A NARRATIVE INQUIRY OF STUDENTS WITH SIGNIFICANT COGNITIVE DISABILITIES AND THE MCAS ALTERNATE ASSESSMENT AS TOLD BY THEIR PARENTS

By

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DEDICATION

There exists no greater well of faith, hope, and love for another than that of a parent. My mom and dad instilled in me the belief that, with hard work and determination, I could accomplish anything. I miss them each and every day, but I hear their voices always.

My children inspire me to dream big and think big. It is because of them that I challenge myself to be a better person. Their intelligence, humor, strength, and love sustain me. Kayla, you will be an amazing teacher who will instill strong values in those students lucky enough to have you. You will live a life carefully constructed with a foundation based on love. People always tell you that you are me, but they are wrong; you are a much-improved version. Johnny, my son, you make me so proud with your service to our country. You are kind and thoughtful and always ready to look out for others. Your humor and charisma will take you far. I am immensely proud of you and your future is so very bright. Both my children have put up with a mom who has missed moments in their lives due to the pursuit of my own dreams. Without complaint, they have offered me nothing but support. For this, I am eternally grateful. You are everything I had hoped and wished for and so much more. I love you … no backsies, no closies, no highers.

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ABSTRACT

Assessment and accountability are hotly debated topics in the field of education. Finding ways to include students with significant cognitive disabilities, a requirement under federal law, remains a challenge. In Massachusetts, students with significant cognitive disabilities participate in the Massachusetts Comprehensive Assessment System’s (MCAS) Alternate Assessment. The MCAS Alternate Assessments are automatically placed in the lowest achievement level; failing. This practice required investigation to determine the impact on the students with significant disabilities who participate. The purpose of this narrative inquiry was to explore the lived experiences of the parents/guardians of student with significant cognitive disabilities to answer two questions: 1. What is the lived experience of parents/guardians of students with significant cognitive disabilities who automatically fail to achieve a high-school diploma due to the MCAS requirement? and 2. How do these parents/guardians describe the impact on the students? Ten parents/guardians participated in this narrative inquiry. The conclusions of this research suggest that it is necessary to include parents/guardians in policymaking efforts that involve their children with significant cognitive disabilities. The parents/guardians believe that the MCAS Alternate Assessment policy gives an inadequate representation of their children’s abilities.

Keywords: Massachusetts Comprehensive Assessment System, alternate assessment
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Chapter 1: Introduction

The No Child Left Behind Act (NCLB), the 2002 reauthorization of the Elementary and Secondary Education Act, raised the bar in holding schools accountable for student outcomes (Education Week, 2018). NCLB was the outcome of a collaboration between civil rights and business groups, as well as members of the Bush administration, and Democrats and Republicans on Capitol Hill (Education Week, 2018). The goal of NCLB was closing the achievement gap between poor and minority students and their peers by setting high standards and accountability for schools and districts (Education Week, 2018). Since then, many policymakers and educators have debated the impact of these federal measures, but none more than educators of one of the most vulnerable school populations: students with significant cognitive disabilities.

In Massachusetts, all students must meet local graduation requirements and pass the Massachusetts Comprehensive Assessment System (MCAS) in English language arts, mathematics, and science to earn a high school diploma (Massachusetts Department of Elementary and Secondary Education [DESE], 2018b). All students take the same test, and those with mild to moderate disabilities may take the test in its original format or with accommodations (Massachusetts DESE, 2018b). For those students with significant cognitive disabilities, an alternate assessment measuring alternate standards is available, but in Massachusetts, those alternate assessments automatically are automatically placed in the failing category, and the students automatically become nongraduates (Massachusetts DESE, 2017b). The determination regarding how a student will participate in the MCAS takes place at the student’s annual individualized education program (IEP) meeting (Massachusetts DESE, 2018b). It is important to understand how the MCAS policy developed.
Background

On April 26, 1983, President Ronald Reagan addressed the United States from the State Dining Room at the White House, holding up a report titled *A Nation at Risk* (Graham, 2013). The author of the report was the National Commission on Excellence in Education under the direction of Secretary of Education Terrel Bell over 18 months (Graham, 2013). *A Nation at Risk* examined the quality of education in the United States, and it found it grossly inadequate (Graham, 2013).

In response to the publication of *A Nation at Risk*, states and local education agencies engaged in standards-based education reform (National Commission on Excellence in Education, 1983). The general message of the report, that the United States was “falling behind” other nations, was further supported by such reports as the *Third International Mathematics and Science Study* (2000), *The Forgotten Half* (1988), and *The Scans Report for America 2000* (1999) (D. R. Johnson, Stout, & Thurlow, 2009). One outcome of these reports was an emphasis on more rigorous requirements for high-school graduation. Subsequent changes in graduation policies required higher standards for all students and exit exams that link to the receipt of a high school diploma (D. R. Johnson, Thurlow, & Schuelka, 2012). Currently, 19 states require students to pass an exit exam to earn a diploma; 15 fewer than in the 2009-2010 school year (Advocacy Institute, 2011; Fair Test, 2017; Gewertz, 2017; Hyslop, 2014). The number of states requiring high-school exit exams is the lowest level since the mid-1990s (Fair Test, 2017). Thirteen states, including Massachusetts, required these exit exams for the high-school class of 2017, down from 26 that used, or planned to use, exit exams as a graduation requirement (Fair Test, 2017). The best ways to include students with disabilities in these reforms has presented an ongoing problem for policymakers and stakeholders impacted by the policy.
Prior to 1997, it was common to exclude students with significant cognitive disabilities from these assessment and accountability measures (Harsen, 2009). The term *significant cognitive disabilities* refers to the small number of students whose intellectual functioning is well below average, and who also have deficits in adaptive behavior (National Dissemination Center for Children with Disabilities, 2012). The Individuals with Disabilities Education Act (IDEA) of 1997 required the inclusion of students with significant cognitive disabilities in adequate yearly progress (AYP) calculations (Gordon, 2006). NCLB increased the federal role in holding districts and schools responsible for the progress of all students, with a special focus on the achievement of students who fall into subgroups such as English-language learners, students with disabilities, economically disadvantaged students, and minorities (Klein, 2017). States that did not comply with the new requirements would risk losing federal money (Klein, 2017). IDEA (2004) reinforced the requirement for students with disabilities in the accountability system.

The United States Department of Education (USDOE) issued nonregulatory guidance in 2005 that established alternate achievement standards (USDOE, 2005). The USDOE guidance maintained that “States are required to hold all students to the same standards except that the December 9, 2003 regulation permits States to measure the achievement of students with the most significant cognitive disabilities based on alternate achievement standards” (USDOE, 2005, para. 3). States have designed alternate assessments for those students who cannot meet the same standards as their typically developing peers, even when provided accommodations to access the assessment (Kleinert & Thurlow, 2001). The purpose of an alternate assessment is to “ensure all students are assessed, while providing a method for the inclusion of students with disabilities” (Musson, Thomas, Towles-Reeves, & Kearns, 2010, p. 67). While the data on participation in state-wide assessments are available on the states’ websites, it is difficult to
gather information on which students must meet which requirements in each state (D. R. Johnson et al., 2012; Thurlow, Albus, Lazarus, & Vang, 2014).

NCLB put in place measures that highlighted gaps between underserved populations and their peers (Every Student Succeeds Act [ESSA], 2015). This focus on accountability was critical in ensuring an equitable education for all children, but it proved difficult to implement with fidelity (ESSA, 2015). In 2012, the Obama administration began allowing flexibility to states regarding the specific requirements of NCLB (ESSA, 2015). States had to create rigorous and comprehensive plans to “close achievement gaps, increase equity, improve the quality of instruction, and increase outcomes for all students” (ESSA, 2015, para. 3). ESSA, signed by President Obama in 2015, allows for the state-defined alternate diploma for students who participate in the alternate assessment (ESSA, 2015).

Accountability and assessment are not only heatedly debated ideas in the field of education and in the discourse around the education of students with disabilities in general, but they are also specific to students with significant cognitive disabilities (Bouck, 2013). Aron and Loprest (2012) raised debate about the appropriateness of using the same models to measure the performance of students with significant cognitive disabilities as their typically developing peers. The inclusion of students with disabilities in higher accountability measures has both intended and unintended consequences.

Therefore, this study examined the lived experience of students who participate in alternate assessment through the lens of their parents/guardians. The intent was to raise awareness of the consequences of high-stakes exit exams at the high-school level on a vulnerable population and to inform policy.
Prior to the enactment of Education for All Handicapped Children Act (EHCA) in 1975, the future of students with disabilities was not bright (Office of Special Education and Rehabilitative Services, 2010). In 1967, state institutions held almost 200,000 people with significant cognitive disabilities in facilities where the conditions were poor (Office of Special Education and Rehabilitative Services, 2010). In 1970, schools in the United States educated only one in five people with intellectual disabilities, and many states excluded students based on their disabilities (Office of Special Education and Rehabilitative Services, 2010). States excluded families from making informed decisions about their children, and there were no resources to maintain significantly disabled children at home or in neighborhood schools (Office of Special Education and Rehabilitative Services, 2010).

In the mid-20th century, the practice began to change through federal initiatives. Pursuant to the 10th Amendment, most oversight of education is at the state and local levels. Increasingly, the federal government has promulgated regulations to ensure that all students receive equal protection in the education they receive, per the 14th Amendment and Brown v. Board of Education. This is especially true with respect to special education. Most significantly, President John F. Kennedy and his family forever changed public attitudes toward people with intellectual disabilities (John F. Kennedy Library, 2018). As a result of the President’s Panel on Mental Retardation in 1961, federal funds were dedicated to the education of individuals with significant cognitive disabilities (Special Education News, 2017). There was also a new emphasis on using federal resources to address issues relating to the education of students with disabilities. This emphasis led to increased interest at the federal level, which, in turn, led to more funding, through President Lyndon B. Johnson’s 1965 Elementary and Secondary
Education Act (ESEA), part of the War on Poverty (Education Post, 2016; Pelsue, 2017; Special Education News, 2017).

**States’ implementation of federal law.** Though public-school oversight is the purview of the states and local government, public schools generally follow federal guidelines (Pelsue, 2017). For public schools to receive federal funds, they must comply with federal regulations and guidelines (Pelsue, 2017). State legislatures set mandatory requirements for student graduation (USDOE, 2017). When states have mandates for courses, the local school district must follow them, but it may offer courses over and beyond those required (USDOE, 2017). Some states delegate more authority to local education agencies to develop their own curricula based on general goals set by the state (USDOE, 2017).

**Massachusetts Education Reform Act of 1993.** Spurred by *A Nation at Risk* and its national attention, the Massachusetts Business Alliance for Education (MBAE) spent two years researching and publishing its own highly influential report, *Every Child a Winner* (Anthony & Rossman, 1994; Chester, 2014). Many credit this report with creating an intellectual framework and political incentive to create the Massachusetts Education Reform Act (MERA) of 1993 (Chester, 2014). Taking effect on June 18, 1993, MERA led to increased funding to schools, but it also created high standards and required more accountability across the Commonwealth’s schools (Anthony & Rossman, 1994; Chester, 2014; MERA, 1993).

The reforms in the MERA take one of three forms: programmatic, organizational/procedural, and/or fiscal (Anthony & Rossman, 1994). The six programmatic reforms concentrate on remediation of K-12 programs (Anthony & Rossman, 1994). MERA requires that the State Board of Education (“the Board”) “establish the goals and standards for the public education system and a mechanism to monitor and report on the progress of that system in meeting those
goals and standards” (Anthony & Rossman, 1994; Chester, 2014, p.3). These goals served as the foundation for determining the required academic subjects taught in public schools (Chester, 2014). The Board delegated the creation of these curriculum frameworks to the Commissioner of Education (“the Commissioner”) (Anthony & Rossman, 1994). The Board and the Commissioner developed academic standards within the core subjects that set forth the “skills, competencies, and knowledge” that each student would need to attain by the end of each grade (Chester, 2014, p. 8). With high expectations for student performance that should be comparable to “typical students in the most educationally advanced nations,” Massachusetts adopted the first curriculum frameworks in mathematics and English language arts in 1996 and 1997 (Chester, 2014, p. 8).

Another core element of MERA was the establishment of the annual administration of student assessments that align to the state standards (Chester, 2014). MERA specifically required that the testing program:

- Test all students who are educated with Massachusetts public funds, including students with disabilities and limited English proficient students;
- Measure students’ knowledge of the material contained in the Massachusetts Curriculum Frameworks; and
- Report on the performance of individual students, schools and districts. (Chester, 2014, p. 10)

The Board adopted the MCAS to meet this requirement (Chester, 2014).

In 2000, Massachusetts legislators promulgated 603 CMR 30.00, creating a new state standard for high school graduation called a competency determination (CD) (Chester, 2014). This CD requires that students must meet 10th-grade standards, as measured by the MCAS, to be
eligible for a diploma in Massachusetts (Chester, 2014). Originally, the basis of the CD was the 10th-grade mathematics and English language arts tests only (Chester, 2014). However, since 2010, students have also had to pass science and technology/engineering (biology, chemistry, introductory physics, and technology/engineering) (Chester, 2014). To earn a CD, students must earn a scaled score of at least 240 or a cut score between 220 and 238 on these tests (Massachusetts DESE, 2018a). If a student scores below 240, he or she must have an educational proficiency plan in place to demonstrate how he or she will reach a proficient score (Massachusetts DESE, 2018a).

For high-school students, the achievement levels for the MCAS are advanced, proficient, needs improvement, and failing (Massachusetts DESE, 2018b). Students who score a 260 or above on the MCAS achieve the advanced level classification (Massachusetts DESE, 2018b). Students who are in the proficient achievement level achieve scores ranging from 240-258 (Massachusetts DESE, 2018b). Students who are in the needs improvement achievement level range from 220-238 (Massachusetts DESE, 2018b). Students in the advanced, proficient, and needs improvement categories are eligible to earn a diploma if they have also met local graduation requirements (Massachusetts DESE, 2018b). Students who are placed in the failing achievement level earn scores ranging from 200 to 218, and they are not eligible to receive a diploma (Massachusetts DESE, 2018b). Students may take the MCAS multiple times after 10th grade to reach proficiency and to earn a diploma (Massachusetts DESE, 2018b).

The MCAS has been administered since 1998, and at that time, it required schools to assess students in English language arts and mathematics in Grades 4, 8, and 10 (Chester, 2014). As NCLB required that states expand assessment and accountability, the MCAS came to include each grade from three through eight, and once in high school during the 10th grade for
competency (Chester, 2014). While Chester (2014) heralded the MCAS in his report, Building on 20 Years of Massachusetts Education Reform, he acknowledged that the MCAS has been less useful in informing instruction for individual students (Chester, 2014). Because it is a summative assessment, the results do not emerge until the school year is over (Chester, 2014).

At a meeting of the Board of Elementary and Secondary Education on February 27, 2018, the board made changes to 603 CMR 30.00, along with regulations relating to MCAS and CDs (Massachusetts DESE, 2018a).

**Summary of amendments to MERA.** In the spring of 2019, the phasing in of a next-generation MCAS in English language arts and mathematics will begin (Massachusetts DESE, 2018a). The new achievement levels will be exceeding expectations, meeting expectations, partially meeting expectations, and not meeting expectations (Massachusetts DESE, 2018a). The next-generation MCAS scale runs from 440 to 560: exceeding expectations scores fall between 530 and 560, meeting expectations scores fall between 500 and 529, partially meeting expectations scores are between 470 and 499, and not meeting expectations scores are between 440 and 469 (Massachusetts DESE, 2018a). The transition plan from legacy to next-generation MCAS requires that the current CD requirements remain in place through the class of 2020 (Massachusetts DESE, 2018a). The next-generation MCAS will begin fully in the spring of 2020 (Massachusetts DESE, 2018a).

**Problem Statement**

Como (as cited by Marchant, 2004) likened the high-stakes testing movement to a “Trojan Horse…. Schools welcomed the testing without knowing the hidden danger inside” (p. 2). The MCAS policy automatically places students with significant cognitive disabilities who participate in the alternate assessment in the lowest proficiency grouping: failing (Massachusetts
DESE, 2017b). The rationale for this policy is that MCAS Alternate Assessments are based on alternate achievement standards (Massachusetts DESE, 2017b). Because passing the MCAS is one of the two requirements to earn a diploma, students who take the MCAS Alternate Assessment do not graduate, and they earn certificates rather than diplomas. As this assessment practice continues, more information is necessary to understand the impact on students with significant cognitive disabilities better.

The existing body of research on the assessment of students with disabilities primarily focuses on how the inclusion of students with significant cognitive disabilities in high-stakes testing impacts teachers, administrators, schools, and districts. However, there is a clear shortfall in research regarding students with significant cognitive disabilities and the outcomes associated with their participation. The consequences of high-stakes testing on students with significant cognitive disabilities require further investigation.

**Purpose of the Study**

The purpose of this qualitative narrative inquiry research was to explore the experiences of the parents of students who participated in the MCAS Alternate Assessment at one large, urban high school. The parents of students with significant cognitive disabilities shared their experiences, which fell into four categories: discovering their child’s disability, school culture, society’s views about disability, and graduation options. The themes that emerged will help to inform the body of research about the impact of the MCAS Alternate Assessment on students with significant cognitive disabilities. The potential impact of this study is to share the stories of the people affected by the policy with legislators and policymakers.

**Research Questions**

This qualitative narrative inquiry addressed these two questions:
1. What are the lived experiences of parents/guardians of students with significant cognitive disabilities who automatically fail to achieve a high-school diploma due to the MCAS requirement?

2. How do these parents/guardians describe the impact on the students?

**Conceptual Framework**

When considering the impact of high-stakes testing on students with disabilities, the researcher built a framework to guide the inquiry that emerged from the literature. Guiding the framework for this study was Lev S. Vygotsky’s *sociocultural development theory* and its relationship to high-stakes testing for student with disabilities, diploma options for students with disabilities, and the historical context of the MCAS (how and why it exists). This conceptual framework to study students with significant cognitive disabilities and the impact of high-stakes testing informed the research.

Vygotsky formulated the most comprehensive framework for inclusive and humane practices in special education (Gindis, 1995, 1999; Rodina, 2006). He considered disability a sociocultural developmental phenomenon in which primary disabilities are organic, and in which secondary factors impact secondary disabilities (Gindis, 1995). He argued that human development is not a direct “path of quantitative accumulations or maturation, but a series of qualitative, dialectic transformations, a complex process of integration and disintegration, gaining and losing” (Gindis, 1995, p. 157). Vygotsky further described a primary disability as one that prevents students from mastering most social skills and acquiring new knowledge at the same rate and in the same manner as their typically developing peers (Gindis, 1995, 1999; Rodina, 2006). Vygotsky’s theory suggests that social and natural developments stop not because of the primary disability, but because of society’s response to the disability (Gindis,
1995, 1999; Janisch, Liu, & Akrofi, 2007; Rodina, 2006). According to Vygotsky’s theory, many of the behaviors that students with intellectual impairments exhibit, such as emotional dysregulation and behavioral infantilism, are actually secondary disabilities that they acquire through their social interactions with the world (Gindis, 1995). It is the student’s social interactions that further disable a student with an intellectual disability, and not the primary disability (Gindis, 1995, 1999).

Vygotsky’s approach was unique, in that he understood disability as a “developmental process, not a static condition” (Gindis, 1995, p. 157). He opposed concepts of quantitative diagnostic procedures, because he believed that a student with an intellectual disability could have more impaired function due to “cultural underdevelopment” than the organically caused disability (Gindis, 1995, p. 158). Vygotsky considered cognitive testing (IQ) as an insufficient measure to determine the difference, because IQ tests measure natural and higher processes together, and they make them equal, which is inappropriate in his theory (Gindis, 1995).

Vygotsky referred to standardized tests as an “arithmetical concept of handicap,” because the basis for determining value was the sum of all the negative characteristics (Gindis, 1995, p. 158). Rather, Vygotsky believed in a strengths-based approach to assessing students that should concentrate on qualitative indicators such as strategies employed to problem-solve, accepting and benefiting from help from the examiner, and the student’s emotional reactions to doing well or struggling with a task (Gindis, 1995). From this developmental approach to assessment, dynamic assessment, Vygotsky formed his most famous theory: the zone of proximal development (ZPD) (Gindis, 1995).

Finding the difference between what a student has already attained and the student’s potential ability to learn became the basis for his quest to find alternatives to the standardized
tests for students with disabilities (Gindis, 1995). Vygotsky called this difference the ZPD (Gindis, 1995). The ZPD is a foundation for social constructivist theory, in which learning is a shared process in a social construct, where students are capable of more competent performance when they receive proper support (Gindis, 1995, 1999).

Proponents of high-stakes testing. There are, of course, questions about the validity of Vygotsky’s methods and theories (Gindis, 1995, 1999; Palinscar, 1998). Some view Vygotsky as an alternative to Piaget’s influential concepts, which formed the predominant theoretical framework for child care and education in the United States (Gindis, 1999). In his theory, Piaget suggested that learning follows maturation; as students mature, so do their cognitive competencies (Gindis, 1999). However, Vygotsky very clearly viewed learning as a shared process in a social construct (Gindis, 1995, 1999). Both Vygotsky and Piaget believed that cognitive development was a combination of mental processes and environmental factors (Gindis, 1999).

The problem with such increased emphasis on testing is not necessarily the test itself, but the instances where the tests have unintended, negative consequences for individual students or groups of students (American Psychological Association, 2018). However, it is also important to recognize that high-stakes testing can have a positive impact on those students and schools who are low performing in the form of targeted interventions and increased funding.

The MCAS has had a positive impact on many students with mild to moderate disabilities. Since the requirement that schools report all data on student performance on MCAS to Department of Elementary and Secondary Education (DESE), there has been an increased focus on subgroups and their achievement. Hehir, Schifter, Grindal, Ng, and Eidelman (2014) found evidence that students with mild to moderate disabilities benefitted from inclusion in the
general education classroom with their typically developing peers. Students with mild to moderate disabilities who were fully included in general education settings earned higher MCAS scores, graduated at higher rates, and were more likely to remain in their home schools than students educated in substantially separate classes (Hehir et al., 2014).

**Rationale for research.** Many see high-stakes testing as the outcome of educational reform meant to increase positive outcomes for students. However, these tests have negative consequences for students with significant cognitive disabilities (Janisch et al., 2007). The impact of this emphasis on high-stakes testing has relationships to deeply held educational philosophies and the ways those philosophies operate in schools (Gunzenhauser, 2003). Gunzenhauser (2003) defined philosophy of education as “the vision for the purpose and value of education” (p. 51). High-stakes testing has a significant effect on the philosophies of education, as the testing brings with it a default philosophy that places inordinate value on the outcomes or scores achieved on tests rather than the achievement that such scores purport to represent (American Psychological Association, 2018; Gunzenhauser, 2003). The lack of ability to reflect on teaching through engaging in dialogue about practices and goals within the school community contributes to this default philosophy (Gunzenhauser, 2003). Teachers may engage in practices that are counterintuitive to their own philosophies, creating a scenario in which teachers cannot achieve the visions they have of themselves as educators (Jones et al., 1999). Nor are teachers able to experience the autonomy and creativity that is inherent in the profession (American Psychological Association, 2018). Instead, some teachers find themselves engaged in educational practices, such as teaching to the test, that they do not view as educationally sound due to pressure to meet school and district targets (American Psychological Association, 2018;
Gunzenhauser, 2003). Teachers are unable to set their own visions and priorities due to the system of accountability.

