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**AUTISM SPECTRUM DISORDER POLICYMAKING IN NEW MEXICO:  
AN ETHNOGRAPHIC CASE STUDY**

**by**

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**DISSERTATION**

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy,  
Special Education**

The University of New Mexico  
Albuquerque, New Mexico

**December 2017**

## Dedication

I dedicate this research to individuals marked with autism, developmental disability, and other neurodevelopmental differences. It was for all of us that I did this work. May we look forward to a future in which there is truly “nothing about us, without us.” I also wish to express my deepest gratitude to all of the participants in this research who gave of their time, their words, and their thought to this effort. I not only learned at your feet, but I also came to love and honor each one of you as the irreplaceable human being that you are. It is my hope that this research will make a difference to your work going forward. I also wish to extend my great appreciate to my children, natural and of the heart: Marylyn, N’tani, Deborah, Mary, Paul, and Peter. To the grandchildren, Charlotte, Roman, and Zac: my delight in all of you kept me warm and happy through this work. Make your lives a blessing for Gramma Elie. To my beloved *bashert* and blessing, my husband Baruch ben Lev Hersh, my Bruce. Not one course, interview, or word written, would have happened without you. For my parents, Robert and Madeline, who had no clue what they were getting into with me. And for those who came before them: My grammas, Frannie, Esther-the-Queen, and Annie; Grandpa Johnston, the bike-buyer, Bapoo Vince, of the Hershey bars, and Bumpa Frank, who fixed all my toys. You created my world and brought me to this special moment. “As my people went from land to land, something passed from hand to hand . . . it’s the way we study, the book we study, the way we study the way.”

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**ABSTRACT**

Understanding how ASD policy is made at the state level is important to the various institutional and individual stakeholders who make, apply, and are governed by it. Critical disability theory was applied to this qualitative study of ASD policymaking in New Mexico. This study examined how policymakers and stakeholders brought their identities, knowledge, values, and beliefs to policymaking in New Mexico. The study was guided by the question, “How is ASD policy in New Mexico constructed?” The research used the following methods: (a) individual interviews of policy stakeholders, (b) observations of public policy meetings, (c) document review. Six major themes emerged: Tension in the Discursive Field, Dividing Practices, Reifying Autism, The Use of Force, The Government of Autism, and Autism Tsunami Policy Paradigm Shift. Analysis also uncovered related sub-themes. The study findings addressed interactions among governmentalities, discourses, violence, and resistance that, together with outside influences, may produce a paradigm shift in ASD policy in New Mexico.

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## **Chapter 1**

### **Introduction**

Disability is a social construct that people together create from the biological conditions within individuals and the interactions among their social affiliations, institutions and governments (Jones, 1996). This idea need not imply that the biological condition underlying the disability construct does not exist independently of the social construct (de Valenzuela, 2014). However, social constructivists do assert that through their social interactions, people develop a discourse and construct knowledge about what an individual's biological condition means (Foucault, 1994; Tremain, 2002).

In the United States, the medical model is the prevailing construct used to diagnose, identify and label individuals with disabilities (Dirth & Branscombe, 2017; Mercer, 1992). Medical doctors, professionals, and paraprofessionals identify and label biological differences and/or the phenomenological characteristics they create (Hyman, 2010). These labels arbitrarily sort continuous traits dichotomously (Gould, 1996b; Hyman, 2010), which divides the population into those who are “disabled” and those who are not (Foucault, 1994; Tremain, 2005).

In public and private schools, educators use the medical model to screen and sort students by marking individual characteristics that interfere with current teaching practices derived from the prevailing educational models set by policymakers (Allison, Auyeng & Baron-Cohen, 2012; Lord & Jones, 2012). At the school level, teachers and support staff construct these models and practices around a narrow set of standards that define a ‘normal’ range of learning styles (Gallagher, 2006; Jones, 1996). Medical and school professionals give individuals who exhibit physical, intellectual, and sensory

processing differences from this norm disability labels defined by law and regulated by state and federal educational standards (IDEA, 2004). Contrary to the law, which requires the schools to meet the individual needs of each student, these labels sometimes determine the educational interventions and practices used for students with disabilities (Mehan & Hertweck, 1986; Sansoti & Sansoti, 2012).

Since the middle of the 20<sup>th</sup> century, policy in special education has been changing together with changes in the methodologies and methods used for research in the social sciences, education and special education (Dorn, 2002). Researchers in special education traditionally worked within a positivist ontology/epistemology (Kauffman, 1987). Special educators have traditionally made policy decisions based on that research to maximize efficient use of resources and to achieve specific learning objectives, but did not concern themselves as much with the associated social consequences to students (Gallagher, 2006; Kauffman, 1987). During the last years of the 20<sup>th</sup> century, different understandings of the nature of disability (Mercer, 1992) have influenced research, policy and practice in special education, creating what some scholars call a philosophical divide in the field (Kavale & Mostert, 2004). Academics and educators represent this divide through academic skirmishes over specific policies such as Response to Intervention and inclusion (Kavale & Mostert, 2004). However, the divide exists because of larger questions about the place of special education services within American education (Kavale & Mostert, 2004; Villa & Thousand, 2005).

The philosophical divide in special education is also related to “the narrowing of the normal” (Levin, E. H., 2009, para 2), a trend in the American civil society in which a broad range of conditions, characteristics, and behaviors are constructed as abnormal in

social contexts. Scholars in the sciences, social sciences and education (Annamma, Boele, Moore, & Klinger, 2013; Bogdan & Knoll, 1995; Danforth, 2007; Gould, 1996a; Hyman, 2010; Molloy & Vasil, 2003) have commented on this construction, which narrows a full range of human difference into mutually exclusive binary categories of disability/ability (Devlin & Pothier, 2006). In the field of special education, Bogdan and Knoll (1995) described two assumptions that characterize the philosophical divide: First, that disability is a condition that resides within an individual; and second, that the binary distinction between “disabled” and “non-disabled” is objective. I believe that the trend toward this binary division of individual differences creates a wider range of conditions that are defined as “in need of services” and a narrower range of what is worthy of being left alone; my characterization of this is “the narrowing of the normal” (Levin, E. H., 2009). Thus, what the civil society once tolerated, it now defines as a master status, that is a status that “influences every other aspect of life, including personal identity” (Rosenblum & Travis, 2006, p. 2). I contend that the narrowing of the normal not only results in the relabeling of a previous range of typical functioning, but also changes the ways that governments and members of the civil society treat such differences.

In 1990, autism (now called Autism Spectrum Disorders; ASD) was included in the list of disabilities covered by a reauthorization of the Individuals with Disabilities Education Act (IDEA; see Appendix A for a list of abbreviations). At this time, the criteria for educational diagnosis was broadened to include high-functioning individuals who are verbal and exhibit average to above average intelligence test scores (American Psychiatric Association, 2013). Although many of these individuals demonstrate high intellectual functioning in various domains (Motttron, Dawson, Armando & Wang, 2007),

I believe their identification with the label ASD in the educational system reduces their differences to disability alone, a master status that overshadows their very real gifts and erases their individuality (Foucault, 1994; Rosenblum & Travis, 2006). As students, they are affected by how policymakers construct ASD as disability and what information is used to make educational policy (Bogdan & Knoll, 1995; Devlin & Pothier, 2006; Tremain, 2005). Because public education is one of the primary socializing institutions for children in the United States (Dewey, 1966; Ravitch, 2001), special education policy contributes to the construction of ASD as disability in American society (Bogdan & Knoll, 1995; Molloy & Vasil, 2003). For these reasons, I believe research on special education policy related to ASD can illuminate how assumptions in policymaking may construct autism narrowly as a disability.

### **Background of the Problem**

Special education policy in the United States developed alongside the field of special education itself (Gallagher, 1994), as parents worked to get their children with disabilities into public schools to be educated side-by-side with their peers who were not labeled with a disability (Dorn, 2002; Itkonen, 2009; McLaughlin, 2010). In 1975, Congress passed Public Law 94-142, which mandated that students with disabilities receive a free, appropriate public education (FAPE) in the least restrictive environment (LRE), meaning that they were to be taught together with their peers to the maximum extent possible (Gallagher, 1994). This legislation has been reauthorized and amended, first as the Individuals with Disabilities Education Act (IDEA) in 1990, and later as the Individuals with Disabilities Education Improvement Act, which is often distinguished as IDEA 2004 (Gallagher, 2006; Laudan & Loprest, 2012). The legislation was developed at

the same time as other educational legislation such as No Child Left Behind (NCLB), however, the IDEA legislation became the main driver for policymaking in special education (Gallagher, 2006).

**The philosophical divide.** The philosophical divide (Kavale & Mostert, 2004; Sowell, 1995) developed among academics and decision makers of special education policy through reinterpretations of the meaning of LRE . These reinterpretations are based primarily on the Supreme Court decision *Brown v. Board of Education of Topeka* (1954), the court unanimously held that the racial segregation of students into separate education settings is “*inherently unequal*” (emphasis in original). With the reauthorization of PL 94-142 as IDEA, some special education policymakers reinterpreted the LRE default as full-time placement in the general education environment and with all special education services delivered there (Gallagher, 2006; Villa & Thousand, 2005). IDEA 2004 emphasized access to the general education curriculum and to the testing and evaluation related to it (Laudan & Loprest, 2012; McLaughlin, 2010; Sansoti & Sansoti, 2012). These changes introduced a controversy over the definitions of LRE and inclusion, during which time some scholars and policymakers began to refer to specialized settings such as resource rooms and full-day special education classrooms as “segregation,” (Kauffman & Hallahan, 2005; Kavale & Mostert, 2004; Villa & Thousand, 2005). Others expressed concerns about this project (Dorn, 2002; Kauffman & Hallahan, 2005) and regarded it as ideological in its language and aims (Kavale & Mostert, 2004). Some researchers in the field suggested that settings and placements for special education needed to be more firmly based on positivist research that demonstrated the efficacy of interventions in particular ways (Kauffman,

1987; Kauffman & Hallahan, 2005; Kavale & Forness, 2000). Students with ASD often exhibit behavioral differences and environmental sensitivities considered disruptive in the inclusive classroom (APA, 2013; Fenton & Krahn, 2002; Kamp-Becker et al., 2013; Klin, Volkmar, & Sparrow, 2000; Lord & Jones, 2012). For these reasons, the arguments across the philosophical divide are part of the context for special education policymaking for these students and influence the social construction of ASD in American schools (Baker, 2002; Danforth, 2007; Molloy & Vasil, 2003).

**Autism Spectrum Disorder.** Prior to 2013 when the American Psychiatric Association formally published the *DSM-5*, some of the diagnoses now included under the ASD umbrella were designated in the APA *DSM-IV-TR* (2000) under the umbrella of Pervasive Developmental Disorders (PDD). The *DSM-5* characterizes ASD by five basic criteria. The first two, “deficits in social communication” (para. A) and “restrictive, repetitive patterns of behavior” (para. B) comprised the criteria to measure severity, for which a table was also provided. The three following criteria limit onset of symptoms to early childhood (para. C), specify that they must cause significant impairment in function (para. D), and disambiguate ASD from Intellectual Disability (ID; para. E). There is a specific caveat added in the 2013 criteria that individuals with “well-established DSM-IV diagnoses” of autism, AS, or PDD can be brought in under the new ASD diagnosis (Note, para. F).

