60 Million U. S adults use health blogs, online support groups and other health-related social media applications. http://www.manhattanresearch.com/products/Strategic_Advisory/CCH/
and about assistive technologies via electronic communication - primarily by networking with other parents and professionals on listservs and through Internet research. Little is known about the accuracy of the information that the parents obtained or how parents evaluated the information. Furthermore, this study did not explore whether parents thought they were misinformed or received inaccurate information and it did not gather information about specific listservs or social media sites. Future research could explore these issues.

**The Prior Authorization Process**

As discussed in Chapter 2, all state Medicaid programs require prior authorization for speech generating devices before they may be approved. As part of this process, a Medicaid reviewer completes an assessment of the required documentation. The documentation that is required varies among the states (Golinker, 2006a). While all states require an augmentative communication evaluation report, a physician’s prescription verifying medical necessity and a vendor’s quote, some states require additional documentation and procedures. Some states require physicians to complete a Medicaid form. As part of the prior authorization process Medicaid may request the evaluator rule out competitor’s devices and in some states the individual must have a trial period of training with these other devices. Also some states require that the individual rent a device for a trial period of training before it can be considered for purchase. From a policy perspective it would be useful to determine how parents and other stakeholders perceived the prior authorization process and whether they felt aspects of the process influenced the funding outcome. This could be accomplished by surveying parents and other stakeholders in several different States and comparing results.
**Speech-Language Pathologists and AAC Competency**

Parents in this study described the challenges they faced in getting devices implemented in their children's school programs – problems attributed to limited resources, lack of knowledge and inadequate training. They indicated that speech-language pathologists and teachers were not adequately trained to use and integrate the technologies in the classroom. Some recent research indicates that these findings may be representative of a large group of speech-language pathologists. The most recent survey of speech language pathologists who work in the public schools indicated that 27% thought they did not have adequate training in augmentative communication technologies (ASHA, 2008). However, this number also included how speech-language pathologists rated their level of training in other technology related areas and therefore it is difficult to determine the significance of this finding. Therefore, it would be useful to survey speech-language pathologists more specifically about their training in augmentative communication. It would also be helpful to survey university-speech-language pathology training programs to determine whether they perceived that their programs were meeting the students’ needs and contributing to best practices. It would also be important to conduct a survey of speech-language pathology graduate students to determine their perceptions of the training.

**Factors that Promote or Hinder Implementation of Assistive Technologies in the Classroom**

This study revealed that parents thought that implementation of assistive technologies was significantly more difficult than getting devices funded. Future research should examine the perceptions of a larger group of parents concerning implementation of assistive technologies in the classroom and their perceptions of
the factors and strategies that promote or hinder implementation. This information could be obtained through surveys and/or focus groups involving parents, speech-language pathologists, teachers, school administrators and vendors.

It would be also be valuable to gather and compare data from several national groups who are involved in assistive technology services and research. Several states have implemented programs to help integrate assistive technology in classrooms through funds from The National Assistive Technology Technical Assistance Partnership\textsuperscript{36} which is funded under the Assistive Technology Act of 1998 (P.L. 105-399; 29 U.S.C. §2201). It would be useful to interview or survey individuals involved in these projects to determine their perceptions of how the programs are working.

In terms of education policy level, the National Association of State Directors of Special Education and the U.S. Office of Special Education have developed assistive technology policy guidelines for states to follow. It would be useful to survey state directors of special education to determine their perceptions of how these guidelines were working. In terms of federal funding for assistive technology to school systems, the American Recovery and Reinvestment Act of 2009 (ARRA)\textsuperscript{37} appropriated new funding for school programs under Parts B and C of the Individuals with Disabilities in Education Act (IDEA), which included funding for assistive technology devices and training. Recipients are required to provide information on how these funds are

\textsuperscript{36} This is a cooperative agreement between the U.S. Department of Education and RESNA. The grant (Grant #H224B050003; CFDA 84.224B) is administered by the Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services at the U.S. Department of Education.

\textsuperscript{37} P.L. 111-5. Additional information on the allocations of funds through this Act can be found on the U.S. Department of Education website http://www.ed.gov/policy/gen/leg/recovery/factsheet/idea.html
allocated and used. It may be useful to survey school districts to determine their perceptions of how funds have met the needs of staff and students.

In terms of augmentative communication researchers, it may be instructive to interview individuals from the AAC Rehabilitation Engineering Research Center. This Center has been conducting AAC research for many years and individuals involved in its projects are nationwide experts in the field of augmentative communication. It may be useful to determine their perceptions about problems with implementing devices in educational settings and their recommendations.

Lastly, it may be useful to interview the legal advocates who are part of the Protection and Advocacy for Assistive Technology Project (PAAT). These advocates work in all fifty states, Puerto Rico and Guam. This project receives its funding through the National Institute on Disability and Rehabilitation Research, U.S. Department of Education. This project primarily provides nationwide support services to the network of attorneys who work with the PAAT on AT advocacy issues. They also provide support services to public legal service and legal aid programs and to private attorneys if they are working on AT related issues.

**Advocacy Training Programs**

Three of the ten parents in this study reported that they attended advocacy workshops offered through local service organizations. Parents reported that in these programs they learned about children’s entitlements and parental rights under IDEA. Parents thought these workshops helped them advocate for their children. As discussed in Chapter 6, Barton (2004) argues that advocacy training should employ relational and rule-based perspectives in order for parents to effectively advocate for
their children. It would be useful to examine parents’ perceptions of these programs and compare their perceptions with the purpose of the program and the perceptions of the facilitators.

**Final Remarks**

This study examined how a small group of parents gave meaning to the law and how their legal consciousness was embedded and emerged out of daily experiences. It also illustrated how law on the street compared with law on the books. This research offered a hypothesis and concepts that other researchers may use to study similar research questions. It may encourage other researchers to explore the legal consciousness of people who work with children with disabilities to determine when and how the law may influence funding and implementation of assistive technologies and the strategies that may enhance its effects. It is my hope that future research in these areas will ultimately improve the lives of children and their families.
References


KCMU (2009b) Medicaid: A Primer.


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<tr>
<th>Case</th>
<th>State</th>
<th>Person Interviewed</th>
<th>Marital Status</th>
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Key:
Shaded areas indicate Phase II interviews
BCBS – refers to a Blue Cross Blue Shield, employer-based health plan
*authorization for a new device is pending
**over the years the child has had several different speech generating devices. The public school paid for 1 device and health insurance paid for 2 devices.
***parent did not report name of plan
Table 2 Ease of Funding Compared to Ease of Implementation

Participants were asked to rate the degree of difficulty they experienced with the funding process and the degree of difficulty with implementation at school, using a 4-point scale:
1. Easy
2. Slightly difficult
3. Moderately difficult
4. Extremely difficult

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Key:
Shaded areas indicate Phase II interviews
BCBS – refers to Blue Cross Blue Shield employer-based health plan
*parent did not know type of health insurance plan
**BCBS paid for first device, authorization for second device is pending
***The child has had three different speech generating devices. Insurance paid for two and the school funded the other.
Appendix A: Case Studies

Sample Interview Questions

Open-ended Questions
Tell me about X (child)
Tell me about your family
Tell me about your child’s school program

Specific Questions about Knowledge of Assistive Technologies and the Funding Process
How did you first learn about communication devices? Did you talk to anyone?
When did you first start thinking that X might need a speech generating device? Did you talk with anyone?
How did you get the device for X? Who was involved in the process?

Questions about Disputes
Did anything trouble or bother you?
Was there anything that was not as you would have liked it to be?
   Did you have any experiences with funding that troubled you?
   Did you have any experiences that were not as they should be?
Was there anything you thought should have been handled differently?
Did you talk with anyone about the problems?
   Did you argue with anyone about this?
   Did anyone help you?
   Do you think the law was on your side?
What advice would you give other parents?

Specific Questions about Rights and the Law
What do you think about IDEA?
   What rights does your child have at school? How did you find out about this?
Does your child have an IEP? What does it say?
If you disagreed with your child’s IEP, what would you do?
What rights do you have under IDEA? How do you know about this?
   Do you think your child has a right to have a SGD? Where did you get this information?
Does your child have medical insurance? What is the name of the insurance? What does it pay for?
How did you learn about the health insurance benefits? Did anyone help you?
What is the process for getting funding for equipment under your health insurance?
Does anyone help you with the process?
Case Analysis #1

Demographic Information

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<th>Age and gender of child</th>
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<td>Speech generating device</td>
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I. Case Facts

This case involves 10-year-old, identical twin boys who each have a medical diagnosis of athetoid cerebral palsy, per the parent. Each boy uses a power wheelchair, has limited spoken communication and uses a speech-generating device. Pregnancy and delivery were reportedly normal and the children were not diagnosed with any disabilities at birth. When the children were 2-3 months of age the parent noticed the children were not developing normally. She discussed this with her pediatrician several times. The pediatrician did not think there was anything wrong with the children. He felt the children would develop normally, just more slowly because they were twins. The parent disagreed. Eventually the pediatrician arranged for the family to see a geneticist who referred her to a neurologist. The neurologist
agreed with the parent and helped her obtain early intervention services. By the time
the children began receiving early intervention services they were 2 ½ years old. The
occupational and physical therapists in early intervention also told the parents that
things would be fine; the boys would be fine by 5 years of age.

When the boys started attending preschool the parent noticed that they were
communicating with each other with invented signs. They were “making sentences”
with invented signs. The boys reportedly understood each other but few people
understood them. The parent was distraught about this and she was determined to
find her children a communication system that would enable them to communicate
with others and to generate sentences. She approached the school and that is when
the struggles began.

The parent described many disputes with the public school about which
communication devices to use and how to train the boys to use the devices. After
she failed to work things out with the school system, the parent decided to obtain an
independent augmentative and alternative communication (AAC) evaluation and to
seek private speech-language therapy. She accessed her health insurance to pay for
these services. Based on the recommendations and help from private augmentative
communication specialists, the parent sought funding for the devices through her
private health insurance. She continued to try to collaborate with the teachers and
school speech-language pathologist about using the devices. They did not agree and
she contacted administrators in the school, after reading information the school gave
her about procedural safeguards. The situation improved but by that time the
children were leaving the preschool to enter kindergarten at another school. The
II. Analysis - Legal Consciousness

Primary research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? How does a family obtain information about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

How did the parent think about the law? The narrative revealed the parent had multiple perceptions of the law. Perceptions emerged and were constructed as she interacted with a variety of people. These interactions influenced the decisions she made about assistive technology devices and services for her children.

Perceptions of the Law

The primary theme that emerged within the narrative was that the parent was empowered by the law. The law provided a framework for her to think about, talk about and assert her rights and her children’s rights. While she infrequently spoke about specific rights under the formal law, she believed her children were entitled to have a speech generating device (SGD) and to receive training to use the device. The parent successfully navigated the health insurance regulations to obtain funding for speech generating devices for both children. She had many disputes with the
public school about her children’s assistive technology skills and needs. I use the term “up against the law” to refer to these interactions, a phrase I adopted from Ewick and Silbey’s sociolegal research (Ewick and Silbey (1998). While she had frequent disputes, she persistently asserted her rights and her children’s rights. She advocated through informal dispute resolution methods, interacting with a variety of people who she thought might help her, insisting that the children receive specific technologies and services. She was highly confident, determined, strategic and resourceful.

The parent’s perceptions of the law were shaped through interactions with a variety of people, which in turn influenced her actions. When she had disputes with physicians, teachers and therapists, she talked with a variety of people to obtain information and support. She talked with family members, other parents, and therapists. These interactions influenced her decisions and actions. They led her to seek an independent evaluation, obtain private speech-language therapy for her sons, obtain funding for the speech generating devices through her health insurance, and opt out of the public school summer program. When the parent recognized she needed to know how to write measurable IEP goals, she contacted professionals to gain this information. This knowledge empowered her to advocate for her children at IEP meetings. Interactions with some health care providers helped her learn how to navigate her health insurance system and the public school administration. At times, the parent decided to avoid conflict in order to preserve relationships with some individuals who had authority. Lastly, it is interesting to note that the parent reported she had little support from her husband. In fact she reported her husband told her he did not support her. How did this influence her actions? This did not deter
her. In fact, it seemed to have the opposite effect. She became even more
determined. She commented many times, “I knew I was right.”

**Empowered by the Law**

*Health Insurance Regulations and the Funding Process – Confidence in Benefits, A Long but Manageable Funding Process*

While the parent did not know the scope of benefits under her Blue Cross Blue Shield (BCBS) plan, she thought the plan would cover the devices and it did. She had prior experience with funding requests for durable medical equipment and this influenced her perceptions. When the children were younger she successfully submitted a request through BCBS for power wheelchairs for the children. In terms of the funding process, the parent reported she had little difficulty. The independent augmentative communication specialist helped her with the documentation. This specialist is nationally known in the field of augmentative and alternative communication. Also, the vendor assisted her with submitting the funding request to her insurance. The parent’s prior experience with getting durable medical equipment funded through her health insurance and the assistance she received from individuals who were knowledgeable about assistive technologies and funding may have contributed to the funding outcome. Overall the parent felt the process was long but manageable and she had a positive outcome.

**IDEA: Up Against the Law Yet Empowered by the Law**

This parent felt up against the law because she often disagreed with professionals who were implementing IDEA and faced multiple barriers when advocating for her sons to receive assistive technology devices and services. She disagreed with people about what her children were capable of doing, what teaching methods to use and
which speech generating devices would meet their needs. These disagreements led to multiple disputes. This parent felt up against the law for other reasons. She did not have confidence in the people who were responsible for implementing IDEA. She had little confidence that they had the necessary knowledge and skills to work with her children. The narrative revealed that at times the parent distrusted, possibly feared, some of the people in charge with implementing the law, people who she felt had power over her children. The narrative also revealed there was a complex relationship between the parent and professionals who evaluated and worked with her children. The parent felt the “experts” did not know her children as well as she did. Furthermore, she felt that they did not value her insights. These factors fueled many disagreements between the parent and the professionals. The parent recognized that her lack of education and training might have limited her ability to assert her rights and claim her children’s rights.

The narrative revealed the parent felt up in the law in another way. This concerned the cultural meaning associated with the label “mental retardation”. Though she recognized the label was necessary in order to her children to receive health care benefits, she rejected this term. Furthermore, she feared this label was defining people’s assumptions and expectations about her children. She felt the therapists and teachers were limiting services because they felt the children were mentally retarded and thus less capable of learning.

How did the parent’s perception influence her actions? Despite these disputes with the public school, the parent was empowered by the law. The law provided a legal structure for her to assert her rights and claim her children’s rights. She went outside the school to obtain independent physical and speech-language evaluations
and therapies for the children and she continued to advocate for services in the public school.

**Personal Factors that May Have Influenced the Outcome**

Throughout the narrative the parent reported how she “knew” she was “right” about what her children needed. She relentlessly advocated to obtain assistive technology devices and services, despite the fact that she reported that her husband did not agree with her and was not supportive. The parent rarely talked about the children’s rights. Rather, she advocated based on a relational perspective - what she believed her sons needed and were capable of achieving, based on her knowledge as a parent. I refer to this orientation to advocacy as *relational* and I adopted this term from sociolegal research conducted by Engel (1991) and Barton (2004).

The excerpts below illustrate the themes and concepts described above.

**Early Interactions with the “Experts” – “Moms Know their Children”**

In the following section of the narrative the parent described the interactions she had with physicians and therapists about her children’s development. While she was concerned about their development, the professionals were less concerned. She believed she was right and after several discussions with the boys’ pediatrician, he agreed to refer her to a geneticist, who then referred her to a neurologist. She reported that the “neurologist agreed there was an issue” and helped arrange for the children to receive early intervention services. By then the boys were 2 ½ years old.

**Denise:** Tell me about your boys

**Parent:** My sons are ten-year-old twins. They’ll be eleven in September. They have identical physical disabilities. They’re identical twins. If you see one child, it looks like athetoid CP. You add the second one to the mix, and then all the professionals are
scratching their heads, going, “Ahetoid CP isn’t identical with identical twins. What is this?” We have no answers.

**Denise:** Oh, okay.

**Parent:** We use the term “CP” just because it explains to everybody why we need power wheelchairs, why we need communication devices—all of that. But we suspect that we have some kind of metabolic disorder. So far, nobody’s been able to find it in testing. Both boys got their power wheelchairs when they were three, communication devices at four.

**Denise:** So this disability was present at birth.

**Parent:** The disability was present at birth. The disability was, quite honestly, I’m sure, present before birth. I remember when I was pregnant with them, thinking that, “You know what? Something’s just not quite right. There’s so much movement, but it’s not anywhere near as strong as it was with my other two kids.” And I remember asking the doctors a couple of times about that and having them say, “Well, you know, there’s two of them. It’s just tight. They can’t, you know, get a good swing to give you a good kick.” But after the boys were born, we were actually sent home from the hospital assuming nothing was wrong—you know, whatever. I do remember a doctor commenting that they were very floppy after birth. What—how it presented itself at the beginning was low muscle tone. So by four months old, even though they were smiling, they were tracking, they knew who Mom was, they knew family members—all of that—they couldn’t hold up their head. It was like a newborn in a four-month-old body, you know, everything just really, really loose. It took us until the boys were six months for anybody to really take seriously the fact that they were still like newborn bodies.

**Denise:** Why was that?
**Parent:** I think people are very used to seeing cerebral palsy as the tight kids, the high-toned kids, and these two were just low-toned. And I think the other thing was that they were so alert and so obviously aware who Mom was, who the people were in the room, following people with their eyes, interacting, laughing, giggling, smiling—everybody thought, "They can’t be having problems, because they’re so alert and sharp. It’s just temporary low tone. It’s going to get better. You know, just leave them alone and they’ll develop”—a little more slowly, because they were twins.

**Denise:** That was what you were hearing from your pediatrician?

**Parent:** That’s what we were hearing from our pediatrician. Even when we started getting the boys hooked up with early intervention and the OT and PT.

**Denise:** And when was that?

**Parent:** That would have been, I think, about six months. We finally got people in there at six months.

**Denise:** Six months. So what prompted that?

**Parent:** At four months, I had talked to the doctor about “Why aren’t they, you know, doing anything? You know, my other kids were rolling all over the floor; these guys, you know, can’t hold up their heads; and whatever.” And he said, “Ah, give it more time. Proportionally, heads are bigger than the rest of the body. And just wait.” And then at six months, when they went back in and my first question was, “Why are they still not doing anything?”, at that point, he set his paper down and really started paying attention to me. “What do you mean they aren’t doing anything?” You know, they’d already been interacting with him with their eyes and smiling and carrying on and all of that. But when he heard that not doing anything meant they weren’t grabbing toys as well as they weren’t physically active, then he started to get concerned. So at that point in time was when we got them set up with the early
intervention with OT and PT. But even the OT and PT evals that we had—it still looked like it was just low tone, and we were told by them as well as by the geneticists who saw them later that by the time they started kindergarten, they’d be walking; they’d be talking. They might not be able to tie their shoes and cut with scissors, but to look at them on the street, you wouldn’t know that they’d had this problem. Obviously that wasn’t right.

**Denise:** What you said—so at six months, the doctor—you finally convinced the doctor there was some concern.

**Parent:** Yes.

**Denise:** What happened after that?

**Parent:** He set us up to visit with the geneticist. The neurologist took a little bit longer; I think that was probably closer to a year and a half that the geneticist sent us on to a neurologist, because she couldn’t figure out what was up. He also helped us get set up with early intervention, and so we had OT and PT coming in.

**Denise:** So he was instrumental...

**Parent:** Yes. Once he agreed that there was an issue, he was very quick to get us plugged in and to help us get where we needed to get.

**Denise:** So was he the actual person who referred you? How did he help you?

**Parent:** I think he had his nurse, actually, call and get us set up that way. We ended up making calls as well to follow up, because we didn’t think it was happening as quickly as it should have. But he actually made a phone call to get us going, yes.

Later on in the interview, I asked the parent if she thought the early interactions with the professionals influenced her.
**Denise:** From an early age you talked with the doctors about the boys’ development and they told you not to worry. You persisted and you were right. Do you think those early interactions with the doctors influenced you?

**Parent:** The thing that I think was most helpful to me - in an odd way - was that the experts kept telling me my kids would be basically normal by kindergarten. So I treated them as if they were normal. I expected to see normal receptive language as they developed. I expected them to respond and do things that they were able to. I didn’t worry too much about them getting hurt. That was probably the best thing I could have done. I look at old videos and watch the obvious receptive language at age level, even when they can’t physically sit up alone, and I am amazed that it didn’t seem like a miracle at the time. I just expected it, and it was there. The other thing that ‘experts’ who were wrong taught me was to trust my gut more than what any expert had to say. Moms know their children. When we listen to our gut, we do a better job than when we try to parent by the book or listen too much to experts who don’t know our kids' subtle ways of showing what's going on inside them.

“They Don’t Listen to What I Say”, “I Had No Confidence Whatsoever That They Could Do Anything to Help Me.”

In the narrative the parent discussed several disputes with the school when the children made the transition from an early intervention program to school-based services. The disputes involved disagreements between her and the professionals about what the boys were capable of doing and what communication methods would best meet their needs. Again, the parent stated she knew the children better than the professionals and she did not waver in her beliefs. After a series of unresolved disputes with the school, she decided to seek an independent evaluation and services
outside the school. She stated she had “no confidence” in the school’s ability to help her children.

In the following excerpts the parent described how the teachers and therapists “didn’t have a good handle on the boys” and they assumed the boys were “MR” (mentally retarded). The speech-language pathologist did not conduct an evaluation to the parent’s satisfaction and the school would not permit the children to operate their power wheelchairs in the school building. She then decided to obtain independent physical and speech-language therapies.

**Denise:** So who got you started with augmentative communication?

**Parent:** The speech therapist (in the early intervention program) gave us the PECS (picture exchange communication system). The OT, PT, and speech person worked really hard to get us set up before the guys turned three with whatever they needed. The boys got their power chairs shortly before they were three, because they knew what the system was going to do when it changed when they turned three and when it was school-based.

**Denise:** So they made sure you got—they got the mobility you needed taken care of.

**Parent:** Right. So we had our equipment. We had what we needed. The speech therapist tried to get us set up with a speech eval with the school, but the therapist that we had when they started pre-school when they were three was absolutely awful. And everybody was protecting her. She had had cancer, and that was their excuse why she wasn’t doing her job.

**Denise:** So she was the one that was supposed to help you get the evaluation.

**Parent:** She was the one who was supposed to help us with an evaluation. She was the one that was supposed to make things happen. Her evaluation was basically,
“This is what I do with all of the kids that come this way, and these two are more physically impaired than everybody else.” They were in a MR (mental retardation) preschool. They didn’t really fit.

**Denise:** So that was the transition from EI to—

**Parent:** Transition from EI to school-based. And everyone, from teacher to aide to this speech therapist to the PT, really didn’t have a good handle on what the boys were capable of—that the assumption was—they were MR.

**Denise:** So you went from a good team to a team that didn’t really get it.

**Parent:** Yes. The assumption was that “We have walking, talking MR kids in here, and then we have these kids who have an MR label who can’t do anything physically. They must be more stupid than the rest of them. We can’t let them drive their power chairs.” Meanwhile, I took them alone to supplemental therapy at HealthSouth, let them out of the car in the parking lot one at a time—so somebody had to sit in his power chair and not drive in the parking lot until I got brother unloaded—and drove them in—both of them drove themselves into the room. And the only time they didn’t drive is if there was misbehavior: “Boom, you’re done. You start messing around, I tell you to stop, and you drive in the parking lot—you’re done. I turn you off, I’m pushing you, and brother gets to control himself.” And they understood that.

In the following excerpts the parent described interactions with therapists and family about her concerns about the children using invented signs to communicate. She was concerned that other people would not understand the children and she wanted to teach the children standard signs. The speech-language pathologist disagreed with this approach. She did not agree that the children were using signs to communicate. The parent mentioned that other parents told her how some school staff might not recognize that children were
communicating with sign language because the signs were adapted, due to motor impairments. After speaking with her mother in law who worked in a preschool with children with disabilities, the parent began teaching the children standard sign language herself. The parent and the speech-language pathologist also disagreed about the type of speech-generating devices the children should use.

**Denise:** So what kind of therapy were they going to?

**Parent:** The boys, shortly after age three, started using sign language that they invented. So my mother-in-law who used to work in a preschool for kids with special needs knew some more signs—official ones. So we started teaching them official sign language. The speech therapist at school was appalled when I talked to her about “The boys are starting to sign, and they’re inventing signs. We need to be teaching them, you know, some real signs, or you need to do something, because they’re inventing their own language. And if they were speaking twins inventing their own language, you’d be pretty freaked out right now.” “Oh, well, we don’t teach kids sign language anymore; we—that just isn’t done.” “Well, what is done?” [Sputter] She kind of sputtered, and that was the end of the conversation. Fairly quickly, they were stringing together signs to make sentences. This was all before they were four.

**Denise:** the same speech therapist?

**Parent:** Same speech therapist, same deal. Finally, they gave us a Tech/Talk 8 with a bunch of messages that were things that the boys couldn’t even do—cooking oatmeal, which they couldn’t eat because of their food allergies—different things like that.

**Denise:** So the school had the Tech/Talk

**Parent:** The school had it. They set it up for school. They had, like, a “Let’s read this little book” activity, where you push the buttons in order and it tells the pages of the
story. They really didn’t set it up so that the boys could say anything. It was all just compliance-based “Let’s go along with what’s happening here in the class.”

**Denise:** Did it come home with them?

**Parent:** And it did come home. And it came home, like I said, with these activities that the boys couldn’t even do or things that they were capable of doing more efficiently with their invented sign language. There was a “play doctor” thing on there, but the boys were able to communicate about playing doctor much more efficiently with sign language and by pointing to the thing they needed, instead of stopping with their use of the doctor tools to go to the device to say the name of the tool that they could grab anyway. So it was not helping. Meanwhile, they’re continuing to invent signs. They’re up to about sixty signs that they have invented, plus the ten or so that we were able to teach them otherwise. They’re putting together sentences.

**Denise:** You taught them yourself.

**Parent:** I’m freaking out. I—we taught them ourselves. The school wouldn’t touch it. They wouldn’t even acknowledge that they signed. They saw all the hand movements as flopping around with the hands because they’re physically disabled, yeah, which is a typical, common thing that I hear from other parents as well. My kid’s signing, “More,” but “more” doesn’t look like “more.” “More” looks like this, and they just think my kid’s flapping his hands. Maybe he’s autistic. He’s flapping when he’s really signing, “More, more, more”.

In this part of the narrative the parent described participating in an IEP (Individualized Educational Program) meeting. The team had previously agreed to include a particular speech generating device on the IEP. When the parent received the IEP it did not include this device. The parent became upset and decided to seek
an independent augmentative communication evaluation. She contacted her sister, a speech-language pathologist, about who to contact for an independent augmentative communication evaluation. Thus, rather than insisting the IEP team make the necessary changes, she went outside the school system for an independent evaluation. Again, the parent is convinced she knew what was best for the children.

**Parent:** So I had put on the IEP here that I wanted the boys to have a communication device—at least, this is what I thought I put on the IEP—that allowed them to put together sentences, like they were doing in sign language.

**Denise:** Now, when you say, “I put on the IEP”—

**Parent:** When we had our IEP meeting and we were talking about the boys and we were talking about their needs, I said, “The biggest need is communication, because they’re stringing together sentences of invented language, and we have to give them something that everybody else can understand.” The teacher’s like, “Well, I don’t see that happening here,” and I said, “I know you don’t, because it’s invented sign language and nobody else understands it. But it’s there.” And, “Well, we can use the Tech/Talk more if you want.” I was like, “No, no, no. The problem with this is that they can’t build sentences, and they’re much more powerful communicators with their own invented language than they are with what we’ve given them so far.” The speech therapist never came to any of our IEP meetings in preschool. None. The only meeting she came to was the one that looked like World War III. So she showed me a device, how it was set up to put together sentences. I said, yes that’s what I have in mind because that’s what going to help them stop inventing language and start using real words. Well that’s what we talked about in the IEP draft. What came back in the IEP later and stupid me. I trusted them at this point in time and didn’t look at the second round. What had gone into the draft was mom wants more activities for the Tech Talk. Nothing about the other things that we talked about, nothing about
building sentences, nothing about anything that was important. So when I came
back I was fed up.

**Denise:** And nothing about the other device?

**Parent:** Nothing about this other thing that we had talked about, nothing about
building sentences, nothing about anything that I thought was important. I was so
mad. I called my sister, who’s a speech therapist in Minnesota and said, Janet where
do I go from here to get my hands on somebody who knows something about those
talking boxes that people use? Because these folks are idiots. They don’t listen to
what I say. And I need somebody who’s at least going to understand that I’m
communicating to them in English and be able to give me some answers about what
should be done or why it can’t be done the way I think it should, aside from “That’s
just not what we do here.” And so, she went looking, and I was expecting that we
would drive two hours to Pittsburgh, two hours to Cleveland, two hours to Buffalo to
find somebody. She calls me back and say, “X, one of the experts is at X,” which is
the University where my husband teaches at. I never heard of this. It was X. I don’t
know if you’re familiar with her name or not.

**Denise:** Of course! How did you know about the communication devices?

**Parent:** We had met people who use high tech voice output on the campus where
my husband teaches.

In the following excerpts the parent described her positive interactions with the
speech-language pathologist/augmentative communication specialist at the
University of X, who “understood completely” when she described how the boys were
communicating and agreed with her about their communication needs. This therapist
evaluated the children and helped her obtain a device on loan from the state’s
assistive technology program. This clinician also guided her through funding process.
**Parent:** And so, I called. She was accessible to me. I explained to her what I was trying to say. And after the first two minutes, she understood completely what I was telling her about the invented language and the need to get them something that allowed them to do the same thing, to be that powerful in their sentence building, but so that the rest of us could understand. I mean, like, “This is cool. Set me up with an eval. I’m tired of waiting on the school. We’re just going to do this thing.” And it was probably October, and I had to wait till January for the eval, because I had to wait for the next semester.

**Denise:** So you went to the university?

**Parent:** So I went to the university that—the speech/language clinic there. She spent probably a good six, eight weeks, she and her student clinicians, looking at the boys, doing receptive language evals, seeing what they were doing, having me translate their sign language, putting devices in front of them, seeing what worked and what didn’t—multiple times, because what we found out from the beginning was that whatever device was the last one that they looked at seemed to be the one they did worst on, so that each time, we switched the order and had several times where we looked at different devices in different orders to make sure that it wasn’t just “I’m tired now,” because if we had gone with the first eval, we wouldn’t have had a really good take on what was happening. So she evaluated them with her students. They ended up recommending Pathfinder. And one of the big reasons was that dynamic display really, really distracted the boys, especially X. X is highly distractible. He’s since gotten an ADHD label. But every time that screen changed and—like a TV with a light-flickering thing—really seemed to distract him from what it was he was trying to do. But if he had that Pathfinder part with the paper overlay and just a small area of change, then he could function with that really well. So after about three weeks of working with the boys, she sent us home with a loaner Pathfinder.
Denise: For both of them?

Parent: One to split between the two for the loan. And it was just incredible. The first week—we hadn’t even had it a week—X found the words “fat” and “pig” on the device, and he started calling his oldest brother a fat pig, which is what little kids do, you know—call your big brother a name. And he just cracked up laughing. He knew exactly what he was doing. He’d point at his brother—“Fat pig”—and he’d just bust up laughing.

Denise: That wasn’t easy to find, I bet.

Parent: No. That’s buried in there. Yeah. And X would just ham it up. “What are you calling me a name for?”—you know, on and on and on. And the more John hammed it up, the more he did it for, like, a week and a half. Every time John walked in the room, he grabbed that Pathfinder—“Fat pig! Fat pig!” And he’d laugh and point at John.

Denise: You didn’t teach him that, did you?

Parent: I didn’t teach him. No, I didn’t teach him “fat pig.” He found it, and he knew how he was going to apply it. They were saying, “I want” whatever it was they wanted to eat. They went to the songs. They would sing songs. The two of them got the device, they dragged it out into the middle of the family room floor—they were scoothing on their behinds at this point in time—found “Here We Go ’Round the Mulberry Bush.” And we had never, in a million years, taught them how you’re supposed to, you know, dance around in a circle or whatever. And they started scooching around in a circle after they played it. And that was there little game. And all they needed was the ability to have some control and to get the boys’ output. And they were having these little games, and they were calling their brother names and telling us what they want to eat, telling us books that they wanted—
The parent stated she knew she had a right to ask the school to fund the independent assessment but she decided not to involve the school. She was not confident they could conduct an assessment to her satisfaction.

**Denise:** Did the school fund this?

**Parent:** Oh, no. This was out of pocket. Got the eval—at this point, I didn’t care. I mean, I would’ve put a second mortgage on the home to fly across the country to find somebody who didn’t think I was an idiot and could understand what I was trying to say to them about my boys.

**Denise:** Did you think you had a right to ask the school to fund it, or what were your thoughts on that?

**Parent:** I knew I had a right to ask the school to fund it, but to be quite honest, I didn’t want them involved at all in this part of the deal. I had no confidence whatsoever that they could do anything to help me. They’d already attempted to and hadn’t even understood what I was telling them about my kids, didn’t have a good handle on what the boys were already doing, and I didn’t want them in there in the eval. I didn’t want them messing with what was going on. I wanted a whole new take on it from somebody else who was going to see them fresh, start over, who at least understood what I was saying when I talked to them. And if they came out of the eval telling me that my kids really weren’t doing what I thought they were doing, I would’ve taken it. I would’ve said, “Well, at least you listened to me. At least you spent time with my kids and you looked at them from a perspective of ‘I want to evaluate what these kids can and can’t do,’ not from a perspective of ‘I want to think about what I’m comfortable doing in my setting to support these kids.’
The “MR” Label – A Double Bind

The parent described how the educational system assumed the children were “mentally retarded.” She also described how the children qualified for Medicaid services based on a “MR” label. While the parent had consistently rejected the label “mental retardation”, she recognized that the label qualified the children to receive services.

**Parent** They were in a MR (mental retardation) preschool. They didn’t really fit.

**Denise:** So that was the transition from EI to—

**Parent:** Transition from EI to school-based. And everyone, from teacher to aide to this speech therapist to the PT, really didn’t have a good handle on what the boys were capable of—that the assumption was—they were MR.

**Denise:** So you went from a good team to a team that didn’t really get it.

**Parent:** Yes. The assumption was that “We have walking, talking MR kids in here, and then we have these kids who have an MR label who can’t do anything physically. They must be more stupid than the rest of them.

**Denise:** How did you find out about Medical Assistance for the boys?

**Parent:** About six months after the boys began getting early intervention services, our case manager explained the MA stuff to us and helped us fill out the forms for the twins. When our son on the spectrum began to need OT, PT and behavioral therapy, and we found that much of it wasn’t covered by our private insurance, I pursued with out doctor getting him on MA.

**Denise:** The case manager through...?

**Parent:** MR-BSU.

**Denise:** What’s that?

**Parent:** Mental Retardation Base Service Unit. That’s what they call it. When the boys turned three and we had to do our eval for school—our psychological eval and
subsequently got an MR label, and I sat there in the office and bawled and hated myself for it, but—because I knew it was coming, but I also know it isn’t accurate assessment of their potential. That qualified us to get services through the MR Base Unit.

Denise: So you were assigned a case manager.

Parent: And so then we were assigned a case manager, and we’ve had several. And the last one that we had was just really super-good. She herself has two kids on the autism spectrum. And I think everybody’s battles become somewhat personal to her, you know, whether that’s good or bad. It’s really good for us as parents. Sometimes she makes enemies that she doesn’t need to make with school districts and stuff, because she is so forceful. But she’s an excellent advocate.

Denise: So who linked you up with them? Or how did you know that was coming?

Parent: After—let’s see. The boys must have been not quite three, because we still had our in-home early intervention people there. And the coordinator for that had told us that we were going to have this test, because we needed it when we started the preschool. The results were probably going to be pretty nasty. I think all the therapists told us that the boys were probably going to have an MR label; and that when they did, one of the good things about that was that we would qualify for support through the MR Base Unit; and that that would involve a case manager to help us coordinate services and maybe some kind of funding. And it opened up the option to eventually be part of the waiver program.

**Gaining Decision-Making Power through Knowledge**

In the following excerpts the parent described how it took her long time to acquire the knowledge she felt she needed to write IEP goals. She also began acquiring knowledge about other augmentative communication topics. She gained some of this
knowledge through her experiences with the IEP process. She also obtained knowledge by reading journal articles and textbooks. The augmentative communication specialist at the university recommended these resources to her.

**Denise:** Looking back, is there anything you would have done differently?

**Parent:** I wish I knew more about IEPs. I think I would have written different IEPs with the boys in preschool had I known more about how to do it and how to make it work. I tried to change IEPs as much as I could, but I really didn’t understand enough about how they’re normally written and how to make them happen.

**Denise:** They don’t tell you.

**Parent:** No, of course not. And I laugh when I’m talking to other parents. I say, “It took me five years of IEPs before I finally figured this out—this whole goal-writing thing and how to make goals that are documentable and tight.” And now, when I share goals with professionals, they look at my goals and they just go, “Holy cow, my goals are not as tight as your goals,” because you can’t argue with them. “Here’s what you’re going to do. Here’s how you’re going to document it.” There’s no flinch room. You either did it, or you didn’t do it. And it’s just really directed towards whatever the goal is supposed to be. And that’s just from, like I said, five years of trying to wrap my brain around this so that I could write better IEP goals.

**Denise:** How did you learn that?

**Parent:** I got hold of stuff from Carolina Center for—I can’t think what they call it now—Literacy and Disabilities, Chapel Hill and Karen Erickson and so on. I—

**Denise:** How’d you find out about them?

**Parent:** I don’t know how I found about—out about them. I think—I do too. I know how I found out about them. I had read the AAC textbook by Beukelman. I had read articles from Janet Sturm. She wrote two chapters in the old version, and they were the only two in there that made any sense to me about—
Denise: Because it’s more for speech therapists?

Parent: Right, right. Well, it wasn’t that part. It was about—she was the only one who seemed to be saying that kids like mine can start putting words together—can start having writing experiences like everybody else in their class. They’re just doing it a different way. And so I actually looked up her phone number and called her. We had some questions in kindergarten about the boys. And I called her up, and I said—

Denise: How’d you know about the book?

Parent: I think I borrowed it from Dr. Hill. I grabbed some stuff from her library shelf. And I remember her telling me that those were the two articles that I should read the most, because I would probably get the most out of them. And so I called her up on the phone, and she was such a nice person. We talked for, like, an hour and a half about what we could do to help the boys with writing skills, how they could begin to write even though they don’t know how to read yet, and all of those things. And I think she may have mentioned to me X, and so I looked up X’s name on the Internet and found the X for Literacy and Disabilities—eventually got X’s name, and X offered to send me sample IEP goals that they had written for the deaf/blind classroom, which didn’t completely apply to my boys, but close enough. So I looked at those. I spent a lot of time studying those. And I could tell that they were very different from the ones I was usually seeing in class—that it wasn’t about flash cards and documenting compliance as much as it was—shall I start in with a given?—“Given opportunities for daily self-selected writing, the student will blah-blah-blah.” I thought, “You know what? That’s the approach I want to take, because I don’t want it to be all about flash cards and disinformation and isolation and ‘Will you comply?’ as much as “Given these experiences, we want to see thus-and-so start happening.”

Denise: What they’ll do.
**Parent:** Right. “We want to see what they’ll do if we give them these experiences.”

So the first—

**Denise:** You wish you had known more about that.

**Parent:** I wish I had known more about that.

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**Experiences Obtaining Funding for Speech Generating Devices – A Lengthy, Though Orderly Process with a Positive Outcome**

The parent decided to submit a funding request through health insurance. She had been through a funding request before when the children needed power wheelchairs. At that time a physical therapist from her son’s early intervention program helped her with the funding process. During that time she noted that the physical therapist called the insurance company on a regular basis and this strategy was effective. That experience prepared her to submit a funding request for a speech generating devices. She also described how the speech-language pathologist at the university was experienced in obtaining funding for SGDs and helped her with the funding process. These excerpts illustrate the parent’s persistence and take charge attitude.

**Parent:** So we decided to go ahead and submit for funding for private insurance. And I needed to tell the school that this was what we were doing, this was what we were up to, and they came unglued.

**Denise:** So what insurance did you have?

**Parent:** We have Blue Shield, and the boys also have the Medical Access card. So...We have to start with the Blue Shield, and then, if they deny, then Medical Access picks up.

**Denise:** When did you know that?

**Parent:** Dr. X told me, and I also knew that from the funding for the power chairs.

**Denise:** So you had been through—
**Parent:** Power chairs had been a funding issue, and our PT pretty much handled it all for us. But she had been calling every two weeks, saying, “Where are my power chairs? Where are my power chairs?”

**Denise:** Through Blue Cross or through Medical—

**Parent:** Through Blue Cross. Yeah.

**Denise:** Mm-hmm. So you had gone through that experience.

**Parent:** So we had been through that, and it took, like, three or four months for them to approve, because they weren’t going to give it to three-year-olds. They just had immense concern about “Can a three-year-old drive a power chair?” I said, “Well, there’s two of them. What else are you going to do? I can’t push two push wheelchairs. You don’t make adapted strollers for two three-year-olds who have outgrown regular strollers, you know. What else am I going to do? I’m going to teach these kids to drive the power chair. The PT knows they can. I know they can. It’s going to happen.” So she handled all the calling on that—the PT did. The next round was my deal, with the communication device. And so, I had learned enough from her to know that once I knew the papers were submitted, calling the insurance company quite often was going to be a good thing. So I called, like, every two weeks after I knew all the paperwork had been submitted.

**Denise:** Well, how did—when you say “all the paperwork,” how did you know that?

**Parent:** I kept in touch with Dr. X. She told me when she had submitted what she needed to submit. I had to go get a—

**Denise:** How did she know what to submit?

**Parent:** Because she’s a funding genius. She still gets things funded in spite of the exclusive provider agreements with insurance companies. If she recommends a different device, then the insurance company has a deal with it.

**Denise:** She wrote up the eval.
**Parent:** She wrote up the eval. I had to ta—yeah. I had to take the paperwork to the family doctor to get prescription needs to say. You know, go for it.” And then—I don’t think he had to write an actual letter of medical necessity. I think just the prescription and signing off on the paperwork from the speech therapist was enough.

**Denise:** X added what to include in the report for funding purposes.

**Parent:** Yes. She wrote the report, and I think all the doctor had to do was sign off on her report and write the script. And our doctors basically said, “You know what? Whatever. Other people recommend whatever the OTs, PTs, and therapists think your kids need. If you’re cool with it, I’m signing the paperwork, because they know their field and I know mine, and I know your kids are pretty sharp.”

**Denise:** So did—who paid? Who wound up paying for it?

**Parent:** It ended up being paid for by Blue Shield. And I don’t know if—and they picked up the eighty percent that the Blue Shield didn’t or if the company just says, “Eighty percent is good enough.” I didn’t worry about that.

**Denise:** You didn’t have to pay anything.

**Parent:** We didn’t have to pay anything.

**Denise:** And you didn’t submit paperwork to anybody else other than your private health insurance.

**Parent:** Correct, yeah. We submitted paperwork to them, and then I just kept calling them, saying, “Is there any other paperwork you need? What’s the progress on this thing? Let me know if there’s anything else I can do to make this happen.”

**Denise:** How did you know who to talk to at your insurance company?

**Parent:** I just called their 800 number, and I just hung out on the phone however long I was on hold, until I talked to somebody and said, “This is what I’m calling about. This is what I want to know. Do you need anything else?”—you know, that
good old “I’m attempting to be helpful, but I want to keep reminding you that it’s
been thus and so long and I haven’t heard anything yet.”

Denise: This went on for three months?

Parent: Mm-hmm, yeah. So then—and we had a little glitch in that they approved
rental of the device, but they didn’t approve purchasing it at first. And I called them
back and said, “You know, this is weird to me, because we didn’t submit for rental of
the device. We submitted to purchase a device. We don’t need to rent one in the
meantime. We just need to get one.” “Oh, okay, we’ll get that squared away.” And
then, a week later, they did. And we were official. So the funding process was long,
but it wasn’t horrible.

Denise: I see.

Parent: It was—yeah, probably. Let’s see. I think the paperwork was probably
submitted in April, and it was November when we got approved, so five months, like
that. But the stuff that was the hard part was the school district. And had our
insurance not approved it, I would be fighting the school district through first grade,
probably, to get the device.

Denise: Did you think that the school had a—did they have a right to provide it?

Parent: Oh, absolutely. They should have provided it. They should have started out
by listening to me as a parent when I said, “My kid’s inventing sign language and
putting words together. Something needs to be done here.” But the speech therapist
never even saw my kids alone. Basically, what she did the whole time they were in
preschool was, she went into the preschool class and taught it for a half hour a week
so that the teacher could go fill out her paperwork. She never had one-on-one time
with any of those kids, so she never did any artic with anybody that needed that,
never worked with any of the Downs kids on word formation—certainly never worked
with my guys on anything.
**Enforcing the IEP: Navigating the School Bureaucracy**

In the following excerpts the parent described how the school became “unglued” when she asked them to help her obtain a device on loan through the state of Pennsylvania’s assistive technology program. The device was listed on the IEP and the parent argued that the school was not meeting its obligations - it did not implement the IEP as written. She called various people in the school district. They did not help her. She eventually called the “head of the intermediate unit” and she prevailed. The assistive technology specialist at the university helped her identify whom to contact. Again, the parent was persistent and resourceful.

**Denise:** You had a loaner through X?

**Parent:** Yeah. Yeah. She got it through the assistive tech lending library in Pennsylvania. So when I talked to them... oh, my goodness. I talked to... who did I talk to first? I think I talked to the people that were in the classroom: the speech therapist and the teacher. And they were all upset, and they weren’t going to take this device into the classroom to use it, because they were convinced it wasn’t going to work. So the biggest hassle came when I talked to the school, because what we wanted to have happen between—the loaner device had to go back, and it was going to take us probably three or four months to get the insurance funding. We wanted them to provide us a long-term loan and to start using it in school.

**Parent:** Even though we had been through an outside eval, and I wasn’t asking them to go back and pay for the eval that we had had. I wasn’t asking them to pay for anything. All I was asking them to do was to sign up for a loan for three or four months until we got our devices and to use the thing in the classroom.

**Denise:** So were you asking them to pay for the loan—to continue to pay for the loaner?
Parent: The loaner would’ve been free. There was not a money issue here at all.

Denise: So—because it was through the state program?

Parent: It was through the state program, but Dr. X could not renew her loan, but somebody else could write a loan for the same kiddos and get the device.

Denise: So how did you know all that? She—Dr. X told you?

Parent: Dr. X. I checked with her, because it seemed to me like the easiest way to make it happen, since I’d had people dragging their feet all along, would be if she could just renew her loan until then. And she said, “I can’t. They won’t let me.”

Denise: Because she’d no longer be the provider.

Parent: Right. They won’t let me renew the loan, but the school district should be able to, and it won’t cost them anything” and whatever, because if it cost money, I was just going to pay for it. I was just going to do it and let them worry about it later. Summer was coming, and I knew that there would be issues with letting us have it over the summer. So they cut loose. They just lost it. And so I called the next person up, the assistive technology guru at the intermediate unit, and told her what was up. And she pretty much had a twenty-minute temper tantrum on the phone and told me what a bad parent I was, that I had gone outside of them to get help, and on and on and on about how awful this was. I mean, I was just an idiot and didn’t care and—etc. And I just sat there thinking, “This is the most unprofessional thing I’ve ever witnessed.” And I knew that the best thing for me to do was to keep my mouth shut and, you know, hold the high ground so they couldn’t talk about “Oh, that parent, she just blah-blah-blah-blah-blah.” So I got off the phone with her and breathed deep for about half an hour and then called the head of the whole intermediate unit and told him, “Listen. This is the deal. This is what I put on the IEP in September. This is what they wrote down. They haven’t done anything to help my kids. I talked to you guys in September. It is March now. You wouldn’t help me, so I
went and got my own eval. And I don’t care if you pay for that eval or not. I’m not asking you to do that. All I’m asking is that you support the professional who did this outside eval by providing my kids with the device that was recommended in the interim until my insurance covers it.”

**Denise:** How did you know who to call?

**Parent:** The next name up from the people at school, I got from Dr. X. The name after that, I just went right to the top. I just said, “You know what? This lady was just over-the-top unprofessional. I am calling her boss or her boss’s boss. I don’t care which. I’m just getting the first name I can get.” So I went on the intermediate unit stuff....

**Denise:** Online to find out—

**Parent:** You know what? No, I didn’t go online, because we actually didn’t have a computer at home. I went through, like, the procedural safeguards and all of that kind of stuff—paperwork, and I—that they had given us before—you know, all that junk that you might as well wallpaper your bathroom with, because you never look at it. Well, I dragged it back out. I looked for the person on there who was the top dog, and I called him. And I said—

**Denise:** You saved all these papers.

**Parent:** Yeah, I always have a stack of them. I’m not one of these moms that’s real good about getting them in the filing cabinet in the little separate folders or whatever, but I had a big pile of them shoved in the closet. Dragged them out, called him, told him what my issue was, didn’t spend too much time mentioning that the behavior of the other person was appalling, but just said, “Look, this is what needs to happen here. This is a no-brainer. These kids do not have speech. They do not have the sounds required to make speech, and they’re inventing their own twin language. There’s nothing here that shouldn’t make sense that they need a way of
communicating that the rest of us understand, instead of investing their time inventing a language that they then have to teach us and that nobody at school is wanting to learn.” So then he got behind us. And I think because I had done that, I really didn’t have any problem at all getting the loan for over the summer as well. But—

**Denise:** So what did he say to you?

**Parent:** What did he say to me? He said to me that he could understand that yes, my kids aren’t making the sounds that would lead to speech and so on, that they would need a method of communicating that was more—can’t think the word he said, but basically more normal, as opposed to their invented sign language and, you know, that it was unfortunate that I felt like I had to go outside of the school district, who were really supposed to do this, because I felt like I wasn’t being served and, you know, kind of let me know—a little slap on the wrist—“You weren’t supposed to have done this, but now that you have and you’ve called me,” that he would talk to people and he would figure out what their problem was.

**Funded But Not Implemented**

After the parent obtained the devices through her health insurance, the children began bringing the devices to school. In the following sections of the narrative the parent discussed how the school was not incorporating the device into the child’s educational program during the summer program. The teachers and speech-language pathologist were not implementing the goals on the children’s Individualized Education Program. The parent said that implementation problems led to communication problems between one of the children and his teachers. She talked with the teacher but the issue was not resolved. She expressed fear that if she further pursued the matter with the teacher, the teacher might “sabotage” her child.
At that point she feared the children might be harmed. Since it was the end of the extended school year and the children were going to a different school next year, she pulled the children out of the program. She continued private speech-language treatment.

**Denise:** So you had it funded, and then what happened?

**Parent:** So I had it funded. The school continued to be pretty ticked that the boys were coming back and forth with these devices. I was using language activity monitoring so that I could see what we were doing, what the boys were trying to say, what words groups I should be teaching, because they were flying through the device too fast. I mean, they were putting together sentences. They were trying to say things, and I had no clue how to help them.

**Denise:** Was it being used at school?

**Parent:** It was being used at school a little bit. I could see that it came out during circle time, and the boys made a couple of selections on it during circle time, and then I could see huge lists of color words. And X—

**Denise:** They were teaching them colors.

**Parent:** With flash cards, yeah. Yeah, yeah, yeah. X came home. He had about a week and a half where he was coming home from school and he was upset. I could tell he was upset. Something wasn’t right. He’d come home; sometimes he burst into tears. Sometimes he just wanted to sit on my lap and be held. And normally, he got home and it was lunchtime, and it was time to eat, and he was hungry, but he had to sit on my lap and be held for a while first. Couldn’t figure it out. Couldn’t figure it out. Kept asking him what was wrong, and he kept saying, “Sad, sad.” “Why are you sad?” And he couldn’t explain to me why he was sad. And finally, one day, he came home and he wasn’t sad anymore; he was angry. And I could tell he was angry, and something must have happened at school, so I asked him how he was feeling. He
said he was feeling angry. And I said, "What happened?" And he told me that he was in group time with—he named a teacher—and she wanted him to say "blue," and he didn’t want to. And then he motioned that she took his device away, and he got angry. He told me the whole story.

Denise: On his device.

Parent: On his device—told me the whole story. The only thing he did off the device was show that she had taken the device away and that he was angry. And so I called her—he hasn’t even had lunch at this point. He—neither has X. They’re both—X is so upset, and X is just sitting there listening and kind of going, “Uh-huh, uh-huh.”

Denise: They’re in the same class.

Parent: They’re in the same class.

Denise: So they both see what’s going on.

Parent: Yeah. So I call a teacher, and I said, “You know, something must’ve happened today, because X’s really upset. Can you tell me what went on today at preschool?” —because there wasn’t a note. Always helps to play stupid. So she tells me the exact same story, to the fact that it was the color blue where he stopped and he got upset and he didn’t want to—that they were doing the color flash cards, and X all of a sudden got all upset, and he wouldn’t tell her “blue.” And he folded his little arms, and he went, “Grr,” to her. And he told her “angry” on the Pathfinder, and he told her all kinds of other things on the Pathfinder, but he wouldn’t say “blue,” so she took the device away. And I was blown away. She had no idea how that verges on child abuse. And the sad thing is that they had an IEP goal to talk about feelings. So you very quickly—

Denise: A teachable moment.
**Parent:** Yeah—very quickly could have kicked into “I’m going to work on this IEP goal, and we’re going to talk about how you feel and how I feel and how this thing is going.”

**Denise:** So how did you—did—in terms of the IEP, did you get it changed so that it incorporated goals associated with the Pathfinder?

**Parent:** It had goals associated with the Pathfinder, and I wish that I knew more at that point about IEP goals. What they had basically done was, they had taken some of the goals and benchmarks in Dr. Xs report and written them as IEP goals. So it was some real general stuff. I added the one about feelings, because I thought that that’s huge for a kid who doesn’t speak. “I don’t want you to show your feelings by hitting or biting people. I want you to tell me your feelings using words.” And I thought that that was also something that the teachers could comprehend the value of.

**Denise:** So that was in there.

**Parent:** That was in there, and then there were these other things about using negation and using other things. And the terminology was very highfalutin. And I think it just—the teachers just said, “Pfft, we’re not even worrying about that.” So they really didn’t—

**Denise:** So they didn’t—they listed the goals from Xs report, but they didn’t—

**Parent:** But they didn’t follow them, because there were no goals about color words, and that’s what they kept working on all the time. And there was a goal about feelings, and they didn’t work on that ever, obviously. So at that point in time, X shut down at school. He did not say another word at school from then on. This was, like, March, and school got out the end of May. He said nothing at school for two months. He continued to grow at home, but he just—I don’t know what he did, if he did anything with his hands, but he wasn’t even requesting a snack at school. He
was just like, “These folks are idiots, and when I try to tell them something, they don’t listen, so I’m not even going to talk to them.” So we cancelled summer school for the boys that summer, because it was just such a bad situation, just to see him just completely shut down. And I went in and visited a couple times and peeked through the glass, and this kid who normally has all kinds of expression and everything was just sitting there deadpan the whole time. He was just completely shut down.

Denise: How about your other guy?

Parent: X kept going. He kept working. He was doing fine. Yeah. So it wasn’t both of them, but we pulled them both out of summer school, because we—I thought, “You know what? I can’t do any more damage to this little guy. I’ve got to start him at a new school in kindergarten, and I need him to have some level of trust with the new teacher.

Denise: Thank goodness you were at the end of preschool.

Parent: Yes. I think if I had not been, if this had happened in about November, I think I would have been even more fervent about pulling him out. I think I just would’ve said, “You know what? I’m home-schooling this kid for the rest of preschool, because you can’t do this to this little guy.” So—

Denise: Now, did the school notice that this child was upset? Was there any effort on their part? What rights do you think you have?

Parent: Their big deal was compliance. If he was noncompliant, it didn’t matter why he was noncompliant. It didn’t matter if he was hurt, if he was sick, if he was angry. He just was noncompliant, and he was supposed to comply no matter what. That was the way they worked in that classroom, and their mentality was that it’s really great to work with these MR kids because they’re so compliant.

Denise: So what rights did you feel you—
Parent: He’s my kid, and I had a right to do whatever I wanted to. I had perfectly good rights to pull him out. I had perfectly good rights to file a complaint. I had perfectly good rights to do whatever I wanted to. I saw what happened as verging on child abuse, and I could have pursued—

Denise: So you pulled him out of the summer school, or you didn’t enroll him in summer school.

Parent: Right. I could have pursued all kinds of things, I would think, against that teacher for that kind of behavior.

Denise: Which—why didn’t you?

Parent: There was some fear that she would retaliate, that she had already screwed up my kid enough and that she would be worse to him if she knew that something was pending. There was also the fact that we were going to get out of there, and I didn’t want to ever have to see her or talk to her again, including whether it was, you know, in a meeting to try to set things straight or whatever. I just didn’t want anything to do with her. And I had other fish to fry. I had them going to a new school district for kindergarten. I needed to get everybody off on the right foot. I had X, who had shut down during school—decided that school was “a place where there’s a bunch of idiots who don’t listen to me and take my voice away if I try to talk to them.” And we needed to kind of get over that and help him through to the idea that kindergarten is going to be a fun place where you learn and people like you. And it just seemed like too many other important things than to fight the battle on principle at that point, although I think we had a perfect right to and I think we could have definitely stirred things up. We were so close to being done, and I knew that this teacher was never, ever going to change. The part of her that needed to change was her preconceived notions about kids with disabilities, and that wasn’t going to
change. She wasn’t going to get beyond that they’re supposed to be so compliant and just sit there like lumps.

**Denise:** How about the speech therapist? Was she—did ever—did she ever get back in the picture at all?

**Parent:** She was awful.

**Denise:** She never really—

**Parent:** No, she never did anything. She just taught class so that the teacher could go fill out her paperwork. And that’s what she did the whole rest of the summer. So we made sure that we were connected with outside therapists and got the help we needed.

**Denise:** So you continued at HealthSouth.

**Parent:** Yep. Yep. Boys continued there, with therapists who, by the way, admitted that they knew absolutely nothing about aug com. But they knew a lot about getting little kids to talk more and putting them in natural situations where they needed to use their voice and making them do it. And so, it was perfect, because that’s what I needed. I didn’t need somebody to program the device.

**Denise:** You already knew how to do that.

**Parent:** I was doing that part of it. I had figured that out. If I didn’t know, I called tech support and said, “Hi, it’s the dummy here again. I need to ask questions. Show me how to program this, that, or the other thin in here.” And so, we had that part under control. I just needed somebody who was going to push them to continue to use their words in different settings and to help X understand that using your words made good things happen instead of made people mad at you so they took your device away.
Parent Carved a Role as Expert

The parent described that she is satisfied with the new school. She was collaborating with the teachers and therapists and felt as if she was part of a “team”. The parent has carved out a role for herself: she did all the programming of the children’s speech generating devices and helped modify the curriculum for boys’ inclusion class. She and the school appeared to be sharing the decision-making power. The parent has also assumed another role. She was volunteering for the AAC Institute, an organization that provided information on augmentative communication for parents and professionals. She did presentations at conferences and wrote articles for the website.