The phenomenon of high-stakes testing, and the standards movement that created the testing, derives from a behaviorist, positivist philosophy that places great value on that which is quantitatively measurable (Crotty, 1998). For the purpose of this research, high-stakes testing describes the use of standardized tests to determine the quality of schools, high-school graduation, and the governance of schools and districts as it specifically applies to students with disabilities (Gunzenhauser, 2003). “Psychometricians (those skilled in the administration of and interpretation of objective psychological tests)” have taken a view that what we know scientifically, we only know with a certain probability (Gunzenhauser, 2003, p. 52). Psychometricians believe that all knowledge is built on “foundations but is fallible: it is our best approximation of the truth until we are proven false” (Crotty, 1998; Siegel, as cited by Gunzenhauser, 2003, p. 53). Psychometricians make the distinction between what researchers attempt to measure and what they actually measure (Gunzenhauser, 2003). Teachers echo this distinction when they express frustration when they are sure a student knows something, but the student is not able to demonstrate said knowledge in a test question (Gunzenhauser, 2003).

Quantifying student achievement is a much more complex process than a cut-off score for a high-school diploma. Vygotsky pointed out that not all types of achievement are measurable, but that schools use standardized tests because they can measure students’ achievement towards standards (Gindis, 1995, 1999; Gunzenhauser, 2003; Rodina, 2006). Policymakers and other proponents of high-stakes testing claim that these tests are “scientific” or “objective,” but that philosophy is grounded in the belief that all tests are appropriate, because schools administer them “to all students equally and without bias” (Gunzenhauser, 2003, p. 53).
However, school officials who are using tests to make high-stakes decisions must ensure that students undergo testing on a curriculum that they have had a fair opportunity to learn (American Psychological Association, 2018). The high-stakes testing in each state does not exclude or disadvantage subgroups such as racial minorities, the economically disadvantaged, limited English proficiency students, and students with disabilities (American Psychological Association, 2018; Janisch et al., 2007). Although testing has its place in the educational framework, educationalists should not make high-stakes decisions on the basis of a single test score (American Psychological Association, 2018). A test is merely one piece of data that schools should use in conjunction with other data they collect throughout a school year to document a student’s growth through formative assessment (American Psychological Association, 2018; Gunzenhauser, 2003).

Students with significant cognitive disabilities who participate in the MCAS Alternate Assessment become nongraduates partly because the portfolios they complete, with assistance from their teachers, automatically go into the failing category (Massachusetts DESE, 2017b). This led to an exploration of existing research to answer the question, why does this policy exist? The hypothesis that there is an overreliance on high-stakes testing led to the literature review, which focused on three interwoven themes: high-stakes testing for students with disabilities, the diploma options for students with disabilities, and the historical perspective surrounding the MCAS. One notable group of voices absent from these three bodies of literature was the voices of the very people that the laws and policies surrounding alternate assessment sought to serve.

**Definitions**

*Accommodations/Test Accommodations*: Adjustments that do not alter the assessed construct that educationalists apply to test preparation, environment, content, format (including
response format), or administration conditions for particular tests takers, and that they embed within assessments or apply after designing the assessment. Tests or assessments with such accommodations, and their scores, are *accommodated*. Accommodated scores should be sufficiently comparable to unaccommodated scores that administrators can aggregate them together (American Educational Research Association, 2014).

*Accountability System*: A system that imposes student performance-based rewards or sanctions on institutions such as schools or school systems or on individuals such as teachers or mental health providers (American Educational Research Association, 2014)

*Achievement Levels/Proficiency Levels*: Descriptions of test takers’ levels of competency in a particular area of knowledge or skill, usually in terms of categories on a continuum, for example from “basic” to “advanced,” or “novice” to “expert.” The categories constitute broad ranges for classifying performance (American Educational Research Association, 2014).

*Adaptation/Test Adaptation*: (a) any change in test content, format (including response format), or administration conditions increases a test’s accessibility for individuals who otherwise would face construct-irrelevant barriers on the original test. An adaptation may or may not change the meaning of the relevant construct or alter score interpretations. An adaptation that changes score meaning is a *modification*; an adaptation that does not change the score meaning is an *accommodation* (see definitions in this section); (b) a change made to a test that educationalists have translated into the language of a target group and that takes into account the nuances of the language and culture of that group (American Educational Research Association, 2014).
**Adequate Yearly Progress (AYP):** A measurement defined by NCLB that allows the USDOE to determine how every public school and school district in the country is performing academically according to results on standardized tests (USDOE, 2009).

**Alternate Assessments/Alternate Tests:** Assessments or tests that evaluate the performance of students in educational settings who cannot participate in standardized accountability assessments, even with accommodations. Alternate assessments or tests typically measure achievement relative to alternate content standards (American Educational Research Association, 2014).

**Alternate or Alternative Standards:** Content and performance standards in educational assessment for students with significant cognitive disabilities (American Educational Research Association, 2014).

**Cut Score:** A specified point on a score scale, such that educationalists report, interpret, or act upon scores at or above that point differently than those scores below that point (American Educational Research Association, 2014).

**High-Stakes Test:** A test that provides results that have important, direct consequences for individuals, programs, or institutions involved in the testing (American Educational Research Association, 2014).

**Individualized Education Program (IEP):** A documented plan that delineates special education services for a special-needs student and that includes any necessary adaptations in the regular classroom or for assessments and any additional special programs or services (American Educational Research Association, 2014).

** Modifications/Test Modifications:** A change in test content, format (including response formats), and/or administration conditions that increases accessibility for some individuals but
that also affects the measured construct and, consequently, that results in scores that differ in meaning from scores in the unmodified assessment (American Educational Research Association, 2014).

**Assumptions**

Every study involves certain assumptions. This study explored the lived experience of parents/guardians of students with significant cognitive disabilities to promote better understanding of how this policy impacts students. It used a narrative approach to explore the relationship between this MCAS policy and the lived experience of the students who participate. Creswell (2013) defined the term worldview as “a basic set of beliefs that guide action” (p. 6).

The parents are appropriate for inclusion in this narrative inquiry because they have all experienced the same phenomena under study; the lived experience of parents/guardians of students with significant cognitive disabilities and their participation in the MCAS Alternate Assessment (Wargo, 2015). The parents/guardians who the researcher interviewed wanted to share the stories on behalf of their children with a belief that they may have a voice with which to share stories that may influence policymakers (Wargo, 2015). Parents/guardians wanted not only to share the negative experiences their children had, but also to celebrate the joys of raising a child with a disability.

**Scope and Delimitations**

This research took place in one large, urban school district in which 6.7% of students with disabilities participated in the MCAS Alternate Assessment. The researcher’s working knowledge of the pool of participants, as well as her relationship with the school district, provided opportunities for access that might not have been available in another location.
sample included three representatives of each of the categories in which the MCAS Alternate Assessments fall: awareness, emerging, and progressing.

To understand the relationship between this MCAS policy and the lived experience of the parents/guardians of the students who participate better, the researcher used narrative inquiry. Creswell (2013) defined the term worldview as “a basic set of beliefs that guide action” (p. 6). The transformative worldview contains an agenda that includes political change and activism on behalf of those who are oppressed (Creswell, 2013). This worldview is compatible with a narrative qualitative research study. Because narrative inquiry is an in-depth exploration with a rich and layered texture, the sample comprised just 10 participants (one set of parents interviewed together) to achieve a thick and rich set of data from nine interviews (Richards & Morse, 2013).

Narrative inquiry systematically gathers, analyzes, and represents the students’ stories as told by their parents/guardians (Clandinin & Connelly, 2000). This process provides a medium with which to challenge policymakers’ views of truth, reality, knowledge, and personhood by bringing together layers of understanding about students with significant cognitive disabilities and their culture (Clandinin & Connelly, 2000). Complex patterns, descriptions of identity, and reconstructions will provide information about how the students have interpreted events surrounding the MCAS policy and the values, beliefs, and experiences that guide those interpretations (Clandinin & Connelly, 2000). Narrative inquiry constitutes the “social reality of the narrator” (Etherington, 2000, p. 81), and it convey a sense of the researcher’s experience through the depth, richness, and texture of the narrative (Clandinin & Connelly, 2000). This research adds to the body of knowledge on the assessment of students with significant cognitive disabilities.
Limitations

Discussing the details of a child’s disability may be challenging for the participants. Some participants have strong biases towards the school system, the ways in which it assesses their children, and how society perceives their children. These biases may have influenced responses to questions about the MCAS. Some participants had little knowledge of the way states count MCAS in their reporting data, and they did not understand how their child’s participation influenced that data. A few of the participants were not knowledgeable about the diploma options and the failure status of the alternate assessments, which may have skewed their comments and thought processes for some responses.

The number of participants was sufficient to draw conclusions, as saturation of the data occurred. However, not all participants in the diverse community could participate, because there was no translator available in this research. Thus, a small subgroup of participants who speak a language other than English could not take part.

The researcher interviewed parents of students with significant cognitive disabilities rather than students. The parents are legally responsible for the students with significant cognitive disabilities. The students represent a vulnerable population, and they may not understand or be able to express their experiences in a manner that can answer the research questions. In fact, it is the parents who navigate the educational system on behalf of their children with significant cognitive disabilities.

The researcher is a member of this school district. As a result, some participants may not have been able to separate that role from the role of independent researcher. The researcher took measures to establish a professional distance so that past relationships did not influence the data. The interviews did not take place in a school building, the researcher made contacts using
personal cellphones and e-mails, and the researcher told the participants that their comments would not have any impact on the researcher’s decisions regarding school.

The small sample size cannot represent the general population, and the results are particular to this school district. However, this research can inform an understanding of the meaning of these experiences.

**Significance**

In 2017, schools submitted 8,532 MCAS Alternate Assessment portfolios to the DESE (Massachusetts DESE, 2017b). All 8,532 of those portfolios went into the *failing* category, and the state will consider the students nongraduates in 2019 at the commencement exercises for their schools. The impact of this policy on these students requires investigation.

The strengths and weaknesses of having an intellectual disability vary among those students who have them, just as they vary among those who are typically developing. There is now a national commitment for access to a free and appropriate public education for all students with intellectual disabilities (Office of Special Education and Rehabilitative Services, 2010). Massachusetts is part of that national movement to improve employment and life outcomes for people with intellectual disabilities (van Gelder, Nichols, & Tummino, 2013). Many individuals who society once marginalized can now live and work successfully in society with appropriate supports (van Gelder et al., 2013). The attitudes about and perceptions of people with significant cognitive disabilities have been changing over time (Office of Special Education and Rehabilitative Services, 2010; van Gelder et al., 2013). Assessing the values, attitudes, and beliefs of the parents/guardians of students with significant cognitive disabilities and their experiences with the MCAS Alternate Assessment adds to the existing body of literature about current practices.
Summary

The purpose of this qualitative narrative study was to explore the experiences of 10 parents of students who participated in the MCAS Alternate Assessment. The researcher organized the narratives by each of the performance levels: awareness, emerging, and progressing (Figure 1). Sharing the lived experience of the parents/guardians of the students who participated in the MCAS Alternate Assessment through a narrative inquiry could encourage policymakers to revisit MERA (1993) in light of ESES’s (2015) allowance for state-defined alternate diplomas.

![Standard MCAS Performance Levels](chart)

Figure 1. Standard MCAS and MCAS Alternate Assessment performance levels. Adapted from Principal’s Manual for 2017 MCAS-Alt, Boston, MA: Massachusetts DESE.
Chapter 2: Literature Review

In Massachusetts, students seeking to earn a high-school diploma must meet the competency determination standard in addition to meeting all local graduation requirements (Massachusetts DESE, 2018b). MCAS measures a student’s knowledge of key concepts and skills outlined in the Massachusetts Curriculum Frameworks (Massachusetts DESE, 2018b). Students with mild to moderate disabilities who receive specialized instruction via an IEP take the MCAS with or without accommodations (M. Lanner, personal communication, January 18, 2017).

A small number of students with the most significant cognitive disabilities who cannot take the standard MCAS tests even with accommodations participate in the MCAS Alternate Assessment (Massachusetts DESE, 2017b). The MCAS Alternate Assessments consist of portfolios of specific materials collected annually by the teacher and student (Massachusetts DESE, 2017f; M. Lanner, personal communication, January 18, 2017). The team at the student’s IEP meeting determines a student’s participation in an alternate assessment (M. Lanner, personal communication, January 18, 2017). However, those in MCAS Alternate Assessments automatically place in the failing category, and the students become nongraduates in state reporting data (Massachusetts DESE, 2017e).

Massachusetts has achieved the goal of including all students in assessment procedures, however, it has not meaningfully documented the voices of those the policy affects. The aim of this research was to provide a mechanism to investigate the impact on the students who participate in the MCAS Alternate Assessment.

Literature Search Strategy

The purpose of this literature review was to explore and understand the existing body of work related to the policies, practices, and outcomes relating to the MCAS Alternate
Assessment. Initial exploration led to only one piece of literature: Baron’s (2007) “When Good Intentions Go Bad: The MCAS Graduation Requirement and Special Education Children Note.” Using the references from Baron’s work led to other bodies of work that were broader, including a variety of topics relating to assessment or the assessment of students with disabilities, but not in Massachusetts. This necessitated a broader review of literature.

The extensive literature search included Northeastern library’s databases, journals, periodicals, websites, statutes, legislations, a variety of search engines, and following the resources in relevant pieces of work. Once the researcher gathered the literature, she analyzed it and took a systematic approach to review key words and concepts. A framework emerged that included themes; a historical perspective about the MCAS, high-stakes testing for students with disabilities in general, and diploma options for students with disabilities. From there, the researcher conducted a more focused literature search to drill down to the theories, laws, and ideals that underlie the MCAS Alternate Assessment.

MCAS. The Commonwealth of Massachusetts has a history of cherishing public education. Chapter 71, Section B (known as Chapter 766), enacted in 1972, was the model for the Every Handicapped Child Act (Center for Education Policy and Practice, 2017). Chapter 766 guarantees the rights of all students with disabilities (ages 3-22) to an individualized program that meets the students’ unique needs. MERA (1993) requires that all students seeking to earn a high-school diploma, including all students who attend public schools, meet competency determination standards and local graduation requirements. The assessment that Massachusetts has adopted to determine competency is the MCAS (Massachusetts DESE, 2018b). To meet the competency determination, all students must earn a score of at least 240 on the Grade 10 MCAS in each subject: English language arts (ELA), mathematics, and science (Massachusetts DESE,
2018b). Students who participate in the standard MCAS have multiple opportunities to retake the test until they pass (Massachusetts DESE, 2018b).

All students with disabilities must participate in the MCAS, regardless of the severity of their disabilities (Massachusetts DESE, 2017b). Students with mild to moderate disabilities participate in the MCAS under routine conditions or with accommodations, while students with significant cognitive disabilities participate in the MCAS Alternate Assessment (Massachusetts DESE, 2017b). The decision regarding alternate assessment participation occurs at the student’s IEP team meeting. The team must agree that the student cannot demonstrate knowledge and skills on the computer- or paper-based MCAS test under routine conditions even with accommodations (Massachusetts DESE, 2017d). Further, students who participate in the MCAS Alternate Assessment are:

- Working on learning standards that have been substantially modified below grade-level expectations due to the severity of the disability, and are
- Receiving intensive, individualized instruction in order to acquire, generalize, and demonstrate knowledge and skills, and are
- Unable to demonstrate knowledge and skills on an on-demand computer- or paper-based test, even with accommodations and accessibility features. (Massachusetts DESE, 2017d, p. 3)

Each student with significant cognitive disabilities participating in the MCAS Alternate Assessment completes a portfolio of specific content collected annually (Massachusetts DESE, 2017b). The portfolio may include work samples, data charts, videos, and other supporting information that demonstrates a student’s entry point into meeting the state standards (Massachusetts DESE, 2017b).
The school determines the accommodations or modifications that it will provide for an assessment, if any, at that student’s IEP team meeting each year (Massachusetts DESE, 2017c). Only students with the most significant cognitive disabilities in the Commonwealth participate in the MCAS Alternate Assessment (Massachusetts DESE, 2017b). Each student taking the standard MCAS receives one of the following ratings: failing, needs improvement, proficient, or advanced (Massachusetts DESE, 2017b). However, the DESE automatically places alternate assessments in the failing category, because the students are undergoing assessment on alternate achievement standards (M. Thurlow, personal communication, August 16, 2017). The rationale for the failing category is that students would not be able to pass the standard test (M. Lanner., personal communication, January 18, 2017). Because students are working below grade level, and they have to meet only one strand of the standard instead of the whole standard, like their typically developing peers, the assessments go into the failing category (D. Hand, personal communication, August 17, 2017). Another rationale given is the fear that a student’s performance may be inflated by placement in another achievement level other than failing (D. Hand, personal communication, August 17, 2017). With this information, the logically consequent question is: Why should students participate at all? Students with significant cognitive disabilities participate in the MCAS Alternate Assessment because the school can earn accountability points for each student’s assessment (Massachusetts DESE, 2017c), and it can measure the student’s progress as required by federal law (D. Hand, personal communication, August 17, 2017).

In 2012, after receiving a USDOE waiver from using AYP for accountability, Massachusetts replaced AYP with the Composite Performance Index (CPI) (Massachusetts DESE, 2017b). According to the DESE, “all groups (districts, schools, and subgroups) are
expected to halve the distance between their level of performance in 2011 and proficiency by the year 2017” (Massachusetts DESE, 2017e). Using the 100-point CPI to measure progress towards this goal of narrowing proficiency gaps, DESE assigns 100, 75, 50, 25, or 0 points to each student taking the MCAS and the MCAS Alternate Assessment based on how close the student came to scoring proficient or advanced (Massachusetts DESE, 2017c). The CPI is the result of dividing the total number of points by the number of students in the group, and it is a number between 0 and 100 (Massachusetts DESE, 2013). If a group achieves a score of 100, it means that all students in that group are proficient (Massachusetts DESE, 2013).

Even though the MCAS Alternate Assessments automatically go into the failing category, they count in the CPI data, and each student may be able to earn 100 points (Massachusetts DESE, 2013). Students with significant cognitive disabilities can potentially contribute 100 CPI points to the overall performance of the school, which is the motivation for schools and districts to continue to require students to participate in the MCAS Alternate Assessment (M. Lanner, personal communication, January 18, 2017). The DESE provides the following explanation for the policy: “all students are capable of learning at a level that engages and challenges them. Teachers who have incorporated learning standards into their instruction cite unanticipated gains in students’ performance and understanding” (Massachusetts DESE, 2013). An additional advantage to using this approach is that some social, communication, motor, self-help, and other daily living skills can be addressed during activities in which teachers teach learning standards, as outlined in the Massachusetts DESE’s Resource Guide to the Massachusetts Curriculum Frameworks for Students with Disabilities (Massachusetts DESE, 2017c).

Baron (2007) asserted that there is a disconnect between the goals of the special education programs in Massachusetts and the MCAS. As educators seek to ensure that gaps are
closing between students with disabilities (as a subgroup) and their typically developing peers,
students with significant cognitive disabilities are experiencing further marginalization through
the use of the MCAS Alternate Assessment. The 8,532 students with significant cognitive
disabilities who participated in the MCAS Alternate Assessment in the 2016-17 school year will
have failed the MCAS and, therefore, will be nongraduates in 2019 (Massachusetts DESE,
2017f). Mitchell Chester, the former Commissioner of Education for the Commonwealth of
Massachusetts, credited the strong public-school system for the Commonwealth’s “centuries-old
belief in public school” and the agenda set forth in the MERA (Chester, 2014, p. 1). The current
system of placing the MCAS Alternate Assessments in the lowest achievement level seems to
contradict this sentiment.

**High-stakes testing for students with disabilities.** “Students with disabilities” is an all-
encompassing term that includes 13 disability categories. Federal funding is tied to each label
within the broad term (Bursuck, 2010). Disability categories can be useful to understand which
students are likely to leave high school with a diploma (Achieve, 2013). The 13 categories are:
learning disability, speech or language impairment, intellectual disability, emotional disturbance,
autism, hearing impairment, visual impairment, deaf-blindness, orthopedic impairment,
traumatic brain injury, other health impairment, multiple disabilities, and developmental delay
(Bursuck, 2010). Students who fall within “intellectual disability,” “autism,” or “multiple
disabilities” are students with significant cognitive disabilities for this literature review. While
we should not use labels to inform perceptions and attitudes towards people with disabilities,
they are an important tool in protecting the civil rights of students with disabilities and ensuring
that adequate funding goes to the schools and districts responsible for their education (Bursuck,
2010). The diverse characteristics within the categories have clear implications for testing and graduation policies.

There are three typical approaches to alternate assessments: portfolios, performance assessments, and rating scales (Elliott & Roach, 2007; Vander Ark, 2013). A performance assessment is a test in which the student performs real-world tasks that require mastery of the actual skills the test measures (Vander Ark, 2013). Teachers complete rating scales based on a list of skills they observe (National Center on Educational Outcomes [NCEO], 2016). Portfolios contain samples of student work, and the student and the teacher complete them in collaboration to show mastery of a standard. (M. Lanner, personal communication, January 18, 2017). In Massachusetts, students submit these portfolios, but the state does not expect them to master the entire standard (D. Hand, personal communication, August 17, 2017). Instead, students should show an entry point to accessing a standard that depends on the students’ abilities (D. Hand, personal communication, August 17, 2017).

The NCEO published a brief entitled “Understanding Subgroups in Common State Assessments: Special Education Students and ELLs” for the Race to the Top Assessment Consortia which compared the use of regular and alternate assessments (NCEO, 2011). The NCEO’s claim is that many assessment developers can create valid assessments for typically developing students, but they fall short in understanding the unique needs of students with disabilities. Students with disabilities make up 13% of students in public schools, but each state has variations in its own percentage of students with disabilities (NCEO, 2011).

In 2008, the NCEO looked at the percentage of students in each special education disability category in all 50 states, utilizing the reporting data found on the IDEA website (NCEO, 2011). The data yielded recommendations from the consortia based on an analysis of
the disability categories by state. The data showed “considerable variability” within each of the disability categories, and the populations of students with disabilities varies across the states (NCEO, 2011, p. 2). This makes tracking data about the performance of students by disability type across states difficult. Each state is unique in its size and the composition of the population of students with disabilities. Because of this, the NCEO recommended consistent participation and accommodation policies for the states to use in reporting the results of assessments (NCEO, 2011, p. 3).

Since 2001, states have had to publish the results of the alternate assessments, but there is wide variation in how states are defining performance indicators for students with significant cognitive disabilities (Bechard, 2001; Browder et al., 2005). The variability in state reporting supports the conventional wisdom that states are struggling to incorporate the alternate assessments into a structure that previously did not include students with significant cognitive disabilities. For example, some students use symbols for communication rather than words or sentences. States could improve the validity of the alternate assessments by defining the terms “reading, mathematics, and science” for those students who use symbolic communication (Browder et al., 2005).

While the intent of expanding high-stakes testing to students with significant cognitive disabilities is to provide equal protection, the uneven and varied testing methodologies and reporting appear to contradict that goal. There are numerous variables that determine how a state decides how to report the scores on alternate assessments (Bechard, 2001). One model for reporting includes all the students in every assessment (Bechard, 2001; Fair Test 2017). Another model separates those students who take the regular assessment with or without accommodations or the use of nonstandard accommodations, which comprises 98% of students taking the regular
assessment (Bechard, 2001). In this model, only 2% of students can participate in the alternate assessment (Bechard, 2001). The latter is the model Massachusetts implements (Massachusetts DESE, 2018b).

Elliott and Roach (2007) also identified three technical challenges in alternate assessments. They found that schools use alternate assessments with a very small percentage of students with significant cognitive disabilities, but they place high demands on teachers to implement and develop them. A key finding in their work was that the teacher’s role in producing a portfolio influenced the validity of the assessment (Elliott & Roach, 2007).

Karvonen and Huynh (2007) compared the relationship between the IEP and the alternate assessments. After analyzing 292 IEPs, they found that half of them did not have reading comprehension goals and one third had none for mathematics. Because the alternate assessments are requirements to measure reading and mathematics skills, more work is necessary to ensure that IEPs contain the necessary goals to use the IEP’s priority skills as a link to the alternate assessment (Karvonen & Huynh, 2007). Some alternate assessments have inconsistencies from the outset. When IEP teams determine the criteria that students should meet, this may encourage teams to lower the standards for a student so that he or she reaches proficiency relatively quickly. When scoring assessments, Browder et al. (2005) also cautioned against placing the scores of students who take the alternate assessment in the lowest performance category, as those students are effectively “left behind” (p. 219).