Despite the APA’s sea change in the diagnosis for ASD, much of what researchers learned when ASD was called ‘autism’ or ‘PDD’ was carried into new research. This can be demonstrated simply by noting that citations from papers and reports published before 2013 are still used in research published over the ensuing years



until the present. ASD is still behaviorally defined and diagnosed (Carpenter, 2012), and is heterogeneous in phenomenology and severity (Frith, 2012; Happe & Frith, 2006; Hyman, 2010; McLaughlin, 2010; Mottron et al., 2007; Wotr & Scattoni, 2013). ASD has been characterized in two forms: a) low-functioning autism with ID, or b) high-functioning autism (HF-ASD) with at least average IQ scores (Ciesielski & Harris, 1997; Frith, 2012). ASD comorbidity commonly includes anxiety and depressive disorders (Carpenter, 2012; Lord & Jones, 2012), as well as links to obsessive-compulsive disorders (Jacob, Landeros-Weisenberger, & Leckman, 2009; Mack et al., 2010) and possibly schizophrenia (Just & Pelphrey, 2013; Ozonoff & Jensen, 1999; Wakabayashi, Baron-Cohen, & Ashwin, 2012). According to the latest information posted by the US Centers for Disease Control, ASD affects 1 in 68 children, and is five times more common in males (1 in 42) than females (1 in 189). Furthermore, its prevalence has been rising from 1/150 in the year 2000 to 1/68 by 2010 (Autism Spectrum Disorder Data and Statistics, 2014). The rising numbers have been attributed to increased attention to autism by researchers, physicians, therapists, and educators; changes in diagnostic criteria; the development of better diagnostic tools; and to adverse environmental influences (Banerjee, Riordan, & Bhat, 2014; Carpenter, 2012; Pasco, 2011). Behavioral and neuroimaging research aimed to elucidate the genetics (McCarroll & Hyman, 2013; Rosti, Sadek, Vaux, & Gleeson, 2014), developmental neurobiology (Aylward, Minshew, Field, Sparks, & Singh, 2002; Courchesne, et al., 2007), and neuropsychology of ASD (Ciesielski, Courchesne, & Elmasien, 1990; Ciesielski, Harris, Hart, & Pabst, 1997; Frith, 2012; Mottron et al., 2013). Such research may also lead to therapies and educational interventions for individuals diagnosed with its various forms (Chen et al., 2012; Frith,

2012; Happe & Frith, 2006). Educational interventions in the schools are put in place through the making of special education policy focused on ASD at the local, state, and federal levels (Burnett, 2012; Gallagher, 2006; Hardman & Dawson, 2008; Sansoti & Sansoti, 2012; Simpson & Crutchfield, 2013).

HF-ASD refers to those types of autism in which the individual so labeled has no delay in acquiring language and who score at the normal to gifted range on intelligence tests (Kamp-Becker et al., 2013). Until the publication of the *DSM-5* in 2013, individuals now identified as HF-ASD were often labeled with Asperger Syndrome, which was not categorized under ASD. However, some researchers are now questioning this lumping of HF-ASD with classic (Kanner's) autism because neuropsychological testing shows differences in sensory processing that may not be reduced to a cognitive deficit (Mottron et al., 2007). Recently, neuropsychological testing and imaging studies are tracing what may be a fundamental difference between individuals labeled with HF-ASD and the majority who are also labeled with ID (Frith, 2012; Just & Pelphrey, 2013). There is preliminary evidence that high-functioning individuals are often hyper-verbal and perform well on tests of visual and verbal creativity (Mottron et al., 2013). Results confirming these and other ASD differences in gifted individuals is just beginning to be published, and may provide evidence for splitting the HF-ASD diagnosis from that of the prevalent classic autism (Kristina Ciesielski, personal communication, April 11, 2015). This debate between the lumpers and the splitters around the various ways that ASD phenotypes are expressed and how the condition ought to be diagnosed, is an indication of how much the normal has been narrowly constructed using the medical model as discussed above.

### **Statement of the Problem: Recent Trends in ASD Educational Policy**

Since the turn of the 21<sup>st</sup> century, two pieces of legislation have created broad mandates that affect the making of educational policy for general and special education in the United States. One is NCLB, passed by the United States Congress in 2001 and signed into law early the following year (Vinovskis, 2009), and the other is IDEA 2004 (Gallagher, 2006). Both of these pieces of legislation have driven policy developed at the national and state level, making changes in curriculum and instruction for all students (Gallagher, 2006; Hardman & Dawson, 2008) as well as the institution of numerous assessments and high-stakes testing (Hardman & Dawson, 2008; McLaughlin, 2010). All of these things have brought about controversial changes in policy at the national, state, and local levels (Gallagher, 2006).

**No Child Left Behind.** The NCLB mandate is the prime driver of a national policy meant to “ensure that all children have a fair, equal, and significant opportunity to obtain a high quality education, and reach, at minimum, proficiency on challenging state academic achievement standards and state academic assessments” (No Child Left Behind Act of 2001, 2002). Students identified as being in need of special education services are part of this mandate and NCLB specifically requires that interventions for their learning must be the result of science-based research (Simpson, 2005). Academics and policymakers involved in ASD research and education have also called for research-based intervention requirements (National Research Council, 2001).

However, due to the unique ways in which ASD manifests in individuals and the increased prevalence of diagnosis, there was considerable controversy surrounding recommended educational interventions for ASD (Connor, 2013; Gallagher, 2006;

McLaughlin, 2010; Villa & Thousand, 2005). In particular, NCLB provided a very narrow standard for the definition of scientifically valid research results, giving unqualified approval only to empirical studies that rely on large statistical samples and repeatability (Simpson, 2005; Simpson & Crutchfield, 2013). In creating lists of best practices such as those featured at the What Works Clearinghouse, the US Department of Education has moved “the testing of educational practices toward the medical model” (Smith, 2003, p. 126) by making double-blind, random sampling with control and experimental groups the gold standard for research (Simpson, 2005; Simpson & Crutchfield, 2013; Smith, 2003). Mesibov and Shea pointed out that the elements of good research listed by the Department of Education limits the research likely to be used, favoring only goals that are easily measured, rigid treatment models, and inflexible or conflicting concepts of what evidence is and what it means (2011).

In my own quick review of the current state of the What Works Clearinghouse (Institute of Educational Studies, 2015), I found that the review process described on the website would definitely limit the studies that meet the standard, given that many autism intervention assessments take place in the classroom using various forms of the single-subject design (Simpson, 2005; Simpson & Crutchfield, 2013). Indeed, among 50 studies I found with the keyword autism, almost 90% were rated as “ineligible for review.” It appears that early concern and controversy about the narrow scope of science-based practices for autism has been born out to the present (Simpson & Crutchfield, 2013). Like “evidence-based” medicine, “evidence-based” education is actually statistically based, and directed to the median condition rather than addressing the individual needs of students as required by IDEA (Annamma et al., 2013; Gould, 1996).

**IDEA 2004 and inclusion.** Even before PL 94-142 was enacted, the first papers critiquing the practice of special placements for individuals given a disability label were published (Deno, 1970; Dunn, 1968), igniting a controversy about exclusionary settings for students with disabilities in American public schools. Dunn (1968) argued that placement in special classrooms was not particularly effective for minority group students with disability labels, and Deno (1970) expressed concern about how students in special education were labeled and placed within a cascade of services that resulted in a series of more and more restrictive environments. This is the context for the PL 94-142 mandate that students with special education needs should not only receive a FAPE, but should also be placed in the LRE (Dorn, 2002; Gallagher, 1994). In the 1997 reauthorization of IDEA, Congress strengthened the documentation requirement for the LRE (Dorn, 2002; Kavale & Forness, 2000). The 2004 IDEA reauthorization inserted stronger language still, which was understood by some professionals and policymakers to be a mandate for full inclusion as the default placement for special education services (Gliona et al., 2005; Kavale & Mostert, 2004). To this day, there are widely varying interpretations of what is meant by the mandate for inclusion (Witmer & Ferreri, 2014) and there is little research about how local educational agencies define and make decisions about it (Sansoti & Sansoti, 2012).

**Local changes in policy.** There is also little research about how policy decisions are or should be made about special education for ASD, nor what guidelines and criteria should be considered to meet them (Sansoti & Sansoti, 2012). Although inclusion is expected for students with ASD, some studies have concluded that districts base the amount of time a student labeled with ASD is included in general education on a

judgement of the severity of the student's ASD characteristics (White, Scahill, Klin, & Volkmar, 2007; Witmer & Ferreri, 2014). However, there are good research results from neuropsychology that show that judgments about the severity of ASD based only on IQ measurements and verbal skills may not be an accurate predictor of academic success (Lord & Jones, 2012; Witmer & Ferreri, 2014). Witmer and Ferreri (2014) also pointed out that because most decisions about inclusion at the district level are based on functional assessments rather than on the academic needs of students, such policies restrict access to the general education environment for students identified with HF-ASD. These authors asserted that other educational policies require high-stakes testing of students with ASD based on the skills taught in general education settings. They pointed out that this means that students with ASD often do not have access to the instruction necessary for the required testing (Witmer & Ferreri, 2014). Finally, there is evidence that it is becoming acceptable for students receiving services for ASD to be placed in more restrictive environments in order to be taught behavioral regulation and adaptive skills before being exposed to the general education curriculum (Sansoti & Sansoti, 2012). In the largest school district in New Mexico, Albuquerque Public Schools is creating special centers where students identified with ASD will receive intensive services depending on their social-communication and adaptive living needs (Albuquerque Public Schools, 2015). The information at the APS Website about these programs is very general, so it is hard to know how much access these students will have to the general education curriculum.

### **Rationale**

As I have shown in a brief survey of recent literature above, there appears to be a philosophical divide about special education policy at the national level that manifests in arguments by academics and policymakers over specific issues such as inclusion and Response to Intervention (Connor, 2013; Gliona, Gonzales, & Jacobson, 2005; Kauffman & Hallahan, 2005; Kavale & Mostert, 2004). The discussions result in the crafting of broad policies from federal legislation that are then sent to the states, each of which has its own representative government and educational bureaucracy that writes regulations (see Manna, 2006). These legislative and bureaucratic mandates are passed on to the school districts that then wrestle with how to implement them within the various constraints under which they operate (Dorn, 2002; Eidenberg & Morey, 1969; Gallagher, 2006; Manna, 2006). High level concerns about justice, equality, inclusion, and access to citizenship get lost as states and districts struggle with the practical aspects of educating students with disabilities (King, 1987; Manna, 2006; Simpson, Mundschenk, & Heflin, 2011).

What is missing here is an understanding of the people who make ASD policy in New Mexico and what they actually do to accomplish the task. Who are they and what are their backgrounds? What motivates them to persevere in this work? What information do they have and how do they apply it? Making such policy is not a simple transition from federal mandates to the states and local districts, due to the nature of federalism in the United States (Hardman & Dawson, 2008; Manna, 2006), which I will discuss more in Chapter 2. A study of how a state such as New Mexico makes policy around ASD, which has a rapidly rising incidence and is the subject of a great deal of scientific

research, may well reveal important insights into the philosophical divide within and about special education as a field.

### **Why New Mexico?**

I planned to examine the networks of individuals, institutions, and organizations, as well as the actions and products that influence them for ASD policy development in New Mexico, USA. First, the study site is one of convenience, because I am a New Mexican, and all of my experience related to autism policy and special education has been here in the Land of Enchantment (see Ware, 2000). I am familiar with the politics of education in New Mexico, including the state government, the legislative process, and the bureaucracies that fund, manage, and direct such policy here. As a teacher, a parent and an individual labeled with disability, I am already connected with people involved in the educational and policy networks for ASD in New Mexico in numerous ways.

However, New Mexico is also a unique study environment. The majority population of the state is Hispanic (U.S. Census Bureau, 2012) and the culture, foodways, and political practices of that culture influence how people approach their work, families, and communities (Wiegler, Levine, & Stiver, 2015). Native American populations and variants of non-Hispanic European ethnic groups, add to New Mexico's unique lifeways (Woodward, 2011). All of these things combine to create a unique environment for policy-makers. I will discuss the history and demographics of New Mexico more extensively in Chapter 3.

### **Purpose of the Study**

My purpose for this dissertation was to critically examine the decision-making process of key stakeholders in New Mexico in the development of disability policy



around ASD in light of their knowledge, assumptions, and values. In this study, I addressed the follow question with four sub-questions:

### **Questions to be Addressed**

How is ASD policy in New Mexico constructed?

1. Who are the key decision-makers in ASD policy in New Mexico?
2. What information do they use to inform their decision-making process?
3. What are their assumptions and values about disability and ASD, and how do these operate in their decision making?
4. To what extent does ASD policy take into account current perspectives in the neurobiology and neuropsychology of ASD?