Denise: So you went to a new school when the boys turned six.

Parent: Right. Yes. Our relationship is, I think, a strange and wonderful one in the world of special ed. I do all programming for X and X’s devices. I also kind of manage the adaptations for the classroom for the inclusion class. So when the boys have, you know, say, a unit on the planets—or they studied the fifty states last year—I’m kind of offering the overall perspective of “This is what we should cover. Tell me what things are important. Let’s find a way to put those things in really basic language, and let me know what you need.” I made little stickers that show where the new words are found on devices, helped them lay out—“Okay, we need to start getting some organization strategies. The guys are not going to take notes. Let’s do this.”

Denise: So how did you decide to assume that role, and how did the school react to that?

Parent: I think it started because I knew that it was going to be such a huge thing for regular-ed teachers to have X and X in their classroom. It’s so typical to want to
teach the kids all of those special little words that are highlighted in the textbook. And I didn’t want X and X wasting time or wasting space on their device learning words like “germinate” when they don’t even know how to say “grow.” I wanted to make sure that we put the focus on more useful words and got the boys that underpinnings of vocabulary before we moved on into some of those other things. And I knew that this wasn’t going to be a part of the regular-ed teacher training. They weren’t going to think that way automatically. And I wanted the speech therapist to spend her three or four days a week not making adaptations for my kids but working with my kids’ intervention. I told her—I said, “I can make adaptations. I can program devices. I can’t do the interventions that you can. You have the background there. You can do it.” And our speech therapist was just awesome when the boys started there—just really had a good handle on “Our goal here is building sentences, building some language competence, not just on participating in class through a variety of words that they’re never going to use anywhere else.” It seemed to work pretty well. We really haven’t had too many teachers that have been—felt like I was treading on their turf. Most of them had been kind of relieved that I’m helping them, and the ideas that we’re coming up with seem to be working really well within the classroom.

Denise: You’re all working together.

Parent: We’re all working together as a team. We’ve had a couple teachers that had a really hard time adapting. We had one who normally teaches the gifted class in third grade, and she just kind of twitters around like a little bird with lots of words. She had X, and he’s very distractible, and all of this little twittering like a wren, you know, with the body movements and everything—she’s just all over the classroom—just overwhelmed him. And she was not able to change her style enough so that when she could tell he was overwhelmed, she took most of the word level down and
said less words. She wanted to say more words to explain it better. And it so it just—it was not a good match. And I think she felt as helpless about it as anybody, because she’s such a good teacher, and she’s so used to making those connections. And she said to me and to a different teacher, “You know, I just—I know I’m not connecting with him like I want to, but I can’t seem to make it happen.” So, you know, it’s a struggle that’s hard work for the teachers. And sometimes I don’t have really good answers, because the answer there for her that I could come up with was, “Change your whole teaching personality.” And that’s hard to do when you’ve been teaching for twenty-five years, you know. It’s just not—doesn’t come easy.

Denise: How did you get involved with the AAC Institute?

Parent: When I was so upset with the school district and we were really struggling with what they wanted to do with the boys versus what I wanted to do with the boys, and one of their compromises was putting them on Picture Word Power instead of Unity, I spent several hours looking at Picture Word Power at home to get familiar with it, because they were convinced if I just spent time with it and looked at it, I would see that this was so much more practical than Unity. And the more I looked at it, the more I thought, “You know what? This isn’t going to work for my boys. They don’t have any word recognition. They don’t have letter recognition now, and there are so many things here.” Some of the words that I knew they were already saying on Unity, you had to find them by hitting the Verb button plus the letter that verb started with. I thought, “They’re never going to be able to do that. They’re not there yet. Maybe two or three years from now, they could have gotten it, but not in preschool.” And so, to help me think I was right—so I wrote up this thing about why I thought that Picture Word Power was better than Unity, and I happened to show it to Dr. Hill once during therapy. And she looked at it later, and she called me up and said, “You know, you seem to really have some writing talent. Is that something
you’re ever interested in using?” I said, “Well, yeah. You know, I wrote that just because it helps me think. That’s what I do. But I used to do quite a bit of writing.” She said, “I may have a use for that down the road.” And then she asked me something almost scarier—is, “How do you feel about getting up in front of people and presenting?” And I said, “Well, you know what? I haven’t done it in years. I’ve just been home being Mom. But it doesn’t bother me. I kind of enjoy it.” So she set me up that she and I would do a presentation at CSUN and share it. And it was kind of a parent-perspective, “what the clinician did to help the parent with the things that they thought were important” kind of a presentation. And then, things just kind of rolled on from there.

**Denise:** Because she was already involved with the AAC.

**Parent:** Because she was already involved with the AAC Institute, and I think her least favorite part of it is working with the public, doing the presentations part.

**Parent:** She’s awesome one-on-one. She’s an excellent researcher. She’s really good at documenting what she does so she can get funding. But she’s not so comfortable up in front of people and doing that. And very quickly, we decided that parent support was a big part of what needed to happen. Parents are too alone, and I’m pretty passionate about—I don’t want other parents to have to go through what I went through as well. So I began writing the monthly articles for the AAC Institute and starting to get involved with doing the presentations and working at the booth.

**Denise:** So it kind of spiraled.

**Parent:** So it kind of spiraled into that. Shortly after, I felt like we had the guys squared away. They had their devices. We had the school system on board and going the right direction, and things were good there. Then I had the time that I could do something to help other families. Yeah
**Did Personal Factors Influence the Process? - "I Was Just So Convinced I Was Right"**

In the following excerpts the parent described herself as “stubborn”. She also described how her personality has changed with the experiences. She stated that she used to be more willing to compromise.

**Denise:** Is there anything that you would say that bothered you about the whole process of getting funding or getting the device implemented.

**Parent:** Preschool was awful. It was absolutely awful. My husband probably almost divorced me at that point in time. He could not understand why this woman that he’d been married to for fifteen or sixteen years—and we’d never had a fight; I mean *never*, because I was always so willing to compromise, and we always made something work—why I would not compromise on this thing at all. It was, “This is the device my kids are going to use. This is what’s going to happen. And if you don’t like it, get out of the way, because the train’s going to run you over.” And he just couldn’t wrap his brain around that and couldn’t understand why all the professionals at school were wrong and I was right, in my mind, and why I was so right that I wasn’t even going to make a compromise. Finally, finally, he said, “All right, you know, whatever. You do it your way. I’m stepping out of this. You just work it out.” And it was basically...

**Denise:** It was all on your shoulders.

**Parent:** “I’m not doing anything, because I don’t support you. But I know you’re going to do this anyway, so I’m just going to stand back. Don’t even tell me what you’re up to.” And...

**Denise:** That must have been hard. You really fought alone. I mean, you didn’t have—

**Parent:** It was really, really tough.
Denise: Who did you feel was on your side?

Parent: I was just so convinced I was right. I just knew that my boys had more potential than what the school acknowledged. And I knew that if they were being successful at HealthSouth, they were being successful at X Clinic at X, they were being successful with me at home, there’s no reason why I should change what’s successful in three places to make it work for these people who were basically idiots as far as understanding the potential of my kids. And I don’t know; I think, because I’m just so stubborn, that when I’m convinced that I’m doing the right thing, I’m not going to change. That was the part of it that carried me through—was, “This is my kids, this is my babies, and I know for sure that this is the right thing to do. And if nobody else in the world believes me, that doesn’t make it any less right. This is what needs to happen.” And since then, X has come around and began to understand why I would not budge.

III. Parents Perceptions Compared to the Positive Law

How did the parent’s perceptions of health insurance laws and IDEA compare with the positive law? There are several legal issues to consider.

Health Insurance Laws

The parent expressed confidence that health insurance would fund the devices for her children. While she did not state specific laws or regulations, she was empowered by the law as a way to make legitimate claims to assistive technology for her sons. Over the years she learned how to navigate the health insurance prior authorization process for durable medical equipment. The vendor and independent evaluator helped her navigate the health insurance regulations for the speech generating devices. She had a positive outcome for both children.
IDEA

Advocating for Rights

Did IDEA regulations enable the parent to advocate for her children’s AT rights under the law? I believe the regulations did enable her to advocate for her children. IDEA regulations, adopted by the state of Pennsylvania specify parents rights in four major areas: prior written notice (34 C.F.R. §300.503; 022 Pa. Code 14.102 (a)(2)(xxix)), consent for services (§300.300; 022 Pa. Code 14.102 (a)(2)(xiv)), participation in developing the child’s Individualized Educational Program (IEP) (§§300.320-300.322; 022 Pa. Code 14.102 (a)(2) xxvii)) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 022 Pa. Code 14.102 (a)(2) (xxix), (xxx)). While the parent read about her due rights under the law, she did not formally exercise these rights. While she did not assert her formal rights, she ardently and persistently advocated through informal dispute resolution methods. She had meetings and telephone conversation with several IEP team members, insisting the school was not meeting its obligations. She also talked with school administrators who had increasing levels of authority until she reached someone who agreed to help her. She prevailed. The school eventually agreed to implement the device to her satisfaction. However, there were times when she felt the obstacles were too great, and then she went outside the school system to obtain the devices and training through health insurance.

Resources, Training and Competency for AT Equipment and Services

Did the school provide adequate resources, training, competency for AT equipment and services, in order for the child to receive a free appropriate public education (FAPE)? Possibly not. The parent reported that the school did not have the
knowledge and expertise to evaluate the children or to train them to use the devices. If accurate, this would not be consistent with the law. IDEA guarantees rights concerning AT devices and services in order for child to achieve a (FAPE) (34 C.F.R § 300.5, 300.6, 300.34, 300.42, 300.101, 300.105, 300.320, 300.324). These regulations have been adopted by the state of Pennsylvania in its special education regulations (022 Pa. Code §14.102(a)(2)(i),(vii),(ix),(x), (xi),(xxix), (xxx), (xxvii)). Assistive technology devices and services include providing an evaluation to determine a child’s assistive technology needs (§300.6(a)) and providing training to the child (§300.6(e)), family (§300.6(e)) and educational staff (§300.6(f)). In terms of providing a device, the school may not be the primary payor. According to IDEA regulations, the public school is responsible for providing an assistive technology device (§300.5), unless a non-educational agency, public or private, is responsible for providing it according to federal and state laws (§300.154 (b)(1)(i)). If the non-educational agency does not fund the device then the public school is responsible for providing it. Also, the public school may also seek reimbursement from the non-educational agency (§300.154 (b)(i)(2)). The parent thought that the school was responsible for providing the device, though she opted to access health insurance. The children had health insurance which funded the devices. Thus, her perception may have been a departure from the law.

**What is an Appropriate AT Device?**

On another legal issue the school’s decision may have been consistent with the law. The parent and the school disagreed about which device the children could and should use. Neither IDEA nor Pennsylvania state regulations (022. Pa. Code §14.102 et seq.) include an approved list of AT devices. Based on the federal regulations, the IEP team determines the child’s skills and needs in order for the child to receive a
free and appropriate public education (34 C.F.R §303.101). Based on IDEA regulations, the school is not obligated to provide the best or state of the art equipment. The term “appropriate” is a rather ambiguous term and open to some interpretation by the IEP team. The concept of an “appropriate education” is based on the landmark Rowley Case (458 U.S. 176 (1982)). In Rowley the Supreme Court determined that FAPE does not mean a school must provide the “best” education or one designed to maximize the student’s potential (Board of Ed. of the Hendrick Hudson Sch. Dist. v. Rowley, 458 U.S. 176 (1982)). The Rowley case was also important in another way: it acknowledged a collaborative relationship between the school and parents. In Rowley the Supreme Court noted that both the States and the family have a partnership in the child’s educational program.

“the primary responsibility for formulating the education to be accorded to (a child with a disability), and for choosing the education method most suitable to the child’s needs, was left by the Act to state and local educational agencies in cooperation with the parents.” (Rowley at 207).

In this case the school offered the children SGDs (which it may have not been obligated to do, as stated above) and the IEP team may have had reason to believe that the devices met the children’s educational needs, consistent with the federal and state regulations. Thus, it is possible that school complied with the law in this respect.

**Individualized Educational Program (IEP)**

There are two legal issues to consider which involve the Individualized Education Program. The first issue concerns implementation of the Individualized Education Program (IEP). The second issue concerns how IEP goals are written. In terms of implementation of the IEP, the parent reported that the childrens’ IEPs were not
being implemented as written and signed. The parents reported that the team was not implementing the specific speech generating devices, which were listed on the IEP, and, later on, the team was not implementing the goals as listed on the children’s IEPs. Is this consistent with the law? If the parent’s perceptions were accurate, this would be a departure from the law. Based in IDEA regulations, which have been adopted by reference in the state of Pennsylvania’s special education regulations (022 Pa. Code §14.131(a)(ix)(6)), the child’s IEP team is obligated to implement the IEP as written and signed. In terms of the IEP goals, the parent reported that as she became knowledgeable about the law, she learned that the IEP goals needed to be measurable – “documentable and tight”. This is consistent with the IDEA regulations, which have been adopted by reference in the state of Pennsylvania’s regulations. Based on state and federal regulations, IEP goals must include measurable goals,

“a statement of measurable annuals goals, including academic and functional goals designed to meet the child’s needs that result from the child’s disability to enable the child to e involved in and make progress in the general curriculum; and meet each of the child’s other educational needs that result from the child’s disability (§300.320(a)(2)(i)(A)(B); 022 Pa.Code §14.102(a)(2)(xxvii)).

**Independent Evaluations**

There are two legal issues to consider concerning an independent evaluation. The parent stated she thought the school might have paid for the independent evaluation (IE). This may be accurate, depending on whether specific regulatory conditions were met. Based on IDEA regulations (34 C.F.R. §300.502 (a-e)), adopted by reference in the state of Pennsylvania’s special education regulations (022 Pa. Code
§ 14.102), the parent is entitled to an independent evaluation (IE) at public expense under specific conditions. The parent is entitled to one independent evaluation each time the parent disagrees with the evaluation conducted by the public agency. In order to request an IE at public expense, the parent would be obligated to discuss the matter with the school and come to an agreement with the school, as to an agency to conduct the evaluation. The agency selected would need to meet the public school’s criteria. Furthermore, when a parent and school disagree about an evaluation and the parent requests an independent evaluation, the school is obligated to file a due process complaint (34 C.F.R. §300.502(b)(2)(i)). The parent did not express knowledge of these regulatory conditions and she opted not to pursue this matter with the school.

The second legal issue concerns whether the school is obligated to consider the results of an independent evaluation (IE). Based on IDEA regulations, which have been adopted by reference in the state of Pennsylvania’s regulations (022 Pa. Code § 14.102, the school must consider the results of the IE if the results concern provision of FAPE and if the IE meets agency criteria (34 C.F.R. §300.502 (c)(1))). In this case the parent reported that the school incorporated the recommendations of the independent evaluation into the children’s IEP. Thus, it is probable that the school did consider the recommendations.
Case Analysis # 2

Demographic Information

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<tr>
<th>Age and gender of child</th>
<th>13 year old male</th>
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<tr>
<td>Diagnosis</td>
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<tr>
<td>Type of School</td>
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<td>Interviewee</td>
<td>Mother (&quot;Ms. Glade&quot;)</td>
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<td>Graduate degree Government administrator</td>
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<td>Race</td>
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<tr>
<td>State</td>
<td>Virginia</td>
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<tr>
<td>SGD</td>
<td>GoTalk, Dynavox 3100</td>
</tr>
<tr>
<td>Purchased by</td>
<td>A state program purchased the Go Talk. The school provided the Dynavox 3100.</td>
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I. Case Facts:

X is a thirteen year old male born with severe multiple disabilities. During the interview the mother reported that his disabilities were the result of medical errors that occurred during her pregnancy and the delivery. The child used two speech-generating devices to communicate; one was provided by the public school and a state program for children with birth injuries funded the other device. The parent had little difficulty obtaining these technologies for her son. However, over the years the parent had many disputes with the school about implementing the assistive technologies in the classroom.
II. Analysis: Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? Where do families obtain information about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

Perceptions of the Law

The narrative revealed the parent was highly engaged with the law in her everyday life. Her perceptions of the law emerged and were constructed as she interacted with a variety of people. These interactions influenced her actions and decisions and determined whether and how she exercised her rights and claimed her son’s rights.

The primary theme that emerged within the narrative was that the parent was empowered by the law. The law provided a framework for her to think about, talk about and assert her rights and her son’s rights. While she infrequently spoke about specific rights under the formal law, she believed her son was entitled to have a speech generating device (SGD) and to receive training to use the device. She successfully navigated the regulations of a state birth injury fund to obtain funding for a speech generating device for her son. While the public school provided a speech generating device for her son, she had many disputes with the public school about
implementing it in the classroom. I use the term “up against the law” to refer to these interactions, a phrase I adopted from Ewick and Silbey’s sociolegal research (Ewick and Silbey, 1998). Despite these difficulties, she persistently asserted her rights and her son’s rights. She advocated through informal dispute resolution methods, interacting with a variety of people.

Health Insurance Regulations: Predictable and Few Barriers to Obtaining Benefits

The parent was generally satisfied with her family’s health care benefits and the benefits she obtained from the state of Virginia Birth-Related Neurology Injury Compensation Program, a state fund designated for children with birth injuries (Virginia Birth-Related Neurological Compensation Act, (Virginia Code § 38.2-5000, et seq.) It is interesting to note that though her private, employer-based health insurance (Kaiser) reportedly did not cover SGDs or much durable medical equipment, she was still quite satisfied with the benefits and care. She favored the type of care she got at Kaiser over another HMO plan she had previously. To her family, Kaiser was more accessible and convenient – after hour care and many departments and specialties in one building. Also, she reported that her costs were consistent and predictable. When describing Kaiser, she stated, “It’s just so simple because they take care of everything.” Since her son had multiple medical problems these factors were important to her. In terms of the state compensation program, she reported that it required multiple documents from multiple people but she did not think this was a burden. She stated the program had “guidelines” and she described the funding process as

“real simple…if the doctor or therapist says that something is medically necessary for him, in most cases they’ll fund it.”
The parent described how she accessed her health benefits to cover various expenses for her son. She was knowledgeable about her health benefits and the process for obtaining the benefits. She described the process for getting equipment as “easy”. During a discussion about funding for equipment and services for her son, the parent reported that she had two funding sources for health care. She had an HMO, which covered some durable medical equipment, but did not cover speech generating devices. In addition, her son qualified for a funding through the Virginia Birth-Related Neurological Injury Compensation Program. She learned about this program while talking with a physical therapist in her son’s early intervention program. Since she learned about this program, she has used it for funding equipment and services, including a low technology speech-generating device. She mentioned that she talked with other parents who used the fund and she built relationships with staff in program, which helped her to navigate the funding process.

**Parent:** I should say that X. has – in addition to the Dynavox, we have a GoTalk, which we got ourselves – I mean we got it privately.

**Denise:** You purchased it yourself?

**Parent:** Through our sort of secondary insurance. And, you know, that involved getting our speech therapist to write a letter and, you know, say that this would be something that would be useful to X. to, you know, have in circumstances when, you know, the Dynavox is too bulky or not available or whatever. We haven’t been using it a lot right now, but you know, I think he’s made good use of that at various times?

**Denise:** So what was that process like? So how did the GoTalk come up?

**Parent:** I think I may have seen it in one of the catalogs or something I get and thought that it would be something that – you know, X could use, you know, just for
when we go out quickly someplace or you know, because it’s the kind of thing, that, you know, you can take to a fast-food restaurant and use.

**Denise:** And what was the process of getting funding? What was that like?

**Parent:** Well, it was pretty easy, really, because it – X has coverage with the Virginia Birth-Related Neurological Injury Compensation Program, and if the doctor or therapist says that something is medically necessary for him, in most cases they’ll fund it.

**Denise:** Okay so you found out you needed the speech therapist to write a letter. You needed the doctor to give you a prescription. You found out by contacting the fund and they told you what you needed.

**Parent:** Right, right. Well, they have guidelines. It—I can’t remember now how long it took—probably didn’t take too long, because I think it, you know, was—that was a while ago, and so it was, you know, back in the—more days when things were a little simpler, you know, between smaller staff and fewer kids and [laugh]...

**Denise:** So was this a medical error?

**Parent:** Mm-hmm.

**Denise:** It was in the hospital?

**Parent:** Yeah. I mean, you know, basically, a lot of it was what—in terms of X’s birth—you know, in terms of how he was delivered and what was going on before birth and that sort of thing, and then what they did in the hospital after birth—after he was born.

**Denise:** So it was a series of errors that happened.

**Parent:** Yeah. Yeah.

**Denise:** How does he qualify for the fund?
**Parent:** Because he had a birth injury – basically, you know, brain injury or lack of oxygen at birth and born in a hospital or by a doctor in Virginia that was covered – or a participating member of the fund.

**Denise:** Okay. So he – as soon as he was born, he was automatically covered under this?

**Parent:** No, you have to apply. And we didn’t find out about it until D was about two and a half. So then you have to submit twelve copies or ten copies of, you know, a bunch of paperwork, including all your hospital records, and you know letters from neurologists and you know all this back of stuff and then they review it.

**Denise:** How’d you find out about it?

**Parent:** One of the head therapists from early intervention came across something about it and said X might qualify for this (laugh).

**Denise:** So nobody at the hospital ever told you?

**Parent:** No, no and that’s true of a lot of people. People don’t get informed about it. And if we ever needed to buy a Dynavox for X, that would be how we would fund it.

**Denise:** What is it called again?

**Parent:** It’s the Virginia Birth-Related Neurological Injury Compensation Program. It was set up in 19- about 1989 to – because of the malpractice insurance “crisis” quote-unquote, basically. The only—the state that has a similar program is Florida.

**Denise:** So if X. needs any assistive technologies or durable medical equipment, you could get it funded through that?

**Parent:** Anything that is not paid for by his insurance and is medically necessary.

**Denise:** So insurance first?

**Parent:** Either go through insurance or be clearly not covered by his insurance. In other words, if I can show that, you know, it’s excluded – you know, like his ankle/foot orthotics are clearly excluded under our policy, so I don’t have to submit
that. His wheelchair had to be submitted by his insurance, because they cover half.

So that goes through insurance first, and then the fund pays the other half.

**Denise:** So is his speech generating device covered under your insurance or not?

**Parent:** No, no. Kaiser. It’s not covered. We actually have better coverage for some things than a lot of people do because we – he’s covered for habilitative therapy.

**Denise:** So does that mean speech, PT, OT?

**Parent:** Yeah. Not rehab, but habilitative, which most insurance doesn’t cover until he’s eighteen.

**Denise:** How did you figure all of this out with the insurance? You know, this pays for this, and this pays for that, and – how did you do that?

**Parent:** Yeah, well, you know, that’s one of the reasons I like Kaiser, even though some people, they would hate it. My husband and I have been with an HMO since we’ve been in Washington. It’s just so simple because they take care of everything. You know, now we pay a co-payment for stuff. But there’s no—none of this, like reasonable and customary, you know, cost of things. It’s like, you know ahead of time it’s going to be thirty dollars when you go to the doctor, period. You know, we like our doctors, too. And you know, finding doctors around here is a pain, you know.

**Denise:** Well, how did you pick Kaiser?

**Parent:** We were out of HMO for awhile when my husband was working for a company that didn’t have access to it and I was in the private sector and didn’t have access, where-we were under his health insurance at that point. And so we were, like “Aaaauuugh.” I had gotten a recommendation for a doctor from our previous Group Health association doctor. And my husband was just seeing this group of doctors near his office. It was like, they were so impersonal. One of the things we love is the after-hours care. We almost never have to go to the emergency room. You go in the
building, and they’ve got the x-rays right there, and they’ve got the lab right there, and they’ve got the—you know, everything right there.

**Denise:** And you knew they didn’t cover speech generating devices? How did you know that?

**Parent:** Because I have a book that tells me everything they do and don’t do and I read it.

**Denise:** And then you knew you had the secondary.

**Parent:** Yeah.

**Denise:** And how was the process?

**Parent:** The fund can be simple. It can also be difficult, depending on who’s managing things. It used to be sort of a one-person operation when we first got into it. But it’s gotten bigger and they’ve gotten more staff, and some of the staff are a little bit more impersonal. It’s gotten more of a reputation, at least among families, as being more difficult. I’ve at least up to this point, had a pretty good relationship with people and not had too much trouble. The person who was the main case manager for a number of years just left. So right now, I have no relationship with the, you know, sort of case manager.

**Denise:** You’re assigned a case manager?

**Parent:** Well, they have this main person that is the case manager. The administrative person seems really nice, so I’ve bee kid of going through her (laugh) to get stuff in because she was kind of directing traffic while they were in between people. So I don’t know. And nobody trusts the director, because they think he kind of talks out of both sides of his mouth (laugh). But, you know, I tend to be a person who takes people at their word and tries to hold them to their word. You know, if somebody fells me something, I expect them to live up to it, and I will go back to them and say, “But you told me…” And I’ll try to get it in writing-like, send them an
email and expect to get an email back, or if you tell me this and I’ll send you an email and say, “This is what I understand.”

**IDEA: Up Against the Law Though Empowered to Advocate Through the Law**

**Problems with Implementation**

While the school provided SGDs for her son to use over the years, the parent thought there were significant problems with implementing the technologies in the classroom. Therefore, she believed her son did not learn to use the devices effectively. Throughout the narrative the parent described many disputes with the public school concerning implementation problems. The parent thought these problems were the result of staff who were not adequately trained to use SGDs. As she persistently advocated for her son, she used phrases that revealed struggles she had, such as “I argued and argued and they said, “no, no, no”, “fight the system”, “push”, “they don’t want to be obligated”. When asked why she thought the school did not conducted an augmentative evaluation, she responded.

lack of training, coordination, and—I hesitate to use the word, but competence ...“I’m not sure they could do one....We never had a speech therapist who knew anything about augmentative communication. In fact, my speech—my private speech therapist told me, in observing one of X’s speech therapists in school, that he—that she was committing child abuse by what she was doing with him [laugh].

How did her perceptions influence her actions? She persistently advocated for her son through informal dispute resolution procedures, meeting with teachers and therapists to discuss her son’s need. She hired a private speech-language therapist to work with her son at home, attended workshops on assistive technology, researched devices on the Internet and talked with other parents on listservs and
within a support group. Furthermore, she considered obtaining an independent assessment.

**Rules and Regulations: Complex and Perplexing**

The parent thought that the law’s rules and procedures were difficult for staff to understand and they did not always make sense to her either. When discussing how staff wrote the IEP goals, she stated:

“jargony” ... “I don’t think even the teachers understand it half the time... You know, when you’re talking about, you know, doing something on four out of five—doing it four out of five times on three trials and, you know, three occasions or something [laugh]— Thinks like that just, you know, kind of make my eyes glaze over.” [laugh].

Here is another example of how the parent thought the law was difficult to understand.: The parent discussed how the annual progress reports were not consistent with other reports that described her son’s progress toward his IEP goals:

“They put together some book describing how he’s doing wonderfully against these goals. And he’ll get a pass advance, but he’s making almost no progress against his IEP. He’s getting twos and threes on his IEP goals, which is—two is no progress, and three is sort of maybe progress. He’s got fours on his physical therapy—you know, physical, like—adapted PE goals [laugh]. So....”

The parent discussed another issue that confused her: Sometimes a device was included in the child’s IEP and sometimes it was not included. She thought it was dependent on who wrote the IEP.

**Parent:** Well, the school system provides the devices. And so, you know, basically, you know, it was really a question of, “Is this going to be something that he’s going
to continue with?” And, you know, one of the things is that they’re very reluctant to specify, you know, one device over another. And so...

**Denise:** And why is that?

**Parent:** I don’t know. I don’t know. You know, they—now they seem to. Sometimes they’ll write it into the IEP, and sometimes they won’t. It’s very strange. It depends on who is doing it. But I think that they are—they seem—they don’t want to be obligated to do anything [laugh], which is very—seems very strange to me, you know, because you know you’ve got a kid who needs this device, and, you know, what are the choices? You’re going to give him a device; you’re not going to give him a device, you know [laugh].

Here is an example of how the parent thought that the school may have misunderstood the regulations.

**Parent:** Oh, he was also supposed to take a Standards of Learning test, you know, the, you know, high-stakes test this year, because they figured out that he could take the social studies test. Well, in January, we put it in his IEP: He would take the social studies SOL in January. They sent out a—the state sent out a memo: “If you take one SOL, you have to take them all.” Well, of course he’s not on grade level on any of his courses, but, you know, it’s—in social studies, it’s close enough that they could teach him, you know, the basic curriculum in social studies. So he got screwed, so he can’t take the SOL—couldn’t take the SOL [laugh].

**Denise:** Oh. Did they change the rules?

**Parent:** Yes, in January [laugh]! Or they may have realized that they should have had this all the—all year long—that this was the requirement of No Child Left Behind that they test everybody in everything [laugh].
As her child became older, these perceptions caused her to be cynical about the law and disillusioned with the law.

**Denise:** So you sit at these meetings, and you may not agree with what they say. And when you challenge them, you get some unusual answers.

**Parent:** You know, at some point, you just start thinking that it’s almost not worth it.

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**Disparities in Power and Influence**

At times the law intimidated the parent and made her feel disempowered. When she attended IEP meetings there were many professionals sitting at the table who knew the rules and regulations much better than she did. She discussed how “frustrating” these meetings were.

“And so we’ve had many, many frustrating meetings with people. You know, I walk into an IEP meeting, and typically—not so much this year, but when he was in elementary school, there would be at least fifteen to twenty people in all of our IEP meetings. And finally, toward the end, I started taking one of my friends to a couple of the meetings, just because I felt like my husband and I would go—for a long time, I went by myself, and then I started making my husband go. And then I started taking—I took to a couple of the meetings one of my friends, who is an expert in all the regs and that sort of thing and is actually the chair of the local advisory committee for students with disabilities, because I thought, “Well, at least she can back me up on what I’m saying and some—at least, you know, maybe kick me under the table if I’m starting to say something wrong or kick them [laugh], verbally or, you know, something if they’re—what—they’re saying things wrong, or at least glare at them.”
This section of the narrative revealed that the parent thought that the professionals had far greater decision making power than she did.

**Denise:** So what do you think about the whole IEP process and, you know, the educational law of educating kids with needs like this? Do you think the law is on your side?

**Parent:** I think it’s a mixed bag. You know, I think, obviously, the—you know, there are some protections, but I think it is—I think, you know, the school system has most of the weight. The parent has, you know, very little weight. You know, I think particularly the more challenged the child is—you know, I think if you have a child with, you know, mild learning disabilities or something like that, you know, fine, whatever. But, you know, if you’re—you know, the way the system is set up, for a child like X, it’s basically—gives them the right to just kind of write him off.

In the following excerpt the parent tried to assert herself only to be told, “We are the experts.”

**Denise:** And his speech therapist—what does she do?

**Parent:** Mostly working with his communication device.

**Denise:** So she does work with the device?

**Parent:** Yeah. Yeah. Yeah, although I heard that this particular speech therapist may be leaving the school, which I may not be too upset about, because even though she has quite a bit of experience in using the DynaVox and, you know, augmentative communication, she hasn’t ever really been willing to work with X in any way on real—what I would consider real communication. You know, she is working with him on answering questions in the class...

**Denise:** Yeah, but not social...
**Parent:** But not, like, social communication and not providing the DynaVox at all times. You know, he gets the DynaVox when he needs to use it in class, and then they take it away from him.

**Denise:** Where does it go?

**Parent:** Back into the case or onto a counter somewhere.

**Denise:** It’s not on his wheelchair?

**Parent:** No.

**Denise:** He doesn’t have a wheelchair mount? It’s not ever mounted?

**Parent:** It’s at home. They don’t want it in school. They were going to send it back to ATS, and I said, “No, I want to use it at home. Let me keep it. I’ll send—you know, when you go out on your community-based instruction trips, you ought to be using it, so I’ll send it in for those.”

**Parent:** I’m shocked.

**Parent:** And I argued and argued and argued, and they said, “No, no, no, no, no. He uses it inappropriately, so he can’t use it.” And I said, “That doesn’t make sense. How can he learn to use it if he can’t have it? And, you know, it’s not right—it’s not good practice.” And they said, “We’re the experts.”

Another part of the narrative revealed the parent thought there would be retribution if she asserted her rights under the law.

**Denise:** So there’s no—you said they’ve never really evalu—he’s never really had an AAC evaluation.

**Parent:** No.

**Denise:** Even though there’s this technology group that there and and there’s the speech therapist—but they’ve never evaluated him.

**Parent:** No. No, in ten years of being in the school system [laugh].
Denise: And w—is there—have you ever asked for that?

Parent: I think I’m afraid if I ask for it, they’ll say, “Well, he obviously can’t use the DynaVox” [laugh]. Let’s go back to a Superhawk.”

These experiences with the law influenced her actions. She brought a friend to meetings who she thought was more familiar with the law than she was. Also, this perception of the law may have encouraged her to become more knowledgeable about assistive technologies through Internet research and by interacting with parents on multiple listservs.

**An Unjustified Diagnostic Label**

The parent thought the school had no basis for labeling her son “severely cognitive impaired”. She believed that her child had never been tested and thus this label was not justified. In disagreeing with this decision, the parent may have been concerned about the implications associated with labeling her child in this manner, though she did not articulate this.

Parent: Oh, and then, in Virginia—and I don’t know if this is anyplace else or not, but to qualify for taking the alternative testing, the non-testing, you have to be declared to be significantly cognitively impaired, among other things. And yet X—I mean, they cheerfully checked this off for X, but he’s never been tested as significantly cognitively impaired. I don’t know how they can con—in any good conscience do that.

Denise: Did you ask them—you ever ask them?

Parent: Oh, absolutely. Every time they want to do this, I say, "No! How can you do this?"

Denise: And what do they say?
**Parent:** "Well, it has more to do with other stuff than with—I mean, it’s more than just intellectual disability” or something, you know."

Over the years the parent consistently expressed her disagreement with this label but the school insisted it was necessary in order for him to qualify for alternate testing. She had begun to acquiesce, stating,

“You know, at some point, you just start thinking that it’s almost not worth it."

**Gaining Support from Other Parents**

The parent used the term “frustrating” to describe her experiences with her son’s educational program. She felt the staff did not have the knowledge to educate her son. Over the years she felt “intimidated” in school meetings, sitting at a table with a large number of people. As described above, she began bringing a friend with her who she thought knew more about the law and regulations than she did. This friend was part of a group of parents she met with and continued to be involved with.

**Denise:** So tell me about X’s education, taking it from the beginning.

**Parent:** Well, X’s been in the school system since he was three years old. He was in early intervention before that since he was about, well five months—four or five months old (laugh). So he’s been a part of the system since he was a very young child. His education has been... “frustrating” would be the word I would use to describe it, because I don’t think anybody really knows how to educate a child like D, because of his—between his motor s—motor issues, his vision issues, and his communication issues, it’s very difficult. It’s very challenging to determine what he knows. And the school system is very hung up, to use a kind word, on knowing what the kid knows before they will move on to something else. So if they can’t prove that
he knows something, they basically stick with teaching him the same thing over and over again.

**Parent:** And then he gets bored, and so he shuts down, and (laugh) he refuses to cooperate... And so we're had many, many frustrating meetings with people. You know

I walk into an IEP meeting, and typically – not so much this year, but when he was in elementary school, there would be at least fifteen to twenty people in all of our IEP meetings. And finally, toward the end, I started taking one of my friends to a couple of the meeting, just because I felt that my husband and I would go- for a long time, I went by my self, and then I started making my husband go. And then I started taking-I took to a couple of the meetings one of my friends, who is an expert in all the regs and that sort of thing and is actually the chair of the local advisory committee for students with disabilities, because I thought, “Well, at least she can back me up on what I’m saying and some-at least, you know, maybe kick me under the table if I’m starting to say something wrong or kick them (laugh), verbally, or you know, something if they’re saying things wrong, or at least glare at them.” And you know it helped a little bit, but it still was just very frustrating and, you know, still is very frustrating in terms of trying to get somebody to given X. an education that we feel is appropriate for meeting his needs and allowing him to fulfill his potential, you know, not knowing what that is. I don’t want it to be limited.

**Denise:** Now, you mentioned there was this woman—I think she was a friend of yours that knows the regulations. She came with you to a couple meetings.

**Parent:** Yeah. Yeah.

**Denise:** What made you sort of think about that as a strategy?

**Parent:** Well, you know, I know I’ve—you know, people have oftentimes recommended bringing somebody to a meeting and that sort of thing and also, you
know, having advocates and those kinds of things, you know, just having some moral support [laugh].

**Denise:** Oh, yes. Have you ever had an advocate?

**Parent:** No. No.

**Denise:** Did she give you any good advice?

**Parent:** Yeah, we kind of strategized before the meeting, you know, about—because I had—was developing kind of comments on the, you know, draft IEP and had, you know, some interactions with the school people at that time, you know, in terms of comments on other kinds of things that I’d shared with her and, you know, gotten comments on my comments, you know, or at least her reaction to “Am I going too far with this?” and that sort of thing. And...

**Denise:** Right. Is she still helping you?

**Parent:** Indirectly. I mean, I—you know, we talk regularly, and there’s a group of us—there’s actually four of us that get together, just sporadically. You know, we used to get together a little more often, but, you know, every three or four months, we kind of—you know, one of use says, “Hey, maybe it’s time to get the [laugh] group together,” and—

**Denise:** Do they all have kids with disabilities?

**Parent:** Yeah. Really.

**Denise:** And she does also?

**Parent:** Yeah. Her son is just a little bit older than D

**Denise:** And I bet you hear some similar things.

**Parent:** Yeah. Yeah. Everybody—each one of us has, you know, slightly different issues.
**Parent as Advocate: Parents Supporting Parents**

Here the parent described how she and a group of parents volunteered to advocate for changes in her son’s early intervention program. She reported that this involvement helped her feel she had some “control.” She uses the terms “fight”, “change” when describing how she was involved in these activities with other parents in program. She also described getting support from interacting with the parents when the children received their therapies.

**Denise:** And early – was he in early intervention?

**Parent:** He was in the early intervention program as a baby through age three – until he was three.

**Denise:** And what was that like?

**Parent:** Oh, that was fine. I mean, that was all therapy and, you know, loving stuff, and you know, the-there were the frustrating moments with that, though, but you know, the - because Fairfax County was making changes to the way they were operating the program. And you know, the parents – that was – several of us parents got involved with that.... And I was on the panel to review the proposals for the contractors, which was very interesting. But it led me to really want to stay with the county staff.

**Denise:** Oh. How did you get selected, or did you volunteer?

**Parent:** I volunteered, because I-I – you know, as a concerned parent, I wanted as much control over this as I could get (laugh). You know, I could see where the control was going to be, and they also set up a parent advisory board, which I volunteered to be on and said “Me, me, me!” (laugh).

**Denise:** And so he stayed there for how long?

**Parent:** Until he turned three. And then he went to the school program.

**Denise:** Did you meet a lot of parents?
**Parent:** Well that’s the other interesting thing that happened, because the law had changed to require them to do more of the therapy in the natural environment. And so, it used to be that everybody came to the center at the same time, and all the – all the parents would get together in the, you know, the side room and the kids would be having therapy in the other room, and the parents would chat, and so on and so forth. And then the main way that the parents then were getting together was these meetings to fight the fees (laugh). So instead of meeting, you know, while our kids were having therapy, we’re meeting in evenings to, you know, fight the system, change, the system, you know. But I did meet several parents of some of the kids who were in the system at the same time as D was – we still get together.

**Funded but not Implemented**

The parents described how the child was introduced to speech generating devices in early intervention. She reported these devices were not integrated into the child’s educational program – not “used effectively.” The devices did not come home with the child and school did not educate the parent about the technologies. As the child got older, the school provided higher level devices for him to use and provided the parent with training. The parent described that she was involved in selecting higher level devices for her son and learning to program them. She attended training sessions at the school to learn to use these devices and obtained information about devices through email groups. She described herself as “being on top of things, “pushy” and she indicated that the school recognized she might “ask for things.”

The school and the parent had disagreements about whether the device could come home with her son, on the bus, and come home over the summer. The school agreed
to send the device home on the bus and the parent signed a form indicating she would return the device to school in the fall.

While the school system provided the devices, the parent reported the devices have not consistently been written into the child’s Individualized Education Program.

**Denise:** So when did you start thinking about augmentative communication for X.

**Parent:** Well, I guess when he was in early intervention he was getting speech therapy. And I think, you know, at that time, we did some picture symbols. They were doing – like making choices.

**Denise:** That was in early intervention?

**Parent:** Yeah and then in preschool, you know, that was continuing. And then they started doing, you know, with the switches like the Big Mac. They had a lot of devices, because they were using ones that they call, like, a Superhawk and the Four Talker – I forget what that’s called – Cheap Talk-that’s one of the ones that they had.

**Denise:** So these were available to kids like X.

**Parent:** Right, right. But I don’t think they were used terribly effectively. You know, that’s one of the things looking back, you know, in – I just don’t think that, you know the use of the devices was all that effective. You know, the assistive technology department sort of, at that time – I think they may be doing better now – you know brought devices into the preschools, and you know, they might have said, “Well you could let the kids, you know, choose a snack or do this or do that.” But it wasn’t that well integrated into what they were doing. And, you know, they – you know, so the kids weren’t really learning to communicate, and the parents were not being educated in that sort of thing at all.
Denise: So the device didn't come home at that point.

Parent: No, not all all. Then when D was getting close to-I think they started maybe using of the early Dynavoxes, the 2C – with him a little bit. And then they – when he was getting close to kindergarten, they started using the 3100 – Dynavox 3100 with him.

Denise: It sounds like, from an early age, they felt he had the potential to use the devices.

Parent: Yeah. Well, to some extent, they did, but you know, I think they also see me as one of the parents that was going to be pushing for stuff (laugh). And, you know, sometimes I think that it’s like the squeaky wheel gets stuff, and, you know, I was one of those parents that was always on-you know, on top of things, and you know, asking about things and doing things. And so, he –you know, I went to the training, you know, for the Dynavox and – you know, with the school.

Denise: So was it the speech therapist? The teacher? Was it you that said, “Try this?”

Parent: It was probably a combination. You know, they, -I know that they were bringing different devices in into the school took, you know, try out. And I probably, you know, between being on various email groups and that sort of thing, would have, you know, brought, come across different things like the Dynavox, you know, made that suggestion. And they also, you know, had different trainings available.

Denise: To parents?

Parent: Yeah

Denise: So you went to those when you were informed about them.

Parent: Right, right.

Denise: So tell me about the funding, getting X. a device – like when it first started and how it happened and who was involved.
**Parent:** Well the school system provides the devices. And so, you know, basically, you know, it was really a question of "Is this going to be something that he’s going to continue with? And, you know, one of the things is that they’ve very reluctant to specify you know, one device over another.

**Denise:** And why is that?

**Parent:** I don’t know. I don’t know. You know, they –now they seem to. Sometimes they’ll write it into the IEP and sometimes they won’t. It’s very strange. It depends on who is doing it. But I think that they are – they seem-they don’t want to be obligated to do anything (laugh) which is very – seems very strange to me, you know, because you know you’ve got a kid who needs this device, and, you know, what are the choices? You’re going to give him a device; you’re not going to give him a device, you know (laugh)

**Denise:** And when did it start coming home?

**Parent:** Pretty early on. I think as soon as, you know, we got training to be able to do the programming and that sort of ting. There was a little bit of an issue – just trying to remember. At one point, there was an issue, because it-with a bus. There was an issue about taking it on the bus, I remember. And we had to, for a while, actually take it back and forth to school (laugh) which is weird. And the-

**Denise:** Oh, they were worried it would be damaged or something on the bus?

**Parent:** Yeah. And then they kind of realized-they decided that it was okay to put it on the bus. And at that point, you know, -we

**Denise:** In a bag or something?

**Parent:** Yeah. I mean, it’s in a carrying case. You know, once they decided that the transportation people were willing to, you know, have it on the bus- and I think it was the transportation people that weren’t willing to have it or something (laugh). That was the real stumbling block.
Denise: Somebody felt uncomfortable with it... responsible for it.

Parent: Yeah. Right, right. Then they said, “Yeah, the device can come home.” And then there was also, you know, the “Can it come home over the summer?” issue, you know, like the first year (Laugh)

Denise: So what happened next?

Parent: You had to sign a form that you’d send it back in the fall (laugh).

Inadequate Training, Knowledge and Coordination Among School Departments

When asked what troubled her about getting devices for her son, the parent stated the school did not conduct a complete assessment of his augmentative communication skills. She did not asked for a complete assessment because she feared the school might decide he cannot use the device they provided. She also cited problems with communication and training between the assistive technology department and the speech-language therapy department. The parent thought the therapists and teachers did not have the knowledge to work with her son and they were not taking advantage of training opportunities. While the speech-language pathologist used the devices with her son, the parent thought she did not use them in an effective manner in the classroom.

Denise: Let me think. So was there anything that troubled you about the whole process of getting these devices for X?

Parent: Well, I think in the sort of, you know—the long-term picture, the main thing that has troubled me is the fact that nobody has ever really looked at his kind of big picture in terms of his communication needs. You know, they just sort of give him stuff and expect him to be able to use it [laugh]. In other words, there’s never been
a real evaluation of what’s appropriate and what his real access methods are. And we’ve...

**Denise:** Why do you think that is?

**Parent:** Lack of training, coordination, and—I hesitate to use the word, but competence.

**Denise:** In the school.

**Parent:** In the school system. You know, we have two separate departments. We have the assistive technology department, and we have the speech department, and never the twain should talk to each other in the past. They’re doing better now. But in the past, you know, there was not much crossover. We never had a speech therapist who knew anything about augmentative communication. In fact, my speech—my private speech therapist told me, in observing one of X’s speech therapists in school, that he—that she was committing child abuse by what she was doing with him [laugh].

**Denise:** Because?

**Parent:** She was doing such inappropriate stuff with him, you know, trying to get him to—she was doing articulation therapy with a non-speaking child. And, you know, basically, you know, the kinds of things she was doing were just completely inappropriate, you know.

**Denise:** So you suggested she go to see X in school.

**Parent:** We’ve had school therapists come see her at our house, and she’s gone to see them in school, in the past. Not recently, but—

**Denise:** Okay, and how—have you initiated that, or is this—

**Parent:** Yeah.

**Denise:** You did.
**Parent:** Yeah. Well, to some extent, both, but, you know, it just seemed like we were making so much more progress at home [laugh] than they were making in school that it was like, “Maybe you could learn something [laugh] from seeing what X does [laugh].” But it just never seemed like they would believe, even by seeing what she was doing, that [laugh]—

**Denise:** So when she came home to—told you this, what happened then?

**Parent:** I mean, we can’t change the school speech therapist. That’s the thing. It’s like, “Bah,” you know, “let’s just get through this year and hope they get somebody new next year,” you know. But, you know, in terms of, you know, the—we’ve gone back and forth on different access methods, you know, to the point that one year, we would use direct select; then they would try to switch to single-switch scanning; and—I kept saying, “This is ridiculous. He can’t do that, because the timing for him to do, you know, ‘Okay, listen, listen, listen, hit! Listen, listen, listen hit!’—he can’t do that.” And, you know—but yet, they were so hung up on it for ages that they kept making him do that. And then finally, you know, nobody would—then we were doing audio touch. Somebody suggested that as a possibility, so we tried that. And then finally, somebody showed me how to do—to set it up for two-switch scanning to get rid of the menu stuff at the top, because that’s a real pain in the neck.

**Denise:** Who suggested this?

**Parent:** One of the therapists in the assistive technology program. So once I learned how to do that, I said, “This is the way to do this,” and—

**Denise:** So he’s doing okay with that?

**Parent:** Yeah

**Denise:** And his speech therapist – what does she do?

**Parent:** Mostly working with his communication device.

**Denise:** So she does work with the device.
**Parent:** Yeah. Yeah. Yeah, although I heard that this particular speech therapist may be leaving the school, which I may not be too upset about, because even though she has quite a bit of experience in using the DynaVox and, you know, augmentative communication, she hasn’t ever really been willing to work with X in any way on real—what I would consider real communication. You know, she is working with him on answering questions in the class...

**Denise:** Yeah, but not social...

**Parent:** But not, like, social communication and not providing the DynaVox at all times. You know, he gets the DynaVox when he needs to use it in class, and then they take it away from him.

**Denise:** Where does it go?

**Parent:** Back into the case or onto a counter somewhere.

**Denise:** It’s not on his wheelchair?

**Parent:** No.

**Denise:** He doesn’t have a wheelchair mount? It’s not ever mounted?

**Parent:** It’s at home. They don’t want it in school. They were going to send it back to ATS, and I said, “No, I want to use it at home. Let me keep it. I’ll send—you know, when you go out on your community-based instruction trips, you ought to be using it, so I’ll send it in for those.”

**Denise:** I’m shocked.

**Parent:** And I argued and argued and argued, and they said, “No, no, no, no, no. He uses it inappropriately, so he can’t use it.” And I said, “That doesn’t make sense. How can he learn to use it if he can’t have it? And, you know, it’s not ri—it’s not good practice.” And they said, “We’re the experts.”

**Denise:** “Using it inappropriately”? What does that mean? Doesn’t select the right—
**Parent:** It means he selects things that he—I mean, he’s—you know, hits the switch when he shouldn’t be, you know, hitting it and things like that [laugh]. And so exactly how is he supposed to learn to not do that [laugh]? Like, what’s the aide supposed to be doing? You know, maybe keeping his hand off the switch or redirecting his attention, you know?

**Denise:** And how do kids that talk behave? They say things that they’re not supposed to say, and they do things they’re not supposed to do! Isn’t that right?

**Parent:** Right! You got it!

**Denise:** So there’s no—you said they’ve never really evalu—he’s never really had an AAC evaluation.

**Parent:** No.

**Denise:** Even though there’s this technology group that sits there and and there’s the speech therapist—but they’ve never evaluated him.

**Parent:** No. No, in ten years of being in the school system [laugh].

**Denise:** And w—is there—have you ever asked for that?

**Parent:** I think I’m afraid if I ask for it, they’ll say, “Well, he obviously can’t use the DynaVox” [laugh].

**Denise:** But he is using it.

**Parent:** Well, his current speech therapist thinks he can’t. But I think she’s leaving, so I’m hoping that maybe he’ll get somebody else next year that’s better—easier to work with. You know, sometimes it’s better not to ask for things if you don’t necessarily want a different answer than the one you have.

**Denise:** So you thought if you stirred the pot a little bit, they might say, “Well, then, let’s just”—

**Parent:** “Let’s go back to a Superhawk, because obviously he can’t—you know, he’s not doing anything with the DynaVox, so why are we using this?” So, I mean, I
would consider going privately for an evaluation, but I’m not sure I would ask for one through the school system, because given my experience, I’m not sure they could do one.

**Denise:** They’ve never suggested he needed a more in-depth assessment.

**Parent:** No.

**Denise:** So in terms of, if I understand you correctly, things that troubled you, these are the things that bothered you

**Parent:** The lack of coordination—now they’re doing some cross-training. The augment—the assistive technology people are going to the staff meetings of the speech department people and doing training on augmentative communication so that the speech people know what it is, you know, so that—in a lot of schools, they don’t have any kids using the devices. So, you know, a lot of times, these speech people would never see a kid using a device, but you never know. You know, you could be assigned to a different school. You could have a kid come in anytime. You should have some knowledge. So, you know, they’re doing this cross-training, you know, so that when these, you know, things come at, they’ve at least heard the terms, seen the devices...

**Parent:** The new speech therapists who are being hired now in the next—the last couple years—

**Denise:** Should know a little more.

**Parent:** —have that basic thing. But the ones that have been out there for five, ten years don’t. And, you know, unless they’ve gone back and gotten some continuing education or have an interest, you know, they couldn’t care less. They don’t know nothing [laugh]. Or they’re—you know, they’re not—they don’t have that education. So...

**Denise:** What about the teachers? How are they involved in this whole technology?
Parent: Unless they get a kid that’s using a device, they’re completely clueless, you know. And what’s frustrating—there’s another frustration for me. My son goes to a program that is de—supposedly designed for kids with physical disabilities. Most of the kids in that program walk, talk, and use pencils. Why are they in this program? I don’t know. But what’s frustrating to me—you know, I’ll leave the subject of why these kids are in this program, but what’s frustrating to me is, Fairfax County has a really terrific Saturday thing they call the RATE Conference—Real Assistive Technology Education or something—in Education—R-A-T-E. And none of the teachers from my son’s program went, last year or this year.

Denise: It’s a training program?

Parent: Yeah. They had all—it’s morning and about lunchtime, early afternoon, so it’s not even all day Saturday. Why none of these teachers went, I don’t know. It’s open to parents, so I go. You know, it’s great. They have stuff about Boardmaker. They have stuff about literacy for kids with augmentative communication. They have stuff about, you know, all different kinds of, you know, disability issues—you know, just about any—Web site stuff, you know, resources—all different ki—just about anything you could think about. And it’s teachers giving these classes based on their experience. You know, one of them was about, you know, switch access for different, you know, software. And there were only two people in that class: me and one other parent. Where were all the teachers?

Denise: And this is offered through the school system?

Parent: Yes. Yes. None of these teachers went from this program that I—my son is in. I was just flabbergasted [laugh]. I mean, this shows their level of commitment to my son: not there [laugh].

Denise: Now, is he in a self-contained program?

Parent: Yeah.
Denise: Self-contained?

Parent: Yeah. I mean, he can take a couple of electives in the general population in the school. At this point, in his sixth-grade year, he took a sort of elective grouping they call the Wheel, where they go into a whole bunch of, like, six-week classes. And one of them was drama. One of them was family and consumer science. One of them was a language class, art, you know, the I—you know, sort of mini-courses, almost, to kind of get a taste of those, you know. And most—some of them were worthwhile. Some of them weren’t. The drama class was great, because the drama teacher was great. Some of the others were “Meh,” so far as I was concerned. He’s taking a course called Tech Tools, which is using the computer. And here was another example of incompetence and really stupidity: They had him doing a single-switch software program most of the year, because they didn’t bother—it was like a coloring program. You know, like, “Click the switch, and something”—you know, cause-and-effect program, which—like, how stupid is this? He—you know, that’s for fun. He can do that at home.

Denise: All year?

Parent: Mm-hmm. He was supposed to be having the assistive technology person come in and bring in other things for him to do, like adapted keyboards, adapted mice, other programs. And they—I’d gone to this class at the RATE Conference for—to see a specific program called Connect Switch Software, where they can have access to—through this different pro—software to all of Microsoft or any other software that’s out there. And they were supposed to come in and set this up for X to use. Well, I don’t think they ever did get this set up. It just forever took them. Well, they finally got set up a program called Clicker 5, which is a writing program, I guess. But it took them till, like, March or April to get that set up. What’s so hard about that? I mean, that should have been the first day of class, but they didn’t even
call the technology person until I said, “Why haven’t you called in ATS?”, at his IEP meeting in February! It took me to get them to do that. I observed them in November using this single-switch software program and the aide reading his email sitting beside him!

**Denise:** No!

**Parent:** Yes, reading his AOL email! I complained to the head of the thing, and I said, “Why is this aide reading his email in his class monitoring X?” [Laugh]

**Denise:** Did he get a different aide?

**Parent:** No! [Laugh]

**Denise:** Oh, that’s infuriating.

**Parent:** So, no child left behind except my son and all the other kids like him in Fairfax County [laugh] and many other places, too. I mean, I shouldn’t single out Fairfax County, but probably just about every other school system in the country.

**Denise:** That’s what I hear when I talk to parents.

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**Parent as Informed Consumer – Networking with Other Parents**

In these excerpts the parent described that over the years her son needed a variety of services and equipment. To deal with this complexity she prioritized his needs and did “research” to obtain information about the equipment or services her son needed. She obtained most of the information by talking with parents on listservs. She did most of this work herself, though her husband helped with some tasks.

**Parent:** So, you know, my experience has been that if I’ve requested something and I’ve had the right backup for it, like the letter from the doctor, the letter from the therapist, you know—

**Denise:** How did you know you needed all that?
Parent: Research. Well, my philosophy has always been—and I kind of learned this, I think, back when X. was about maybe three or four years old. I really had to focus on something, whatever the most important thing was at the time, because if I tried to pay attention to everything, I could do nothing. “He needs physical therapy; he needs occupational therapy, he needs speech therapy, he needs devices, he needs shoes, he needs this, he needs that, you know, he needs to be loved, he needs to, you know do everything. Well, okay, what does he need today? What is the one thing that I need to accomplish? And so I would say, “Okay, I’m going to focus on doing that one thing, getting the research, getting the whatever. You know, whatever that this is, if it’s going to take a lot of research, you know, just get that one thing out of the way, and then go on to the next big thing.”

Denise: How do you find out?

Parent: Figure out what the sources are—what the best, you know, options are. You know I’ve always been on email groups. And so, I guess back in the early days, it was mainly one or two, but, you know, over the years, I’ve kind of accumulated a few more. And not I’ve kind of dropped off of reading most of them.

Denise: Well, there’s so much.

Parent: But you know, I kind of dip into them once in a while to see what’s going on and, you know, answer questions or look for information or ask a question or something.

Denise: I see, then, that parents are a great resource to each other.

Parent: Oh yeah. It’s huge. And, you know, we have some local groups, too, that are really nice.

Denise: So you’ve talked to other parents, and they share their experiences and get information that way, too?
Parent: Yeah. But there’s a really good augmentative communication group. Well, you’ve, I think you know, got—that Promoting Augmentative Communication Together group is really good. The other group that I’ve belonged to for a long time is the CP Parent. I don’t read a lot of the emails there now, but, you know, the people there are really knowledgeable, and, you know, a lot of the issues aren’t that important for me right now. But everyone once in a while, you know, I’ll kind of see what the topics are and, you know, look at something or maybe ask a question or answer a question on that.

Denise: So has your husband been involved in this, or has this been kind of you and—fallen on your shoulders mostly?

Parent: Yeah. A lot of it is my—is me. X is, you know, involved in certain ways, but I think in terms of things like doing research on, you know, communication devices or something like that, you know, that’s—that would be me [laugh].

Denise: How about dealing with insurance? Is that you, too?

Parent: Yeah.

Denise: Yeah. The phone calls would be you, and doing the research would be mostly you.

Parent: Yeah. Yeah. It seems like, you know, he’ll take D to appointments, but I have to make the appointments [laugh].

III. Perceptions of the Law Compared with the Positive Law

Advocating for Rights

Did the law enable the parent to advocate for her son’s AT rights and assert her rights? I believe the regulations did enable her to advocate for her son and obtain some assistive technology rights. The parent obtained a speech generating device through a state birth injury fund. She reported that over the years became
increasingly confident in navigating this system to obtain benefits for her son through this program. IDEA regulations specify parents’ rights in four major areas: prior written notice (34 C.F.R. §300.503), consent for services (§300.300), participate in developing the child’s Individualized Education Program (IEP) (§§300.320-300.322) and due process to challenge decisions made by the child’s IEP team (§§300.500-529). These regulations have been adopted by the state of Virginia within its special education regulations (8VAC 20-81-100, 81-190, 81-200, 81-210). While the parent did not assert her formal rights, she ardently and persistently advocated through informal dispute resolution methods. She had frequent meetings with IEP team members and talked with school administrators. There were times when she thought the obstacles were too great, and then she went outside the school system to obtain the devices and training through health insurance.