Stockall and Smith (2013) concluded that both teachers and administrators saw gaps in the connections between the standards and what they considered meaningful curricula designed for the unique needs of students with significant cognitive disabilities. It is evident that the failure of a teacher to gather appropriate data effectively for inclusion in a portfolio could
inadvertently impact the student, which further calls into question the validity of alternate assessments as a single measure of student proficiency (Laitsch, 2006). Finally, Browder et al. (2015) suggested that the complexity of alternate assessments requires a common language and expectations nationwide.

The lack of consistency in alternate assessments has prompted an equally varied set of suggestions on what to do about the tests. In support of alternate assessments, Musson et al. (2010) suggested that including students with disabilities in state assessments ensures that states consider those students when they make policy decisions. While Elliott and Roach (2007) supported the use of performance assessments and rating scale approaches over portfolio assessments, they suggested that only leaders in each state can make the decision about which approach works best for that state. Each state must determine for itself which alternate assessment to implement. This is not, they argue, something that should be common across the country.

ESSA requires that the parents/guardians of students with significant cognitive disabilities who take alternate assessments know that:

- their child’s academic achievement will be measured based on alternate achievement standards and
- participation in an alternate assessment may delay or otherwise affect their child’s completion of the requirements for a diploma. (Massachusetts DESE, 2017b)

E. Johnson and Arnold (2004) used the Commonwealth of Massachusetts as an exemplar for transparency when they informed parents that “results may indicate ways in which documentation in the portfolio could be improved, and may not as yet fully reflect what the student has been taught or has learned,” (p. 274).
Using a pattern-matching technique, Musson et al. (2010) searched the websites of all 50 states’ Department of Education (DOE) websites. They found that the majority (86%) of states were in compliance with federal law by not including IQ levels or existing disability categories in their alternate assessment eligibility criteria. However, almost all (98%) DOE websites indicated that a student needed to have a “significant cognitive impairment’ or ‘significant cognitive disability” to participate in the alternate assessment and that the IEP team determined that eligibility (Musson et al., 2010, p. 71). In their conclusion, they identified several implications of their research. The most relevant factor for this literature review is that the federal government allows states to outline their own participation guidelines for the alternate assessment through ESSA and IDEA, but it does not provide sample guidelines or “clear-cut eligibility criteria” (Musson et al., 2010, p. 77). This conclusion demonstrates a need for states to use research to help to guide necessary revisions to participation guidelines.

Towles-Reeves, Kleinert, and Muhomba (2009) stated that Browder et al. (2003) were the first to review the use of alternate assessments. They used that original work to conduct an analysis to determine whether states have implemented its recommendations. They found that the relative “infancy” of alternate assessments makes it difficult to track the quick evolution of the field (Towles-Reeves et al., 2009, p. 244). However, ongoing and targeted professional development is necessary so that teachers may ensure the alternate assessments are of high quality (Towles-Reeves et al., 2009). If educationalists use alternate assessments to evaluate programs, they must link these assessments to other measures of student outcomes that include nonacademic skills (Towles-Reeves et al., 2009). Finally, Towles-Reeves et al. asserted that “at least minimal” gains have been made in the areas Browder et al. (2003) identified.
After examining data from 42 states, Browder et al. (2005) recommended a national policy that identifies the standards and scoring methods for alternate assessments. Because students with significant cognitive disabilities vary widely in their skill sets, linking the alternate assessments to students’ IEPs is preferable (Browder et al., 2005). Priority skills the students’ IEPs identify could be the basis for an alternate assessment for each student (Browder et al., 2005). Many researchers see potential benefits to students if states implement the recommendations for reform with fidelity. The field is quickly growing, so that ongoing continuous data collection is warranted, and common language and practices within each state is necessary. It is important to track the models of alternate assessments and the ways the states report them to explore potential pros and cons in each model as well as implications for use over time (Bechard, 2001).

There is no standard way in the United States to measure the performance of students with significant cognitive disabilities. Some states use high-stakes tests as a measure to determine graduation. This is a problem in Massachusetts, where the alternate assessments automatically go in the failing category, rendering the students who take them nongraduates. By default, the students taking the alternate assessment do not have equal access to achieving a diploma.

**Diploma options for students with disabilities.** In response to NCLB and public demands to increase the achievement levels of America’s students, states have adopted a variety of policies that include increasing high-school graduation requirements, developing exit exams, and offering options for the traditional diploma (Burdette, 2007; NCEO & National Technical Assistance Center on Transition [NTACT], 2017). In Massachusetts, the class of 2003 was the
first to have its high-school diplomas withheld based on 10th-grade scores in 2001 (Borofsky, Bowse, & Davis, 2013).

The USDOE’s (2005) nonregulatory guidance identifies what information schools must share with parents through the IEP process. First, the schools must inform the parents of “potential consequences, if any” for their child if the child participates in an alternate assessment (USDOE, 2005). The DOE gives the example that if the school will not permit a student to graduate with a traditional high-school diploma, it must inform the parent (USDOE, 2005). Second, under NCLB, states cannot count student scores as proficient because the state has exceeded the 1% cap; they must provide the parent with his or her child’s actual score (USDOE, 2005). However, the state does not have to inform parents that it will count the student’s score differently (USDOE, 2005). ESSA now requires that the participation rate in each subject area be 1% of the total tested population (ESSA, 2015). There is no limit on accountability, but states must apply for a waiver if they exceed the 1% participation rate (ESSA, 2015). Massachusetts has applied for, and received, approval for a waiver on participation (D. Hand, personal communication, August 17, 2017).

Students with significant cognitive disabilities typically receive instruction linked to standards that prepare students for life after high school; however, they must meet different performance standards (Achieve, 2013). There are two actions necessary to address the graduation requirements for these students according to Achieve (2013). First, policies and procedures must be in place to ensure that students with significant cognitive disabilities are in classes with high expectations, based on college and career-ready standards (Achieve, 2013; Thurlow et al., 2014). Schools often track students with significant cognitive disabilities from their first years of schooling, which results in a lack of exposure to the content and social
interactions necessary for the students to gain the skills they need for postsecondary employment (Achieve, 2013). Second, stakeholders such as parents, employers, and postsecondary education partners should engage with policymakers in defining successful completion of school (Achieve, 2013; Thurlow et al., 2014).

The NCEO focused on graduation requirements and diploma options for students with significant cognitive disabilities who participate in alternate assessments based on alternate achievement standards in its 2014 policy analysis (Thurlow et al., 2014). The findings revealed that almost 70% of states’ policies indicated that students with significant cognitive disabilities could earn a traditional diploma (Thurlow et al., 2014). In those states where these students could not earn a diploma, all but one offered a different exit document (Thurlow et al., 2014).

Tracking the data can be challenging and misleading. It is not readily available on states’ websites, and nor is implementation consistent (Thurlow et al., 2014). The pathway for students with significant cognitive disabilities is arduous (M. Thurlow, personal communication, August 16, 2017). Competency portfolios are available to students with significant, but primarily noncognitive disabilities such as autism and emotional problems, who perform classroom work at grade level, cannot access the standard MCAS for a variety of reasons, and are seeking to earn a score that would allow them to earn traditional high-school diplomas (Pelychaly, 2017). Very few students with significant cognitive disabilities in Massachusetts receive encouragement to attempt a competency portfolio, because it is laborious, and students must demonstrate grade-level performance in course work (D. Hand, personal communication, August 17, 2017). Students with significant cognitive disabilities often do not receive instruction at grade level, and they would not be able to submit a competency portfolio (M. Lanner, personal communication, January 18, 2017).
ESSA allows for each state to create a state-defined alternate diploma (M. Thurlow, personal communication, August 16, 2107). NCEO and NTACT (2017) published a joint brief, *Considerations for Developing State-Defined Alternate Diplomas for Students with Significant Cognitive Disabilities*. The brief made recommendations to states wishing to create a state-defined alternate diploma: (a) define state-defined diploma, (b) examine the necessary policy adjustments to incorporate the state-defined alternate diploma into current educational policies, (c) determine course and exit exam requirements that will align with the requirements for the regular diploma, (d) revise the assessment participation requirements to ensure that only students with the most significant cognitive disabilities participate in alternate exit exams to earn a state-defined alternate diploma, and (e) provide professional development to promote access to the general curriculum and opportunity to learn for students with the most significant cognitive disabilities (NCEO & NTACT, 2017). While 24 states offered diploma options for students with disabilities, and others had multiple diploma options, including “certificate of attendance or completion,” for all students, at the time of the NCEO and NTACT brief, none had diploma options that meet the criteria of ESSA (NCEO & NTACT, 2017). This is an area that needs further investigation and research as implementation of the law proceeds (NCEO & NTACT, 2017).

**Conclusion**

The literature has identified varying degrees of implementation of the NCLB and IDEA regulations regarding the inclusion of students with significant cognitive disabilities in high-stakes testing. The states take several approaches to include portfolios, performance assessments, and rating scales (Elliott & Roach, 2007). The graduation outcomes also vary among the states, with 70% of states allowing students to earn a diploma after completing an
alternate assessment (Thurlow et al., 2014). ESSA requires that states use portfolio assessments only and allows for states to create state-defined alternate diplomas (ESSA, 2015). The impact of these policies requires further exploration.

In Massachusetts, the MCAS Alternate Assessments automatically place students in the failing category, and the students receive certificates of attendance at their graduation ceremonies (Massachusetts DESE, 2017b). For some schools and districts, this policy may have a significant impact, depending on the percentage of students with significant cognitive disabilities submitting alternate assessments and the total number of students with disabilities participating in the MCAS (Massachusetts DESE, 2017b). If the subgroup “students with disabilities” does not meet its targeted graduation rate in any given school or district, the school or district may be at risk of state intervention (Executive Office of Education, 2017). In Massachusetts, these data are readily available and easy for stakeholders to understand and monitor. However, the literature did not describe the lived experiences of the students with significant cognitive disabilities who participated in alternate assessments.

Summary

Determining appropriate graduation policies and testing approaches for students with disabilities remains a challenge for states and districts across the United States (M. Thurlow, personal communication, August 16, 2017). Massachusetts has met the intended consequence of inclusion in mandated assessment, but the challenge has been how best to include students with disabilities in these accountability measures.

There are several unintended and negative consequences of the current model for graduation requirements and diploma option policies (D. R. Johnson et al., 2009). Failure rates on assessments, unnecessary grade-level retentions, increased dropout rates, and students not
receiving a standard diploma at the end of their schooling are some of the consequences
(Johnson et al., 2009).

Massachusetts will not implement a state-defined alternate diploma in 2018, and there is
currently no active consideration to do so in the future (D. Hand, personal communication,
August 17, 2017). More research is necessary regarding the inclusion of students with
significant cognitive disabilities in the MCAS Alternate Assessment, with a focus on the
unintended consequences of placing those who take these assessments in the failing category and
the students earning a certificate rather than a diploma.
Chapter 3: Research Methodology

The purpose of this qualitative narrative inquiry research was to explore the experiences of the parents/guardians of students who participated in the MCAS Alternate Assessment at a large, urban high school in Massachusetts. It was vital to select a research methodology that best answered the research questions under investigation (Tashakorri & Teddlie, 2010). Determining an appropriate and valid research method required consideration of how the research problem aligned with personal experiences and the audience for the study (Creswell, 2013). The choice of narrative inquiry ensured the voices of the participants would be dominant. This chapter discusses the four main aspects of research methodology: design, sampling, data collection, and data analysis (Tashakorri & Teddlie, 2010), and it documents the implementation of the research design.

Research Design and Rationale

Quantitative and qualitative research methods serve different purposes and answer different types of research questions. Quantitative research tests objective theories and uses statistical or mathematical analysis of the data (Babbie, 2010). It focuses on relationships between measurable variables, so researchers can analyze numerical data using statistics (Creswell, 2013). Researchers typically gather data using structured research instruments, and the results come from large sample sizes that represent a population (Babbie, 2010; Creswell, 2013). Quantitative research studies are replicable and repeatable due to their high reliability (Babbie, 2010). The researcher presents data in the form of numbers and statistics, typically in tables, charts, or figures from surveys (Babbie, 2010; Patten, 2014).

Creswell (2013) asserted that qualitative research is an “approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (p. 4). The strength of qualitative data is that it is rich, it has a holistic approach to complex issues, and
it provides vivid descriptions that have a basis in reality and have a “ring of truth” to the reader (Miles, Huberman, & Saldana, 2014). Implied in the term “qualitative” is the emphasis on qualities of entities and on processes that researchers do not measure through experiment, but rather they interpret directly (Babbie, 2010; Creswell, 2013). Qualitative researchers stress social constructs with an emphasis on values (Babbie, 2010). Relationships between the researcher and what he or she studies, and the constraints of inquiry are also important (Babbie, 2010).

When conducting qualitative research, a researcher must identify a worldview that helps to guide the research (Creswell, 2013). The plan to conduct research requires that the researcher consider philosophy, research designs, and specific methods that align to a philosophical worldview (Creswell, 2013). The research, the assumptions the researcher brings to the study, and the methods and procedures that the researcher selects are all relevant to this worldview (Creswell, 2013). Creswell (2013) defined a worldview as a “general philosophical orientation about the world and the nature of research that a researcher brings to a study” (p. 6).

The worldview most aligned to this narrative inquiry research is transformative, in which the researcher’s inquiry involves political and action research to address issues of social justice, discrimination, and oppression (Creswell, 2013). The research has a focus on action and reform that changes the lives of the participants, institutions, and the researcher (Creswell, 2013). The researcher begins with an issue as the focal point of the study, and he or she is careful to conduct the research so as not to marginalize the participants further (Creswell, 2013; Patten, 2014). The study of the lived experience of those that have been marginalized and the strategies they have used to overcome the oppression are also important (Creswell, 2013).
Michael Connelly and Jean Clandinin first used the term *narrative inquiry* in an article in 1990 (Caine, Estefan, & Clandinin, 2013; Clandinin, Pushor, & Orr, 2007). A narrative inquiry researcher believes that the human experience is one in which humans lead lives full of interpretation shaped by experiences (Caine et al., 2013; Clandinin et al., 2007). The stories researchers collect reflect the participants’ daily lives and the ways they view the world (Clandinin et al., 2007). Narrative inquiry is similar in some ways to other forms of qualitative inquiry due to its focus on the social constructs of ethnography and the stories of phenomenology, but it has clear distinctions (Clandinin et al., 2007). The ways the researcher seeks to understand and evoke experiences that come to the forefront in the inquiry drive narrative inquiry (Caine et al., 2013; Clandinin et al., 2007). Narrative inquiry involves the belief by the researcher that experiences are continuously interactive, and that they result in a change to the respondents and to the researcher (Caine et al., 2013).

It may seem that narrative inquiry is easy to design and execute, but it is not (Clandinin et al., 2007). Narrative inquiry is much more than *telling stories*; it is a complex form of interweaving curiosity about how people are living and seeking to understanding experiences that the inquiry shapes (Caine et al., 2013; Clandinin et al., 2007). The focus of a narrative inquiry is on lives and how people live them with the belief that life is an education (Clandinin et al., 2007). The data from this research provide a voice for the lived experience of the participants with regard to an issue of social justice impacting those with significant cognitive disabilities.

**Positionality Statement**

I would like to be a passionate advocate for my students and their families. My biggest concern all along has been whether I would be able to remain unbiased during this work. I have
very strong feelings about the attitudes and perceptions around people with significant cognitive disabilities. Sometimes, I am unwilling to see the viewpoints of others who do not agree with me, but I need to lower my guard to listen carefully to what others are saying. People with disabilities have had to fight long and hard for their rights. I have worked to remove my bias from this research. Whenever I was confronted with a viewpoint different from my own, I accepted the viewpoint and included it in the research. While there were opportunities to be defensive, I worked hard not to engage in that behavior. I accepted that the perceptions of the participants were real, and that my opinion of their experiences is moot.

Determining whether I am an insider or an outsider was my first hurdle. Locating myself in relationship to the participants was a bit of a challenge. I have worked in the field of special education for the past 24 years, which gives me a wide range of experiences regarding students with disabilities. My brother was not diagnosed as dyslexic until his fourth high school. However, I do not have a significant disability, and nor do my children. In some regards, I am an insider, because I work very closely with students, parents/guardians, and educators, and I care very deeply about this work. On the other hand, those same parents/guardians could view me as an outsider, because I cannot relate to their experiences in the same way. I am keenly aware that my day has a beginning and an end, but there is no “clocking out” for my students and their families. As a school administrator, am I an insider or outsider in policy? In some ways, I am very much an insider. I am on the front lines of creating, interpreting, and implementing policy in my local district. In the bigger scheme of policy change, I am very much an outsider.

It is my belief that it is inherently wrong to predetermine the outcome of an assessment, particularly when that determination results in a failure. This is not to say that I believe that students with significant cognitive disabilities should earn the same diploma, but that evaluating
other options would be worthwhile. I was particularly interested to talk to those who helped to create policy in this area. When the MCAS Alternate Assessment began, the portfolios did not count as failures in state reporting data. When looking at school measurement in Massachusetts, we look at growth data and proficiency data. Students who take the MCAS Alternate Assessment earn points towards growth targets, just as their nondisabled peers do. My hope is that I explored this research with an open mind. I am convinced there is another solution. I needed to be able to listen to stakeholders who do not believe what I believe or have the same views. I was ready to accept this and to include it in my processing. I believed I would be more open to other diploma options for students with significant cognitive disabilities, but not to options that carry failure status with the high-stakes assessment.

**Participant Selection**

The large, urban high school in this study has a total enrollment of 4,132 students. Of those 4,132 students, 500 receive special education services via an IEP. Of those 500 students, 344 students take the MCAS with or without accommodations. The remaining 156 are students with significant cognitive disabilities who participate in the MCAS Alternate Assessment.

The researcher utilized the student management system, Infinite Campus, to make a random selection of nine of the 156 students who fit the criteria of students with significant cognitive disabilities who have automatically failed, or will automatically fail, to achieve a high-school diploma due to the MCAS requirement. The researcher put all the names into an Excel spreadsheet. Then, the researcher inserted a new column to the right of the last column of names, sorted the list by the scores, and categorized them with the terms awareness, emerging, and progressing. The researcher randomly selected names within the three categories of scores. Once the researcher had identified the students, she contacted parents via telephone to explain
the research without revealing a position on the MCAS policy. One parent agreed to participate, but missed two appointments, and the researcher selected a replacement. The other nine parents agreed to participate at first contact.

**Procedures for Recruitment and Participation**

The researcher submitted the Application for Approval for Use of Human Participants in Research form to the Institutional Review Board at Northeastern University in September. The researcher submitted a Research Study Request form D-6A to the Research Committee of the district where the research took place. Both received approval.

Each participant read and signed the informed consent form (Office for Research, 2008). The researcher met with each individual parent/guardian or pair of parents/guardians and recorded the participants’ individual narratives. She sent the recordings to an online transcriptions service, GoTranscript, and they came back within 24 hours. The transcribers at GoTranscript signed a nondisclosure agreement (GoTranscript, 2018). GoTranscript cut the transcriptions into 5-10-minute segments, and transcriptionists could only see the segments they received (GoTranscript, 2018). Once the transcription finished, GoTranscript deleted the files from its system (GoTranscript, 2018). The researcher retained the transcripts for the data analysis process.

**Data Collection**

The researcher collected stories from 10 parents of students with significant cognitive disabilities who have automatically failed, or will automatically fail, to achieve a high-school diploma due to the MCAS requirement. This provided a spectrum of experience, from students who have taken the MCAS Alternate Assessment and are going to participate in graduation
ceremonies and earn a certificate rather than a diploma, to those who have already left the district and are experiencing postschool life without a diploma.

The interviews took place in a variety of settings; seven in the homes of the parents, one in a small café, and another at the library. After the first interview, the researcher identified strengths and weaknesses in the interviewing process. She addressed weaknesses before conducting the remaining eight interviews (Ezzy, 2002). The weaknesses included allowing the participant to go off topic for too long and taking too long to refocus the conversation to ensure the participant answered the research questions.

The interview process followed the elicitation technique phases summarized by Jovchelovitch and Bauer (2000). The four-step process consists of initiation, main narration, questioning, and concluding talk (Jovchelovitch & Bauer, 2000). In the initiation phase, the researcher explained the context of the narrative inquiry in broad, bias-free terms to the respondent (Jovchelovitch & Bauer, 2000). In this phase, it was crucial that the researcher did not share personal opinions or beliefs, kept the initiation content broad and free from specifics such as dates and times, and ensured that the topic was of personal significance to the respondent (Jovchelovitch & Bauer, 2000). This researcher was careful to remain neutral and not to reveal any biases. During the main narration, the researcher gave a prompt and allowed the respondent to share his or her story (Jovchelovitch & Bauer, 2000). The main narration remained free from interruptions unless the respondent requested a break or signaled the end of the narration (Jovchelovitch & Bauer, 2000). Then, and only then, did the researcher interject with the next prompt. The researcher provided no comment other than nonverbal signals of active listening and encouragement to continue (Jovchelovitch & Bauer, 2000).
The researcher did not take notes during the interview, as the participants were sharing very personal stories, and note taking had the potential to distract the participants (Jovchelovitch & Bauer, 2000). However, the researcher did take field notes directly after the interviews. When the narration ended, the third phase began, that of questioning (Jovchelovitch & Bauer, 2000). In Phase 3, the researcher was able to fill in any gaps in the study by asking exmanent questions (questions that come from the researcher and that are informed by the literature) that cover topics that may not have come up in the narrative (Jovchelovitch & Bauer, 2000). These exmanent questions were translated into immanent questions (questions that come from the respondent’s narrative) by using the language of the respondent to fill any gaps in the narrative (Jovchelovitch & Bauer, 2000). The researcher was careful not to ask “why” questions, but only questions about events such as “what happened then” to elicit relevant narrative data from the respondent (Jovchelovitch & Bauer, 2000). The researcher did not ask about opinions or invite justifications or rationalizations. Instead, the researcher waited for these to occur spontaneously (Jovchelovitch & Bauer, 2000). For this narrative inquiry, the researcher completed the following steps (Table 1):
Table 1

**Phases of the Narrative Inquiry**

<table>
<thead>
<tr>
<th>Phases</th>
<th>Script</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1: Initiation</td>
<td>Please tell me about (child’s name).</td>
</tr>
<tr>
<td>Phase 2: Main Narration</td>
<td>Active listening and probing, including prompting when necessary.</td>
</tr>
<tr>
<td></td>
<td>Prompts included:</td>
</tr>
<tr>
<td></td>
<td>• Tell me about the MCAS Alternate Assessment.</td>
</tr>
<tr>
<td></td>
<td>• Could you tell me about (child’s name)’s plans after high school?</td>
</tr>
<tr>
<td></td>
<td>• Is that everything you want to say on the MCAS Alternate Assessment and (child’s name)?</td>
</tr>
<tr>
<td></td>
<td>• Is there anything else you would like to say?</td>
</tr>
<tr>
<td>Phase 3: Questioning Phase</td>
<td>The researcher sought to elicit new and additional material that added concrete texture. Questions were immanent, and they came directly from the main narration. After the researcher listened attentively, she posed questions such as:</td>
</tr>
<tr>
<td></td>
<td>• What happened before/after/then?</td>
</tr>
<tr>
<td></td>
<td>• Tell me more about…</td>
</tr>
<tr>
<td></td>
<td>• What were your feelings about…?</td>
</tr>
<tr>
<td>Phase 4: Concluding Talk</td>
<td>The researcher turned the tape recorder off and small-talk ensued. The researcher documented the contextual information in field notes that provided insights and impressions to assist with interpretation and rich analysis.</td>
</tr>
</tbody>
</table>

It is important that the researcher uncovers the multilayered context, is reflective, and re-stories accurately (Creswell, 2006). Narrative research often involves the deep inquiry of just one participant (Creswell, 2006). However, increasing the size of the sample allows for more precision in the re-storying and identification of themes (Patten, 2014). The researcher transcribed the first two recordings and then sent the final seven recordings for transcription. She then re-storied the narratives into a framework (Creswell, 2006). The stories opened with a summary of the participant. Then they discussed the discovery of the students’ disabilities. The rest of the narration varied based on the information the participant chose to share. While the individual shared his or her story sporadically and nonsequentially, the analysis placed emphasis on sequence (Creswell, 2006). This allowed for
the narrative to have a beginning, middle, and end (Creswell, 2006). Beyond the chronology, the researcher identified themes that emerged across the narratives (Creswell, 2006; Miles et al., 2014). The researcher maintained the integrity of the narrative inquiry research approach.