### **Researcher Experience, World View and Positioning**

As the primary instrument of my research, I bring my professional and personal ideas and experiences to my work. In this respect, I wear three hats. One is professional, one is parental, and one is personal.

Wearing my carefully constructed and much-mended professional hat, I taught for 10 years in public and private schools. I taught science in general and special education classrooms and I was a special education teacher in an elementary gifted/twice-exceptional program. In these settings, I taught students labeled—or not—with various learning differences and developmental disabilities labels. As a teacher, I was responsible for carrying out the mandated curricula and policies of the districts in which I taught. I sat on the professional side of the Student Assistance Team (SAT) and the Individualized Education Plan (IEP) table. I participated in identifying and labeling students with disabilities and in placing them in various special education programs and settings. As a

teacher, I experienced the results of two educational reforms (NCLB and IDEA) as they were implemented in New Mexico classrooms.

Under my parental hat, which is a bit worn and battered, I am the mother of an adult son who was diagnosed with Asperger Syndrome and labeled as Speech-Language Impaired/Other Health Impaired when he was seven years old. Our navigation of the educational system in New Mexico was a bumpy ride, full of tears and tantrums; private, public, charter, and home-schooling; and the implicit demand that my parental involvement in my son's education was to be my full-time job. My son's intellectual gifts were not officially identified until his final two years of high school, by which time his antipathy toward educational institutions was consequential and profound. In my parental role, I experienced and responded to the interpretations and regulations of NCLB and IDEA from a different point of view: one that resulted in successfully lobbying Governor Susana Martinez regarding high-stakes testing, navigating versions of inclusion and segregation, and the narrowing of normal that created great stress for me, my son and our whole family.

I am still unpacking my third hat, which is funky, odd and bendable. It was shaped by my refugee grandparents, my elementary education in a rare full-inclusion university lab school, my classical secondary education, my libertarian upbringing, and my own "autist"<sup>1</sup> characteristics. During the time when our family was struggling with what my son's identification meant, I received my own. I was diagnosed as an

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<sup>1</sup> A note on language. Speaking strictly as a professional, I abide by the currently politically correct use of person-first language. As an individual with ASD, however, I reserve the right to assert my own identity as an "autist" or "autistic" or "Aspergian." I am asserting my right to construct autism as an important part of my identity, not something to be explained, fixed, or otherwise tampered with by neurotypicals (see Charlton, 2000; Connor, 2013).

“Aspergian.” It has provided me great explanatory power regarding my sensitivities, my educational struggles and triumphs, and my social awkwardness. And even more so, it explains my gifts. I have only recently decided to “come out” as Aspergian, and I have yet to decide whether that was wise or not. As an individual who owns a disability label, I have experienced the imposition of the assumptions of others about who I am and what I am capable of doing, sometimes in very violating ways.

Under my third hat, my advocacy for my son and my self-advocacy have come together. I have long recognized that powerful gifts exist together with the disability construction of ASD. Recently, I completed Partners in Policymaking, a set of trainings for disability advocacy sponsored by the UNM Center for Development and Disability under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act; Vieweg et al., 2012). The trainings focused on developmental disabilities. Partners was about how people with disabilities can work together with family and friends to take our place in the world. Following Partner’s, I became a Fellow in Leadership Education in Neurodevelopmental and Other Disabilities (LEND) program. LEND was initially authorized by the DD Act, but is now financed through the Autism Collaboration, Accountability, Research and Support Act (Autism CARES; Health Resources and Service Administration, 2015; Viehweg et al., 2012). LEND is sponsored in New Mexico by the same agency that sponsored the Partners program, but this time it is for graduate level professionals. These programs, and their origins and sponsorships will be discussed in detail in Chapter 2. Whereas Partners showed me the world we want to make, LEND showed me how far we have to go to get there. For me, this experience of being identified with a disability is just beginning.

**Intellectual influences on my worldview.** My worldview was shaped by the weaving together of various experiences and intellectual traditions. They include the experiences of my refugee grandparents who raised me during early childhood, my classical education which was both formal and informal, my informal libertarian education and commitments, and my in-depth Jewish education that has continued over my lifetime. I have woven all these strands together to make my own tapestry, my own sense of who I am, and what I think about the world.

My grandparents hailed from Eastern European families that came to the United States to escape Russian communism and German National Socialism. They left behind extended families that were destroyed during a revolution and two world wars. I was raised to love and appreciate the founding values of the United States and to detest the consequences of European collectivism, whether of “the left” or of “the right,” both of which subjugated the individual to the state, orchestrated the deaths of hundreds of millions of people, and obliterated an entire culture.

I started school in 1964 when my parents enrolled me in a rare, integrated inclusion program at the university lab schools. During these early educational experiences, I learned, socialized, and played together with children with many different dis/abilities and from all walks of life. During my junior high and high school years, I received a classical education, during which I learned Latin and Spanish, and to a lesser extent Classical Greek, French and Russian. In a separate school, I began to study Hebrew as well. True to the ideals of a classical education, most of my subject studies—literature, history, science, and the arts—were conducted through the use of primary texts and works. I appreciate the breadth and depth of the education that my parents worked

hard to acquire for me. It has provided me a love for learning and the ability to participate in “the Great Conversation” that attends Western culture.

My parents also provided me with an in-depth political and libertarian education through their commitments and experiences. My father came to libertarian politics from his college New Left activism in the early 1960s, and my mother, from a principled, immigrant conservatism. My dad was an Objectivist, and my mom was skeptical of it. At my parents’ kitchen table I completed my education in political thought by reading and discussing classics from the French and Scots enlightenment traditions, the communist and socialist movements of 19<sup>th</sup> Century Europe, and modern Objectivist and libertarian thought. Following my own, brief “left turn” in young adulthood, I returned to my libertarian roots, which continue to undergird my respect for each person as an individual, and the natural rights with which each one is endowed quite separately from government.

What is perhaps the most integrating intellectual impact on my worldview is that provided by my Jewish education, which has been a life-long love, and is more in-depth than what the typical child receives in synagogue. Out of my own interest, I pursued studies in Hebrew and Aramaic languages, the Hebrew bible, Talmud, Jewish history and culture, and post-Holocaust Jewish thought. In the process, my childhood memories and cultural understandings contributed to a renewed commitment to Jewish religious and cultural values that have endured for generation upon generation. Although they are often conflated into the term “Judeo-Christian” by well-meaning non-Jews, Jewish values are distinct from those of Christianity, and Jews retain an identity that is different from the Christian majority in the United States. Judaism encompasses various cultures and

peoples, and its shifting centers of civilization have created a distinct intellectual tradition that extends beyond religion. The Jewish intellectual tradition was made secular during the 19<sup>th</sup> century European Jewish enlightenment, the *Haskalah* (Etkes, 2010). My Jewish values, religious and secular, integrate all of the various influences on my world view and have provided me a way to maintain my religious heritage and keep my intellectual balance. I continue to struggle with how to be a Jew in the United States in the early 21<sup>st</sup> century. Even as I do so, outside influences on the identity of American Jews continue to evolve, and the political and social ground is once again shifting under us, forcing American Jews to reconsider our American identities.

Lately, while searching the stacks of Zimmerman Library for background on critical theory, I encountered the history of the Frankfurt School and its influence on social research. Its members were predominantly Central European Jews and heirs of the *Haskalah*. As I read of the physical and intellectual migrations of its members during the 1930s and 1940s, I felt as if I was excavating the intellectual tradition of my grandparents' generation. I encountered their ideas with a sense of déjà vu, sadness, and great familiarity. I recognized myself and my intellectual commitments as a living outcome of their struggles, one they would have never expected. I stand on their shoulders, as the Emmy Award winning Cantor Doug Cotler wrote:

As my people went from land to land, something passed from hand to hand. And it isn't just the words and stories, of the ancient laws and the golden glories. It's the way we study, the Book we study. It's the way we study the way. (Cotler, 1990).

**Impact on research.** My research is a qualitative study. This means that I, as the researcher, am the primary instrument of the research (Merriam, 2009). It was through me that the data was interpreted, and through me that its significance was described. Further, qualitative researchers recognize that no research is entirely objective and free of the biases of the researcher, and therefore we commit to exposing our own perspectives at the beginning (Gould, 1996b; Merriam, 2009).

My life experience and intellectual history mean that I approach each person as an individual human being, each a whole world of inestimable worth. I make judgments about what he or she says through the lens of compassion for the human condition. However, I recognize that my informants and I are embedded in the culture, traditions, and social mores of 21<sup>st</sup> century American life, and more particularly those of New Mexico, a unique state with its own history and culture, which I will discuss in the case description in Chapter 3. Individuals create policy through the lens of their own values and concerns as they interact in various social and political networks. It was important for me to take these into account as I interpreted my data through theoretical lenses. In the end, however, my worldview influenced how I judged the effect of political and social networks on policy and its impacts on the rights of the individuals for whom it was made.

I will be using a Foucauldian analysis of critical theory (Tremain, 2005) as my theoretical lens, my understanding of it differs from that of the various anti-liberal scholars who use his analysis. Although I agree with Foucault that not “everything is bad, but that everything is dangerous” (*On the Genealogy of Ethics*, as cited in Tremain, 2005, front matter), as a libertarian, I am also an heir to the classically liberal intellectual tradition. Like Foucault and the critical disability theorists, I find governance and the

surveillance state to be problematic. However, I see the problem to be the limits placed on the liberty of individuals to think, act and interact freely in the civil society.

Therefore, although the lens through which I view the world is certainly critical, my theory is libertarian rather than Marxist. I see the individual as the primary object of oppression, and groups in which they are involved as associations of individuals.

Individuals may compose groups through their freedom of association or they may be placed in them by others for beneficent or totalitarian purposes. However, the prime movers of any group are individuals, who may have various levels of affiliation to and power in the group. I understand groups of individuals to be in constant flux, as individuals affiliate and disaffiliate, and as the individuals and groups are recruited in or resist the projects of others. These differences between my understanding and that of the various other schools of critical theory and critical realism will influence how I understand and interpret and analyze my data.

**Philosophical considerations.** My philosophical orientation comes from my undergraduate and graduate background in the natural sciences and philosophy. Informed by my scientific training and practice, my guiding philosophy has been rational realism, which is a form of philosophical objectivism (Mulder, 2004). As in rational realism, I posit that there is an objective reality—an ontological realm of objects and facts—that exists independently of conscious awareness or observation. Likewise, I posit that reality can be known through a combination of observation, experience, and reason. However, I have come to understand that such knowledge is not strictly representational, but inevitably incomplete due to the limits of human perception. Human error can occur in concept formation, and the social construction of bodies of knowledge (see Frazer &



Lacey, 1993). With the addition of this last understanding, my epistemology parted ways with that of rational realism. My philosophical understanding is now more closely aligned with Maxwell's (2012) description of critical realism. I will discuss Maxwell's critical realism further in Chapter Two.

### **Theoretical Framework**

My theoretical framework is the philosophical perspective by which I interpret the world with which I interact, as well as that by which I understand the academic fields of special education and disability studies. Lastly, it includes the methodology by which I will interpret and understand the results of this study. Here, I introduce my theoretical framework and the particular forms of it that I used to inform my research and analysis.

**Critical theory.** The lens through which I interpret the world and which informs much of my thought and action is Critical Theory. This philosophical position was a project of the members of the Frankfurt School in Germany between the two world wars (Held, 1980). Their project was to develop a theory for the new sciences in the social fields that would at once explain social structures and behaviors, provide useful information, and do away with the artificial division between the researcher and what she researches (Hosking, 2004). Although I reject the Marxist roots of Critical Theory, I believe that our theories about the world guide our work, that our work needs to have value beyond our momentary intellectual pleasure, and that as researchers, we always bring our own values and biases toward what we are doing. Furthermore, I believe that relationships of power and oppression do operate in the world, and that no social theory can ignore them and still accurately describe social systems. I will discuss the particulars of critical theory further in Chapter 2.