**Resources, Training and Competency for AT Equipment and Services**

The parent reported the school never conducted an assistive technology evaluation and did not provide training for the child to use the device or for her to use the device. She also reported that staff were not adequately trained to use the devices. If accurate, this would not be consistent with federal regulations or Virginia’s special education regulations. Under federal regulations, adopted by the state of Virginia in its special education regulations, the school is obligated to provide assistive technology devices and services in order for a child to receive a free appropriate public education (FAPE) (34 C.F.R §§300.5, 300.6, 300.34, 300.42, 300.101, 300.105, 300.320, 300.324; 8 VAC20-81-100 F (1), 8VAC20-18-110 F (2)(g)). Assistive technology services include providing an evaluation to determine a child’s assistive technology needs (§300.6; 8VAC20-81-10). Furthermore, the federal and state regulations clearly state that assistive technology services include training to
the child (300.6(e)), family (300.6(e)) and educational staff (300.6(f)), (8VAC20-81-10)).

School-Purchased Device Used At Home
The parent reported that initially the school would not permit the SGD to come home with her son. She thought there might have been a problem with liability on the school bus. Eventually, the school allowed the child to bring the device home, including home over the summer. Based on IDEA regulations, which have been adopted by the state of Virginia in its special education regulations, the child may have access to the device at home or in other setting if the IEP team determines it is necessary in order for the child to receive FAPE. (306.105(b)); (8VAC20-81-100F (2)). Thus, it is probable that the school’s decision was consistent with the law.

Development of the IEP
The parent reported that a device was not consistently included in the child’s IEP. Federal regulations, which have been adopted in the state of Virginia special education regulations, require that the child’s IEP team consider whether the child needs assistive technology devices and services (34 C.F.R. §300.324(a)(2)(v)); 8VAC20-81-110(F)(2)(g)). Based on what the parent reported, more information would be needed to determine whether the IEP was developed in a manner consistent with the law.

Health Insurance Coverage for SGD
The parent reported her Kaiser health insurance plan did not cover speech generating devices. According to an AAC funding database available through the Assistive Technology Law Center, some Kaiser plans have covered speech generating
devices\textsuperscript{38}. However, further information about the plan is needed to determine if and why the parent’s Kaiser plan excluded speech generating devices.

\textbf{Personal Factors That May Have Influenced the Outcome}

The narrative revealed some personal factors that may have influenced the process and outcome for obtaining funding for the speech generating devices and services to implement the devices. This parent reported she was highly educated. When her son needed equipment or services she did “research” to determine the best options. She was assertive with people; she described herself as “on top of things” and a “squeaky wheel” and she stated the school recognized these characteristics.

\textsuperscript{38} http://www.aacfundinghelp.com. The Assistive Technology Law Center reports this is not a complete list. It spans from 1990’s-2003 and is based on information that some assistive technology companies provided.
Case Analysis # 3

Demographic Information

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<thead>
<tr>
<th>Age and gender of child</th>
<th>5 year old male</th>
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<td>Diagnosis</td>
<td>schizencephaly, per parent report</td>
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<td>public</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Martial Status</td>
<td>Married and lives with husband</td>
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<tr>
<td>Interviewee</td>
<td>Mother (&quot;Ms. Brady&quot;)</td>
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<tr>
<td>Parent’s education level and vocation</td>
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<td>Speech generating device</td>
<td>Vantage Plus</td>
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<tr>
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I. Case Facts

This is a 5 year old male with a medical diagnosis of schizencephaly, per parent report. The parent reported the child has multiple disabilities. He is non-ambulatory and uses a wheelchair. He uses a speech-generating device for communication. The parent reported the child’s cognitive skills are intact. He attends an integrated preschool in a public school.

The parent had significant difficulty obtaining funding for a speech generating device (SGD) through employer-based medical insurance. The insurance company denied her request. She appealed and she was successful. The parent has also had significant difficulty getting the SGD implemented into the child’s educational
program. She attributed this difficulty to staff’s lack of knowledge and training in assistive technology, in part, due to limited resources at the school caused by fiscal problems. In 2006 the parent requested an assistive technology evaluation through the school and is still waiting.

II. Analysis - Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? Where do families obtain information about the law? How do their perceptions of the law compare to the positive law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

Perceptions of the Law

The narrative revealed that this parent was highly engaged with the law in her everyday life as she sought assistive technology devices and services for her son. The law empowered her to assert her rights and advocate for her son’s rights. She faced challenges in obtaining assistive technology devices and services and I use the term up against the law to refer to the challenges. I adopted this term from Ewick and Silbey’s sociolegal research (Ewick and Silbey, 1998).

This parent’s interactions with people, in combination with personal factors, influenced her perceptions of the law. These perceptions influenced the decisions she made and ultimately determined whether and how she exercised particular rights.
Empowered by the Law and Up Against the Law

The parent had many struggles with her health insurance and the school. While she was confident her health insurance would fund the device, it initially denied the funding request for the speech generating device. While the appeal process was lengthy, she was persistent and organized and she prevailed. She had two, rather contrasting perceptions of the appeal process. She thought the process was orderly in that the insurance company explained the process for filing the appeal and the process was highly procedural. In another sense she thought the process was not predictable. The parent reported that she was not always certain what to do and she learned by “trial and error”.

The parent thought the school was not complying with the Individuals with Disabilities Education Act (IDEA) in terms of assistive technology services for her son. She described problems with the administration hiring unqualified staff, in part, due to financial problems. She stated that the staff at her child’s school were not adequately trained to use his speech generating device and were slow to incorporate his speech generating device into his educational program. She talked with school staff about the problems but was not satisfied with the outcome. After recognizing all the obstacles and carefully considering her child’s needs, she decided to go outside the school for services. She then turned to her health insurance to fund therapy services at a local hospital.

The parent advocated through informal dispute resolution processes, making telephone calls and arranging meetings. She interacted with a variety of people who she thought might help her. As she talked with people, she gained some knowledge
of the formal law, which enabled her to advocate for her son. When she thought she needed information about the law, she talked with other mothers, contacted a local advocacy group or went on-line.

**Funding for Speech Generating Devices: Health Insurance vs. School**

The parent reported that she carefully considered her funding options. While she thought the school might be obligated to provide a device, she chose to submit a funding request through health insurance. She expressed several reasons for this decision: ownership, a potential conflict with the school, and the school’s lack of knowledge and limited financial resources. These factors influenced her decisions, which determined which rights she exercised.

**Massachusetts Common Health: Difficult to Navigate**

The parent reported it was very difficult for her to apply for benefits through this program. She reported that Medicaid staff were not well trained and information was difficulty to access. She was denied several times because staff thought she was applying for a different Medicaid program. She networked extensively to obtain the benefits.

**"Right" to Have Speech Generating Device**

The parent felt that since her son could not speak he had the “right” to have a speech generating device. She felt that under the law, the “state” may be obligated to provide the device in order for him to be a productive citizen. I believe she used the term “right” to mean that he was entitled to the device, in a rather general sense. In other words, when asked about a specific law, she did not refer to any laws or regulations that may guarantee her son this right. While the parent recognized her
child had the “right” to have and use speech generating devices, she infrequently spoke about the formal law. In fact, she stated she knew very little about the law. However, the law provided a structure that enabled her to think about rights and claim rights.

**Personal Factors: A Powerful Combination of Resources**

The parent attributed her success in advocating for her son to her ability to communicate. She stated that she learned this skill from her parents and siblings. This parent worked as a professional fundraiser and her networking skills were apparent. She was assertive, skillful and persistent. She decided early on that it was important for her to network with a variety of people to obtain her son’s rights under the law. She sought information, guidance and support from community organizations, her friends, and other parents, including parents on listservs. By talking with other parents and professionals, she obtained information about health insurance benefits, assistive technology devices, assistive technology evaluation and treatment services, and funding for assistive technologies. These interactions empowered her to advocate for her son which determined which rights she decided to exercise. Her experiences with the law influenced her in another way. She became vice president of the local parent’s advisory group. In this role she helped a community of parents advocate for services for their children in the public school.

These themes are illustrated within excerpts from the narrative.

**Learning About Speech Generating Devices – Networking with Parents and Healthcare Professionals**
In following excerpts the parent described how she first heard about speech generating devices and about augmentative communication services for her son by networking with a variety of people. She was having marital problems and a social worker suggested that she contact a counselor. This counselor was a parent of a child with a disability. When she contacted the counselor, the counselor told her about a support group for parents and children with augmentative communication needs at a local hospital. When she went to the support group meeting at the local hospital, this counselor/parent told her about her experiences getting a speech generating device for her son at X Children’s Hospital. The parent then contacted X at this hospital to obtain an augmentative communication evaluation for her son. The parent stated that the social worker has been very helpful to her – a source of support and information.

Denise: ...Last time we talked X just got a Vantage—or recently got a Vantage Plus.

Parent: Yes.

Denise: And you told me a little bit about how it all happened and so forth. So if you could just start at the beginning—meaning, when did you first start thinking about a device for X, and who helped you put—or helped you get it and helped you think about it more?

Parent: Okay. When he was—X is now going to be five any minute now in March. And I’ll never forget the first time I heard this idea—it was back with one of our OTs back in Early Intervention, and she said, “I picture X in an electric wheelchair using a talker, just like Stephen Hawking.” Now I wasn’t particularly prepared to hear that, so I freaked out and didn’t really acknowledge it. And then, of course, you know, up—it’s now almost just a year and a half ago—I—probably two years ago now, I started going down to doing some extra stuff at Children’s, and then I heard about the speech clinic at Children’s Hospital in X, and then they have a satellite office in X.
We hooked up with X (speech-pathologist) there, who actually—we went down; we did a full—we were there for several hours, and she pulled out a couple of different types of devices, and she—the one we ended up settling on—or that works really well with the Vantage right then and there, so we picked that one and started the process.

**Denise:** You mentioned that you went to Children’s Hospital. So you—how did you decide to go there?

**Parent:** Somebody told me about it. Somebody—another parent told me about it here in X. X Medical Center had a social, an ice cream social where a bunch of kids and adults—young adults came and got together with their families, and it was all about using the device while they were, you know, having an ice cream social. And I was like, "Oh, cool." So then somebody mentioned—the same parent said, "Well, we went down to Children’s; they were much—they were very aware of lots of alternatives”—you know, just more people

**Denise:** Ooh, I do want to ask you about that in a minute, but something you just—something just stuck—let me just ask you about something you mentioned. You said that another parent told you about the CEC, and then you went—did you go to the ice cream social?

**Parent:** I did.

**Denise:** So that parent invited you, or another parent?

**Parent:** I’ve got—yeah, just—I don’t know. I just—it was happening, and they said, “You can come.”

**Denise:** And you saw other kids using devices.

**Parent:** Yes.

**Denise:** That must’ve been exciting.
**Parent:** Yeah, it was pretty freaky, because, you know, if you don't get your—if you don't see it, you don't—you're not aware of it. And it was wonderful, though, because you could see some real physically complicated care kids managing to make themselves known and—oh my God, it was so wonderful to see everybody. I just went to—they had another event a couple weeks ago, and it was just great.

**Denise:** So was this a parent in your district who you knew, or a friend...?

**Parent:** Okay, you can't—you know, like, it was at—my husband and I were seeing a marriage counselor, and she's a marriage counselor, and she has a child with special needs herself. So she shared that info with us. That's where her son got his.

**Denise:** Oh, okay.

**Parent:** Wasn't quite a friend, but... [laugh]

**Denise:** But that was really an interesting coincidence.

**Parent:** Well, no, it was actually great, because I had reached out to somebody—actually, there's a woman named X; I don't know if you know—in Massachusetts, they have a regional consultation program, which is divided up to five different regions, where these programs service at really complicated care kids—medically complicated care. And we'll qualify for that, although he's not as complicated, certainly, as many of the other kids, because he doesn't have a feeding tube, or he doesn't have a vent or a trach or any of that stuff. But X is another one of those people who deserves a million compliments and awards, and rewards, and hopefully will get them in the afterlife if she doesn't get the millions beforehand. She—I called—I was having a bad day, and I talked to her, and she hooked me up, and she said, “You know, this woman's a counselor, and she's got a kid with special needs.” So now I've sent actually several friends of mine for those bumps in the road when you can't really communicate with your own—your partner and you just need [laugh]...
Denise: Absolutely.

Parent: And it’s great because she understands the concepts behind where they—you know, there’s only so many times you can say, “I’m sick of doing the f-ing appointments all the time,” you know. It sounds like you’re just bitching, and you’re not really; you’re just—you need to share [laugh].

Denise: Yeah, I know. I’m with you on that. So this was through—was this through Mass Health?

Parent: Nope. Consultation Program, yeah. It’s a public health—it is a part of the Department of Public Health, but it’s not MassHealth related, I don’t think.

Denise: Department of Public Health, okay. And so she—you were seeking advice from her, and she mentioned this program—she mentioned this counselor.

Parent: Right.

Denise: This is the kind of thing that really interests me, because I’m learning about how parents get connected with services, and that’s not always really obvious.

Parent: Oh my God, it’s not at all.

Denise: Let me go back to something else you said. What does the Massachusetts Regional Consultation Program offer X?

Parent: They give—they’re there to provide—oh God, I’m going to screw this up....

Denise: No problem; just take your time.

Parent: She does support for families with complicated medical care. So she does things like... gets them out into the public—and it’s Early Intervention agent on loan. X’s (social worker) really gracious about letting people stay. Alum can continue to participate, which is a wonderful thing. She—they—she had, like, every Tuesday, when, you know, she does a skating party, she does a Children’s Museum event, where the Children’s Museum is closed so you can bring your own—your family, and you can go use the Children’s Museum without having everybody ask questions
about why your kid is—you know, so you can get used to doing things—from my perspective, it was, you could get used to doing normal things that you would normally do with your family without having, you know, to fight the other adults there. The kids you don’t mind so much as the adults that really kind of get to you. So she does that. She—they provide services; she does trainings, and, like, she’s got coming up in a couple weeks a Couples Night, which is a light dinner and conversation about the struggles of raising a kid. She runs a conference—couple years ago, she did the best conference ever, and it was all organized; it was a day long thing at an EI’s place down in central Mass, and all parents—different parents presented from—either about, “How did you find”—you know, like, one woman did partner with—there’s a lady who started this organization called Whole Children, which is, like, a kid’s sports center, almost, in Hadley, Mass, which basically allows kids to play soccer. Like, my son could play soccer or whatever on a—like, an adapted team—stuff like that. She—then there was this other parent couple who got up and talked about—they gave you a template of the transition—you know, the document or the transition to IEP, you know, if you go from a family plan to an IEP—and how to transition that. It was amazing! So she does that. And then most important, that’s the sidebar of this, which I love—mostly is because I met one of my best friends, Laura, there, because she lived down the street. We started walking together; we got to know each other; we had completely different situations with our kids but so similar situations with our lifestyles. So it was just really—that, I think, is the most—one of the most important aspects of her program.

Denise: Ah, okay. Well, it sounds like she has a lot of fun doing it, too.

The parent reported that she gained information from networking with other parents and professionals on listservs. She is on a listserv from Massachusetts Family Voices,
a family advocacy group, which is how she learned about a community meeting featuring the Massachusetts Director of Public Health. She went to this meeting to ask this individual for help her with the Common Health application. She stated she learned about this listserv from a social worker. She also described her experiences with another listserv for parents who have children with augmentative communication needs. She learned about this listserv from "surfing the net."

**Denise:** How did you learn about the Mass. Family Voices listserv.

**Parent:** I learned about them from X from the Western Regional Consultation Program – a program for kids with more complicated care – medically that is. She was introduced to me by early intervention. She’s amazing. She’s really an amazing woman. She knows everybody, and she knows, like—you know, so when I got denied from Mass Health for the fifth time, before I got—gotten—she gave me the—you know, she hooked me up with the right person to get the local Springfield office head. And I called him up crying, and he fixed— you know, he started working on it—so, you know, like that kind of stuff. She knows everybody.

**Denise:** How does it help you?

**Parent:** They have a listserv that shares information between parents and providers. On it I get so much info about other services and organizations, and ideas for our situation. In addition, MFV runs these really cool topical conference calls that you can listen in on live or play back after. I love them.

**Denise:** Are you on any other listservs?

**Parent:** I joined a Web site in the summertime; it’s a listserv for parents from YAK—I think is the group. Oh my God, it’s, like, so great, because everybody’s helpful. It shares info and talks you through, and—I don’t really talk online— I don’t really write to people, but I’m a lurker, as I like to refer to it. But it’s just been—I really appreciate the sharing of this community.
Denise: How did you find out about YAK?

Parent: Surfing the Net looking for information on talkers.

Denise: A lot of parents mentioned to me about the online communities and how they’ve benefited. Even if they don’t post or reply, just getting information and hearing what other parents are doing and their experiences with different aspects of the device has been really helpful.

Funding Options: Health Insurance vs. School

Factors: Ownership, Potential Conflict with the School, Knowledge

The parent carefully considered her funding options. Networking with other parents and professionals influenced her thoughts and actions. The parent stated that when she started thinking about a device for her son she did not know the school might be obligated to conduct the augmentative communication assessment. She described how she learned about an independent augmentative communication specialist who could conduct an assessment by talking with a parent. In terms of funding the device, she thought that the school was a potential funding source but decided early on that she wanted to “own” the device. She thought the best way to achieve ownership was to submit a funding request through health insurance. She also indicated that she went through her insurance because did not want to another “fight” with the school. Over the years she had many interactions with multiple people in the school who she thought did not have the knowledge and expertise to use assistive technology with her son to meet his needs.

Denise: You mentioned that you went to X hospital. So you—how did you decide to go there?

Parent: Somebody told me about it. Somebody—another parent told me about it here in X (her city). X Medical Center had a social, an ice cream social where a bunch
of kids and adults—young adults came and got together with their families, and it was all about using the device while they were, you know, having an ice cream social. And I was like, “Oh, cool.” So then somebody mentioned—the same parent said, “Well, we went down to X.” (hospital where the AAC specialist was); they were much—they were very aware of lots of alternatives”—you know, just more people

**Denise:** Now, when you decided to go through your health insurance, what do you think—I know you heard about it from this counselor; you heard about the X but, like, what made you not ask the school and go directly to the X (hospital where the AAC specialist was) instead?

**Parent:** Initially, it was just stupidity or lack of knowledge that I could do it through them. And then when I found out, I already started, and then I started thinking about the—I just wanted to own it. I wanted X to own it, because you never know what the schools are going to take from you [laugh]. And it would be hard-pressed to say that they would take a device from the kid, but you know what? They’ve oft—they’ve already—the wonderful speech therapist who has changed—you know, done a 180-degree turn on the device, has, on occasion, taken it to another place to show somebody else. And I’m like, “No, you bring X with you if you’re going to take it. It’s his device; it’s not your device.” So I understand the concept; it’s just easier to take—you know, “Let me just run this for 20 minutes.” Well, 20 minutes turns to 40 minutes, and 40 minutes—you know, it’s just too much time to be without your own voice.

**Denise:** Absolutely.

**Parent:** So—and I understand it. You know, I—trust me: I am not about making—it’s hard enough getting him out the door every morning, so I understand it’s just easier. But, you know, guess what? Easier for you doesn’t necessarily mean correct for X.
**Denise:** And why didn't you have the school pay for it?

**Parent:** It was going to take too much time, and another school was going to – I was just – it was one more fight that I wasn’t really willing to make.

**Denise:** So technically you knew that the school should pay for it, but you decided it’d be better for you – for your family and for X if you –if he had his own device.

**Parent:** I knew that the school could pay for it and has paid for them for other people, but philosophically, I’m not really sure the school’s always the best place to do all this stuff – you know, provide all those services. I don’t –it’s the only way that they’ve defined this nation, but I don’t think the delivery mechanism is really appropriate, either. So I didn’t want it to be owned by the school; I wanted it to be owned by me.

**Denise:** So when you say the school is not always the best place... What do you mean?

**Parent:** Well, like I mean, new technology –it’s a lot of work, and they’ve got a lot of work themselves dealing with what they have to deal with on a daily basis. So, I’m not going to say they do it wrong; they just – you know, there’s some people that embrace technology; and there’s some people that don’t. And I think that the school system needs to embrace technology, no matter what. And they do pretty well by having their computer labs; yadda yadda yadda. Then it comes to my situation, you know for kids with special needs, the technology aspect of things you know, it runs the gamut from an orthotic or a prosthetic or kinesio tap or any of that stuff to a talker. So you know, having that element- having a person who’s a specialized assistant tech person would be – or two, or several in a district as large as X’s would be pretty important, if you ask me. But that’s the bottom of the totem pole.

**Denise:** You said earlier that going through the school ...it was one more fight that you were not willing to go through. What do you mean by that?
**Parent:** He's in school for several months before anyone at pre-school even thought about it...it was a total focus on verbal communication for him which, with his diagnosis and physical capabilities is really not appropriate. So I think my statement about this is that the local school district SLPs are not at all prepared to even consider/or are typically aware of AAC as an option. That's why I wound up at X's (hospital) using my insurance rather than working with the school dept. However, after X (her son) had his device, the school system has purchased at least SIX additional machines very similar to X's - the same brand -for other students. So learning by example is pretty damn important with regard to the training, curiositym exploration by typical school district SLPs. I don't want to say lazy, but if someone's not really motivated to keep learning in whatever role they have in life (both in and out of schools) one might easily miss even the existence of AAC completely. Could the school system have evaluated him more quickly? Could they have had a check list to review/compare while discussing his situation? Might they have been able to help educate me as the district has so much real life experience from other students similar to X who have gone before? We're back to internal communication, development of best practices and individual responsibility as a professional in a school district - which our district is lacking. Of course I am only speaking of special education right now - however after a few years into the system I may have more to say about regular ed!

**Denise:** So can you think of anything that you would say bothered you during the process or you would have liked to see go better, with regard to getting the device for X?

**Parent:** A couple of things. I was talking about this to somebody today at—well, you know how I imagined how somebody mentioned to me first, and I was so not ready to be there. And that was three years ago, so that—you know, is understandable.
But I think that as, you know, the—our whole culture and our whole society starts to embrace technology more and more, it’s going to be easier. But I think what’s worse is that most of our providers—most of our therapists—most of my personal—X’s personal therapists and providers don’t know about this—didn’t know about this stuff before we found out about it and did it. So, like, I had one person, of all the different people, say that to me. Nobody else knew it. Like, I go to the school meeting—I was at the school meeting today, and X’s the first kid to use one in five years at our preschool. So it’s a whole new crop of therapists, teachers, and parents. So they don’t know what that—and, you know, speech—the speech department had changed—you know, they’re outsourcing all of speech now and are working with an organization to help streamline therapy delivery. All that stuff has changed, and if they’re not—and it’s expensive, so the schools don’t want to buy it. So they’re not learning about this kind of stuff; they’re trying to—they’re not pushing the learning of that; you know what I mean? Sharing the info?

The Health Insurance Funding Process – “I had to fight them.”

While the funding request was denied, the parent appealed the decision and prevailed. She was determined and persistent to achieve a positive outcome. While there were multiple steps to the appeal process, the parent reported that the insurance company explicitly stated the procedures she needed to follow. Thus, her perception of part of the process was that is was relatively orderly. However, she also stated that the process was somewhat unpredictable. She was not always certain how to proceed and she learned by “trial and error”.

It terms of people who helped her during the process, she mentioned the independent augmentative communication specialist, the previously mentioned social
worker, friends and a parent who had been through the funding process. In the following excerpts the parent described how the independent augmentative communication specialist at the local hospital helped her submit the funding application through her health insurance.

**Denise:** So in terms of who’s been involved in this process... you, obviously...

**Parent:** Mm-hmm. I mean, I had to give all the credit to Megan O’Brien at Children’s, because she’s the one who made it fun, made it exciting, made it appealing to me and my husband so that we got it; we understood it much better after that. Clear—literally, though, Megan—I—we owe this device to Megan, and she’s the one who said, “This is what you need.” And she—you know, they were willing—I didn’t even realize how much they could’ve helped with getting the school to provide it, dadadadada. They did everything for me for my insurance. And then there’s another woman named X who’s an OT, who—

**Denise:** Oh, I know X. I used to work with her. She is so knowledgeable and has been doing this for so many years, even longer than me!

**Parent:** Oh my God, she’s awesome. And I need to—actually, I was just thinking that since I’m going to write—email Megan. So I want to go down there; they’ve been very gracious that she—they have Monday afternoons and Friday afternoons; I think that they have for, like, not—no patients, usually. So they let us come down, like, at four o’clock and come bring—and with my questions or whatever I need. And they see him without having to make me wait seven months or twel—she’s booking, like, a year out.

**Denise:** So you still go for some training advice.

**Parent:** It’s—yes, yeah, just a shot in the arm, a little [laugh]—I need a little X and X face time [laugh].

**Denise:** Oh, I know.
**Parent:** The key to the funding thing, though, is that the consistency is one person covering it starting—start to finish. You can’t really pass it off and say, “You call the guy now,” because then you’re playing Bad Cop Good Cop, and that doesn’t really work very well with insurance companies.

**Denise:** Yeah, you have to be consistent and make sure you talk with the same person if you can.

**Parent:** Yeah.

**Denise:** And who paid for the Vantage Plus?

**Parent:** My private insurance actually did.

**Denise:** They paid the whole thing?

**Parent:** Yep. But I had to fight them. I called them, and I wrote them, and I sent them a 32-page fax of pictures of my son using it and showing how cute he was and smiled. And I called the guy who was doing my case every day for two weeks.

**Denise:** So first they denied.

**Parent:** Yes. And I appealed. That’s the word, “appealed.” I appealed it.

**Denise:** And what did they deny based on? Do you remember?

**Parent:** I just—I think it was just a kind of “Oh, no, we wouldn’t cover something like that. Why do you need a speech thing?” And I had to explain what his whole situation was and get all the paperwork that said why he physically can’t speak, so he needs this to speak for him—and his medical diagnosis. So then they took it and sh—and I’m not sure, but one physician has added the tech—the term “cerebral palsy” to some of X’s paperwork. And that’s a better global—X’s diagnosis is schizencephaly, and cerebral palsy is something people can get their brains around.

**Denise:** So you think that might have helped.

**Parent:** I wouldn’t be surprised—coupled with my persuasive personality [laugh].

**Denise:** I think that was probably a bigger factor, because you didn’t give up.
**Parent:** Well, the guy was such a nice guy, and the poor guy who was at Blue Cross Blue Shield [laugh]—I went and thought, “This is what else I did, okay.” And then I’m remembering this: My friend Sarah, who I met through—she worked at Early Intervention, and now she and I are good friends. She has a daughter who’s got some challenges, too. Well, Sarah got one, and I said, “Well, who do you have for insurance?” She goes, “It got covered in my insurance.” And I’m like, “Really?” She goes, “Blue Cross Blue Shield.” I’m go—but it was from a different state. So I got her [laugh] case number. I called the guy who was doing my case, and I said, “This guy—Blue Cross Blue Shield got—Illinois covered it”—or wherever the state it was—“and this is the case number, and sh—they said they—if you need paperwork to say it, but this is how they got it; you know, this is the kid that got approved; I have documentation”—you know, she said, “This is—go look up this; this is their ID number, dadadadada.” I don’t know how—whether or not they even did anything with that information, but I did say, “Other Blue Cross Blue Shields have done this in the past, so you should do this.”

**Denise:** Well, good. So they denied, and then you appealed. Did they tell you what the appeals process would be like?

**Parent:** Mm-hmm. Yeah, oh, it’s very—you know, you have to write a letter. You have to—and then if they don’t—and if they don’t—they review it and then they still don’t appeal, you can go to an in-person hearing. But I didn’t have to go there—do that.

**Denise:** Okay. So they told you exactly what you had to do at the appeal.

**Parent:** Yep.

**Denise:** Did anyone help you? How did you get this information?
**Parent:** Just through reading our insurance information and talking to reps from BCBS. Trial and error, lots of calls and making up my own ideas until someone gave me what I wanted.

**Denise:** And they paid for the whole thing, even though you only have $895 allowance for DME.

**Parent:** Yes, because I get—maybe it didn’t go under “DME.” Maybe it was under some other kind of label.

**Denise:** Did anyone else help you?

**Parent:** I had support from X (social worker) and other friends.

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**Funded but Not Implemented**

**Barriers to Use: Lack of Knowledge and Training and Financial Constraints**

In the following excerpts the parent discussed that few people who work with her son are familiar with assistive technologies. This has been a particular problem in her child’s school program. She described how difficult it has been to obtain assistive technology services at the school. She talked about how the staff are not knowledgeable about how to use her son’s speech generating device and implement the device in the classroom. The parent reported that her town and school district have financial difficulties and this has impacted service delivery. Since the school did not provide assistive technology services, the parent used her health insurance to obtain the services at a local hospital. She found out about these services from another parent. These excerpts illustrate how involved this parent is with her son’s education and how she has worked collaboratively with the school team to help them use the device with her son. Her experience with her son has influenced her in another way. She has become the vice president of a parent advisory group in her
school district. In this role she networked and advocated for her son and for other parents and their children. She stated “networking is the key”.

Denise: So can you think of anything that you would say bothered you during the process or you would have liked to see go better, with regard to getting the device for X?

Parent: A couple of things. I was talking about this to somebody today at—well, you know how I imagined how somebody mentioned to me first, and I was so not ready to be there. And that was three years ago, so that—you know, is understandable. But I think that as, you know, the—our whole culture and our whole society starts to embrace technology more and more, it’s going to be easier. But I think what’s worse is that most of our providers—most of our therapists—most of my personal—X’s personal therapists and providers don’t know about this—didn’t know about this stuff before we found out about it and did it. So, like, I had one person, of all the different people, say that to me. Nobody else knew it. Like, I go to the school meeting—I was at the school meeting today, and X’s the first kid to use one in five years at our preschool. So it’s a whole new crop of therapists, teachers, and parents. So they don’t know what that—and, you know, speech—the speech department had a changed—you know, they’re outsourcing all of speech now and are working with an organization to help streamline therapy delivery. All that stuff has changed, and if they’re not—and it’s expensive, so the schools don’t want to buy it. So they’re not learning about this kind of stuff; they’re trying to—they’re not pushing the learning of that; you know what I mean? Sharing the info?

Denise: So how have you found this out? I mean, are—how have you found all of this out about the school?

Parent: I go straight to the school department, and then I just meet—well, I’m president now of the specialized PAC, so I’ll be involved in that probably for another
16 year—18 years? How many years is it for school? Sixteen—so high school—I’ll probably be very involved in that or have to be involved at least for another ten years, if not more, because X’s going to need a para for many years, even though cognitively he’s fine. And then, you know, you—my big thing is—so my husband’s really into action movies and stuff, so I start—this is like—I’m not—I know this sounds silly, but he sees some of the stuff that they do on the movie—in the movies, and you’re like, “Oh my God,” and when I started realizing that technology is really going to help X in the long run, that’s when it kind of shocked me. It’s like, you see these robots and people with, you know, bionics—all those bionic men and stuff like that. I don’t mean it to sound trite, but you know, the truth of the matter is, we have the technology [laugh]. And you need to be able to—so networking is key. You know, you have to go talk to—like, I have a friend from high school who’s married to this guy who used to work at X University, who is a researcher in the biomechanical physical therapy kind of stuff or whatever, and he hooked—I hooked up with him and started talking to him, and he’s hooking me up with somebody else. You know, I mean, so you’ll learn about this; like, so now X has this new thing called a dynamic movement orthotic that’s a body suit and a little hand of—a little glove to help strengthen and make this stuff util—more utilitarian for him.

Denise: So you talk a lot to other parents, which leads you to other parents and different resources.

Parent: Yeah, typical parents—you know, parents of typical kids, too.

Denise: Were you surprised that the school just didn’t—they certainly weren’t the first to tell you about anything?

Parent: Oh my God, no. Even physicians’ offices; nobody knows—I mean, X’s, like, this phenomenon in the physician office. They love it. He comes in; I—you know, I write the letter, I go through the whole process of trying to get the talker, and I go
to his four-year thing, and they’re like, “Where’s the talker? I’ve got a room full of, you know, nurses and doctors coming to check it out.”

**Denise**: Amazing.

**Parent**: They didn’t know it.

**Denise**: So how have the school staff taken to the device?

**Parent**: They’re pretty – they were not necessarily gung ho, but as they’ve gotten used to it – and honestly, it’s midway through the year; they – the beginning of the school year, it was rough, because nobody – you know. They’re overwhelmed when they start school with a whole new slate of kids, even though they knew X already. I think it’s great now they’ve got the classes kind of under control; the teachers, the parents, the therapists – we had a great meeting today, where they’re all like they love it, they don’t use it as often as they could, or they need some other ways to use it so that it makes it more useful, like for the PT and the OT. How can we make it so that it can do their work without him needing to necessarily have access to it every second? But what they’re going to do now is offer him choices, and he can answer those choices- make those decisions himself, like they do with other kids, and then put it aside until they need to ask him for the next activity, which – you know, that was just a little brainstorming that took place today!. But it would never have happened if I hadn’t had everyone together.

**Denise**: And did you call the meeting, or did they?

**Parent**: I did, Yeah, it was just a progress; I haven’t done one since... And his IEP is due again in March, but that’ll be the transition plan to kindergarten so.

**Denise**: You mentioned they were not gung ho in the beginning. Did they tell you why? How has the school speech pathologist been involved?

**Parent**: Honestly, I think that it all has to do with each person/teacher/para and yes, the speech pathologist having to learn something new. That sounds basic, but if
you’re used to doing things one way, and this new technology comes out and you have to change not just one thing, but really every single way you do things, perhaps a bit dramatic, but you get the picture, some are very resistant. In our district in particular, our therapists are really strapped and pushed hard which is really unfortunate, but special ed is the "red-headed stepchild" who is treated differently. We’re working to change that though! And the good news is that they now have contracted to an outside clinic, the one X and others in school system go to and the pre-school SLP is on board. We'll see what happens with K-12! I have big fears honestly as we get ready for K.

**Parent:** Well, like I mean, new technology – it’s a lot of work, and they’ve got a lot of work themselves dealing with what they have to deal with on a daily basis. So, I’m not going to say they do it wrong; they just – you know, there’s some people that embrace technology; and there’s some people that don’t. And I think that the school system needs to embrace technology, no matter what. And they do pretty well by having their computer labs; yadda yadda yadda. Then it comes to my situation, you know for kids with special needs, the technology aspect of things you know, it runs the gamut from an orthotic or a prosthetic or kinesio tap or any of that stuff to a talker. So you know, having that element- having a person who’s a specialized assistant tech person would be – or two, or several in a district as large as X’s would be pretty important, if you ask me. But that’s the bottom of the totem pole.

**Denise:** Do they have somebody?

**Parent:** They have a woman who’s now currently-they haven’t had any-my first request went in May 2006-2007 and today is the first time I’ve met an assistive technology person.

**Denise:** So what do you mean by you made a request?”
**Parent**: I—it was in the IEP to request an assistive technology eval.

**Denise**: Ah, okay, so you requested an eval.

**Parent**: Because they didn’t have anybody—you know—the special ed. department in X was a mess for awhile, and it’s back—it’s coming back. But they still don’t have full staffing like, you know—they don’t have full time autism specialists, and they have two full preschool classes—three, now, full preschool classes of, that run twice a day. But there are 30, 60, 90, there’s 90 kids. They don’t have a specialist. The specialist kind of stuff gets thrown to the bottom of the list.

**Denise**: And it wasn’t until just recently that you met this person?

**Parent**: Today. They just—they have—they don’t even have a full-time person; they have a teacher, who teaches in the RISE program, which is a significantly, cognitively, and physically delayed kid. They have a STRIDES program that goes K through 12, which—ugh, don’t get me started on that one, but it’s like a segregated environment for really significantly challenged kids. She’s a RISE teacher, and she has agreed, after many months of begging and pleading, to do some part-time—one a month, or one every other week, of assistive tech evals to help move this along, because they can’t find anybody, supposedly.

**Denise**: So how do you think that sits with the law?

**Parent**: That’s completely against the law. Everything’s complete—the way that they’re operating right now is completely against the law, but they get around it because, well, A, who knew the—but did you know that the principals hire the paraprofessionals so that any training that should be done for all the paraprofessionals gets roundabout, because the principals are hiring it and they hire a permanent sub and say that the job is posted? So then none of this is, of course, out loud—said out loud, but we’ve observed this. So, like, the PAC is meeting with each of the principals of the school to get to know them and to start establishing a
relationship so that—you know, I don’t want to go in with both guns, you know, firing. I want to try to build a rapport, get people to understand these things, and that—although they can work around it by hiring somebody for ten dollars an hour or with no training or very little schooling themselves to be your para, when it’s supposed to have this, this, this, and this—that they need to—instead of just getting by, they need to actually do the training. They need to make this program a very—a better program. So I know, you know, and I understand that it’s so hard, because you understand for the—you know, I have my own personal budget issues. You know, like, when you look at the city issues—when you look at the school department issues, then you look at the city budget, then you look at the state budget, you know, you sort of—I’m not trying to rob Peter to pay Paul, but, like, the—even the states are just—you know, let’s hope that the stimulus package that has an increase now in it for special education services, from eleven to seventeen million, which is peanuts compared to what it’s taking—but let’s hope that passes, you know. Let’s hope they don’t rip that part of the budget out—or the package out.

Denise: Has anyone helped you with the school issues?

Parent: Largely all the help I’ve gotten are through other moms of special education kids and the wonderful X (case manager). She knows everyone and always, always helps me out when I need her. I fortunately like to get together with people too, so we often have our subcommittee meetings or girls nights out walking to vent, share, boast. I’m really blessed to have found some great folks.

Denise: You mentioned you were vice president of a PAC? How did that happen?

Parent: I went to the meetings as soon as I heard about them in the Fall 2008. There are so few parents involved it’s amazing. They were trying to combine the special ed PAC with the English Language Learners and Title 1 PACS which I felt was
really inappropriate so I was vocal. That led me to be nominated by the other 6 women there into becoming the vice president.

**Denise:** What does that involve?

X; I would love it if I could really help get more parents involved and get us either on the school committee, the city council or even just an active advocate, but that’s pretty hard to do all at once. We meet monthly and there is a core group of about 8 moms. Half of us go to a subcommittee meeting at a local pub after to vent to each other. This year, though, our focus has been on reaching out to the principals. Did you know that in X they are really czars of their own little kingdoms who do all the hiring and pay for training of all our paras? Talk about power! It’s our effort to bring us together r to serve our kids properly while maintaining civility and fortunately its stating to work, which is cool. We are hosting the first annual Appreciation Celebration on June 11, which is what we’re in the throws of planning right now. This is really cool. We’re inviting parents to nominate a caregiver or person their kid has liked or been treated especially well by for a big dinner cooked by our vocational special ed high school students! How cool is that? I’ve also invited the Mayor, the school department... well, many of them... the city council, the school committee members, the principals, and of course all the therapists and paraprofessionals. Hopefully they’ll come. Well, not all, perhaps, but the winners anyway!

**Denise:** You mentioned you talked with other parents, parents of kids with and without special needs. Where do you meet all of these people?

**Parent:** Clearly I’m blessed with the gift of gab. All of which I learned from my parents. I just talk to everyone about everything. People, and I mean this, come out of the woodwork to help X. Once he meets someone, they just do their best to help us with whatever.
Denise: You told me about the program for families at X but I did not realize X was getting private therapy there. That's great! I'd love to know more about when you started there and why?

Parent: We started at the clinic in Sept. because I found out from another Mom in the PAC that her son does private speech there. They actually have a HUGE waiting list for regular speech, but there are two therapists, X and X who are all about AAC. It's awesome! They love doing this and are literally - THE - place to go in Western Mass to get any insight. Well, there is another person SLP who has her own business, but I found X first. I went because I had no real focus for X nor was I able to go weekly to X, which I considered, and the school SLP didn't know what to do with us either.

Denise: Is Blue Cross paying for it?

Parent: BC is paying for the standard number of visits per year - I think it's now 12. We also have that company which monitors the payments to BC, and they pay the difference between the high deductible that X’s company’s plan allows for. Then Common Health has been paying for the rest of the visits. So far, so good. I must admit that Common Health is worth every penny we pay for it.

Denise: Has the speech-language pathologist there collaborated with the school speech pathologist?

Parent: YES! Thankfully, our participation has helped forge a contract between the X Clinic and our school system! Get this great development - X and X had started a small summer camp last year run out of the X school district for AAC users. This year they wanted to expand it. Well, unfortunately - X is really not supported well apparently by the Medical Center, so they weren't going to be able to do it. Then b/c of our connecting the school district and X, it will now be a collaborative effort between Skinner and the X Public Schools! It is going to run for 5 weeks, at the
place where X’s summer program is run (it's literally an accessible (mostly) outdoor camp!) Isn't that cool? I am so excited!

**Parent’s Perception of Her Son’s Rights Under the Law**

The parent reported that she believed her son has a “right” to have a SGD. Based on the narrative, she uses the term “right” in a rather general sense, referring to what he is was entitled to, though she did not mention a specific law. In terms of her knowledge of the law, specifically IDEA, she mentioned she had little knowledge of the formal law. What she knew she learned from other mothers. When she needed to learn something more, she contacted a local advocacy group.

**Denise**: So if you think back, or even think about it now, what rights do you think X has under the law in terms of getting a speech generating device?

**Parent**: So I’m –my understanding of the law, is, like, you know, his right – he -it’s part of his –and he has a right to have one, like, the-you know, the -technically, the state should pay for it. If it’s really part of his-you know, if it’s a device that is necessary for him to become a productive citizen. That’s my understanding, which may or may not be accurate when I think about it.

**Denise**: What law do you mean?

**Parent**: I’m not sure.

**Denise**: So....Let's say a parent was having disagreements with the school about getting a communication device for their child or having teachers and therapists use the communication device appropriately in the classroom. Sound familiar? What rights would you tell them you have as a parent under IDEA and where did you get your information?

**Parent**: I get the bulk of my info from other moms. Or I apparently make it up the way I see it, which is really all about common sense. I also ask the director of Mass
Family Voices for help b/c she's a stickler to details and clearly knows and understands (emphasis) what IDEA states. I know that there is a law and I just presume that the things I want for X are included in it. So I'm embarrassed to say that I'm really not up to par on the actual law - although I do have a link to it on my favorites. And any other parent that comes to me with a question about it - if I don't think the request is outrageous or wrong - I absolutely tell them that it's the law - again not really knowing exactly if it is. I figure that if it's not actually part of the law, the school will know and fight back. Then I'll read it to find a way to make it what I want....

**Breaking Down Barriers When Applying for Common Health Insurance – Networking to Obtain Information**

In the following excerpts the parent described how she had difficulty obtaining health insurance benefits for her son through Common Health of Massachusetts. She learned about Common Health through the previously mentioned social worker. She recognized her son might qualify for this insurance. She also recognized that this insurance might cover equipment her son needed. This was important to her because her durable medical equipment benefit under her employer-based health insurance plan was limited to $895.00 and this amount would cover a small amount of the cost of the SGD. In terms of applying for Common Health, the parent reported her application was denied several times. From a listserv she learned about a community meeting with the Director of the Department of Public Health. She thought this person might help her obtain the insurance so she decided to attend the meeting. The parent reported this strategy was effective.
The parent also described how she obtained information about Common Health insurance application process by talking with professionals and parents at a support group. She described how one of her friends helped her with the Common Health application. She stated this friend had experience filling it out for one of her own children. She also obtained emotional support from some of these interactions.

**Parent:** So I was having a nightmare getting it—we ended up getting Common Health, which is the supplemental disability insurance through the state—through Mass Health. And they kept denying us, and I’m like, “I don’t want MassHealth; I want Common Health. I’m going to pay you for this. I just want it for equipment for my son,” because I knew he was going to need the chair and, for the future, he’s going to need more equipment. And my personal insurance, you know, DME, is—covers only $895, and all this medical equipment is thousands and thousands and thousands of dollars. So—

**Denise:** So they thought you were applying for Mass Health?

**Parent:** Right, and I—even though I filled everything out wrong, it was just one thing. So I’m, like, getting annoyed. So I hear that the new Director of Public Health—Depart—Director of the—or Department Head, whatever his name—title is, John Auerbach

**Denise:** Oh, I know who that is.

**Parent:** From Public Health—what a great guy! So I hear he’s going to perform—he’s going to be in Worcester like, in—just south of Worcester. So I’d say, “All right.” I—it comes on “Mass Family Voices,” which is a listserv and everything. So I hear—read this thing, and I go to this meeting. I sign up, and I go to this meeting, and I drive my little sorry self out to Worcester and I’m ready to do battle.

**Parent:** And it’s a CHNA meeting, C-H-N-A, Community Health Network Alliance or something like that, for south-central Massachusetts. When I go, there’s got to be 40
people there, because, you know, they’re meeting John Auerbach, right? He’s a good
guy. I’m the last person, oddly enough, to speak. I’m in the middle of the room; it
shouldn’t happen that way, but it did. And I—you know, at the—I said, “I’m a
parent; I didn’t know this was really a provider thing, so I apologize. And I’m from X,
Mass; I’m not even part of your district; I apologize. But I can’t get my son to get
approved for Common Health; nobody knows what the hell Common Health is. And
you know, I wanted to come meet you, because you’re the leader, and you should
know that this is ridiculous. And I’ve made 17 phone calls, and no one knew—of the
17 phone calls, 16 did not know what the hell I was talking about. And I’ve lost—my
case is lost, and it’s been—I’ve been denied four times.” So he, of course, lovely
John Auerbach, the most gracious kind man, says, “Oh, I’m so glad you’re here,”
and—you know, I said it was great; it was a wonderful thing. But what was most
enlightening for me is that all these providers start complaining how parents don’t
attend. So finally—you know, I said my piece initially, and I was keeping quiet,
because I didn’t want to just jump in and say, “Oh, great idea,” or, “Bad idea,” or
whatever. But finally I said, “You know, at the risk of offending each and every one
of you, we love all your programs; we just have some nights where we can’t go out
one more time, or we’re working and we can’t go to your program in the daytime, or
we can’t find coverage. It’s not that we don’t like it; it’s just that sometimes you
want to just be a family and sit at home and not go out to a meeting in the middle of
supper.”

**Denise:** Isn’t that the truth.

**Parent:** And they were so, like, “Well”—you know, one group came up and kind of
gave me grief, and the other people were like, “Okay, thank you for telling us,” and
patted me on the back, but I was just like, “You know, it’s”—I did not know the
million programs all—you don’t know all the programs that there are, because there
are so many things going on all the time, there’s not one general calendar. It’s always one giant Google calendar that all these programs had to put their stuff on, and they’d realize what the conflict was.

**Parent:** And finally, after I met John, the next day I got four—I got two calls from two different people [laugh], and then I got calls from those people until it got solved, which was less than a week later [laugh].

**Denise:** Wow. You got to the right person. And you knew that you needed to go to that meeting.

**Parent:** I know it was—it did work for me. I’m sure other people do a better job of it, but I needed that support.

**Denise:** How did you learn about Common Health?

**Parent:** From X (social worker). She pushed me to do it and I’m, so glad we did!

**Denise:** How did you learn about the Mass. Family Voices listserv.

**Parent:** I learned about them from X (social worker) from the Western Regional Consultation Program – a program for kids with more complicated care – medically that is. She was introduced to me by early intervention. She’s amazing. She’s really an amazing woman. She knows everybody, and she knows, like—you know, so when I got denied from Mass Health for the fifth time, before I got—gotten—she gave me the—you know, she hooked me up with the right person to get the local Springfield office head. And I called him up crying, and he fixed—you know, he started working on it—so, you know, like that kind of stuff. She knows everybody.

**Denise:** Did anyone else help you?

**Parent:** My friend just listened to me as I cried when I kept getting denied. But another friend of mine sat down with me, and we went through the application together, because she had done it before. So she said, “No, fill this in; write this; write this,” because it’s so daunting; it’s 12 pages.
Denise: For the Common Health.


Denise: Twelve—yeah, it’s like a book.

Parent: I’m a college graduate, and I couldn’t—I felt very daunted by it.

Denise: So a friend helped you fill out the application, and then—how many times did you have—did you go back and forth with this thing? You said five.

Parent: My application was denied five times.

Denise: You mentioned Massachusetts Family Voices. How did you learn about that organization?

Parent: from X form the Western Regional Consultation Program. It’s a program for kids with more complicated care-medically.

Denise: How has it helped you

Parent: They have a lisserv that share info between parents and providers. I get so much info about other services or organizations, and ideas for our situation. In addition MFV runs these really cool topical conference calls that you can listen in on live, or play back after. I love them.

III. Perceptions Compared to Positive Law

IDEA: AT Devices and Services /Individualized Education Program

Though the parent opted to go through health insurance for funding, the parent thought the school might be responsible for providing a SGD. According to IDEA regulations, if another non-educational agency, public or private, is obligated to provide the funding by state or federal law, then the public school is not the primary payor (34 C.F.R. §300.154 (b)(1)(i)). Also, the public school may seek reimbursement from the non-educational agency if it fails to provide the special education or related service (34 C.F.R. §300.154(b)(2)). These regulations have
been adopted by the state of Massachusetts’ special education regulations, by reference (603 C.M.R. 2801). The child had health insurance which did fund the device. The parent’s perceptions were consistent with IDEA regulations in that the public school may have provided the device, though it was not obligated to do so. In terms of assistive technology services, initially the parent was not aware that the school might be obligated to conduct an assistive technology evaluation in order for the child to receive a Free Appropriate Public Education (FAPE) (§300.106). Over the past several years the parent repeatedly requested an AT evaluation from the school. The parent also requested training to help her son use the device in the classroom. She stated that the school had not provided this to her satisfaction. She thought that staff did not have the knowledge and skills to implement the device. Under federal and state regulations the school is obligated to provide assistive technology services, which include an evaluation and training in order for a child to receive a FAPE (34 C.F.R 300.6, 300.42, 300.101, 300.105, 300.320, 300.324; 603 CMR 28.01 by reference). Therefore, if accurate, this is not consistent with IDEA regulations, which have been adopted by reference by the state of Massachusetts in its special education regulations.

The parent also reported that the request for an assistive technology evaluation was written into the child’s IEP but the school had yet to provide the evaluation. If accurate, this would not consistent with IDEA regulations, which have been adopted by reference, by the state of Massachusetts (§§300.320, 300.324, 603 CMR 28.05).

How has the parent responded? She went outside of the school system and obtained training through her health benefits program. She also continued to advocate for her son to receive an AT evaluation and training to use the SGD at school through
informal dispute resolution measures - by meeting with his teachers and speech-language pathologists.

Advocating for Rights

Another question to consider is whether health insurance and IDEA enabled the parent to advocate for her son to receive some AT rights. I believe they did. In terms of health insurance, while the parent did not talk about specific laws and regulations, she asserted her rights and her son’s rights in order to obtain benefits. She expressed knowledge of her benefits, navigated complex systems and was successful. In the state of Massachusetts Blue Cross Blue Shield plans have paid for speech generating devices. Her exact benefits under this employer-based plan were not known and when asked how it was covered, the parent was not sure. The parent reported that her DME benefit was $895.00 and the device retailed for $7,000 dollars, though private insurers typically pay less than that amount. In terms of training to use the SGD, the parent believed her health insurance would cover the cost of therapy. She obtained these services through a local hospital and the services were funded by her health insurance. She did not report any problems with her health insurance covering these services. In terms of benefits under Massachusetts CommonHealth (130 C.M.R 505.004), based on the state’s eligibility criteria, her son may qualify for services. The parent pursued this because she knew her son might need the benefits. She reported the process was very difficult because the staff at the Department of Medicaid thought she was trying to apply for regular Medicaid, which her family did not qualify for. Though the process for applying was difficult, she persisted and prevailed.
In terms of IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations, a parent has rights in four major areas: prior written notice (§300.503; 603 C.M.R. 28.05, 28.05), consent for services (§300.300; 603 C.M.R. 28.07), developing the child’s Individualized Education Program (IEP) (§§300.320, 300.321, 300.322; 603 C.M.R. 28.05) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 603 C.M.R. 28.08). Consistent with IDEA regulations, in Massachusetts a parent may resolve a dispute in several ways: informal measures (as this parent did), through mediation, through a formal complaint by contacting the Office of Program Quality Assurance Services, by requesting a due process hearing, and if necessary, by appealing a hearing decision to a state of federal court (§§300.500, 300.529; 603 C.M.R. 28.08). In this case, the parent asserted her rights to challenge decisions primarily in an informal manner - by talking with teachers and administrators, insisting the school was not meeting its obligations – rather than invoking the formal law.

39 http://www.aacfundinghelp.com. The Assistive Technology Law Center reports this is not a complete list. It spans from 1990’s-2003 and is based on information that some assistive technology companies provided.
Case Analysis #4

Demographic Information

| Gender and age of child       | 7 year old male             |
| Diagnoses                    | apraxia of speech, per parent |
| Type of School               | public                      |
| Interviewee                  | Mother ("Ms. Dean")         |
| Race                         | Caucasian                   |
| Martial Status               | Married, lives with husband |
| Educational level and vocation of parent | Completed high school          |
|                              | Associate degrees: dental hygienist, and nursing assistant |
| State                        | MA                          |
| SGD                          | Vantage                     |
|                              | Prentke-Romich Co.          |
| Funded by                    | MassHealth                  |
|                              | Initially denied by Tufts   |

I. Case Facts

This is a 7-year-old boy with a diagnosis of apraxia of speech, per his mother. The mother reported that the child was born with a tethered spinal cord, which resulted in developmental delays. The child received early intervention services, attended a public, integrated preschool and is enrolled in a public school in the first grade. He received speech-language pathology and occupational therapy services at the public school.

The parent began having disputes concerning her son’s communication needs when he was in early intervention. The parent disagreed with the speech-language
pathologist's treatment approaches and the frequency of treatment. When the child entered preschool she began having similar disputes with the staff. The preschool did not think the child needed a speech-generating device and they refused to include it in the child’s Individualized Education Program (IEP). The parent removed the child from the preschool and asserted her due process rights. The parent prevailed.

While the parent was having disputes with the Early Intervention (EI) team, she hired two private speech-language pathologists to work with child and to conduct an independent augmentative-alternative communication (AAC) assessment. Private funds and health insurance funded these services. Based on this evaluation she submitted a funding request for a speech generating device to health insurance. The parent had some difficulty obtaining funding for SGD. Tufts initially denied the funding request. She also submitted the request to MassHealth which funded the device.

II. Analysis - Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? Where do families obtain information about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?
**Perceptions of the Law**

The narrative revealed that the law was a significant part of this parent’s everyday life and the main theme that emerged was that the law empowered this parent to advocate for her son’s rights and assert her rights. The parent’s perceptions of the law were shaped through interactions she had with a variety of people and by personal factors. These interactions and personal factors influenced the decisions she made and determined whether she invoked particular rights.

**Empowered by the Law and Up Against The Law**

The narrative revealed that the law was prevalent in this parent’s daily life because the she faced numerous challenges as she advocated for her son to receive assistive technology devices and services that she believed he was entitled to receive. The law enabled her to think about her son’s rights, talk about these rights, assert her rights and obtain his rights. The parent had disputes with her child’s teachers and therapists and health insurance providers. Each of these disputes led to a variety of actions she took to resolve the grievances. I use the term “up against the law” to describe these challenges, which I have adopted from Ewick and Silbey’s (1998) sociolegal research.

The parent used the law to resolve grievances, formally and informally. She advocated through informal dispute resolution processes. She talked with therapists and teachers about devices and services that she believed her son needed, based on her knowledge as a parent. I refer to this orientation to advocacy as *relational* and I adopted this term from sociolegal research conducted by Engel (1991) and Barton (2004). When these methods failed, she used the formal law to resolve the grievances. Through advocacy training she gained knowledge about the formal law
and this knowledge enabled her to advocate for her son. She also obtained knowledge by talking with other parents on listservs, through Internet research and through interactions with therapists and vendors. Personal factors influenced her decision to invoke the formal law. Her brother, an attorney, encouraged her to obtain legal help. She hired an attorney with financial help from her family. As she interacted with the attorney, she gained knowledge of the formal law and the narrative revealed that the parent thought that she played an active role using the formal law. Therefore, the law helped and hindered this parent at various times during the process of obtaining assistive technology devices and services. Several themes were noted and are discussed below.

**IDEA: Lack of Confidence in the Law/Not Implemented as Intended**

For this parent there was a difference between the law as written and the law as implemented. The formal law was not determinate. In other words, while the laws and regulations were there, she felt the law was not implemented as intended. As the parent interacted with various professionals, she developed a lack of confidence toward some people who implemented the law. She thought that some professionals who worked with her son were not adequately trained to provide assistive technologies and services that she thought her child was entitled to receive. The parent responded by seeking services outside the school system and by using the formal law to resolve grievances.

**Perception of Assistive Technology Rights: Broad Legal Rights vs. Rule-Based Rights**

The narrative revealed that the parent thought about her son’s assistive technology rights in two ways. She thought about these rights under law as rather broad legal
rights, based on what was just and fair, such as a right to have a device because her child had a disability. The parent also thought about assistive technology rights based on the rules of law. She used the language of the law when discussing her child’s rights under IDEA to have an assistive technology evaluation and to have a device to access the curriculum, although she recognized that the school may not be obligated to provide a state of the art device for her child. As noted above, she obtained knowledge about the law by taking advocacy classes and this knowledge enabled her to advocate for her son.

**Perception of Health Insurance Benefits and the Funding Process:**

**Confidence in Benefits and a Manageable Process**

The parent expressed confidence that her health insurance would cover a SGD for her son. She mentioned that she believed the device was medically necessary and therefore health insurance would fund it. She chose to access her health insurance benefits for several other reasons. As stated above, she did not think that early intervention was obligated to provide a device. Furthermore, she wanted ownership and control over how the device was used. In terms of the process for obtaining the device, she described multiple steps, multiple people and multiple documents but overall it was sequential and manageable. While Tufts health plan denied her request, she had a positive outcome with Medicaid. She attributed the positive outcome, in part, to the help she received from the independent evaluator and the vendor.

**Personal Factors: A Powerful Combination That Enhanced the Role of Rights**

Within the narrative the parent discussed several factors that may have influenced her perceptions of the law and the decisions she made. She had a learning disability
and she recalled how her mother advocated for her. Her brother, an attorney, advised her early on to get legal advice in order to advocate for her son. Her parents were very supportive and advised her early on to obtain private speech-language services for her son. The parent has an older son who has learning disabilities. He received special education services and she had disputes with this child’s early intervention program. Thus, when her younger child needed services, she was familiar with the program. Based on the narrative the parent thought that these factors helped her advocate for her son. They helped her navigate bureaucracies, instilled confidence and provided financial support.

Excerpts from the narrative illustrate these concepts.