**Data Analysis**

The researcher collected data from nine narrative interviews, analyzed them, and organized them to “reflect a participant’s values, attitudes, and beliefs, representing his or her perspectives or worldview” (Saldana, 2016, p. 131). She had the interviews transcribed word for word. She then analyzed the transcripts using initial, first, and second cycle coding methods (Miles et al., 2014; Saldana, 2016).

**Values coding for narrative inquiry.** In qualitative inquiry, a code is often a word or phrase that “symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute” to the data (Saldana, 2016, p. 4). The portions of data the researcher coded consisted of transcribed narrative inquiries of the 10 participants for the nine students. The coding assisted with the synthesis of the data, which combined segments into a whole to create themes and findings.

**Initial coding.** Initial coding allows the researcher a starting point for further exploration, and it indicates the direction in which the researcher should take the study (Saldana, 2016). The coding at this stage was strictly provisional, and it was open to modification as analysis progresses (Saldana, 2016). In this stage, the researcher highlighted each line of the transcripts using Microsoft Word’s highlighting feature, with a focus on only those segments that directly answered the research questions. The researcher omitted extraneous data that did not relate directly to the research questions. The highlighted text was then ready for first- and second-cycle coding.
**First-cycle coding.** Values coding reflects a participant’s “values, attitudes, and beliefs” while representing the participant’s worldview (Saldana, 2016, p. 131). Each of these constructs has a different meaning, but values coding absorbs all three (Miles et al., 2014; Saldana, 2016). Values are “the principles, moral codes, and situational norms that people live by” (Daiute, as cited in Saldana, 2016, p. 131). Values are those things that we view as important in ourselves, other people, things, or ideas (Saldana, 2016). An attitude is the way in which we think and feel about ourselves, other people, things, or ideas, and it is part of a “relatively enduring system of evaluative, affective reactions based upon and reflecting the evaluative concepts or beliefs, which have been learned” (Shaw & Wright, as cited in Saldana, 2016, p. 132). A belief includes our values and attitudes, but it intertwines personal knowledge, experiences, morals, prejudices, opinions, and other perceptions of the world (Saldana, 2016).

“Values, attitudes, and beliefs are formed, perpetuated, and changed through social interactions and institutions, and our cultural and religious (if any) memberships” (Charon, as cited in Saldana, 2016, p. 132; Lieberman, as cited in Saldana, 2016, p. 132). The researcher used the highlighting feature on Microsoft Word to go back through the data and to change the highlighted text to one of three colors representing values, attitudes, and beliefs. The researcher used footnotes to assign sub codes to give further meaning to the text (Saldana, 2016). In a table format for each participant, the researcher assigned direct quotes to one of the variables; values, attitudes, or beliefs. Once the researcher had coded units according to values, attitudes, and beliefs, she categorized the units and reflected upon their collective meaning and interactions under the premise that the three constructs are part of an interwoven system (Saldana, 2016).

**Second-cycle coding.** First-cycle coding initially summarizes segments of data (Saldana, 2016). Second-cycle coding is an advanced way of reorganizing the data coded through first-
cycle coding (Saldana, 2016). The researcher used the second cycle to compare themes across the transcripts to develop a clear metasynthesis of the data (Saldana, 2016).

Pattern coding in second-cycle coding is a way to group those segments of data into smaller categories, themes, or concepts (Saldana, 2016). Pattern codes pull the data from the first-cycle coding into meaningful “units of analysis” (Saldana, 2016, p. 236). Similarly coded passages from the data corpus were put into a table to describe major themes and a “network of interrelationships” (Saldana, 2016, p. 238). Some themes were conceptually similar, and the researcher combined them (Saldana, 2016).

**Trustworthiness**

Standards of trustworthiness in qualitative research serve to convince the reader that the inquiry’s results are worthy of attention (Shenton, 2004). Qualitative researchers do not use instruments that establish validity and reliability, as quantitative researchers do, but the researcher must ensure that the study’s findings are credible, transferable, confirmable, and dependable (Loh, 2013). Trustworthiness occurs when all four factors are evident.

In this research, the researcher established credibility through triangulation (Patten, 2014). Triangulation involved cross-checking field notes against the transcriptions to evaluate the extent to which they aligned (Mays & Pope, 2000). The researcher analyzed transcribed interviews, along with observational field notes, to ensure trustworthiness (Mays & Pope, 2000). The purpose of triangulating these sources of data was to corroborate the evidence (Ezzy, 2002).

Transferability describes how the qualitative researcher demonstrates that the findings of the research apply to other contexts (Miles et al., 2014). While there is debate about the generalizability of qualitative studies and who is responsible for that generalization, this research
may be transferable to parents/guardians of students with significant cognitive disabilities in Massachusetts who participate in the MCAS Alternate Assessment (Miles et al., 2014).

The researcher’s neutrality in the research helps to assure confirmability (Miles et al., 2014). In the current study, the researcher stated and acknowledged potential bias (Miles et al, 2014). Dependability occurs when other researchers can repeat and replicate the study (Miles et al., 2014). The researcher used an inquiry audit to establish dependability by having a second reader examine the research process, as well as the analyzed data, to ensure the findings are accurate and replicable (Miles et al., 2014.).

**Ethical Procedures**

The researcher ensured confidentiality by using pseudonyms in the narrative data. All interviews took place off campus after school hours, and the researcher told participants that their comments and insights were confidential, so that they could be free to be candid. Per the agreement with the school district for this research, the district remains anonymous. This also helped to ensure that the participants are not easily identifiable. The researcher stored the data, once collected, on a personal computer, and she kept the field notes and recorder in a locked file.

The researcher presented a certificate documenting completion of the Protecting Human Research Participants protocol to Northeastern University’s Internal Review Board. All participants signed informed consent forms confirming their willingness to participate in the study. The informed consent forms outlined any potential risks and any benefits to the participants (Appendix A).

**Summary**

Selecting a narrative inquiry to answer the research questions relating to the MCAS Alternate Assessment required a sensitive approach to working with the parents/guardians of
students with significant cognitive disabilities. The researcher put precautions in place to ensure that she conducted this research ethically while maintaining high standards. The methods she applied in this research revealed themes that inform stakeholders and that add to the body of existing literature on the subject of the assessment of students with significant cognitive disabilities.
Chapter 4: Findings

The purpose of this qualitative narrative inquiry research was to explore the experiences of the parents of students who participated in the MCAS Alternate Assessment at one large, urban high school. The parents of students with significant cognitive disabilities shared their experiences; discovering their child’s disability, school culture, society’s views about disability, and graduation options. These research findings may inform policymakers and legislators about the impact of MCAS’s Alternate Assessment on students with significant cognitive disabilities.

Students with significant cognitive disabilities who need alternate assessments for their 10th-grade high-stakes Massachusetts testing automatically go into the lowest proficiency grouping: failing (Massachusetts DESE, 2017b). Students with significant cognitive disabilities who participate in these alternate assessments undergo assessment on alternate standards, but they must meet the same accountability measures as their typically developing peers (Massachusetts DESE, 2017b). In 2017, schools sent 8,532 MCAS Alternate Assessment portfolios to the DESE (Massachusetts DESE, 2017f). All 8,532 MCAS Alternate Assessments went into the lowest achievement levels, needs improvement (Grades 3-8) or failing (Grade 10) (Massachusetts DESE, 2017f).

To understand the impact of this policy on students with significant cognitive disabilities better, the researcher used a narrative inquiry to answer the following research questions:

1. What is the lived experience of parents/guardians of students with significant cognitive disabilities who automatically fail to achieve a high-school diploma due to the MCAS requirement?

2. How do these parents/guardians describe the impact on the students?

The parents/guardians are legally responsible for the students, who represent a vulnerable population, and who may not understand or be able to express their experiences to answer the
research questions. In fact, it is the parents/guardians who navigate the educational system on behalf of their children with significant cognitive disabilities. Therefore, the parents are the participants in this study. The narrative inquiry methodology captures their stories and lived experiences.

**Description of the Data**

The participants were seven biological mothers, one adoptive mother, and one pair of biological parents. The parents of the students who are over eighteen are also the legal guardians of their adult children. Table 2 lists participants in order of when the interviews took place. The demographic data table include the marital status of parents, grade and age of students, and the achievement level of the students, an explanation of which follows in the data analysis section.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Demographic Data of Participants</th>
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<tr>
<td>Marital Status of Parent/Guardian</td>
<td>Achievement Level of Student</td>
</tr>
<tr>
<td>Eden/Alex</td>
<td>Married (not Alex’s biological father)</td>
</tr>
<tr>
<td>Cindy/Benito</td>
<td>Single</td>
</tr>
<tr>
<td>Lisa/Kamiyah</td>
<td>Married</td>
</tr>
<tr>
<td>Diana/Eric</td>
<td>Married</td>
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<tr>
<td>Fatima/Isaiah</td>
<td>Married</td>
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<tr>
<td>Charlotte/Tommy</td>
<td>Married</td>
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<tr>
<td>Claire/James</td>
<td>Married</td>
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<tr>
<td>Steve and Sarah/Cameron</td>
<td>Married</td>
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<tr>
<td>Felicia/George</td>
<td>Married</td>
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The researcher arranged for transcription of the interviews of the nine participants from the audio recordings. In narrative inquiry, the researcher first re-tells the stories and then analyzes them to discern themes and subthemes relating to the research question. Then, the
researcher conducts a cross-narrative analysis to determine themes in common across all the participant experiences. The next section details the data analysis for this study.

**Data Analysis**

The researcher used a social constructionist approach, representing the data in the following narratives. She organized the narratives by student achievement levels: awareness, emerging, and progressing. DESE created these achievement levels. She grouped the data according to achievement level, because similar themes emerged within the narratives of these particular subgroups. A comprehensive understanding of the achievement levels helped to guide this research.

Students with significant cognitive disabilities who are in the *awareness* level have little understanding of the learning standards in the content areas (Massachusetts DESE, 2017f). Students in the awareness achievement level require “extensive prompting and assistance,” and their performance is “primarily inaccurate” (Massachusetts DESE, 2017f, p. 20). *Emerging* achievement levels include students who demonstrate a simple understanding of only a few of the learning standards in the content standards below grade level (Massachusetts DESE, 2017f). Students in the emerging achievement level require frequent prompting and assistance, and their performance is limited and inconsistent (Massachusetts DESE, 2017f). Students in the *progressing* achievement level are closest to grade-level expectations. Progressing achievement level students have a partial understanding of a “limited number” of learning standards in the content areas (Massachusetts DESE, 2017f, p. 20). Students in the progressing achievement level require minimal prompting, and their performance is “fundamentally accurate” (Massachusetts DESE, 2017f, p. 20).
The analysis progressed through the lens of values coding reflecting participants’ values, attitudes, and beliefs representing their worldview (Saldana, 2016). Values coding is particularly useful to explore “cultural values and belief systems, identity, intrapersonal and interpersonal participant experience” (Saldana, 2016, p. 132). It is possible to interweave the coded data across all three constructs, and to code data as all three; value, attitude, and belief, or any one or two (Saldana, 2016). The goal of this values coding was to capture the participants’ worldviews. The grounding for the coding was the participants’ perspectives (Saldana, 2016).

The values codes were “the importance attributed to ourselves, other people, or ideas” (Saldana, 2016, p. 131). For this research, the researcher clarified the definition to mean “what parents think is important.” The attitudes codes were “the way we think and feel about ourselves, other people, things or ideas” (Saldana, 2016, p. 131). The researcher also clarified the attitudes codes to mean “how parents think/feel.” Saldana (2016), defined beliefs as an interweaving that “includes values and beliefs, adds personal knowledge, experiences, opinions, prejudices, and other perceptions of the social world” (p. 132). For this research, beliefs included “how parents view their child in society” (see Appendix A).

The re-storied narratives are in a thematic and chronological order, but the narratives do not include codes. The reason for not re-storying by coded themes is that the themes from the data often fell into more than one category: values, attitudes, or beliefs. The re-storied narratives instead follow the way the participants chose to share their own stories.

**Achievement level: Awareness.** The first group of narratives represents the stories of students who fall in the awareness achievement level. This level includes students who are working well below grade level (Massachusetts DESE, 2017f), and who require multiple prompts and achieve mostly inaccurate performance (Massachusetts DESE, 2017f). Students in
this achievement level require the most support and assistance to perform tasks in all aspects of
daily life, including independent living skills.

*Eden’s story about Alex.* Alex no longer attends public school, having transitioned to
postsecondary life after turning 22 in July 2017. Alex’s primary disability is neurological, with
significant cognitive disabilities. At the beginning of the interview, Eden was nervous, and she
expressed concern that she may not know everything to be an appropriate candidate for this
study. However, once she learned about the narrative inquiry and its purpose, she relaxed and
shared her story. At times, Eden became emotional recounting her experiences raising Alex. At
other points in the interview, Eden expressed pride and joy in her parenting of Alex. Eden told
her story as ideas came to her, and not in a linear fashion.

Eden has been committed to ensuring that Alex has a life that is of the highest quality,
ensuring his participation in all aspects of growing up such as proms, graduation, birthday
parties, etc. Eden has a high-school diploma, and she did not attend college. She was a young,
moved mother when she discovered her then-husband had severely shaken her baby son.

Well, his disability is, you know, he was born … he was born normal … there was
nothing wrong with him except he was overweight, not overweight, but he was nine
pounds. So, his disability, was he was shaken as an infant, he was shaken, um, he was
shaken by his biological dad. So that was an issue we had to deal with. And so, because
of that, that caused a whole [lot of] different things to happen with him because he’s
legally blind because of all the bleeding in his eyes, and he has a seizure disability, and so
he has a feeding tube and stuff. He never had a G-tube before, but you know a year after
they gave him the G-tube, because they realized he was having, you know, issues with his
throat, so that was his disability. So, I guess all that combined together; they put it under
cerebral palsy, and of course, he’s not able to walk; he’s in a wheelchair, and you know he depends on me and other people for his total care.

Alex’s biological father remains in prison for this crime. Eden has since remarried and had another child; a daughter with autism. Her current husband is devoted to Alex and supports Eden in her care for him and their daughter. She described her extended family as “close-knit,” with her parents living only 15 minutes from her home. Eden also said that she enjoys spending time with her sisters, nieces, and nephews, who live close by. Eden does not work outside of her home due to the needs of her children. Alex has frequent seizures, as many as 15 per day, that sometimes require hospitalization.

Eden described her experiences raising Alex as being easier when he was in elementary and preschool, because he was smaller, and his needs were easier to meet. She is a very devoted mother, who participated in all aspects of Alex’s schooling, including attending all meetings relating to his IEP. She repeatedly described her experiences with the local school district as positive, with one exception early in Alex’s schooling.

I got to know a lot of people all over the place on different levels…. So, my experience has been good. It was kind of rocky at first between, you know, preschool and the kindergarten and … the [elementary] school. It was kind of rocky then. I had a lot of issues with you know some, one department head. Other than that, everything’s been good with him, you know, when I go to … the IEP meetings … [they] explain everything to me, what I need to do and, you know, and … I had some help talking to all the people about his IEP, you know “what is this” and “what is that,” and I’ve been well informed with him, so it was good.
Eden returned to the theme of her relationship with the school staff repeatedly throughout the interview.

Another theme that reoccurred throughout Eden’s story was her references to Alex’s personality and his influence on those around him as positive. As she spoke about Alex’s impact on others, her body language and demeanor became more open. At one point in the interview, Eden put her hands in her lap and hung her head as she said that raising a child with disabilities is difficult: “It’s kind of tough, you know, having Alex with a disability.” Once she admitted this, she quickly shared that she has had help, and that “everyone is really good to him.” To validate Eden’s perception of Alex as a contributing member of his community further and to counteract her comment that raising a child with disabilities is difficult, Eden shared a story about a peer of Alex’s who wrote a letter to her.

When he was [in] junior high school, I met this student [who] wrote this letter, and she was like, “you know, I really, really enjoy Alex’s company. He makes me feel so, so wonderful. A lot of times I might have issues going on at home and I sit down there and I talk to him and he just smiles and it’s like, wow he understands me.” She wrote me this letter, and it’s like, wow, this is really, really nice just to hear that. So that is a compliment I get about Alex wherever he goes.

Eden’s demeanor changed again when talking about the transition from high school to a postsecondary day program for people with significant cognitive disabilities. She described this transition as very challenging. Eden explained that fear for the future and a lack of confidence in the staff initially replaced the comfort associated with the school knowing Alex and having all his supports in place via his IEP. This adult setting eventually proved a positive place for Alex,
but it was not without complications. Alex’s constant seizures made the staff uncomfortable at first, which made Eden nervous.

Eden had been working with the adult facility to train the staff to tell the difference between a seizure that required a trip to the emergency room and a mild seizure that did not require medical intervention. For Eden, this was a difficult time in which she was struggling to trust the new caregivers, but also becoming frustrated at their lack of knowledge. Eden described an event that occurred right before Christmas that brought the transition issues to a head. Alex required hospitalization after a series of seizures. This was clearly a defining moment for Eden, as this was the longest part of the interview in terms of her uninterrupted speech. While Alex was at the adult day facility, he had a seizure that staff could not control with medication. The facility called Eden to inform her that they had had to call emergency services because they were fearful for his well-being. Eden had been working with the facility to administer his medication and to give him some wait time to “come around,” and she was beginning to gain trust in their ability to care for Alex. She viewed this as a setback in some ways, but also that the facility made the “right call,” because Alex had also been having increased seizures at home. Eden was particularly affected by this hospitalization, because it occurred so close to Christmas, a time she considered very spiritual, and because he was in the Intensive Care Unit. This ordeal was central to her presentation about raising a child with significant cognitive disabilities, and it was one of the few times she allowed herself to let her emotions well up and to project them in the form of tears.

Eden acknowledged that Alex could have hospitalizations in the future, and she expressed concern as to how Alex’s complex medical profile would impact her ability to care for him later in her own life as she ages. She was also worried about the impact on her daughter
with autism, whom she described as looking up to Alex in a traditional relationship between a younger sister and an older brother.

When asked about her thoughts and experiences with the MCAS Alternate Assessment, Eden explained that she has been aware of the assessment since Alex was in elementary school. She stated that his teacher worked with him on alternate standards, although those were not her words. Eden recognized that Alex would not be able to learn the same skills as his typically developing peers, but she thought the teachers did their best to assess Alex in the most appropriate ways. Eden specifically mentioned that Alex used switches in school. Switches are one form of adaptive equipment that allows students who cannot communicate in a traditional manner to interact with the world around them. Alex had a limited ability to use switches due to the severity of his disability.

Alex participated in the MCAS Alternate Assessment at the lowest entry point: awareness. Eden had difficulty differentiating between the certificate of attendance and the graduation ceremony itself. She described the ceremony as a highlight of her and Alex’s life. Students with significant cognitive disabilities who may not be able to sit on the field through the duration of the graduation ceremony may sit under a tent with staff and have their names called first to receive their certificates. Then, they can leave the field and not wait for the rest of the graduates’ names, which can take over two hours.

That was really beautiful. I spent a lot of money on all the pictures. I also got, I think. I spent money like on a little miniature wedding for him! But I thought it was really, really beautiful you know. But I wasn’t going to have him sit there for four hours, but just the fact that it was it was being offered for he could go first, you know, the group could go first. So, I, I go to all the graduations and I always see all the kids in the wheelchair[s]
being called, and it was nice, but when it was my experience, I was like “oh my God!” I tried hard not to cry, because I didn’t have my tissues with me, but it was beautiful, you know, he was dressed nice. I liked, you know, the graduation thing, which was kinda better than what I had. [Laughs.] You know, but it was nice, the cap and gown, and the yearbook was beautiful. Every single part of it was really nice. The people were nice, the teacher was really good … so that was a really best experience I had in, not the best, but one of the greatest that I had with him in high school. You guys were really good with him.

Eden struggled for clarity regarding the different outcomes for students with significant cognitive disabilities and the terminology associated with the MCAS and graduation. She required a third prompt that specifically asked about the MCAS Alternate Assessment and the certificate of attendance versus a diploma. Eden was pensive as she paused to gather her thoughts. When she spoke, she made it clear that she was aware that there was a difference between what Alex would achieve and what his typically developing peers would achieve. However, she felt strongly that the words Certificate of Attendance were demeaning and not representative of the work and perseverance that students with significant cognitive disabilities overcome to achieve their goals.

Sometimes I wish he had a diploma … but I understand his limitations. And if the students have limitations there’s not much that they can do to, you know, earn a diploma, because they’re not like regular students that do all the arithmetic, all the English, and all the history stuff. So at least there’s the alternative for them that at least shows that for all their efforts of being in school, at least they get a certificate that says “well yes, I went to school you know. I participated and everything and I got a certificate to show for it.”
mean this, it’s kinda like sad, but in a way still kinda, you know, makes me feel good at least he has something that says, “I was here.”

Eden expressed pride in Alex’s accomplishments, and she said she would advocate for a diploma option if one were available to students with significant cognitive disabilities in Massachusetts. Specifically, she wanted to honor the work of students with disabilities in a more meaningful way than only awarding a certificate after being in school from the age of three to 22.

That would be great to actually see it [for] the other kids … instead of a certificate of attendance. Anyone can go to school. Anyone could have great attendance, but what about the achievements that they did and all the goals that they met … doing their IEP classes? It took a lot for them. “I just didn’t show up and sleep all day. I did do something.” So at least he should have the word diploma and not certificate. Anyone can come to school.

Eden acknowledged that her son would not benefit from a change in policy with regards to the change in creating an alternate diploma, but she hoped that future generations of students with significant cognitive disabilities would benefit from a change.

At the end of the interview, Eden shared her hopes for Alex’s future. She expressed fear and trepidation about his overall health and well-being. Her goals are for Alex to live a “comfortable life,” in which his medical needs are addressed and he can travel to meet new people. She hoped that Alex would have sufficient supports in place for the eventual reality that she will someday not be able to care for him as her own mortality becomes an actuality. When the interview was over, Eden expressed gratitude for the opportunity to share her story about Alex and her hopes that more positive outcomes for students with significant cognitive
disabilities will be available in the future, perhaps by the time her daughter in elementary school now reaches high school.

**Cindy’s story about Benito.** Cindy is the single mother of Benito, a 17-year-old male with autism. Benito is in the 10th grade, and he participated in the MCAS Alternate Assessment in the 2017-18 school year. Benito’s biological paternal family does not have contact with him. Cindy reported that she and her mother are Benito’s sole source of care and support, although he does see her cousin’s children every so often. Cindy was battling breast cancer, and she expressed grave concern about the reality of facing the disease while worrying about the need for support to care for Benito during her illness.

Cindy has attempted to network with other parents of students with autism in the district in which her son attends school, but she reported feeling isolated in her parenting. Benito has participated in youth sports aimed at creating opportunities for students with disabilities, and Cindy has tried several parent groups to create connections to other parents/guardians who are raising children with autism, but she did not feel as though she “fit in.”

She was welcoming, but she expressed concern about her ability to be “useful” to a study. Cindy had prepared a list that included everything she wanted to say. As the narrative progressed, she became more open and engaged in the process. Cindy was forthcoming, but she apologized several times for her thoughts about her belief in the school system’s ability to make decisions that supported Benito’s progress and development.

Cindy placed a high value on the quality of both her life and Benito’s life in terms of a safe and comfortable living and school environment.