**Foucault and critical disability theory.** The basis of my critique in the fields of special education and disability studies is a Foucauldian analysis of Critical Disability Theory (CDT; see Tremain 2002; 2005). The philosophy of Michel Foucault (1926-1984) involved the relationship between knowledge and power in human interactions across disciplines and areas of human endeavor (Tremain, 2005). Foucault conceptualized the subjugation of individuals through state and social processes such as discipline, surveillance, objectification of the body, and the technology of normalization (Foucault, 1995; Tremain, 2002). These technologies simultaneously separate individuals labeled with a disability from society and subject them to particular forms of social control (Tremain, 2005). I will be using this concept of the governance of disability to understand the values and assumptions policymakers, stakeholders, and opposition groups bring to the ASD policy table in New Mexico. I will discuss CDT and Foucault more extensively in Chapter 2.

### **Conceptual Definitions and Assumptions**

Sometimes researchers provide operational definitions for their work. In my work, I will be using concepts that have very specific meanings that are not often carefully defined. Therefore, I will define my terms and relate them to the assumptions I bring to this research.

**The social construction of disability.** Underlying my approach to this research and my use of CDT is the concept of the social construction of disability. The social construction of disability is a translation from the definition of an individual condition to the way that individuals and their concentric social circles think, talk and act about it (Bogdan & Knoll, 1995). Whereas a condition can be objectively defined, its

identification as disabling is contextual (Jones, 1996), and depends on the “complex interplay of a variety of internal and external factors” (de Valenzuela, 2014, p. 2) understood in the context of the values of a particular society (Bogdan & Knoll, 1995). Researchers who view disability as a social construct seek to shift the focus from the individual who is labeled with a certain condition, to the ways in which it is understood as disabling in the society and the privileges and limitations that the construct imposes (Jones, 1996).

When I discuss ASD as a disability, I do so with the understanding that it is socially constructed. This does not imply that I believe that the condition is not real, but that I look for how the label “ASD” functions in ways that objectify individuals who carry it, thus subjugating them to particular regimes of discipline and normalization (Foucault, 1994).

**The normal curve and normality.** Like the biological term *heritability*, the statistical term *normal* is misunderstood, misused, and abused (Fenton & Krahn, 2002; Gould, 1996b). Colloquially, it is used to denote what is expected in a given situation, or to describe what is average about some factor or trait (Barnes & Noble, 2003). However, in the sciences, the normal curve represents the range of variation in a continuous trait (Gould, 1996b). A continuous trait is one that has a range of gene expression in a population rather than the dichotomy expressed: not expressed (Williams, 1996). I used to give this example when teaching genetics: whether one can roll one’s tongue or not is a discrete trait in human populations. However, height measurements are continuous across a human population. Every individual in a population has some measure of a continuous trait. In my example, every human being has height. Continuous traits for a population,

such as height or scores on intelligence tests can be expressed as a normal range about a statistical average (Gould, 2007). Along with Gould, I argue that it is meaningless to apply the statistical term “normal” to individuals. Nor do I think it is reasonable to expect anything other than the entire range of variation of a given continuous trait in any population (every evolutionary biologist knows this, but see Gould 1996a; 1996b; 2007). Normal means the entire range of the continuous trait expressed in a given population, or what Gould (1996a) called the “full house.” In general, important traits such as intelligence are highly conserved in populations, which means that the range of variation is relatively unimportant to an individual’s ability to function and reproduce (Williams, 1996).

When I discuss *normal* in this dissertation, I assume that it means the expectation that the entire range of variation for any continuous trait will be present in a population. At the same time, I recognize that normal has evolved in educational fields to mean a much narrower range within highly-valued traits (e.g. intelligence test scores or top-down sensory processing) important to an individual’s function in school (Annamma et al., 2013). This concept-stealing (Rand, 1984) is in itself a social construct that reveals certain unspoken assumptions and values that belong to particular ideologies (Annamma et al., 2013). In education, the construct of normal is reduced to absurdity when the absolute average expression of a highly-valued trait becomes the goal (Annamma et al., 2013; Gould, 1996b).

In my work, I assume that disability is ‘normal’ in any population. I understand this in two ways. First, in that I expect a wide range of values for a given continuous trait so that some individuals will express lots of it, others very little, and still others will

express values somewhere in the middle. Secondly, given the number of traits necessary to make a human being, all of us will have less than ideal health or ability in a number of discrete and continuous traits.

**Foucault's concept of normalization.** Foucault's use of the term normalization has a very specific meaning within his philosophy of governmentality and bio-power, which I discussed earlier in this chapter. In sociology, the term normalization means the ways in which culturally or socially acceptable ideas in a society become understood as obvious or natural (The Oxford Dictionary of Critical Theory). However, Foucault conceptualized normalization as a technology of governmentality in which human beings are turned into subjects for discipline, control and punishment because they do not measure up to the social construct of an idealized norm (Sullivan, 2005). It is important for me to provide a disambiguation of Foucault's concept of normalization from the *normalizing principle* commonly used to promote more included lives for individuals labeled with severe disabilities such as ID.

### **Scope and Delimitations of the Study**

My goal for this study was to examine ASD policymaking in New Mexico and understand how it socially constructs autism. I intended to gain an understanding of the people who make ASD policy in New Mexico, and learn how they interact with other individuals, institutions, and the state government to accomplish their goals. Such policymaking involves relationships that reach outward toward regional and federal institutions and inward to local governments and school districts. Although some of these relationships are mentioned in the study, the research did not include local, regional or federal entities. Furthermore, once policy is made, it must be implemented and assessed

to determine its efficacy. Although fascinating, I did not include these aspects. Furthermore, the results of policymaking govern children and adults who receive diagnostic, medical, and educational services, I did not study these results for this dissertation.

## **Chapter 2**

### **Review of the Literature**

In this literature review, I will discuss the relevant literature about educational policymaking and my theoretical framework in order to locate my research topic and guiding theory within the scholarship of my field. I will begin by considering the history and implications of the growth of United States federal policy for K-12 public schools in both general and special education, its relationship to state and local policy, the stakeholders involved, and the relationships among them. I will then turn to my theoretical framework, Critical Theory and in particular, CDT. I will discuss the general literature for each of these theories, as well as how each relates to the social construction of special education and the policies that guide it, and more narrowly, to the social construction of ASD through policy. All of these guided my methods, which is the subject of Chapter 3. My theoretical framework also undergirded the discussion of my findings in Chapter 5 of the dissertation.

### **The History and Evolution of Federal Education Policy**

Policy is the process by which power is used to achieve some result by a polity—that is, individuals acting together in the name of some larger association—be it a family, a private organization, or a public institution such as a government branch, bureau or agency (Gallagher, 2006). When people make decisions about the use of power to achieve certain ends, there is usually conflict among stakeholders about who decides and who benefits, as well as whose resources will be used (Gallagher, 1994). Policymaking brings various interested individuals and groups together to resolve these conflicts (Eidenberg & Morey, 1969; Gallagher, 1994; 2006).

**Federalism and education policy.** Public education policymaking in the United States has existed since before the beginning of the republic in some parts of what would become the United States (Mondragon & Stapleton, 2005; Ravitch, 2001; Woodward, 2011). The policymaking process for public education is no simple matter because the United States is a union of sovereign states, each of which cedes a limited amount of power to the federal government as defined in the United States Constitution (Manna, 2006; Marsh & Wohlstetter, 2013). In Article I, the Constitution defines the limited powers of the federal government (U.S. Const. art. I § 8). In the Bill of Rights, which consists of the first 10 Amendments to the Constitution, the framers underscored the limited nature of federal power by stating that “The powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people” (U.S. Const. amend. X). The federal government is therefore restricted to the use of powers needed to protect the rights of the people and preserve the Union, whereas the Constitution assigns all other powers to the states and the people (Skousen, 2007). For this reason, the states and the people, who represent themselves through local government, are empowered to deal with issues of the public weal, such as education (Eidenberg & Morey, 1969; Marsh & Wohlstetter, 2013; Skousen, 2007). In this way, the powers of the servant government remain close to the people who created it (Hamilton, Madison & Jay, 2006; Skousen, 2007).

Education policy is not a constitutionally mandated duty of federal government, and has traditionally been the province of local school districts and boards of education (Eidenberg & Morey, 1969; Mehta, 2013). During the 20<sup>th</sup> century, states took an interest in the education of their fellow citizens and developed education policy at the state level



(Ravitch, 2001). This has resulted in the growth of state educational bureaucracies in response to state issues such as economic development (Mehta, 2013; Ravitch, 2001; Viteritti, 2004), or to federal mandates such as civil rights legislation (Eidenberg & Morey, 1969; Viteritti, 2004). However, with the Supreme Court of the United States ruling to desegregate the schools (*Brown v. Board of Education*), more direct federal control of local and state school administration was made possible for the purpose of protecting the civil rights of students (Ravitch, 2001; Viteritti, 2004).

Scholars have raised questions about the 20<sup>th</sup> century growth of federal interest and control in educational matters that by rights belong to states and local governments (Eidenberg & Morey, 1969; Kessinger, 2011; Manna, 2006). However, the aggregation of power over the states applies not only to public education, but to other issues such as healthcare, welfare, and commerce (Eidenberg & Morey, 1969; Levin, M. R., 2009; Pestritto & Atto, 2008).

The perception that the federal government is a “central” or “national” government with control over the several states has its roots in the Progressive Era of the early 20<sup>th</sup> Century (Levin, M. R., 2009; Pestritto & Atto, 2008; Schweikart & Allen, 2004). As a result of the progressive politics of President Theodore Roosevelt and that of his rival, President Woodrow Wilson, three initiatives that began the centralization of federal power were enacted in 1913: the passage of the Federal Reserve Act; the ratification of Amendment XVI, creating the federal income tax; and the ratification of Amendment XVII, providing for the direct election of senators (Pestritto & Atto, 2008; Schweikart & Allen, 2004). All three of these actions advanced the progressive project of weakening federalism and increasing the powers of the federal government over those of

the states, as well as the power of the executive branch over Congress (Hayek, 2007; Pestritto & Atto, 2008). The powers of the states over the federal government were weakened by the loss of state-level representation to the federal government (U.S. Const. amend. XVII) and by the establishment of federal direct taxation of the populace (U.S. Const. amend. XVI). The income tax allowed the federal executive branch to bypass the states and establish a monetary hegemony over them and the taxpayers (Hayek, 2007; Levin, M. R., 2009), using the Federal Reserve System to finance debt in ways that the states may not (Wright, 2008). Federal grants and payments to the states can be used as a carrot and a stick to bribe and force states into some action (King, 1987; Rosenthal, 1987; Welch & Thompson, 1980). In the first case, the federal government offers grants that pay some part of the cost of compliance with federal legislation directed at the states or their local governments and institutions (King, 1987). In the second, the federal government threatens the withdrawal of funds for non-compliance with initiatives that are piggybacked on federal legislation that the states have already agreed to enforce (Welch & Thompson, 1980). In this way, the federal government is able to involve itself in heretofore state and local matters with the complicity of the states (King, 1987; Rosenthal, 1987; Welch & Thompson, 1980).

**A History of federal interest in general education policymaking.** Although there have been expressions of interest in education by US politicians from the early days of the Republic (Ravitch, 2001; Viteritti, 2004), toward the middle of the 20<sup>th</sup> century, federal involvement in public education began to grow in both size and strength (Eidenberg & Morey, 1969; Kessinger, 2011; Manna, 2006; O'Connor, 2014). Very early federal interest was confined to the support of the states by use of federal lands for

education with the Morell Act of 1835 and the Homestead Act of 1862 (Schweikart & Allen, 2004; Woodward, 2011). However, beginning with the American ascent to world power status at the end of WWII, federal interest became less about the education of individual citizens and more about national politics and prestige on the world stage (Kessinger, 2011; Manna, 2006; Spring, 2005).