**Asserting Rights Under the Law and Up Against the Law**

**Networking Fostered Advocacy**

In the following sections of the narrative, the parent described many disputes between herself and educators about services for her son. These sections of the narrative revealed how the parent talked with a variety of people to obtain information. This information helped her advocate for her son.

Here the parent discussed how she learned about early intervention services because her older son received services through this program. She found about early intervention services by talking with another parent. After that, she knew she could self-refer her younger son to the Early Intervention (EI) program and she advocated for him to receive these services.
**Denise:** Tell me a little bit about how you got connected with the Early Intervention Program (EI).

**Parent:** EI was—because of my older son, who was delayed in many things, at six months of age for my older son, he wasn’t doing any of the developmental things he should’ve been doing, like rolling over, sitting up independently—so my pediatrician sent me to our local children’s hospital to have a PT (physical therapy) assessment. And that PT assessment—the PT made reference to early intervention. Never did anyone—my pediatrician or this PT person—tell me that that’s actually a service—you know, an organization. I just thought it meant “intervene early.” So I was working one day, and I had a patient in my chair, and I inquired what the mom did for work, and she was a physical therapist that worked in a school district. So I’m like, “Oh!” So, you know, I inquired to her, saying, you know, “My son’s, you know, blah-blah-blah”—I don’t know how old he was, but “he’s not, you know, rolling over yet.” And she says, “Oh, you should get Early Intervention.” And I said, “Yeah, I know; I think we should intervene early.” And she said, “No, it’s a program that they come and service and help your child.” I was, “What?” So she said, “In fact, I can tell you the phone number, because I used to work there.” So she gave me the phone number; I called right from my office that day and self-referred myself to EI for my older son

The parent discussed the dispute she had with the early intervention team about lack of speech-language services for her son. She persistently advocated for her son to receive these services she felt he needed and navigated a bureaucracy in order to obtain these services.

**Parent:** Originally what happened was, my EI provider was not providing me with a speech and language pathologist, and I thought my child needed some of that—had
that expertise firsthand instead of going through, like, an educator that would talk to the speech and language pathologist.

**Denise:** So that’s what the problem was?

**Parent:** We did have—yes; originally, we did have a speech and language pathologist, and she left the EI agency that I was working with. And that’s when they said that they could provide an educator in place of the SLP. And I adamantly said no, and I called a person within my EI system, and I don’t know exactly—she was on the state level—what her title was, but her name was X.

**Parent:** I believe, off the record, someone at EI told me that that’s the next level I could go to. And I couldn’t tell you who at EI did, but that’s, I believe—was someone within the EI agency that said, “Well, you know, if you’re not satisfied, you can appeal to the next—you know, to call this person, X.

**Denise:** So you asked somebody within EI.

**Parent:** Yes.

**Denise:** Okay.

**Parent:** And it was—and it might have been even the director, to be honest with you, because when they weren’t going to give me an SLP, I had to speak all the way up to the director. And that was in November of—2001, 2002 one, two—2003. It was about a year before he actually turned three. It was around Thanksgiving time, because the director was going away and she wouldn’t be able to talk to me during Thanksgiving. And I called her early in the morning and got her one day and—unexpectedly in the office. I was just going to leave her a message. When I talked to the person at the state level of EI, X, and explained my concerns to her—that I had another child that was in EI and had speech services and, you know, I just knew it was different. Even though he was delayed in speaking, it was way different than that, and I needed someone that had this information firsthand. And after I talked to
her for about 40 minutes on the phone, she asked me if it would be okay for her to advocate for my son, and I said, “Of course. Please do.” And lo and behold, once that happened, what they originally did was send out an SLP to do it like an assessment with the educator, and it was still going to be just the educator. And I think I placed another call to that lady, and she actually called again to advocate on my son’s behalf, and I got an SLP through EI that came to the meeting—they actually came out for individuals’ family service plan meeting. And I had—I didn’t have the director, but I had the two people right below her come out to my house with my case manager. And I’ll be honest with you: it was very intimidating for me, because I never had that ever happen before—that they were dotting all their I’s and crossing all their T’s.….  

**Denise:** So why did you think they all came?  

**Parent:** I think they wanted to make sure that they were doing their job correctly and that I was holding them accountable, I believe. I mean, I had my older son in EI; and he had several of these Individual Family Service Plan meetings; and never did anyone, you know, from the higher-ups come out. And I—part of me thinks they wanted to intimidate me. I hate to say it like that, but…  

**Denise:** I understand.  

**Parent:** But I didn’t care. My kid needed this, and—so when they finally sent out someone, I think it was, like, the beginning in—I want to say… maybe the week before Christmas or January. They—she actually was coming out twice a week for two hours, and—you know, so I’d go from no SLP to twice a week. You know, so someone got the gist of the need—at least I think so.
During this time her parents advised her to hire a private speech-language pathologist. These excerpts illustrated how the parent networked with other parents to obtain information and services.

**Parent:** When all that was going on, my parents stepped in and said, “Look, you need to have a speech and language pathologist. You need to find someone.” So I was a member of the Mothers Club in Newburyport....

**Denise:** And what is that?

**Parent:** Newburyport’s Mothers Club was organized about 11 years ago, and it was a group of mothers that got together that would meet monthly. And way back then, they had a newsletter, and they also had different speakers come in and speak monthly for, like, a month night out. And in this newsletter, you could pay for advertising, and there was an ad that a mom had placed that was an SLP, who I—you know, I actually saw her at a music class that was posted on the wall. And she was just accepting new patients. She had just had her second child, who was—I think when I called her, her baby was a week old. So I had to wait, like, four weeks or so before she was able to see Tim at first—do the intake. And I’m pretty sure the intake happened—I want to say it happened in November or early December. X’s birthday’s in October, I think, so October, November, December—so that would’ve been right. So she did her initial assessment, and we met with her—I think she did her initial assessment in—I think she did over two sessions, and then I went back to go over the findings of her evaluation. And then she started working with Tim maybe—I think she had two sessions with X, and at—the third session is when she asked me if anyone ever mentioned apraxia speech. And I said no, and she said, “Well, don’t panic, and don’t go home and look it up on the Internet, but I think that’s what he has.”

**Denise:** So she was a speech therapist.
**Parent:** Yes.

**Denise:** Okay. And so how did you know about this moms group?

**Parent:** A neighbor of mine was a member, and she had a child around the same age as my older son. So it started out being—it was a mom that moved from California that had it in her neighborhood, and she started it here. And now they have—I think they have over 300 members.

Here the parent described another dispute with early intervention program and the parent asserted her rights. She “fired” the speech-language pathologist (SLP) because she felt the SLP was not doing her job.

**Parent:** And all the while, I have the EI person coming two hours to my home, as well as going an hour for outside therapy. And I sat in on all the sessions, pretty much, and I could see that it was—the approach was totally different. So I kind of inquired a little bit, and my private speech therapist was very professional in her response to my questions. And actually, I encouraged them to speak to each other, because I thought, you know, we’re all working for the same good here. And when that happened, things seemed to change with my private speech therapist. She seemed to be more—I think things changed in the regard that she was educating me more—almost, like, quicker. She was giving me more information firsthand and, you know, me looking up stuff and asking her. The EI person was very rigid in her approach. My son had to sit at the kitchen table to work with her. My older son—if he was home and he wanted to participate too, he had to sit there, but he had to sit there the whole time; he couldn’t just come for the beginning and then leave midway. Yeah, she was really rigid. So when she talked to my private therapist and they sh—I shared the notes back and forth, it didn’t seem like he—even though he was getting two hours of EI, it really wasn’t—it wasn’t appropriate. I mean, there’s
no polite way of saying it: It was not appropriate for apraxia. So what happened was, we’re going along with the private speech therapist, we’re also going along with the EI therapist, and I think it was in July that I fired the EI speech therapist. And I’ll be honest with you: I didn’t realize how much stress this EI person was bringing into my house, but the minute I got rid of her, it was like a whole weight was lifted off my shoulders.

Invoking the Formal Law to Obtain Rights - A Powerful Combination of Personal Factors and Networking

The following sections of the narrative revealed how the parent began to invoke the formal law to resolve her grievances. During this time the child turned three and entered the public school system. In preparation for her first meeting with the school, she hired an attorney. Why did she do this? Her brother, who is an attorney, recommended this to her. At the meeting, the school recommended a 504 Plan which she rejected. The school then offered an IEP but the parent rejected it twice – initially because the school offered group rather than individual treatment and the second time because the IEP did not have measurable goals and did not include the treatment she felt the child needed. How did she learn about the law? She learned about the IEP from her attorney and other parents on listservs. Also, she began taking advocacy training through a local organization, which she learned about from another parent in a support group. At the meeting with the school she brought information she obtained from her private therapist, through Internet research, advocacy training and a letter from her son’s physician. Her lawyer was present.

Parent: And then the IEP meeting occurred—we had one in June, before he turned three, the last day of school. But I rejected that IEP in totality.
Denise: So tell me about that.

Parent: Yeah. It wasn’t appropriate. It didn’t have measurable goals.

Denise: And how did you know, like, it needed measurable goals?

Parent: I had—at the time, I didn’t know what I didn’t know about EI—about the school system, about IEPs. So I started researching it.

Denise: But “it” meaning...?

Parent: Well, I didn’t know what an IEP was. And on a listserv that I was on—there’s actually a listserv in Massachusetts and New England, “Apraxia.” There was a woman on there that lived in my state who was kind enough to forward me her child’s IEP and told me, you know, “It’s very individualized.” And I didn’t get that then. I totally get it now, but I’d never even seen an IEP. So she shared her daughter’s with me, and one of the things that I looked at—it was—there—you could measure it. It was concrete; it was black and white; and at the end of three months or whatever, you could determine what the results should be.

Denise: So you had a good example.

Parent: I did. But I also, at that time, started taking—in Boston, there’s a Federation of Children with Special Needs, and they have advocacy workshops for parents

Denise: And how did you find out about them?

Parent: I don’t know. I’m trying to remember. Maybe through someone on the support list?

Denise: OK

Parent: Yeah. And so, they offered this parent advocacy program, so—I should back up a little bit. At my first IEP meeting, or qualification meeting, my parents paid for a lawyer to be present.
Denise: So tell me about that. Why do you think they did that? Even before you rejected it, right?

Parent: Yeah. My brother’s an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help X, and that he didn’t know them well enough, but there were lawyers that specialized in it. And I called the—actually, how did I get the lawyer? Oh, I know. The lawyer took the class that I took through the Federation, like, the year before, and one of her clients that she helped out pro bono, which you have to in the beginning—is that she actually worked with someone that I knew whose child had apraxia—or nephew had apraxia. So I got her name. She gave me the lawyer’s phone number. The lawyer actually had a child that had apraxia speech, so she already knew about apraxia, so I didn’t have to explain what it was.

Denise: So let me see. Your brother, who was a newly practicing attorney, knew that there were laws—special education laws, and he wanted you to have that information, and he thought the best way would be to have an attorney.

Parent: Right. He actually came, too, to my meeting.

Parent: In the beginning of that meeting, they spent 20 minutes saying that he should be on a 504 plan. And here’s a kid who’s three years old, or going to be three years old in two months, who has 12 approximations. I mean, it was ludicrous; I have no idea—well, I do now know why they did that, but it was a gross waste of their time and mine.

Denise: So you were glad, overall, that you had that support.

Parent: Absolutely.

Denise: And your parents—were they there?

Parent: No.
**Denise:** No, okay. And so, you went to this meeting, and they—you rejected it, because they wanted a 504 plan.

**Parent:** No, I rejected the 504 plan, but then they went right into an IEP to see if he was—you know, he qualified, because he had a neurologically based disorder. What happened after that is, they really just wanted to give him a half-hour—if I remember correctly, a half-hour small group instruction, as well as the two half-days of preschool, which was, like, two hours and 40 minutes of preschool.

**Denise:** This was his IEP, correct?

**Parent:** Yes. And I said, you know, “He needs one-on-one. It doesn’t—it’s a small group; unless you have another child that’s exactly where he is, it’s not going to work.” The SLP from the school district was retiring that day. She was there for many, many years—30. She actually took care of my brother-in-law when he was a student there.

**Denise:** Oh

**Parent:** So she wrote up the goals, and they were half-assed, and I rejected them, and—I rejected everything. So I talked to the SPED director during the summer, because they don’t meet during the summer. And since preschool didn’t start until the second week of school starting—that she guaranteed that we could have another meeting the first week of school. At that meeting, I had the SLP that was still left at the school as well as the new one that was hired the day before that day and, you know, other people from the team—you know, the OT, the PT... I had the preschool teacher.... In the September meeting, I think X was there.

**Denise:** So this was the second IEP meeting?

**Parent:** Yup. And we hashed out some things. I was able to get three half-hour, one-on-one speech, which was a challenge, but I was able to advocate for that—

**Denise:** And how do you think you—why do you think you were successful?
**Parent:** The benefit of having the SLP they just hired—was brand new, so she didn’t really know X. They couldn’t really—I don’t think that the other SLP could reject it, knowing that he had a diagnosis of apraxia. I think that’s—I came in with data that—you know, I researched it and came in with concrete research that showed it—that it was needed. I brought—the late-talker book was one of the books that I brought in. The Children—Childhood Apraxia Speech Association—I brought in their information off their Web site. I brought in, I believe, a letter from my neurologist saying that he needed to have private, you know, one-on-one speech therapy. I mean, I loaded my stuff with data. And then we discussed it; we talked about the goals. I didn’t sign anything at that meeting.

**Filing for Due Process: Empowered by the Law**

When the school refused to use the child’s SGD in the classroom, the parent thought that was the ultimate legal violation and she turned to the formal law - she filed for due process. The parent stated she was familiar with the process from the advocacy training class she took. She stated that *she* helped the lawyer prepare the documentation.

**Parent:** Then we came to our meeting in December, and then that’s when I had both X (private speech pathologist) as well as X (other private speech pathologist) at my meeting, and myself, my attorney, and—

**Denise:** And who called all the meetings?

**Parent:** It was put into the ed plan to see where he was in six weeks. I did.

**Denise:** Okay. You did.

**Parent:** I needed to make sure that we were on track and see how the things were progressing.

**Denise:** So that was December....
**Parent:** Yes, December 12 or 13, believe it or not. I think it was the 13th.

**Denise:** Your memory is amazing.

**Parent:** Well, it was a bad day in my life, so... it was—so we went in, and we wanted to add the device on as a goal to the IEP. And essentially, they said no. Prior to that, about a week or so—two weeks before that, there was a teacher’s meeting. And I called up the preschool teacher, and I talked to her—actually I talked to her in the hallway. I said, “Geez, you know, if you saw the device, it’s not intimidating; it’s really easy; you know, they have so many things already built in for circle—time and weather and things like that. You know, I’d love to come in and show you the device, you know, just so you’ll see and know what you’re talking about during the meeting.” And she agreed that—“Great!” And then she talked—must have talked to the administration, because she called and left me a message on my machine saying that she could not see the device. It wasn’t approved on the ed plan, so she couldn’t even look at it. So that kind of gave me a little heads-up on what was going to happen. And when it came around—they went around and voted, like, on the table—went around the table, and some of the concerns was, the vice principal said he would use it as a crutch and never learn how to talk. The school SLP said, “Absolutely not”; she would not support it. Her research showed that it is not helpful. And when I—I did go to see Dr. X that following January—two-day conference about it—UMass Amherst. And I asked her that question, and she said, “And what research was she looking at—from the 1960s?”

**Denise:** And how did you find out about the conference with Dr. X?

**Parent:** Probably on the apraxia listserv

**Denise:** On the listserv, uh-huh.

**Parent:** Yeah, on the listserv.

**Denise:** Okay. So she—so nobody supported it at the meeting.
Parent: No one at the school supported it. My—both my private therapists, my husband, myself, my attorney—we all supported it. And never did I think it was going to be a huge ordeal.

Denise: So you had your attorney at all the meetings?

Parent: Yep.

Denise: Okay. So then what happened?

Parent: They said, “Absolutely not,” and that was his last day of preschool.

Denise: So you pulled him out.

Parent: Mm-hmm. We pulled him out. So I continued on doing the thing with our two private speech therapists.

I continued on—the lawyer filed papers for due process hearing.

Denise: Did he talk to you about what—how did you decide to file due process?

Parent: Because I took the training at the Federation. I knew that was the only recourse that I’m going to have, because they weren’t allowing my child to be who he needed to be and to access the curriculum. If he can’t speak, how do you know he’s accessing the curriculum? Also, I got a picture—this is one thing that makes me cry even today—of the preschool kids having their picture taken in the fall, and the PECS pictures exchange for feelings was hanging above all their heads. So even if my son was sad, he couldn’t go and pick that thing off, even if he stood on a chair.

Denise: How ridiculous.


Denise: What did they think he was going to be able to do?

Parent: I have no idea. You know why? Because my kid was quiet, and he sat when you told him to sit; you know, he followed the rules. I honestly think that was his detriment. He was a good kid that sat and did what he was supposed to do, quiet and happy.
Here the parent described how she worked with her attorney to file for due process. She had knowledge of the process from taking advocacy classes and was actively involved in preparing the documentation for her case.

Denise: So you worked with your lawyer, and you knew from your advocacy training that—what the legal recourse was.

Parent: Yup. So we filed for due process, and I met with the lawyer again. And at this point, the lawyer’s—I’m writing all the letters, and she’s just saying, “Yeah, that’s okay,” because I was trying to save money, because my—this is—the lawyer fees were cutting out of my speech fund (fund her parents gave her.)

Denise: Oh, okay. How did you know what letters to write?

Parent: Because the advocacy training—

Denise: At the ad—that was really helpful to you. Okay.

Parent: Huge.

Denise: So you did a lot of the documentation.

Parent: I did all the documentation.

Denise: You did all the documentation. Okay.

Parent: Except the actual filing of the paperwork for due process. But I met with her, and I spelled it out—you know, what the issues were. In Massachusetts, you need to have a preconference hearing date. And that’s essentially kind of the last hurrah—that you can re-cash everything. And to be honest with you, I could’ve went to mediation, but because the speech therapist was so poor in her quality of work with him, I could not give in on that. That was not a negotiable item for me.

Denise: So who told you your options in terms of, you know, mediation versus—?

Parent: Through the training.

Denise: Through the training, okay.
Parent: I thought if an SLP did not speak—did not support his speaking device, obviously she didn’t get it. And then what I saw as being the inappropriate speech therapy—I mean, she was wrong in how her approach was.

Denise: Yeah, that was huge.

Parent: Yeah, and I couldn’t negotiate that, because she was the only one that did that age group.

Denise: Right.

Here the parent discussed the preconference hearing. The hearing officer was a former speech-language pathologist and the parent thought this helped her case.

Parent: So we had a preconference hearing. Unfortunately, at that preconference hearing, our original hearing officer was out sick or dealing with a case or something. In—let me back up. In the state of Massachusetts, that January, they changed their process with due process. And what they did was that they assigned your case to a hearing officer, and your hearing officer couldn’t hear another case until that was totally completed, to expedite hearings so they wouldn’t drag out and drag out. So I don’t know if our hearing officer was out sick or if there was a little snafu in the schedule, but we got assigned a new hearing officer for the preconference hearing. She actually used to be an SLP before she got her law degree. And because she knew about apraxia, or at least speech-generating device, it kind of saved time, because you didn’t have to educate her, because she already knew all that.

Denise: That was amazing.

Parent: It was luck. It was the grace of God. I really do think that. So at this preconference hearing, they actually brought the school SLP there, which I was shocked, and so was my attorney. And it was my husband, and my husband doesn’t
get dressed up for too many things, but he did wear a suit—or a coat, you know, with a collared shirt, which, you know, he is a t-shirt-and-jeans kind of guy. So what came to be was that they—the hearing officer asked the school SLP, “What is your experience with, you know, augmentative communication devices?” In her 18 years, I think she only had four students that ever used it, and they were all high school students. She never had a preschooler. So that told me that she didn’t—and it was a while ago; it wasn’t, like, recent history for her. So that told me that she really didn’t know what she was doing or talking about. And the lawyer negotiated with the school district attorney and the hearing officer, and I think that essentially, the hearing officer’s role during preconference hearing—my understanding is that she’s supposed to say that whatever case—you know, “Look, you really don’t have a strong case here; I don’t know why you’re wasting our time; you need to settle this.” And I’m sure that’s what she told the school district. When they came out, they said that they—the super—the assistant superintendent wanted to meet with me. In our school district, the superintendent was retiring as of July 1. Now, I think this hearing took place in—the preconference hearing took place in March....

**Denise:** So did you know anything at the conclusion of the preconference hearing?

**Parent:** No.

**Denise:** No, they just got the facts.

**Parent:** Yep.

**Denise:** Okay. And then you went to the next meeting.

**Dispute Resolution**

After the preconference hearing the parent, her attorney and the school district had a meeting to resolve the dispute. The parent reported that the school district offered to have the child switch schools and she agreed. The parent also reported that the
school district agreed to each of her requests: reimbursement for all the private speech-language therapy and transportation to and from the school. She then withdrew her complaint.

She decided not to ask the school to reimburse her for attorney fees because she thought she would need to go to a hearing, which she did not want to do.

**Parent:** And then we went—they asked us to have a meeting—I think they offered to switch schools. I think they did. And I accepted that. This is the part that I don’t recall, because—I know we had a meeting with the new school at the end of April, and that was one of my sticking points—is that I didn’t want to go back to my elementary school—my local elementary school. I also wanted them to pay me for all my private speech that my parents paid for. I wanted attorney fees, but I gave on that, because I knew it wasn’t going to fly unless we went to due process hearing. And then I wanted transportation to and from the school. So when we met—so we had a—the hearing officer requested that we have another IEP meeting at the new school, and we did that at the end of April. In Massachusetts, there’s something called extended—I forget what it’s called—extended evaluation times, where it can be longer than two weeks but not as long as—no longer than six weeks. And that’s where, you know, a student comes into the school, they want to see who the student is, and blah-blah-blah. So prior to this IEP meeting in April with the new school within the same school district, we met with the SLP at that new school....

**Denise:** Hold on a minute; I just want to back up. So did—after the preconference hearing, what came next?

**Parent:** They determined that X would be able to switch schools, and he would be able to go to the new school. And—

**Denise:** Okay. Did you have another hearing?

**Parent:** No. No, we withdrew our complaint.
**Parent:** What happened was, when we had this new IEP meeting—prior to that IEP meeting, one of the things that we wanted to do was meet with the SLP at the school—the new school. So we sat down with her. The first thing is that she found out he was in private speech therapy and asked us if it would be okay if she went and observed a session, which—we’re like, “Hallelujah!” We nearly fell off the chair. We’re like, “Yeah, well, it’s kind of far; it’s the next town over.” She said, “Oh, I’ve gone as far as Danvers,” which is about 20 minutes from where we were, half an hour from where their school is. And what came to be was, she had already worked with my private therapist on an augmentative communication device for another student at the school.

**Denise:** Oh!

**Parent:** Yes, that was luck. And, you know, so when we met with her, she seemed like she was willing to work with us, accept my son for his disability, and she knew about apraxia speech and was willing to work with our private therapist....

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**Funding Options for the SGD: Early Intervention Program vs. Health Insurance**

With guidance from her son’s private speech-language pathologist, the child was evaluated for an augmentative communication system and the parent began to carefully consider her funding options. She decided to access her health insurance to fund the SGD rather than ask the school. Why? There were two primary reasons. Her son was not yet enrolled in kindergarten and she did not think the early intervention program was obligated to fund a device for her son. Also, she was concerned that her child would not have access to it at home if the school owned it.
Several people helped her with the assessment and funding processes. The private speech-language pathologist arranged for an augmentative communication evaluation and assisted her in the funding process. The vendor was knowledgeable about health insurance benefits and also assisted her with the funding process.

**Parent**: And this was all happening when X—the same month that X says, “You know what? He’s not really making progress; it’s taking us months to get to final b. I really think we should look into an augmentative communication device.

**Parent**: So X (private speech therapist) helped me make arrangements with a woman that came out from a company that—I believe she did many things, not just speech-generating devices. And she had the—Vantage was one of the devices that she had, and I think she had, like, the Prentke Romich Company—the next one down from that is—oh, what’s it called? Not a Mighty Mo.

**Denise**: The Springboard.

**Parent**: Springboard, right. But because we were getting funded and we were going to request funding through my private insurance as well as the state insurance—

**Denise**: So how did you decide to do—request funding through your—through those insurances?

**Parent**: Well, it’s what we had, so...

**Denise**: And you didn’t want to go through the school, for some reason?

**Parent**: He wasn’t three yet; he wasn’t in the school yet. That was one of the biggest problems, to be honest. . So, you know, yes, they do have rights, but you’re fighting so much for so many other things that it’s sometimes easier if you have private insurance to go through, because then you run into the other problem of—which doesn’t make sense to me at all—the school system will keep the device at the school, and they’re only entitled to use it between the hours of 8 and 3 when
school—or not during the summer. If you own the device, they can’t tell you have to
leave it at school at 3 o’clock.

**Denise:** How do you know that?

**Parent:** I heard that from other parents on-line.

**Denise:** OK. So then what happened when the company sent someone out.

**Parent:** She came out to the house, and I forget what they called it. It was—should
probably know what it was, but it was like a trial for different devices to see what
would be a good fit. But one of the things we had to look at was, even though Tim
was only three—less than three years old, no matter where we got our funding, it
had to be good for five years, because that was, like, the standard, I guess.

**Denise:** And how did you know that?

**Parent:** My private speech therapist.

**Denise:** Okay.

**Parent:** So we took that information, and we had to—I had to project, and I kept on
envisioning my son being an eight-year-old, because that—three plus five is eight.
And he would be in second grade. So with that in mind, you know, I really had to
think. But one of the most amazing things that happened was—when she had the
speaking device, they played a game with a fish or something for the touch screens,
so he could see if he can manipulate it, and he did fine. And they did several
different sizes of the squares. But one of the things that happened that opened up
my eyes at that time was, she went to body parts, and she pushed “Arm,” and the
device said, “Arm,” and my son, crystal clear, said, “Arm.” And he never had said
that word before. Nor did he say it after for many, many months. But I didn’t get at
the time that that was actually going to be able to assist him to speak, not just
speak for him. I know that’s kind of weird to say it like that, but... he was going to
reap the benefits of having, you know—and I read that it takes the pressure off. You
know, you can add more pressure onto an apraxic kid—the more, for some reason, the impulses get scrambled or—stress plays a role in it. And for him, knowing that he could have this to rely on—that might take that pressure off. And I was shocked that he could say, “Arm.”

Denise: How exciting.

Parent: Yes, it was. And, you know—and it showed me that—I know he was a smart kid, but man, he took to it like water—fish to water. So it was, like, a no-brainer. And the Springboard would not have met his needs for very long.

Denise: No.

Parent: So we put in the paperwork; we had to get—I had to get signatures on something that says—well, X had to do an assessment, a very detail-oriented assessment. We had to show medical necessity. And because he was allergic to bees and he couldn’t communicate, “I just got stung by a bee! Help! I need my EpiPen,” that was the pushing factor for me, besides just getting his being able to communicate. We also needed to get a written prescription from his medical doctor.

Denise: So how did you know about all these things?

Parent: X (private speech-language pathologist)

Denise: Okay, so she helped you with the process.

Parent: Yep. She wrote a phenomenal report—it wasn’t just a template from a manufacturing company. It was explicit to Tim. It showed—you know, she proved why the device was important, why that particular device was appropriate—I’m trying to think. It was, like, an eight-page report. That was $500, I think; that was—that my parents paid for, too. So everything was paid out of pocket.

Denise: Okay. But the device was going to go through Mass Health.

Parent: Nope, the device was supposed to—originally went through my primary insurance, and that was the delay.
Denise: That was Tufts, right?

Parent: Yes, at the time, it was Tufts. And Tufts denied it verbally, but they didn’t give it to me in writing for, like, two and a half weeks. And at the device company, I spoke to a woman in the funding department who told me she was going to submit it to both insurances at the same time. And I said, “Well, you can’t do that, because it needs to be denied by one insurance before the other insurance might pick it up.”

Denise: And how did you know that?

Parent: Because of her expertise in funding. She knew that; I didn’t.

Denise: So the funding person at the company knew that.

Parent: Yup.

Denise: Why did Tufts deny the funding request? Based on what?

Parent: Tufts said his device was not medically necessary. I could have appealed it but since we had Mass Health and they approved it I didn’t. The funding company actually applied to both health insurances at the same time so there would not be a delay. We actually applied for Mass health since they also have a program called Insurance partnership program that helps people pay for their private insurance.

Denise: So what advice would you give parents about getting funding, either through their insurance company or their school?

Parent: Private insurance first, and then sometimes private insurances either wouldn’t pay for the whole device, but then you get into the situation I feel is that you can negotiate with the school system. And if they know that you’re going to take some of that burden of responsibility financially off their shoulders, they’ll cost-share the device, and then at least you have a stake in the device. You can say, “Well, we paid 30% of it, and okay, it needs to come home.” I mean, I would think that in my situation at the school district—that I had such a poor SLP that I think they probably
would—she would’ve kept it at the classroom. But the new SLP that we got—I think she would advocate it for him to be able to take it home, without a doubt.

**Parent’s Perception of the Child’s Rights**

The narrative revealed that the parent thought about the assistive technology rights in two ways. She thought about these rights under law as rather broad legal rights, such as a right to have a device because the child had a disability. The parent also thought about assistive technology rights based on the rules of law. She referred to her child’s rights under IDEA to access the curriculum, to have an evaluation and to have a device, though she thought the device may not be a state of the art device. The parent also described her right to have an independent evaluation if she disagreed with the results of the evaluation that the school conducted.

**Denise:** So in terms of X’s rights under the law. What do you think X’s right are under the law.

**Parent:** Rights that are under the law, that—I mean, I think an example of rights is to bear arms in the United States. The Constitution gives us that right. So the dictation of different statutes in the government is what allows us to have rights. And it’s a long process to get them, but once you do get them, it’s even a challenge even a challenge to maintain.

**Parent:** So rights are things that you’re entitled to as a state—as a citizen of the United States.

**Denise:** Okay. And what do you think X’s rights are under the law?

**Parent:** To have access to a speaking device and to get—because he has a disability, it matters to help compensate for his disability—that he’s entitled to be—have access to it and use it.
Denise: And do you think—do rights—what—are there any other rights in terms of funding rights?

Parent: Unfortunately, no.

Denise: Okay. All right. And what about funding rights under the IDEA?

Parent: Funding rights under IDEA... I’m not—

Denise: For the speech-generating device. Are there—

Parent: Under IDEA? Well, I know under social education laws, which—I mean, I—let’s see: IDEA, ADA, and then... under—if a child’s enrolled in school and they need to have access to the general curriculum, which is a law: everyone is entitled; it’s an entitlement; everyone’s entitled to have that. And they’re unable to access the general curriculum, because speaking is one of their disabilities and they’re not intelligible. So my thought is that if you can’t understand what a child’s saying, how do you actually know that they’re accessing the general curriculum? And—

Denise: Good point.

Parent: Oh, yes. And for funding, I know a lot of families have difficult time when the school district provides a device. The situation oftentimes is that they only have to have an appropriate—they don’t have to have the best. Their accessibility—and I know, at least in the state of Massachusetts, there is an assistive technology evaluation that every student, not just a special education student, is entitled to, to help them access the general curriculum.

Denise: What do you think—are there any rights that some—a child like Lee would have under the law for the school to pay for a device?

Parent: I mean the—they should. If I—well, it depends what the assistive technology assessment states. So if we went in and—when he was nonverbal and unintelligible, and I said to the school, you know, “Look, we have to have an assistive technology evaluation done so we know,” and then they came back and
said, “Okay, you know what? This—the person did this whole assessment, and he really thinks the one thing that he needs is really just a Pext book,” say, for example, and I as a parent didn’t agree—think it wasn’t comprehensive—I can ask for an independent educational evaluation that the school district has to pay for. Unfortunately, in Massachusetts, I’m tied, because they pay so poorly. For me to find a competent professional that would accept their low payment—that it’s really hard in Massachusetts, in my opinion. I have a friend in New Jersey; she got an IEE for her child, and the school district paid $6,000+ for neuropsych and observation and everything. That would never fly in my state. They—you know, you have to find a provider that’s willing to accept the payment, which—it’s miniscule. I mean, it’s like—I don’t want to say pennies on the dollar, but—

Denise: No, I can imagine.

Parent: It—for a neuropsych exam, I think—I want to say—and this is off the top of my head—like, $1,100.

Denise: I’ve heard thousands for sure.

Parent: Oh, yeah, well, $1,100 that they’re going to pay. I paid privately for my older son, and his evaluation, I think, was $3,800.

Denise: Oh, my gosh.

Denise: So you’ve heard from other parents that this is a problem.

Parent: Yes, about getting funding. So when you go through the school system, yes, a child does have a right to have access to the general curriculum. If they’re not intelligible or unable to verbalize anything, then under, I believe, the law, they are entitled to have some means of communication. Then you get the sticking point of what type of communication is appropriate, and that’s where, I think, a lot of parents probably have problems with. I mean, I don’t know—I mean, I know one child that went to this school that got—he has apraxia speech; he also has mild cerebral palsy
and some cognitive issues. And they got him—was it a Techtop that has a little card to slip in?

**Denise:** Mm-hmm, mm-hmm.

**Parent:** Okay. So that’s what they gave him

**Denise:** Yeah, it’s not a dynamic display.

**Parent:** No, and they didn’t even use. It. So, you know, yes, they do have rights, but you’re fighting so much for so many other things that it’s sometimes easier if you have private insurance to go through, because then you run into the other problem of—which doesn’t make sense to me at all—the school system will keep the device at the school, and they’re only entitled to use it between the hours of 8 and 3 when school—or not during the summer.

**Parent’s Perception of Personal Factors That May Have Influenced the Process**

The parent mentioned several factors that may have influenced the process. These factors included her brother who is an attorney, the parent who has a learning disability, the parent’s mother who advocated for the parent to receive special education services, the parent’s mother and father who had the resources to fund private therapy for the child, and the parent who has another child with a disability who received special education services. When asked about her husband, the parent explained that he attended some meetings, though he was not always helpful because he might insult people. She stated he was “not very politically correct”.

**Denise:** You mentioned—about your learning disability, and—wondering how you felt, or if you felt, this influenced how you advocated for X.
Parent: Yes, because I saw my mother—how my mother advocated for me. My mother, believe it or not, got extended school year services for me before Chapter 766 came in to being in Massachusetts.

Denise: And when you say you saw how your mother advocated—

Parent: Well, she—you know, what I—one of the things that happened to me in second grade in December was, our teacher—the teacher I had, Ms. X—if you didn’t finish a certain number of boards by 11 o’clock in the morning—I think it was three boards by 11—of work—that you had to sit in the corner. Now, it happened to me in December—my recollection is it happened in December—and I came home crying and told my mom that, you know, this had happened. And she was down to school that day. That’s my recollection; she tells me it wasn’t that day; she did call [laugh]. But the point of the matter is that—and I also got D’s on conduct, and the teacher said the reason why—because my mother asked me, “Are you yelling? Are you pushing in line? Are you talking out of turn?”, and I was like, “Nope, nope, nope.” The reason why was because every afternoon, I’d lay my head down on the desk and cry, and that’s why she gave me a D in conduct. So my mother said, “Don’t you think there’s a problem here? This is happening on a daily basis; what’s going on?” and, you know, etc. So, I mean, my mother advocated for pencils. They used to give you free pencils in school, and then they stopped it. I remember her writing a letter campaign. You know, so she’s a strong advocate, and, you know, I did learn through her: If something isn’t right or you don’t think something is right, you need to act upon it, because it’s not going to change on its own.

Denise: Tell me a little bit about how you got connected with EI.

Parent: EI was—because of my older son, who was delayed in many things, at six months of age for my older son, he wasn’t doing any of the developmental things he should’ve been doing, like rolling over, sitting up independently—so my pediatrician
sent me to our local children’s hospital to have a PT assessment. And that PT assessment—the PT made reference to Early Intervention. Never did anyone—my pediatrician or this PT person—tell me that that’s actually a service—you know, an organization. I just thought it meant “intervene early.” So I was working one day, and I had a patient in my chair, and I inquired what the mom did for work, and she was a physical therapist that worked in a school district. So I’m like, “Oh!” So, you know, I inquired to her, saying, you know, “My son’s, you know, blah-blah-blah”—I don’t know how old he was, but “he’s not, you know, rolling over yet.” And she says, “Oh, you should get Early Intervention.” And I said, “Yeah, I know; I think we should intervene early.” And she says, “No, it’s a program that they come and service and help your child.” I was, “What?” So she said, “In fact, I can tell you the phone number, because I used to work there.” So she gave me the phone number; I called right from my office that day and self-referred myself to EI for my older son.

**Parent:** When Michael was born, he had a flat skull, and we watched it and watched it and watched it. And you know, you’re supposed to put babies on their backs now, so I followed it to the T. So his flat skull really—and he has very low muscle tone, so he had very little movement inside of me. And apparently, when he developed, he was up against my pelvis, and that’s why he got into this world with such a flat skull, and then putting him on the back just made it even worse. So when he was whatever age—I forget—March, April, May, June—he was six months old. That was one of the things that came out: that he—the doctor said—his pediatrician said he should wear that helmet to help reshape the scalp—I mean his head. And the helmet at the time was, like, $850, which was a huge amount of money for my family. And the insurance denied it. They said it was cosmetic.

**Denise:** Oh my.
**Parent:** So my pediatrician, or my neurologist—I forget who; I think it was my pediatrician—had to write a letter saying if he didn’t have this $850 device, then he would probably need cranial surgery, and, you know, essentially, “Either you pay $850 now, or you pay for those thousands of dollars of surgery later”—type thing. So after two appeals—I had to appeal it to two tiers in our insurance company—they finally agreed to reimburse us the money that—it was my husband’s grandmother that paid for it, actually, because he didn’t have MassHealth at the time, because MassHealth would’ve paid it. So here comes Tim three and a half years or four years later... lo and behold, same problem: needs to have a helmet. And our insurance at the time paid for it 100%.

**Denise:** So let me go back to one thing you mentioned that we hadn’t talked about, which was, your parents said something to you about what they thought X should get.

**Parent:** For therapy?

**Denise:** For speech therapy.

**Parent:** What—you know, I—we don’t have a whole lot of money, and at the time, money was extremely tight. And I didn’t have the $125 fee for an hour for a private speech therapist. So what my parents did was, they came in, and they gave me a huge lump sum of money and said, “Here, we want you to put this in an account and use it for Tim’s speech therapy.” So they did that, and when they did that, then it took the pressure off of me to ask them permission every week.

**Denise:** Sure. What a good idea.

**Parent:** —and, you know—and use that money to pay for his speech.

**Denise:** So why do you think they did that—I mean, other than the fact that they’re your parents?
**Parent:** Because they knew that his speech was way behind, and it—you know, he—we need—my mother’s also a nurse, so she knows that if you need something that has specialized specialty, then you need to go get that specialty—that someone else not having the information firsthand is going to trickle down; it’s going to get watered down, maybe—and that really, he needed some of the—had that information firsthand.

**Parent:** At my first IEP meeting, or qualification meeting, my parents paid for a lawyer to be present.

**Denise:** So tell me about that. Why do you think they did that? Even before you rejected it, right?

**Parent:** Yeah. My brother’s an attorney; he was a new attorney. He probably was only practicing for a year. And he told me that special education has lots of laws to help X, and that he didn’t know them well enough, but there were lawyers that specialized in it. And I called the—actually, how did I get the lawyer? Oh, I know. The lawyer took the class that I took through the Federation, like, the year before, and one of her clients that she helped out pro bono, which you have to in the beginning—is that she actually worked with someone that I knew whose child had apraxia—or nephew had apraxia. She actually gave me the lawyer’s phone number. The lawyer actually had a child that had apraxia speech, so she already knew about apraxia, so I didn’t have to explain what it was.

**Denise:** So let me see. Your brother, who was a newly practicing attorney, knew that there were laws—special education laws, and he wanted you to have that information, and he thought the best way would be to have an attorney.

**Denise:** So how about your husband? How was he involved?

**Parent:** My husband took a backseat in the beginning, and then when they started giving me a hard time, I—let me think. He came to the first meeting, actually, and
then he—he didn’t come to all of them—I don’t recall, but maybe he did. I think he did come to all of them in the beginning for X. It was my older son—when he started to be on an ed plan, I went without him; I left him at home. My husband is not very politically correct and says it like it is, even if it’s not politically correct to say it so. I mean, he had no problems telling the superintendent and the SPED director that he knows a few people that should be fired and if—would they like the list, he’d be most happy to help them with it. And he was told to keep his voice down in the conference. But you know—and it’s like, my friend who calls him the Wild Factor; you’re just never quite sure what he’s going to say. And it did add more stress to me having him there, because I was like, “Ugh, what’s he going to say now?”

### III. Perceptions Compared to the Positive Law

Based on the narrative, there are several legal issues to consider. These issues are discussed below.

*Funding for the Speech Generating Device: Health Insurance vs. School*

In terms of private health insurance, the parent believed her health insurance should and would fund a SGD for her son. In the state of Massachusetts Tufts health plans have paid for speech generating devices\(^4\); however, Tufts health insurance denied her funding request. The plan indicated that the device was not a medically necessity. Since her exact benefits under this employer-based plan are not known, it would not be possible to determine her legal rights and whether she should have appealed the decision. However, given her child’s medical condition, it is possible that if she did appeal this decision, she may have prevailed. Rather than appealing the decision, she also submitted the funding request through Massachusetts Medicaid
(130 C.M.R. 400.000-499.000) with assistance from the vendor. Medicaid paid for the device, which is consistent with Medicaid law. For children from birth through age 21 years, the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is a mandatory service under Medicaid (42 U.S.C. §1396a(a)(10)(A); §1396d(a)(4)(B); §1396d(r)). Under this program, a state must provide any of the services listed in the Medicaid Act, including optional services, whether or not the service is included in the state's Medicaid plan (§1396d(r)(5)). Under the EPSDT, SGDs are covered under one of several benefit categories: home health care services, including medical supplies and devices; prosthetic devices, rehabilitation services, preventative services, and speech-language pathology services. While Medicaid may pay for a SGD, it is the payor of last resort (130 C.M.R. 503.007). In summary, in this case, the Medicaid funding decision was most likely consistent with the law.

The parent did not think the child was entitled to funding through the Early Intervention program; she thought the child had to be enrolled in a public school in order for the school to fund the device. Was the EI program responsible for providing a device for her child? The answer is possibly. Based on IDEA, the child is entitled to assistive technology devices as services (20 U.S.C. §1432 (E)(xiii)). However, according to IDEA the public school is the payor of last resort (20 U.S.C. §1440(a)). The law states that the public school is not obligated to fund a device if there is another public or private source that is obligated by state or federal law to do so. According to Massachusetts Department of Health’s Early Intervention operation standards, the child is entitled to services from an assistive technology specialist.

http://www.aacfundinghelp.com. The Assistive Technology Law Center reports this is not a complete list. It spans from 1990’s-2003 and is based on information that some assistive technology companies provided.

However, these standards do not specify that the state is obligated to provide the child with an assistive technology device. In Massachusetts, the Early Intervention lead program is the Office of the Health and Human Services, Department of Public Health. Services are paid for through the Department of Public Health, Medicaid, and private health insurance. Thus, the law is not clear with regards to if or how a recommended device may be funded for a child in an Early Intervention program in Massachusetts.

**IDEA: Entitled to a Specific Device?**

The parent indicated that the public school might be obligated to provide a communication device. She also stated that the school might not be obligated to provide a state of the art device; cost may be a factor. Were the parent’s perceptions consistent with the formal law? Possibly. According to IDEA regulations (34 C.F.R. §300.5), which have been adopted by reference in the state of Massachusetts special education regulations (603 C.M.R. 28.01), the school is obligated to provide an assistive technology device in order for the child to receive a FAPE. However, the school is not obligated to fund the device if another public or private agency is obligated to do so by state or federal law. Furthermore, the school is not obligated to provide the best or state of the art equipment. The term “appropriate” is a rather ambiguous tem and open to some interpretation by the IEP team. The concept of an “appropriate education” is based on the landmark Rowley Case (458 U.S. 176 (1982)). In Rowley the Supreme Court determined that FAPE does not mean a school must provide the “best” education or one designed to maximize the student’s potential (Board of Ed. of the Hendrick Hudson Sch. Dist. v. Rowley, 458 U.S. 176 (1982)). The Rowley case was also important in another way: it acknowledged a collaborative relationship between the school and parents. In Rowley the Supreme
Court noted that both the States and the family have a partnership in the child’s educational program.

“the primary responsibility for formulating the education to be accorded to (a child with a disability), and for choosing the education method most suitable to the child’s needs, was left by the Act to state and local educational agencies in cooperation with the parents.” (Rowley at 207).

Consistent with IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations by reference, after an assistive technology evaluation it is likely that child’s IEP team would determine which device would be appropriate for the child (34 C.F.R. §300.320-324; 603 C.M.R. §28.05, 28.07.) It is difficult to know whether the school and the parent would have agreed.

**IDEA: Right to Have a Device to Access the Curriculum**

The parent stated she felt her son had a right to have a communication device to access the curriculum. Based on IDEA regulations which have been adopted by the state of Massachusetts in its special education regulations, her perceptions are probably accurate, though certain provisions apply. IDEA regulations state that the child is entitled to assistive technologies if it is part of the child’s special education (34 C.F.R §300.105). The IDEA regulations, 34 C.F.R §300.39 (a)(1), define special education as:

“specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings.”

IDEA regulations part 300.39(3)(i)(ii) define “specially designed instruction” as:

“adapting, as appropriate, to the needs of an eligible child under this part, the content, methodology, or delivery of instruction to address the unique needs of
the child that result from the child’s disability; and to ensure access of the child to the general curriculum, so that he or she can meet the educational standards within the jurisdiction of the public agency that apply to all children”.

The federal regulations specify that the IEP must state how the child is involved in and making progress in the general education curriculum (§300.320). Furthermore, under the federal regulations, the child’s IEP includes a statement of the supplementary aids and services a child needs in order to “be involved in and make progress in the general curriculum” (§300.320(a)(4)(i)(ii)). Supplementary aids and services include assistive technology devices and services. Also, federal regulations state that the IEP must consider the child’s AT needs (§300.324). The state of Massachusetts special education regulations define the term “special education” similarly to the federal regulations (603 C.M.R. §28.02(20)) and adopt, by reference, the federal regulations associated with developing the IEP (603 C.M.R. §28.05). Thus, the parent’s perception is probably consistent with federal and state regulations.

**IDEA: Independent Evaluations**

The parent believed that she would be entitled to an independent evaluation at public expense if she disagreed with the evaluation that the school conducted. She expressed concern that the school would have control over where she obtained the evaluation. She thought that cost may be a significant factor and this could impact the quality of the assessment. These perceptions are accurate, in part. According to IDEA regulations (§300.52) the parent is entitled to an independent evaluation at public expense if the parent disagreed with the evaluation that the school conducted, each time the public school conducted an evaluation with which the parent disagreed. While the parent may choose an evaluator, the evaluator must meet the
public school’s criteria. The state of Massachusetts’ special education regulations are consistent with these federal regulations. However, in Massachusetts a school may ask the parent to pay part of the fee. This is based on a sliding fee scale (603 C.M.R. 28.04(5)).

**IDEA: School-Purchased Device Used Outside of School**

The parent stated she would be concerned that if the school provided the device, they could limit her son’s access to the device when the school was not in session. Based on IDEA regulations, the child may have access to the device at home or in other setting if the IEP team determined it was necessary in order for the child to receive FAPE. (§306.106(b)). Massachusetts special education laws do not make reference to this.

**IDEA: Content of the Individualized Education Program**

Another legal issue concerned the content of the Individualized Education Program (IEP). The parent rejected the plan because it did not have measurable goals. She said that having measurable goals was an IEP requirement. She was correct. According to IDEA regulations (§300.320 (2)(i)), which have been adopted the state of Massachusetts in its special education regulations (603 C.M.R 28.05), the IEP must include measurable goals. How did she know this? By talking with other parents and through advocacy training.

**IEP Team Meetings**

The parent reported that the child’s private speech-language therapist attended an IEP meeting. According to IDEA regulations, which have been adopted by the state of Massachusetts by reference in its special education regulations, this is consistent
with the law. The parent is entitled to have an individual attend meetings who has knowledge or special expertise concerning the child (§300.321 (a)(6); 603 C.M.R. §28.02 (21)).

**504 Plan vs. IDEA**

The parent rejected the 504 plan and this is another legal issue to consider. The parent rejected the 504 plan because she felt it would not meet her son’s needs. She believed his communication skills were too severely impaired. Was this child eligible under Section 504? The answer is yes. However, based on the law, the child was also eligible for benefits under IDEA. When both apply, IDEA rules and regulations will apply to the 504 entitlements\(^{42}\). A discussion follows.

Section 504\(^{43}\) is an anti-discrimination statute. Based on Section 504, a child with a disability cannot be denied participation in a public school program or the benefits that such a program provides. Section 504 ensures that a child with a disability, as defined by this law, receives a FAPE and related services to enable them to participate in a public education program as adequately as a non-disabled child. Section 504 provides rights and protections to a child who is disabled, as defined by this law, but is not eligible under the IDEA. Thus, Section 504 typically covers students with less severe disabilities than the IDEA. In contrast to IDEA, Section 504 regulations do not use the terms AT devices or services. Section 504 uses the term “auxiliary aids” when referring to AT devices and services and mandates that these aids must be provided by the public school for individuals with sensory or manual

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\(^{42}\) per discussion with Professor Wendy E. Parmet, School of Law, Northeastern University, October 14, 2009

\(^{43}\) Section 504 was modeled after the Civil Rights Act of 1964 and served as the foundation for the Americans with Disabilities Act (42 U.S.C. §§ 12101 et seq.).
impairments and impairments in speaking (§104.44 (d)). Unlike IDEA, Section 504 does not require the school to provide an individualized educational program (IEP) that is designed to meet the child’s unique needs and provide the child with educational benefit. Rather, under Section 504 the public school program must develop an “individual accommodation plan” for the student. This plan specifies the accommodations and modifications that will be made to the child’s regular education program.

Eligibility under IDEA is based on whether the child has a disability, based on an evaluation, and whether the child needs special education and related services, each as defined by IDEA and Massachusetts special education regulations. According to IDEA and Massachusetts special education regulations, this child meets the definition of disability because he has a speech or language/communication impairment (§300.8; 603 C.M.R. 28.02(7)(g)). Based on IDEA regulations, which have been adopted by Massachusetts in its special education regulations, the child is eligible for related services because he needs speech-language therapy – a related service (§300.34). In view of his severe communication impairment he would most likely need specially designed instruction to allow him to use his SGD to access the curriculum, consistent with the definition of special education under IDEA and Massachusetts special education regulations (§300.39; 603 C.M.R. 28.02 (9)).

**IDEA: Warranty for the SGD: Is the School Obligated to Pay?**

The parent stated that the school was obligated to pay for the warranty for the family-owned SGD. Is this consistent with the law? Possibly. IDEA regulations state that the public school is responsible for maintaining, repairing and replacing assistive technologies
(34 C.F.R. §300.6(c)). The Office of Special Education Programs has issued a policy letter on this topic. In 1994 the Director of OSEP supported a family’s request that an Illinois school district assume liability for a family-owned assistive technology. In the letter, the Director of OSEP, Thomas Hehir wrote,

“It is reasonable for States to require school districts to assume liability for an assistive technology device that is family-owned, but used to implement a child’s IEP”44.

However, neither IDEA nor Massachusetts special s regulations specify that the public school has this responsibility for family-owned assistive technologies. Thus, it is likely that this decision would be made at the local level, on a case-by-case basis.

**Advocating for Rights**

Another important question to consider is whether health insurance regulations and IDEA enabled the parent to advocate for her son to receive some AT rights under the law. I believe the law empowered this parent to advocate for her child.

In terms of health insurance, while the parent did not speak about specific laws and regulations, she navigated complex systems and obtained her son’s benefits. In terms of IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations, a parent has rights in four major areas: prior written notice (§300.503; 603 C.M.R. 28.05, 28.05), consent for services (§300.300; 603 C.M.R. 28.07), developing the child’s Individualized Education Program (IEP) (§§300.320, 300.321, 300.322; 603 C.M.R. 28.05) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 603 C.M.R. 28.08).

44 Letter from the Office of Special Education and Related Services regarding a school district’s liability for family-owned assistive technologies used in public education order for the child to receive a FAPE.
Consistent with IDEA regulations, in Massachusetts a parent may resolve a dispute in several ways: informal measures (as this parent did), through mediation, through a formal complaint by contacting the Office of Program Quality Assurance Services, by requesting a due process hearing, and if necessary, by appealing a hearing decision to a state of federal court (§§300.500, 300.529; 603 C.M.R. 28.08). In this case, the parent asserted her rights. She rejected the 504 plan, rejected the IEP and filed for due process. The parent withdrew her complaint after the school department agreed to her requests: include the device in the child’s IEP, transfer her child to another school, provide transportation to and from the school to home, reimburse the parent for the cost of private therapy, and cover the warranty for the device.

OSEP Policy Letter to Anonymous, 21 IDELR 1057 (8/9/94) 34 C.F.R. § 300.6(c)
Case Analysis # 5

Demographic Information

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<tr>
<td>Martial Status</td>
<td>Married and lives with husband</td>
</tr>
<tr>
<td>Interviewee</td>
<td>Mother (&quot;Ms. O’Brien)</td>
</tr>
<tr>
<td>Mother’s education level and vocation</td>
<td>Associates degree homemaker</td>
</tr>
<tr>
<td>State</td>
<td>MA</td>
</tr>
<tr>
<td>Speech generating device</td>
<td>Vantage – Prentke-Romich</td>
</tr>
<tr>
<td>Purchased by</td>
<td>Mass Health and BCBS</td>
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I. Case Facts

This case involves a 15-year-old female with a medical diagnosis of cerebral palsy, per the parent. The child has multiple physical and cognitive disabilities. She uses a wheelchair for mobility and a speech generating device for communication. The child is enrolled in a public school in a special needs program. Over the years the school provided assistive technology evaluations and services to this child and it provided a variety of low technology speech generating devices for her to use at school and at home. The child reportedly “outgrew” these devices. The parent recently took the child to see an augmentative communication specialist at a local hospital who recommended a higher level device. The device was funded through private and public health insurance programs. The parent reported there were no disputes with
the public school or the health insurance programs during the evaluation and funding processes.

II. Analysis - Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? How does a family obtain their knowledge about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

The analysis revealed that interactions with people shaped her perceptions of the law and influenced her actions. The narrative revealed several themes, which are discussed below.

Empowered by the Law – A Collaborative Approach to Advocacy

The narrative revealed that the law enabled the parent to think about rights, talk about rights and challenge perceptions of injustice. While she did not talk specifically about health insurance regulations, she talked about benefits and successfully obtained benefits. In terms of her daughter’s education program, early on in the interview the parent discussed that she was an integral member of her daughter’s educational team and was actively involved in decision making. The parent reported that she regularly collaborated with her daughter’s educational team - she consistently talked and met with her child’s teachers and therapists. She described
how interactions with a variety of people on her daughter’s educational team influenced her decisions about obtaining a speech generating device for her daughter. These interactions impacted how she advocated for her daughter and which rights she exercised.

While the parent had a collaborative relationship with the school, at times she thought the team did not have the knowledge and expertise to work with her daughter. She stated she had to “push” the team to obtain some services she thought her daughter needed. She advocated through informal dispute resolutions processes, meeting with teachers and health care specialists, based on what she thought her daughter needed and should have.

**Funding Options: Health Insurance vs. School**

**Decision-Making Factors: Ownership and Ease**

The parent thought that her employer-based health insurance and her daughter’s public health insurance should fund a device for her daughter because it was medically necessary. While she thought the school might fund the device for her daughter, she decided to access her health insurance rather than the school. She made this decision for two primary reasons. She wanted to own the device and she was concerned that if she went through the school it may take a long time, particularly if there was a problem with the school’s budget.

The parent reported that she obtained useful information about the funding process from the vendor’s website. After obtaining this information, she thought she could manage the process. However, based on what other parents told her, she was prepared for a potentially difficult experience. In contrast to what she heard from
other parents, she reported that the funding process was not difficult. She reported that the insurers were cooperative and the device was funded within two months.

**Knowledge About the Law through Networking**

How did the parent obtain knowledge about the law? The parent indicated she did not spend much time reading and learning about the formal law. She obtained most of the information about speech generating devices, funding, and IDEA by talking with the assistive technology specialist in the school, talking with the independent AAC specialist at a local hospital, by doing research on the Internet and talking with other parents on listservs. She also gained information from the child’s teachers and aides, insurance personnel and the vendor.

**Personal Factors Which May Have Influenced the Parent’s Thoughts and Decisions.** As discussed above, this parent thought of herself as integral member of her daughter’s educational team and she was actively involved in decision making. Also, she deliberately encouraged collaboration among team members. There were two other factors that may have influenced the parent’s perceptions and decisions. Many times during the interview the parent talked about how important it was for her to do independent research about assistive technology and teaching methods. She recognized that information empowered her to advocate for her daughter. She felt that by doing research she could be more confident that the team made the right decisions for her daughter. Also, her husband had been on the school committee and was aware of some fiscal problems the school was having. The parent mentioned that this influenced her decision to obtain funding for the device and the evaluations through health insurance, instead of the school.
Excerpts from the narrative illustrate these themes.

**Parent as Part of the Educational Team: Interactions with People Shaped the Parent’s Perceptions Which Influenced her Decisions**

Over the years the parent developed a collaborative relationship with her daughter’s educational team. She interacted with them on a regular basis and was actively and involved in the decision making process. She identified several influential people on this team who helped her during the process of obtaining a device for her daughter. She also identified other individuals who were less helpful. Interactions she had with each of these people shaped her decisions concerning which device to get for her child and how to obtain funding. The parent described how the assistive technology consultant within the school district was knowledgeable about assistive technologies and encouraged the parent to obtain a more sophisticated device for her daughter. She mentioned that her daughter’s aide and the teachers were also very involved in the process of obtaining a new device. They attended the evaluations with the independent AAC consultant, provided input and consistently implemented the recommendations. The parent also stated that the assistive technology vendor was helpful to her, as were the people she talked with at the health insurance companies. In terms of people who were less helpful, she specifically stated that over the years the public school speech pathologists were not knowledgeable about assistive technologies. Because of this lack of knowledge, the parent and the school staff decided that the assistive technology consultant at the school would be primarily responsible for training her daughter to use assistive technologies, rather than the speech-language pathologist.

**Denise:** Okay. So the focus of what I’m trying to do is to learn parents’ experiences in getting funding for speech-generating devices for their children and experiences—
anything that you can think of along the way that you were involved in. So just if we could start at the beginning—the beginning meaning, “When did you first start thinking about this technology for X, and who mentioned it to you?”—that kind of thing.