From the time he was born to the time he was 15 year[s] old … I never had to raise my voice with him. He listened … but around 15, he started getting a little aggressive. So, I
feel like my son is nervous to go to school, because he’s always at the bottom…. I hate to say it, but he’s at the bottom of the barrel. I wish some people would put some money together and help them to make the place more bright … ’cause it’s old and it’s gloomy and you know they [the teachers] try their hardest, but there’s not enough.

Cindy assigned Benito’s poor attendance at school and new issues around behavior to the fact that he does not like his high school. Later in the interview, Cindy acknowledged that Benito’s attendance has always been a problem, saying that he usually loves school in the beginning, but then around October his willingness to attend fades.

Cindy shared a desire for Benito and her to have more opportunities for collaboration within the community, particularly with other families who represent the community of disability. Cindy became quiet and then took a breath as she fought tears to describe her feelings of isolation.

Outside of school Benito, he’s very social, but now he doesn’t have friends and that hurts … it hurts my feelings. Like when he was at [middle school] I sent flyers out and made a nice flyer and I … had the teacher put it in all … I think there were three [substantially separate] classrooms. It had a picture of Benito and it said … “I’m inviting everyone down to [local restaurant] for pizza and soda and everything’s on me. We can get together and know each other so they can have a life outside of school. Maybe we could get the kids together for playdates and stuff.” I want Benito to have a life outside of school. I sent these flyers out twice, and the first time one kid showed up; the other time nobody, no one showed up. It was free. Everything was free.

Cindy explained that her friends’ kids had outgrown Benito, and she was hoping to find new social connections, not just for Benito but also for herself. This had a profound impact on how
Cindy viewed herself within the social construct of her community, and it increased her feelings of isolation and separateness. When asked, Cindy excused the parents as probably being too tired from working. She also offered an explanation that some parents do not accept their child’s disability.

I have a girlfriend whose son’s father had her embarrassed to accept the fact that her son is special needs. He never got any help, he’s not as bad as Benito, and he went through … fighting all the time in school, because they didn’t have him in the right class. He was getting picked on, and they never got him any type of help. I think some parents are embarrassed, and I think sometimes it’s a hassle.

Cindy went on to explain that she has taken Benito into his own community since he was very young, despite the hard work that went into these experiences, because she placed a high importance on his value within his community and society’s willingness to accept him. “People don’t always understand that everybody has value. Everyone has their own light that they can shine,” she said.

Cindy was apologetic as she referred to the list she created, and she began to share the concerns she had with the school system. In particular, Cindy felt that she had not received enough information from the district to make informed decisions about Benito’s placement in school and participation in his education, saying, “I don’t know anything basically about too much about what Benito’s doing in school.” She reflected on his younger years and being more “aggressive” in seeking out information, but said “I hate to say it, but I gave up a little bit.” Cindy said she would often leave the offices of the school department crying because she felt Benito was put into classes that “sometimes were over … his head” and that would “really tick
me off.” Benito was moved to a substantially separate classroom before he went to middle school, but Cindy did not find that an exact fit either.

I don’t know how he could get an education when he has to constantly look over his shoulder because he don’t know if Johnny’s gonna have a bad day and just hit him in the head with something. I think they need to have different … classrooms for children maybe, children like Benito but that don’t have aggression. They need to put these kids in classrooms without that, and I don’t know how they could do that, I mean, maybe … probably asking too much. They just keep sticking him someplace where he’s too … it’s too much for him, or they’re sticking him someplace where he’s nervous.

Cindy ended this part of her story by saying that she felt teachers should pay more individual attention to ensure that each student is receiving the appropriate services.

As the interview moved into areas of transition, Cindy became visibly upset, but she wanted to continue without a break. She began talking about her own fears about the future for Benito given her ongoing battle with breast cancer and her lack of support. Cindy explained that she and Benito have no family apart from her mother, who she would not expect to take over Benito’s care.

Who is taking care of these kids when you’re single like me? I’m an only child, so it’s not like I have cousins or people that can watch him or a brother or a sister. I don’t have any type of day care or child care for children or adults with special needs. He’s scared. He doesn’t want to be a man. He’s like, “No, no. I’m not gonna be a man. I’m a boy. I’m a big boy.” He doesn’t want to be a man. He wants to stay with mommy and he’s very attached to me. My mother always says, “if Benito could live in Cindy’s back pocket he would.”
At the end of the interview, Cindy checked her list, and she was assured that she had said everything she intended to share. She again expressed pride in her parenting of Benito and her desire for things to be better for the families and the students with significant cognitive disabilities. Cindy wanted to clarify that she believes that both a more meaningful diploma option and participation in the graduation ceremony are important for Benito and other students like him. “Yes, he should get the cap and gown, too!”

**Charlotte’s story about Tommy.** Charlotte has three children; a 22-year-old son, a 6-year-old daughter, and Tommy, who is 15 years old and in the ninth grade. Charlotte is married to her daughter’s father, but she is not in a relationship with Tommy and his brother’s father. Tommy also has siblings from his biological father’s current marriage. Charlotte was soft-spoken, and she required prompting to share her story in the beginning. When she became more comfortable, she shared more, but she was still somewhat reserved throughout the interview, and she required multiple prompts to elaborate on different parts of the interview.

Charlotte described Tommy as being a “happy kid … very social, and eager to please.” She was proud of his uniqueness, saying “there is only one of him,” but she pointed out that things are becoming more difficult as he gets older and lacks the understanding to navigate his social world. “He wants to fit in with the regular kids. I don’t think he sees a difference between him and somebody else.” This comment required further probing, as it was such a powerful commentary on how Tommy views himself within social constructs. Charlotte hesitated before changing direction and talking more about how others view Tommy. She described Tommy’s disability as one that is not physically obvious to others, which can create problems socially.

He’s always been treated … because he’s always been big … he’s always been looked at like an older child, but once they see, start interacting, I see how their body language
comes off. If something is said, even right in front of him, he doesn’t even realize. He just laughs it off… I don’t think he would know that’s why they were laughing, because he has never said anything about people being mean. He just thinks everybody’s trying to be nice, and then you’re his friend.

Charlotte did not appear angered or defensive of Tommy, but more resigned to the attitudes of others towards Tommy. She described experiences in which she has observed people “even adults” dismissing Tommy or being overly friendly and treating him like a child. If someone is rude to Tommy, he will say to Charlotte, “maybe they’re just having a bad day today” in an effort to explain away the behavior. Charlotte said that while she can read the body language and attitudes of others in those situations, Tommy is unaware: “I don’t let it bother me because it doesn’t bother him. If it did bother him, then it would bother me, and I would have to say something. I just keep my mouth shut.” Charlotte ended this segment of the interview by shrugging her shoulders and shaking her head as if the issue was not one on which she wished to dwell.

Charlotte shared her frustration at Tommy’s diagnosis which remains confusing for her.

The neurologist he saw, I really didn’t care for because he kept trying to throw these letters, ADHD/ODD, this … all these alphabets. I’m like “okay.” He had mentioned some about autism and they said they don’t like to label kids. He would always ask me what I think, and I’m like “You’re the doctor. I don’t know this stuff.” … I ended up switching and getting some answers.

Charlotte did not notice any delays in Tommy meeting milestones, except he did not walk until he was two years old. Other than that, there were no concerns about his development until he went to kindergarten. Tommy began wetting his pants and regressing socially. Charlotte
described the teacher as “rough,” and insisting that Tommy go back to wearing diapers while at school, but Charlotte remained firm that she would not allow Tommy to “go backwards.” This first experience with school shaped Charlotte’s opinions about the system in which Tommy enrolled, and she lacked trust that Tommy was receiving proper support. From Grades 1-3, the school labeled Tommy as a child with behavioral issues, and in Grades 4-6, he would skip the building. Charlotte fought to have him moved to a different school, but she reported that her concerns did not lead to action. She described this as her biggest regret in raising Tommy, because he “lost a lot of learning. I think he would be a lot further ahead with reading and everything if I didn’t keep him in that school.”

Like to Eden and Cindy, Charlotte reported having little knowledge of the outcomes of the MCAS Alternate Assessments.

I don’t really follow MCAS. I don’t really know much about them. To me, MCAS, I don’t think it is something that they should judge the kid’s grades by, because it’s one test, and a lot of kids don’t test good. Whether it’s a special ed. child, or a regular student. Back in my school days, we didn’t have that kind of stuff, and the way they’re changing schools now, I don’t think it’s good. I think they’re making it worse.

When she received an explanation of the MCAS Alternate Assessment, Charlotte was most concerned with the actual graduation ceremony and ensuring that he would participate wearing a cap and gown. She reported that the certificate instead of diploma would not bother him.

Yes, so the diploma part doesn’t bother me, and it’s not going to bother him. He doesn’t know. He knows he’s special ed, but I don’t think he knows what special ed is. He asked me last night if my daughter was special ed. She’s six, and I said, “no.” Then she started
crying, because she thought she’s not special…. I don’t talk to him like he’s different. I don’t treat him like he’s different.

While Charlotte claimed to treat him no differently than his older brother, she acknowledged that she is much more cautious about his ability to navigate his community independently. Charlotte is afraid to let Tommy go to neighbors’ homes or to meet other neighborhood youth in the community park. She naturally moved her story to her expectations for Tommy’s future, making the observation that Tommy would not be able to live independently even though Tommy views himself as living on his own, driving, and working independently in the future. Charlotte’s biggest concern for Tommy is his inability to navigate his social world in a way that would discourage others from taking advantage of him. While Charlotte is not yet ready for Tommy to be in a romantic relationship, she hoped that someday he would find happiness with a mate, but she pointed out that such a person would probably also have special needs. Charlotte hesitated for a moment before explaining further that “I don’t want him to be by himself, because eventually, I’m going to be gone. I don’t want him to have to be by himself for the rest of his life.”

Ending the interview, Charlotte wanted to ensure that she recognized and appreciated the hard work of teachers in special education. “I can imagine teachers having more than one special ed student, having to understand each one is different, so it’s hard.” However, she thought more work is necessary in transitioning students with disabilities from one teacher to the next.

The past year’s teacher when they go to another teacher, I think they should meet and give them ideas of how the child operates … but that doesn’t happen. You have to start from scratch, and it’s hard on the kids.
Themes for the awareness level. The researcher used the transcripts and field notes to discern themes from the data (Table 3). The parents of students in the awareness achievement category placed a high value on school relationships. Eden, Cindy, and Charlotte felt very connected to their children’s teachers, although those relationships were not always positive all the time. There was confusion among this group of parents when talking about the graduation ceremony versus the diploma. The focus for Eden and Cindy was on the ceremony itself, while Charlotte was aware that Tommy would not receive a diploma. They all placed high importance on the ways in which society views disability.
Table 3

*Themes from Awareness Level Transcripts*

<table>
<thead>
<tr>
<th></th>
<th>Values</th>
<th>Graduation Ceremony v. Diploma</th>
<th>Society’s Views on Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>School Relationships</strong></td>
<td><strong>Society’s Views on Disability</strong></td>
<td></td>
</tr>
<tr>
<td>Eden and Alex</td>
<td><strong>Staff who [are] good to him</strong></td>
<td>Just the fact it was being offered</td>
<td>I met this student…. “I really, really enjoy Alex’s company”</td>
</tr>
<tr>
<td>Cindy and Benito</td>
<td><strong>He is at the bottom of the barrel</strong></td>
<td>Yes, he should get the cap and gown too!</td>
<td>He doesn’t have any friends, and that hurts</td>
</tr>
<tr>
<td>Charlotte and Tommy</td>
<td><strong>They just kept telling me “there’s no other school”</strong></td>
<td>Damn, I wish they could get a diploma</td>
<td>He has feelings … he does have value</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>Attitudes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>School Relationships</strong></td>
</tr>
<tr>
<td>Eden and Alex</td>
<td><strong>Good experience in school</strong></td>
</tr>
<tr>
<td>Cindy and Benito</td>
<td><strong>I used to cry…. I gave up a little</strong></td>
</tr>
<tr>
<td>Charlotte and Tommy</td>
<td><strong>I complained. To this day I regret him staying in that school</strong></td>
</tr>
</tbody>
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<thead>
<tr>
<th></th>
<th><strong>Beliefs</strong></th>
</tr>
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<tbody>
<tr>
<td></td>
<td><strong>MCAS/Diploma</strong></td>
</tr>
<tr>
<td>Eden and Alex</td>
<td><strong>I know for a fact he can’t do it.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>I mean I wish he had a diploma … but I understand his limitations.</strong></td>
</tr>
<tr>
<td>Cindy and Benito</td>
<td><strong>I really don’t think the MCAS shows his true ability</strong></td>
</tr>
<tr>
<td>Charlotte and Tommy</td>
<td><strong>It’s not going to bother him. We don’t know the difference.</strong></td>
</tr>
</tbody>
</table>
School relationships was also a theme under the attitudes coding. While Eden maintained a positive attitude about school, Cindy and Charlotte expressed concerns. All three parents admitted to having fears about the future, with a focus on their own ability to care for their children with disabilities as they age or face their own mortality. The parents also shared how they thought and felt about their children’s long-term dependence.

The interwoven and connected themes throughout the narratives in the beliefs coding were the MCAS and diploma, the fact that things were easier when their children were younger, and the transition to adult life. While Eden understood that Alex would not be able to achieve at the same level as his peers, she did express a desire for Alex to have earned a diploma. Cindy was more focused on the assessment as a representation of Benito’s abilities. Cindy thought that the MCAS cannot represent Benito’s “true abilities.” Charlotte was far less concerned about the MCAS and the diploma. Charlotte was not convinced that either had any bearing on the outcomes for Tommy, and she did not believe that he would internalize the lack of a diploma.

All three parents expressed that school, behavior, interpersonal relationships, and their child’s interactions in their community were easier when the children were younger. In Eden’s case, this mostly related to Alex’s physical needs, but for Cindy and Charlotte, this theme related to their own abilities to parent effectively. Eden shared her beliefs about transition relating to the jarring move from high school to postsecondary day habilitation services. The shift from the school upholding requirements about meetings to the new reality of adulthood, where the parent must seek support, was jarring for Eden. Cindy feared that Benito is afraid to grow up and become “a man,” but she was unsure what he thought that really meant. Charlotte shared her apprehension about Tommy engaging in a meaningful adult romantic relationship. She hopes
that Tommy will eventually find a partner with whom he can share his life, but she expects that this person will also have significant cognitive disabilities.

**Achievement level: Emerging.** The students who go into the emerging achievement level have a simple understating of only a few learning standards in the content areas (Massachusetts DESE, 2017f). They are working well below grade level, and they require frequent prompting and assistance (Massachusetts DESE, 2017f). The performance of students in the emerging achievement level is limited and inconsistent (Massachusetts DESE, 2017f). The students in this achievement level have some level of guided independence, but they require assistance to navigate their community both in and out of school.

**Diana’s story about Eric.** Diana is married to the father of her five children, all of whom are typically developing with the exception of Eric, who has autism. Throughout the interview, Diana rocked her newest baby as Eric poked his head in a few times to check on his mother and perform his ritualistic behaviors: turning off lights, running his hand along furniture, etc. The interview would pause as Diana redirected Eric to another area of the house to sit with a sibling.

Diana began her story by saying that she has felt “really lucky” from the time Eric entered school, describing his teachers as “second moms.” Eric entered the school system at three years old, going to preschool. Diana described this as a very difficult first step in entrusting his care to others. “I literally cried probably more than him when he first went in ’cause I was so afraid to let him go.” Speaking for her husband, Diana said the connections that they have made with his teachers over the years have been very close in comparison to those they have established with their other children’s teachers.
You know about their family and you talk to them and you have that … it’s a very
different relationship we try to build a relationship early with each teacher he has had so
that we can really have that communication early on.

These relationships were key to assuaging Diana and her husband’s concerns about Eric during
the day, given that he is unable to communicate to them verbally.

When prompted to share the story of Eric’s initial diagnosis, Diana, like Charlotte,
expressed frustration at the lack of information that was available to her as Eric’s pediatrician
attempted to rule out diagnoses.

Right before he was three, there was sort of confusion with the pediatrician: he said that
they didn’t think it was autism. They thought maybe he couldn’t hear because he spoke
but then regressed, so he had about 40 words and then going into two years old he started
to slowly not talk…. He was really connected to us, some called him a Momma’s boy, so
they said “well, that’s not autism.” So it took way longer than it should’ve. We only got
into early intervention … maybe four months before his third birthday, which was a
shame, because if he had gotten diagnosed earlier, we would have had more time.

Diana was frustrated but forgiving of the situation, shaking her head as she explained that more
could have been done sooner if there had been more information about the drastic change in Eric.

Diana described the impact of Eric’s disability as being felt most keenly by his older
sister by 15 months. His sister wondered what happened to Eric, who had gone from following
her around “like her shadow” to not playing with her at all. Diana referred to this time in the life
of the family as a “grieving period” for the child who had been Eric before the onset of his
symptoms. His obsessive-compulsive behaviors began to dominate the schedule of the family
when Eric’s rigidity would not allow for the family to have relaxed time. Diana struggled to connect with her son in the same way that she could connect with his siblings.

   It’s so different in the way, I’m gonna cry, how you connect with them because, him not being able to speak, I don’t feel like I even know him in the same way. I wanna be able to talk to him and know what he feels and what he thinks … you know funny things that happened to him. The communication … his wants and needs are basic, so anything abstract is, we don’t know. We are a very close family, and that is hard.

Diana was careful about how others would perceive her words, and she was quick to relay the positive aspects of having a child with autism. “I would never have realized if it wasn’t for Eric to just appreciate life, and so in some ways he’s made our family stronger … you know our lives richer.”

   When the inquiry shifted to Eric’s future, Diana was adamant that Eric’s happiness was the biggest priority for the family in whatever form that takes for him. She hoped that Eric would be able to find something he likes to do every day that may not be a job necessarily, but some sort of routine that keeps him busy. Diana fought back tears as she acknowledged that Eric’s future is a great unknown. In his younger years, Diana and her husband held hopes that Eric could one day live independently, but those hopes have faded as Eric has aged.

   I think that the reality is that he would live with us and I wouldn’t really want him in a group home situation. I would worry more than anything. Some people would be like, “oh maybe it’s like a relief,” but to me it would be more stressful ’cause I would worry all the time. We have a huge family … someone will always help with Eric.

   Diana again became emotional as she described an interaction she had had with her younger son when the son was five and Eric was eight. “He said, ‘you know when you have a
cane; my wife and I will take care of Eric.’ I started crying so hard because it’s like … he knew at five years old that my biggest fear is what happens when I’m not here for Eric.”

When prompted about Eric receiving a certificate rather than a diploma, Diana said that she struggled with that quite a bit because he will have gone to school from the age of three to 22, longer than his typically developing peers. While she said that she wasn’t sure what she expected, she was not expecting something so different than his peers would receive. Ultimately, though the diploma and the MCAS Alternate Assessment would have little impact.

It doesn’t really matter, it’s just something that the label of it … it seems weird or feels wrong, but I don’t think it matters in the long run anyways. The MCAS … seems more work for the teachers. He had a teacher in elementary school and she was like, “I have to get everything right and if I make a mistake it counts against them” … which sounds crazy to me.

Diana’s feeling overall was that students with disabilities put in longer hours and even have extended school years in the summer. For this reason alone, she felt that they should receive more than a certificate upon completion of school. Interestingly, Diana thought that the parents/guardians of those students who are “higher functioning” would probably be more annoyed or disappointed than those like she and her husband who have “lower functioning” children. Diana backtracked her use of the terms about functioning, saying there is an “umbrella” of skills, and all students with significant cognitive disabilities have strengths and weaknesses like any other student. Diana recounted team meetings in which those kinds of labels would hurt her feelings and cause her to resent members of the team who were using terminology that limited Eric.
They would label Eric, like he could do something at the 12-month level, and it just burns as the parent, but you … just let it go and realize that it really doesn’t mean anything … like what he looks like on paper and what he is as a person is entirely different. Diana wondered what it would be like for Eric not to be able to communicate, so she spent a day practicing silence and described the experience as “frustrating.”

Diana closed the interview by talking about the value she and her family place on Eric and their choice to focus on the positive aspects of having a family member with autism. “He wakes up happy every day. He doesn’t get caught up in the little things … stupid things we all worry about.” Diana expressed a hope that all children with disabilities will receive good treatment and that their “amazing” qualities will receive more recognition in society than how society values disability now.

**Fatima’s story about Isaiah.** Fatima is the mother to three adopted children, each of whom has significant cognitive disabilities. She has one adult biological daughter, and she is in the process of adopting a great nephew. This interview focused on Isaiah, who is a twin, and who struggled with medical issues for much of his young life until moving to the United States and receiving care under the watchful eye of Fatima. Fatima is a strong advocate in the community, and she runs an unofficial community group of other parents of students with disabilities; she ran unsuccessfully for school committee. Her goal was to make the schools better for students with disabilities. Fatima’s storytelling was sporadic and sometimes hard to follow, but she came back to the inquiry successfully with a little prompting. Fatima, her husband, and her adult daughter have all worked in the field of adult services for people with disabilities; she brought a unique perspective to the discussion around the MCAS Alternate Assessments and the outcomes for students who participate.
Fatima began the interview by talking about her experiences in the school system, which she said were considerably better when the three siblings with disabilities were in elementary and middle school. She said that the transition to high school was very difficult. Outside of an experience they had living in another district, Fatima described her current experiences with the school system as the worst she has had to date. She cited the lack of access to other programs and the conditions of Isaiah’s classroom as two of her major concerns.

Isaiah was born with a complicated medical condition that required him to have a feeding tube through right through his first years in elementary school. Fatima shared her claims that the original school district did not properly handle his care with a sense of indignation. She referred to his current health and success as evidence of her unfollowed recommendations. Felicia cited the school system listening to her as one of the values most important to her. “It’s really important that people working with my children listen to me. I know my children. It really bothers me when other people don’t listen to what I’m telling them when it comes to my children.”

Fatima focused on the need to instill as much independence in her children as possible, and she stated that the school system has discouraged her children from this goal by setting low expectations.

My goal … [has] always been to prepare them so that … if anything should happen to me or my husband, we know that our children … are capable. One of the things that I don’t like is that they sit in one classroom; that is very limiting. They don’t need constant supervision. They can go off and have conversations with other students. I feel that the schools are just limiting these children. I fight so hard against a lot of things … because I don’t want to see … my children limited.
Fatima further described the school system and society as wanting to “box them up” and limit their potential without individualizing for the students.

Like Diana, Fatima rejected the team meetings for Isaiah as representative of who he is as a real person. The use of standardized testing as a true measure of her son’s abilities offended her, as did a failure of the team to recognize him as a whole being.

I’m listening at the IEPs and I’m thinking to myself, “Oh God, I just want to choke all of them” because they don’t know my kids … they come up with all these things and that’s great … from your point of view here in school, but I feel like there’s a bigger picture for kids with disabilities.

Fatima wondered why students with significant cognitive disabilities do not receive access to the mainstream curriculum in which all other students must participate; foreign language, physical education, art, etc. While she recognizes a need to explain disability to students and enculture them to their community, Fatima wants the school community and society at large to focus not on the weaknesses of disability, but the strengths. In her view, the high school her children attend currently sets low standards and isolates students with significant cognitive disabilities, which is not preparing them for life beyond high school unless they are going to spend days in adult day habilitation facilities. Interestingly, Fatima believes her children are with students with whom they do not belong. This was an interesting statement juxtaposed against her belief that students with disabilities should be included.

I saw Isaiah’s class at [local store] ’cause I had to meet them over there where they were Christmas shopping and I thought … “okay, well Isaiah could be in a different class.” He’s got that little speech thing going on but….}
Fatima wants her children to be in classes with more typically developing peers, but she does not want her children in classes with students who are “lower” than hers. This was an interesting contradiction in her narrative.