*Federal involvement begins to grow.* The federal government's involvement in public education began to grow with the *Brown v. Board of Education* decision in 1954 (Mehta, 2013). *Brown* required federal legislation and enforcement to protect the civil right of students of color to access the regular public schools (Vinovskis, 2009). In the same decade, American politicians and the press used the Soviet launch of Sputnik to rally support for passage of the National Defense Education Act of 1958 (Kessinger, 2011; Manna, 2006; Ravitch, 2001; Vinovskis, 2009). This legislation provided limited federal funding to develop education for subjects affecting national security (e.g. math, science, and foreign languages) and created National Defense Student Loans for college-level students studying related fields (Eidenberg & Morey, 1969; Kessinger, 2011). At the same time, local and state educators, politicians and citizens expressed concern "that our schools—especially instruction in math and science—were inadequate" (Kessinger, 2011, p. 264) as well as that American education had become inferior to the Soviet Bloc countries and other perceived competitors (Eidenberg & Morey, 1969; Spring, 2005). Kessinger (2011) also noted that the prevailing complaint was that progressive practices in public schools were responsible for American educational inferiority. He maintained that the press and certain interest groups pushed a "back-to-basics" educational approach

that “included higher standards, regular assignments, homework, recitations and frequent testing and evaluation” (p. 264) as remedies (Kessinger, 2011).

In 1965, Congress passed the Elementary and Secondary Education Act (ESEA; Eidenberg & Morey, 1969). Title I of this legislation represented the first time Congress provided a continuing federal funding stream to the states for any educational program (Eidenberg & Morey, 1969). Several other authors also marked this as a substantial change toward more direct federal involvement in public schools (Kessinger, 2011; Manna, 2006; Mehta, 2013). However, Congress limited the scope of federal power by designating funding only to schools with a high number of economically disadvantaged students and left matters of school governance and accountability to local and state authorities (Mehta, 2013).

The ESEA passed Congress because supporters used a “masterful political strategy” (Kessinger, 2011, p. 268) by which many political organizations and advocacy groups, each with different values and worldviews, focused on points of agreement (Eidenberg & Morey, 1969). In their case study of the passage ESEA, Eidenberg and Morey emphasized the tremendous political skills needed to shepherd such a bill through Congress. They pointed out further that the ESEA required people with different political philosophies and ideologies to come to an agreement within a federal political structure that maintains a separation of powers. They argued that compromise is difficult to achieve when such basic principles differ among powerful lobbies (Eidenberg & Morey, 1969). Spring (2005) commented that ESEA was successful because it eschewed “general federal aid to education in favor of categorical aid” while tying “federal aid to other national public policy concerns, such as poverty, defense, and economic growth” (Spring,

2005, p. 121). ESEA also allowed aid to parochial and religious schools because the House allocated the funds for specific federal education programs and tied them to the students and not to the schools they were attending (Eidenberg & Morey, 1969; Spring, 2005). Further, the ESEA mandated that the states receive and manage the funds themselves in order to avoid the appearance of federal control over local school districts and states (Eidenberg & Morey, 1969; Kessinger, 2011; Spring, 2005). Later federal programs, such as National Assessment of Educational Progress (NAEP) allowed voluntary participation and mandated similar local and state control so that increased federal involvement in education avoided the appearance of direct federal control of the schools (Kessinger, 2011; Vinovskis, 2009).

***Paradigm shift: A Nation at Risk.*** In 1981, President Reagan's Secretary of Education Terrell Bell created the National Commission on Excellence in Education at the executive branch cabinet level (Manna, 2006; Ravitch, 2001; Vinovskis, 2009) because the White House declined to sponsor it at the presidential level (Mehta, 2013; Vinovskis, 2009). The commission, composed of 18 members from a variety of political and educational backgrounds, produced a unanimous report called *A Nation at Risk* that presented a pessimistic view of the state of American public education at the time (Guthrie & Springer, 2004; Kessinger, 2011; Vinovskis, 2009). The report concluded that America's schools were failing to provide a high-quality education and that this represented a risk to the nation's economic and national security (Guthrie & Springer, 2004; Ravitch, 2000; Vinovskis, 2009; Viteritti, 2004). Even at the time, many scholars considered *A Nation at Risk* to be overly pessimistic and alarmist (Kessinger, 2011; Mehta, 2013; Spring, 2005; Vinovskis, 2009). More recently, Guthrie and Springer

(2004) wrote “in retrospect, it is apparent that the report was wrong” (p. 8) about both conclusions. Several authors argued that a paucity of data and poor analysis flawed the report’s conclusions (Guthrie & Springer, 2004; Vinovskis, 2009; Viteritti, 2004). Nevertheless, the public response to *A Nation at Risk* precipitated increasing federal involvement with public education in the United States (Guthrie & Springer, 2004; Kessinger, 2011), as both federal and state governments worked on reform programs based on its conclusions (Guthrie & Springer, 2004; Manna, 2006; Vinovskis, 2009).

Although many scholars and public policymakers questioned the strident conclusions of *A Nation at Risk* and found them wanting, its publication substantially added to public concerns about education policy at the federal level (Guthrie & Springer, 2004; Kessinger, 2011; Mehta, 2013; Spring, 2005). Guthrie and Springer (2004) posited that “the principal policy legacy” of the report was “to accelerate a paradigm shift” (p. 26) about how to measure educational success, so that government agencies now demonstrate progress by measurement of student achievement rather than basing it on federal dollars spent on particular programs. Mehta (2013) also argued that *A Nation at Risk* represents a paradigm shift in policymaking by “linking the educational to the economic and shifting the problem from poor students to all students” (p. 300). He pointed out that the National Commission on Educational Excellence wrote not only about changes in the US economy, but also about changes in social values as the dominant culture moved out of the expansive and permissive zeitgeist of the 1960s. He asserted that *A Nation at Risk* composed a “master narrative that seized the nation’s attention and would set the terms” (p. 300) for future educational policy development (Mehta, 2013).

Following the publication of *A Nation at Risk*, the state governors asserted their right to control educational reforms, and only with the passage of the NCLB legislation did the federal government reassert leadership in education policymaking (Guthrie & Springer, 2004; Manna, 2006; Mehta, 2013; Vinovskis, 2009; Viteritti, 2004). Guthrie and Springer (2004) identified two consecutive waves of reform precipitated by *A Nation at Risk*. The first wave consisted of state and local reforms that the authors characterized as “low hanging fruit” (p. 27), such as the requirement of increased coursework for graduation and more time spent on schooling. Within the first year following *A Nation at Risk*, a majority of the states were developing, enacting and implementing such reforms (Guthrie & Springer, 2004; Ravitch, 2000). It was also during this first wave of school reform that the new paradigm precipitated by *A Nation at Risk* was constructed, resulting in an altered understanding of the goals and purposes of education, its importance to the states, and a restructuring of the politics of education policymaking (Manna, 2006; Marsh & Wohlstetter, 2013; Mehta, 2013). In his work on policy development, Manna (2006) suggested that this illustrates the political science adage that policies create politics. Mehta (2013), who argued that the new understandings of the goals and purposes of education are the essence of the paradigm shift, countered that they show that paradigms create politics.

Guthrie and Springer (2004) posited that a second wave of reform developed from ideas about systems change and from market theory. Changing the educational system required the analysis and alignment of its parts (e.g. standards, student assessments, teacher education and development) whereas the proponents of the market theory suggested that the structural problems in education result from public schools as a

government monopoly and the inefficiencies that go with it (Guthrie & Springer, 2004; Ravitch, 2001). Although market-based educational reform was the subject of much public discussion and debate, the state focus on driving change systematically in order to improve education made room for further federal reform (Guthrie & Springer, 2004; Mehta, 2013; Vinovskis, 2009).

***Federal involvement in reform after A Nation at Risk.*** While the states took the lead on school reform at home, the federal government under presidents George H. W. Bush, William Jefferson Clinton, and George W. Bush, began a series of policy meetings and initiatives that became the federal reform movement (Guthrie & Springer, 2004; Mehta, 2013). The first of these was the Charlottesville Educational Summit in 1989, billed by organizers as a meeting between President G. H. W. Bush and the National Governors Association. Together, the administration and the governors ratified *A Jeffersonian Compact*, in which they proposed a common set of educational goals for the nation (Vinovskis, 2009). For the administration, this was an opportunity to demonstrate the political will to enact standards-based reform, and for the governors it was an opportunity to garner federal political and financial support for the burgeoning state standards movement (Mehta, 2013; Vinovskis, 2009). However, the G. H. W. Bush administration's legislative initiatives on education were not successful, some failing due to internal politics, and others because Bush did not win reelection in 1992 (Ravitch, 2000; Vinovskis, 2009; Viteritti, 2004).

The Clinton administration developed several education policy initiatives that continued federal involvement in standards-based educational reform. First, the administration proposed Goals 2000, a package intended to fund the development of



content standards based on the National Governors Association goals (Vinovskis, 2009). After some wrangling in Congress over service-delivery and specific content standards, the body passed the bill in 1994 (Vinovskis, 2009). The final Goals 2000 bill authorized funding for the states to develop voluntary content standards (Mehta, 2013; Vinovskis, 2009). In the same year, Congress passed Clinton's reauthorization of ESEA, which tied federal funding to the development of state standards and assessments, and required schools receiving funds to demonstrate adequate yearly progress toward goals and standards (Vinovskis, 2009). Congressional legislative and conference committees reworked both bills to avoid a fight over federal imposition of standards on the states (Mehta, 2013; Vinovskis, 2009).

*No Child Left Behind.* The 2001 reauthorization of ESEA, which the George W. Bush administration named NCLB, marked the moment when the federal government asserted leadership for national education policy (Guthrie & Springer, 2004; Manna, 2006; Mehta, 2013). Guthrie and Springer (2004) identified NCLB as the "driving, transitional force" (p. 31), a third wave of the educational reform movement that began with the publication of *A Nation at Risk*. They identify it as "the major mechanism that now controls American public education" (p. 31; see also Manna, 2006; Spring, 2005, Vitteritti, 2004). With NCLB, the new paradigm created by *A Nation at Risk* "created a convergence among state reforms on which the federal government could piggyback," (Mehta, 2013, p. 313). Meanwhile, it could point to the state standards as evidence that states retained control over education policies (Guthrie & Springer, 2004; Manna, 2006; Mehta, 2013; Spring, 2005). However, through NCLB, federal officials can shape the educational policy that directs the operation of every public school and the education of

every public school student in the United States (Guthrie & Springer, 2004). Guthrie and Springer (2004) went on to identify two ways that the federal government ensures state and local compliance with NCLB right down to what teachers do in the classroom. First, they pointed out that NCLB received overwhelming support from the Congress and the people. They also showed that individual states or districts that oppose the law, or even some of its provisions, face the opposition of voters and stakeholders locally. Secondly, they pointed out that through NCLB, the federal government gives billions of public dollars to the states as grants, all of which require compliance with the federal law (Guthrie & Springer, 2004). This money acts as both a reward for compliance and a punishment for the assertion of state powers over federal control (Mehta, 2013). In what Mehta (2013) termed “a neat move of jujitsu” (p. 314), the federal government declared that the requirements of NCLB were voluntary, and thus do not violate the separation of powers, even though they imposed monetary sanctions on the states that failed to meet the standards (Mehta, 2013). At the same time, the federal government funding only composes a small fraction of NCLB’s costs, the majority of which are borne by state and local education agencies, which gives the federal government a lot of power for its buck (Kessinger, 2011; Manna, 2006; Ravitch, 2011; Vinovskis, 2009).

*The Common Core State Standards.* The Common Core State Standards grew out of policy initiatives to create national standards for public education (Lavenia, Cohen-Vogel, & Lang, 2015; Marsh & Wohlstetter, 2013; McDonnell & Weatherford, 2013). Following *A Nation at Risk*, federal and state actors attempted to legislate national education standards several different times (Lavenia et al., 2015; Marsh & Wohlstetter, 2013; McDonnell & Weatherford, 2013a; Ravitch, 2011; Vinovskis, 2009). These efforts

were unsuccessful because of opposition to the federal imposition of policy on the states, as well as arguments over the ideological content of specific curricular proposals (McDonnell & Weatherford, 2013a; Lavenia et al., 2015). At a national summit on education in 1995, the National Governors Association had declared the pursuit of national education standards a failure for political reasons and suggested that any further development of standards must remain the purview of individual states (Ravitch, 1995). Nevertheless, the Common Core was adopted by 46 of the states by 2011 (Lavenia et al., 2015), only fifteen years after national standards had been rejected.