**Parent:** Okay. Well, I think we started looking at it when she was in about third grade. We have an AAC consultant that worked for the district—the school district. And she’s always been very pro-device—you know, communication device. And so she worked with X (her daughter) on and on off since first grade and started with just, you know, BoardMaker, pictures, and that kind of thing and then worked up to a s—I think it’s called a static device—that doesn’t, you know, move; it’s not dynamic; it’s just—you insert the sheets, and it’s just very basic. And then we kind of went to using software on a computer to see if she would be able to even use a device. So then two years ago, you know, the woman just basically said, “She really needs to have one.” And we started doing research, and that’s what finally moved us towards that.

**Denise:** And so, when you say you started doing research, what would that mean?

**Parent:** Well, I—you know, the consultant recommended one device, but I wanted to be sure that that was what I felt was indeed, you know, good for her. So basically, I just looked on the computer and did a chart of all the devices that were out there, the pros and cons, what kind of software they had on them, and pretty much narrowed it down to just a couple, including the one that she had picked out. And then, you know, my daughter’s been seeing the communication program people at X (hospital) since she was probably about in fourth grade. And we would go every six months, and they would kind of do a summary of recommendations after the visit. And so we went to see them before we actually ordered the device, and they concurred with the consultant that, you know, the Vantage Plus was a good choice
for my daughter. And so, basically, we just narrowed it down that way, and that’s how we picked it out.

**Denise:** Who recommended the AAC consultant at the hospital?

**Parent:** The AT consultant at the school did.

**Denise:** Okay. So let’s see; you mentioned the consultant who works for the district. So what is her background, and how did you get connected with her?

**Parent:** That’s kind of a long story. She’s actually a special education teacher for kids that have severe disabilities, and she was working for a collaborative in Massachusetts. And I met her at the summer camp that my daughter attended. She actually had her for a teacher. And she moved out this way, and I’m the one that suggested she look at our district for getting a job. And basically, she didn’t have any background, you know, educationally, other than what she went for, you know, for her teaching background. But she had always been very involved in working with kids with devices, so she had that knowledge. And I’m not sure if she has any, you know, background in, you know, academics for technology, but she’s always been extremely knowledgeable. So they hired her as a consultant, and I’m sure that she must have some background in that for them to do so. And so she’s been there since my daughter’s been in first grade. And she’s been working for the district on and off, because in between, she had two kids. And—but she was back to the district full-time about four years ago. So she’s been working with my daughter ever since, and she knows her extremely well, so it’s been a great fit. And we actually have written into the IEP that she works with Kelly Ann an hour and a half a week.

**Denise:** And how did you get that done?

**Parent:** You know, basically, I guess it was... there are so few speech therapists that actually have any experience in using devices that they—our team all agreed that having this consultant work with X was better than trying to get her working with a
speech therapist that had no knowledge of the device. So she still sees a speech therapist a half-hour a week, but the majority of her communication part of her IEP is with the consultant. So I think they realized that, you know, they were lacking as far as, you know, speech therapists. So they agreed to sort of replace the communication piece with this consultant.

**Denise:** So let me just summarize. So you met this woman at a summer camp that X was going to.

**Parent:** Yes.

**Denise:** And did—she moved to your area, and you suggested she get a job with the district, and that came to be.

**Denise:** Yeah. So who do you—who would you say has helped or hindered the process?

**Parent:** Well, I would say that the person that helped the most was the AAC consultant. She really worked on those forms and made sure that the wording and—you know, she read all of the information from the PRC funding department as well and knew what the insurance companies would be looking for. The insurance companies themselves—I think that they were—they worked with us. You know, it was a great process with them, at least the people I spoke to on the phone. They were just super-nice. I’d have to say that both the speech therapists weren’t overly helpful.

**Parent:** And for different reasons. I mean, you know, unfortunately, you know, through the years, we’ve had speech therapists that have not been knowledgeable but have gone over and above to try to learn and try to help. And you know, at this point, we just had two that were not doing that. But we sort of went around them, so...
**Denise:** Yeah. It sounds like this AAC consultant was somebody that was really important in the whole process.

**Parent:** Yes, yes. And I’d have to say, you know, her one-on-one aide and her, you know, special education classroom teacher were very behind us and very supportive. So that helped.

**Denise:** Tell me about how the teachers and aides helped?

**Parent:** I think, you know, while the consultant was filling out the paperwork, she asked them a lot of questions. I mean, the one-on-one aide worked with my daughter, you know, intimately, so, you know, she would have a lot of input, and the same with the classroom teacher.

**Denise:** Makes sense.

**Parent:** Yeah. And you know, I think you have to be involved, and I think you have to push, but I think you have to push with the knowledge that you’re going to be there to help out.

**Denise:** Okay—and that you need to be involved—is what you’re saying.

**Parent:** Yeah, yeah. I mean, I—you know, I could have stood there and screamed. And you know, when they don’t know where to look or they don’t have anybody, you know, in the district that could help them, you know, that’s where I think the parent has to figure out, “Okay, I’m going to help and research and find out what I want for my daughter, and then I’m going to go to them and tell them about it and see what they think.”

**Denise:** And how are things going now?

**Parent:** Good. It’s been a long road, you know, basically because it’s—my daughter’s skills are so scattered, and we really needed to find a way to teach her and make the most of her usage. It took us a long time to figure out that X is not going to speak in sentences, because she can’t think in sentences. So we would—we
had to backtrack and really use the device not just for communication, but reinforcement of academic skills, her scheduling, social—so it’s a lot more than just communication. It reinforces everything. All—you know, they use it in every aspect of her day.

**Denise:** That’s wonderful.

**Parent:** It is. It—you know, they’ve really done a fantastic job, and—you know, I mean, there’s always hindsight, but, you know, it’s all—we’re all muddling through.

**Denise:** I understand.

**Parent:** You know, so—but I have to say that this support has been great. You know, the—we go to see the communication program at X every six months, and at least one staff from the school comes with us—either the consultant, her aide, or the classroom teacher. Recommendations are written up, and immediately the whole team comes back with those recommendations and implements them in the next six months.

**Denise:** How did you know that was happening?

**Parent:** I really didn’t know in the beginning that the school was following up on the recommendations from the CEC, though I did know they were doing some of it through daily communication with them. Before the next follow up, I pulled out the summary that X (AAC specialist at the hospital) sent us after the appt. and realized that the school had done everything! We did work together, but they were keeping better track of it than I was. After the first couple of times, I would check the recommendations a couple of months afterwards to make sure we were addressing everything. Sometimes my help was required to get going on some of the things, but I knew that they were making every effort to prepare X for the next visit. I think communication is key after every session with the AAC school consultant which does
happen twice a week - they write an update in X’s daily log...actually all the therapists do that. It’s a wonderful tool and I'm happy to say most are consistent.

**Denise:** So if you were going to give another parent advice about working with schools, working with health insurance companies about getting technology for their child, what would you tell them?

**Parent:** Geez, it all depends on who you’re working with. I would say to do your research first, ask—you know, ask other parents, ask questions online, you know, look at all the device companies and—you know, everybody says that you know your child best. You know what they’re capable of. And then, you know, bring what you find to the staff and get their input. And you can also judge, I guess, how well they’re going to receive it, but if they think that you’re going to be a huge part of this and help them make the child successful in—at home and at school, then I think that they won’t feel like you’re throwing it in their lap.

**Denise:** Makes sense.

**Funding Options: Health Insurance vs. School**

There were several factors that influenced the parent’s decision to seek funding through her health insurance. She indicated that she wanted to own the device. She recognized that if the school purchased the device they might own it, which could potentially limit her child’s access to the device. Her husband was on a school committee and he told her that the school district was having financial problems. Thus, the parent was concerned that it could take a long time for the school to make a decision about funding a device. Furthermore, she thought that she was paying insurance premiums for this purpose and therefore her insurance should pay for the device.
Based on the narrative, this parent was highly knowledgeable about the funding process and was actively involved during the process. She obtained her knowledge from talking with other parents on listservs, from her husband, from an assistive technology vendor, the assistive technology specialist at her child’s public school and the assistive technology specialist at the hospital. She carefully read her health insurance manuals to determine her benefits. She reported that she heard from other parents that the funding process could take a long time and that the forms were difficult to complete. Thus, she made follow-up telephone calls to determine whether documents were completed accurately, submitted and received. Thus, the parent’s perception was influenced by interactions with people and these interactions impacted her decisions.

**Parent:** Okay. So anyway, once we had selected the Vantage Plus, then it was time to try to order it and figure out who was going to pay. And basically, we knew that I wanted to go through our own insurance. And there was never any question about whether the school district was going to pay or not. I wanted this device to be owned by us.

**Denise:** And why was that?

**Parent:** Just because when she outgrew the other one, we had to hand it back the district and... I guess because I wanted to be able to have the device in the home when it wasn’t in the school. And not that there would be any question on that, but I was also thinking about—you know, when she ages out of the district at 22, were we going to have to start looking at getting another device or, you know, returning this one to the school at some point? And just knowing how school district budgets work, I just didn’t want the red tape to hold up my daughter getting a device. So I just felt this was an easier route to go.

**Denise:** So who helped you make this decision?
**Parent:** As far as who was going to pay for it?

**Denise:** That you were going to access your private insurance.

**Parent:** I think it was m—you know, it was really me that wanted that from the beginning. My feeling is, we would pay a hefty amount for our insurance, both of them, and we can use them for evaluations or durable medical equipment, I would rather go that route.

**Denise:** Okay. So when it was time to order it, you were already—you had already been thinking that you were going to ask your private insurance to fund this.

**Parent:** Yes. And the other thing that kind of influenced my decision is—you know, we purchased the device from PRC, and I went on their Web site, and they have a whole section on funding. And, you know, it’s even—it is so detailed that you can even click on your state, and it tells you exactly what the requirements are for insurance—you know, state insurance and private insurance and the process in order to get the device approved. And it seemed like a fairly easy process as long as, you know, we filled out the correct forms. And I thought, “Well, I think I’d rather go this way, you know, for a $7,000 device. It looks like it’s going to be easier than trying to get this approved through the school.” And then we would have ownership of it, and I just felt better that, if it’s my daughter’s device, you know, we actually have the finally say on what’s going to be—how it’s going to be programmed and that type of thing.

**Denise:** Okay. And you had a little bit of inside knowledge about the fiscal problems within the school district.

**Parent:** Oh, yes, yes. And I just—you know, I mean, I know that shouldn’t influence, but, you know, here, along with a lot of places, regular ed funding and special ed funding is pitted against one another, and when the budget becomes tight, it’s always special ed’s fault that so much money goes in there. And I just felt that if
my insurance can pay for this—that I would rather use my daughter’s school funds for things that it will not pay for, so it—like transportation and, you know, job coaching and that sort of thing.

Denise: So how did you know your medical insurance might fund this?

Parent: Basically from what I read on the PRC site.

Parent: Yeah. I mean, they—it seems like they have experience working with all of the Medicaid state agencies and most private insurances. So, you know, they have developed applications and forms to submit right to the insurance company and any backup, you know, as far as input from speech therapists and school staff and the parents and, you know, how to submit it so we get, you know, the funding.

Denise: Okay. And what is your daughter’s insurance?

Parent: I’m trying to think if it was—it was HMO Blue, Blue Cross Blue Shield, and then she has MassHealth Medicaid that picks up, you know, everything that’s not covered by the primary.

Denise: And how does she qualify for the MassHealth?

Parent: Basically because she’s disabled, but, you know, in our situation, it’s really—it’s a program called Common Health, which is part of MassHealth. And we actually pay, based on our income, a monthly premium, and it’s not cheap.

Denise: You know, I have heard this from other parents.

Parent: Yes. But when Kelly Ann turns 18, then, you know, we no longer pay. So if she is in the system for this—and now I’ve heard there’s a waitlist for MassHealth. So—and before—you know, based on what income my husband had, or if he was even working—because, you know, it’s—over the years, he’s, you know, in technology, and it’s been up and down—you know, they adjust the premiums according to your salary. And also, they pay for things that primary insurances don’t
a lot of the times. So we felt that the monthly premium did outweigh, you know, the negatives.

Denise: And what did they—what are those things?

Parent: Well, our primary insurance does not pay for nursing. It doesn’t pay for orthotics. It doesn’t pay for things that are trials—alternative medicine. And a lot of that, MassHealth will pick up. So we felt that—and you know—and over the years, I mean, sometimes we’ve really made out. You know, I mean, the cost of the nursing was really high. And right now, I’m sure we’re paying into it more than we are getting, but we never know when something’s going to come up, you know, like a wheelchair or—that all of a sudden, we need to have that backup.

Denise: That makes perfect sense.

Parent: Yeah.

Denise: So how do you know so much about your insurance? I know that might sound like a simple question, but it’s a complicated usually.

Parent: Yeah, it is. I read the manuals, you know, for Blue Cross; I read what—exactly what was, you know, covered; I read everything on the PRC site; and then I contacted Blue Cross Blue Shield—and the same with MassHealth. And basically, it—you know, if my daughter’s disability there—it is severe, so it isn’t so much, you know, perception. You know, she really is—it was medically necessary for her to have a device, and that’s the big question: if it's medically necessary, then that's when they’ll pay. And she needs a way to communicate, and she does not—I mean, she does talk some, but it’s, you know, not enough to make herself understood. So that was the way I sort of knew that, yes, they were going to pay for this.

Denise: So when you say “contacted,” what does that mean?

Parent: I called them. I just looked on the back of my insurance card, and I called them.
Denise: Did you think the school would pay for the evaluation?

Parent: I never did ask the school to pay for the evals as I knew our insurance would take care of it. My husband was, at the time, on the school committee and I had first hand knowledge of the dire straights of the school budget, so I thought if our insurance would cover it, that was the way to go. If our insurance didn't cover it, I would have fought to have them at least hire a consultant for an evaluation. I think however, that the consultant that she had and has presently would have made some good suggestions as far as a device, but the info X (the hospital) gives us on follow up visits is invaluable. I don't think I would have known that if we hadn't been there to begin with. It's a matter of being at the right place at the right time for once!

The Funding Process: Orderly and Relatively Predictable

The parent described how she was actively involved in the funding process and was prepared to complete each step in the process. She had heard “horror” stories from other parents about the process and was determined that she would have a better experience. She worked collaboratively with a variety of people to achieve this: the independent augmentative communication specialist, her child’s physician, teachers, the school speech-language pathologist and the vendor. She also talked with parents on a listserv

Denise: And how was that experience? (experience with the health insurance companies).

Parent: You know, both of them were really great. I really have to say, they have always been great. I mean, there are times—sometimes I, you know, call MassHealth when I think, “Oh, that was, you know, slow.” But you know, I used to think that
insurance people were there to give you a hard time, but really, they have always been very helpful.

**Denise:** That’s really good to hear.

**Denise:** Okay, so then you—let me just summarize. So you decided it was in X’s and your family’s best interest to go through your insurance.

**Parent:** Yes.

**Denise:** And then what happened?

**Parent:** Well, we printed out—you know, I contacted PRC’s funding department, and they kind of walked me through what I needed to do from then. I printed out all the forms that we needed, and it was two sets, because one would first go to Blue Cross, and then the other would go to MassHealth. We figured out exactly what we wanted to order: you know, we needed the device—and what software should be on it—a carrying case, because, you know, my daughter’s not in a wheelchair all the time. And so, we just, you know, filled out the order form and then filled out all the paperwork that went with it. And then there was a lot of backup that we had to get, as far as forms that needed to be filled out by a licensed, you know, SLP and by school staff. And so I sent the forms to Children’s Communication Program, and our—I don’t know what you call her—the person that sees her...

**Denise:** The consultant?

**Parent:** Yeah, the—well, the person at the hospital filled out both the same forms. I filled out a version from my point of view, the speech therapist did, and the AAC consultant from the school district—they—we all filled out pretty much the same form. And I attached everything and sent it in to PRC, and they’re the ones that submit the forms to the insurance company.

**Denise:** What about your doctor? Did she have to—or he have to fill any forms out?
Parent: Yes. I—they actually needed a prescription, and I’m not even sure who that came from, whether it was her pediatrician or—I think it was her coordinated care physician at Children’s. She’s, like, a developmental pediatrician.

Denise: Okay. And how did that process go—the forms and the people filling out...?

Parent: It went great, with the exception of the speech therapist at the time. She was probably one of the worst ones we’ve ever had. And, you know, we really needed her credentials, you know, as part of the package, even though the AAC consultant knew much more about what needed to be said.

Denise: But the person at X (hospital) was a speech pathologist as well, correct?

Parent: Yes, but they needed the school. They needed the school SLP to fill it out. So I can’t actually remember if—I actually think that the AAC consultant filled out the paperwork and the SLP signed it, because the SLP was so clueless and not very helpful, and so we at least got around it this way.

Denise: So it wasn’t enough to have the speech therapist at the X (hospital); you also needed the school speech pathologist, who was clueless.

Parent: Yeah. Actually, I think it was—all we needed was the school, but I figured as much as we could provide—I mean, if they knew that we were seeing someone at X Hospital for communication—that that would just be an added, you know, step—you know, a plus in getting the device.

Denise: Makes sense. Okay, because you had an evaluation—X had the evaluation both at school and at X correct?

Parent: Yes.

Denise: Mm-hmm. So I see what you mean. Okay, so you got all the forms, and then you sent them to the vendor.

Parent: Right.

Denise: And then what happened?
Parent: Well, we sent them in April, and they said that it could take four to five months if we were lucky. And I can’t actually remember how I came to call or know about it, but I think I received something in the mail from... oh, I know what: in July, I called PRC and asked if they had heard from the insurances, and they said no. So I called both Blue Cross and MassHealth, and Blue Cross said that it had been approved and they were sending the paperwork out. And then I heard—and I can’t remember who from—if it was—geez, I don’t remember who told me, but they said, “You know, your primary insurance says that it’s approved, but it’s only approved for how much they want to pay.” So, you know, that could be only, like, a small portion of it. So I called MassHealth, and I just remember the gentleman being super. And he said, “It has been approved, or it’s on the verge of being approved in the next couple of days.” And I said, “Well, what does that mean? Is that everything that the insurance—Blue Cross is not paying for?” And he said yes. So I asked if I should call back, and he said, “Sure.” So I called back in two days, and he said, “Yep, it’s approved, and all the paperwork is coming to you.” So in that respect, I was very surprised. And a lot of other people have been surprised that from April till July—you know, with such a short time to get, you know, a device approved.

Denise: And so, it sounds like they talked to Blue Cross or—and had worked it out.

Parent: Yes, yes. And I think that was kind of a catalyst, because I said—I had told the gentleman at MassHealth that I just spoke to Blue Cross and they’d approved it, and I think what happened then is, they contacted the insurance company—you know, Blue Cross, and then went from there. And maybe that’s how it got approved a little faster.

Denise: Okay. So you were really on top of it the whole way.

Parent: Yeah. Yeah, and I guess because, you know, being involved in the Yahoo! list, you hear all kinds of horror stories. So I just really wanted to make sure the
process was working. And I got a lot of help from the PRC funding department. They kind of told me how it all worked and that—you know, I asked if it would help if I had contacted the insurance companies, and they said, “Definitely.” And then after I had contacted both insurance companies, I called PRC and told them what they had said, so they knew the paperwork was coming.

Denise: Mm-hmm, okay. When you say you heard horror stories... tell me about that.

Parent: That people would wait for six months and then get denied, and most times on a technicality that the forms weren’t filled out right or they had forgotten something or, you know, it just wasn’t included in their plan—a lot of things like that, and just having to wait forever only to find out that the funding is not coming through. So I sort of wanted to be prepared and find out what was happening, you know, along the way. Was there something that was holding up the process?

Learning About the Formal Law through On-line Communication with Parents

The parent mentioned that she has not spent much time learning about the formal law. She stated she learned some things about the formal law from reading posts on a listserv for parents who have children with augmentative communication needs. Based on other parts of the narrative described above, the parent is knowledgeable about some IDEA concepts, such the IEP. She is also knowledgeable about her health insurance benefits as they pertain to durable medical equipment.

Denise: What options do you think the law gave you—or gave X?

Parent: The option for a right to have one—the option that, you know, it’s considered medically necessary—that if our insurance did not pay for it, then the school would have to.
Denise: And how did you know that?

Parent: Basically, by, you know, the people on the Yahoo! list. You know, I mean, I take everything that’s said with a grain of salt, and—but you know, a lot of the people are—when they say something, they say, “This is where you can find out where it is,” and exactly what it says. And I think, you know, you have a responsibility to find out exactly what’s true and what’s not.

Denise: How do you—how did you learn about X’s rights under the law?

Parent: I’d have to say I’m not real good about reading all kinds of, you know, rights law and, you know, all kinds of state laws. Basically, I learned about it on the Yahoo! list.

Denise: Okay, because you do know a lot.

Parent: Yeah, I guess—you know, there was a time that someone brought up that they thought—I can’t remember. It was recently where they thought that a device was mentioned that they had a right—the kids had a right to take it home, if it was purchased by the school. And that was one of the first times I went to IDEA and looked up that section, just so I knew how it read. And it was indeed true that a child’s—you know, if a school district buys the device, the child has a right to use it wherever they are.

Denise: So you had read a parent talking about it.

Parent: Yes, and they actually said that they couldn’t remember where it was in IDEA, and they didn’t find it, so I—from my own knowledge, I wanted to know what it said. So I went to IDEA and figured out where it was.

III. Parent’s Perceptions Compared with the Positive Law

Health Insurance Funding of Speech Generating Devices
The parent reported that the private health insurer first paid a portion of the cost and then the public plan paid the rest. While details of the family’s private Blue Cross Blue Shield (BCBS) plan are not known, in several states BCBS plans have paid for SGD$\textsuperscript{45}\textsuperscript{45}. In terms of MassHealth Common Health (130 C.M.R. 505.004), it is the payor of last resort (130 C.M.R. 503.007) and thus, in this case, the funding decision was likely consistent with the law.

**IDEA: Assistive Technology Services and Devices.**

How did the parent’s perception of IDEA compare with the positive law? The parent stated that she thought that the school might fund a device for her daughter. In the past the school did provide low technology speech generating devices for her daughter to use and training for her daughter to use the devices. However, according to IDEA regulations, if another non-educational, public or private agency is obligated to provide the funding by state or federal law, then the public school is not the primary payor (34 C.F. R. §300.154 (b)(1)(i)) and the public school may seek reimbursement from the non-educational agency if it fails to provide the special education or related service (34 C.F.R. §300.154(b)(2)). The child had health insurance which did fund the device. Therefore, it is possible that the school may not have been obligated to provide the device.

The parent stated that the AT consultant at the school recommended an independent augmentative evaluation. Did the parent think the school might fund the assessment? She was not sure. The parent stated that she knew that the school was having fiscal problems. This influenced her decision to use her health insurance to

\textsuperscript{45} http://www.aacfundinghelp.com. The Assistive Technology Law Center reports this is not a complete list. It spans from 1990’s-2003 and is based on information that some assistive technology companies
obtain funding for the evaluation. She reported that if her health insurance did not cover the evaluation, she would have asked the school to hire a consultant to conduct the evaluation. Based on IDEA regulations, which have been adopted by reference in the state of Massachusetts special education regulations, a child is entitled to an AT evaluation if it is necessary for the child to receive a FAPE (§300.5, §300.105; 603 CMR §28.01). The AT consultant at the school recommended an independent evaluation but one cannot assume that child’s IEP team concurred. Thus, in order to determine whether the school was obligated to fund the assessment it would be important to know if the child’s IEP team made this recommendation. If so, the school may have been obligated to provide the assessment at no cost to the parent.

Contents of the Individualized Education Program (IEP)
The parent mentioned that her daughter’s IEP specified that the AT consultant would work with her daughter an hour and half a week. She indicated that the IEP team, including the parent, made this decision and wrote this decision into the IEP. The parent recognized the importance of writing this decision into the child’s IEP.

According to IDEA regulations, the IEP must include all special education and related services (§300.324). This is consistent with state of Massachusetts special education regulations (603 CMR §28.05).

Advocating for Rights
Did the law enable the parent to advocate for her daughter? Based on the narrative, I believe it did. In terms of health insurance, the parent was knowledgeable about benefits. She successfully navigated two complex systems and obtained these provided.
benefits. In terms of IDEA, based on IDEA and the state of Massachusetts special education regulations, the parent has rights under the law to participate in the development and modification of the child’s IEP (§§300.320, 300.321, 300.322, 603 CMR §28.07). In this case, the parent asserted her rights. She actively sought to be part of her child’s educational team. From regular interactions with the team and other individuals, she became knowledgeable about IDEA procedures. This enabled her to advocate for her daughter and participate in decision making.
Case Analysis # 6

Demographic Information

<table>
<thead>
<tr>
<th>Age and gender of child</th>
<th>5 year old male</th>
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<tr>
<td>Diagnosis</td>
<td>apraxia of speech</td>
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<td>Type of School</td>
<td>2 schools: public and faith-based</td>
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<tr>
<td>Race</td>
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<tr>
<td>Martial Status</td>
<td>Married and lives with spouse</td>
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<tr>
<td>Interviewee</td>
<td>Mother (&quot;Ms. Blair&quot;)</td>
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<td>Mother’s education level and vocation</td>
<td>B.A. in education Early childhood educator</td>
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<td>State</td>
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<td>Speech generating device</td>
<td>Vantage</td>
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<tr>
<td>Purchased by</td>
<td>authorization pending from Mass Health and Care First Blue Cross Blue Shield</td>
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I. Case Facts

This is a 5-year-old boy with a medical diagnosis of apraxia of speech, per parent. He communicates using a speech-generating device, along with manual signs, gestures, and word approximations. He attends an integrated public preschool part time and a faith-based school part time. He receives speech-language services at the public and faith-based schools. At the private school, therapy is funded through a private foundation. A group of parents at the faith-based school started this foundation and this parent was part of this group.

According to the parent both school systems did not have the knowledge or expertise to provide assistive technology services for her child. Thus, the parent decided to
obtain augmentative communication services outside of the school systems. Her health insurance paid for these services. Based on recommendations from independent evaluations and training, she purchased some relatively low cost assistive technologies with her personal funds and private health insurance funded one speech generating device for her son. She is in process of accessing health insurance to purchase a more sophisticated and costly device.

The parent is considering enrolling her son in the faith-based program full time next year. If so, she wondered whether her son might qualify for speech-language services in the public school as well as the faith-based school. She questioned whether the public school was obligated to continue to provide speech-language services for her son if he was not enrolled in a public program. She stated she would seek legal advice to ascertain her legal rights concerning these issues.

II. Analysis -Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do families obtain their knowledge about the law? How do their perceptions of the law compare to the positive law

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

Perceptions of the Law
The narrative revealed that the law was part of this parent’s everyday life. It was infused into her thoughts and actions as she advocated for assistive technology devices and services for her son. The law empowered her because it enabled her to assert her rights and advocate for her child’s rights. The parent’s interactions with people, in combination with some personal factors, influenced her perceptions of the law, the decisions she made and ultimately determined whether she exercised particular rights. The narrative revealed several interrelated themes which are discussed below followed by excerpts from the narrative. The last section compares the parent’s perceptions of the law with the formal law.

**Health Insurance Regulations and IDEA: Empowered by the Law**

The parent discussed how she thought it was important for her to be informed about the law. She believed that knowledge about the law helped parents advocate for their children. She was knowledgeable about her health insurance benefits and some IDEA rules and regulations. When she talked about the IDEA she used the language of the law to explain her son’s rights under the law, such as IEP and FAPE. She thought many parents did not have this knowledge and therefore, they were at a disadvantage when advocating for their children. The parent reported she obtained knowledge about the law by reading the regulations and talking with other parents who have invoked their formal rights.

Based on the narrative the parent also thought that parents had rights under health insurance laws and IDEA and these rights could be used to resolve grievances.

**IDEA: The Rights are There but IDEA is An “Unfunded Mandate”**

The narrative revealed that the parent thought there was a gap between the law as written and the law as implemented. The parent thought about the law as written set
of rules and regulations that guaranteed rights for her son. She talked specifically about his right to receive therapies, assistive technologies and training to use the technologies. However, the parent also thought the law was not being implemented as intended. She thought this was due to two related factors: financial constraints and lack of knowledge - specifically lack of knowledge about assistive technologies.

She based these perceptions on interactions that she has had with teachers, therapists and other parents. She talked about the school system as “violating” and “denying” a child’s rights under the law due to lack of funding. Due to these perceptions about the law, she sought independent augmentative evaluations and therapies and she persistently advocated for her son to receive augmentative communication services in school. She educated herself about the law by reading the regulations. Furthermore she educated herself about assistive technologies and arranged training for therapists to help them learn how to use her son’s speech generating device.

**IDEA: Complex and “Vague”**

The narrative revealed the parent perceived the law as somewhat complex and difficult to understand – “a little daunting”. She also thought about sections of the law as being open to interpretation – “vague statutes”. She was troubled by areas of the law that she believed were not clear. She mentioned several such issues: whether a child had the right to take a school purchased device home, whether the school had any obligation to pay for a warranty for the device, and whether the public school had any obligation to provide therapies for her son if she enrolled him in a faith-based program full time. She thought that she would need legal advice about these issues.
**IDEA: Some Distrust for People Who Implement the Law**

The parent thought that her knowledge about the law was critical for advocating for her son, though it may not be sufficient to achieve her son’s rights under the law. Why? Because she thought that people in charge with implementing the law might be resistive, withhold information or misinform a parent, which she thought could lead to struggles with the law. She based this perception on interactions that she had with parents who were knowledgeable about the law and had disputes with the school system. The parent reported that while she did not have these types of experiences, the information from other parents influenced her perceptions. It caused her to question whether the public school would give her all the information she needed in order to make an informed decision. Based on this perception, she thought about seeking legal advice.

**Accessing Health Insurance Funding for Speech Generating Device**

**Factors: Ownership, Ease, and Confidence in Benefits**

The parent chose to access health insurance benefits for several reasons. She wanted to own the device, which she thought would give her autonomy over where and how it was used. She had little confidence that the school could adequately assess her child’s augmentative and alternative communication needs or process a funding request and she was concerned that they would not cover the cost of the device. She was relatively confident that health insurance would fund the device. Because she thought her son needed a relatively expensive SGD, she decided to apply for MassHealth benefits, a decision she had been putting off.
The parent reported that the independent augmentative communication specialist
and the vendor help her understand the funding process. She thought the process
was relatively orderly and manageable.

**Common Health – A Complicated Application Process**

The parent thought the required paperwork for the Common Health application was
too laborious and therefore she put off applying for the benefits. Until now, this
coverage was not particularly critical; her son did not need much durable medical
equipment and the equipment he did need was paid for by her private health
insurance. Things are different now. She reported that her son needs a more costly
speech generating device so she decided to go forward with the application process.

**Personal Factors and Personal Circumstances – A Potentially Powerful
Combination of Resources**

The narrative revealed that the parent perceived there were several personal factors
that influenced her decisions. These included her knowledge about the law, her
personal financial resources, her private employer-based health insurance benefits,
support from her son’s faith-based school, and confidence that her family and friends
would provide financial support if she needed it. In terms of her private health
insurance, the parent reported that her husband worked for the city and participated
in selecting insurance plans for the employees. He advocated for plans that included
a good durable medical benefit because he knew this was important for X. The
parent also discussed another resource. She was one of the founding members of a
private organization that provided therapies to children with disabilities at her son’s
faith-based school. She believed she has a significant resource within this
organization – the director is a speech-language pathologist. She believed that this
resource may enable her to advocate for her son to receive the therapies he needed at the private school. The parent did not mention whether her professional background may have affected her perceptions about the law or her decisions.

These themes are illustrated in excerpts from the narrative.

**Public School System: Lack of Experience with Speech Generating Devices**

In the following section of the narrative the parent described that the public school had little knowledge and experience with children who need speech generating devices. She reported that there were no other children with disabilities in her child’s preschool program. In response, she educated herself and trained therapists at her son’s schools to operate and use the devices in the classroom.

**Parent:** When the issue of technology has come up—I was in a—I remember being in a—it’s not even in an IEP meeting, just parent-teacher conference and one of the therapists was the speech therapist, and I said something about, you know—if we wanted to pursue technology, how would they go about getting it? And all—the director of the program, the classroom teacher, and the speech and language therapist, all of whom have been working in our town for at least a dozen years each, looked at each other just, like, totally puzzled, like they had never had a kid in their preschool who needed a piece of technology. And they they said, “Well, we could try calling”—first they were just puzzled.

**Denise:** Oh my.

**Parent:** And they said, “Well, there’s a boy in the high school who’s in a wheelchair, and he has a”—and I was like, “No, that’s not going to help me.” And really, it was kind of striking, because in the whole time that my son has been in this integrated public school program, there has never been a child with a mobility issue in the
program; there has never been a deaf child or a blind child; there has never been a child other than X who I’ve seen who has needed a piece of technology like this.

**Parent:** Our town, I think—I know we have an excellent program for children who are deaf and hard of hearing in the next town over, and I’m sure that’s—all of those parents would prefer their kids to be in the—in that early learning preschool, which has an excellent reputation. It’s possible that children who have vision issues are going to X (private school). They might have a preschool program for the school for the blind. And there is a X (another private school) which is also in another town over, that I know deals with children in wheelchairs and with mobility issues and cerebral palsy and things like that. So I can only assume that there aren’t very many kids like that, and they are not in our—they are not served in our town. So they really had—I mean, they didn’t say, “Oh, no, we’ll—sorry, we don’t think he needs that,” or, you know, “We don’t trust your private therapy report”—whatever. They basically just said, “We don’t know. If you come to us and say you need that device, we don’t know—we’ll have to start from square one and figure out what to do.”

**Denise:** Oh.

**Parent:** So that was kind of disheartening, but at the time, we were only looking at something that was—that we could still fund - we knew we could self-pay through our insurance, which is what we ended up doing. We purchased a LEO to use at home and at school.

**Denise:** And who paid for it?

**Parent:** We—our insurance paid for the whole—they paid for the device, a copy of Boardmaker, a carrying case and a keyguard, and the power cord—you know, the whole thing came in, I think, maybe $100 under our durable medical for the year.

**Parent:** And he doesn’t need any—he doesn’t need signs; he doesn’t need picture exchange; he doesn’t need technology to be a receptive learner. He needs all those
techniques to be an ex—to express his knowledge. So the more the teachers are already thinking of ways, you know—particularly in terms of assessment, how they can use it as a tool for assessment, and how to think outside the box. I know they’re very overwhelmed, to some degree. It’s nice that they are trying to figure out how to meet their needs in the classroom. And I think that—I’m hoping that it’s not an overwhelming amount of technology—that they’ll look at it as a tool.

**Funding for Speech Generating Device: Health Insurance Funding Vs. School Factors: Autonomy, Ownership, Ease**

In the next section of the narrative the parent discussed her reasons for using her health insurance to provide funding for her son’s speech generating device. She was somewhat confident health insurance would cover some of the expense and she wanted to “own” the device. In this part of the narrative the parent described how she thought she might need to file an appeal if her insurance denied the funding request. She mentioned that she learned how health insurance companies may negotiate prices with vendors from other parents on listservs. She also described how she recognized that the public school may be responsible for funding the device but she lacked the confidence in the process and outcome.

In this section of the narrative the parent also described how she made decision to apply for MassHealth when the speech-language pathologist at the local hospital recommended a new, more costly speech generating device for her son. Several years ago a therapist in her son’s early intervention program told her about MassHealth. However, she put off applying for benefits because she thought the application would take too long to complete. Now she thought she might need funds from MassHealth to help pay for the new device.
The parent described the funding process as "very easy" because the vendor and the speech pathologist told her exactly what she had to do – what documents she needed and how to obtain the documents. However, she also reported that the first time she applied for funding through her private health insurance the vendor lost the funding packet, which caused a delay.

**Denise**: And how did you decide to go to—go with your insurance?

**Parent**: Well, that—since they—since we could use it, and it would cover the whole thing, and we still want the autonomy to have our own device that we could use outside of—out of the public school setting, we—that’s why we decided to go for insurance. And it was...

**Denise**: And who told you that you wouldn’t be able to have that autonomy if this—if, for example, the school provided it

**Parent**: They’re still so...puzzled.

**Parent**: And also, I didn’t—I couldn’t even imagine how much time it would take for them to figure out, you know, how to access—maybe the money for that school year’s budget is—maybe they—you know, if the money for that school year’s budget was already spent, where were they going to pay for a device for X to use in school? And where were they going to find it.

**Parent**: Then I came home, and I said to my husband, “Oh, we really need to look at the tax thing so we can single out the thing for Mass Health, which we hope will, you know, cover the rest—what our insurance won’t cover for this $9,000 device.” And that’s pretty much where we’re holding. And then, of course, the bottom fell out of the financial market, and I’m anticipating that MassHealth probably won’t pay for anything. But we still have to apply.
Denise: And I remember, when I talked to you last time, you had been putting that off.

Parent: Since X was born we’ve been meaning to apply for Mass Health supplemental insurance and I look at that form and I don’t want to start the process. We just need—my husband is self-employed, so the finances—the—at the time we were waiting for—we needed to submit tax documents, so now the tax documents are actually here.

Denise: So how did you decide to go with Mass Health now?

Parent: X’s Early Intervention therapist had told us that we should apply for Mass Health when he was a baby. And we never really had, thank God, needs—we didn’t really have medical issues that passed our private insurance to the point where we felt like we needed to apply, so we never did. But now we pro—we would like some assistance paying for it. Also, at this point in the—were he staying in the public school full-time, I would probably push the school district further, particularly since he’s moving into the elementary school. But we’re 99% sure he’s going—fully private next year. And while it would be interesting for me—to me, maybe, on some level, to see whether a child who has an IEP and has a demonstrated need for a piece of technology to be successful in school, and I would even be willing to take him to speech therapy in the public schools. Would they make the device accessible to us? I’m not—if it’s taking so long for me to apply to Mass Health, I can’t even imagine how long that kind of process would take.

Denise: Okay, so you mentioned that now you’ve applied to Mass Health. Who do you think will pay for the device?

Parent: I think because of—it—we—it’s—they still have only a $1,500 durable medical, which it falls under. And I think—I mean, from what I think happened, from my understanding, is that the—Mass Health requires the private insurance to pay the
full amount of their—whatever their—whatever our policy specifies, and then the
dist—the manufacturer of the device has some kind of special insurance price that
will cover the difference, but that it’s—in the end, nobody ends up really paying
$9,000.

**Denise**: So once—so your private insurance will cover the—you hope, the $1,500,
and then it will go to Mass Health.

**Parent**: Right.

Here the parent described how the speech pathologist and the vendor helped her
with the funding process.

**Parent**: And the LEO—when we applied—when we went through the process of
purchasing the LEO, the people at Assistive Technologies had a very organized,
thorough funding packet, which was very easy to—you know, they basically said, “Go
to your doctor; have them copy this letter. Go to your state AAC clinician, and have
them copy this letter. Make sure you have this, this, this, and this, and send it to
us.”

**Denise**: So the company guided you.

**Parent**: Yes. A told us—told—you know, when she recommended the LEO, she
included the Website and a—you know, a photocopy of the information about how to
contact the company to get a funding packet. So I assumed that that’s just—you
know, was a very easy way to handle it, and it was.

**Denise**: Yeah. They hire people just to do that.

**Parent**: The worst thing was that they—somehow, the first entire funding packet
that I sent them got lost.

**Denise**: You had made copies of everything.

**Parent**: Yes.
**Parent:** The Prentke Romich Company - they have an even more elaborate funding department. And we’ve also been in touch with our district representative—his name is F—to come and do a product demo for as many people who are involved with X now and will hopefully be working with him next year as possible. It’s just a—like a one-and-a-half-hour overview of what it’s possible for the thing to do. I’d like his teachers for next year to start thinking about it

**Denise:** Oh, such a good idea. So how are you navigating all of these insurance companies? Is anyone helping you? How did you find out everything you did find out about, you know, the cap with your private insurance and that they have to—

**Parent:** Well, we switched private insurances. When we switched private insurance, my husband went through a... Chamber of Commerce private thing, where the—because he’s in the town that he works in. So they came with a bunch of different plans, and he—among the criteria for picking a plan, in addition to, you know, as low premiums as possible and as low co-pays for offices as possible, was that they have a reasonable durable medical equipment, you know, amount that—that was one of the criteria.

**Denise:** Oh, okay. So you checked that out when you were choosing.

**Parent:** Right, and also, you know, other things that are priorities for us as a family, but that was a particular.

**Denise:** Mm-hmm, sure.

**Parent:** And the other stuff—I don’t—X has been very helpful (e.g. the speech-language pathologist from the local hospital).

**Parent:** She’s been helpful, and there’s—the department there has a lot of knowledge, so she’s been good about finding things out from other people if we need it.
Denise: We talked about your insurance, and... so you’re in a wait-and-see mode for them. You’ve completed all the paperwork?

Parent: Yeah, and I assume that—I’ve already prepared myself for some kind of denial. I’m assuming that there’s some kind of an appeal process that you can, you know, go through when they deny your request.

Denise: Okay. And you’re waiting for a denial first from your private insurance, correct? Or you’re waiting—no, you’re waiting for them to tell you what?

Parent: I actually don’t—they—the PR (Prentke-Romich) people said—I mean, they—it seems like they do all the insurance contacting for you.

Denise: Right, right, that’s one good thing.

Parent: So I’m actually not waiting for—I’m just waiting for them to say, “Oh, too bad.” I don’t know actually what they say. Do they come and say, “Oh, too bad; now you have to do this, this, and this,” or do they say, “Oh, too bad; don’t worry; we’ll do this, this, and this”? I don’t know.

Denise: So you don’t even know what your insurance, which is rather new, is going to do and what Mass Health is going to do, though the—like you said, the economy is really in a slump, so...

Parent: They could do nothing.

Denise: So what will you do if they pay for—if somebody pays for part of it?

Parent: I’m not sure. Somebody did mention—I was reading on line—some parent had mentioned that their private insurance paid and then their secondary insurance wanted to split the difference with them.

Denise: Okay. So that might be something you could find out.

Parent: I don’t know also—I have this sense, from what I was reading, that the difference is not the difference between—is not $9,000 minus $1,500—that the difference is $9,000 minus our deductible—our private insurance and—but that Mass
Health would be dealing with some kind of a different actual payment rate with your cost for this month than what’s listed as its list cost.

**Denise**: And so you read this on a listserv where lots of parents share their experiences.

**Parent**: But I don’t know—I didn’t actually call, you know, Mass Health and say, “If I—if someone with private insurance applied, and they were applying for this device, and it costs $9,000, what is the amount that you will agree to pay for it?”

**Denise**: Do you think there’s ever going to be a chance that your private organization will be paying for these devices.

**Parent**: I mean, the—there is grant money, which I think our family will probably access by using it to pay for a classroom assistant. I don’t know—as far as I know, no—as far as I know, it’s not—it’s—there’s nothing that would preclude someone from using—applying to use the grant money for a piece of technology, but no one has.

**Denise**: There’s no precedent. Okay. But there doesn’t—you don’t have anything that says you can’t, or, you know, they—

**Parent**: I mean, it’s a very philanthropic individual who has physically designated that his money not go into the operating budget of the organization but be directly dispersed to families.

**Parent as a Liaison Between the Public and Faith-Based School**

In the following excerpts the parent described how she was taking an active role in arranging training for teachers and therapists at the private and public schools. She mentioned that the director of private organization who provided therapy at her son’s faith-based school was a speech-language pathologist and how this person was
taking the lead to train the staff. The parent also described how she actively sought to obtain training to use the device with her son.

**Denise:** Any other people that have been involved in the process that have helped you along the way?

**Parent:** Right. There’s—we have some—a private organization that gives X therapy in the private school classroom that he goes to, and the director of that program—it’s a pretty new organization. They haven’t served anyone with a need for technology in the classroom. But the director of that program is a..before she took this administrative position, was a speech therapist for many years, so she’s been good about—she’s actually bringing someone to the meeting with X (the vendor), whom she hopes will be able to be an advisor to the classroom teachers next year, because when I was with X (the independent evaluator) at our last meeting, I said that one of the things—in addition to the funding, one of the things that, I think, is really kind of a mental block for me is that I don’t—I’m a techno—I’m not afraid of technology. I don’t think I’m going to break the computer. I don’t—I know how to back things up and whatever. And I understand how the Vantage works, but I don’t know how to teach X how to access the language.

**Denise:** I know exactly what you mean.

**Parent:** But it’s not learning technology for that; it’s learning language

**Denise:** Yeah, concepts.

**Parent:** So I said to her, you know, ”Let’s say, in two months or six months, this thing shows up on my doorstep in a box. Then what would I do with it? I would hate to have $9,000 of equipment that I use to say, ”I want juice.” I mean, I really want him to be able to use it as an expressive language tool.” And she said, ”Oh, you know, the department is actually realizing there’s a need for that, and they’ve tried
to make a commitment in terms of scheduling—that when people got their hands even on a six-week trial, they’ll make an effort to get you in every week.”

**Denise**: Okay. The staff at X Hospital are going to give you some support about teaching.

**Parent**: Right, about how to teach—and they’re going to work with me and X (her child) together and actually—you know, any one of our speech therapists (at the public and private schools) who are able to join us.

**Denise**: And they—and will you have to go there, or will they come to the school?

**Parent**: I would have to go to Children’s. X (the vendor) will not come out to the school more than once.

**Parent**: X from Prentke-Romich has been prompt about answering my e-mails and offered me a variety of dates so that was very helpful. The public school’s therapist—you know, the speech and language therapist, the director of the program—have not been unhelpful; they’ve just been kind of neutral. I think also, realistically speaking, by the time we actually got our hands on a device, we are pretty much out of their program.

**Children with Disabilities Enrolled by Their Parents in Private Schools:**

**Challenges for Parents and Children**

In this part of the narrative the parent discussed her experiences with a group of families whose children with disabilities attend a faith-based school. She discussed the challenges they faced when their children needed therapy services. While the public school provided services, parents faced problems transporting the children to the public school and some parents questioned whether the amount of therapy the children received was worth the effort. Because of these challenges, a group of families started a private organization to provide therapy services at the faith-based
school. In this part of the narrative the parent also described how she felt conflicted about whether to send her child to the faith-based school full time, in part because she was concerned he may not receive the therapy he needed.

Denise: So the private school—it looks like X will be going there full-time, and they’re going to be responsible.

Parent: Right. So the private agency that will give him therapy in the school—right now, his team is a—he has a private speech therapist twice a week that meets him in the private school, and we’re very, very lucky that we found a—an OT who has a master’s degree in deaf education and fluent signer. So she’s been working with him.

Denise: How did you find this organization?

Parent: We started it.

Denise: Oh, you started it!

Parent: It was a graduate organization that grew out of a need in our community, because there—X has the most severe needs of any kid that’s being serviced, but I know it differs from state to state and town to town. In our town, if your child qualifies under an IEP for a speech PT or OT, you have to take your child out of the public—out of the private school and go to the public school setting.

Denise: How did you know that?

Parent: It’s the Massachusetts rule. There are plenty of—there are kids who’ve been through this already, you know, who are in high school now, who—

Denise: So other parents told you.

Parent: Right. For years and years, their parents would send them to private schools, go there at 11 o’clock, drive them across town, wait for half an hour, bring them back to the day school. So it was always a balance of—you know, was what they were getting from the half-an-hour therapy twice a week worth what they were
missing in the day school? The—so it originally started out a collaborative—a couple of the day schools—the Jewish day schools in this area; parents got together and decided to just try to fund—I think at the time, it started out with a PT and an OT to go from school to school to service these kids, so they didn’t have to leave their private school settings and go to public school.

**Denise:** And who was paying for it?

**Parent:** Parents.

**Denise:** So the parents paid for all of this.

**Parent:** Yes, and parents fundraised, and parents hired the staff....

**Denise:** Congratulations! Oh, my...

**Parent:** Thank you. And then we found out that there was a similar organization doing a similar kind of thing, but only for supplementary school, like Sunday school, in—actually in Brookline and Newton. So five or six years ago—five years ago, the two organizations merged, and now they serve at a dozen schools in the greater Boston area. And they continue to run a Sunday program, a supplementary program, a program for teens....

**Denise:** Oh, wow! That’s so exciting!

**Parent:** Yeah, it is. And it—you know, it’s all—it all came out of a bunch of parents—I can’t honestly say we were among the founding parents. We were among the second generation.

**Denise:** But you got involved in the actual developing of the program.

**Parent:** Yeah. So now, the goal is to—the long-term goal is actually to find one of the local day schools to host a program for kids with more severe special needs in their building so the kids can have—can be integrated in the day school setting and get, you know, more intensive therapy. But right now, X’s most probably going to
our local school in the first grade. It’s a dual curriculum, so half a day of general studies and half a day of Hebrew studies.

**Parent:** The coordinator for our area is a woman that I mentioned before who has a speech and language background and has taken a strong interest in making sure that the program is set up properly for X next year in the day school.

**Denise:** That’s really exciting. So he—so he won’t have to leave his program next year.

**Parent:** Right. There—I will—I—it’s—I’m not exactly sure what I’m going to do in the spring. I either will sit for an IEP and see what they offer us and then try to access some part of it after school—I kind of—I would have—I don’t know how to exactly find out—I don’t think they’re going to come out and tell me everything that they would give me, but I don’t know.

**Denise:** Why not? Why don’t you think so?

**Parent:** I mean, I think that they will tell me what he qualifies in terms of services, and if I say, “Well, he’ll be attending a private school from 8 to 3:30,” they’ll say, “Okay, bye.”

**Denise:** Oh, okay.

**Parent:** But potentially, I don’t know—I definitely need to educate myself further. Do they have a responsibility to offer me speech therapy services within the public school day, but at the time—at a time that’s convenient for me? I don’t know.

**Denise:** Mm-hmm, and how are you going to find that out?

**Parent:** I don’t know. I guess I’ll just have to ask them directly. I don’t think they will come out and say, “Oh, fine, you’re choosing to go to public school; it ends at 3:30; we could see X from 3 to 3:30 if that works for you,” because, I mean, I wouldn’t want them—I don’t want to take him out of the day school in the middle of the day, but I would consider doing something like that.
Denise: Because you’re doing it now.

Parent: Well, for a specific thing. I don’t think, at that point, he’s going to need an extra hour of OT a week. I think he will always need an extra hour of ST a week. He has apraxia. If he could get an extra, you know, three 20-minute speech sessions every week, that would be worth it for me. And I also don’t know—I don’t know—at, you know, what—if it’s worth it for me just to keep up his IEP and keep up his triennial review, in the event that we end up in a situation where the day school education just is not working for him, or we want to access other services, or he ages out of—you know, he—the typical day school graduate graduates when they’re 16. He could have services for another five years...

Denise: Right, till 21, right.

Parent: I don’t know it if is worthwhile for me to keep up things with the town just so that—

Denise: Mm-hmm, I see what you mean. Yeah, I see—you’re—you have to cons—you’re considering all your options.

Parent: I’m not—I know that—I know that the public school thinks he’s better served full-time in the public school. I don’t think we’re doing him any kind of disservice by trying in the day school.

Denise: Why do you think they think that?

Parent: Because they—everyone thinks their program is the best. And I think they probably think that a dual curriculum is not something a child can handle. And they—you know, their school day is—has more opportunities in it. He could probably get more actual hours of therapy out of a public school day. But, you know, it’s a balancing effort.

Denise: I understand.

Parent: This is the way it’s falling out for us for now.
**Denise:** So you’re going to wait and see what they say.

**Parent:** Yeah. I don’t want to cut—I don’t want to burn my bridges with the public school.

**Denise:** I think that’s so smart.

**Parent:** You know, I would—and I would like—without counting greedy, I would like parents to be able to take advantage of whatever is—fits in with our schedule and our needs.

**IDEA: Multiple Perceptions: Constraints and Opportunities to Achieve Justice**

When asked about her son’s rights under IDEA, the parent indicated that the law provided important rights for her son, that the written law “guaranteed a lot of things for people” but the law as implemented was not meeting the needs of children with disabilities. How did she develop this perception about the law? She reported other parents told her “horror” stories about problems with getting the IDEA implemented. She believed this was due to lack of knowledge and financial problems and she described IDEA as an “unfunded mandate”. The parent also discussed other perceptions of IDEA: A parent can advocate for their child through knowledge about the law and a parent’s rights under IDEA can be used to obtain a child’s rights.

**Denise:** Oh, okay. Okay. And... let’s see. So I guess the final thing would be just to talk about what you think X’s rights are or your family’s rights are under the current laws. What do you think about that?

**Parent:** Well, the current law being the IDEA?

**Denise:** Yes

**Parent:** I mean, I read so many horror stories from other parents about things, you know, it makes me wonder, like, if these people are educated or—you know, why would school districts go about denying free and appropriate public education to
students? Why would they try to, you know, warehouse all their students in the
district in one school? Why would they not be modifying classroom lessons? Why
would they not care to support the classroom teachers? And I have to think that
they’re—nobody does it because they’re evil; they do it because they don’t have
enough money. Well—or—I mean, I think I’m going to pay for this—not evil; it’s just,
I hope, an ignorance and a lack of knowledge and a lack of understanding. But for
the most part, what I see as being—that the law is positive and should guarantee a
lot of things for people, including X and our family, but that as an unfunded—
unfunded mandate, it doesn’t really have much teeth. I know our town is a
relatively—has very high, you know, MCAS standardized testing scores and a good
reputation academically, but it also has no commercial tax base. It’s purely
residential. And I know that the special ed budget is scrutinized very carefully, and
every couple of years, there’s some scandal in the public paper, because some
parent has sued the school district to send their child to a specialized school for
$120,000 a year or, you know—but has forced the town to bus their child to that
school, because their needs can’t be met in town. And it’s so hard to balance the
needs of the town and, you know, what—there are so many things that—not just
educationally based but—yeah, how do you say, like, “Oh, that’s okay; we don’t need
a new fire truck,” or, you know, things like that? I think that X’s needs are a teeny-
tiny little speck in the greater scheme of things. I think that we’re lucky, because for
the most part, he doesn’t have—for the most part, we can meet his needs just with
our family and the private resources that we have, and that I haven’t had to
depend—I haven’t had to, you know, depend on the law to back me up to get things
that X needs. But I feel so badly for parents who do and have, you know—why
should you have to bring a lawyer into a system.

**Denise:** So you have heard of other parents having to do that?
**Parent:** Yeah, they have to bring a lawyer—I know someone who’s—a couple people who hired advocates, and I think that makes sense. You know, sometimes the—I’m just—it’s just that they seem to think that what should be a supportive, positive so easily becomes adversarial, I think, truly because of the finances—is the main reason.

**Denise:** Yeah, the finances. And you yourself never used an advocate.

**Parent:** No.

**Denise:** Okay, but you do know other families in your community or other families.

**Parent:** Yeah, and I do bake brownies and things when we go in for those IEP meetings.

**Parent:** And I really like—I think that, were we in a different situation and if we didn’t have this desire to have our child in a private school setting....I see other parents very heavily invested in the public preschool program and, you know, have very strong, you know, bonds with the staff and the therapist. Half of the students are typical children, and a number of them have—are siblings of other typical children. Kids who are in the program have to pay to go the program. So I think that—I kind of feel like, in some way, our attachment to the public school program and services that are delivered to the public school is not as strong as it would be if we were in a different situation.

In this last section of the narrative the parent discussed what advice she would give parents of a child who needed a communication device. She described the importance of an assistive technology evaluation and follow-up. She also discussed the importance of gaining knowledge about the law and how she obtained information about the law from information on a website which was developed by
two attorneys who practice special education law. Despite what she knows about the law, she is troubled by parts of the law that she believed were “vague”.

**Denise**: And if—so if you were giving advice to other parents of a child—who had a child who needs assistive technology—maybe not like X, but needs assistive technology for communication—and what would you tell them? About funding or about the laws or...

**Parent**: I think I—the first thing I would tell them would be—because I also read about parents who—I think the first thing I would tell them would be to find the best clinic that you—clinical setting that you can—and the best speech therapist.

**Denise**: That evaluation and ongoing assessment.

**Parent**: Yeah, that has been so important to us, because either—I don’t know if it’s just because no one in our town really knew anything about technology or—having that to back us up and watching X’s progress through that and having that also as a method of proof of his need has been probably the thing that has supported and driven this process the most, because it’s quite possible, for instance, that if we had moved in a different direction, he could be a child—a hearing child who was signing, and maybe we would be pushing now to have an ASL interpreter in this classroom all the time. So it really—and still, I would say that even if this technology worked really well for him, I don’t see him using it 100% of the time. I don’t even see him using it 80% of the time. But I think that when he does use it, it will be the only way for him to express himself. That’s the far—the more sophisticated things he needs to express, because people around him don’t know signing, and he doesn’t have an interpreter. Even though his speech is developing well, no—pretty much only his immediate family and close friends can understand him. So it really—I think that—I don’t know if there will come a time when he doesn’t need it, but I do know that if he does need it, it won’t be his primary form of communication.
Denise: Mm-hmm. So that evaluation and that ongoing evaluation process...

Parent: Very important.

Denise: Okay. Anything else you’d tell a parent?

Parent: I guess to become as informed as they can. I find the—you know, the legal stuff is a little daunting for me, but the Wright’s Law Web site and the Wright’s Law books have been very helpful to me.

Denise: Right to...?

Parent: Pam and—what’s her husband’s name? It’s W-R-I-G-H-T-S—

Denise: Wright’s Law, yeah, okay. Wright’s Law have been helpful to you. Another parent mentioned that, and I have seen—I have gone to that Web site, too.

Parent: They have a great book for parents, called From the Motions to Advocacy, about how to use the system and how—what things to do and what things to kind of—and to avoid.

Denise: So that’s been helpful.

Denise: And available.

Parent: Right, and, you know, anything on the Internet that’s reasonable, sounds reasonable has been helpful.

Denise: Okay. Is there anything else you wanted to talk about or ask me?

Parent: No, just—at some point, I feel like there—like, I did end up finding—Massachusetts has a very vague statute about—if parents purchase a piece of equipment that is required for use in the school, who is responsible for it? You know—or the other way around: If the school purchases something, can the parents have it—can the family have it at home when the child is not in school over the summer? And it basically says something like, “Each district and school has to find a—and family has to find a way to deal—to handle this their own selves.”

Denise: Yeah, case-by-case basis, which is a little scary.
III. Parents Perceptions of the Law Compared with the Positive Law

Medicaid - Payor of Last Resort

The narrative revealed that the parent thought that Medicaid was the payor of last resort. In terms of funding for a speech generating device she believed she had to go through her private insurance first. Based on the law, her perception is accurate. While Medicaid may pay for a SGD, it is the payor of last resort (130 C.M.R. 503.007). In other words, Medicaid may provide funding for a SGD if the private insurer does not cover it or Medicaid may pay a portion of the cost that the private insurer does not cover.

Warranty for the SGD: Is the School Obligated to Pay?

The parent stated she was not sure whether the school would be responsible for paying for the warranty for a family-purchased device. She thought the law was vague on this topic. Based on the regulations, this topic is open to some interpretation. IDEA regulations state that the public school is responsible for maintaining, repairing and replacing assistive technologies that the school provides (34 C.F.R §300.6(c)). However, neither IDEA nor Massachusetts special education regulations specify that the public school has this responsibility for family-owned assistive technologies. The Office of Special Education Program has issued a policy letter on this topic. In 1994 the Director of OSEP supported a family’s request that an Illinois school district assume liability for a family-owned assistive technology. In the letter, the Director of OSEP, Thomas Hehir wrote,
It is reasonable for States to require school districts to assume liability for an assistive technology device that is family-owned, but used to implement a child's IEP\textsuperscript{46}.