Fatima was adamant that more opportunities are necessary for students with significant cognitive disabilities beyond the “warehouses” that currently exist in the form of the adult day habilitation programs. She believes this begins by awarding students who participate in the MCAS Alternate Assessment full diplomas. Fatima was not receptive to the idea of an alternate diploma saying, “I can’t say I like ‘alternate,’ but I do believe they should have a diploma. I believe each one of them should walk across and get a high school diploma.” As echoed by other parents, Fatima felt that the fact that students with significant cognitive disabilities are in school for longer than their typically developing peers should have some bearing on the diploma. Further, Fatima wondered how a fair option could be given that includes measuring students’ growth based on their own potential.

I understand that they have some cognitive abilities, but one of the things I push for them is to do the best with what they have. I think they should have a diploma … they’ve gone to school … they are working to their ability, and there should be a program where they’re getting a diploma because they’re working to their full abilities.

Fatima explained that she has little faith or belief in the MCAS, claiming that high-stakes testing is inherently unfair for all students, not only those with disabilities. She explained that she believes that the intent of the assessment system was to provide better outcomes for students, but instead the accountability system is discouraging children and encouraging an increase in dropout rates.
Fatima ended the interview acknowledging that not all states offer the same level of supports and services to students with disabilities. As a child growing up in Tennessee, her mother brought her cousin from Mississippi to live with them because Mississippi did not offer programs aimed at serving the unique needs of students with significant cognitive disabilities. She wanted to affirm the value of all people with disabilities and to encourage the administrators in schools to look at making changes.

If they were your kids, what would you want? I want school administration to think about it in the terms of being their parents … and all the parents want is what’s best for our kids. I work so hard for them because … I love them…. Then we see the bigger picture and worry even more than when they were little as they grow up.

Felicia’s story about George. Felicia is the married mother of three adult children who are typically developing. George is her youngest child, and he has autism and intellectual disabilities. Felicia was the most reluctant participant of the 10 parents, but she was thoughtful and introspective throughout. Her answers were often short, but direct and to the point. Felicia is an immigrant to the United States. She brought to the narrative a unique perspective as a person in two communities that often experience marginalization; the community of disability and the community of immigrants. Felicia was soft-spoken, but adamant to deliver her message as clearly as possible.

After following a typical pattern of early development, Felicia began to suspect something was “wrong” when George was one-and-a-half. He spoke at six months, but then lost his speech, and Felicia noticed that the fontanel, the soft spot on a baby’s head, was not closing, as it did with her other children. She repeatedly asked George’s pediatrician for help, but she was discouraged to discover the wait for a neurological appointment was six months to a year.
“That’s why it took longer to have him diagnosed…. Then he had intensive ABA from that time until when he was three … and transitioned to public school.” (ABA is applied behavioral analysis; an intervention commonly used with children with autism.) Felicia described the diagnosis as “shocking,” because she had little knowledge about disability, and she did not know where to turn or how to access support. She described this time in her life as feeling “lost.” Adding to these feelings was “being bilingual, and culture, it’s trying to explain it to family members, trying to work it out yourself. It was overwhelming.”

George is now 16. Felicia feels there has been a lot of advancements in society’s acceptance of disability, but not enough. “It’s headed in the right direction, but I think there’s more openness … about other things these days like transgender and stuff. It’s more spoken about. With a person with a disability, it’s not even mentioned.” She used the example of the media attention to the issues surrounding transgender bathrooms as a way to explain her struggle.

When you think about it, I have a male son, but I can’t go into the men’s bathroom, but when I go places that there’s a family bathroom, not a gender bathroom…. You feel “Oh, I can take him and he’s safe and I’m safe.” When he was younger it was … different, but as he got older it became more difficult. You get into all different situations.

Felicia thought it unfair that one marginalized population was receiving such attention over another when advocates have been fighting for the rights of those with disabilities longer. “If a transgender needs to use a bathroom, there was no emphasis on a person with a disability or anything. That’s what I thought when the whole debate was going on.”

Felicia described her experiences with school, like others, as being easier when he was younger and more difficult as George progressed through the grades. When he was in early
intervention, service provision was in the family home, but she was encouraged to take him to group settings. “This was before I got my diagnosed [sic]. He went and he got so upset that he got himself sick. Then I was called from work to go and pick him up because it was too much.” Felicia did not understand at the time that George would require more opportunities for inclusion into groups, and this first experience scared her off. When he first entered the school system, George received less intensive supports than she was used to in early intervention. Over the years, she saw the interventions and supports fade more each year. “It’s always a fight to get them what they need…. It’s like you can’t miss a beat or else it seems they fall through the cracks.” With deeper probing, Felicia acknowledged that George has made progress, but she thinks he could have made even more had the supports been adapted, more intensive, and more individualized to meet his unique needs.

Felicia’s goals for George’s future are that he can enjoy some level of independence, communicate his needs and likes as well as his dislikes, and be in a safe environment. She and her husband know that he will live with them for as long as they can care for him, depending on their own health in the future. When asked if George has friends outside of school, Felicia said he is active in programs, but he requires one-to-one support from staff.

He’s made friends. I don’t know if he’s aware, but the kids he meets … he’s meeting people and they remember him. I don’t know if he recognizes the person. He’ll say, “hi,” but I don’t know his level of awareness. He’s friendly; even being on the spectrum, he shows affection.

Felicia is most concerned for George’s safety. She fears that there are those that would abuse and take advantage of George, and that he would not be able to communicate that to his family. She hopes for a society that is more accepting of disability. Felicia wants the world to be more
 universally designed for a variety of disabilities. She used the example that restaurants have menus available in Braille, but not symbolic menus with pictures, which many people with autism use to communicate. Felicia also shared the joys of raising a child with disabilities. “It’s opened our eyes. It makes you look at things from a different angle, your bias[es] change, you look at the whole picture opposed to what’s in front of you.” She said she would cure George’s autism, “yes, for him, not for me, but to better his life, for opportunities.”

The discussion turned to the MCAS Alternate Assessment and the certificate rather than that diploma. Felicia felt that immigrants, a population of which she is a member, had rights that were unfair compared to those with disabilities.

I was having a debate with my husband. I’m like … “you have somebody from another country come here. They come right into ninth grade. George has been in the school system since he was three. They come, they do four years, at the end of the four years … if they pass the MCAS, they get the whole thing … they get a real diploma. He’s been going since he was three, there’s been hurdles that he had to go through. It wasn’t an easy school experience. Then at the end, he just gets ‘oh he participated.’ It’s like a kid playing sports…. It would be like ‘you participated,’ and then another one gets the trophy.”

When asked if an alternate diploma would have more meaning or less, Felicia said she would have to think about the options, because she had never heard of other options. Felicia’s biggest wishes for the future of all students with disabilities is that there are more opportunities for inclusion while recognizing that they have unique needs that require a separate setting for intervention. “You need to acknowledge that they’re here and they’re part of society…. I’m paying taxes. They are just like little diploma like, ‘Okay, they get this because they’re here.’
Well, what are we to give them? They’re not going anywhere. How do you know what one’s potential is?”

**Themes for the emerging level.** The values of parents who have children who are in the emerging achievement level were isolation, diploma versus certificate, and society’s view on disability (Table 4). Diana described the isolation in terms that described not only Eric’s isolation, but also hers as his mother. Fatima was more concerned about the isolation that currently exists between Isaiah and his typically developing peers in school. Felicia wanted to share that although George is nonverbal and has autism, he can show affection. Unlike the parents of the students in the awareness achievement level, all three parents placed a high value and preference on the diploma over a certificate. Diana, Fatima, and Felicia also placed value on how society views disability. Diana worried that Eric may internalize negative perceptions. Fatima believed that there are still misconceptions about disability and the low expectations that come with those misconceptions. Felicia reported a change in how she views disability and the value that she now places on looking at things from a different angle.
Table 4

Themes from Emerging Level Transcripts

<table>
<thead>
<tr>
<th>Values</th>
<th>Society’s Views on Disability</th>
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<tbody>
<tr>
<td><strong>Isolation</strong></td>
<td><strong>Diploma v. Certificate</strong></td>
</tr>
<tr>
<td>Diana/Eric</td>
<td><em>We can’t really know him the same way.</em></td>
</tr>
<tr>
<td>Fatima/Isaiah</td>
<td><em>They’re able to go off and have a conversation with other students.</em></td>
</tr>
<tr>
<td>Felicia/George</td>
<td><em>He’s very friendly even being on the spectrum, he shows affection.</em></td>
</tr>
</tbody>
</table>

| Attitudes | | |
| **Adult Life** | **School Relationships** | **Disability** |
| Diana/Eric | *I want him to be happy ... that’s the biggest priority.* | *Special ed. is different than regular.... You get to know the teachers.* | *It was very abrupt.... One day it felt like he wasn’t the same kid anymore.* |
| Fatima/Isaiah | *My goal is to prepare him.* | *The school could set up better programs.* | *Kids have disabilities, but they do everything.* |
| Felicia/George | *He will live with us. I don’t think he’ll be able to live on his own.* | *He’s made some progress, but it could be more.* | *It was shocking.... I would change his disability for him, not for me.* |

| Beliefs | | |
| **Fairness** | **Disability Strengths** | **Parenting** |
| Diana/Eric | *He is a person entirely different from ... standardized testing.* | *He doesn’t get frustrated ... he wakes up happy every day.* | *I don’t feel like I know him the same way.* |
| Fatima/Isaiah | *They’ve gone to school longer ... they are working to their ability.* | *[He is] capable of so much more.* | *We all want what is best for our kids. I work so hard for them.* |
| Felicia/George | *“Oh, he participated,” and then the other gets the trophy.* | *They’re here! They’re not going anywhere. They have potential.* | *It’s always a fight and you’re always trying to navigate, try to find what’s best, for him. There’s not much awareness out there.* |
Diana wanted Eric to be happy in his adult life, while Fatima wanted Isaiah to be prepared for life. Felicia thought that George will most likely live with her for his adult life. Attitudes about school relationships were different among the three parents. Diana thought and felt that she had developed deeper relationships with Erica’s teachers than she had with her other children’s teachers. Fatima was disappointed in the lack of programming for Isaiah, and she thought the school system could do a better job in that area. Felicia’s attitudes towards school were mostly grounded in frustration. She said she had to fight for George’s services throughout his schooling. Diana’s thoughts and feelings about disability were that it forever changed her family, and that it had its strengths as well as its disappointments. Her overarching message was that she changed for the better. Fatima expressed anger towards those who would limit her children for their disability. She returned to this theme in her interview several times. Felicia was shocked by her son’s diagnosis on many levels. She had very little experience with disability, and she learned as she went along, but she would not change George’s disability.

Fairness, disability strengths, and parenting were all beliefs that Diana, Fatima, and Felicia held. Diana believed that standardized testing does not properly measure Eric as a person. Fatima was more focused on the fact that students with significant cognitive disabilities go to school for 18 years rather than the traditional 12. She wanted that to have some bearing on accountability measures. Felicia thought that the symbolism of the certificate after the alternate assessment was much like awarding a participation certificate and watching the other team take home a trophy. All three parents also believe that disability has strength in many ways. Diana sees that Eric is happy and joyful each day, and he tends not to fret over the “little things.”

**Achievement level: Progressing.** Students who are in the progressing achievement level have a partial understanding of a “limited number” of learning standards in the content area
Students who are progressing require very few prompts, and their performance is “fundamentally accurate” (Massachusetts DESE, 2017f, p. 20). However, they are working on alternate standards below grade level. Students in the progressing achievement level have more independence than those in the awareness and emerging achievement levels.

**Lisa’s story about Kamiyah.** Lisa is the married mother of one child, Kamiyah, who has an intellectual disability. Lisa has been actively involved in Kamiyah’s education, serving on a variety of committees and ensuring that Kamiyah has participated in a multitude of after-school and weekend activities. Lisa frequently contacts the Special Education Department of the school Kamiyah attends, and she feels that she has been a strong advocate on behalf of her daughter, while also working with the school to improve outcomes for all students. Kamiyah is 20 years old, and she no longer attends her high school, but another school in the district for students who have already participated in graduation and who are transitioning to the adult world.

Lisa’s experience of discovering Kamiyah’s disability was different than the other participants, but no less confusing. In the beginning, Lisa and her husband recognized that Kamiyah was more introverted and shy than her peers, and that she would often play alone rather than joining a group. When she went to kindergarten, Lisa said the manager hired a person specifically to help Kamiyah to navigate the classroom and the norms of school. Even still, Lisa and her husband did not suspect a significant disability. The family moved to its current city when Kamiyah was in second grade, and she went into a class of students with and without disabilities. About halfway through the year, the teacher approached Lisa and told her that Kamiyah had more significant needs, and she might need the support of a substantially separate classroom. The classroom would compromise of only students with disabilities. This was a
major blow to the family as Lisa and her husband accepted their new reality of Kamiyah’s intellectual disability.

Lisa described the earlier years in school as much better than the high-school years. So, then she was in the substantially separate classroom … which started out, it was okay. I think her elementary-school years and her middle-school years were really good. She’s a happy kid, but the thing that troubles me is that she doesn’t have friendships. She lacks social norms and social boundaries. She would always say “but I don’t know what to do. I don’t know how to be a friend.” We got her a therapist.

Lisa described Kamiyah’s high-school years as the most turbulent, mostly because Kamiyah was unable to form meaningful relationships with her peers, which created daily upsets in their household. Kamiyah would come home each day and relay the day’s events to Lisa: “Mummy, I don’t think I really made many friends. People did and said things to me that hurt my feelings.” These daily reports would upset Lisa so much that the whole evening would be ruined for the family.

Lisa became adamant, even slapping her hand on the table, when the subject of the MCAS Alternate Assessment and the diploma options was raised. She said that she now has a better understanding of the issue, while at first she thought it was the high school Kamiyah attended that made the decision to award a certificate instead of a diploma.

It’s a state thing, but I gotta tell ya, I’m really upset about that ’cause our kids, they work hard if not harder you know. It’s a test. It may be an alternative way of testing and a different way, but they gotta know some things to be able to pass…. It should account for something, I think…. The fact that they don’t get a diploma, I feel like that’s a violation of their human rights.
Lisa suggested that an alternate diploma that “means something” and “matters in the world” is necessary, because the options after high school are very limited without a diploma in the world of work. When told that the federal law allows states to create an alternate diploma just as she had described, Lisa was incredulous.

Are you kidding me? We live in Massachusetts one of the smarter states, one of the more progressive states for education. I mean we’re a melting pot of great school and great companies where you can work. Why wouldn’t you give our kids an opportunity to get a diploma? That’s insane to me.

Lisa intends to gather a group of parents and fight the state, because she believes that students with significant cognitive disabilities deserve the right to get a diploma.

Lisa shared her concern for Kamiyah’s future. Her main goals are the same as those of the other parents; happiness, a job, some level of independence. She is most concerned that Kamiyah’s abilities should allow her to become gainfully employed, but her disabilities may be too much for an employer to accommodate reasonably.

I just don’t know any parents … that have kids that are working and are successful. I just worry about our kids at that age, because I just hope that there are jobs out there and there’s supports out there for but I don’t know…. They’re thrown to the wolves. She doesn’t want to be independent … and maybe that’s part of our fault, because we hover.

Lisa believes that more could be done to support the successful integration of students with disabilities into the workforce.

Like Felicia, Lisa resented the lack of opportunity for Kamiyah while she was in high school. She did not like the sense of separateness that existed because Kamiyah was in a substantially separate classroom and unable to have a more “typical high school experience.”
Claire’s story about James. Claire is the married mother of James, who is an 18-year-old junior. Claire was very concerned that her and James’s anonymity be kept. She is a strong supporter of the school system, and she values the work that James’s teachers have put in to ensure his measurable progress throughout his years in school. Claire attends all school events, and she has advocated for James’s inclusion into the arts programs available at his high school. Claire was guarded in her responses, and she chose her words carefully.

Claire began with James’s strengths saying, “I learn something new every day from him.” Claire was proud to report that James met or exceeded all his milestones: “He crawled early, walked early, talked early. Thank God I have a video, because you’d think I’m just being a proud parent.” It was when James went to kindergarten that concerns began to mount. James’s teacher reported that he was not making eye contact and not engaging with the class. Claire repeatedly explained that James was very smart as she shared the discovery of his disability. “They brought it to my attention, and I was like, ‘Really?’ Because like I said, all the milestones were met or exceeded.” James finished kindergarten, and he moved to a different elementary school where there was a program designed to meet the needs of students with autism. At first, Claire did not receive this well, because she and her family had a strong connection to the school, having been student themselves. She acknowledged that the move was the “very, very best thing; very best thing.”

Claire has found strength in James’s disability. She believes that it is the very fact that he has autism that allows him to be intuitive to others’ feelings. “He picks up on feelings and is very in tune.” Claire is proud of the fact that James is very genuine and “doesn’t dislike anybody.” Rather, James brings people together through his disability, which she views as a gift.
Her comfort level with the new school increased when she could attend and observe him with his peers. Claire reported feeling comforted by the amount of support the peers provided one another, with prompts and helping one another with assignments. Even though the peers are kind, James does not have friends outside of school, instead preferring the company of adults. Claire attributed this preference to the fact that he is mature for his age. She has always been pleased with the school system and the care and attention James has received. Unlike Felicia, Fatima, and Lisa, Claire spoke positively about James’s experiences at his high school, citing its inclusiveness as something her family valued. James has loved wearing his school logo clothing and participating in events the school hosts via a program aimed at partnering students with disabilities with their typically developing peers for social events. Claire reported that James has also participated in the Special Olympics at his school, and he has been a member of the school community.

Initially, Claire was eager to discuss the MCAS Alternate Assessment and its benefits for students with significant cognitive disabilities.

I’m just so, so happy that it’s built-in that they can do the portfolio to show their strengths. He did one in middle school that was fantastic, just phenomenal. They did artwork and different segments that made him feel good…. Knowing math is isn’t his strong suit … but the portfolio … definitely highlighted all that. It’s a good option. She disagreed, however, with the outcomes, “Damn, I wish they could get a diploma so they could feel they did 100% their best, more so, maybe than other students because it’s more of a struggle.”

Claire expressed concern about the future for James without a diploma. She said he had wanted to be a doctor when he was younger, but she realized that this would be too much for him
now with the amount of chemistry and math required. She hopes that James will be able to pursue something in the field that requires less education. Like the parents before, Claire does not envision James living independently, but she wants him to have as much independence as he can attain. Claire and her family are close, and James benefits from that closeness and Claire’s unwavering belief in James’s potential.

Repeatedly, Claire expressed her happiness that James can remain in school until he is 22. “He loves the idea which I think is phenomenal. It’s a huge security, because he’s not ready [to leave].” She said that James is old enough to drop out and make his own decisions, but he knows he has more to learn. Claire wants James to attain more math skills before he leaves school. “How do you pay your bills? How do you go to the store? How do you shop? How do you do anything?”

Claire ended the inquiry by reiterating how happy she has been with the school system. She believes that James’s progress has direct links to the partnership she has had throughout his years in school. “Just thank you. Thank you to everyone for everything they have done.”

Steve and Sarah’s story about Cameron. Steve and Sarah are married with two children; a daughter who attends private school and is in her senior year, and a son, Cameron, who is also a senior in high school, but is 20 years old. Steve is an attorney, and Sarah works in business administration. They have a close network of friends and family including siblings and cousins for their daughter and Cameron.

They first noticed that Cameron was not developing at the same rates as his cousins when he was just a baby. He was the oldest, but he was not doing the “what the other kids are doing. So, their kids started rolling over, sitting up, all the milestones, and Cameron was late on everything.” When Cameron was not walking by the time he was one, they started asking the
pediatrician, but they felt dismissed when the doctor said, “every kid is different.” Steve was also late to speak, so they thought maybe things would come along for Cameron. Having never heard of autism, they had no idea that Cameron was displaying the signs already. “Cameron used to flap his hands and stuff … we didn’t pick up on that as being a sign of anything. When we watch his first birthday … you can see it clear as day.” They were finally alerted to concerns by Steve’s sister, who worked at a preschool for students with disabilities, and she recommended early intervention. Cameron was over two years old by the time Steve and Sarah accessed early intervention that included an occupational therapist providing services in their home. One day, the therapist asked Steve and Sarah if they had considered that Cameron had autism. Sarah shared their initial response: “We were shocked. The only exposure to autism we had was the movie Rain Man, so I’m like ‘How dare you tell me that!’” They went and looked up autism online, and they discovered that Cameron had many of the classic symptoms of autism. After Steve and Sarah got an appointment with a neurologist, Cameron received an official diagnosis of autism. Steve and Sarah described the period after the diagnosis as “dark, dark days.”

Cameron’s symptoms became so difficult that the family would avoid going to public places because loud noises would bother him so badly he would completely melt down. “There’s every kid there smiling and happy, and he was just having a huge meltdown.” While they have a close-knit family, they did not get the support from family, because “no one understood. No one could really figure out, and we just felt like we were really alone out there.”

Further complicating Steve and Sarah’s journey with Cameron was the fact that so little information was available at the time. Cameron began preschool as Steve and Sarah continued to seek information for doctors. They waited two years to see the head of pediatric neurology at a hospital in Boston, but Cameron was still seeing doctors while waiting.
increasingly frustrated, but they were anticipating the visit to the neurologist. Their hopes were dashed when the neurologist was not able to provide any answers to their many questions. They wanted to know “are we doing the right things?” and the answer they got back was, “well, you know, every kid is different.”

Honestly, and we’ve seen many doctors, I don’t think any of them know any more than we do about autism. They’re no closer to finding out what’s causing it, and I’m not sure, other than therapies … I don’t think anybody’s any closer to figuring out what to do about it.

They reached saturation with the doctor’s advice, and

I would go to the doctors and I’m like, ‘Can you help me or not? Really. Don’t waste our time. Because we paid so many specialist fees and God knows what else trying to get to the bottom of it.

Steve and Sarah agreed that Cameron has made great progress and has “completely changed over time.” They cannot pinpoint the time when they felt as though they could handle Cameron’s disability. “I have to say, and I don’t think there was a turning point necessarily where I felt like I could handle this, because I still don’t think I can.” A big turning point for Steve and Sarah came a few years ago when they realized that they were expending so much energy on trying to make him “fit in.”

We were … fixing him and making him as normal as possible. I was always so concerned about how much he was stimming and the noises he would make…. I was always telling him, “Stop it. Stop it.” But my sister sent me an article … about this boy who was grown, and he described why he was stimming. He described it as such overwhelming, a feeling of joy and excitement that he cannot contain himself … and I’m
like “You know, I’m not going to ever fix this.” But why should I fix him, he’s not broken. He’s him.

This began a shift in the way Steve and Sarah accepted Cameron’s disability, and it led to other changes for Cameron.

Cameron stayed in the general education setting all the way through school until the ninth grade, when his stress levels and anxiety became overwhelming as he attempted to meet the rigorous curriculum geared for typically developing students who would participate in the regular MCAS testing. Steve and Sarah began to assess Cameron’s attitudes about school and what they ultimately hoped for him to achieve. As the coursework in high school began to involve topics that they were not ready to discuss with Cameron, they realized that the curriculum did not fit him. “We started thinking differently about the whole thing and just kind of like, ‘let me accept him for who he is.’” They decided to allow Cameron to move to a program that is more geared towards life skills and that uses a modified curriculum. The school changed his IEP so that he participated in the MCAS Alternate Assessment. “The pressure was off. He could take classes that actually made some sense to him. It was clearly the right decision. Some kids have the dream to go to college. Cameron’s dream was to work in Home Depot.”

They credit these shifts with impacting all aspects of Cameron’s life, so that they began gearing his social activities to his wants. “We had him on a baseball team, and he hated it. Maybe if he hated everything, we would force him to do it, but he doesn’t hate everything.” They discovered that Cameron likes to run, so they worked with the track coach to get him to practice with the team with support, although he does not go to meets because of the noise.
Sarah described Cameron as a “sad child” who is not sad anymore. Ultimately, Steve and Sarah want Cameron to be happy, however Cameron defines that. They hope to remodel their basement so that Cameron can live with them, but he can have some level of independence.