In their analysis of the state adoptions of the Common Core, Lavenia et al. (2015) discussed the question of why the adoption of national standards deemed impossible less than two decades ago has now happened. They argued that a well-informed policymaking strategy along with a federal program, Race to the Top, combined to make a window of opportunity for the Common Core to succeed. McDonnell and Weatherford (2013a) agreed, stating that although “top-down national standards were a non-starter, the idea of voluntary, shared standards” (p. 8) initiated by interest groups, policy advocates and state government officials and agencies was possible and timely (McDonnell & Weatherford, 2013a, 2013b).

Although many authors emphasized the role of the states in initiating and developing the Common Core, they also recognized that much of the impetus for national standards came from the federal government (Marsh & Wohlstetter, 2013; McDonnell, 2012; Porter et al., 2015; Ravitch, 2014). Porter et al. (2015) stated that the idea of a national core curriculum began at the federal level and that, although they are called state standards, they represent a federal vision for curriculum reform operative in every state

and classroom. Lavenia et al. (2015), while more circumspect about the issue of federal control, recognized that the Common Core was so readily adopted by so many states because of the financial incentives provided by the Obama administration's initiative, Race to the Top. Nevertheless, the federal move for more control over public education may well have the effect of empowering local actors at the district, school and classroom levels because they act at the point where policy is actually implemented (Marsh & Wohlstetter, 2013).

**Summary of federal involvement in general education.** The literature I reviewed in this section demonstrates that federal involvement in K-12 education has evolved from a supportive role to a more active role, which allows the transfer of policymaking power from localities and the states to federal control (Eidenberg & Morey, 1969; Gallagher, 2006; Guthrie & Springer, 2004; Kessinger, 2011; Lavenia et al., 2015; Manna, 2006; Mehta, 2013; O'Connor, 2014; Ravitch, 2011; Spring, 2005; Vinovskis, 2009). This has been accomplished even though most of the financial burden for public education is carried by local and state taxpayers (Lavenia et al., 2015; Marsh & Wohlstetter, 2013), whereas the federal government provides only a small percentage of the funding needed to fulfill the federal mandates (Eidenberg & Morey, 1969; Kessinger, 2011; Lavenia et al., 2015; Manna, 2006; Mehta, 2013). Educational historian and former Undersecretary of Education, Diane Ravitch (2014) agreed. She stated further that the lobbying efforts for NCLB and the Common Core were driven by foundations and for-profit textbook and testing companies that stood to benefit politically and monetarily from the privatization of American public schools (Ravitch, 2014).

Many authors also noted that the policymaking process that has resulted in more federal involvement is not strictly top-down (Eidenberg & Morey, 1969; Gallagher, 2006; Lavenia et al., 2015; Manna, 2006; McDonnell & Weatherford, 2013; Vinovskis, 2009). Rather institutions and organizations at the state and local levels often drive change to influence federal policy (Eidenberg & Morey, 1969; Guthrie & Springer, 2004; Lavenia et al., 2015; Manna, 2006; Marsh & Wohlstetter, 2013; Viteritti, 2004). For example, McDonnell and Weatherford (2013), and Porter et al. (2015) reported that the National Governor's Association initiated the development of the Common Core, and many local education agencies supported the adoption of common standards. Some of the authors have argued that there is resistance to federal encroachments by the local policy makers, as well as by administrators and teachers at the school level (McDonnell, 2012; Porter et al., 2015; Ravitch, 2011; Spring, 2005; Viteritti, 2004).

**Federal involvement in special education policy.** Federal interest in special education policy has a parallel history to that of general education (Gallagher, 2006; Itkonen, 2007). However, the enactment of federal special education legislation had different policy entrepreneurs (Manna, 2006) and different drivers (Gallagher, 2006), and it developed out of a different legal and philosophical framework (Itkonen, 2009; Johnson, 2003).

***Growth of federal involvement through IDEA iterations.*** Parent advocacy groups initiated a right-to-education movement by litigating in the federal courts using a civil rights model based on the *Brown v. Board of Education* (1954) decision that desegregated public schools (Gallagher, 2006; Itkonen, 2009; Zettel & Ballard, 1979). One of the more important cases was *Pennsylvania Association for Retarded Children*

(PARC) v. Commonwealth of Pennsylvania , which was brought to protect the right of every child with disabilities in Pennsylvania to FAPE (Gallagher, 2006). The PARC board had gotten the help of the Council for Exceptional Children (CEC) to draft language for the case, which included the language for FAPE (Itkonen, 2007; 2009). CEC had also drafted model legislation helpful to state advocacy organizations (Itkonen, 2009; Zettel & Ballard, 1979). At the time PARC was decided, there were right-to-education lawsuits pending in 46 states on behalf of children with disabilities (Itkonen, 2009; Zettel & Ballard, 1979).

The strategy of using lawsuits to bring attention to the educational rights of children with disabilities was inspired by the civil rights movement of the 1950s and 1960s (Gallagher, 2006; Itkonen, 2009; Wamba, 2008). Just as the Civil Rights movement had led to the Brown decision (Brown v. Board of Education of Topeka, 1954; Hardman & Dawson, 2008), the parent advocacy movement planned to bring a disputed case to the Supreme Court of the United States to obtain right-to-education protection to children with disabilities in all states (Zettel & Ballard, 1979). However, in a 1973 school finance case, the Supreme Court rejected an argument that public education is a constitutionally protected right (Itkonen, 2009). Moreover, legislators in many states were aware of the legal challenges to school districts and state boards of education, and began developing statutes regarding the education of children with disabilities in public schools (Itkonen, 2009; Zettel & Ballard, 1979).

At the federal level, Congress passed several key pieces of legislation designed to protect the education opportunities of vulnerable populations. These included the Federal Education Amendments of 1972 (PL 92-318), which included the Title IX protection of

females from discrimination in educational settings (Zettel & Ballard, 1979). Another was Section 504 of the Vocational Rehabilitation Amendments of 1973 (PL 93-112), which protected individuals with disabilities from discrimination in any federally funded program (Itkonen, 2009). Pointing to these legislative precedents, advocacy organizations approached Senator Harrison Williams (D-NJ), who was then chair of the Labor and Public Welfare Committee, for help (Itkonen, 2009; Zettel & Ballard, 1979). In 1974, Congress passed another set of federal education amendments, which was interpreted as “early warning legislation, suggesting that the full mandate” (Zettel & Ballard, 1979, p. 11) protecting the right of all children to a public education was forthcoming. The amendments affirmed the right to education established by federal courts and state legislatures, and required state education agencies to develop plans to provide an education to children with disabilities (Itkonen, 2009; Zettel & Ballard, 1979).

In drafting the senate bill that became PL 94-142, Senator Williams collaborated with advocates, congressional staffers, and lobbyists who had an interest in it, including the CEC, a mode intended to produce a more effective piece of legislation (Itkonen, 2007; 2009). After a short debate in the conference committee about compliance language, a compromise was reached and the bill was sent to the president’s desk for signing (Itkonen, 2009).

Public Law 94-142, the Education of All Handicapped Children Act, was signed by President Ford on November 29, 1975. It affirmed the right to FAPE for all students with disabilities; their right to be educated in the LRE; the right to an individual education program (IEP); and rights to procedural due process, non-discriminatory

assessment, and parental participation (Gallagher, 2006; Wamba, 2008; Zettel & Ballard, 1979).

In response to legal and procedural challenges, amendments and reauthorizations of PL 94-142 altered its scope and reach (Itkonen, 2007; Zigmond, Kloo, & Volonino, 2009). Amendments were added in 1986, 1990, 1997 and 2004 (Gallagher, 2006; Itkonen, 2007). During the 1990 reauthorization process, the name of the law was changed from the Education of All Handicapped Children Act to the Individuals with Disabilities Education Act (IDEA; Gallagher, 2006). Of interest for my research, the 1990 amendments also added autism and traumatic brain injury to the list of eligibilities for special education services (Texas Council for Developmental Disabilities, 2013). The reauthorization in 2004, which was given the name Individuals with Disabilities Education Improvement Act (generally called IDEA 2004), was amended to better align the law with NCLB (Texas Council for Developmental Disabilities, 2013).

***Federal courts influence policy through Rowley.*** As the IDEA iterations advanced, advocates continued to use the civil rights lawsuit strategy to address problems with the law. One of these, *Hendrick Hudson School District v. Rowley* (1982), is thought to be a landmark case in special education law (Hardman & Dawson, 2008; Johnson, 2003; Mead & Paige, 2008; Yell, Katsiyannis, & Hazelkorn, 2007). Rowley made its way to the U.S. Supreme Court due to a dispute between Amy Rowley's parents and the school district about what kinds of services were required to satisfy FAPE (Johnson, 2003; Mead & Paige, 2008). The case began with due process hearings and appeals by the Rowleys to get the district to provide an American Sign Language interpreter, but all their efforts were denied (Johnson, 2003; Mead & Paige, 2008). Yell et al. (2013)



reported that the Rowleys then filed suit in federal district court where the judge reversed the previous decisions because Amy was not provided the opportunity to achieve her full potential. The school district appealed this decision to the U.S. Court of Appeals and a panel of three judges ruled 2-1 in favor of the Rowleys (Yell et al., 2007). Because of this split decision, the district had standing to appeal to the Supreme Court of the United States (Mead & Paige, 2008; Yell et al., 2007).

Rowley was argued before the Supreme Court in March of 1982 (Yell et al. 2007). The attorney for the schools asserted that the lower courts had “substituted their own ideas of appropriate programming based on an inaccurate reading of the Education for All Handicapped Children Act [PL 94-142]” and that “the full potential standard announced by the district court was unworkable,” (Yell et al. 2007, p. 4). However, the Rowley’s lawyer argued that the district had not developed an IEP designed for Amy’s unique needs thus depriving her of an equal opportunity to an education (Mead & Paige, 2008). In a narrow decision with three opinions, the majority, a concurrence, and the dissent (Mead & Paige, 2008), the Supreme Court determined that Congress’ intent for PL 94-142 was “more to open the doors of public education to handicapped [*sic*] children on appropriate terms than to guarantee any particular level of education once inside” (Rowley, 1982 in Yell et al., 2007).

The policy implications of Rowley have been far-reaching, and many authors assert that this is what makes it the most important ruling in special education thus far (Gallagher, 2006; Johnson, 2003; Mead & Paige, 2008). Since 1982, state and federal courts routinely cite Rowley as the precedent for decisions about FAPE (Yell et al., 2007). They do so because neither Congress nor the Supreme Court defined the

requirements to provide educational opportunity to students with disabilities as mandated in PL 94-142 (Mead & Paige, 2008; Seligman, 2012). However, the Supreme Court provided two questions that courts could use to establish whether or not a FAPE is being delivered in a given case: “First, has the state complied with the procedures set forth in the Act? And second, is the Individualized Education Program [IEP] developed through the Act’s procedures reasonably calculated to enable the child to receive educational benefits” (Hendrick Hudson School District v. Rowley, 1982, at 206-207). Other courts have also relied on the Supreme Court decision to determine that grade advancement can be used as evidence that an educational program satisfies FAPE (Yell et al., 2007), and to rule that the IDEA does not require school districts to maximize the potential of children receiving special education services (Johnson, 2003; Mead & Paige, 2008).

*IDEA and NCLB.* As discussed above, the 2004 amendments for IDEA were intended in part to combine federal special education mandates more harmoniously with the standards-based reform policies that apply to all public school students (Gallagher, 2006; Hardman & Dawson, 2008; Itkonen, 2007; O’Connor, 2014; Zigmond et al., 2009). This combination provided access to the general education classroom, and its curriculum and assessments, as the default LRE for all students (Hardman & Dawson, 2008; Itkonen, 2007; Sailor, 2008-2009; Zigmond et al., 2009). As a number of authors have pointed out, federal law does not mandate full inclusion in the general education classroom for all students with IEPs (Gallagher, 2006; Kauffman & Konold, 2007; Simpson, Mundschenk, & Heflin, 2011). But as Zigmond et al. (2009) wrote, “the push toward full inclusion” combined with “the standards based education and accountability provisions written into No Child Left Behind in 2001 and reiterated in the reauthorization of IDEA [2004],”

meant that “students with disabilities were to have access to the general education curriculum and to the general education teachers fully qualified” (p. 193) to teach it (Zigmond et al., 2009).