Based on this precedent, there is reason to believe the school district may assume liability for a family owned device but it is not clear whether they are obligated to pay all or part of a warranty.

**IDEA: Adequate Resources, Training and Competency in Assistive Technologies**

The parent reported that the public school speech-language pathologists and teachers knew very little about speech generating devices. While they were receptive to the idea of using the device with her son, they did not have the knowledge or experience to help her or her son. In view of this, the parent sought services outside the school system and made arrangements for staff to be trained. Did the school district provide technology devices and services consistent with the law? Possibly not. Federal regulations, which have been adopted by reference in the Massachusetts special education regulations, guarantee a student’s rights concerning AT devices and services, in order for child to achieve a free appropriate public education (FAPE) (34 C.F.R §300.105). The federal regulations clearly state that assistive technology services include an evaluation (34 C.F.R §300.6(a)) and training to the child and family (34 C.F.R §300.6(e)) and educational staff (34 C.F.R §300.6(f); 603 CMR §28.01). Therefore, if the parent’s perceptions were accurate, this would be a departure from the law.

\textsuperscript{46} Letter from the Office of Special Education and Related Services regarding a school district’s liability for family-owned assistive technologies used in public education order for the child to receive a FAPE.
IDEA: School Owned Devices – Can a Device Go Home with a Child?

The parent thought the law was vague concerning whether a child could take home a device purchased by the school. The parent’s perception is accurate, to some degree. IDEA regulations do state that a device may go home with a child if it is needed to ensure FAPE. However, according to the law, this decision is made on a case-by-case basis by the child’s IEP team (34 C.F.R §300.105 (b)). The state of Massachusetts has adopted these regulations by reference (603 CMR §28.01).

IDEA: Children with Disabilities Enrolled by the Parents in Private Schools

The parent was not certain whether the law entitled her son to receive therapy services if she enrolled him full time in a faith-based school. Based on IDEA regulations, children placed in private schools by their parents are not entitled to services that they would receive if they were enrolled in a public school. According to IDEA regulations and state of Massachusetts special education regulations, the state is not obligated to provide any special education or related services under this circumstance (34 C.F.R §300.137(a); 603 C.M.R. §28.00(1)(e)(1-4)). However, federal regulations do require that the local education administrator (LEA) expend a proportionate share of federal IDEA funds on services for parentally placed private school children with disabilities (34 C.F.R §§300.131-300.132). The expenditures and share of federal IDEA funds are determined based on formula. The formula is based on the total number of eligible children parentally placed in private schools aged 3-21 years in the district, in relation to the total number of eligible children in private and public schools aged 3-21 years in the LEA’s jurisdiction (34 C.F.R §300.133). In this case, the child is receiving services while attending a faith-based school part time. Therefore, there is some reason to believe the school district may

OSEP Policy Letter to Anonymous, 21 IDELR 1057 (8/9/94) 34 C.F.R. § 300.6(e)
continue to provide the services, although there is no obligation on the part of the school district to do so.

**Advocating for Rights**
Another question to consider is whether heath insurance regulations and IDEA enabled the parent to advocate for her son to receive some AT rights under the law. I believe they did. The parent had some knowledge about health insurance regulations and was knowledgeable about benefits. She navigated two complex health insurance systems to obtain benefits. In terms of IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations, a parent has rights in four major areas: prior written notice (§300.503; 603 C.M.R. 28.05, 28.05), consent for services (§300.300; 603 C.M.R. 28.07), developing the child’s Individualized Education Program (IEP) (§§300.320, 300.321, 300.322; 603 C.M.R. 28.05) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 603 C.M.R. 28.08). Consistent with IDEA regulations, in Massachusetts a parent may resolve a dispute in several ways: informal measures (as this parent did), through mediation, through a formal complaint by contacting the Office of Program Quality Assurance Services, by requesting a due process hearing, and if necessary, by appealing a hearing decision to a state of federal court (§§300.500, 300.529; 603 C.M.R. 28.08). In this case, the parent asserted her rights to challenge decisions primarily in an informal manner - by talking with teachers and administrators. While she recognized she had options under the formal law, at times she felt the obstacles were too great and therefore she went outside the school system and IDEA to obtain some services that she felt her son needed.
Case Analysis #7

Demographic Information

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<th>Age and gender of child</th>
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<td>Trisomy 21 per parent</td>
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<td>Type of School</td>
<td>Private integrated preschool recommended by the public school</td>
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<td>Race</td>
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<td>Martial Status</td>
<td>Married and lives with husband</td>
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<td>Interviewee</td>
<td>Mother (&quot;Ms. Cole&quot;)</td>
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I. Case Facts

This case involves a 6.6-year-old boy with a diagnosis of Trisomy 21 per parent. He has multiple medical, physical and cognitive disabilities. His speech is limited to a few words and a few phrases. He uses a speech generating device (SGD) to augment his communication. He attends a private integrated preschool program. At age three years, when the child aged out of an early intervention program, the public school department recommended the child attend this private, integrated program.

The parent began having disagreements with teachers and therapists when her son was enrolled in the Early Intervention program (EI). The parent thought he should receive speech-language therapy as part of the program. The team disagreed; they
did not think he would benefit. After many disputes with the early intervention team about this issue, at age 2 ½ years, her son began receiving speech-language therapy. In the interim, the parent sought private speech-language pathology services at a local hospital. Health insurance funded these services. She also decided to educate herself about augmentative communication methods. She attended workshops and talked with an aunt who worked in special education. With this information she began to fabricate a picture-based communication system for the child to use at home.

When her son turned three, the public school recommended he attend a private integrated preschool and the parent agreed. During that time he was still receiving private speech-language treatment (at a local hospital) and the speech-language pathologist there advised her to obtain an independent augmentative communication (AAC) evaluation. This therapist referred her to a local augmentative communication specialist at a local hospital and the parent arranged for the evaluation.

The child had several visits with this local augmentative communication specialist. Health insurance funded these sessions. The specialist recommended some devices for the child to use. The private school provided devices that were similar to what the specialist recommended. After awhile the parent thought the child outgrew these devices and the independent augmentative communication specialist agreed. The specialist recommended that the child try a variety of higher level devices and have a follow-up evaluation through the state’s Assistive Technology Program – Tech Access. The specialist referred her back to the school system for an evaluation and training with higher level devices. The parent reported that these recommendations
were written into the child’s Individualized Education Program (IEP) by the child’s IEP team.

The parent reported that the school did not provide the assistive technology devices and services, as specified on the IEP, and parent had many disputes with the school about this. The public school system and the private school disagreed about who was responsible for the devices and services. The independent AAC specialist recommended she file a complaint with Rhode Island Department of Education. After advocating for her son through informal dispute resolution methods, the parent eventually filed a complaint with Rhode Island Department of Education. The device was eventually provided through the public school department. However, six years later, the parent continued to have disputes with the school. The school reportedly is not using the device with the child. The parent continued to advocate for her son to obtain the services she believes he needed and was entitled to receive.

II. Analysis -Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? How do families obtain their knowledge about the law? How does a family obtain their knowledge about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?
**Perceptions about the Law**

The narrative revealed that the law became infused into this parent’s everyday life. It became a part of her everyday life because from the time the child was enrolled in a publicly funded early intervention she persistently advocated for her son to receive assistive technology devices and services through health insurance and through the public school. The legal structure of the law empowered her to assert her rights and claim her son’s rights. As part of this process, the parent was frequently up against the law. I use the term up against the law to refer to the parent’s perceptions of feeling caught up in the law due to persisting disputes concerning assistive technology devices and services for her son. I adopted this term from Ewick and Silbey’s sociolegal research (1998).

The parent’s perceptions of the law were shaped through interactions she had with a variety of people and some personal factors. These interactions influenced her decisions and determined whether she invoked certain rights. The narrative revealed there were two main themes: the parent was empowered by the law and felt caught up in the law.

As the parent experienced disputes with people, she began to think about the law as a way to resolve her grievances. When she could not resolve her grievances through informal disputes resolution processes, she invoked the formal law. As the parent gained knowledge of the formal law, she used the law as a tool to obtain her rights and her son’s rights. For example, when advocating for her son she stated she would “threaten” teachers and therapists with “non-compliance” and she reported she achieved some success with this strategy. Thus, based on her statements and actions, the law helped her and the law hindered her.
Interactions with People Shaped her Decisions and Determined Whether and How She Advocated

The parent gained information about IDEA and health insurance benefits from interacting with a variety of people – a family member, a parent in her community, parents on listservs, physicians, her son’s therapists at school, her son’s therapists at a local hospital, the independent augmentative communication specialist and the Rhode Island Department of Education. When she was going through disputes with the school, she said, “I talked to everyone I could.” She tried to find other parents in her district with similar issues but did not find other families who had children similar to her son. She also sought information and guidance from community organizations and other health care professionals and researched information on the Internet.

How did these interactions impact her decision-making? During the process of obtaining a device for her son, these interactions empowered her with knowledge, which influenced her ability to advocate for her son and ultimately determined whether and how she asserted and claimed her rights and her son’s rights. Here are some examples: After talking with her aunt who worked in special education, the parent decided to use picture symbols with her son. She also decided to take workshops to become more educated in AAC methods. When the EI program would not provide speech-language therapy for her son, she sought private therapy, which was funded through health insurance. During an interaction with her son’s private speech pathologist at a local hospital, the therapist suggested that the parent obtain an independent AAC evaluation. This led her to a local AAC specialist who recommended specific devices for her son to try. Also, this AAC specialist gave her information on Rhode Island regulations. Here are some other examples. After interacting with the private school speech-language pathologist and her son’s
pediatrician about the paperwork required by health insurance, she decided not to seek funding for a device through health insurance. She felt the obstacles were too great, but this did not dissuade her from trying to get a device for her child. She turned to the school to provide the device. After multiple interactions with public school administrators, she filed a complaint with the Rhode Island Department of Education. The narrative illustrated other examples of how interactions influenced decisions and perceptions about the law. Excerpts are noted below.

**IDEA: Lack of Knowledge and Resources**

The parent thought that the teachers and therapists did not have the training to evaluate her son’s augmentative communication needs and implement the recommended. She developed this perception from interactions she had with teachers and therapists. She responded by persisting advocating for services through the public school and going outside the school system and IDEA. She obtained an independent evaluation which was funded through health insurance.

**Distrust for People Implementing IDEA**

As the parent engaged with staff in the public and private schools, she began to distrust them. She reported that they did not follow through with things they agreed to do and she thought that some people did not tell her the truth. She responded by logging all interactions and eventually she invoked the formal law.

**Arbitrary Nature to the Health Insurance Waiver Program**

The parent reported she had significant difficulty applying for benefits through a state subsidized waiver program. She reported that another parent recommended she contact her state Senator for assistance. She knew other families who received
services through this program and she thought that eligibility requirements were somewhat arbitrary.

**Personal Factors Which May Have Influenced the Outcome**

The parent’s personal attributes may have impacted the process and outcome. The parent talked about how important it was for her to become “educated” about assistive technology. She recognized that information empowered her to advocate for her son. She also mentioned how important it was for her to stay organized. She logged all phone calls and maintained detailed records. She was persistent and used the term “persistence” to describe how she advocated for her son. The parent also mentioned that she went back to school to become an occupational therapy assistant. She reported that the knowledge she gained through coursework helped her to advocate for her son.

Excerpts from the narrative illustrate these concepts.

**Disputes About Speech-Language Therapy/Augmentative Communication Services Began Early**

Here the parent discussed disputes she had with educators when trying to get speech-language services for her son in an early intervention program. In response, she educated herself about augmentative communication services, she obtained speech-language therapy at a local hospital and she continued to advocate through the public school system.

**Denise:** So tell me about the process for getting a speech generating device start? When did you start thinking about a device for X?
**Parent:** Let’s see…. X started Early Intervention at 14 months of age—during 14 months to three years of age. I just did the PECS systems (picture exchange communication system).

**Denise:** And how did you get linked to early intervention and the PECS system?

**Parent:** We got—X started having a lot of hospitalizations. Our pediatrician referred us after X spent time in the hospital. And so they got involved, and X had a lot of issues: not just speech but also fine motor, gross motor and all that. And so, we tried to find some way of him to communicate like PECS but it was—he doesn’t like to be touched, and so any touch, especially a stranger, really upset him. So the PECS wasn’t working out—

**Denise:** And who introduced you to PECS?

**Parent:** That was the service coordinator at Early Intervention.

**Denise:** And was she an educator, speech pathologist…?

**Parent:** She was, I would assume, an educator. To be honest with you, I’m not really sure. I had to really difficult time trying to get speech therapy for X in Early Intervention. She said he had so many issues and that that was—would just add to the list.

**Denise:** Okay….

**Parent:** Yes [laugh]. I was pretty upset about that, and so that got me to start taking workshops—local workshops whenever I saw something. I started taking a lot of workshops and educating myself. So by the time he was three, he was using pictures from magazines and boxes and I put them on the fridge.

**Denise:** Okay. So you started educating yourself going to local workshops….

**Parent:** I did.

**Denise:** Was there someone who helped you early on?
Parent: I have an aunt in Florida who is a special education teacher for the homebound children who gave me lots of assistance and advice.

Denise: Tell me about that.

Parent: She told me about Boardmaker pictures and gave me advice on making a book for X....

In the following excerpts the parent described how she continued to advocate for her son to receive speech-language services in the Early Intervention (EI) program. She was successful. At age 2 ½ he began receiving these services through the EI program. The speech–language pathologist in the EI program began to address her son’s augmentative communication needs and she told the parent about an AAC specialist at a local hospital who could evaluate her son’s augmentative communication needs. During this time the parent also sought private speech-language and occupational therapy services through a local hospital. She accessed public and private health insurance to fund these services. The parent reported that the private therapists were not familiar with assistive technology.

Parent: X started receiving private speech while in Early Intervention due to my persistence and complaints, because they felt it wasn’t appropriate for him to receive this service in EI. They felt that he had too many other issues to resolve before speech got involved. When we went for an initial evaluation at X (a local hospital). They felt that he should also receive private OT as well, and so we started that. When he turned 3, we started at X (the local hospital) 2 X’s a week – for private speech and OT. The speech therapists were not very familiar with AT and mainly worked on his following directions, making choices, and pictures.... No, the private therapists were of no help in suggesting or receiving the AT device, nor did they
work with it on a weekly basis when we got it. I could tell they were all inexperienced in this area.

**Denise:** Who paid for the therapy?

**Parent:** My health insurance.

**Denise:** You mentioned X began receiving speech therapy in the EI Program. Tell me about the therapy.

**Parent:** The speech therapist was very helpful. She made a book for X with Velcro pieces. The pictures came off and he would give it to us and show us. She was the first one who gave me information on the augmentative communication specialist at the local hospital. He was only in the program for about six months longer.

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**Parent Obtained an Independent Augmentative Communication Evaluation**

The speech therapist at the integrated preschool recommended an independent augmentative communication evaluation. This was funded through health insurance. When asked whether she thought the public school might pay for the independent evaluation, the parent’s reply suggested she has little confidence and trust in the public school.

**Denise:** And what about the speech therapist who evaluated X at the preschool?

**Parent:** When he was—once X graduated from EI and he went to the integrated preschool, there was this speech pathologist who could tell that he was ready for something, and she tried him on several things. She did not evaluate him. She just—trialed. She just trialed them—trialed with some different devices. And they started with the Big Mac and then used the Cheap Talk. She had experience in it. She had other students with development disabilities as well. She had other different devices. She thought he was ready for a higher level device. She recommended the X for an outside evaluation.
Parent: So I took X up to see T (augmentative communication specialist) at the Y (local children’s hospital). I found him online. He recommended the Tech/Speak 6X32.

Denise: Who paid for the evaluation?

Parent: My health insurance

Denise: How was that process?

Parent: We have private Blue Cross through my husband’s employer and what they don’t pay the state Medicaid waiver called Katie Beckett covers usually without question. We must apply yearly now for this waiver and am always made to feel like he won’t qualify from year to year.

Denise: Did you consider asking the school to pay for the evaluation?

Parent: I don’t think our district would ever be forced to pay for X’s fee because they would drag their feet, make promises, say we'll check on that (but really wouldn't).

Persisting Disputes between the Integrated Preschool and the Public School Department About Augmentative Communication Services

In these next sections of the narrative the parent discussed frequent interactions with staff at the child’s school, an integrated preschool which was recommended by the public school. There were many disagreements about his needs. The private school provided several different speech generating devices for the child to use at school but would not permit the devices to come home. After awhile, the parent felt the device being used at school was not meeting his needs. She felt he “outgrew” the device and needed a higher level device, as recommended by the independent evaluator. To determine the most appropriate device, the public school required an evaluation by the state’s Assistive Technology Program (AT), Tech Access. However,
because of the conflict between the two schools, the Tech Access program refused to conduct the evaluation.

**Denise:** What happened after that?

(Note: The parents used information in her files to provide the following information.)

**Parent:** On April 28, 2003 I sent communication book to school that I made for X. It was 2 mos. since we spoke about TechAccess evaluation. I've always been able to talk with his school and private ST's about creating a book but they never really showed interest in getting the ball rolling. X's private ST, I believe was the first one who gave me information on the T (augmentative communication specialist at the local hospital).

Oct. 03: Our initial evaluation for X (her son) at the Y (local hospital for augmentative communication evaluation) was when he was 4 1/2 years old. Referral was through his metabolic specialist in Boston, only after I presented the issue to her at a visit. Recommendations included Tech/Speak 6 X 32.

**Parent:** In November 2003 I requested an IEP review to talk about communication book and device... moving from pictures to laminated pages along with tabs. I requested more pictures from the speech therapist. In February 04 I received the pictures from the speech therapist, due to her computer being broken down. The original tabs that I made were replaced with smaller ones. I requested an IEP review. At this meeting I was told the device he was using at school could not be sent home because it was for school use only.

**Denise:** What happened after that?

**Parent:** In March 2004 he was beyond this single symbol level and I was moving more toward a dynamic device for him. At school he was using a CheapTalk 4 and 8, purchased by the out-of-district program. The school was using a device that he had
obviously outgrown, but no initiative was being taken to move beyond that. I tried to
contact our local assistive technology center, Tech Access, prior to this visit, only to
be told they wouldn’t help me because of the conflict between placements. T at the
hospital (the local augmentative communication (AAC) specialist), he didn’t like that
and actually made a call to the woman I spoke to and gave her an earful right there
on speakerphone. So X (the local AAC specialist) really emphasized the Rhode Island
regs to us at this visit about the school purchasing the device. He told me to do
whatever I had to do to get X a device and that meant filing a formal complaint. He
was furious with the run around I was getting and made it well documented in his
report. He made recommendations for the Dynavox MT-4, E-Talk Impact, MiniMerc
and Speaking Dynamically Pro.

**Parent:** On March 23, 2004 I requested an IEP meeting to discuss X’s
communication needs with the school department and out-of-district team. They
then added the CEC (independent evaluator) report recommendations to the IEP... to
explore augmentative communication devices with support form the speech therapist
and to further discuss options with the Director to determine services needed to
facilitate X’s language skills in the classroom with carryover at home. I requested a
meeting within 30 days to see implementation of additional communication services
in his preschool. I sent a letter to the Director of Special Services describing my
frustrations regarding the team decision to not allow the device to be sent home,
delays in receiving updated pictures for his communication book and not being taken
seriously about an evaluation through Tech Access.

After multiple phone calls and meetings the school department agreed to an
evaluation through the state’s assistive technology program, Tech Access. After the
Tech Access evaluation, the speech therapist at school trialed devices with her son
and recommended a device – the device recommended earlier by the independent specialist.

**Denise:** What happened after that?

**Parent:** May 13. Email from the school ST (speech therapist) stating she received a call from the Child Outreach coordinator, who was the go-between for the school dept. and out-of-district placement, informing her the Director of Special Services wants another opinion from Tech Access because it was stated on the X report (from the independent AAC evaluation). The speech therapist informed me that Tech Access was very backed up and possibly months before any appointment made. This is where the speech therapist made a recommendation to pursue private insurance and Medicaid.

**Parent:** As of May 24, 2004 – Unable to reach anyone by phone and no return calls received. By mid June 04 I was finally given verbal approval through the school dept. for an evaluation to be done through Tech Access. I was told the necessary paperwork was mailed ions ago but found out through multiple calls it was only received a day or two before. Needless to say, I freaked out and demanded an eval as soon as possible but had to wait for a letter to be received by all parties before an appointment could be made. This letter was received late June. In June 30 through July 14, 2004 X was evaluated through Tech Access and the report was sent to the Director of Special Services in early August, 2004. In order to get a copy for myself, I needed to contact the Director's secretary since they paid for the evaluation. I made several requests throughout August only to be put off with varying excuses.

While this speech therapist had earlier recommended the parent pursue funding through health insurance, when this therapist reviewed the paperwork, she thought
it would take too much time. She told the parent that she would need to take time away from X’s therapy to fill it out. Furthermore, her son’s pediatrician refused to complete the paperwork because it was so “involved”.

**Parent:** The speech therapist trialed the devices, recommended a device and then there was a problem with funding.

**Denise:** Tell me about that

**Parent:** The speech-language pathologist at preschool showed me the paperwork. X’s doctor was nervous because it was so involved. He didn’t know how to fill it out. He didn’t know how to cope. He just looked at it and said, “Can you have the speech therapist fill it out?” The speech therapist was worried about who would pay...who would pay for her time to fill it out and it would take away from her speech therapy. It was ridiculous, like that’s not my issue. I was told that X's speech time would be used to fill in paperwork and he could not receive any direct services due to the amount and time required.

**Denise:** Oh my.

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**Invoking the Law: Filing a Formal Complaint Through the Rhode Island Department of Education**

The schools disagreed about who was responsible for providing the device and the parent eventually filed a formal complaint. During these interactions you can sense that the parent thought that she could not hold people accountable and she began to distrust the system. The parent reported she had difficulty completing the paperwork to file the formal complaint because she was not familiar with the law.

**Parent:** Then the school department claimed we were out of district so they weren’t responsible. The preschool said they are not responsible because we are out of district. We went back and forth back and forth until he was five and eventually I
filed a formal complaint. One hand does not know what the other hand does. They are not on the same page in different departments. Once they realized who was responsible to pay for the device, they had to move forward with it.

**Parent:** At the end of August 04 Tech Access made a request for a rental and eventual purchase of a speech-generating device through the public school's speech therapist. It states that X has had a trial with several devices from Dynavox and that the MT-4 was recommended. The school speech therapist had called Dynavox who sent a representative out to the school for trials on many styles.

**Denise:** What happened after that?

**Parent:** In early October 04 I called Child Outreach coordinator and was told to just sit back and wait. She told me the district speech supervisor had reports and will contact the school's speech therapist with any questions. She also told me the two had actually spoke about X the week before, but upon asking the school speech therapist. Not true. In Mid October 04 I spoke with RIDE (Rhode Island Department of Education), after lots of phone tag, to complain about non-compliance of the IEP. I was informed a complaint could be filed given the information I provided. She sent the forms in the mail: complaint form, RI regs and new family friendly regs. She also made phone calls to find out what's happening. I think at this point, I was so tired of being lied to by administration. Then On October 27, 2004 the school department received a letter informing them of a complaint to RIDE. It said “Students IEP calls for an electronic augmentative communication device to be used as part of a total communication system. The parent reports no device has been purchased. The IEP was March 23, 2004. On November 1, 2004 I was notified that device was ordered today! I made many, many phone calls to follow up on this, just to be sure. The purchase order was NOT cut until mid Nov! See, I knew it! In Dec, 2004 the school dept. purchased the Dynavox MT-4 for X. When it arrived at
administration building, it sat in the secretary’s office for TWO weeks before finally being delivered to school!

**Denise:** How did you know how to file the complaint?

**Parent:** I really only have to look in the blue pages of our phone book, find Rhode Island Department of Ed, Special Services Division and make a call. I’m transferred to someone familiar with my district and just tell my story using my logs. This person makes phone calls to confirm, sets a fire under their butt, and gives me recommendations on what to do next. - really quite simple.

**Denise:** How did you choose to file a complaint vs other possible options for resolving the problem?

**Parent:** Many calls were placed to the Assistant Director of Special Services and the Director of Special Services with no real follow through. It just never occurred to me to use the terms “mediation” of “due process” because everyone knew of my concerns and nothing was getting done even after repeated phone calls.

**Denise:** How was the paperwork for filing the complaint?

**Parent:** I had to put down the section of the law that I felt was not being fulfilled. How can any typical person understand the educational laws that well to be able to pick from the list to apply to their particular situation? Needless to say, this particular part held up my application until I was told by a woman at the Dept. of Education that the department of Special Populations would help with that section and for me not to worry about it. And to be honest, the more I think about it, the more I’m realizing that the paperwork that was given to me on my rights was difficult to follow and was quite intimidating to me.

*Networking to Gain Information and Support*
When asked who has helped her during the process, the parent indicated she talked with a variety of people – therapists and other parents on-line – and parents though a local support group. She mentioned getting support from a parent in her geographic area and from the local assistive technology vendor.

**Denise:** Did anyone else help you during the process? Any people or organizations?

**Parent:** I talked to everyone that I could. I asked all of X’s therapists. I went online. I have some emails to/from a local online support group to parents on help with AT Suggestions were given to me to be patient, to keep calling people, or to contact my local Dept of Ed.

**Denise:** Anybody else? You don’t have to give me names, but...

**Parent:** I’ve tried to find people within our area in Rhode Island and have not hooked up with anyone yet. There is a woman within Rhode Island. She’s up in northern Rhode Island, and she has a daughter who’s in her 20s and uses an older type of assistive technology. And she’s been pretty helpful with me. She kind of guides me in different directions. Like, she helped me find this support group online.

**Denise:** Did anyone else give you advice during the process?

**Parent:** I have gotten some advice through Dynavox. The representative has been very, very helpful. She’s only in our area certain times, so it’s not like I can pick up the phone and say, “Do you have time next week to come and see me?”

**Denise:** So what has she told you?

**Parent:** She, well, she does tell me that I’m not alone, that she does this often and that education is the best key to it, or just to become educated and to really just try to pass that along.

**IDEA: Inadequate Knowledge and Training to Implement Device**
The parent thought the law failed to ensure that staff were adequately trained to help her son learn to use the speech generating device. Again, she mentioned how she continued to log all telephone calls to help ensure that people were held accountable. She did not think that the law could help her or her son to resolve the implementation problems.

Denise: Is there anything else that bothered you?

Parent: I still have issues. It’s just of matter of logging all my phone calls. It’s not intimidating when you have those logs in front of you with all the info you need. The hardest part is staying neutral and sticking to the facts. And of course, staying organized. I am still angry there is no assistive technology specialist to help him. They had him repeat kindergarten so staff could learn to use to the device.

Denise: Oh my.

Parent: He’s not getting the therapy that he needs. I’m meeting this week with X’s special ed teacher and the speech therapist to discuss the Dynavox use at school. So far, he opens it and turns it on. Usage is minimal and no new information has been added this year except for my changes to some of his pages such as new teachers. It seems the speech therapist has complained to the Director of Special Ed about having too large a caseload and no time to learn/program the device. I learned this second hand from his teacher when I called the meeting. You’d think they’d have brought it up at the meetings we had recently. Go figure! But I’ve found this to be the case when administration doesn’t help solve the dilemmas that were brought to their attention.

Denise: I understand. We had talked a lot about X and school, and how frustrating the experience had been for you, and how long you had to wait to get X any assistive technology. And—so tell me a little bit about what you think his rights are under the law?
Parent: I just feel that he has a right to communicate, so I feel that they are obligated to purchase him something if he needs assistive technology. But to go beyond that, I feel like I’m in limbo.

Denise: Okay. Do you think you have any other options right now?

Parent: I feel... no, I don’t.

Denise: Okay, because you had mentioned they haven’t done much programming, but you still don’t feel you have any options.

Parent: I don’t feel that I have any options.

Denise: Do you think the law has given you any—gives you any options?

Parent: In order to program? I would have to say no.

Denise: Anything else you would say about IDEA?

Parent: IDEA is a great concept but if you are not putting any money or training behind it, what good is it.

Katie Beckett Waiver Program – Difficulty Navigating the System

In these excerpts the parent described her struggles applying for a health care waiver program. She turned to her Congressman for help. Based on this section of the narrative, the parent thought that the qualification process for the waiver program was somewhat arbitrary.

Parent: We have private Blue Cross through my husband’s employer and what they don’t pay the state Medicaid waiver called Katie Beckett covers usually without question. We must apply yearly now for this waiver and am always made to feel like he won’t qualify from year to year.

Denise: How did you find out about Katie Beckett?

Parent: We were told about the Katie Beckett waiver from Early Intervention after X had his second hospitalization. I had no idea what it was all about but knew it was
important the way our service coordinator delivered the info to us. It was so difficult
to get a return phone call that I needed to contact our local Senator to finally get an
appt. Senator Reed continues to be a great advocate for us when we need him.

**Denise:** You mentioned you are made to feel that he won’t qualify form year to
year. Why is that?

**Parent:** The State’s budget is in dire straits and so cuts have been everywhere.
Once upon a time, all kids who needed help were placed on Katie Beckett with the
thought that helping them now would save money in the long run. X qualified for
this program well before his diagnosis and only because he was significantly delayed
in all areas and he was beginning to have medical issues around age 14 months.
Now, it’s all about saving money. More than half the kids were thrown off the
waiver, and rightfully so for most, but it is the state’s intention to keep as many kids
off the program as possible. I am told yearly that medical needs do not qualify a
child alone, that they must be institution level of care. And since there is no model
for this here, picking and choosing a child at this level can be a matter of personal
opinion. We are sent an extensive packet to fill out, which I usually just copy and use
from year to year. Copies of updated reports and medical are required as well and a
determination is then made as to whether the child qualifies. It’s quite nerve
racking.

When we were first told of this "program" I honestly had no idea what it was all
about. I just knew it was important and that it was imperative to get X on the
waiver asap. But no return phone calls came, which added to my anxiety, and so I
called the Cranston, RI office for Senator Reed. I believe someone recommended
that I call him for help. I think another parent. They assigned someone who took
care of our area, took all the info I had and then made the phone calls for me. I remember getting a phone call within 24 hours with an appt. at my HOME within the week. The woman who came left crying because of our situation at the time and I think she was very sorry for not returning our calls and such. I’ve also called Senator Reed’s office for assistance in other areas pertaining to X, usually related to medical, and they’ve been exceptional! I’d highly recommend anyone to call their representatives, congressman and senator when they cannot resolve issues of any kind, as long as they document what they’ve done and the results.

III. Parents’ Perceptions Compared to the Positive Law

**Funding for the SGD: Health Insurance vs. School**

How did the parent’s perception of her health insurance compare with the positive law? The parent believed that her private health insurance and/or her son’s public health insurance may fund a speech generating device for her son. While health insurance may have covered the device, the parent did not pursue funding through these sources. Why? The school speech pathologist told the parent she did not have the time to complete the paperwork. Also, when the parent asked the pediatrician to complete the paperwork, he refused. The parent felt these obstacles were too great so she turned to the school to provide the device. Thus, these interactions dissuaded her from pursuing funding through health insurance.

There is reason to believe that health insurance may have paid all or some of the cost of the SGD. Over the years the family’s Blue Cross Blue Shield plans had paid for other durable medical equipment. The child also had health care benefits through a Medicaid waiver program known as Katie Beckett. This program may have covered the cost of the SGD if the private insurer did not cover it, or Medicaid may have paid
a portion of the cost that the private insurer did not cover. Children age birth through 21 years who qualify for services under a Medicaid program are eligible to receive benefits through Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) service\textsuperscript{47}. This is a mandatory service under Medicaid (42 U.S.C. §1396a(a)(10)(A)); (§1396d(a)(4)(B)); §1396d(r). Under this program, a state must provide any of the services listed in the Medicaid Act, including optional services, whether or not the service is included in the state's Medicaid plan. (§1396d(r)(5)). Under the EPSDT, SGDs are covered under one of several benefit categories: home health care services, including medical supplies and devices; prosthetic devices, rehabilitation services, preventative services, and speech-language pathology services. While Medicaid may pay for a SGD, it is the payor of last resort\textsuperscript{48}.

\textit{Definition of Durable Medical Equipment}

The narrative revealed the parent might have a misperception about the law. This possible misperception concerned health insurance funding for augmentative communication equipment. The parent would like the independent augmentative communication specialist to help her obtain funding for software programs for her son through health insurance. She did not understand why this specialist had not done this. However, these software programs are not typically defined as durable medical equipment (DME) because they may be used for non-medical purposes and may be useful in the absence of an injury. Most health benefit programs define DME based on these characteristics\textsuperscript{49}.

\textsuperscript{47} Rhode Island Department of Human Services Code of Rules 0300.20.05.10
\textsuperscript{48} Rhode Island Department of Human Services Code of Rules 300.30.25
\textsuperscript{49} While there is no federal definition of DME, most states define DME based on the following features:
- can withstand repeated use
- primarily and customarily used to service a medical purpose
- generally not useful to a person in the absence of illness or injury, and
Parent: The more I think about our situation, I'm becoming more frustrated even with X (independent augmentative specialist) about lack of follow through for X. Why doesn't he put through the insurance a request for Boardmaker at home or other software? Why couldn't he force the school to program suggestions he's made within a specific period of time, leaving me out of this fight?! Why couldn't he set up a specific program on the device instead of making suggestions for me to relay back to the school? I cancelled our last appt. in April/May because I felt nothing would be gained by the visit at this point. I don't think I'll be going back anytime soon. X makes some wonderful suggestions, has great ideas, but then pushes them on me to do what? fight with an SLP who doesn't know much about AT, or doesn't believe in its effectiveness in the classroom setting? Is it worth the day long trip, I just don't think it is anymore.

School Owned Devices – Can a Device Go Home with a Child?

Did the school violate IDEA when it did not permit the device to come home with the child? IDEA regulations, which have been adopted by Rhode Island in its special education regulations (RISER §300.105 (b)) state that a device may go home with a child if it is needed to ensure a Free Appropriate Public Education (FAPE). According to the law, this decision is made on a case-by-case basis by the child’s IEP team (34 C.F.R. §300.105 (b)). In this case the school told the parent it could not be sent home because it was for school use only. The parent disagreed and advocated for the device to come home with her son. She sent a letter to the Director of Special Services but did not receive a reply. More information would be needed to determine if the school’s decision was a departure from the law.

- is suitable for use in the home (O’Connell et al., 2004).
Public School vs. Publicly Recommended Private School- Obligations to Provide Services

Another legal issue concerned whether the public school department or the private school was responsible for providing the device. Under federal regulations, which have been adopted by the Providence of Rhode Island in its special education regulations\(^{50}\), the public school is obligated to provide a Free Appropriate Public Education (FAPE) to a child at no cost to the parents, to children with disabilities in private schools who are referred by public agencies (34 C.F.R. §300.145 through §300.147; RISER §300.145 through §300.147). This includes assistive technologies devices and services (34 C.F.R. §300.5, §300.6, §300.105; RISER §300.5, §300.6). However, the public school is not obligated to provide the devices and services if another non-educational agency is obligated to do so based on federal and state law (34 C.F. R. §300.154 (b)(1)(i)). Furthermore, the public school may seek reimbursement from the non-educational agency if it fails to provide the special education or related service (34 C.F.R. §300.154(b)(2)). Therefore, based on IDEA regulations, the public school is not the primary payor. It is important to note that over the years the private and public schools did provide some low technology devices for the child to use. When a higher level device was recommended by the independent evaluator and the Rhode Island’s AT program, the parent decided to access health insurance to fund it. However, the speech-language pathologist and the child’s physician refused to complete the necessary documentation. The public school eventually agreed to provide the more sophisticated device for the child to

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\(^{50}\) Rhode Island Board of Regents for Elementary and Secondary Education governing the Education of Children with Disabilities has adopted the federal regulations by exact reference. http://www.ride.ri.gov/Special_Populations/State_federal_regulations/special_education_regulations_2008.pdf
use at the private school. This was after several years of the parent advocating informally and formally. Was the public school’s decision a departure from the law? The public school may not have been obligated to provide the device. However, if the parent could not obtain funding for the device through a non-educational agency and if the device was necessary in order for the child to receive a FAPE, then the public school may have been responsible.

**Independent Evaluations**

There is another possible legal issue to consider. Was the parent entitled to an independent AT evaluation at public expense? The answer is perhaps. While the parent thought she may have been entitled to this, she decided not to request it because she thought the school would not expedite the request in a timely manner. Based on IDEA regulations (34 C.F.R §300.502 (b)(1)), which have been adopted in the Providence of Rhode Island’s special education regulations (RISER §300.502 (b)(1)), a parent is entitled to an independent evaluation at public expense when the parent disagrees with the evaluation obtained by the public school, under other conditions as specified.

**IDEA: Adequate Resources, Training and Competency for AT Equipment?**

The narrative raises two legal issues concerning IDEA. Firstly, did the school provide resources, training, competency for AT services and equipment, in order for the child to receive a Free Appropriate Public Education (FAPE), consistent with IDEA and Rhode Island regulations? In terms of resources and training, the answer is that, based on what the parent reported, the school provided some AT resources, consistent with the law. The public school provided the child with some assistive technology devices and services. When it came to training for her son to use a higher
level device, as recommended by the independent AAC specialist and written into the child’s Individualized Education Program (IEP), the parent reported that the school did not have the knowledge and expertise to train her son to use the device. If accurate, this would not be consistent with the law. IDEA regulations, adopted by Rhode Island, guarantee a student’s rights concerning AT devices and services, in order for child to receive a FAPE. The regulations clearly state that assistive technology services include training to the child and family (34 C.F.R. §300.6(e); RISER §300.6(e)) and educational staff (34 C.F.R.§300.6(f)). How did the parent respond? She continued to advocate through informal dispute resolution procedures - meeting with his teachers, speech-language pathologist and school administrators. The parent was also seeking private therapy services for her son.

**Did the Law Enable the Parent to Advocate for her Son’s Assistive Technology Rights?**

Based on the parent’s thoughts and actions, the law empowered her to advocate for her son. While the parent did not talk about health insurance laws and regulations, she recognized her son may have benefits for a speech generating device. She was knowledgeable about the prior authorization process and began to obtain the necessary documents. She reported that halted the process when her son’s physician and public school speech pathologist would not provide the necessary documentation.

In terms of IDEA, the parent secured rights for her son that included low technology AT devices, a higher technology device and training to use the devices through the public school (34 C.F.R §300.5, §300.6; §105 RISER §300.5, §300.6, §105). She
also arranged for an AT evaluation through the state’s AT program (34 C.F.R. §300.6; RISER §300.6), albeit after many months of advocating.

The parent turned to the formal law when she recognized that the child’s IEP had not been implemented as written, when the school did not provide a device for the child to use. She recognized that this was a violation of IDEA (34 C.F.R §300.320, §300.324; RISER §300.320, §300.324) and contacted The Rhode Island Department of Education (RIDE) who informed her a complaint could be filed, based on what she reported. Under IDEA regulations, adopted by Rhode Island, there are formal dispute resolution options that may help the parent obtain a child’s rights (34 C.F.R. §§300.500-536; RISER §§300.500-536). The parent may seek mediation, an impartial due process hearing, an administrative complaint and s/he may appeal a decision. In this case, after the parent filed the complaint, the public school provided the device. While problems persisted with implementing the device, the parent did not think the formal law would help her with this matter. She stated she is disillusioned about this problem. The parent stated she thought was in "limbo" with "no options".
### Case Analysis # 8

#### Demographic Information

<table>
<thead>
<tr>
<th>Age and gender of child</th>
<th>16 year old female</th>
</tr>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>Down Syndrome and autism, per parent</td>
</tr>
<tr>
<td>Type of School</td>
<td>private</td>
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<tr>
<td>Race</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Martial Status</td>
<td>Single</td>
</tr>
<tr>
<td>Interviewee</td>
<td>Mother (&quot;Ms. Von&quot;)</td>
</tr>
<tr>
<td>Mother’s education level and vocation</td>
<td>Some college Homemaker</td>
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<tr>
<td>State</td>
<td>Virginia</td>
</tr>
<tr>
<td>Speech generating device</td>
<td>Laptop computer with communication software</td>
</tr>
<tr>
<td>Purchased by</td>
<td>Medicaid, state waiver program</td>
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#### I. Case Facts

This case concerns a 16-year-old female with a diagnosis of Down Syndrome and autism, complicated by hearing loss, per parent. The child attends a private school for children with autism, recommended and funded through the public school. The child uses a variety of methods for communication – manual signs, word approximations and a speech generating device.

The parent described many disputes she had with school system since X was 3 years of age. The parent felt that the public school was not meeting X’s educational needs, particularly her augmentative communication needs. Over the years she filed two
formal complaints with the Department of Education in the state of Virginia and prevailed. However, the parent reported that the schools did not implement the changes, as agreed upon.

Over the years the parent educated herself about augmentative communication methods and sought independent evaluations to determine her child’s ability to use and benefit from speech generating devices. The evaluations were funded through Medicaid and a waiver program through the Department of Mental Retardation.

**II. Analysis - Legal Consciousness**

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? How do families obtain their knowledge about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?

**Perceptions of the Law**

The parent’s perceptions of the law emerged as she interacted with a variety of people. These interactions, in combination with personal factors, influenced her decisions and determined whether and how she asserted rights. The narrative revealed two main themes: the parent was empowered by the law and the parent was up against the law. She was empowered by the law because it provided a legal framework for her to advocate for her daughter. The law enabled her to think about
rights, talk about rights, assert her rights and her daughter’s rights. She was up
against the law because she perceived there were many constraints which impeded
her from asserting her rights and claiming her daughter’s rights. I adopted the
phrase “up against the law” from sociolegal scholars Ewick and Silbey (1998).

Empowered by the Law and Up Against the Law

The narrative revealed that the law, IDEA and health care regulations became
infused into this parent’s everyday life. It became part of her everyday life because
of her daughter’s multiple disabilities and due to persisting disputes with teachers,
therapists and healthcare professionals about services she believed her child needed
and was entitled to receive under the law. The parent stated she had to “fight”
“push”, “force” “battle with” the school system for 13 years to try to obtain assistive
technology devices and services for her daughter. While the parent experienced
many challenges, the narrative also revealed that law enabled the parent to assert
her rights and claim her daughter’s rights. Thus, based on the parent’s statements
and actions, at times the law helped her and at other times it hindered her.

The narrative revealed that the parent’s approaches to asserting her rights changed
over time. These changes occurred as she gained knowledge about the law and
interacted with a variety of people. When her daughter was young the parent
advocated for her daughter through informal dispute resolution methods. She talked
with teachers, therapists and administrators. During these interactions she
emphasized her daughter’s skills and her needs. She also focused on building
relationships. As the parent became more knowledgeable and experienced, she
began to advocate for her daughter by emphasizing her daughter’s rights under the
formal law. She was less concerned about building relationships and during
interactions she used the language of the law and the rules of the law to advocate for her daughter. On two occasions she resolved disputes through formal dispute resolution procedures.

**IDEA: Lack of Confidence and Distrust for the People Implementing the Law**

The parent expressed a lack of confidence and distrust for some people who implemented IDEA. These perceptions evolved over the years, as she interacted with people in charge of implementing the law. She believed that teachers and speech-language pathologists did not have the knowledge or expertise to assess her child’s communication needs. Furthermore, the parent thought that some people did not tell her the truth and some were not accountable. Based on these perceptions, she began to question people’s motives.

The parent responded to these perceptions in a variety of ways: she sought independent services for her daughter, she increased her knowledge of assistive technology devices, she advocated for services through the IEP process and over the years she filed two formal complaints. Distrust led the parent to respond in another way: she became cynical and engaged in some slightly covert practices. For example, she went to the school unannounced to ascertain whether the child had her device near her and later she installed a monitoring system on the child’s laptop to determine if and how it was being used.

**Personal Factors That May Have Influenced Perceptions and Actions**

The parent described herself as a “rebel” and “a bull in a china shop”. She thought these attributes could have influenced her interactions with staff. Based on the narrative the parent’s communication style may have created an adversarial
relationship between herself and others. There were other personal factors that may have influenced the process. The parent was highly motivated to obtain knowledge and she constantly networked with other parents on a variety of listserves to obtain information about assistive technology devices and services and IDEA. She used this knowledge when interacting with educators, therapists and other healthcare professionals about her daughter’s skills, needs and entitlements under the law. Another personal factor that may have influenced her perceptions of the law and her actions concerned her socioeconomic status. She was single mother and had limited financial resources. She perceived that the school department regarded her as “poor” and she thought the school assumed she could not assert her legal rights. She dismissed this assumption.

“you know, their attitude is, "Oh, these are poor people; they don’t have money for a lawyer. Look, I got a lawyer before. I’ll get a lawyer to come one way or the other. Don’t worry about how I’m going to pay for the lawyer; that’s not your concern.”

Public Health Insurance Benefits: The Good and the Bad

The parent expressed contrasting perceptions about her child’s public health benefits. She was satisfied with her daughter’s Medicaid benefits and benefits through a mental retardation waiver program. She was confident that these programs would fund equipment that her daughter might need. Furthermore, she also thought the Medicaid program was easy to navigate and relatively quick to respond to requests. However, she indicated that in order to access services, consistent follow-up was necessary. Also, she thought the waiver program was bureaucratic and inefficient, which hindered her ability to obtain information in a timely manner. Furthermore, some case managers were not knowledgeable about
the program. These perceptions were based on interactions she had with program staff.

Sections of the narrative illustrate these themes and concepts

Networking: Obtaining Information and Making Decisions

The parent reported that from the time her child was young she obtained most of her information about assistive technologies and communication methods from talking with other parents in her community, talking with parents on listservs and through research on the Internet. When her family moved to a more rural area of Virginia, she had fewer opportunities to interact with parents in her community and then listservs became increasingly important to her. She reported that over the years she has helped other parents, perhaps more than they have helped her, because of her years of experience in advocating for her daughter.

Denise: So tell me when you first started thinking about a device for X, and who kind of planted the seed, and how did you go about it?

Parent: I don’t really know, to be honest with you, because some of these things I’ve been doing so long, I don’t remember how I got the knowledge. Probably from just talking to other parents.

Denise: So tell me about that.

Parent: More than likely, it’s probably—because when I first started out on the Internet, I got into a group of parents on one of these groups. You remember that? And they had a Parents of Children With Disabilities Group that I joined. And it’s probably there, because I think we were discussing some of the things that we were trying to do for X, and I was, like, ready to pull my hair out, because I didn’t know
what else to try. And I think that’s probably where I—in fact, I’m almost positive that’s probably where I got most of my information.

Denise: From this parent group online.

Parent: Yeah. In fact, over the years, most of my information has come from parent groups—and then, of course, look and research on the Internet myself, but most of it has come from parent groups.

Denise: And how about parents in your community?

Parent: It is—where I’m at now, there’s—we’re out in the county, way out in the county.

Denise: So there’s no other kids like X or with X’s—?

Parent: Well, not like X. There’s all the special needs kids, but there’s nobody close by. I don’t know how to explain it. You’ve got farming out here, you know.

Denise: Yeah, I get you.

Parent: So they—in other words, you don’t get together every morning for coffee.

Denise: I get you. Okay, so—

Parent: Before that, then at school, when I would go to meet X or go to volunteer at school, you know, a lot of times I’d meet other parents, and we were in a neighborhood there that we could get together, like, you know, when it’s pretty days outside—sit outside and talk and stuff like that, but—

Denise: Were they helpful to you?

Parent: Oh, yeah!

Denise: Those other parents? Did you get any good information from them?

Parent: Actually, to be honest with you, probably not as much as—and I’m not trying to say this to be smart-aleck....

Denise: Fine, I understand.
**Parent:** It’s not as much as I gave them, because you have to remember, X is older than most of the people.

**Denise:** Right, so you’ve been through it a longer period of time.

**Parent:** Yeah. So a lot of times, it was more like me giving them info. But again, this—all my information came from pretty much other parents, and she had a really good physician who—or pediatric doctor whose child had Down syndrome, so he gave a lot of good information as well.

**Denise:** Her pediatrician.

**Parent:** Yes.

**Denise:** And how did you link up with him?

**Parent:** When she was first born, she had the same pediatrician that my son had. And he probably took care of her for the first two years of her life. But he told me—he says, “I’m not really familiar with Down Syndrome.” And he said some of the issues that we were having, he wasn’t sure about. So he got—he did some research and found out there was a doctor in... a couple cities over from us that had a child with Down syndrome.

**Denise:** That’s wonderful.

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**Up Against the Law and Asserting Her Rights Under the Law**

Over the years the parent had multiple disagreements and confrontations with the school concerning her daughter’s educational needs, particularly her communication needs. She frequently asked the school to conduct communication and assistive technology evaluations. After waiting for several years for these services, she decided to obtain independent evaluations. In addition, she filed two formal complaints with the Department of Education in her state. While she prevailed, she reported that the schools did not implement the changes, as agreed upon.
Over the years the parent gained knowledge of the formal law and advocated for her daughter through the language of the law and the rules and regulations. She learned about the formal law through her experiences and by reading information online and networking with other parents.

From the narrative you sense that the parent did not trust the school to provide the services she thought her daughter was entitled to receive and that the parent had an adversarial relationship with the school over some issues. She became cynical concerning what she considered to be incompetence on the part of educators and therapists. This part of the narrative also illustrated how, once again, she obtained information through networking and how this information influenced her actions.

Here the parent described a dispute with the school about providing sign language instruction.

**Parent:** She entered school when she was two and a half years old—public school. She—well, I mean, she has Down syndrome, so she knows she’s been delayed all her life. She did great in school, though. She loves the school atmosphere. She did fine; it’s just that, you know, people couldn’t understand her. We were teaching her sign language at home, because I got that started when we were taking her to the CP Center (i.e. cerebral palsy center where she received early intervention services) when she was young, like, you know, like I said, two or three years old. And they were teaching her; she was fine. She used, like, her basic signs, and we saw how quickly she, you know, caught onto most of them.

**Denise:** So when you said “they,” was it the therapist?

**Parent:** Yes.
Denise: Okay. So that was a speech therapist?

Parent: Yes, speech therapist. The OT therapist also worked with her with signs as well.

Denise: And they introduced you to signs, and she caught on really fast.

Parent: Yeah. I mean, she couldn’t just, like, sign everything, but she picked up, like, “eat,” “drink”—you know, the basics.

Denise: Yeah, which was helpful.

Parent: Quite. Now one of the things we learned over the years is that she actually picked up more signs at the time than we realized, but she didn’t use them at that time. Well, even to this day—she’s 16 years old—she is still pouring out signs that we forgot about, that we figured she never got and we just totally forget about, that she learned back when she was two to three, four, five years old.

Denise: Amazing.

Parent: Because—and, you know—but that’s a long story, but—and that’s when I started asking for sign language or communication or some form to help her communicate with people, because that’s so important in our lives, when she was two and a half.

Denise: Two and a half, after she got out of EI, right?

Parent: Oh, yes. And she just—we just transferred her right over to the public school.

Denise: Okay. And so then, she was still using sign language then.

Parent: Well, she was at home, because the schools were not—actually, that’s where the stories start coming in. The schools were not real familiar. We had one teacher, her first-year teacher, who had sign, but they weren’t like—she just used it with X, but the rest of the people from then on did not have sign.

Denise: Why not?
Parent: Don't ask me; I still don’t know today why teachers today don’t have sign.

Denise: So they didn’t know sign, is what you’re saying.

Parent: Yes, continuing on, because they did not know the sign like her first teacher did. So—actually the first couple of years, because I think Karen was with her two or three years. So for the first two or three years of her public school, she got some sign in class, because her teacher at that time had sign. When they changed over, she did not have—even the speech therapist did not have it at the time.

Denise: So what did they do? What did they do with her?

Parent: They basically—this is what they do in speech and OT for special needs kids so many times—is, they work on coloring.

Denise: Okay... coloring.

Parent: Coloring, because, you know, when you grow up and you become an adult, you need to know how to stay in the lines when you color.

Denise: Oh, I see.

Parent: Because you probably can’t get a job if you don’t.

Denise: Okay, so they worked on coloring. All right.

Parent: Coloring, yes. In fact, they still try to work on coloring, until I—unless I push them. And that’s why she’s probably going to get kicked out of the school she’s in now, because that’s one of the areas we’re having difficulties with—is with her communication.

Denise: All right, let’s get there, but let’s keep going with when she was a young girl.

Parent: Basically, it’s—that’s it. So in school from then on, I was always every year, you know, advocating, “We need to get her sign language.” And I’ve been fighting for—in fact—well, we won’t go there, but we finally got a signing assistant this past year.
**Denise**: How'd you do that?

**Parent**: Just kept on fighting.

**Denise**: And when you say “fighting,” what did you have to do?

**Parent**: Oh, I just kept advocating for her needs; I kept looking up information on the Internet, explaining to them why it was beneficial for a child with a disability, especially for a child with MR, to have sign language or, you know, be able to communicate.

**Denise**: So you got information off the Internet and your listservs. And who did you talk to at the school?

**Parent**: Special ed director.

**Denise**: Okay. So you would talk to them.

**Parent**: Right. And their—the attitude about sign language is “First of all, the whole world doesn’t know sign language. Did you know that?” Amazing. And my response is, “I’m not worried about the whole world.”

**Denise**: Yeah, because X isn’t talking to the whole world.

**Parent**: I said, “If she’s talking to the whole world, we’ll get translators for her,” you know. The other thing is that she can’t sign—she uses sign approximations. You know what? If you’re a person—a deaf person who cannot hear, and you use sign language, and you lose a couple fingers, do they tell you you’re not allowed to sign?

**Denise**: Mm-hmm. You make really good points.

**Parent**: You know, and so they just tell, “Okay”—or—I said—and they’ll say things like, “Well, she doesn’t spontaneously sign.” I said, “How do you know that if you don’t know sign? You think she’s just moving her hands around the air. She’s been talking to you, and you’ve been ignoring her.”
Here the parent described a dispute with the school about providing an assistive technology evaluation. The narrative revealed the parent has gained knowledge about the IEP process and was using the knowledge to obtain her daughter’s rights under the law.

Parent: Yeah, and it’s a lot—and this is over the years that—I mean, I’ve been fighting, like I said, for years, by her third year, up until just recently, it’s been an ongoing battle with sign language and communication device.

Denise: What did you do?

Parent: Just being a mom, I went out and fought for what I thought she needed.

Denise: What does that mean? Who’d you talk to, and what’d you do?

Parent: Well, I—you start out talking with the teachers. And of course, to be honest with you, they’re like, “Oh, yes, we agree with you; you’re right; we agree.” But then you get to the IEP meeting, and then all of a sudden they become mute.

Denise: So you brought it up at an IEP meeting.

Parent: Oh, many IEP meetings. Many, many, many, many—every IEP meeting—let’s put it that way.

Denise: And what did they say?

Parent: Most of the time, we got nothing. They would be like, you know, “Well, we’ll get back to you.” With X, you learn that when they say they’ll get back to you—that, you know, “You know you’re not going to get back to me.” So now you start saying, “I want it written to the IEP in their prior written notes.” See, this is something that’s accumulated over the years. I didn’t know that the first three, four, six, seven, eight years. You know what I’m saying? As they didn’t, I learned more and more. Well, thing is, once you learn more and more, the schools really fight you. They get really upset with you. They don’t want you there.

Denise: Did they ever do an augmentative—an assistive technology evaluation?
**Parent:** We had one done in 2005.

**Denise:** And how did—who—was that on the IEP? Who decided that?

**Parent:** I decided that I was going to have one done through her MR waiver. And the school goes, “Oh, we would like to go!” I was like, “Sure, you’re more than welcome to come,” because she—then I said, “This has been the case”—and I’m jumping ahead, but I’ll go back and pick up the history.

**Denise:** That’s fine.

**Parent:** But no the school has never, ever provided X with her communication needs.

**Denise:** Why is that?

**Parent:** Because they are conditioned not to do anything unless you force them. So this is stuff parents have to learn to overcome. I don’t honestly know; that’s my thought, or—I honestly don’t know why, because it just makes more sense if you can get the child to communicate. They kept saying they didn’t know if X understood this. They don’t know if she was learning this or how—her comprehension. Well, she has no way to tell you, so how are you going to know? So it makes sense for them to want to give her a way to communicate. What I also found out is that if the parent is willing to give it, they fight hard enough that they think the parent will either give up or get it themselves.

**Denise:** And that’s what you did.

**Parent:** So basically—yeah, that’s what I did, because X needed a way to communicate.

**Denise:** What was the school saying—what kind of communication goals were on her IEP?

**Parent:** Gee, I can’t go back that far.
Denise: Well, that’s okay. I’m just trying to figure out how they justified not doing an evaluation.

Parent: Oh, no, see, that’s the whole point, because I was going to have the AT evaluation done. I’m trying to remember—I think—oh, I know what I did. I—in one of the IEP meetings in 2003, 2004, I gave them a written letter stating that she needed a speech-language evaluation to be done. Actually, I went into more detail: I wanted comprehensive, and it had to be somebody who was knowledgeable with sign language—had a parent help me write it.

Denise: Who—when you said “parent”—parent on the listserv, parent in the community…?

Parent: No, no, on Down syndrome—most help I’ve gotten was from parents from the listserv.

Denise: So parents on the listserv, okay. So you wrote this letter.

Parent: Right

Parent: Well, I directly told them, but then I also directly gave them—hand-delivered them a copy of the letter written to them, too. Now in the state of Virginia, it does not have to be in writing.

Denise: And how do you know that?

Parent: Because I checked with the laws.

Denise: Okay. How?

Parent: I called the Department of Education here in Virginia to find out.

Denise: Ah, okay.

Parent: So—I mean, I do a lot of checking online, so I—to be honest with you, it was probably both, because I probably checked online and then I called them to clarify.

Denise: Makes sense.
**Parent:** Okay, and then there were some other issues, so that—we’ll get to that part later, but anyway, so they were like, “Well, we can have our school psychologist”—I said they cannot do an AT evaluation. They want their school psychologist to do everything. And I said, “No.” I said, “I will have one done.” And that’s when they said, “Oh, we would like to come to that.” So, you know, I’m with the school system; I’m like, “Fine, no problem. Come on.”

**Denise:** Right, and then you finally went to get an independent. And where did you go?

**Parent:** We went to the—actually, the X hospital again.

In the following section of the narrative the parent described another dispute: she disagreed with the Individualized Education Program, refused to sign it and obtained legal assistance. Here, again, she used the law as a tool to assert her rights.

**Parent:** The school that she was at from 2000 to 2004—well, actually 2005, were not meeting X’s needs. And they wanted to send her to another school district that we had been in years before that we actually ended up almost going to due process over. It was a nasty, ugly fight.