Finally, Steve and Sarah shared their thoughts about the MCAS Alternate Assessment and its outcomes. “The bottom line is, it is atrocious that he has attended that school and done the best job that he can, with the mind that he had, [and he] does not get a diploma.” Steve’s legal background was evidenced when he said, “There should be an exceptional law.” Steve said he understood that a law like that may get taken advantage of, because the schools would use it to their advantage. Sarah felt that the policy dishonored their parenting, saying, “we’ve really worked so hard to get him the help he needs and it’s not enough.” They reiterated how difficult their decision to move him to the MCAS Alternate Assessment was for them, but that they did what they knew was best for their son, given their limited options at the time.

**Themes for the progressing level.** The values of the parents whose children fall into the progressing achievement level focused on diploma, inclusion, and society’s acceptance of their children (Table 5). Lisa placed high importance on the diploma, and she thought it terribly unjust that Kamiyah would not receive the recognition she deserved. Claire also valued the hard work of James, and she believed that he should receive more to honor that work. Steve and Sarah were most adamant about the denial of the diploma, because Cameron was on “diploma track” until ninth grade. All three parents also valued their children’s inclusion into the culture of the school as well as society’s acceptance of their child’s disability.
### Table 5

**Themes from Progressing Level Transcripts**

<table>
<thead>
<tr>
<th>Values</th>
<th>Diploma</th>
<th>Inclusion</th>
<th>Society Acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa/Kamiyah</td>
<td>Their work should mean something. They should get a diploma. It’s not fair and it’s not right.</td>
<td>She’s a happy kid, but she doesn’t have friendships ... she’s in the substantially separate classroom.</td>
<td>I worry about how employers will treat her... I don’t know any parents that have kids that are working.</td>
</tr>
<tr>
<td>Claire/James</td>
<td>Damn, I wish they could get a diploma. They did try 100%.</td>
<td>He picks up on feelings and is very in tune with people ... adults really.</td>
<td>I’m very proud that he tries things. He’s an example every day.</td>
</tr>
<tr>
<td>Steve and Sarah/Cameron</td>
<td>We’ve really worked hard to get him the help, and it’s not enough.</td>
<td>I don’t ever want him to feel “less than” or that he is not a success.</td>
<td>He’s a tremendous kid. There have been gifts with this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>School Relationships</th>
<th>Transition</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa/Kamiyah</td>
<td>Teachers were good, but I had to work hard to get things.</td>
<td>She’s got to learn how to be an adult. It’s harder.</td>
<td>We knew it was gonna be a long journey.</td>
</tr>
<tr>
<td>Claire/James</td>
<td>He’s an honor roll student. He loves it.</td>
<td>He feels safe here ... [he] loves the idea of staying until he’s 22.</td>
<td>I learn something new from him every day.</td>
</tr>
<tr>
<td>Steve and Sarah/Cameron</td>
<td>The academic and social pressure ... it was night and day.</td>
<td>We want him to be as independent as he can be and [to] access the community.</td>
<td>We were shocked. Those were dark days.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Beliefs</th>
<th>Parenting is Hard</th>
<th>Students Worked Harder for Diploma</th>
<th>Disability Transcends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa/Kamiyah</td>
<td>We can only do so much. We try, but she struggles to make friendships.</td>
<td>Our kids work just as hard if not harder.</td>
<td>If they don’t want to give like a regular diploma, give something that means something and [that] matters in the world.</td>
</tr>
<tr>
<td>Claire/James</td>
<td>He lacks the confidence.</td>
<td>I wish he could earn it. He tried 100%, maybe harder than the other students.</td>
<td>He’s beyond his years in so many ways.</td>
</tr>
<tr>
<td>Steve and Sarah/Cameron</td>
<td>I used to sit and just sob ... just sob.</td>
<td>What does this say about our prospects for his future?</td>
<td>Why should I fix him? He’s not broken.</td>
</tr>
</tbody>
</table>
Lisa’s experiences at team meetings impacted her attitudes toward school. Lisa described “fighting” for Kamiyah’s services and working hard to get her what she needed. Claire’s attitude towards school relationships was positive. She reported that James loves school and is an honor roll student. Steve and Sarah’s attitudes towards school changed drastically when Cameron moved to the MCAS Alternate Assessment. Steve had spent hours after work trying to help Cameron with homework that he could not complete independently or with Steve’s support. Steve and Sarah have a much more positive outlook to school now that Cameron is happier attending. All three parents had attitudes about transition that ranged from fear and trepidation to hopes and dreams for the future. The attitudes towards disability also ranged. Lisa and Claire knew when their children were much younger that the future for their children would be different than their typically developing peers, and they began to accept the changes much sooner than Steve and Sarah. Steve and Sarah’s attitudes about disability changed over time. First, they described discovering Cameron’s disability as an awful time of isolation and grief. Then, they described it as having its joys as they began to accept Cameron and his autism.

Across the narratives, Lisa, Claire, Steve, and Sarah all believed that parenting was a hard endeavor, made that much harder by the incredible learning and adapting that took place as they navigated disability. They all believed that their children had worked harder in many cases than their typically developing peers to earn a diploma. Finally, Lisa, Claire, Steve, and Sarah believed in the idea that disability transcends. Lisa wanted some option that is individualized to reflect the educational experiences of students with significant cognitive disabilities that also has meaning in the world of work and adult life. Claire believed that James’s disability was a strength, in that he is able to connect to others in a more meaningful way than most. Steve and
Sharon shared that their journey to acceptance took longer than others’ as they decided to stop trying to change Cameron and accept him: “Why should I fix him? He’s not broken.”

**Findings**

Applying a patterns coding method across the 10 participants yielded the five findings listed in Table 6. These patterns emerged from the values coding that the researcher applied to the transcribed interviews of the participants through the lenses of values, attitudes, and beliefs. The researcher created a table of codes for each interview; then, she analyzed the tables to create findings that represent the data collected across all nine interviews. The five themes arising from the data analysis were sense of isolation, increasing knowledge of alternate assessments, desire for more recognition, fear of the future, and increasing difficulty in progression through school.
Finding #1: Sense of Isolation
Parents described a sense of isolation when the diagnosis occurred and a separateness in raising their child with disabilities compared to typically developing siblings and peers. With the exception of Fatima, who adopted three children with significant cognitive disabilities, each of the parents shared their experiences of hearing for the first time that their child had a disability. Eden was particularly affected because Alex’s disability was the result of his biological father shaking him. She did not dwell regarding the onset of his disability, instead choosing to focus on the life she created for him, in which she maintained typical experiences for him consistent with peers his age along the way. The other parents described a sense that something was different for their children as compared to relatives’ or friends’ children of the same age.

Finding #2: Increasing Knowledge of Alternate Assessment
The parents of students who were in the “awareness” achievement level knew less of the specifics regarding the MCAS Alternate Assessments than those in the “emerging” and “progressing” achievement levels.

Finding #3: Desire for More Recognition
Parents believe that their children deserve more than a certificate at the end of their schooling, as their children have worked harder in many cases than their typically developing peers.

Finding #4: Fear of the Future
Parents expressed fear of the future as their children mature to adulthood. This included concern about the care of their adult children when facing their own eventual mortality.

Finding #5: Increasing Difficulty in Progression Through School
Parents of students in the “awareness” and “emerging” achievement levels described both their school experiences and their own parenting as easier when their child was younger.
Diana, Steve, and Sarah described experiences in which they received misinformation from Eric and Cameron’s doctors. Diana expressed frustration and a deep sense of confusion as she navigated the early intervention services. While being accepting, loving, and willing to help, Diana’s family could not relate to her experiences in the same way other parents of children with disabilities could. Steve and Sarah returned to the theme repeatedly throughout the interview. Having two nephews who were born a few months after Cameron, they realized that he was not developing at the same rate as his cousins, and nor was he reaching the same milestones. Steve referred to the months after Cameron’s diagnosis of autism as “dark times,” where they were completely despondent and alone in their search for answers. Steve shared a particularly poignant story in which his own father offered to write a check to cure Cameron so that he could have a normal life. Steve and Sarah now embrace Cameron’s disability, but they said this took years of reflection and introspection.

Cindy, as a single mother, reported feeling “completely alone” when it comes to Benito. She has her mother to help care for him and to provide emotional support, but she said that overall she is isolated. Cindy shared a story in which she sent invitations to other parents to meet at a local pizza place for which she would pay the expenses and her heartache when no other parents showed. She said that many were probably busy with work, but she did not try again to interact with other parents, and she has always felt isolated in her parenting.

Lisa joined every parent group and became active in the Special Education Parent Advisory Council (SEPAC). She fought for Kamiyah’s inclusion in every aspect of her school and social life, but she felt as though she was still isolated in many ways. Over the years, Lisa has reported that Kamiyah is lonely and does not have friends outside of school. When compared to her older child, Lisa reports this as a totally different experience.
Felicia referred to specific concerns relating to her cultural identity and the acceptance of children with disabilities within culture. She felt the most isolated when George was younger and she was raising her other children, but she reported that her family and community has become much more accepting over the years.

Charlotte was most concerned that Tommy is unaware of the unkindness others have shown him over the years. She said that he is isolated within their neighborhood because he is “big” and his peers are more mature than he. Charlotte said that Tommy spends more time with his youngest sibling than he does with his older brother, who is closer in age. Charlotte was more matter-of-fact in her description of discovering Tommy’s disability. She said she accepted it right away, and she was not interested in joining parenting groups in an effort to raise him in a way that was consistent with how she raised her other children.

Finding #2: Increasing knowledge of MCAS Alternate Assessments. The parents of students in the “awareness” achievement level were less knowledgeable of the specifics of the MCAS Alternate Assessments than those in the “emerging” and “progressing” achievement levels. The parents of the students in the lowest achievement level of the MCAS Alternate Assessment, awareness, spoke more about the relationships they and their children had with the school system than about the specifics of the outcomes associated with the MCAS. The parents of the students in the awareness achievement level expressed a gratitude for their experiences within the system, while parents of children who scored at the emerging and progressing level expressed more frustration and a desire for better results.

Those in the progressing level are closer to grade level achievement than those in the awareness and emerging achievement levels. For Steve and Sarah, the decision to allow Cameron to participate in the MCAS Alternate Assessment did not come until his freshman year.
of high school. The dream of achieving a diploma gave way as the pressure to achieve in his
general education classes and to pass the regular MCAS became overwhelming for Cameron.

Eden repeatedly referred to the school system as working hard for Alex and doing the
best for him, but she admitted to having little knowledge about a diploma versus a certificate.
Charlotte and Cindy asked clarifying questions regarding the MCAS Alternate Assessment and
the difference between a diploma and certificate. Cindy said she was embarrassed that she did
not know more, but that her real focus was on her son’s daily care and not the MCAS. Felicia
was dismissive of the question, and she moved onto other topics she considered more relevant.

The parents of students who were closer to the possibility of earning a diploma were
more articulate about the process and decision making at their child’s IEP meeting. However,
the parents of students in the lower achievement levels were less concerned about the details of
the outcomes and more focused on how their children felt among peers and how much growth
their children made over time.

Finding #3: Desire for more recognition. Parents believe that their children deserve
more than a certificate at the end of their schooling, having worked harder in many cases
than their typically developing peers. While not all the parents were as aware of the outcomes
for students who participate in the MCAS Alternate Assessment, nine of the 10 parents
interviewed had strong responses to the awarding of a certificate rather than a diploma at the
graduation ceremony in which their child participated or will participate.

Eden, Lisa, Claire, Diana, Steve, and Sarah all conveyed the message that their children
with disabilities worked harder in many ways than their typically developing peers. They felt
that the obstacles that their children overcame to complete their schooling should be honored in a
way that is more meaningful than what currently exists. Lisa pointed out that many consider
Massachusetts a leader in the field of education, but she described the current policy as a “violation of their human rights.” Felicia expressed frustration about the fact that people who are newcomers to this country have the opportunity to earn a diploma, but her child who was born and raised in the United States does not.

Overall, there was a sense of inherent unfairness of the policy that grants a certificate to students who are entitled to remain in school from the time they are three until they reach 22 and age out. Cindy was not concerned about the policy, instead focusing more on Benito’s attained skills over time and wanting more opportunities and supports from the school. Fatima expressed an interest in finding other solutions that more directly link the postsecondary outcomes of the students in terms of work and independent living to the curriculum and assessments students with significant cognitive disabilities participate in while in school.

Finding #4: Fear of the future. Parents expressed fear of the future as their children mature to adulthood. This included concern about the care of their adult children when facing their own eventual mortality. All 10 participants verbalized dire concern for the future of their children. While some expect some level of independence, others were aware that their child will be completely dependent on others for all aspects of his or her care. Alex has multiple seizures, uses a wheelchair, and is nonverbal. Eden’s hope for him was that he would continue to attend day programs that treat him well. Sarah and Steve have much higher expectations for Cameron, and they hoped that he will maintain some level of independence, although they acknowledged that he will not be able to live independently.

Finding #5: Increasing difficulty in progression through school. Parents of students in the “awareness” and “emerging” achievement levels described both their school experiences and their own parenting as easier when their child was younger. Eden, Cindy,
Lisa, Fatima, Charlotte, and Felicia expressed their experiences of parenting as becoming more challenging the older their child with disabilities became. This was in part to the physical nature of their child’s growth, but it also included their social/emotional needs. Cindy talked about a change within Benito at the onset of puberty typical for teenagers, but very different from what she was used to in terms of his calm demeanor. Lisa was more frustrated by the discrepancies that became more apparent between Kamiyah and her typically developing peers. Fatima also reported a difference in all three of her children with significant cognitive disabilities as they entered high school. Charlotte and Felicia were more concerned with navigating the world with their teenage opposite sex children when in public and trying to deal with issues related to toileting.

Diana, Claire, Steve, and Sarah described their experiences when their children were younger as being more difficult. With time, their children developed more coping skills as they received direct instruction targeting social skills.

Summary

Students with significant cognitive disabilities who participate in the MCAS Alternate Assessment automatically go in the lowest proficiency grouping: failing (Massachusetts DESE, 2017b). The purpose of this qualitative narrative study was to explore the experiences of 10 parents of students who participated in the MCAS Alternate Assessment. This qualitative narrative inquiry addressed these two questions:

- What is the lived experience of parents/guardians of students with significant cognitive disabilities who automatically fail to achieve a high-school diploma due to the MCAS requirement?
- How do these parents/guardians describe the impact on the students?
The questions guided the inquiry and revealed five findings that may help to inform policymakers when making decisions about the inclusion of students with significant cognitive disabilities in high-stakes testing.
Chapter 5: Recommendations and Conclusions

In the wake of the publication of *A Nation at Risk*, a landmark event in modern education, educators and policymakers have been engaged in educational reform at the federal and state level (Graham, 2013). *A Nation at Risk* condemned the state of America’s schools and called for reforms to “right the alarming direction that public education was seen to be headed” (Graham, 2013, para. 3). One outcome of the report was an emphasis on more rigorous requirements for high-school graduation; subsequent changes in graduation policies required higher standards for all students and exit exams that link to the receipt of a high-school diploma (D. R. Johnson et al., 2012)

According to federal law all states are accountable for the achievement of all students. MERA implements federal law holding schools, districts, and the state accountable for the achievement of all students in Massachusetts (Massachusetts DESE, 2017f). The MCAS measures achievement for students in Grades 3 through 8, and again in Grade 10. Students with significant cognitive disabilities who cannot take the standard tests, even with accommodations, participate in the MCAS Alternate Assessment (Massachusetts DESE, 2017f). The student’s IEP team makes decisions as to how each student with a disability will participate in MCAS, and the team documents its decisions in the student’s IEP (Massachusetts DESE, 2017f). DESE must report the results of all students, including those with significant cognitive disabilities, who participate in the MCAS Alternate Assessment (Massachusetts DESE, 2017f). The Grade 10 MCAS scores, as well as local graduation requirements, determine a student’s eligibility to earn a diploma. The results also determine whether each school and district is making progress toward reducing proficiency gaps (Massachusetts DESE, 2017f). This narrative inquiry falls within this context.
**Problem Statement**

The MCAS policy automatically places students with significant cognitive disabilities who participate in the MCAS Alternate Assessment in the lowest proficiency grouping: *failing* (Massachusetts DESE, 2017b). The MCAS Alternate Assessments use alternate achievement standards, which is the rationale for the policy (Massachusetts DESE, 2017b). Because passing the MCAS is one of the two requirements to earn a diploma, students who take the MCAS Alternate Assessment become nongraduates and earn *certificates* rather than *diplomas*. For the students and their families, the policy has repercussions for life after high school in terms of access to postsecondary educational opportunities and some work experiences. The policy also presents the possibility of marginalizing students with significant cognitive disabilities in the educational system.

**Summary of the Literature Review**

This researcher reviewed the literature relating to the MCAS Alternate Assessment, and she found three relevant themes that form the landscape around this problem. The MCAS Alternate Assessment policy has not had extensive study, and it was difficult to obtain literature on the subject. However, it is possible to frame the study of the MCAS Alternate Assessment using the literature on the MCAS, high-stakes testing for students with disabilities, and diploma options for students with disabilities. These three streams contribute to an understanding of the MCAS Alternate Assessment.

The pillars of the MCAS Alternate Assessments are:

- assurance that students with significant disabilities are receiving a program of instruction based on the state’s academic standards;
• assessment of knowledge and skills based on the curriculum frameworks students with significant disabilities have learned;

• inclusion of difficult-to-assess students in statewide assessment and accountability systems. (Massachusetts DESE, 2017f, p. 5).

Students who participate in the MCAS Alternate Assessment fall into one of three achievement levels; awareness, emerging, or progressing (Massachusetts DESE, 2017b). Even though those who take the MCAS Alternate Assessments automatically go into the failing category, they contribute to the CPI data (Massachusetts DESE, 2013). Students may contribute 25, 50, 75, or 100 points towards CPI depending on the achievement levels in which they fall (Massachusetts DESE, 2013). Twenty-five points go to any MCAS Alternate Assessment portfolio that is incomplete because required components are missing (Massachusetts DESE, 2013). Assessments that go into the awareness achievement level may earn 50 points, emerging 75, and progressing the full 100 CPI points (Massachusetts DESE, 2013).

The lack of consistency in alternate assessments across the United States has prompted an equally varied set of suggestions on what to do about the tests. Including students with disabilities in state assessments ensures that those students receive consideration when states make policy decisions (Musson et al., 2010). However, measurement of the achievement of students with significant cognitive disabilities is mired in confusion. States prefer performance assessments and rating scales over portfolio assessments, but only leaders within each state can decide which approach works best in that state (Elliott & Roach, 2007). The approach does not have to be common across the country (Elliott & Roach, 2007). Massachusetts uses a portfolio assessment, and this is unlikely to change (D. Hand, personal communication, August 17, 2017).
ESSA allows for each state to create a state-defined alternate diploma (M. Thurlow, personal communication, August 16, 2107). NCEO and NTACT published in a joint brief, Considerations for Developing State-Defined Alternate Diplomas for Students with Significant Cognitive Disabilities, in 2017. The brief makes recommendations to states wishing to create a state-defined alternate diploma. Those recommendations include determining the coursework and exit exam requirements to align with the requirements for a regular diploma and revising assessment participation requirements to ensure that only students with the most significant cognitive disabilities participate in alternate assessments (NCEO & NTACT, 2017). While 24 states offered diploma options for students with disabilities and others had multiple diploma options, including “certificate of attendance or completion” for all students, at the time of the NCEO and NTACT brief, none had diploma options that met the criteria of ESSA (NCEO & NTACT, 2017). This area needs further investigation and research.

Determining appropriate graduation policies and testing approaches for students with disabilities remains a challenge for states and districts across the United States (M. Thurlow, personal communication, August 16, 2017). Massachusetts has met the intended consequence of inclusion in mandated assessment, but the challenge has been how best to include students with disabilities in these accountability measures.

Purpose

The purpose of this qualitative narrative inquiry research was to explore the experiences of the parents/guardians of the students who participated in the MCAS Alternate Assessment at one large, urban high school. The parents of students with significant cognitive disabilities shared their experiences; discovering their child’s disability, school culture, society’s views about disability, and graduation options. Using a values coding frame, the researcher coded the
transcribed interviews by values, attitudes, and beliefs. The themes that emerged will help to inform the body of research about the impact of the MCAS Alternate Assessment on students with significant cognitive disabilities. The potential impact of this study is to share the stories with legislators and policymakers of the people impacted by the policy.

Methods

The researcher collected stories from 10 parents of nine students with significant cognitive disabilities who have automatically failed, or will automatically fail, to achieve a high-school diploma due to the MCAS requirement. This provided a spectrum of experience, from students who have taken the MCAS Alternate Assessment and are going to participate in graduation ceremonies and earn a certificate rather than a diploma, to those who have already left the district and are experiencing postschool life without a diploma. All of the parents were married except one, and two were remarried to partners who were not the biological parents of the students with significant disabilities. The study explored the experiences of three students in ninth grade, two in 10th grade, one in 11th grade, one in 12th, one who had already graduated, and one who had aged out of high school having turned 22. Three students were in the awareness achievement level, three were in the emerging achievement level, and three were in the progressing achievement level.

The interview process followed the elicitation technique phases summarized by Jovchelovitch and Bauer (2000). The four-step process consists of initiation, main narration, questioning, and concluding talk (Jovchelovitch & Bauer, 2000). Following the phases allowed the participants to share their stories with as little interruption as possible.
Findings

Using values coding, the researcher coded the nine transcribed interviews of 10 parents and organized them by values, attitudes, and beliefs (Saldana, 2016). The researcher analyzed the values, attitudes, and beliefs of the 10 interviewees using pattern coding so that findings emerged (Saldana, 2016). The five findings were a sense of isolation, increasing knowledge of alternate assessment, desire for more recognition, fear of the future, and increasing difficulty in progression through school.

Conclusions

This narrative inquiry explored the lived experiences of the parents/guardians of 10 parents of students with significant cognitive disabilities who participated in the MCAS Alternate Assessment. The students in this study currently attend, or attended, a large, urban high school in Massachusetts. The narrative inquiry addressed two questions:

- What is the lived experience of parents/guardians of students with significant cognitive disabilities who automatically fail to achieve a high-school diploma due to the MCAS requirement?
- How do these parents/guardians describe the impact on the students?

Two conclusions originated from the research that directly answered the two research questions (Table 7).
Table 7

Conclusions

<table>
<thead>
<tr>
<th>Conclusions</th>
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<tbody>
<tr>
<td><strong>Conclusion #1: Parent/Guardian Inclusion.</strong> Parents/guardians of students with significant cognitive disabilities want to participate in decision-making about their child’s education and outcomes for their future after high school.</td>
</tr>
<tr>
<td><strong>Conclusion #2: Inadequate Representation of Disability.</strong> Parents of students with significant cognitive disabilities believe that the current MCAS Alternate Assessment policy is an inadequate representation of their child’s performance, and it devalues them as members of their community.</td>
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Discussion of the Findings

The purpose of this research was to explore the lived experiences of the parents/guardians of students with significant cognitive disabilities who participated in the MCAS Alternate Assessment. A narrative approach was of particular value to address this issue, because it provided a voice for parents/guardians, who have no representation in the current literature. The analysis revealed some of the ways in which parents/guardians experience the MCAS Alternate Assessment and make sense of the policy implications for their children.

Each of the narratives in this study reveals themes of isolation, a lack of awareness relating to the outcomes of the MCAS Alternate Assessment, desire for more recognition, fear for the future, and increasing difficulty in progression through school. The stories expose the impact of the MCAS Alternate Assessment on parents/guardians and their children. Despite the lack of awareness of graduation policies relating to the MCAS Alternate Assessment, parents/guardians shared the great joys associated with parenting a child with a significant disability. As Diana shared, “I would never have realized if it wasn’t for Eric to just appreciate life and so in some ways he’s made our family stronger … you know, our lives richer.”