Some authors completely support this model of full inclusion (Sailor, 2008-2009; Villa & Thousand, 2005). Sailor provided a Response to Intervention model that he argued would effectively blend “the traditional functions of ESEA, IDEA, and Title I in a way that at least raises the question as to the need for separate statutory authority” and that would “imply the need for an ‘omnibus’ education law that incorporates all functions” (p. 255) that now exist separately.

Others recognized the importance of inclusion for the success of all students and at the same time suggested a measured approach in order to develop the culture and supports necessary for students with IEPs to access the general education curriculum and the standards-based assessments (Hardman & Dawson, 2008; McLaughlin, 2010; Sansoti & Sansoti, 2012; Witmer & Ferreri, 2014). McLaughlin (2010), contended that the “two powerful laws” (p. 265) that govern the education of students with disabilities, NCLB and IDEA 2004, are in conflict regarding their underlying assumptions and basic policy goals. She argued that a standards-based IEP produced for NCLB may lack the individualization required to safeguard the procedural rights required under IDEA to provide a FAPE tailored to the student. However, McLaughlin also produced data showing that children with disabilities may not be getting the educational benefit that IDEA promises. For this reason, she suggested a modification of how the IEP is approached so that “the purpose of special education in the schools is altered” (p. 276) to include the NCLB promise of student achievement. In her vision, most students with

IEPs would receive a special education targeted toward state standards in an inclusive setting where special education resources would be “seamlessly blended into general education” (p. 276). She suggested that only a small number of students would need a more individualized and intensive special education for which “resources and services will be more distinguishable from general education” (p. 276). This would require further amendments to IDEA and NCLB in order to ensure both access and educational benefit for students who have an IEP (McLaughlin, 2010).

There are also authors who maintain their support for the continuum of services in order to ensure FAPE under IDEA (Kauffman & Hallahan, 2005; Kavale & Mostert, 2004; Zigmond et al., 2009). For example, Zigmond et al. (2009) expressed a concern that the promise of IDEA to provide a FAPE for students with IEPs could be compromised by the demands of NCLB in a fully inclusive setting. They maintained that a special education often requires individualized and targeted “intensive, direct instruction and systematic, well-scaffolded instructional tasks” (p. 195). They pointed out that such specially designed instruction can be carried out in an inclusive setting, but must also provide “direct/focused intervention to improve students’ learning and accommodations for students with disabilities in the regular education setting”(p. 195).

However, Zigmond et al.’s research findings showed that in all four cases they studied, very little intensive, direct instruction took place in inclusive classrooms operating under the NCLB directives. They also found that special education co-teachers in inclusion classrooms spent most of their time helping the general education teacher rather than teaching, and that most of their contact with students involved behavioral interventions rather than instruction. Zigmond et al. concluded that a FAPE provided in

an inclusive classroom remains “a valued goal of special education; however ‘access’ and definition of ‘place’ should not come at the expense of eliminating opportunities for intense, individualized, and explicit skill/strategy instruction provided by specialists” (p. 201). Therefore, these authors still support the continuum of services in special education (Zigmond et al., 2009).

**Autism education policy.** Like all of special education, students labeled with ASD receive programs and services federally governed by NCLB and IDEA (Gallagher, 2006; Sansoti & Sansoti, 2012; Simpson, 2005; Witmer & Ferreri, 2014). However, because ASD is also a medical diagnosis, other federal laws, court cases and policies affect the state and local policymaking stakeholders involved in ASD education and advocacy (Viehweg, Holt, & Pariseau, 2012). Despite being governed by federal laws, much autism policymaking takes place at the regional, state, and local levels, and is driven by various government, academic, medical and hybrid institutions, as well as by advocacy groups and disability rights organizations (Henderson, 2011; Simpson et al., 2011; Yen & Mao, 2011). In this part of the literature review, I will discuss federal laws and policies as they affect controversial aspects of the education of students labeled with ASD. I will also focus on how the states and various other policymaking and advocacy organizations interact to develop ASD educational policy.

***Federal laws and state agencies.*** In 1990, autism became a special education eligibility under IDEA and was written into the Code of Federal Regulations (CFR; Gallagher, 2006; MacFarlane & Kanaya, 2009). Prior to the 1990 amendments to IDEA, some students labeled with autism were still served in special education under other eligibility categories (MacFarlane & Kanaya, 2009; Yen & Mao, 2011; Zirkel, 2011).

Some students who did not meet the eligibility criteria for the extant categories were served under Section 504 of the Rehabilitation Act of 1973 (Viehweg et al., 2012; Yen & Mao, 2011).

Like all children receiving special education services, students labeled with ASD fall under both IDEA and NCLB (Gallagher, 2006; Hardman & Dawson, 2008; Sailor, 2008-2009; Sansoti & Sansoti, 2012; Witmer & Ferreri, 2014). Although full inclusion is considered the default LRE for all students receiving a special education, a number of academics recommended that students with ASD should continue to be taught by specially prepared teachers; placed in the most appropriate setting for success; and provided with individualized research-based interventions, curriculum and instruction (Sansoti & Sansoti, 2012; Simpson et al., 2011).

Studies indicate that general and special educators support inclusive settings for students with ASD, but they often base their decisions on the student's intellectual level of functioning without considering the social, sensory, and physical needs required to learn in the general education setting (Sansoti & Sansoti, 2012; Simpson et al., 2011). Furthermore, inclusion in accountability testing under NCLB is also required for almost all students with IEPs (Witmer & Ferreri, 2014). Therefore, students with ASD need access to the general education curriculum even when they are receiving specialized instruction in more restricted settings (Gallagher, 2006; Simpson et al., 2011; Witmer & Ferreri, 2014).

NCLB also requires that all teaching methods and interventions must be scientifically validated, which has been a problem in the ASD field (Mesibov & Shea, 2011; Simpson, 2005). One reason is that policymakers consider large-scale studies using

randomized selection and control groups as the “gold standard” for evidence-based research in education (Mesibov & Shea, 2011; Simpson, 2005). However, special education teachers often use single-subject designs and intense, targeted, direct instruction to assess successful academic and behavioral interventions (Mesibov & Shea, 2011; Simpson & Crutchfield, 2013). For this reason, although researchers and special education teachers want to develop and use scientifically-based research methods, there are still very few ASD interventions that meet the highest standards at the federal What Works Clearinghouse (Mesibov & Shea, 2011; Simpson, 2005; Simpson & Crutchfield, 2013).

Several other federal laws and initiatives also impact ASD policy in the United States, mainly because ASD is a medical diagnosis (Viehweg et al., 2012). Viehweg et al. (2012) outlined many of them in a training manual for the Association of University Centers on Disabilities (AUCD). One of the most important laws that they discussed is the DD Act, originally named the Mental Retardation Construction Act of 1963. Viehweg et al. noted that in the DD Act, Congress set up and funded various research and policy institutes associated with state universities and hospitals that provide support to individuals with DD and their families. The law also charged them with the task of developing policymakers and workforce personnel to improve the lives of individuals labeled with DD and their families in each state (Viehweg et al., 2012).

In 2006, Congress passed legislation that specifically addressed ASD. Under pressure from well-organized parent advocacy groups (Diament, 2014), the legislation was passed as the Combating Autism Act, which was designed to expand research initiatives, provide epidemiological data on ASD, and initiate early identification and

intervention (Health Resources and Service Administration, 2015; Viehweg et al., 2012). At the behest of various ASD self-advocacy organizations such as Autistic Self-Advocacy Network (ASAN; Diament, 2014), the name of the law was changed to Autism Collaboration, Accountability, Research and Support Act (Autism CARES) during the reauthorization process completed in 2014 (Diament, 2014; Health Resources and Service Administration, 2015). The amendments provided additional support for all of its original goals, and added goals for increased use of evidence based-practices for the education of students with ASD and universal screening (Health Resources and Service Administration, 2015).

In New Mexico, the federal Division of Maternal and Child Health (MCH) Workforce Development and the University of New Mexico Hospitals Center for Development and Disability (UNM-CDD) together perform the functions delegated to the states by the DD Act and the newer Autism CARES Act (Maternal and Child Health Bureau, 2014). The nationally recognized LEND program, which is part of the workforce development mission of MCH, has recently begun to receive its funding through the Autism CARES Act and the DD ACT (Viehweg et al., 2012). Both pieces of legislation fund the Special Projects of Regional and National Significance (SPRANS) grants under the purview of MCH (Viehweg et al., 2012). A significant part of the LEND curriculum is occupied with policy and policymaking concerns about DD and ASD (Heimerl, 2015).

***Court cases.*** The federal courts have influenced ASD education policy through a series of legal challenges brought under IDEA for relief due to procedural and substantive violations of FAPE and LRE (Hill, Martin, & Nelson-Head, 2011; Zirkel, 2011). According to Zirkel (2011), the number of due process hearings and court cases



for ASD-related claims is much greater than those brought on behalf of children with other disabilities by a ratio of 10:1, even though fewer children with ASD are served in special education. To explain the disparity, he pointed to the high costs of programming for children with ASD that motivate parents and school districts to move forward with costly litigation. Zirkel also suggested that the seriousness of the impairments associated with ASD, as well as the public perception that some treatments can produce an early cure for the condition, provided fertile ground for litigation (Zirkel, 2011).

In an examination of 99 published court cases, Hill et al. (2011) reported that although decisions from 2002-2004 cases produced even splits between parent or school district wins, school districts prevailed at a rate of 2:1 in 2008-2010. In their examination of the data, these researchers stressed that districts tend to win when due process is contested, whereas parents are still more likely to win when there have been substantial violations of FAPE or LRE. Hill et al. emphasized that the quality of the IEP “is the key to IDEA and FAPE and proper evaluation is the key to IEP development”(p. 220). Therefore, these authors recommended that districts improve the quality of evaluation and IEP development by employing personnel with expertise in ASD, matching the individual needs of the student with evidence-based programming, and teaching with the goals of autonomy and self-determination on the part of the student in mind. From the evidence in the court documents, they pointed out that following procedural safeguards and developing good IEPs should “focus on student outcomes and not mere compliance with the documents themselves,” (Hill et al. p. 220). In this way, district personnel can develop an alliance with all concerned about the needs of the child and avoid “the emotional, monetary and temporal toll” (p. 220) of extensive litigation (Hill et al., 2011).

There has also been an increase in litigation about the behavior problems of students with ASD who are included in the general education classroom (Katsiyannis, Losinski, & Mackiewicz, 2013). In order to win such cases, the parents must demonstrate that the behavior stems from the student's disability and that the district has made no effort to assess and intervene to improve the behavior by use of a Functional Behavior Assessment and a Behavior Intervention Plan as required under IDEA (Katsiyannis et al., 2013; Sansoti & Sansoti, 2012). Such litigation thus drives local policy by requiring districts to obtain the expertise necessary to provide students labeled ASD with a FAPE and LRE (Katsiyannis et al., 2013; Sansoti & Sansoti, 2012).

*Autism diagnosis and identification as policy.* Neuroscientists construct ASD as a neurological condition identified by medical diagnosis (Lord & Jones, 2012). The parameters for diagnosis in the United States are laid out in the *DSM-5* (APA, 2013), and for other parts of the world, in the International Classification of Diseases (ICD) published by the World Health Organization (2012). Prior to 2013, *DSM* editions classified Autism as one of a number of PDD that also included Asperger Syndrome, Fragile X Syndrome and Childhood Degenerative Disorder (APA, 2013). However, in the new *DSM-5* edition, the autism-related diagnoses were reordered through a committee recommendation to base them on the new information coming from the neurosciences (APA, 2013; Hyman, 2007). Responding to research, translation and clinical concerns about ASD diagnostics, the *DSM-5* committee defined all autism types as Autism Spectrum Disorder (ASD), and provided a qualitative severity rating rather than list a series of separate disorders (Lord & Jones, 2012). The new diagnostic criteria were

placed in two dimensions, social-communication and restrictive, repetitive behaviors (see APA, 2013).