**Denise:** So what happened there?

**Parent:** Oh, that’s where, you know, I would not sign the IEP, because the IEP was not meeting her needs.

**Denise:** What school was it?

**Parent:** Back up. This was at the X school district, back when she was—that was the first district she ever entered—was that district. And she lost the teacher that she had originally and the ones coming up after that did—they just let her play. I’d go in to check on her, and she’d be running around the room, you know, and I’d be like,
“Isn’t she supposed to be sitting down doing work?” “Yeah, but she’s happier just running around, so we let her.” I said, “Then what is she learning from that?”

Parent: They said things like, “Send her to the X school,” which is the one we had problems with. And I refused, and they couldn’t—you know, they couldn’t teach her then; what made them think they’re going to be able to teach her now? They hadn’t made all that many changes, you know?

Denise: That was where you almost went to due process. You didn’t want to go back there.

Parent: Oh, no, no. Would you? If you told your doctor that you went to have toenail cut and they cut your toe off, would you want to go back and try them again?

Denise: So what did you do?

Parent: So anyway, they wrote an IEP that I did not agree with; I would not sign it. So they threatened to pull her out of that class and send her to another class that was even worse. I’m like, “Oh, no, no, no.” So I went through—back then it was called the Rights of Virginians with Disabilities.

Denise: What are they?

Parent: An organization that—and those are people that provide lawyers for people who are low-income like we were and still are. And now it’s called...and I can’t remember, but basically it’s the same thing; it’s just kind of changed over the years,

Denise: So how’d you find out about them?

Parent: Oh, I called the Department of Ed to file a complaint. And they were talking about—“You might need to go to due process,” you know, and I—“here’s the information,” and they sent me all this paperwork... information, and then that—listed “If you’re not able to, you know, attain a lawyer, you might contact these people. They might help.”

Denise: And they did.
Parent: And what they did is that they’d take it case by case, and if they thought your case warranted them stepping in, they would do it; they would find a lawyer.

Denise: So did they help you?

Parent: Yes, they did. They did very much.

Denise: So what’d they—what happened?

Parent: We didn’t have to go to due process. The lawyer came in, and we had a meeting with the school and their lawyers, and our lawyer made them look like fools, basically, and walked out of there with—and the school was hanging with their tail between their—you know, their legs, basically.

Denise: What’d they agree to do?

Parent: They put her back in the class she was supposed to be in. But we still had problems with implementing the IEP. That has not changed to this day.

In this section of the narrative the parent reported that the school did not use the child’s device in the classroom and did not provide sign language instruction. She tried to resolve the problem through the IEP process and eventually filed a complaint.

Denise: Okay. So she’s at this at this new school at 2005?

Parent: ’Five, yes.

Denise: What’s happening with her device?

Parent: It’s about the same. I mean, every once in a while, somebody will open it up and use it, like I said, at the time, a little bit for her to watch a movie or something like that, you know, as more of a reward system.

Denise: So then what happened?

Parent: Well, I kept going in, and I kept making programs for her to use, and I kept telling them, “There’s programs; here’s how you access them.” They just weren’t
using it, so you just—at every IEP meeting, I kept asking for AT training. And we
still, by the way, have not got AT training yet. So I keep going back, and you know, I
am not one that wants to go all full gun and go, “Okay, we’re now going to due
process,” because, you know, sometimes that can harm more than help.

**Denise:** I understand.

**Parent:** So, you know, if I’m going to go to due process, it’s going to be the last
resort of anything that I do. This is ’9, so it’d be 2007, I believe—no, two thou—wait
a minute; I’m trying to remember when I did it—2007. I wrote up a formal request
again, handed it to them at the IEP meeting again, waited to see what they were
going to do—give them enough time to set up something. They didn’t do it. So in
2008, I filed a state complaint.

**Denise:** And how did you know how to do that?

**Parent:** You just call the Department of Ed. They send you the paperwork. Or
actually, now you can download it off the Internet, off their Web site.

**Denise:** So you did that.

**Parent:** So I did that, and I sent it in, and they thought it had enough merit. They
contacted the school district and told them they had 10 days to get it rectified to the
satisfaction of the parent, or they would have to come in. Now, I don’t know what
they mean by that, but evidently it’s not a good thing, you know. And so, we worked
on that; she—so they finally found some—actually, I found the person and contacted
them. It was a person at the school for the deaf and blind—state school for the deaf
and blind who was able to do that, because one of the—anything that I ask for now
with X—the person needs to have sign language. So even though X may not be that
great expressively with sign language, she’s very good at—receptively—you know,
receptively with sign language. So when you’re talking to her, you need to be
signing, because she can’t hear all the different sounds. So finally, we got one set up.

**Parent:** I requested that it be somebody that is—you know, is knowledgeable in sign language to do the evaluation, because that’s where I was getting all this thing about how she, you know, could not sign spontaneously and, you know, the whole nine yards and how the whole world didn’t sign and all—I mean, just—I think they were looking up any excuse they could—even if it sounded stupid to them, they still used it. You know what I’m saying?

**Denise:** Yeah. So you went to due process

**Parent:** No, no, I never went to due process.

**Denise:** Oh, you never went to due process. Okay.

**Parent:** No, didn’t have to, because when I threatened to go and I told them I’m not playing—I said, “I don’t care”—and you know, their attitude is, “Oh, these are poor people; they don’t have money for a lawyer.” I said, “Look, I got a lawyer before. I’ll get a lawyer to come one way or the other. Don’t worry about how I’m going to pay for the lawyer; that’s not your concern.”

**Denise:** Oh.

**Parent:** I said, “Because I am determined,” and I said, “You will meet her needs one way or the other.” Then I got demanding, because I was mad then. So we did—they finally set up—and again, this is one of those things—I contacted another—an organization—a rehab organization for them—the state, and they told me who to contact for this and who could do that. And I took all these things, and I gave them to the special ed director, and I said, ”Now”—because she kept telling me, “We can’t find anybody for this; we can’t find anybody for that.” So I took—I said, “Here, here’s the names. Call them.” So we finally got it set up to get the speech-language
evaluation done. And we got that done, and it took two months to get the report back. So do you wonder how our kids get service to begin with [laugh]?

**Denise:** So what did they recommend?

**Parent:** Well, they—guess what? They recommended the same thing that Mom had been recommending all the years. And that was somebody who had—fluent in sign language that could teach X how to converse with sign language. So we got that recommendation, so I had that with me so that when the school started, I said, “Oh, no, no, this is what they said she needs.” I said, “You are not providing FAPE for her because she—you can’t even—she doesn’t have a way to communicate. You don’t know what she’s learning. You can’t teach her, because you don’t know how to teach her, because you can’t use a language that she understands. So with that attitude—and they were getting kind of worried about FAPE—they agreed to find somebody. Well, that took almost another year—to find somebody, because they were looking, like, for interpreters, and I kept saying, “No, it’s not an interpreter that we really want. I’m looking at a kid or—I shouldn’t say ‘kid,’ but, you know, somebody that’s in school—I mean like college—that’s studying sign language that maybe wants to become an interpreter one day that can use some extra money that is fluent enough in sign that they can understand sign and use sign and speak at the same time.

**Denise:** And teach her.

**Parent:** Right. So we finally got one in—it will be a year in this coming June that we finally hired somebody. We got one, and she ended up having to go back somewhere to school, so we only had her for a couple of months. But she recommended one of the—one of her classmates that was in the signing class with her. And so we got this girl in. The thing is, the school has never given her any guidance or did not give her a job description or any goals to use, so she doesn’t really—I mean, she works with X, she signs with X, but she doesn’t really know—she’s doing more interpreting than
signing, and that’s not helpful for X, because X needs to learn those signs first. So we’re now in the process—bringing you up to date, we’re in the process now of going to, like, a job description for her, goals to go into IEPs that she can use as a guideline—but see, you know, this is all new, so this is something we’ve had to learn over the time period and what’s needed.

**Denise:** And you’re writing this, or they’re writing this, or...?

**Parent:** Well, if you want to get it done, I guess I’ll write it and then let them go over and pick it apart, which is okay with me; I don’t care. If you don’t get it started, it doesn’t get done. So—my fault being, I get something written down, and they go tear it apart and put it together the way they want it, but at least we’ll get something done. So as far as the sign goes, that’s where we are right now: she has a sign assistant that—we call her a sign assistant—that works with her Monday through Friday for four and a half hours each day at school, because, see, the thing is, when I called her when I would—when I email this girl and ask her, “What new signs are you teaching X?” she’d come back with a “I haven’t had time to teach her signs—new signs.” I’m like, “Well, that’s what you’re there for.” So the thing is, she—I mean, this is one of the things—she contacts me, or I contact her—what needs to be done. The school district doesn’t really do much other than pay her and check for her time at school.

**Barriers to Obtaining Funding**

The parent described the experiences she had accessing her daughter’s state Medicaid benefits and her benefits through a Medicaid waiver program. She used these benefits to obtain independent augmentative communication evaluations and speech generating devices for her daughter. The parent discussed how was satisfied with the Medicaid program, how it was “faster” than getting services or equipment
through the school. In contrast, she described how difficult it was to obtain funding through the waiver program, which is administered by the Department of Mental Retardation. This part of the narrative, once again, illustrated how this parent obtained information from talking with other parents.

Denise: Ohhh. How did you decide to go through Medicaid?

Parent: Because everything we pretty much do, we go through Medicaid, because we get it done faster. And I know you’re going to go, “What? Medicaid, you get it done faster?” Yes, they are faster than the school system. That doesn’t mean we got it, like, the next day.

Denise: No, I understand.

Parent: It took a while to get it. But, I mean, looking at when I went and we did the AT eval the first time, within—because it took time to put the paperwork in, of course—

Denise: Who helped you with that? Did anybody help you?

Parent: The—here’s—when you have Medicaid—I have to be honest with you—there’s not a lot of paperwork you have to do. They pretty much—the doctors or the therapist do write it; you sign what you need to sign, and they put it through.

Denise: Okay, so this—the hospital was instrumental in the process.

Parent: Mm-hmm.

Denise: Good. Okay.

Parent: There’s really—when it comes to Medicaid, I know people frown upon it, but I’ll be honest with you: it’s a major headache in some areas, but in other areas, like doing the paperwork, what you have to do with them is follow up with them constantly.

Denise: Okay. And you did that, I imagine.

Parent: Oh, yeah. I’m the world’s worst pain in the butt; you know what I’m saying?
Here the parent discussed the benefits her daughter receives through a waiver program administered by the Department of Mental Retardation. A parent told her about the program, she applied and her daughter obtained funding for AT equipment through this program. Over the years the case managers assigned through this program have not been consistently knowledgeable about benefits. Thus, the parent thought she had to be proactive in obtaining information – which she obtained from other parents - and then she persistently encouraged the case managers to help her apply for funding. While she was satisfied with her benefits, she was not satisfied with how the program operated. She thought the program was fragmented and not well organized.

**Parent:** I talked with her case manager for her—you know, her MR waiver, and I said, “Could we have more?” He said, “Well, that’s another issue.” Now that’s something that I was not told about. I just, in fact, in 2005, learned—was it two thousand… no, I’m sorry—in 2004, just learned that part of her MR waiver was AT funding. And she had that MR waiver since Virginia came out with it.

**Denise:** And how did you apply for it, and how did you know about it?

**Parent:** Well, again, I learned from another parent.

**Denise:** Mm-hmm. Was this a parent online?

**Parent:** Actually, she’s a local parent, but I didn’t know her personally; I actually met her through online—through one of the groups.

**Denise:** Oh, interesting!

**Parent:** Yeah. So she’s—and when I say “local,” because we’re in the county, so anybody that’s within the next, you know, probably 100 miles [laugh]—anyway—but it was really interesting, and she was telling me about how she had gone and gotten things through her MR waiver. I’m like, “I didn’t know you could”—I mean, I knew
you could get pull-up pin diapers going through the MR waiver—you know, stuff like that, but I did not know we could get any technology through this.

**Denise:** And how did you first learn about the MR waiver?

**Parent:** Actually, we had a good case manager, because, you know, X being Down syndrome, she automatically was put into the system.

**Denise:** At—when she was born?

**Parent:** When she was born and went on Medicaid. So you have to have a case manager when you’re on Medicaid. So she had a really, really good case manager, Vivian, up until we moved to the county here in 2000. So she had an excellent one; when she discovered about the MR waiver when it first came out, she came up to me and she—well, she called me; she says, “I need to come talk with you about some things.” So she came over, and she says, “New program. It’s called MR waiver. Would you like to put X on?” She said, “It’s really great.” And I said, “Yeah.” So we put X on it. Well, it was brand new, so even they didn’t know a lot about it at the time. They just knew that it’s one of those things you wanted to get on right then. So X got approved immediately back then. There was no waiting list back then; that—I mean, people didn’t know about it, so there was no waiting list; you know what I’m saying?

**Denise:** So this case manager was really helpful to you on that.

**Parent:** Oh, she was. I love her to death. I’ll be honest with you: If they cloned that woman—there’s not many people that I’d like to clone, but there have been a few over the years. She is one of them. But yeah, so she got us on it. Well, then, you know, about a year or so later, we moved from that district to the other district. And people out here didn’t know what the MR waiver was, to be honest with you, at first. You’d be amazed at how much parents teach those who are supposed to be serving them what’s going on.
Parent: [Laugh] But anyway, so we came out here, and they didn’t actually have a case manager for her out here. So she was under the direct supervision of the supervisor for a while. So we didn’t get much done, because, you know, he could never manage to find time to come out and do the monthly—you know, whatever they do—kind of thing. So finally I find her a case manager—you know, a permanent case manager—and she started to come out very sweetly—she’s still with us today—very sweet lady, but not a clue about a lot of stuff that’s going on. So basically, we learned together. So I’ve mentioned stuff about, you know, a friend of mine whose child got equipment through the MR waiver, and how she did it. And I said, you know, “Can we do this for X?” And she’s like, “I don’t know,” but she’s, “what did she call it again?” And I told her, and she’s, “Well, let me go and look at up.” Well, she called me about two weeks later, and she said, “Oh, yeah, they do have some technology available—you know, funding available, and you have $5,000 a year.” You know, that’s a lot of money.

Parent: That is a lot—I mean, not—I couldn’t go out and get her, you know, a $9,000 device, but $5,000 a year—actually, there’s some years we have a hard time trying to figure out what to get that she doesn’t already have sometimes, you know? But we started out with—I said, “Well, can I get her a laptop?” because I already—by that time, I’d already gotten Boardmaker, like, static boards.

Denise: Okay, and you learned about that by...?

Parent: Again, the parent group. And to be honest with you, almost anything I’ve learned—most—unless it’s a medical—and even medical comes from parents. But I would say 90 to 95 percent of what I’ve learned is through this parent group.

Denise: Yes, that’s amazing.
**Parent:** When we learn something new, we get on there; we share it with other people, you know, because it seems to be one of these things that—it’s “Don’t tell unless they ask.”

**Denise:** Okay. So you want—you found out about the MR waiver, and you wanted—you got a laptop for her.

**Parent:** Right. So—well, actually, it was really funny, because she said, “I don’t know if you can get a laptop.” She’s—I said, “Well, can we ask?” I mean—because everything you go through, you’ve got to get it approved, and yet the—and the funny thing is that you’ve got to get professionals to write a request letter justifying why you need it. And so that’s another story, because most of the parents come from the parents to begin with, because the people go, “I don’t know what to write; what do you want me to write? I’ll sign it.”

**Denise:** So what did you do?

**Parent:** So I went to—I’m trying to remember who the first one we got to write the justification letter was. Let me think; now who was the first one? It was her pediatrician. I had to stop and think because it’s been so, you know—I mean, that’s only four years ago, but hey, I’m old; I forget.

**Denise:** I’m with you. I’m your age.

**Parent:** So anyway—so we got the request letter; we turned it in; we waited, and we waited, and we waited. And I called back, and I said, “Have you heard anything from them yet?” “No, let me follow through.” So we waited, and we waited, and I called back, and I emailed, and I said, “Have you heard anything yet?” And it’s like, “Oh, we forgot to do such-and-such; I have to send out another—get the doctor to send out another request letter.” I’m like, “Geez, people, hello?” Anyway, it took months and months and months. It was almost a year. Well, actually, I take it back.
It was about four months before we got the approval letter back. And then from there on, it was almost a year before we actually got it ordered.

**Denise**: What took so long?

**Parent**: Because they kept making mistakes here, because it was all different—something new they hadn’t been doing. They didn’t know how to really do it and how to put it through. They didn’t have to remember. Her case manager—she takes—I love her to death, but this lady—I’ve never had a job where you get as many vacation days as she took.

**Denise**: [Laugh] You’re so funny.

**Parent**: I mean, they only work four days a week to begin with.

**Denise**: You’re so funny [laugh].

**Parent**: No, I’m serious, because every time you turn—I mean, we had meetings, and everybody goes, “Do you have a vacation this week? Can we put a meeting in for this week?” because that lady is always taking vacation time. No wonder you couldn’t get things done. And then not only that, but then you got the system itself that drags their feet. So it’s almost—well, it took over a year by the time we wrote the letter, but it took almost a year just to take orders.

**Denise**: So who did you say was dragging the feet?

**Parent**: Well, I guess Medicaid or—not Medicaid per se, but the...

**Denise**: Department of Mental Retardation or Mental—

**Parent**: Yes, yes.

**Denise**: DMR?

**Parent**: Right, because they have to go to this person to that person to this person. It’s just like, “Geez, y’all—you know, in your pursuit to make things better, y’all actually make them worse over the years, because not everything’s, you know... what do you call it?—cubical, in other words, “This department only does this; this
department only does this,” whereas—used to—when you go up there, they all did it all, and so they knew what was going on.

Denise: Yeah, it’s more fragmented now.

Parent: Oh, yes! And that was the word I was trying to think of; I couldn’t get it out. But the thing is, nobody—one person doesn’t know what the other person is doing.

Denise: So X got her laptop....

Parent: So she finally got her laptop; we also got lots of software, because I’ve been doing research on there. The software is much easier to get approved than the laptop was. We also got a printer for her, because what good is it to have a laptop but you couldn’t print out the board? And we also got laminated pouches and, you know, stuff like that. Also got ink cartridges, but see, again, I was told, “I don’t know—I don’t think you can do that.” I said, “Well, then, it’s not going to hurt to ask.” So guess what? Yes, the printer cartridges were approved as well.

Denise: Wonderful.

Parent: Of course, as you know, with a budget cut, all this stuff is probably going to come to an end sooner or later. But right now we’re safe.

Denise: So then what happened?

Parent: Thing is, we got that, I got Boardmaker put on there, and we started working with her at home with the computer. I got her comfortable using the laptop, because she loved computers anyway; I mean, that child’s a natural for the computer. She didn’t have much of a choice, though; I mean, you know, from the day she was born, she sat in my lap while I worked on a computer, you know. So she’s kind of destined to be on the computer. But anyway, so she’s got—I mean, X has a knack for computers that you would not believe.
Funded but Not Implemented

While the parent had some difficulty obtaining funding for devices, she expressed significantly more challenges associated with getting the devices implemented. In these next excerpts the parent reported there were problems with staff learning to use the devices and staff did not provide opportunities for her daughter to use the device in the classroom. Over the years her daughter made little progress with these devices. The parent eventually decided to obtain a laptop computer for her daughter with communication software. She learned about this technology by doing research on the Internet. She continued to have problems with getting this device implemented at school. The parent doubted that the school was using the device with her daughter so she installed a monitoring device on the computer.

Parent: They (the speech pathologists at the local hospital) trained me on how to use it, and then they told me “You can go in and you can train the teachers and the speech therapist how to use it.” So I went into school, and I took it in, and I explained to them this was her, you know, communication device and how to turn it on and how to check for the batteries—the whole nine yards—and how to make the sheets for it. And they’re like, “Oh, we can’t use that; we have to get our technician or whatever to come out and show us how to use it.” I said, “Do they know anything about communication devices?” “Well, I’m sure they do!”

Denise: What kind of technician were they talking about?

Parent: Their computer technician.

Denise: Oh, okay.

Parent: So they set up an appointment with the technician to come out, and he comes out, and he goes, “I don’t know anything about this! This is not computers!” You know, “Why did you call me in on this?”

Denise: How ridiculous.
Parent: They’re like, “Oh, well, then, you’re going to have to get somebody to come out and teach us how to use it.” I said, “I just told you. I can teach you how to use it. It’s not hard. You push a button—‘Hello.’ You know, it’s easy.” So I called the hospital, and so the speech therapist wrote them a letter saying how I had been trained, how I could show them how to use the device, and it was very simple to use.

Denise: It is.

Parent: So we went in; they go. They reluctantly said “You can show us.” So I showed them. We discussed what, you know, symbols and icons to put on that X might need starting out. And then they proceeded to put it in the back of the room, nowhere near X—didn’t bring it over for use, and it sat back there. I knew this because by that time, I was catching onto—“You people are not doing what you say you’re doing.” How did I catch onto that? I don’t know; just little—just, like, instincts. So I started popping in, sometimes almost daily, sometimes two or three times a week. And when I came in, they never knew what time I was coming in, so they didn’t have time to go pull the device out as if they were using it. So basically, when we fast-forward to today, guess what? We have the same issues, except I can’t pop into the school every day like I used to, so I used modern technology to put a monitoring system on her laptop to see if it’s being used. But this is basically what it’s been like.

Parent: So she finally got her laptop; we also got lots of software, because I’ve been doing research on there. The software is much easier to get approved than the laptop was. We also got a printer for her, because what good is it to have a laptop but you couldn’t print out the board? And we also got laminated pouches and, you know, stuff like that. Also got ink cartridges, but see, again, I was told, “I don’t
know—I don’t think you can do that.” I said, “Well, then, it’s not going to hurt to ask.” So guess what? Yes, the printer cartridges were approved as well.

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Denise: Isn’t that great?

Parent: She is really good. You know how they say when you have a disability, you have some other area that you’re really good at?

Denise: Yeah.

Parent: Well, computer technology is one of those areas she’s good at.

Denise: That’s her strength.

Parent: —for X. Yeah. So she was doing really good, so I thought, “Okay, well, we’re ready to send it in.” So we sent it in—

Denise: To the school, you mean?

Parent: To the school. By this time, she’s going to the private school.

Parent: And you know, she took it up there.... You know how you get—I—because where she goes now now is an hour away from us, and I don’t have transportation at home. So I have to go when I can get my son to take off and take me up.
Denise: So it’s harder to know what’s going on.

Parent: Right. So, you know how you get suspicious, like something’s not right, you know? I mean, even before there was—if you know anything about computers at all, you know that you can look up in your startup menu—it’ll tell you the last-used program.

Denise: Oh, definitely, yeah.

Parent: Well, none of those were ever—none of—Boardmaker was never popping up in that list.

Denise: So she wasn’t—they weren’t using—

Parent: Boardmaker’s what we have to use; it’s the software that we use for her communication device.

Denise: Right. You use Speaking Dynamically Pro, right?

Parent: Yeah, Speak-UP Dyna—well, we use that; then we use another one called Speak-UP Dynamically, which is actual—your actual communication part of it. And—so that was never popping up. I’m like, “Okay, well, how are y’all using this if the program’s not being opened?” So I got on the Internet, and I’ve—you start to type in things like, you know, “monitor,” you know, “computer,” you know, and I got all this kind of stuff that’s like, “That’s not what I’m talking about!” So I tried different words, and I can’t remember all the different words that I tried, but finally something popped up where it said, “You can find out what other people are doing on your computer.” So I said, “Hmm, that might be something I can use.” So I researched it more, went to it, and had a trial program. I downloaded it, put it on, and it goes into what they call spy mode, so nobody knows it’s running but you. Well, then, of course, when I put it on, it was going to school, and it’s coming back, and they weren’t using it, you know. Well, I mentioned it to the teacher; I said, “Look, I’m sorry; I don’t mean to disrespectful, you know, but I needed to find out.”
And she said, "No, I’m glad you did," because, see, at this school, they have one lead teacher, and then they have a bunch of TAs. So X has about five or six different TAs that work with her throughout the week. Actually, each day, she probably has three or four that work—because I know she has four that work with her each day—different ones, because they rotate them out. So, you know—so the teachers, they’re not always seeing what they’re doing. They’re just assuming. So we mentioned that; so she said, “Well, we’ll talk with my TAs and make sure they’re doing that,” blah-blah-blah. And for a little while, they were actually opening it up. They were—I don’t know if they were actually using it per se, but they would get on there. And then it became—X got on there, and they let her watch movies on it, and they let her play games on it and stuff like that, so it became more of a reward system for her than an actual communication system.

**Denise:** And where was the speech therapist?

**Parent:** Well, we had quite a few coming through. And I have to be honest with you: Over the years, before this school, during the public schools, once we left the CP/Children’s Hospital, the public speech therapist, OTs, and PTs—I don’t even know how they got those names, to be honest with you. I’m being totally honest with you. I’m not saying all of them; I’m talking about the ones we worked with.

**Reflecting on Personal Factors**

Here the parent discussed some factors that may have influenced interactions and the outcomes. She discussed how her communication style has changed over the years. When advocating for her daughter, over the years she has become less interested in building relationships and more confrontative. Once again, the narrative revealed that over the years the parent lost confidence in some people who implemented the law, which caused her to become cynical and less diplomatic in her
interactions. Furthermore, she became particularly disillusioned with administrators and questioned their motives.

**Denise:** So if you think back, is—what would you say kind of helped you in advocating for X? Was there anything about you, your family—anything in particular?

**Parent:** No... actually, I think knowledge, the more I learned, because I have to be honest with you: I am a—I’m a rebel. So—and rebels not always—even when we have the best intentions, we’re not always sophisticated enough to do what we need to do in the right way. In other words, I don’t play their games. I don’t have time to play their games. So sometimes, that’s a drawback. So that’s what I’ve learned. You know, when people say, “What positive things have you learned?” you’ve got to learn about the negative things that you’ve learned. And one of my negatives is the fact that I’m like a bull in a china shop. My intentions are good; I have good—the good point in my advocating is to have a lot of good knowledge that I’ve learned over the years. And I’ve learned where to go now to get more knowledge and who to ask and—you know what I’m saying?

**Denise:** I do.

Parent: I know... on and on and on. But the other thing I learned, though, is that, you know, I don’t have patience with these people.

**Denise:** It’s hard to have patience with them.

**Parent:** I’m very—well, exactly. I’m very blunt, which they don’t like. I mean, I told the special ed director, “If you can’t do your job, let me know; we’ll find somebody who can.” That’s not really very diplomatic. But after all, X’s 16 now, so I’ve been dealing with this all of her life. You know what I’m saying?

**Denise:** I do.

**Parent:** So after a while, you stop being—you know, I don’t bring cookies to the meetings; I don’t—you know, I don’t say, “Oh,” make them feel like it’s their idea. I
don’t do that. I do a lot of their work, like maintain the board, adding new things when they do occasionally ask for something on the two programs they’re willing to use occasionally, you know. Do you say—I mean, in fact, just—I got an email from her teacher yesterday. He asked me, like, the Wednesday before they went out on spring break, to put an icon on her emotions program for “strong.” Well, I put it on there. Well, he emailed me yesterday saying, “I was going through X’s program, and I noticed you haven’t got around to putting the icon on. Do you need help?”

**Denise:** Oh, right.

**Parent:** And I’m like—because of all these issues going on, I didn’t answer the way I really wanted to. So I just wrote back to him that, you know, there—in fact, I counted up—she has over 500 individual boards that go to her communication device that I have made over the past four years. One leads to another to another to another, if that makes sense. And I said, “Yeah, literally hundreds of boards there. If you would be more specific to which program you are using, then I’m more than happy to make sure that I move those icons that I put in this other emotions board over to the other ones to meet your needs.” So he emailed me back; he goes, “No, that’s okay.” Basically, he said, “I must’ve, you know, opened the wrong board.” Basically what he’s saying is, he doesn’t know anything about her communication device. He doesn’t know what else is on there, you know. But what I wanted to say was, “You know, I don’t need help. You go ahead and do it yourself,” because I know he can’t. But I didn’t do that, because I’m holding my mouth until we have this meeting, until we find out whether this administrator literally is going to kick X out of school because she’s mad at her mama.

**Denise:** Ohhh. Well, I hope not.

**Parent:** Well, you know what? This is the way I—this is where I’m at: I’ve been praying—and I’m sorry; I don’t mean to push religion on you, but I’ve been praying
very hard that whatever happens, happens for the best interest for X and for me, not for the administrator, not for the special ed director—but what is best for X, because I’m at this stage now in her life and my life that it doesn’t make sense to continue to pay. They pay $57,000 a year for her to go to that school, not to mention the related services that go along with it. That’s extra—and the transportation. That’s just for tuition. And they pay $57,000 a year, and these people can’t even go to the dollar store and pick up a microwave plate.

Denise: Well, I would love to know what the final outcome is if you would just shoot me an email.

Parent: Yeah, I will, once we know.

Denise: Yeah, I’m really curious to see what happens.

Parent: This school, when she first started there, was wonderful. I mean, it wasn’t perfect, but it was wonderful. It was not until we had a change of our administration that it went downhill so quickly. And there have been parents that have pulled their kids out, or there have been districts that pulled their kids out of there.

Denise: But as far as what you were telling me, they never really embraced the communication methods.

Parent: No, they never have. They never have. And the thing is, we finally got a speech therapist at this school, but she just came in on this school term, and to what—and it’s funny, because when she first came in, I was very leery of her, because we’ve had really poor ones to begin with. She has turned out—she’s a new speech therapist, just coming out—you know, starting her work field—excellent person, good—and she advocates for X’s needs. Guess what? They are not going to continue—this company—working with them anymore. And what we’ve noticed is, whenever you get somebody good that advocates for the child’s needs, they get rid
of them. OT is the same thing. OT—last year, they got rid of the OT service. The OT that X had—no, the OT that she’s got right now—

**Denise:** So they contract?

**Parent:** They contract. And see, last year, they said they were—they’re not going to contract anymore; that’s why they were letting them go, because they were about to hire in service. Well, they never did; they hired another contract company. But I fought for—to keep the OT, because this is the first OT in X’s school years, other than, you know, when she was going through the PT and Children’s Hospital, that actually worked with her and made improvements to the point where she’s beginning to write.

**Denise:** That is frustrating.

**Parent:** So I fought for her, and the school district agreed with me, and so they told the private school they were going to retain her and not use their OT, which really ticked that administrator off, big time. That’s actually when our problems really started escalating. So we did keep the OT. It was a good decision to make; I would go back and do it again. I would love to do this with the speech therapist, but she’s with a group—she’s—see, the OT was the owner of her company when the speech therapist was an employee of the company, and so she doesn’t have—we don’t have as much leeway with trying to get her there, versus a person like Wendy, who is her OT, that is the owner and can make snap decisions on what she can do and not do. You know what I’m saying?

**Denise:** I do.

**Parent:** But the thing is, what we notice as a pattern is, whenever you get somebody that works and advocates for the child’s needs and goes against the wishes of the administrator, they get sent off.

**Denise:** Well, do email me and tell me what happened. I hope it’s for the best for X.
Parent: Me too. And you know, it'll work out; it may not work out there, but it will work out. I mean, the school district has no choice: they have to find somebody who can teach her.

III. Parents' Perceptions Compared to the Positive Law

-Advocating for Rights

Did health insurance regulations and IDEA enable the parent to advocate for her daughter’s AT rights under the law? I believe the regulations did enable her to advocate for her daughter.

Health Insurance Regulations

While the parent did not talk about specific health insurance regulations, the parent was knowledgeable about benefits and she successfully navigated two complex systems to obtain these benefits for her daughter.

-Assistive Technology Benefits Through The Mental Retardation/Intellectual Disability Waiver Program (MR Waiver) (12 VAC 30-120-213)

The parent reported she received funding for a laptop computer and software through this waiver program. Based on the regulations, this program does cover assistive technologies in this category. Under this program "assistive technology" or "AT" is defined as specialized medical equipment and supplies and include:

- devices, controls, or appliances, specified in the consumer service plan but not available under the State Plan for Medical Assistance, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live.

This service also includes items necessary for life support, ancillary supplies
and equipment necessary to the proper functioning of such items, and durable and nondurable medical equipment not available under the Medicaid State Plan. (12 VAC 30-120-211).

This waiver program provides services and equipment to children and adults who have a diagnosis of mental retardation or are under 6 years old and at risk for a diagnosis of mental retardation. Individuals must be at risk for placement in a public or private intermediate care facility (ICF) as defined in 42 CFR 483.440(a). The most common diagnoses include cerebral palsy, epilepsy and autism. To qualify the individual’s income level must be 300% of the current Supplemental Security Income payment standard for one person. The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) manages the program. Case managers are assigned to coordinate services.

**IDEA**

IDEA regulations specify parents’ rights in four major areas: prior written notice (34 C.F.R. §300.503), consent for services (§300.300), participation in developing the child’s Individualized Education Program (IEP) (§§300.320-300.322) and due process to challenge decisions made by the child’s IEP team (§§300.500-529). These regulations have been adopted by the state of Virginia within its special education regulations (8VAC 20-81-170, 81-190, 81-200, 81-210). This parent asserted her rights formally and through informal dispute resolution processes.

**FAPE Requirements**

The parent reported the school provided sign language instruction only after she argued that the school was not meeting FAPE requirements. The parent’s perception may have been accurate. Based on federal regulations, which have been adopted by
the state of Virginia, a FAPE includes special education and related services that conform with an individualized education program (IEP) (34 C.F.R. §300.17 (d); 8VAC20-81.100(F)). Based on federal regulations, which have been adopted by the state of Virginia, the IEP must take into consideration the child’s communication needs. When a child has a hearing impairment, the regulations state that the educational program must consider the child’s communication mode and consider opportunities for direct instruction for child (§300.324(a)(2)(iv); 8 VAC20-81.110F(f)). It is important to note that the regulations use the word “consider”. The regulations do not state that the school is obligated to provide this instruction.

**IDEA: Parent’s Right to Reject the IEP**

The parent reported that she has rejected portions of her daughter’s IEP. Under IDEA regulations, which have been adopted by the state of Virginia, the parent is a member of the IEP team and is entitled to reject part or all of a child’s IEP (34 C.F.R 300.300(d)(3); 34 C.F.R. 300.321(a)(1); 8VAC 20-81.110).

**IDEA: Assistive Technology (AT) Services**

The parent reported that the public school did not provide an AT evaluation. If accurate this would not be consistent with the law. Based on federal regulations, which have been adopted by the state of Virginia, the school is obligated to provide an assistive technology evaluation in order for the child to receive a FAPE (§300.105; 8VAC20-81.100F).
Case Analysis #9

Demographic Information

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I. Case Facts

This case involves a 13-year-old boy with a diagnosis of cerebral palsy per parent report. The child has multiple disabilities. He is non-speaking and uses a power wheelchair for mobility. He is enrolled in a special education program within a public school. Since the child was 4 years of age the parent took him to an assistive technology center at a local hospital for augmentative communication evaluations. Over the years the specialist at this center recommended various speech generating devices, which her son used with limited success, per the parent. The parent described the child as “passive”. She reported that he “does not initiate” communication and is disinterested in using the speech generating devices. The
parent stated that these issues have been very challenging for her family and the child’s teachers and therapists.

In terms of funding for the speech generating devices (SGDs), over the years the parent purchased two SGDs for the child and the school provided one device. These devices were relatively low cost items – under $300.00. Over the years the child also needed costly medical equipment, such as a power wheelchair and custom leg braces. To pay for these items the parent accessed her health insurance. She also obtained funding for some mobility equipment through the public school system.

The parent reported that over the years the public school speech-language pathologist and teachers have not been familiar with assistive technology. Therefore, there have been problems with implementing the speech generating devices in the classroom.

II. Analysis - Legal Consciousness

Main research questions: As families seeking funding for speech generating devices, how do they think and act in relation to the law? What are their experiences and perceptions of the law? How do their perceptions of the law compare to the positive law? Where do families obtain information about the law?

Other research questions: What individuals or organizations did the parent perceive helped or hindered the process in obtaining funding? Did the parent indicate there were any personal factors that influenced the process?
Parent’s Perceptions of the Law

The narrative revealed there were two primary themes. The parent was empowered by the law because it enabled her to think about and claim her son’s rights and her rights. At times she was constrained by the law, by health insurance regulations and IDEA. This perception emerged due to problems she had with accessing benefits through Medicaid and because she thought that the school was not implementing the speech generating device in an effective manner, which led to disputes with educators. I use the term up against the law to refer to the parent’s perception of the law’s constraint. I adopted this term from sociolegal scholar’s Ewick and Silbey (1998). The narrative also revealed parent’s perceptions of the law were shaped by interactions with a variety of people and some personal factors, which influenced whether and how she asserted particular rights.

Multiple Perceptions about IDEA: Achieving Its Purpose, Rights are There, Up Against the Law

The parent expressed multiple perceptions of the law. In one sense the parent thought that IDEA was achieving its purpose. The public school was providing her son with special education and related services that he needed in order to learn. It was also providing speech generating devices. Because her son had significant disabilities, she was confident the law would ensure that her son received these services and devices. She also thought that IDEA provided her due process rights, which she could assert if she had to, though she did not think this would be necessary.

The parent also expressed another perception of the law. In terms of assistive technology services, she thought the law was not implemented as intended. She had
multiple disputes with the public school because they did not implement her son’s augmentative and alternative communication devices in the classroom. She thought this was because staff were not knowledgeable about assistive technologies and intervention strategies. She responded by educating herself about assistive technologies and this enabled her to advocate for her child. She also went outside IDEA and the public school by hiring an augmentative communication consultant and by seeking assistive technology services at a local hospital, which was funded through her health insurance.

**Health Insurance: Relatively Confident in Benefits, Difficult to Navigate**

Over the years private and public health insurance programs provided funding for medical equipment for her son and the parent expressed confidence that these programs would continue to provide medical equipment for her son. The parent reported that she accessed health insurance benefits, rather than asking the school to provide the equipment. She made this decision because she wanted to own the equipment. She also thought that if she used health insurance to fund equipment, this would give her “leverage” with the school system; the school system might provide other services and devices for her son. However, she also indicated that she thought the process for obtaining a more sophisticated SGD for her son through health insurance may difficult and involve a lot of time and effort. The parent also discussed that Medicaid was very difficult to navigate. She expressed a great deal of frustration concerning how difficult it was to obtain information from Medicaid staff.

**Personal Circumstances**

The parent stated that she thought her family had better health insurance coverage for durable medical equipment than other families. She also stated that she thought
her school district had better resources than other districts in the state. In view of these factors, she had confidence in her health insurance benefits and some confidence that the public school would meet her son’s educational needs.

**A Relational Orientation to Advocacy**

The parent persistently advocated for her son’s AT rights through informal dispute resolution processes. She advocated based on what she believed her son needed and was capable of achieving, based on her knowledge as a parent. I refer to this orientation to advocacy as *relational* and I adopted this term from sociolegal research conducted by Engel (1991) and Barton (2004).

Based on the narrative, the parent’s perceptions of the law emerged as she interacted with people and gained experience advocating for her son.

**IDEA: Multiple Perceptions of the Law**

The parent expressed multiple and somewhat contrasting perceptions of the law. She had one perception which concerned the range of special education and related services and assistive technology devices her child was entitled to. In this respect, she was confident that IDEA would meet her son’s needs. She also thought that she had due process rights under IDEA, which were there if she needed them. In terms of the quality of services, this was another matter. She was dissatisfied with how assistive technologies were implemented in the classroom. These perceptions are discussed below and illustrated with examples from the narrative.

- “I have never had to rely on it for support.”
During the narrative the parent did not talk explicitly about the formal law. When asked about IDEA, she thought she did not need to be concerned with it. For her, the law was in the background, a system of rules and regulations she could invoke for resolving grievances if her child was not receiving special education services. She believed the law provided her son with the range of services that he needed and she had no disputes to bring before the law about special education services. She stated, “I never had to rely on it for support.” The parent believed there was never any question that her son qualified for services and he was never denied any services. Her son had significant disabilities, which were visible, and she believed this enabled him to qualify for a wide range of services.

The parent thought the law might be more important to children who were less disabled than her child, such as “kids with learning disabilities.” Also, she thought the law might be more important to parents who want their children to be in an inclusion program. She described her son’s program as substantially separate and she believed this program met his needs.

Some examples from the narrative illustrate this theme.

**Denise:** What do you think about IDEA?

**Parent:** I don’t know how to answer that. He’s still in school. IDEA is a pretty broad concept.

**Denise:** Right. I mean how do you think IDEA has worked for you?

**Parent:** Um I don’t know. Because my son has significant disabilities that are obvious, he uses a wheelchair no one has ever denied him services of any kind. Can I say, they are being executed to the best of their ability? I don’t know. But they are giving them at the best of their ability in the broadest coverage. I think if you had a
child who has less significant disabilities, I think those parents have more of a challenge than I do. Um you know, the kids with learning disabilities. I have a friend battling her school system now. He does well in some areas but can’t read. You know that’s tougher and you might have to pull in more laws and regulations and things. Um, I wrote a blog, including X, we chose, not by total plan, but by.. we did not have an inclusion plan in mind. We didn’t’ say, and I’m generalizing when I say this, but families with Down Syndrome want their kids to be in an inclusion classroom. We did not have such a plan so instead chose to educate X where he was going to be more successful and inclusion in other areas where he might be more successful. So he goes to a substantially separate academic environment and he goes to afternoon programs where it’s just social with other kids.

Denise: Okay

Parent: Um so um you know I know parents who fight for inclusion and I know parents who fight not for inclusion, who wants their kids in really substantially separate, private focused programs um and they’re the ones that often have more often litigious issues because the law says they need to be in a least restrictive environment.

Denise: That was not an issue for you, per se.

Parent: No, no. What would be my alternative? I mean probably inclusion in an awesome thing if it is done well. I can’t, I don’t how to have it done well. I don’t think I have the personal fortitude to make sure it’s done well. I’d have to be in the classroom educating them everyday, educating them about everything. I don’t honestly feel it’s fair to have a teacher having to adapt coursework for one child and then relying on an aide in the back of the classroom to give it to him. That just doesn’t strike me as being a very effective way to do inclusion and I know that’s not
how it’s meant in the best of worlds but I think that’s realistically what happens and I didn’t want to have X in that situation.

**Denise**: You know so much. How did you learn about IDEA? What do you think it is important for parents to know?

**Parent**: I learned about IDEA from attending Federation workshops. It's a subject parents would never need to know about until they have to. While I believe it's important for parents to know about, it's something parents can fall back on in a litigious situation. I have never had to rely on it for support.

**Denise**: What about when you were trying to get AAC devices and strategies implemented throughout X’s day? Did the law give you any options?

**Parent**: I never pulled that string but perhaps I should have.

**IDEA: Providing Assistive Technology Devices**

The parent reported that over the years the public school system purchased low technology speech generating devices for the child to use, based on the recommendations from an independent evaluator. She has been satisfied with how the school provided the devices. Over the years she also purchased some low technology devices with her personal funds for him her son to use at home. In terms of an augmentative communication evaluation, the parent did not think the school had the expertise to do the assessment. Various people, possibly her parents and/her pediatrician, recommended a local augmentative communication specialist and she arranged for an evaluation with this specialist.

**Denise**: I think when we talked, you had mentioned that X Center was involved (in evaluating her son for an augmentative communication system). How did you find out about X Center?
**Parent:** Well, I parents—people—I don’t even remember who it was, but everyone said, “Oh,—you know, maybe it was my pediatrician even, and they said, you know, “Wait for X. Don’t see X. Wait for X.” So I did.

**Denise:** Why did you decide to see X?

**Parent:** I don’t think the school had an augmentative communication specialist.

**Denise:** When was that?

**Parent:** Yes, oh gosh, somewhere around three or four, because there’s always a long waitlist to get to see X—you know, a 10-month waitlist. We called that right away. And so he was probably closer to four. And X recommended, I think, the Tech Speak 32 And it—shortly thereafter—I don’t remember the exact time period, but it was requisitioned by—no, he didn’t get that until he was in, like, a K–2 class, actually. He didn’t get that in preschool; he got that the next class up.

**Denise:** So who paid for that?

**Parent:** The school—no, the collaborative he goes to, not my town.

**Denise:** Did the school ever conduct an evaluation?

**Parent:** No

**Denise:** Did they pay for X’s evaluation?

**Parent:** No, my insurance did. I have good insurance.

**Denise:** Do you think the school had any obligation to do any evaluation?

**Parent:** I heard that some schools are paying for evals. I really don’t know.

**Denise:** And how was that experience (getting the device that was recommended by the augmentative communication specialist)

**Parent:** Purchasing it?

**Denise:** Mm-hmm.

**Parent:** Fine. They purchased it right away. They’re still using it. They still have it.

**Denise:** With him?
Parent: Mm-hmm.

Denise: Did it come home with him?

Parent: Mmmmm... that’s a good question. No, but not because—because he doesn’t use it; that’s why it doesn’t come home with him. He doesn’t like it. So it’s not that they wouldn’t send it home. His usage of it is very spotty. So it wasn’t, like, something that he, you know, really got into and was using it a lot. He didn’t. So I think that’s why it didn’t come home. It was used for specific school tasks, you know.

Denise: So who was involved in deciding on the funding for the Tech Speak?

Parent: I know his teacher and the director of the collaborative purchased it. And they actually purchased a less expensive version of it. They—there were two different models, I guess, and they purchased one that was less expensive, but the same basic thing: 32 cells.

Denise: And you—did they involve you in the process?

Parent: Yep, yep.... Meetings and I talked with them.

Parent: Yep, absolutely

Denise: Okay. And then what happened?

Parent: And then, you know, he used that for specific tasks—school’s, you know, activities. He never—you know, it was definitely used for didactic material, not sort of communication, you know, stuff. He had various print backups—you know, various print communication books. And that—we had a home one, and we had a school one, you know, with all the pictures of his friends and, you know, all the stuff that... I’m trying to think. He had a couple years—yeah, you know, he had a good number of years where he didn’t use any kind of device and—with regularity, I should say, because he wouldn’t. So, you know, that was kind of frustrating, because, you know, it’s like, you know—but the schools have been saying, “Well, you know, if we present
the device to him, it’s a turnoff, and he’ll shut down, and he won’t complete his activity.” So they chose, you know, to try to get him to complete the activity using other methods. And I think the device was there sometimes, and X’s pretty fussy. X’s picky, you know. He responds well to some people and not to others, so—and you have to be jumping up and down and standing on your head and funny and, you know, not serious like me. So, you know, he does well with some people who treat him that way, and others who don’t—he doesn’t participate as well. This is when he was younger; it’s still true to some extent, but still better. So... I’m trying to think what else we had at home. I mean, I bought a seven-level communicator—I mean, I bought a bunch of stuff for home.

**Implementing Assistive Technologies: Up Against the Law**

While the parent reported she did not have to be concerned about the law, she discussed her struggles and conflicts with getting assistive technologies implemented in the classroom. She thought the most significant problem that she faced concerned speech-language pathologists and teachers who were not knowledgeable about assistive technologies and therefore did not implement them in the classroom on a consistent basis. She used words such as “demand”, “obstacle, “push” to describe her experiences in advocating for her son to receive these devices and services. In advocating for her son, she did assert some rights under the law, though she did not articulate that she thought about her actions in this way. She talked with teachers and therapists on a regular basis and she hired augmentative communication specialists. The parent’s struggles with the law may have influenced her in other ways: she was active on multiple listservs and obtained information about assistive technology devices and services from parents and professionals. She started her own
business selling augmentative communication products and she became a board member of the Federation for Children With Special Needs.

Some examples from the narrative illustrate this theme.

Denise: Okay, and—so let’s see. So he used a lot of low tech devices?

Parent: Mm-hmm.

Denise: And up until—including now?

Parent: Yes. And I continually—to—continued to query all the way through whether or not X should be introduced to PECS (picture exchange communication system). And, you know, they all looked to me like, “He doesn’t have autism,” you know. I’m like, “Who cares? That’s not the point. He can’t request, you know.” So he’s still never gotten PECS, but I’m the only person who felt that he should. You know, X (the independent AAC specialist) kind of said, “Yeah, I guess so,” you know, even—because X doesn’t have a diagnosis of autism, they never use PECS with him as an early—you know, he had Choice Board. He went right to Choice Board and had no problem with it. I mean, he understands symbols; he understands what they are. But he can’t request, you know. He can’t initiate anything. So, you know, right away, I don’t know why they didn’t start him on that. Why don’t they start everybody on that when they’re three, you know? Instead, they went right to Choice Board, because he doesn’t have autism.

Denise: So you—that’s what the school decided.

Parent: And T too. (the independent augmentative communication specialist)

Denise: And T

Parent: Yeah, they all—no one had suggested PECS, ever.

Denise: And when you did, —what happened?

Parent: Well, first of all, none of them are trained in PECS.
Denise: Oh, okay

Parent: So they looked at me like, “Oh, um, well, maybe,” you know, but it’s not an autism classroom, so none of them are trained in PECS. So really, practically, how on Earth was that going to get accomplished? So finally—I mean, recently, after several years of—I should say that he had many—probably four years of sort of non-participatory behavior. We call it noncompliance, you know. He would just shut down. He was—X’s not an aggressive kid or anything, but he would just not participate—you know, push the machine away—“I’m done.” And finally, it got—you know, that’s where the big debate came in: “How can I ask him to use a device when I can’t even get him to use—point to a picture, you know? I put the device there, that’s just one more thing—he’s going to say, ‘No, I don’t want to do that.’” So that became a pretty major obstacle in his education, actually. You know, the reports just came back that X wasn’t participating in anything. So, you know, they tried various behavior modification things—you know, reward systems and things, and that worked a little bit. So finally, this year—actually last year’s IEP, they said, “I want him to have an ABA evaluation for behavior support—behavior modification,” and I said, “Fine,” and they had an ABA person come in. And they’re still working on the plan. I mean, it’s not ABA, like, discrete trial training; it’s a behavior modification plan, you know, like “How do you keep them on track?” And they’re not—they’ve just—you know, so they came and X switched schools this year. He started in the middle school program, which is much better, much better for him. The teachers have much more technology savvy. She used to run the assistive tech program at his collaborative. She’s got—you know, there are at least three or four device users in her class, computers— you know, she’s much better. Depends a lot on the teacher, you know; his previous teachers, I could tell, were not very technically hands-on.
Like, they would do it, but they’d have to wait for somebody else to come in and do something, you know.

**Denise:** Mm-hmm, then initiate it.

**Parent:** Yeah, or I’d have to ask. And then there was always the compu—“Well, that computer was a Mac, and this printer’s this, and he needs a joystick,” you know. There’s always, like, one obstacle after another, which eventually got accomplished, but it took a long time, because the teachers themselves didn’t know how to do it. So he’s finally in a classroom now where the teacher knows how to do a lot of these things. And I insisted that they get an assistive technology AAC person for the speech pathologist in that class, which they did, so—which they had in the collaborative; she just wasn’t working with X. So now we have a great one and a good teacher. And, you know, they’re doing a lot more computer-based activities, which he likes, and he can use a mouse or a joystick.

**Denise:** So the speech pathologist wasn’t tech-savvy.

**Parent:** No, no. In fact, I heard horror stories from other parents. Like, she wouldn’t write a recommendation or referral for a device. “No, I’m too busy. I don’t know how to do it. It takes too much work.” Yeah. At—we did not request a device during that time period, so I didn’t have that experience, but another parent did. And eventually, she got around to writing it, and they got her a DB4. So—but—so I had this SpringBoard now, and so they said—they were like, “Yeah, bring it in,” you know. So he’d been using it in school, and then it dropped, and now it’s out for service.

**Parent:** He was introduced to, you know, sequencing devices on and off throughout those years. They used them sporadically. I mean, they may have used them in school, but I didn’t see it come home. Sometimes it would come home with, you know, Message of the Day, sometimes not—depended on the teacher and the therapist. And he had a couple—he had certainly many years where the speech— you
know, had a very junior speech pathologist, and she wasn’t that—very good with him. He experienced the same speech pathologist twice, in fact, and he wasn’t particularly successful with her either time.

**Denise:** When you say “not successful”, what do you mean?

**Parent:** I mean, it is kind of a specialized thing, so you really do have to have somebody who’s familiar with devices and not the speech pathologist—well, I shouldn’t say that—not the speech pathologist who’s right out of school. You know, you really—I had to beg and whine about that repeatedly for a long time—that they were not experienced enough. She wasn’t—she didn’t know how to engage X on a device, whereas when I go to this augmentative communication camp, they can sit down with him for one minute and get him to do it.

**Denise:** When you say “beg” and “white”, what did you do?

**Parent:** Well a lot of has to do with the inclinations, interests and abilities of the speech pathologist and teacher. One in particular not really into it I think it is hard to make someone do something that they don’t really wanna know about. She would never say that, of course. I think her own personal inclination was not to be hands on about technology

**Denise:** Did they seem experienced?

**Parent:** No not at all.

**Denise:** So what did you do?

**Parent:** I went to IEP meetings. When it came for IEP reviews, um, you know, I had to like rewrite the speech, the aug com sections. Oh, I had a private consult go in and check it out. I hired a private aug AT person to come in and do an assessment. That was a disaster. You can imagine how well that went over. They didn’t like that at all. All they had to say was that she was disruptive. She came in and did one or two visits and I don’t remember and she wrote up an assessment. And it pretty
much confirmed what I thought - that they certainly were not making augmentative communication available at all times. And they refuted her. Said she wasn’t, wasn’t, it wasn’t non-biased, she wasn’t able to do an objective assessment.

**Denise:** Did you pay for this?

Yes. I did. Well, no, she never charged me because she knew she didn’t do a good job. She sort of dropped the ball.

**Denise:** So what happened after that?

**Parent:** Not much.

**Denise:** You mentioned you rewrote IEP goals

**Parent:** Did the team agree? Did they agree with them?

**Denise:** Well, um. I think they denied it. A lot of it was denial. Oh, we are doing that. You know.

Denise: **But you had these goals.**

**Parent:** I sent them this stuff about engineering the environment. Have it set up so that, you know, so he has opportunities to communicate on the way to the gym and everything. They just sort of didn’t get that.

**Denise:** Was it in...You said you rewrote the goals. Were they in the IEP?

**Parent:** Well, I don’t know. I think this was part of the discussion of the goals. I can’t exactly remember. I think we got to the point that we agreed upon on a few of them that they could implement.

**Denise:** I understand.

**Parent:** But it wasn’t until he actually switched classrooms where the teacher had a very different philosophy that the augmentative device or book, whatever it is, needed to be with him all the time that things started to change. X switched schools this year. He started in the middle school program, which is much better, much better for him. The teachers have much more technology savvy. She used to run the
assistive tech program at his collaborative. She’s got—you know, there are at least three or four device users in her class, computers—you know, she’s much better. Depends a lot on the teacher, you know; his previous teachers, I could tell, were not very technically hands-on. Like, they would do it, but they’d have to wait for somebody else to come in and do something, you know.

Denise: Mm-hmm, then initiate it.

Parent: Yeah, or I’d have to ask. And then there was always the computer—“Well, that computer was a Mac, and this printer’s this, and he needs a joystick,” you know. There’s always, like, one obstacle after another, which eventually got accomplished, but it took a long time, because the teachers themselves didn’t know how to do it.

Denise: Oh

Parent: So he’s finally in a classroom now where the teacher knows how to do a lot of these things. And I insisted that they get an assistive technology AAC person for the speech pathologist in that class, which they did, so—which they had in the collaborative; she just wasn’t working with X. So now we have a great one and a good teacher. And, you know, they’re doing a lot more computer-based activities, which he likes, and he can use a mouse or a joystick.

Denise: That’s great.

Parent: I am not the only one who felt that in this previous classroom he was in. The same situation happened with the other girl who s a Dynavox user.

Denise: How do you know?

Parent: She told me (the parent). I know. She has been in school with X since preschool so we talked about it. They had the exact same experience. The speech pathologist actually refused to do the augmentative communication evaluation.

Denise: So the speech pathologist wasn’t tech-savvy.
Parent: In fact, I heard horror stories from other parents. Like, she wouldn’t write a recommendation or referral for a device. “No, I’m too busy. I don’t know how to do it. It takes too much work.” Yeah. At—we did not request a device during that time period, so I didn’t have that experience, but another parent did. And eventually, she got around to writing it, and they got her a DV4.

Denise: Oh. Well, maybe things will improve.

Parent: I mean, it is kind of a specialized thing, so you really do have to have somebody who’s familiar with devices and not the speech pathologist—well, I shouldn’t say that—not the speech pathologist who’s right out of school. You know, you really—I had to beg and whine about that repeatedly for a long time—that they were not experienced enough. She wasn’t—she didn’t know how to engage X on a device, whereas when I go to this augmentative communication camp, they can sit down with him for one minute and get him to do it. So their recommendation was—to me was, “Start using the devices for fun things,” you know. So that’s what we’ve done; it’s just—used it for socializing

Denise: So the main thing that bothered you—let me try to understand—was that—getting things implemented in the schools by the teachers and therapists, who were typically not tech-savvy.

Parent: Yes.

Denise: Okay.

Parent: Up until this year. This year, they’re better.

Denise: Because you demanded an assistive technology specialist?

Parent: No. He moved to a different class, yep.

Parent: I was demanding—you know, I wouldn’t say “demanding,” but yeah, I was on pace about it for years. And, you know, it just sort of never happened. I kept talking to the director of the program, how you really need to have an assistive
technology person in that class, and it never happened. And fortunately, you know, then he switched to another class where they have all that stuff, so it’s better.

**Networking to Obtain Knowledge About Assistive Technologies and Knowledge about IDEA**

Over the years the parent consistently obtained knowledge about assistive technology services and devices on Internet. She obtained catalogs from vendors and information from parents and professionals on listservs. This knowledge helped her advocate for her son. Also, based on this information, she made decisions about specific devices to consider or purchase. In terms of knowledge about the IDEA, she reported that she obtained information by attending parent advocacy training sessions through a local service agency. She could not recall specific information she learned. She is now on the Board of this agency.

**Denise:** How did you find out about the devices?

**Parent:** Going through catalogs and on the Internet.

**Denise:** Ok

**Parent:** Yeah, and things that were reasonably inexpensive you know, not over the top in expense, you know—couple hundred dollars or—things like that I purchased.

**Denise:** And so, you found out about these by going on the Internet. Did you find out about them by talking with other parents at all?

**Parent:** No, mostly just catalogs. No, there aren’t too many other kids I know who use devices—I mean, just the kids in X’s class. I’m on a lot of listservs.

**Denise:** Gosh. One thing I’m really learning is how much parents get information on the listservs.

**Parent:** Yeah, I’m on—I do a lot of Yahoo groups. I mean, I think there are others as well.
Denise: So over the years how have listservs been useful to you?

Parent: Tremendously. Tremendously helpful. Either they are professionals who are using it or they’re really cutting edge parents. Or parents just starting out. It’s huge. First of all you find out about products. You hear a lot about problems people have with the products. The professionals sometimes, you know, suddenly promote things. There’s a couple of them. There’s ones that are professional. Do you know about Qiet? Oh my god. Those people are crazy. They are really good. A lot of AT professionals and special educators who know all the websites and all the products and all the distinctions between reading programs. Really, really interesting. All the AAC applications. These people know all the new stuff.

Denise: So that’s been helpful to you to gain information.

Parent: Yes. Really helpful. And then you can ask questions. You know, I mean you don’t always...I have to say you don’t always get relevant answers but you can ask things.