**Discussion in relation to the literature.** As educators seek to ensure that gaps are closing between students with disabilities and their typically developing peers, ways to include
students with significant cognitive disabilities in assessment practices and accountability measures remain problematic in Massachusetts. The 8,532 students with significant cognitive disabilities who participated in the MCAS Alternate Assessment in the 2016-17 school year failed the MCAS and, therefore, those that were in 10th grade will be nongraduates in 2019 (Massachusetts DESE, 2017f).

Many assessment developers can create valid assessments for typically developing students, but not for students with disabilities (NCEO, 2011). There are gaps in the connections between the standards and a meaningful curriculum for students with significant cognitive disabilities, as teachers and administrators have noted (Stockall & Smith, 2013). The failure of a teacher to gather adequate evidence of a student’s progress toward the standards further calls into question the validity of the MCAS Alternate Assessment as a single measure of student proficiency (Laitsch, 2006). Furthermore, the research cautions against placing the scores of students who participate in alternate assessments in the lowest performance category, as those students are effectively “left behind” (Browder et al., 2005, p. 219).

The MCAS Alternate Assessments ensure that all students contribute to state reporting data, and that those with significant cognitive disabilities receive consideration when states make policy decisions (Musson et al., 2010). The MCAS Alternate Assessment portfolios provide important data on student growth, but the literature does not support automatically placing those who take the MCAS Alternate Assessments in the lowest achievement level. The MCAS Alternate Assessments should also have links to other nonacademic skills to evaluate students with significant cognitive disabilities and the programs they take (Towles-Reeves et al., 2009). One suggestion is to link the assessments to the students’ IEPs through the identification of
priority skills (Browder et al., 2003). A consistent application of research-based methodologies for alternate assessments is necessary.

This research focused on how parents/guardians make meaning of the MCAS Alternate Assessment and the resulting lack of a diploma upon exiting high school. Baron (2007) asserted that there is a disconnect between the goals of the special education programs in Massachusetts and the MCAS. The stigma many associate with disability and the perceptions of the students with significant cognitive disabilities complicate making sense of these policies.

**Discussion in relation to the research.** While parents/guardians openly shared their struggles, they also shared the joy in everyday accomplishments and triumph over obstacles. In each of the nine narrative inquiries, parents/guardians reported feeling left out of the decision-making processes regarding outcomes for their children with significant cognitive disabilities. Lisa sits on many parent committees within the school district, but she is unable to find a forum in which she feels she can impact policy.

Parents/guardians reported attending IEP meetings throughout their child’s schooling, but not making the connection between the IEP and graduation. While Eden participated in all Alex’s meetings when he attended public school, she reported being unaware that Alex technically failed MCAS and was a nongraduate. “I go to the IEP meetings … [they] explain everything to me.” Yet, Eden was unable to articulate the difference between graduation and a diploma. When reflecting on a diploma, Eden said, “I mean it’s kinda like sad, but in a way … [it] makes me feel good at least he has something that says, ‘I was here.’” Cindy expressed a resigned acceptance of the MCAS Alternate Assessment policy: “No one ever told me he wasn’t getting a diploma. I mean … I put two and two together. How could he?” ESSA mandates that
schools make parents/guardians aware of the diploma options available to their child when making the decision to participate in the MCAS Alternate Assessment (ESSA, 2015).

With the exception of Steve and Sarah, each of the parents/guardians conveyed a sense of confusion with regards to the MCAS policies. Steve and Sarah were more aware because Cameron was once in a general education setting with the goal of earning a diploma. The decision to change his IEP so that Cameron would engage in a modified curriculum and the MCAS Alternate Assessment was a very difficult one for Steve and Sarah. They had spent his schooling up until his freshman year with the expectation of Cameron earning a diploma. Sarah summarized their feelings: “The bottom line is, it is atrocious that he has attended that school and done the best job that he can with the mind that he had, [and he] does not get a diploma.”

Each of the parents/guardians expressed frustration and confusion regarding the receipt of a certificate rather than a diploma. Eden understood that Alex has significant cognitive disabilities and that his learning is at a very different achievement level than his typically developing peers. Eden remembered the graduation ceremony in which Alex participated as being a very special event for the family, but she struggled to make a connection between the graduation ceremony and a diploma. When talking about graduation, Eden pointed to the ceremony itself as being a highlight: “It was nice, the cap and gown and the yearbook was beautiful … one of the best experiences I had with him in high school.” Later in the inquiry, Eden made the point that a diploma is more meaningful and reflective of Alex’s achievement in overcoming major obstacles.

I mean, I wish he had a diploma … they did and all the goals … doing the IEP classes for the whole 12 years or whatever years they were in school. That was effort; it took a lot for them to actually do certain things. I want him to say, “I got a diploma because I did
do something. I just didn’t show up and sleep all day. I did do something.” So at least he should have the word diploma and not certificate: anyone could come to school.

Lisa also feels that this policy dishonors the efforts of Kamiyah and her peers with significant cognitive disabilities.

It’s a state thing, but I gotta tell ya, I’m really upset about that ’cause our kids, they work hard if not harder you know. It’s a test. It may be an alternative way of testing and a different way, but they gotta know some things to be able to pass…. It should account for something I think…. The fact that they don’t get a diploma, I feel like that’s a violation of their human rights.

Cindy is adamant that a single test cannot demonstrate what Benito knows and is able to do, a theme that was interwoven throughout the narratives.

Study Limitations

This study offers only a limited window into the experiences of parents/guardians and their lived experiences of their child’s participation in the MCAS Alternate Assessment. The study was limited by the reliance on parents/guardians of one urban school district to participate voluntarily. Discussing the details of a child’s disability may have been challenging for the participants. Some participants had strong biases towards the school system, the ways in which it assessed their children, and how society perceives their children. These biases may have influenced responses to questions about the MCAS Alternate Assessment. Some participants had little knowledge about the ways in which the MCAS Alternate Assessments count in state reporting data, and they did not understand how their child’s participation influenced that data. A few of the participants were not knowledgeable about the diploma options and the failure
status of the alternate assessments, which may have skewed their comments and thought processes in some responses.

The number of participants was large enough to draw conclusions, and saturation of the data occurred. However, not all participants in the diverse community could participate, because the use of a translator was not an element of this research. Thus, a small subgroup of participants who speak a language other than English could not receive consideration.

The researcher interviewed parents of students with significant cognitive disabilities rather than the students. The parents are legally responsible for the students. The students are a vulnerable population, and they may not understand or be able to express their experiences in a manner that can answer the research questions. In fact, it is the parents who navigate the educational system on behalf of their children.

The researcher is a member of this school district. As a result, some participants may not have been able to separate that role from the role of independent researcher. The researcher took measures to establish a professional distance so that past relationships did not influence the data.

The researcher acknowledged her own biases. The researcher’s perspectives as a school administrator working with students with significant cognitive disabilities may have influenced her analysis of the data. However, the researcher recognized this possibility and ensured that she analyzed the data without bias by using a chain of evidence to support all findings.

The small sample size cannot be representative of the general population, and the results are particular to this school district. However, an understanding of the meaning of these experiences can be informed by this research.
Recommendations

The lived experience of parents/guardians and their children who participate in the MCAS Alternate Assessment necessitates action and further study. The data suggest that the parents/guardians require a forum in which to address their values, attitudes, and beliefs as they pertain to their children’s disability. A replication of this study with more parents/guardians from different regions within Massachusetts, including urban and suburban schools, would be useful to inform policy decision-making. It would also be important to conduct this study in states like Florida and Louisiana, where an alternate diploma is available to students with significant cognitive disabilities who participate in alternate assessments.

Recommendations for further study. Since this study focused on one urban high school in Massachusetts, further study could include a diverse mix of districts around Massachusetts, including suburban and urban districts and affluent and poverty-stricken communities. A longitudinal study that examines the impact on the MCAS Alternate Assessment policy over time as students mature into adulthood would also be useful. Future study could include outcomes linked to independent living, employment, and higher education.

Future research could include an examination of school and district data from the Massachusetts DESE website. This research would investigate the impact of the MCAS Alternate Assessment’s failure achievement levels on a school or district’s overall accountability ratings. Where NCLB allowed for only 1% of MCAS Alternate Assessments to count towards accountability, ESSA allows for only 1% of students with disabilities to participate in the MCAS Alternate Assessment. This may mean that many students in the progressing level would no longer become participants in the MCAS Alternate Assessments, but they would need to participate in the standard MCAS with accommodations. It will be necessary to monitor the
outcomes for all students with significant cognitive disabilities who participate in the MCAS carefully.

This future research could help to identify areas of strength and weakness in the current MCAS Alternate Assessment policy. Continued research would also create opportunities to inform the policy decisions stakeholders make. It would be important to ensure that future research and policy discussions consider parents/guardians as stakeholders.

**Recommendations for action.** Students who participate in the MCAS Alternate Assessment automatically go into the lowest achievement level (*failing*) and do not receive a diploma. ESSA allows states to create alternate diplomas based on alternate achievement standards as defined by each state (NCEO & NTACT, 2017). States are currently experimenting with different diploma options for students with disabilities (Johnson, Thurlow, & Stout, 2009). Massachusetts is one of only six states that require the same coursework and high-stakes assessment for students with disabilities and their typically developing peers to graduate with a diploma (Achieve & NCEO, 2016). Massachusetts is one of only eight states that have no diploma option available exclusively for students with disabilities (Achieve & NCEO, 2016).

It is important that students with significant cognitive disabilities meet high expectations and standards. However, if they must meet same graduation requirements and diploma options as all students, there must be a careful probe of policies for evidence of efficacy (Johnson et al., 2009). There is no one-size-fits-all approach to policy change, but there are specific strategies that may apply to different areas of work (Research to Action, 2018).

One definition of policy change is a “series of efforts by grantmakers, national, state or local public agencies, system administrators, school leaders, and teachers to translate newly adopted education policies into tangible next steps that would likely lead to improved outcomes
for students” (Grantmakers for Education, 2011). Tools that influence policy discussion include communication and public will building, convening of stakeholders, and research in best practices or that highlights performance can be useful to help to support policy change (Grantmakers for Education, 2011). A focus on seeing successful policy changes through implementation ensures that the work improves student outcomes (Grantmakers for Education, 2011). Long-term goal achievement occurs through the “rigorous yet participatory process” whereby stakeholders identify the necessary conditions (Center for Theory of Change, 2007, para. 1). Education policy requires balanced, individualized, and creative approaches (Robinson as cited by Strauss, 2015). Michael Fullan is a worldwide authority on educational reform, systems change, and change theory. Fullan has brought to light many challenges faced by education policymakers.

Fullan (2006) asserted that change theory or change knowledge can be effective in education reform strategies if people who understand the dynamics of how the factors operate to achieve specific results use them. Theories alone are not enough to drive change; instead, a theory of action must be explicit (Fullan, 2006). Researchers must make connections between strategies and desired outcomes (Fullan, 2006; Center for Theory of Change, 2007). Change theory focuses on filling in and mapping out missing information on what change initiatives do and how they lead to the achievement of desired goals (Fullan, 2006; Center for Theory of Change, 2007; Organizational Research Services, 2004). This design is backwards, because it first considers the goals and then designs the interventions to achieve them (Center for Theory of Change, 2007).

Fullan (2006) described theories of action as ways of using change knowledge to design effective strategies. Researchers use change knowledge deliberately in both a self- and group-
reflective manner (Fullan, 2006). There are seven core underlying premises to Fullan’s theory of action:

1. a focus on motivation;
2. capacity building, with a focus on results;
3. learning in context;
4. changing context;
5. a bias for reflective action;
6. tri-level engagement;
7. persistence and flexibility in staying the course. (p. 8)

Fullan (2006) contended that motivation is the most critical premise, and that the other six premises hinge upon the achievement of the focus on motivation. Motivation is not achievable in the short term, but it develops over time (Fullan, 2006). If the strategy does not gain momentum in motivation within the time frame set, it will fail (Fullan, 2006). There must be conditions to mobilize “key aspects of motivation including; moral purpose, capacity, resources, peer and leadership support, identity, and so forth” (Fullan, 2006, p. 8). The combination of these conditions creates the motivation for change (Fullan, 2006).

In this research, motivation exists among some of the parents. Lisa pointedly shared her frustration with the current policy and her desire for change.

Are you kidding me? Why would you deny our kids? We live in Massachusetts … one of the more progressive states for education. I’d like to gather up some parents and say, “you know what you guys? You’re wrong and we’re going to fight you to the bitter end because our kids deserve it.”
The motivation for policy change cannot come just from the parents/guardians alone, but it needs to include other stakeholders such as school personnel and organizations such as the Arc of Massachusetts.

Fullan’s (2006) second premise involves capacity building with a focus on results. To build capacity, there must be a strategy that increases the effectiveness of the group (Fullan, 2006). The parents/guardians will need to build their capacity by aligning with like-minded organizations such as the Arc of Massachusetts. The Arc of Massachusetts’ web page states that its mission is “to enhance the lives of people with intellectual disabilities … and their families … through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society” (Arc of Massachusetts, 2018, para. 1). There is a section on the Arc of Massachusetts’ webpage dedicated to policy issues impacting people with intellectual disabilities. This policy page identifies areas that the Arc of Massachusetts is committed to influencing (The Arc of Massachusetts, 2018). Creating a partnership with the Arc of Massachusetts would help to increase capacity.

Fullan’s (2006) third premise identifies the need to learn in context. Policymakers, educators, parents/guardians, and other stakeholders would need to come together to understand the MCAS Alternate Assessment policy and its impact on the students with significant cognitive disabilities. This learning would build the capacity for Fullan’s fourth premise that theories of action must have the capacity to change the larger context. “Lateral capacity building” occurs when schools and districts learn from each other, and two change forces result; knowledge and motivation (Fullan, 2006). It would be necessary to gauge the interest of other schools and districts in Massachusetts to create lateral capacity. Partnerships among the schools and districts would strengthen the advocacy.
Fullan’s (2006) fifth premise calls for a bias for reflective action for the previous four premises to move forward. This bias for reflective action includes a shared vision and ownership, as well as behavior changes before beliefs (Fullan, 2006). The “prettiness of the planning document is inversely related to the amount and quality of action” (Fullan, 2006, p. 10). Planning cannot be a substitute for action. All stakeholders will need not just to identify, but also to reflect upon the shared vision of changing the MCAS Alternate Assessment policy. Like the concept of engaging the Arc of Massachusetts to build capacity, Fullan recommended a system of tri-level engagement among school and community, district, and state. Stakeholders must foster the “permeable connectivity” to promote mutual interaction and influence across the levels (Fullan, 2006, p. 11). This permeable connectivity means that stakeholders pursue strategies that support the interaction and influence within the three levels (Fullan, 2006). This tri-level engagement could be the work of a task force for implementing Fullan’s model. Finally, Fullan stressed the importance of maintaining resolve through persistence and flexibility to achieve the six previous premises.

Policy change is neither easy nor without barriers. Those who want to engage in investigating the MCAS Alternate Assessment policy will need what Fullan (2006) described as “rigid persistence” (p. 11). This rigid persistence may lead to push-back from policymakers. Fullan claimed that this action theory is reflective and inquiry-based, and thus it allows for self-correction and refinement.

**Recommendations for schools and districts.** The USDOE’s nonregulatory guidance identifies what information schools must share with parents through the IEP process (USDOE, 2005). Massachusetts is supposed to be an exemplar for transparency with a policy that says that schools and districts must inform parents/guardians that “results may indicate ways in which
documentation in the portfolio could be improved, and may not as yet fully reflect what the student has been taught or has learned” (E. Johnson & Arnold, 2004, p. 274). However, this research has revealed gaps in parents’ understanding of their child’s educational outcomes. It is a federal requirement that schools and districts must create protocols that ensure parents/guardians are well informed about the outcomes relating to a student’s participation in the MCAS Alternate Assessment.

ESSA requires that parents/guardians of students with disabilities who take alternate assessments be clearly informed as part of the IEP process that

- their child’s academic achievement will be measured based on “alternate achievement standards” and
- participation in an alternate assessment may delay or otherwise affect their child’s completion of the requirements for a diploma. (Massachusetts DESE, 2017a, para. 3).

As part of a coordinated program review by DESE’s Program Quality Assurance Section, schools should include this requirement in student folders.

Across the narratives, the theme of isolation recurred. Steve and Sarah described the time after Cameron’s diagnosis as “dark days.” However, they felt a sense of belonging and security when they joined a support group within their community. Steve and Sarah reported that their sense of belonging and their shared experiences with other parents/guardians facing similar issues mitigated their isolation. Schools and districts must create opportunities to build partnerships with and among parents/guardians to help to reduce feelings of isolation. Since 1986, Massachusetts state law has required that all public school districts maintain a parent advisory council open to parents/guardians of students eligible for special education (Massachusetts DESE, 2010). SEPACs have the ability to influence policy decisions at the local
level (Massachusetts DESE, 2010). SEPACs can provide opportunities and activities to give parents/guardians a voice in decision-making (Massachusetts DESE, 2010). A district must hold at least one workshop annually that focuses on the rights of parents/guardians (Massachusetts DESE, 2010). Monitoring of adherence to the guidelines of holding regular SEPAC meetings to foster communication is necessary. The SEPAC meetings would be the first place that parents/guardians could begin to develop a sense of community and belonging, because the meetings are within the community in which the parents/guardians live.

Conclusion

Despite the limitations, the narrative inquiry revealed valuable insights into the lived experiences of parents/guardians of students with significant cognitive disabilities who participate in the MCAS Alternate Assessment. The parents/guardians want the best possible outcomes for their children that honor their values, attitudes, and beliefs. These values, attitudes, and beliefs reveal the struggles and the persevering resilience of disability. Each parent/guardian expressed the desire for change and the removal of the stigma associated with significant disability.

Sarah and Steve were slow to accept Cameron’s disability and his need for a modified curriculum. Sarah explained the efforts that she and Steve exerted to try to make Cameron as typical as possible.

We tried … fixing him and making him as normal as possible. I was always so concerned about how much he was stimming and the noises he would make…. I was always telling him, “Stop it. Stop it.” But my sister sent me an article … about this boy who was grown, and he described why he was stimming. He described it as such overwhelming, a feeling of joy and excitement that he cannot contain himself … and I’m
like “You know, I’m not going to ever fix this.” But why should I fix him? He’s not broken. He’s him.

The MCAS Alternate Assessment policy suggests that students are “broken” by labeling them failures. Baron (2007) asserted that there is a disconnect between the goals of the special education programs in Massachusetts and the MCAS. The connection must be more explicit for students with significant disabilities, and any reform must include parents/guardians of the students who participate in the MCAS Alternate Assessment. Lisa summarized her thoughts about participation in the MCAS Alternate Assessment: “I feel like it’s a violation of their human rights.” This contradicts ESSA and IDEA’s goals of inclusion.


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Appendix A

Appendix A: Script for Recruitment

The researcher will call potential participants on the phone and use the following script:

Initial Phone Call
1. Hi, this is Dianne Davis, and I’m calling to tell you about a study that I’m conducting for my doctor of law and policy program at Northeastern University. The study looks at the experiences of the parents/guardians of students with significant disabilities in the high school program and the assessment of their progress. I would like to interview you about your child and his/her experiences with alternate assessments. … Your participation is voluntary and you can decide not to participate, or to terminate your participation at any time during the study. You will be asked to share yours and (child’s name) experiences so that I can create a narrative, a sort of story, about those experiences. Your names will be changed so that you cannot be identified. This study has been approved by the Northeastern Internal Review Board and the Brockton Public Schools. However, neither will be aware of your participation as I will keep your name in confidence. Our initial meeting may be about an hour long and we may need to have follow up conversations. I was hoping you would be interested in sharing your story with me in the next week or two. (If yes, go to 2. If no: Thank you for your time. Have a great day.)
2. Before we schedule our time, is there anyone else in your family that you think would have something to share? Who might you include when we meet?
3. I can meet you in any place that you feel comfortable. Where might that be?
4. It is important that I accurately gather your information and that I share it the way you intended. For that reason, I would need to record our conversation. I may have your session transcribed by a professional transcriptionist, but that person would not know you or be able to identify you. I will provide you with a pseudonym as we discussed.
5. Please be sure to take down my cell phone number in case you have to change the location or if something else comes up.
6. Thank you very much. I look forward to seeing you on (day/time/location). Again, my name is Dianne Davis and I can be reached at (cell phone number).

Follow-Up Phone Call

Hi, this is Dianne Davis and I am calling to remind you that we are meeting on (day/time/location). I look forward to seeing you. Thank you for your time.
Appendix B

Signed Informed Consent

Northeastern University, College of Professional Studies

Name of Investigators: Principal Investigator, Dr. Kimberly Larson, Student Researcher, Dianne Davis

Title of Project: A Narrative Inquiry of Parents of Students with Disabilities and their Experiences with Alternate Assessment

Informed Consent to Participate in a Research Study

We are inviting you to take part in a research study. This form will tell you about the study, but the researcher will explain it to you first. You may ask this person any questions that you have. When you are ready to make a decision, you may tell the researcher if you want to participate or not. You do not have to participate. If you decide to participate, the researcher will ask you to sign this statement and will give you a copy to keep.

Why am I being asked to take part in this research study?

You are being asked to participate in this study because you are the parent/guardian of a child with disabilities who has experienced alternate assessment.

Why is this research study being done?

The goal of this research study is to share the experiences of parents/guardians of the students with significant disabilities who have participated in alternate assessments.

What will I be asked to do?

If you decide to take part in this study, you will be asked to share your experiences with your child’s progress in high school and alternate assessment. You will be asked to describe your child’s experiences also. The conversations will be recorded.

Where will this take place and how much of my time will it take?

You will share your story in a mutually agreed place that is private and free from distraction at a time that is convenient for you. The sessions will not last more than two hours and you may stop at any time and schedule a follow-up session if you feel that is necessary. You will be asked to review and confirm that the researcher appropriately captured your thoughts.

Will there be any risk or discomfort for me?

Interviews will be held in confidence and our names will never be used in association with the study or any of its outcomes. There will be no records in the Brockton Public School system of your participation. Sharing your experiences about your child may be uncomfortable at times, and if you find it uncomfortable, you can take a break or you can decide to end the interview.

Will I benefit by being in this research?

There will be no direct benefit to you for taking part in this study. However, the information gathered may help to advocate for students with disabilities.

Who will see the information about me?

Your part in this study will be confidential. Only the researchers on this study will see the information about you. No reports or publications will use information that can identify you in any way or any individual as being of this project. You will be provided a pseudonym when the researcher writes the narrative. The researcher’s notes and recordings will be destroyed once the narratives are written.

IRB# CPS17-11-10
Approved: 12/19/17
Expiration Date: 12/18/18
In rare instances, authorized people may request to see research information about you and other people in this study. This is done only to be sure that the research is done properly. We would only permit people who are authorized by organizations such as the Northeastern University Institutional Review Board to see this information.

**Can I stop my participation in this study?**
Your participation in this research is completely voluntary. You do not have to participate if you do not want to and you can refuse to answer any question. Even if you begin the study, you may quit at any time.

**Who can I contact if I have questions regarding this study?**
The student researcher is Diaune Davis who can be reached at Davis.di@husky.neu.edu. Dr. Kimberly Larson is the Principal Investigator and can be reached at K.Larson@northeastern.edu.

**Who can I contact about my rights as a participant?**
If you have any questions about your rights in this research, you may contact Nan C. Regina, Director, Human Subject Research Protection, Mail Stop. 560-177, 360 Huntington Avenue, Northeastern University, Boston, MA 02115. Tel: 617.373.4588, Email: n.regina@neu.edu. You may call anonymously if you wish.

**Will I be paid for my participation?**
No.

**Will it cost me anything to participate?**
No.

**I agree to take part in this research.**

__________________________________________
Signature of person agreeing to take part.

__________________________________________
Printed name.

____________________________
Date

__________________________________________
Signature and printed name of person who explained the study to the participant above and obtained consent.

____________________________
Date

IRB# CPS17-11-10
Approved: 12/19/17
Expiration Date: 12/18/18