Parent: And then also the local ones; like, I’m on the board of directors at the Federation for Children with Special Needs here in Massachusetts. So Mass Family Voices—that’s a good one.

Denise: How did you get involved with the Federation?

Parent: Good question. Um How did I learn about them. I don’t remember. Coincidentally the executive director happens to live in my town so my mother in law called him and told him we were coming back to Sudbury Mass so he had a heads up that we were coming.

Denise: How did they help?

Parent: I didn’t meet with them right away. They run a lot of workshops. I’m sure I went to IEP workshops. I’m sure I went to training.

Denise: What did they tell you?
Parent: I really don’t remember.

Parent: Yeah. I haven’t been very helpful, because I know I haven’t had a problem with funding.

Denise: Oh, I think you’ve been really helpful.

Selecting an Augmentative Communication Device: What is Appropriate?

The narrative revealed that based on the parent’s experiences, children she knew were obtaining speech generating devices that were too sophisticated for them. She attributed this to independent evaluators who she thought were too quick to recommend these devices without good evidence that the children could use them. What influenced this perception? She knew children who obtained costly devices and did not use them well. This is important to note because it shaped the decisions she made concerning devices for her child and it influenced her decision to start a business selling low technology augmentative communication products. For this parent there were differences among the independent evaluator’ recommendations, the school’s perception of these recommendations and what she believed her son needed. She advocated for her son, based on what she believed he needed. While the independent evaluator recommended higher level devices, she was not convinced that her son could use these devices. The school was also not certain. While she thought the school or her health insurance might be obligated to fund the device, she would not pursue it unless she was convinced. Therefore, the parent has not pursued funding for more sophisticated devices.

Some examples from the narrative illustrate this theme.

Denise: How did you find out about X (the independent augmentative communication specialist)
Parent: Well, I parents—people—I don’t even remember who it was, but everyone said, “Oh, the communication enhancement”—may—you know, maybe it was my pediatrician even, and they said, you know, “Wait for S Don’t see Y (another evaluator). Wait for S.” So I did. But I have to say, John’s only so good. I mean—because all he can do is write up a piece of paper, and that didn’t—that really never succeeded with us well. Not that X’s suggestions were bad; they weren’t. But the school system would be, like, “Oh, yeah, that’s nice.” It’s not that they refuted it, but the fact that it’s on a piece of paper—and I would’ve really had to push. They didn’t suddenly jump on that piece of paper and adopt wherever he said. They had their own speech—and generally—I mean, they concurred. It’s not like there was a big difference. But they didn’t rush out and buy all these devices that X—so X would’ve had X on a, you know, DynaVox years ago. And I’m still questioning—that would’ve been a waste of money.

Denise: Okay, so you as well as the school didn’t think that it was a good use of funds.

Parent: Right. I mean, there—I’ve seen a lot of kids—I mean, I’ve seen some severely disabled kids who were purchased devices at a very, very early age, you know, and sat there. I mean, to this day, they can’t use them, you know. So we weren’t going to rush out for that. And there’s too few—obviously, you know, there’s philosophy as well. If you increase the expectation, he’ll be expected to use it; on the other hand, why am I going to have the school system pay $7,000 for a device he’s not going to use? So that’s why we went with all these interim things. And finally—I’m jumping ahead here—let’s see. So between the ages of, like—up to the age of 10, probably, he used a variety of low- and medium-tech devices: print materials, Tech/Talk, Step-by-Step—things like that. It wasn’t until—well, I purchased the SpringBoard, finally. I went out and pur—I guess because I read
about it somewhere—that they made refurbished SpringBoards that I could—that
were, like, $800, not $3,000. So I purchased that.

**Parent:** I know you’re specifically looking at funding, but that really wasn’t as much
of an issue as just getting the teachers to use it. That—I find the big problem to be
the difference between what is specked out on X’s piece of paper and implementing
it in the classroom. That is the big challenge, because you can go out and get a
device. I have—you know, again, I don’t have a whole lot of—I haven’t been rejected
from an insurance company yet, and I really don’t think I would be, because I think
they would write us a good-enough case that it would be paid for, although then I
guess it comes up—again, when maybe X gets a little older and we want a device
that’s got a CPU, you know, like Internet access and all that stuff on it. I hear that
gets tough, because then they won’t pay for some devices if they’re used not solely
for speech generating; I don’t know.

**Denise:** How did you find that all—their parents or...?

**Parent:** I’m online a lot. I’m on a lot of listservs, so it’s probably come up there.
That’s how I hear a lot of—that’s how I hear about what’s new.

**Denise:** Mm-hmm, exactly. So you heard about that on listservs.

**Parent:** Yes.

**Parent:** I don’t know if you’ve actually ever gone to my Web site, but I have a—I
started a Web site.

**Denise:** Yes, I have.

**Parent:** SayItWithSymbols.com. And the focus of that was to come up with practical
stuff that parents could use that didn’t cost over $300.

**Denise:** It’s fabulous.

**Parent:** So, you know, I’m sort of putting together a thing that says, “The essential
augmentative communication kit you should have: You should have a step-by-step
sequencing device,” you know; “You should have a communication book”—and I have all the kind of books in there that you could get, you know—“Symbol magnets,” you know; “Ways to make symbol things on your fridge,” you know...

Denise: I think it’s fabulous.

Parent: Low-tech stuff...

Denise: Little toolkits.

Parent: Yeah, to get parents started, you know—stuff that any parent would buy, you know. I’m assuming, unless you’re really in dire straits and totally unemployed, you would buy a $300 device, you know. You don’t have to buy an $8,000 device. You know, it’s too—that’s too technical. You can’t make a decision like that by yourself, but you could buy a CheapTalk, you know, for use at home.

_Funding Options for Speech Generating Devices: Health Insurance vs. Public School_

The parent was confident that either her health insurance or the school would provide funding for a device. Her past experiences with these funding sources gave her this confidence. How would she make this decision? She expressed specific criteria that would influence this decision: cost, ownership, and whether the child clearly demonstrated the ability to use the device. Over the years, the school paid for some low technology devices and she paid for some devices herself. When her son was ready for a higher level device she would use her health insurance. By using health insurance she would “own” the device, which was important to her. She also thought that if insurance paid for a costly device, the school might be more willing to pay for other things. She used the term “leverage” when explaining this. While the parent was fairly confident that her health insurance or the school would pay for a
device, she expressed some uncertainty about obtaining funding from either source and she also thought the process could take time and involve effort.

The parent recognized that she had greater resources than other parents. She believed that if a family did not have health insurance to cover the cost of a device, the school should provide it. However, the parent may have been conflicted about this. In the narrative there was a discrepancy between what the parent said about whether the school or health insurance was obligated to pay for the device. At one point she stated that parent should use their health insurance rather than the school. At another time, she said the school was obligated and if the parent wanted to use their health insurance that was a “bonus”.

**Denise**: Okay. Then who do you think is going to pay for the mount? (wheelchair mount for the communication device)

**Parent**: My insurance. I’m very cool with using my insurance if they will. But my insur—supposedly, my insurance has 100% DME coverage. ‘Course, that doesn’t mean they’re going to pay for everything, but—

**Denise**: Good point.

**Parent**: If it’s deemed necessary, they should pay 100% of it. So I’m perfectly happy to use my insurance.

**Denise**: And how did you know that your insurance has 100% DME coverage? Because not all parents know that; that’s why I’m asking.

**Parent**: How do I know that? For two reasons. One, when my husband started with this new company about a year ago, the man he replaced was a wheelchair user and told him, because they had lots of conversations about wheelchairs and durable medical and, you know, vans and—so he told him. And then, of course, I got the
spec stuff, and it was in there. So I continually call and ask, you know, when—like, what exactly does that mean? I guess it means I have no co-pay on it; it doesn’t mean they pay everything. You know what I mean? You have to go through the whole referral process. But then, once it is approved, there’s—they pay everything.

Denise: So after you found out about the durable medical equipment provision, you read the printed information.

Parent: Yes. And then every time something comes up, I sort of call and say, “Really? That would be covered 100%,” and they’re like, “Yeah.” Of course, I haven’t used it—well, no, I’ve used it for other medical equipment supplies, but I have not used it for augmentative communication stuff yet.

Denise: So if you had to give advice to another parent—because this is all about how parents can be helped—my study is—a parent who had a child who needed a speech-generating device, what would you tell them in terms of funding?

Parent: I would say to go through the eval—the school evaluation process, either through their school system or private, and, you know, then weigh what the outcome is, because, you know, they’re all geared toward high-tech devices, you know. And that may or may not be appropriate, given the age and, you know, ability of the child. And, you know, obviously, some people are in a position where they have to have the school system funded, so—

Denise: What do you mean?

Parent: Well, if they don’t have insurance that’s going to cover it, then they have to rely on the school system to pay for it, or pay for it themselves, but who’s going to pay for an $8,000 device themselves? I don’t—I haven’t known anyone who’s done that.

Denise: Not too many people can do that.

Parent: Yeah.
Denise: Do you think the school would do it?

Parent: Oh, absolutely.

Denise: They would. Okay.

Parent: Well, yeah, the parents will have to insist. I mean, I’m perfectly comfortable letting my insurance go first, but I don’t think all people have that luxury of having that insurance that would pay for everything. I always use my insurance for—actually, that’s not true. The school system pays for X’s equipment. They pay for his stander and his—a walker and stuff, so they have bought him mobility equipment. They’ve bought that.

Denise: And how did that decision get made?

Parent: On who’s going to pay for it?

Denise: Yes.

Parent: They’ve never really asked me to pay for it. I live in a pretty nice suburb, though, so... so far, you know, the PT will ask me, “Are you okay with having your insurance”—because she has a vendor who comes in, and the vendor obviously knows how to work with insurance companies, so she asks me, ”Can we put this through your insurance first?” And I generally say, ”Yes, absolutely.”

Denise: So in terms of advice to other parents, what would you tell them their rights would be under the law, in terms of funding for speech-generating devices?

Parent: I would say, first off, that the school system should pay for it if the child’s evaluated and it’s tested and it—you know, I definitely would vote when—the practicality side, because I think that is a waste of the school system’s money to buy something if the child’s not going to use it. But if it is deemed and it is practical, I think it’s the school system’s responsibility. And if the parents want to use their insurance, that’s a total bonus, and I think the parents should be open to doing that. But if they don’t have insurance, then it—the school system should help them.
Denise: But you think they should go with the school first if it looks like it’s going to be practical—used in school.

Parent: I think the expectation should be there that school would pay for it. That would be the expectation. But if there is insurance, I find—every now and then, I do hear some parents who don’t want their insurance to pay for it. Well, why not? I don’t get that.

Denise: What do they say?

Parent: Maybe they have a cap on their insurance, you know, that only pays a certain amount of money, probably. No, no, I often—I wouldn’t say “often”—I mean, because this doesn’t come up that often; there aren’t many kids I know who own devices. But yeah, I have definitely heard parents say, “No, I’m not going to use my insurance.” You know, they want to save that for something else. But I happen to have a lot of insurance, so… if my insurance only paid a portion, MassHealth would pay the rest of it. I mean, any kid who’s got significant durable medical equipment needs should have secondary insurance.

Denise: I think you mentioned you always started with your insurance. This is a very interesting topic for me because I have found that parents sometimes struggle with this. How did you make your decisions?

Parent: We almost always use our insurance to purchase equipment for our son, for three reasons. First, we then own the equipment; second, our insurance will cover it. We have private insurance (Aetna HMO) with excellent DME coverage if you use their preferred providers and we have MassHealth as well. Between the two, just about everything is covered. Third, if our insurance will pay for it, it saves our school system dollars and gives us more leverage to ask or other things. They have purchased some necessary equipment for our son over the years however without complaint.
Medicaid –Difficult to Navigate, Complex Paperwork and Empty Threats

While the parent was satisfied with her son’s Medicaid benefits, she thought the system was very difficult to navigate. The people she spoke with at the MassHealth office were not always knowledgeable and some people gave her conflicting information. Also, she reported that the paperwork was quite complex. She also expressed another perception of this program. The thought that yearly eligibility process was designed to threaten and intimidate people. She thought of this process somewhat like a game because the program did not follow through with the threats. Some examples from the narrative illustrate this theme. In view of her perceptions, she avoided contact with MassHealth and asked her husband to help her fill out the paperwork.

Denise: Yeah. And how did you find out about MassHealth?

Parent: I think when my son—when we moved back here and my son—you know, I signed him up to receive DMR, Division of Mental Retardation Services—whatever they’re called now—DDS or Developmental Disability Services. I think they said, “Have you checked into MassHealth yet?” I hate them; I hate them.

Denise: You do?

Parent: Oh, my God.

Denise: Why?

Parent: If you never have to call them, you just stay away. They are so messed up, especially when you’ve been used to dealing with, like, Blue Cross, where they’re so good. And Aetna’s okay, but, oh, gosh, depends who you talk to there. They’ll tell you totally different things. So I can honestly tell you, I probably haven’t talked to a person there in years. And we had to—I had to send in the paperwork that’s sent to me. They decide my premium; we also have premium assistance; they pay that.
And, you know, I also get PCA hours. I get—but that hasn’t been a problem, either. They’ve covered everything that I’ve submitted, so there hasn’t been a problem.

**Denise:** So do you download the paperwork from the Internet, or how do you get your paperwork from them?

**Parent:** They mail it to me.

**Denise:** But you have to call.

**Parent:** No. Like, once a year—you have to reapply every year. They—oh they’re very good about. They absolutely send you their update forms... you know. They send it to you and—so due by June 14, and, you know, you just get it in. And all they care about, I’m sure, is your salary.

**Denise:** Well, it is—it’s means tested, but in his case, I guess X qualifies for this.

**Parent:** Yes, yes. Yeah, you know, the pa—I get a lot of questions about MassHealth. You know, people are like, “Oh, really? Is it worth it?” If you have a child with any durable medical, it’s definitely worth it. I mean, his braces alone are $1,600 each, you know. So it’s definitely worth it. But if you have a child with autism or something and you don’t have that, yeah, you get PCA hours, but that’s going to cost as much as your insurance premium, you know. But in our case, it’s, you know—it’s pretty much a requirement. How am I going to—I mean, his wheelchair costs as much as a car.

**Denise:** How did he qualify for MassHealth? Under what provision? Do you know?

**Parent:** I don’t know. Are there different provisions? I don’t know.

**Denise:** It’s—it varies by state.

**Parent:** I would say Massachusetts is probably pretty liberal.

**Denise:** Yeah. How long has he had it?

**Parent:** Since he’s about three or four, I think. Yeah. I’ve had it a long time.
Denise: One parent that I’ve been talking to is—wants—she keeps telling—she’s told me several times she wants to apply, but she’s—she finds the form just too daunting.

Parent: Oh, it’s daunting. Oh, yeah, they’re horrible, horrible—the first ones, I guess. But, you know, you’ve just got to get over that and just do it. And then they send you one every year, and it’s not so bad. But my husband—I give it to him in a little folder, and he fills it out on the train ride—the parts that he can, you know, and—because he fills out—you know—he does the [inaudible] portion and leaves blank what he doesn’t know. So he—you know, he’s a captive audience there in his captive time. So he does part of it, then I do part of it. And that’s about once a year. Other than—they never call or anything; you just get threatening letters, you know. And besides, I haven’t gotten any threatening letters in a while. “Unless you reply, your services will be cut off,” you know. Oh, please. None of that happens, actually. It’s just—they send threatening letters.

III. Parents Perceptions of the Law Compared with the Positive Law

Based on the narrative, there are several legal issues to consider:

**Funding for the SGD: Private and Public Health Insurance.**

How did the parent’s perception of her health insurance compare with the positive law? The parent believed that her private health insurance and/or her son’s public health insurance might fund a speech generating device for her son. Why did she think this? The parent reported she had generous DME coverage and the insurance company had never denied a request for medical equipment. Over the years the family’s Aetna plan paid for expensive durable medical equipment (DME) for her son. Thus, it is reasonable to assume that her Aetna plan may cover some or all of the
cost of a SGD. The child also has health care benefits through MassHealth and the parent thought that if Aetna did not cover the device, that Medicaid would fund it. Based on the law, it is reasonable to assume the parent’s perceptions of her son’s MassHealth benefits are accurate. Children age birth through 21 years who qualify for services under a Medicaid program are eligible to receive benefits through Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) service. This is a mandatory service under Medicaid (42 U.S.C. §1396a(a)(10)(A); §1396d(a)(4)(B); §1396d(r)). Under this program, a state must provide any of the services listed in the Medicaid Act, including optional services, whether or not the service is included in the state's Medicaid plan. (§1396d(r)(5)). Under the EPSDT, SGDs are covered under one of several benefit categories: home health care services, including medical supplies and devices; prosthetic devices, rehabilitation services, preventative services, and speech-language pathology services. While Medicaid may pay for a SGD, it is the payor of last resort. In other words, Medicaid may provide funding for a SGD if the private insurer does not cover it or Medicaid may pay a portion of the cost that the private insurer does not cover. See Chapter 2 for details about the EPSDT program.

**Definition of DME**

The parent indicated she “heard” that health insurance may not cover software programs and Internet access features that may be integrated into a SGD. This may be accurate. Most health benefits program would not categorize these technologies as durable medical equipment (DME) because these can be used for non-medical purposes and may be useful in the absence of an injury.

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51 130 C.M.R. 503.007
52 While there is no federal definition of DME, most states define DME based on the following features:
IDEA: Is the Child Entitled to a Specific Device?

The parent reported that over the years the school provided her child with some low technology speech generating devices. The parent thought that the public school might be obligated to provide a more sophisticated device if her son could use it. Is the parent’s perception consistent with the formal law? Possibly. According to IDEA regulations (34 C.F.R §300.5), which have been adopted by reference in the state of Massachusetts special education regulations (603 C.M.R. §28.01), the school is obligated to provide an assistive technology device in order for the child to receive a free appropriate public education - FAPE. However, the school is not obligated to provide a device if a non-educational agency, public or private is obligated to provide it, based on federal and state law (34 C.F.R. §300.154 (b)(1)(i)). Moreover, the public school may seek reimbursement from the non-educational agency if it fails to provide the device (34 C.F.R. §300.154(b)(2)). There is another legal issue to consider. It concerns the term “appropriate”, as used in free appropriate public education. This term is rather ambiguous and open to some interpretation by the IEP team. The concept of an “appropriate education” is based on the landmark Rowley Case (458 U.S. 176 (1982)). In Rowley the Supreme Court determined that FAPE does not mean a school must provide the “best” education or one designed to maximize the student’s potential (Board of Ed. of the Hendrick Hudson Sch. Dist. v. Rowley, 458 U.S. 176 (1982)). The Rowley case was also important in another way: it acknowledged a collaborative relationship between the school and parents. In

- can withstand repeated use
- primarily and customarily used to service a medical purpose
- generally not useful to a person in the absence of illness or injury, and
- is suitable for use in the home (O’Connell et al., 2004).
Rowley the Supreme Court noted that both the states and the family have a partnership in the child’s educational program.

“the primary responsibility for formulating the education to be accorded to (a child with a disability), and for choosing the education method most suitable to the child’s needs, was left by the Act to state and local educational agencies in cooperation with the parents.” (Rowley at 207).

In summary, it is possible that the school may provide a more sophisticated device if the team agreed that the child needed the device in order to receive a FAPE. However, since the child had health insurance which may pay for the device, the school may be considered secondary payor.

**IDEA and School Owned Devices – Can a Device Go Home with a Child?**

The parent reported that the school would have permitted the device to come home with the child if the child demonstrated he could use it. Since her son did not consistently use the device, the device remained at school. Is this consistent with the law? According to IDEA regulations, which have been adopted by reference by the state of Massachusetts special education regulations (603 C.M.R. §28.01) a device may go home with a child if it is needed to ensure FAPE. According to the federal regulations, this decision is made on a case-by-case basis by the child’s IEP team (34 C.F.R §300.105 (b)). Thus, the parent’s perception is likely consistent with the law.

**IDEA: Assistive Technology Devices and Services**

In this case, did the school provide adequate resources, training, competency for AT equipment and services, in order for the child to receive a FAPE? The answer is possibly not. The parent reported that the child did not receive an AT evaluation.
While the school provided some assistive technologies for the child to use in the classroom, the teachers and therapists were not knowledgeable about the technologies and did not implement the devices with the child in the classroom. Based on IDEA regulations, which have been adopted by reference in the state of Massachusetts special education regulations (603 C.M.R. 28.01), the school is obligated to provide assistive technology services in order for a child to receive a free appropriate education (FAPE) (34 C.F.R §§300.6, 300.34, 300.42, 300.101, 300.105, 300.320, 300.324). Assistive technology services include an evaluation to determine a child’s assistive technology needs (§300.6), and training to the child, parent and educational team (§300.6). Thus, in terms of AT services, the school may not have complied with the law if it did not conduct an AT evaluation or provide training to the child, staff, and family in order for the child to receive a FAPE.

**Independent Evaluations**

The parent was not sure whether the child was entitled to an independent evaluation at public expense. She thought that some schools paid for outside evaluations, based on “IEP regulations”, but she did not know under what circumstances schools might do this. According to IDEA regulations (34 C.F.R. §300.52), and the state of Massachusetts special education regulations (603 C.M.R. §28.04 (5)(c)), a parent is entitled to an independent evaluation at public expense if the parent disagreed with the evaluation that the school conducted. The parent is entitled to one independent evaluation each time the parent disagreed with the evaluation conducted by the public agency. While the parent may choose an evaluator, the evaluator must meet the public school’s criteria. In terms of covering the cost of the evaluation, based on Massachusetts special education regulations, the school may ask the parent to pay part of the fee. This is based on a
sliding fee scale (603 C.M.R. 28.04 (5)(c)). In this case, the parent did not report that she disagreed with an evaluation that the school conducted because the school did not do an evaluation.

Concerning independent evaluations, there is another legal issue to consider. The parent reported that the school did not accept the results and recommendations from the independent evaluation. Is this consistent with the law? Based on Massachusetts special education regulations, the school must consider the evaluation but has no obligation to accept it or to modify the IEP (603 C.M.R. §2805 (5)(f)).

**Did the Law Enable the Parent to Advocate for her Son?**

Another important question to consider is whether health insurance laws and IDEA regulations enabled the parent to advocate for her son? I believe the law empowered this parent to advocate for her son’s AT rights and to assert her rights. While she did not articulate specific laws and regulations, the parent recognized that her son was entitled to AT and she persistently advocated for these rights. The law provided a framework for her to think about rights, talk about rights and claim rights.

In terms of health insurance, the parent was knowledgeable about benefits and successfully navigated health insurance procedures to access benefits for her son. When and if she thought her child was ready for a more sophisticated device, she was prepared to go through the prior authorization process with her health insurance.

IDEA and Massachusetts special education regulations enabled the parent to advocate for her son to receive some AT rights under the law. IDEA regulations and
the Massachusetts special education regulations enabled her to advocate for her son through informal dispute resolution processes, such as talking to teachers, therapists and program directors and through formal methods when discussing goals at IEP meetings. The parent had other rights to assert under the law, though she chose not to assert them. IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations, a parent has rights in four major areas: prior written notice (§300.503; 603 C.M.R. 28.05, 28.05), consent for services (§300.300; 603 C.M.R. 28.07), developing the child’s Individualized Education Program (IEP) (§§300.320, 300.321, 300.322; 603 C.M.R. 28.05) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 603 C.M.R. 28.08). Consistent with IDEA regulations, in Massachusetts a parent may resolve a dispute in several ways: informal measures (as this parent did), through mediation, through a formal complaint by contacting the Office of Program Quality Assurance Services, by requesting a due process hearing, and if necessary, by appealing a hearing decision to a state of federal court (§§300.500, 300.529; 603 C.M.R. 28.08). Despite some grievances, the parent did not assert her formal rights under the law. When asked about this decision, she stated, “I never pulled that string but perhaps I should have”.


Case Analysis #10

Demographic Information

<table>
<thead>
<tr>
<th>Age and gender of child</th>
<th>15 year old girl</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>cerebral palsy per parent</td>
</tr>
<tr>
<td>Type of School</td>
<td>public</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Martial Status</td>
<td>Married</td>
</tr>
<tr>
<td>Interviewee</td>
<td>Mother (“Ms. Klass“)</td>
</tr>
<tr>
<td>Mother’s education level and vocation</td>
<td>B.A Former discharge planner/case manager homemaker</td>
</tr>
<tr>
<td>State</td>
<td>Massachusetts</td>
</tr>
<tr>
<td>Speech generating device</td>
<td>Mini Mercury</td>
</tr>
<tr>
<td>Purchased by</td>
<td>Harvard Pilgrim, waiver program, school</td>
</tr>
</tbody>
</table>

I. Case Facts

This case involves a 15-year-old girl with a diagnosis of cerebral palsy. The child has multiple disabilities and is medically fragile. She uses a power wheelchair for mobility and a speech-generating device for communication. She is enrolled in a public high school. According to the parent, the child has no cognitive disabilities. She is enrolled in regular education classes.

The child began using assistive technologies when she was in kindergarten. Over the years her daughter has used three different speech generating devices. Health insurance paid for two devices and the school provided one device. The parent reported no problems with obtaining funding through either source. However, the
parent did report disputes with the school about services the parent believed her
daughter was entitled to receive. She has worked collaboratively with educators and
therapists to ensure her daughter obtained these services.

**II. Analysis -Legal Consciousness**

Main research questions: As families seeking funding for speech generating devices,
how do they think and act in relation to the law? What are their experiences and
perceptions of the law? How do their perceptions of the law compare to the positive
law? Where do families obtain information about the law?

Other research questions: What individuals or organizations did the parent perceive
helped or hindered the process in obtaining funding? Did the parent indicate there
were any personal factors that influenced the process?

**Perceptions of the Law**

The narrative revealed two primary themes. The parent was empowered by the law
because the law enabled her to assert her rights and claim her daughter’s rights. The
parent was also disempowered by the law. She thought about the law in this manner
because of disputes she had concerning implementing assistive technologies in the
classroom. I use the term *up against the law* to describe this. I adopted this term

The law was part of the parent’s everyday life. Her daughter had multiple disabilities
and she needed a variety healthcare and educational services on a consistent basis.
The parent’s perceptions of the law were shaped by a combination of personal
factors and through interactions with people. These personal factors and interactions
determined whether and how particular rights became active.

**Health Insurance Regulations and IDEA: Empowered by the Law**

This parent felt the law was on her side. The parent believed her daughter was never
denied her rights under the law and she expressed confidence that the law would
meet her daughter’s educational needs. While she felt the law was on her side, she
also indicated she had to be actively involved in order to obtain and enforce her
daughter’s rights under the law. Furthermore, while she thought she has never been
involved with the law, she described several examples of invoking the law to solve
problems. The narrative also revealed that this parent focused on building
relationships and she believed that this approach helped her advocate for her
daughter and achieve positive outcomes.

**Powerful Combination of Personal Factors**

The parent reported there were several factors that influenced her ability to advocate
for her daughter. These included her professional background as a discharge
planner, wealth, her marriage and strong ties to her community.

**Empowered Through Networking**

The parent attributed some of her success with getting devices funded and
implemented to networking with other parents. She mentioned that over the years
she talked with other parents at Special Education Advisory Council meetings, at
other school meetings and at medical appointments for her daughter. She found out
about these meetings and groups by talking with parents. Through these encounters
she found out about the Federation for Children with Special Needs. She contacted them and enrolled in advocacy training.

Excerpts from the narrative illustrate the themes.

**Empowered by the Law - A Relationship-Based Approach to Advocacy**

While the parent did not think she has been involved with the law from a rule-based perspective, the narrative revealed she was highly engaged with the law when dealing with her daughter’s education and healthcare. In the following excerpts the parent described several examples of legal problems she has dealt with, such as the public school denying her daughter access to the newly built library, rejecting part of her daughter’s Individualized Education Program, asking the school to fund a speech generating device and preparing prior authorization requests through health insurance. The parent addressed these legal issues by establishing and building relationships among people who she believed could influence the process. I refer to this orientation to advocacy as *relational* and I adopted this term from sociolegal research conducted by Engel (1991) and Barton (2004). Throughout the narrative she talked about being part of a “team” and working “within” the system to advocate for her daughter’s rights under the law. Thus, this parent focused on solving problems through collaboration and negotiation.

The parent had a take charge attitude and she advocated in a tactical manner, carefully reviewing options and engaging people who she thought could influence the process. She was highly determined to learn how to navigate systems. She thought that some parents did not invest the time to learn how to advocate and were too
quick to seek legal help. The parent also mentioned personal factors, which impacted her thoughts, actions and ability to advocate for her daughter.

Here the parent talked about her daughter’s rights under the law and how she and her husband advocated for her daughter to have access to the public school library.

**Denise:** So in terms of X’s rights, what rights do you think X has under the law for communication?

**Parent:** You know, **Denise,** I have no idea.

**Denise:** Well, just what you think as a parent for your daughter.

**Parent:** As a parent, I think—I know she has a right to a—what’s it—free and adequate education. But she has never been denied something that I truly believed she’s needed, so I have never had to investigate that or take it to that level. You know, there—I’m not saying it’s been easy. Just this past September, I wanted her to be able to go to the library at the high school, because we just—you know, our taxes just renovated this wonderful library God knows how many millions of dollars. And I was told that she couldn’t, because there was some code in Massachusetts that said that the building had to be evacuated in under three minutes, which bothers me.

**Denise:** Oh my.

**Parent:** Exactly. So it kind of got my dander up a little bit. So I called the Fire Prevention Officer in town and asked him what the ruling was, because I found it strange that they had just built this huge library and built these great new staircases with wells on the outside of the building, but neither one could get a wheelchair out, and there were four kids in the high school that are all in chairs. So—

**Denise:** Something’s not right.
Parent: No. So when all of this... then we wrote a letter. And I think the school system knows that if my husband Dennis is involved—that it’s a big deal. I handle all the little stuff—

Denise: Why is that?

Parent: Because he comes in—he—I do my thing; I handle X’s stuff. He is very involved with her, but I handle the school and the Merc and that kind of stuff, and he handles the power chair, and we all have our little roles.

Denise: Absolutely.

Parent: But he wrote—he’s also—he’s an educator. So he wrote a letter to the principal, the Director of Special Education, X’s liaison, and the superintendent, and I delivered the letter. And within 24 hours, we had a meeting with the Director of Special Ed, the principal, the Fire Prevention Officer—

Parent: So we ended up putting together an evac team, practicing the evac team, getting people comfortable that X does all the rides at Disney, including Tower of Terror and Splash Mountain—that them carrying her down in those little evac chairs is not going to hurt her in any way as she’s laughing hysterically going down the—and I think they just needed to be educated. I don’t think that they were denying her something because they didn’t want to have to deal with it. I think no one had ever challenged it before. And she has a right to be up in the library and taking classes on the second floor as much as any other kid. And once we pulled the team together and they knew that we were looking to work with them—we weren’t working against them—it all worked out in the end. You know, I know some families that would’ve called an attorney right away. That’s not going to get you anywhere.

Denise: Why do you think that wouldn’t get you anywhere?

Parent: I think you’ve got to work within the system, and then, if something’s not right, then go to those extremes. I think people are just jumping into getting
attorneys and mediators and all this kind of stuff without even trying, and how are you going to learn the process if you never have to do it yourself?

Here the parent described how she thought it was important for parents to be part of the “team” and work “within the system” to achieve goals.

**Denise:** Let’s see. So what advice would you give to parents? Well, write everything down; that’s the first thing you said.

**Parent:** Right, document.

**Denise:** Document.

**Parent:** Document. And I think playing on a team. You’ve got to be part of a team. You can’t always go in with your guns loaded and be angry.

**Denise:** And you see that quite a bit?

**Parent:** I do. I think people think—and it is X’s right to have whatever she needs to get through school, but I don’t start my IEP meeting saying that. You know, I start my IEP meetings—hopefully, I have—that I thank the people for what they’ve done, because I know it’s not easy—and hopefully that I—all people sitting around that table—I have an example of something that they did that I think went above and beyond. And if they don’t, then they’re the ones left out at the table. I think you’ve got to work within the system, and then, if something’s not right, then go to those extremes. I think people are just jumping into getting attorneys and mediators and all this kind of stuff without even trying, and how are you going to learn the process if you never have to do it yourself?

**Denise:** So your meetings have gone well, it sounds like.
This next part of the narrative illustrated how the parent is engaged with the law. She talked about how long it took to write her daughter’s IEP and how she has rejected parts of her daughter’s IEP.

**Parent**: It does. It takes a long time to write X’s IEP. We’re never within the regulations.

**Denise**: And why is that?

**Parent**: Because she’s so multilayered. She’s so physically involved but so cognitively appropriate, age-appropriate, that at times it’s just that we, school and me and technology—I don’t think we’ve caught up with what she can do. So it’s all a trial and error. And then you have to make sure everything’s measurable. You know, you’ve got to follow the guidelines. And she doesn’t fit in a little perfect box.

**Denise**: So you’ve had to—have you had to have a lot of revisions to her IEP during—

**Parent**: Yeah, and I don’t think I’ve ever rejected a full IEP. I know that I have accepted parts of it, and we’ve added parts or taken parts out or, you know, whatever.

**Denise**: So how did you learn about—you said trial and error. Like, how did you learn about—you mentioned goals, measurable and so forth—how did you learn all that? Because you know so much.

**Parent**: I think that going through a Federation workshop when X was really young probably helped.

**Denise**: How did you find out about them? How did they help?

**Parent**: A parent told me about them.

**Denise**: Is there anything else you can think of that would be important for me to know in terms of this whole process and who’s been involved and things that troubled you?
**Parent:** I think you need a really good speech pathologist, and not just one that knows the whole correct way to pronounce words, but someone—I think with kids like X, you need people that can look outside the box and be creative. X’s missed a lot. On Mondays, she has speech and OT. And actually, the OT isn’t even an OT; she’s a COTA but she gets it. I don’t care what someone’s letters are after their name. I don’t get hung up on that kind of stuff. But she gets it, and she gets that X right now is at a point where she needs to initiate her own thoughts, not a prescribed one that’s programmed into the Merc, but her own true thought. Well, because they co-treat on Mondays, we have either had snow days or the kids have been, you know, off because of some holiday, I think, since Christmas—before Christmas. So I wrote a note in her book last week that said, “Mag’s missed a lot of your co-treat days. Monday”—this week she has midyears—“I’m picking her up at school at nine. I would love if the two of you would come to the house and co-treat.” And they did.

**Denise:** That’s excellent.

**Parent:** You know, instead of saying, “You have to make up the last six sessions that were missed,” you know, “Come to the house; see her in her own environment.”

Here the parent discussed that her daughter’s school liaison has been instrumental in advocating for her daughter and how the parent requested this particular person to continue to work with her daughter. Again, the parent is very engaged with her daughter’s educational team and focused on building relationships with people.

**Parent:** And I think you have to get the right liaison, not from the—X has a great liaison right now who has been a regular ed teacher—has been a special ed teacher. X took U.S. history for the first time this year, **Denise.** She got a 93, in high school.

**Denise:** Oh, my... she’s amazing!
Parent: Yep. You know, we can’t have too many open-ended questions.

Denise: Of course.

Parent: It takes too long, and it’s too hard. And I’m not saying—I’m sure—on the test she took yesterday, I’m sure there were some questions in there that could’ve been a little bit more challenging. But she gets the general concept, and that’s our goal—is to expose her to as much as we possibly can. So she’s never going to pass the MCAT.

Denise: So when you say “liaison,” what do you mean by that?

Parent: She is the teacher that oversees X’s curriculum and is the liaison from the teachers to the special ed department.

Denise: Okay. From—is she employed by the district?

Parent: Yes.

Denise: Okay.

Parent: She teaches, actually. She has taught X in the past. She doesn’t have her this semester or next semester.

Denise: And who does she report to?

Parent: She reports to the chairperson in the special ed department.

Denise: And is she—have you had her for many years?

Parent: We had her in middle school, and then she left and went to the high school, and then we just picked her back up this past September. I actually requested her.

Denise: And so X has always had somebody in that capacity?

Parent: That’s just the way the school system works.

Denise: So that person has been supportive and helpful.

Parent: This one, yeah. There have been others that have not.

Denise: In what ways?
**Parent:** You know, I think when you look at X, you see a kid that belongs in a life skills program.

**Denise:** When you look at her physical challenges?

**Parent:** Her—yes. When you meet her—if you just met her in, you know, the grocery store and you knew about programs, you would—that might be your thought. Donna saw more than that—the Liaison. She said, “**Parent,** she doesn’t belong in there.” I’m like, “I know. A, cognitively, she doesn’t belong in there; and B, let’s be realistic: she’s never going to be living on her own. What are we—we’re not gaining anything from either side of this coin.” She said, “Well, I think we need to challenge her.” “Great. Let’s do it.” She goes, “That’s more work at home.” “That’s okay.”

**Denise:** Wow, that’s great.

**Parent:** And then next semester, she’s taking health, which she could probably teach the class.

**Denise:** She’s spent part of it—living it.

**Parent:** Right. And then the first semester of her junior year, she’s taking sociology. Now, this is on top of—she’s in regular language and lit classes. That’s her strength.

**Denise:** That’s so excellent.

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**The Funding Process - Orderly and Predictable and Achieving Success Through Collaboration**

The parent approached the funding process in a manner similar to how she approached other health and education issues: she gained information, reviewed her options and brought people together to participate in decision-making. While she reported that the process for obtaining funding through health insurance had
multiple steps, involved multiple people and included several documents, she believed it was direct and straightforward. After she gained experience with the process, she actively took charge of the process. The parent tactfully engaged individuals in a collaborative process in an effort to promote a positive outcome. She stated, "I felt in control." She was successful: over the years: health insurance paid for two devices and the school paid for one device. Excerpts from the narrative illustrate these concepts

Denise: And how did you get funding?

Parent: The first one was through our insurance.

Denise: And how did you decide to go through your insurance?

Parent: I think we tried that path, and if it didn’t work, then we were going to try through the school system.

Denise: And what made you—what led you to that two-step kind of thinking?

Parent: Because X is in public school; she doesn’t go to any private school. And at that point, I don’t think the school had experienced anyone using assistive technology.

Denise: Oh, she was unique to them.

Parent: She was and still is. So we tried the insurance first, and—hoping that if she got a device, and we demonstrated that she could use it, and it was within the school setting—that when it came time to get a new one or repair something or replace something, then we’d already have school on board—again, the whole team effort thing. I think school bought the second one, which was another iBook-type laptop thing.

Denise: And how did you decide to have them purchase for her?
**Parent:** Basically, we said at the IEP meeting, “She’s getting ready; she’s going to need a new device”—you know, for whatever reason; I can’t remember what it was—“and we think that we should alternate—that you guys should fund this one.” And since she had already used it and demonstrated that she could do it, it was a no-brainer.

**Denise:** Mm-hmm. And they agreed.

**Parent:** Yes. Now at this point in X’s life, there wasn’t a speech pathologist within the school system that had a background in augmentative communication.

**Denise:** So what’d you do?

**Parent:** We would go to the Communication Clinic, on a very regular basis. And then, when it came time for this device—the third, so this is her third...

**Denise:** And this is the Mini-Merc, right?

**Parent:** Yep. We went through insurance, because it was that—you know, we—school had bought one, so we—it was our turn. And there was a woman named Joan who took on the augmentative needs of X, and X was in fourth grade at that time. So by now, we had demonstrated that X can use the device, that someone within the school system can implement the school stuff that needed to be used...

**Denise:** And who was this X?

**Parent:** She was a speech pathologist that just landed in X Public School.

**Denise:** Okay. So she was the first one with any experience in your situation.

**Parent:** Yep. And when it came time for the Mini-Merc—ask to get a new one, we demoed a bunch of different ones at Children’s, and at this point I had to have some knowledge of what I liked about the laptop, what I didn’t like. And mainly, those were portability issues. When you have a kid as involved as X, you don’t need another extra bag, because you already have two. We needed less cable. We needed
it to be able just to be picked up and carried. I didn’t need, you know, to have to put
stuff together. It needed to work on the fly. And the Merc does, and it works great.

**Denise:** And she’s still using that one, correct?

**Parent:** She just finished her midyears yesterday and used her Merc to take the
multiple-choice part of her midyear exam.

**Denise:** Oh, my gosh, she’s amazing. So your health insurance is what?

Here the parent begins to discuss her health care benefits – private, employer-based
and a Medicaid waiver program.

**Parent:** Currently, we have Tufts, and X participates in the... what’s it, the CCM
Program? The Complex Care Medical part of Medicaid or something? We have a
different team than the straight Medicaid.

**Denise:** Mm-hmm, mm-hmm. Most—I think I’ve heard this from several parents.

**Parent:** It’s wonderful.

**Denise:** Mm-hmm. You still have to pay the premiums, right?

**Parent:** Actually, we don’t pay a premium, because X qualifies for the Kaileigh
Mulligan Program. Because of her complex medical needs, we don’t pay the
premium.

**Denise:** Okay. And that’s for kids with complex medical needs.

**Parent:** Yeah, you have to have, like, two skill needs, and one of them has to be
invasive, and there’s this whole criteria.

**Denise:** Okay. And f—am I remembering—is this right—that you used to have
Harvard Pilgrim?

**Parent:** Yes, yep.

**Denise:** And they—did they fund any of these devices?
**Parent:** They must have funded the first.... I don’t know. I know whatever health insurance we had at the time funded the first one, whether it was Tufts at that time or Harvard. We’ve only had two in X’s lifetime.

**Denise:** Okay. So I think you said it was Harvard, and they probably funded the iBook.

**Parent:** Yep, the very first one.

**Denise:** Okay. And the school funded the Mini-Merc.

**Parent:** No, the school funded the second iBook in eighth grade.

**Denise:** Oh, the second iBook. And—okay.

**Parent:** And Tufts—oh, did we have Tufts then, 2005? No, we had Harvard—funded the Mini-Merc.

In the next section the parent described her experiences with staff from the Kaileigh Mulligan Program. Here, once again, she referred to the importance of relationships. She discussed how the “people know X” because they come to the house to reevaluate her every year. The Medicaid staff have “personal contact” with her and the parent believes this is helpful when they review prior authorization requests.

**Parent:** I didn’t feel like I—also being part of this CCM Program when stuff is submitted to Medicaid for payment. These people know X. They come up to the house every year to reevaluate her. They put a name with a face. So it’s really hard for them, I think, to look at—“Oh, here’s a PA, a prior authorization for X King.” “Oh, yeah, I can’t see her using this.”

**Denise:** Oh, okay.

**Parent:** You know what I mean? There’s some—there’s a personal contact with all of it.

**Denise:** They come to your house.
Parent: They have, yeah; they come out, and they also handle the private-duty nursing. So she’s not just a number to them.

In the following excerpts the parent stated that obtaining funding was a multistep process. Initially she relied on an independent evaluator and later she found the vendor’s website very helpful. Each time her daughter needed a new device she gained more experience with the funding process and she deliberately assumed greater responsibility for the process. The parent identified several people who helped her determine which devices and services her daughter needed: the speech-language pathologist at a local hospital, a school speech-language pathologist and the public school “liason”, a teacher who worked with her daughter from an early age. She also mentioned that the vendor was helpful, specifically information on the vendor’s website about the process for obtaining funding. According to the parent, over the years the school speech language pathologists were not helpful because they were not adequately trained in assistive technology devices and services.

Denise: So what was the process like going through Harvard Pilgrim and through the CCM Program?

Parent: Basically, just getting everything together—getting all your paperwork, making copies of all of your paperwork, sending it certified mail, calling a week to ten days after you mailed it to ask if they’ve received it—just making sure that they knew that we were on top of things. I think that helps.

Denise: And how did you know what paperwork to get together and who to call and those kinds of things?

Parent: Well, with the Merc, it was much easier, because this is our third device and they have the great Web site. With the first device, I relied heavily on the Communication Clinic.
Denise: So they were helpful.

Parent: They did it all. You know, they know we need whatever, whatever, and I just got it and brought it in. But I think parents need to take an active role. You can’t—I think we—just happened that that situation—the first one just happened to work. But now we—I just do it all.

Denise: How does it work with Harvard Pilgrim and the CCM Program?

Parent: I don’t know if they work together or not.

Denise: Did they pay—did Harvard pay for everything, or did they—did CCM pay for part of it?

Parent: I think—now that you’ve asked that question, I think that probably Medicaid paid for most of it, because with my—our primary insurance, I think we’re only allowed $1,500 in DME a year, which is a pair of AFOs (ankle foot orthoses)

Denise: So let’s see. Anything else about the funding process? When you—tell me about how—what it was like going through the health insurance and going through the school to get the funding—to get the devices.

Parent: Well, I found that the Assistive Technology—that’s the company that makes the Merc—they Web site was so useful. I could click on their Web site, and I knew that I needed to get this letter, this documentation—"Copy your health insurance cards; fill out this form"—I felt in control. I felt like I had a clue of what was going on. So I think that was huge.

Denise: That was for the Merc, so that was really good. Okay.

Personal Factors: A Powerful Combination of Resources

Several personal factors and social circumstances influenced the parent’s thoughts, actions and, possibly, the outcomes. The parent recognized that her professional background prepared her to advocate for her daughter. She also discussed that her
family had “resources” –they were well educated, her husband was a teacher, and they worked well together to solve problems. Furthermore, the parent also believed that being part of the community for a long period time helped her advocate for her daughter. Here, again, there was a focus on relationships.

**Denise:** So what I want to do today is just have you tell me your experiences in getting funding for... X, right?

**Parent:** Yes.

**Denise:** ...over the years; and who’s been involved; and how you learned what you know; and then, at the end, just what’s some advice you might give other parents.

**Parent:** Okay. I think what we probably need to get on the record somewhere is, prior to staying home, I was a discharge planner/case manager. So I think my background helps.

**Denise:** Okay. Yeah, you had told me you were a case manager before you... Tell me why you think that that helped you in your situation.

**Parent:** I think it helps in many reasons. One, it helps with the whole documentation piece. You know, as soon as I pick up the phone, I write a date on a piece of paper and ask the person their name. And I think it helps because if I find that I’m not being heard, I don’t have a problem asking to speak to a supervisor. This really hasn’t happened with an AT device, but just recently, I was trying to get X a piece of equipment covered, and I realized that the person I was talking to—and I had to spell every diagnosis and spell every med. It was a waste of my time, because they had no clinical background. So I had no problem saying, “Can I please speak to a nurse or a physician or a respiratory therapist or just someone so I’m not spelling ‘cerebral palsy’ every time?” Dennis and I are very well-educated, and we can work
together, and we can sort out issues or obstacles—I feel sorry for the people that
don’t have those resources.

**Denise:** That’s a very good point. So in terms of who’s been involved, you
mentioned the X (local hospital). Tell me about the school a little more.

**Parent:** We are fortunate that we live in a great town. And I’m not saying that we
haven’t had our differences, but Dennis and I have both grown up in this town, and
X’s been in public school since the day she turned three. And it’s worked, for the
most part. And I think that because we approach things as a team—that she has a
tendency... I can’t really think of any time she has been denied something that I truly
believe she’s needed. And I think the school system knows that if my husband
Dennis is involved—that it’s a big deal. I handle all the little stuff—

**Denise:** Why is that?

**Parent:** Because he comes in—he—I do my thing; I handle X’s stuff. He is very
involved with her, but I handle the school and the Merc and that kind of stuff, and he
handles the power chair, and we all have our little roles.

Here the parent discussed how networking has been important to her. Through
networking she built relationships and gained information.

**Denise:** So you’ve—so let me just summarize. So you feel that, you know, having
this background helped you—helped empower you to work the system.

**Parent:** Yep.

**Denise:** Okay, that makes sense.

**Parent:** And work *within* the system. You know, sometimes I—when I hear families
say, you know, “It’s us against them; it’s this and that”—no, we’re all a team.
**Denise:** So when you said just now that you heard families say—do you—is it family—how do you learn from other families? Are these families in your neighborhood...?

**Parent:** When I used to go to, the Special Ed Parent Advisory Council, or—you know, you’re sitting at an appointment and you’re waiting there for hours, you know, you end up talking to whoever you’re sitting next to—those kind of things, or just families that may s—you know, if someone’s second cousin has CP and they said, “Oh, I know this woman Danni; you need to talk to her”—those kind of things. It’s all networking.

**Denise:** Mm-hmm, so one person talks to another person....

**Parent:** Exactly, and that’s how you’ve got to get these devices covered. You just—you’ve got to network.

**Denise:** Mm-hmm. What does networking mean to you?

**Parent:** It means talking to people, sharing of information—not just me giving, giving, giving, but also learning something, because you don’t know when your path’s going to cross with someone again.

Here the parent described how she spoke with other parents in an Early Intervention Program. She helped parents understand that they were part of a “team” and she empowered them to advocate from a “parent perspective”.

**Denise:** Okay. So Medicaid paid for most of it, because you’d already satisfied your $1,500 DME allowance, okay. What else? Let’s see. You talked a lot about how you feel it’s a team.

**Parent:** Yep.

**Denise:** And do you think this is typical, or is it somehow related to how you approach things, or what have you heard from other parents—that kind of thing?
**Parent:** I think it’s more related to how I approach things. But I think it’s an important message that other parents need to hear. You know, any time I’m asked to speak in front of a group of parents or speak in front of a group of professionals—I mean, that’s a message that has to get out.  

**Denise:** So what do you—do you do that pretty regularly?  

**Parent:** I have spoken the past couple years twice a year at our local EI program. I’m part of a team that does a whole competency training on learning through play. And we’ve kind of taken—take a look at all the competencies and then add our own twist to some of it. So the parent perspective part of it is a little different than some of the typical ones, because I think that these—especially the new EI providers need to know that, yeah, they just, you know, went to school for four, six, eight years, whatever it took them, but I lived it 24 hours a day. And it’s important for everyone to be realistic.

### III. Perceptions of the Law Compared With the Positive Law

**The Individualized Education Program (IEP): Measurable with Guidelines**  
The parent reported that the IEP must be “measurable” and has “guidelines”. The parent’s knowledge is accurate. According to IDEA regulations (§300.320 (2)(i)), which have been adopted the state of Massachusetts in its special education regulations (603 C.M.R 28.05), the IEP must include measurable goals. In terms of guidelines, based on federal regulations, which have been adopted by the state of Massachusetts in its special education regulations, there are specific procedural guidelines that educators and parents must follow when developing, implementing, reviewing and updating the IEP (34 C.F.R. §300.324; 603 C.M.R. 28.05).
Parent’s Right to Reject and IEP

The parent reported that she has rejected portions of her daughter’s IEP. Under federal regulations, which have been adopted by the state of Massachusetts, the parent is a member of the IEP team (34 C.F.R. §300.321(a)(1)) and is entitled to reject part or all of a child’s IEP (34 C.F.R §300.300(d)(3), 603 C.M.R. 28.05 (3)(b)).

When IEP’s Must Be in Effect

The parent reported that her daughter’s IEP took a long time to develop and she believed the process took longer than the regulations permitted. The regulations are somewhat vague concerning when IEP’s must be in effect. According to federal regulations, an IEP must be in effect at the beginning of each year (34 C.F.R. §300.323 (a)). The federal law obligates the school to conduct a meeting within 30 days of determining that the child needs, special education and related services (§300.323(c)(1)). The school must provide these services as soon as possible following the development of the IEP (§300.323(c)(2)). According to Massachusetts special education regulations, an IEP team may write a partial IEP if the IEP team does not agree on all aspects of the IEP and then the partial IEP would be implemented immediately (603 C.M.R. 28.05 (3)(b)).

IEP Team

The parent reported that a “liason” from the school department was a vital team member of her child’s IEP team. She was instrumental in enrolling her child in regular education classes and advocating for her daughter to use her speech generating device to take an exam. When asked about the liason, the parent responded, “This is how the school works.” Based on the federal law, which has been
adopted by reference in the state of Massachusetts special education regulations, the parent was accurate. The IEP team includes a representative of the local educational agency and under the federal and state laws this person is qualified to provide, or supervise specially designed instruction (§300.321 (a)(4); 603 C.M.R. 28.02).

**IDEA: Adequate Resources, Training and Competency for Assistive Technologies**

The parent reported that over the years she obtained independent evaluations because the school system was not trained in assistive technologies. She reported that a special educator was in charge of overseeing her child’s AT needs because the speech-language pathologists did not have the knowledge or training. Are these conditions and decisions consistent with the law? According to federal regulations which have been adopted by reference, in the state of Massachusetts special education regulations (603 C.M.R. 28.01), the public school is obligated to provide assistive technology services in order for the child to receive a free appropriate public education (FAPE) (§§300.6, 300.105, 300.320, 300.324). Services include an evaluation and training to the child, family and staff. Thus, if the parent’s perceptions were accurate, the school may have violated the law if it did not provide an AT evaluation and training in order for the child to receive a FAPE.

The parent also reported that the school system paid for one speech generating device for her daughter, a device that was recommended by an independent evaluator. The child had health insurance which paid for other devices. In terms of purchasing a device for a child, the school is not obligated to provide a device if a non-educational agency, public or private, is obligated to provide it, based on federal and state law (34 C.F.R. §300.154 (b)(1)(i)). Moreover, the public school may seek
reimbursement from the non-educational agency if it fails to provide the device (34 C.F.R. §300.154(b)(2)).

**Medicaid: Payor of Last Resort**

The parent reported that Medicaid paid for her daughter’s communication device after she exhausted her DME benefit under the private health insurance. This is consistent with the law. While Medicaid may pay for a SGD, it is the payor of last resort (130 C.M.R. 503.007)

**Medicaid: Kaileigh Mulligan Program** (130 C.M.R. 519.007)

The parent believed she did not pay a premium for this program because her daughter qualified for the program based on her complex medical problems. In part, this is accurate. A child is eligible for this program if s/he is severely and permanently disabled, under 18 years of age, and requires a level of care equal to care provided in a hospital or nursing facility. There are additional requirements. The child must be approved for home care and require home care that costs no more than institutional care costs. The program does not consider a parent’s income or assets in determining financial eligibility. However, the program does consider the child’s assets. To qualify, the child cannot have countable assets of $2000 or greater or a monthly income of $60 or greater. If so, the family may be responsible for a deductible.

**Did the Law Enable the Parent to Advocate for her Daughter?**

Another important question to consider is whether health insurance laws and IDEA regulations enabled the parent to advocate for her daughter? I believe the law empowered this parent to advocate for her daughter’s AT rights and to assert her
parental rights. While she did not articulate specific laws and regulations, the parent recognized that her daughter was entitled to AT and she persistently advocated for these rights. The law provided a framework for her to think about rights, talk about rights and claim rights.

In terms of health insurance, the parent was knowledgeable about benefits. She successfully navigated health insurance procedures to access her daughter’s health care benefits.

IDEA and Massachusetts special education regulations enabled the parent to advocate for her daughter to receive some AT rights under the law. IDEA regulations and the Massachusetts special education regulations enabled her to advocate for her daughter through informal dispute resolution processes, such as talking to teachers, therapists and program directors and through formal procedures such as discussing goals at IEP meetings. The parent had other rights to assert under the law, though she chose not to assert them. IDEA regulations, which have been adopted by the state of Massachusetts in its special education regulations, a parent has rights in four major areas: prior written notice (§300.503; 603 C.M.R. 28.05, 28.05), consent for services (§300.300; 603 C.M.R. 28.07), developing the child’s Individualized Education Program (IEP) (§§300.320, 300.321, 300.322; 603 C.M.R. 28.05) and due process to challenge decisions made by the child’s IEP team (§§300.500-529; 603 C.M.R. 28.08). Consistent with IDEA regulations, in Massachusetts a parent may resolve a dispute in several ways: informal measures (as this parent did), through mediation, through a formal complaint by contacting the Office of Program Quality Assurance Services, by requesting a due process hearing, and if necessary, by appealing a hearing decision to a state or federal court (§§300.500, 300.529; 603
C.M.R. 28.08). Despite some grievances, the parent did not assert her formal rights under the law. She resolved grievances, to her satisfaction, using informal methods.
### Appendix B: Matrices

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<th>Perception of IDEA Empowered:</th>
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<th>Case 2 “Glade”</th>
<th>Case 3 “Brady”</th>
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<td>ERC, EPR</td>
<td>ERC, EPR, EAGP</td>
<td>ERC, EPR</td>
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<td>-Potential to Claim Rights (EPR)</td>
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<td>-Potential to Resolve Disputes (EPD)</td>
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<td>-Achieving Its General Purpose (EAGP)</td>
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<td><strong>Up Against (UA)</strong></td>
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<td>Perception of health insurance</td>
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<td>Factors that influenced funding Decisions</td>
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<td>PES, NSGD</td>
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<td>Assistance (ASSIST) - Independent evaluator (IE) - vendor (V) - parents in the community (PC) - parents on listservs (PL) - local advocacy groups (LAG) - family (FAM) - school personnel - state dept. of ed (DOE) - social worker</td>
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<td>- health insurance did not cover SGDS (NSGD)</td>
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### Perception of funding process
- **Case 4 “Dean”**: OP
- **Case 5 “O’Brien”**: OP
- **Case 6 “Blair”**: OP

### Perceptions of barriers and assistance

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<tr>
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<th>Assistance (ASSIST)</th>
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### Personal factors
- **Case 4 “Dean”**: PER, FAM (financial resources, support, brother is an attorney), M (mother has learning disability, oldest child has disabilities)
- **Case 5 “O’Brien”**: PER, FAM (husband on school committee)
- **Case 6 “Blair”**: FR, O (support from faith-based private school, and faith-based community)

### Degree of formal legal knowledge
- **Case 4 “Dean”**: General understanding
- **Case 5 “O’Brien”**: General understanding
- **Case 6 “Blair”**: General understanding
<table>
<thead>
<tr>
<th>Case 4 “Dean”</th>
<th>Case 5 “O’Brien”</th>
<th>Case 6 “Blair”</th>
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<td><strong>How gained legal knowledge</strong></td>
<td>L, I, AW, A, P</td>
<td>L, I, RFL</td>
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<td>--listservs-(L)</td>
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<td>-Internet sites (I)</td>
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<td>-books (B)</td>
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<td>-other parents (P)</td>
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<tr>
<td>-friends (F)</td>
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<td>-advocacy workshops (AW)</td>
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<td>-attorney (A)</td>
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<tr>
<td><strong>How asserted rights</strong></td>
<td>IF, RO, F</td>
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<td>Perception of IDEA Empowered:</td>
<td>Case 7 “Cole”</td>
<td>Case 8 “Von”</td>
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<tr>
<td>-Rights Consciousness (ERC)</td>
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<td>Together with the Law (TW)</td>
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<td>UA -implementation problems/inadequate knowledge and resources</td>
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<td>Factors that influenced funding decisions</td>
<td>S, R (school SLP and MD refused to complete health insurance paperwork)</td>
<td>OW, S, PEHB</td>
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<td>-ownership (OW)</td>
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<td>-school did not have knowledge or resources (S)</td>
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<td>-prior positive experience with school (PES)</td>
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<td>Case 7 “Cole”</td>
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<td>Case 9 “Smith”</td>
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<td>-health insurance did not cover SGD (NSGD) -resistance (R)</td>
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