Hyman (2010), a member of the *DSM-5* Committee on Autism, asserted that psychiatric nosologists have recently moved away from categorizing *DSM* conditions under the medical model. He pointed out that medical personnel define disease as an abnormal condition stemming from a known cause with a known course that presents a risk for pathophysiology. Hyman (2010) argued that a disease diagnosis represents a definite discontinuity between pathology and health, whereas *DSM*-defined conditions are continuous with typical functioning. He concluded that a *DSM* condition cannot be ascribed to one cause, and often has heterogeneous symptomatology and courses. Hyman pointed out that the *DSM* also defines psychiatric and neurological conditions dimensionally as well as categorically (see also, Lord & Jones, 2012). Dimensions of a condition are interacting systems of characteristics for which clinicians can designate a series of check-points, define levels of risk, and identify a spectrum of neurodiversity that is continuous with typical human functioning (Hyman, 2010). This view is supported by recent advances in the genetics, developmental neurobiology, and neuropsychology of ASD, all of which provide evidence for the definition of ASD as a spectrum condition in which individual defining characteristics vary over time and space, as well as across the identified population (Baron-Cohen, 2002; Hyman, 2007; Pasco, 2011).

The authors of two reviews (Lord & Jones, 2012; Pina-Camacho et al., 2012) and one brief report (Weitlauf, Gotham, Vehorn, & Warren, 2014) about the new *DSM-5* diagnostic criteria for ASD, all expressed concern about some of the changes. Lord and Jones (2012) pointed out that the science of ASD thus far does not support its

classification as a disease or even a family of diseases, nor do the findings provide a clear connection for an etiology drawn from brain characteristics to behavior. They concluded that the new *DSM* criteria for ASD provided a better avenue for the pursuit of research and development in the neurosciences. However, they argued that the criteria would better serve diagnostic purposes if it recognized the diverse strengths and limitations associated with the condition, focused on providing information for the selection of services to individuals and families, and helped them recognize and accommodate the associated behaviors (Lord & Jones, 2012).

Concerned that the language impairments observed for ASD are no longer specified directly in the *DSM-5* criteria, Pina-Comacho et al. (2012) argued that a wide variety of research findings do not support collapsing the social deficits together with the speech and language difficulties that are often a part of the condition. Although they agreed that impairments in pragmatic language use belong with the social-communication domain, they stressed that semantic language impairments are a clinical indicator that ought to be a separate domain (Pina-Camacho et al., 2012).

Meanwhile, Weitlauf et al. (2014) rejected the conceptualization of previously described forms of ASD through the use of severity labels in the new *DSM-5* criteria. The team's research results showed inconsistencies among the cognitive, adaptive and autism symptom severity markers for all ages of individuals labeled with ASD, so that severe symptoms within an otherwise mild-to-moderate profile were not properly rated as such. They found these results worrisome because the levels of support dimension was intended to replace the different categories such as Asperger Syndrome and PDD-Not

Otherwise Specified so that clinicians would address individual needs rather than provide services based on broad categories (Weitlauf et al., 2014).

I use the term “identification” to talk about the ways in which schools determine the eligibilities for students with disabilities under IDEA (2004). The re-ordering of the DSM criteria for ASD has also altered the criteria for identification of students with ASD under IDEA (Allison et al., 2012; Booth et al., 2013; Kamp-Becker et al., 2013; Oliveras-Rentas, Kenworthy, Roberson, & Martin & Wallace, 2012; Schanding, Nowell, & Goin-Kochel, 2012). Screening and evaluation for ASD are the basis for decisions about the identification of individuals who qualify for special education under IDEA based on the autism eligibility (Allison, Auyeng, & Baron-Cohen, 2012). Researchers are in the process of developing and evaluating screening instruments and tests for the new ASD criteria in the *DSM-5* (Allison et al., 2012; Boot, et al., 2013; Kamp-Becker et al., 2013; Mazefsky, McPartland, Gastgeb, & Minshew, 2013; Schanding et al., 2012).

Individuals identified by screening instruments are generally referred for a full medical diagnosis and/or evaluation for special education services under IDEA (Carpenter, 2012; Pasco, 2011). However, as MacFarlane and Kanaya (2009) pointed out, medical diagnosis is not required under IDEA for a student to receive special education services and the states all have different requirements for special education eligibility. Although all states must use the definition of ASD provided in the Code of Federal Regulations, some states also require criteria from the *DSM* and/or a medical diagnosis as well (MacFarlane & Kanaya, 2009). In New Mexico, the Public Education Department (PED) requires the school IEP teams to use the Code of Federal Regulations’ definition of autism (MacFarlane & Kanaya, 2009) and the criteria for educational impact in the

state Technical Assessment and Evaluation Manual for special education eligibility (Burnett, 2012). Children who do not meet those criteria may still be served in New Mexico under the PDD rubric through age 9 (Koscielniak, 2010; MacFarlane & Kanaya, 2009), or under several other eligibilities (Burnett, 2012).

**Summary of special education policy.** The literature on special education policy show differences from that on the general education policy. First, the parent advocacy organizations that began the right-to-education movement took the civil rights movement as a model and used the federal courts to reach their goals (Gallagher, 2006; Hardman & Dawson, 2008; Itkonen, 2007; 2009; Wamba, 2008; Zettel & Ballard, 1979). Not only did *Brown v. Board of Education* (1954) influence the tone and tenor of the court battles, both *Brown* and the Civil Rights Act of 1963 were models for education as a civil right, an idea carried into PL 94-142 (Itkonen, 2007; 2009; Zettel & Ballard, 1979). The federal nature of special education policy is reinforced by the the federal courts, and the federal executive branch, both of which powerfully enforce it on the states (Hardman & Dawson, 2008; Johnson, 2003; Mead & Paige, 2008; Seligman, 2012; Yell et al., 2007). Furthermore, federal education reform legislation, such as NCLB, also applies to students in special education, and to special education teachers and administrators, who must reconcile laws and regulations that often appear to be at cross-purposes (Hardman & Dawson, 2008; McLaughlin, 2010; Zigmond et al., 2009). Federal legislation and regulation also dictate the terms for the inclusion debate, a policy promulgated in both NCLB and IDEA in their current forms (Gallagher, 2006; Hardman & Dawson, 2008; Kauffman & Hallahan, 2005; Kauffman & Konold, 2007; Kavale & Forness, 2000;

Kavale & Mostert, 2004; McLaughlin, 2010; Sailor, 2008-2009; Villa & Thousand, 2005; Zigmond et al., 2009).

At first glance, ASD policy and policymaking appear to be concentrated at regional, state and local levels (Heimerl, 2015; Henderson, 2011; Koscielniak, 2010; Texas Council for Developmental Disabilities, 2013). Private interests such as parent advocacy organizations, self-advocacy organizations and professional organizations all contribute, often vociferously, to the autism policy debates (Allison et al., 2012; APA, 2013; Carpenter, 2012; Diament, 2014; Heimerl, 2015; Hyman, 2007; Simpson et al., 2011). However, much of the local, state and regional work that goes on around ASD is developed in response to federal legislation and policy that drives the diagnosis, identification, education and treatment of individuals labeled with ASD (Health Resources and Service Administration, 2015; Itkonen, 2007; Koscielniak, 2010; Sansoti & Sansoti, 2012; Simpson, 2005; Simpson & Crutchfield, 2013; Texas Council for Developmental Disabilities, 2013; Viehweg et al., 2012). Cases brought by parents are tried in the federal courts under federal statutes such as IDEA (Hill et al., 2011; Katsiyannis et al., 2013; Yen & Mao, 2011). Furthermore, the funding for regional, state and local services, research, technical assistance and workforce training that all benefit individuals labeled with ASD are the result of federal legislation such as the DD Act and Autism CARES (Health Resources and Service Administration, 2015; Heimerl, 2015; MacFarlane & Kanaya, 2009; Mesibov & Shea, 2011; Viehweg et al., 2012).

As with general education public policy in the United States, the literature I reviewed here demonstrates that although regional, state and local entities participate in and often initiate policymaking (Heimerl, 2015; Henderson, 2011; Texas Council for

Developmental Disabilities, 2013), the federal government interest, involvement and control over the process has been increasing (Hardman & Dawson, 2008; Johnson, 2003; McLaughlin, 2010; Mead & Paige, 2008; Zigmond et al., 2009). As with general education policy, federal involvement not only affects the large-scale policy structure, it also reaches into the districts, schools and classrooms to influence and control very local policies and procedures (Hardman & Dawson, 2008; MacFarlane & Kanaya, 2009; McLaughlin, 2010; Simpson, 2005). This reach can be seen in the vociferous policy arguments about inclusion (Kauffman & Hallahan, 2005; Kavale & Mostert, 2004; Sansoti & Sansoti, 2012; Villa & Thousand, 2005) and in the policymaking power of diagnosis and identification for ASD (Carpenter, 2012; Health Resources and Service Administration, 2015; Hyman, 2010). I contend that it is in these spaces that individuals who display ASD characteristics meet the social environment in which their disability is constructed.

### **Models of Policy Construction**

The history and evolution of federal education policy also provided scholars the opportunity to think about how it is constructed. Eidenberg and Morey (1969) described the legislative policymaking process in their study of the historic passage of the 1964 ESEA, and Manna (2006) developed a policymaking model from his work on the reauthorizations of ESEA through NCLB. In both works, the authors not only described how policymakers developed their ideas, but also how they influenced one another at various levels in order to alter, enact and enforce policy initiatives (Eidenberg & Morey, 1969; Manna, 2006).



**Eidenberg and Morey's legislation model.** For their case study about the passage of the original 1964 ESEA, Eidenberg and Morey (1969) developed a model based on the concept of policy feedback mechanisms to describe how policymaking worked within federalism. They compared the legislative process to that of landing a rocket on a distant planet, pointing out that “one is not likely to hit a predetermined target without correcting the course after the launch” (p. 177). They asserted that policymakers must have some mechanism for two-way communication among the various stakeholders in order to communicate changes in a bill's timing and trajectory. The authors characterized the mechanism as a system through which information moves back and forth through formal and informal channels. They identified the formal systems as the branches of government, each of which operates through a series of designated people, procedures and rules, all of which may change because of elections and the deliberative actions of legislative bodies. They also described informal feedback channels, through which various key players can communicate with one another quickly in order to guide and control the formal process. Feedback comes to policymakers and politicians connected to the voting bodies via interest groups, advocacy organizations, and vocal constituents, as well as from other governmental agencies and actors (Eidenberg & Morey, 1969).

Eidenberg and Morey (1969) maintained that the legislative policy system is “timeless.” However, they also wrote that government policy and legislation is always “a series of temporary decisions made under changing circumstances,” (p. 215). They concluded that the “American system appears to be an almost perfectly balanced mechanism of equal forces” (p. 242) that reduces the likelihood of rapid, radical change

by balancing a democratic decision-making process with constitutionally derived limitations on government, as well as guaranteed individual rights. At the same time, they pointed out that, at least for educational legislation, expert opinion and vocal interest groups may make the system less than truly representative of the interests of the citizenry (Eidenberg & Morey, 1969).

**Manna's "borrowing strength" model.** In a more recent work, Paul Manna (2006) developed a theoretical model to explain federal transgression of state power over education policy by "focusing explicitly on the interrelationships between the federal government and the states" (p. 7). He not only explained how these relationships produced increasing federal involvement in education policy, but also showed how the integration of federal and state actors in policymaking has produced changes in American federalism (Manna, 2006).

Manna posited that policy entrepreneurs might initiate broad education policy agendas at either the state or federal levels. However, he pointed out that governments at both levels must have the license and the capacity to act in order to pass legislation. Manna defined the license to act as the political wherewithal and "strength of the arguments available to justify government action" (p. 29), whereas the capacity to act "includes the human, budgetary and institutional resources or infrastructure" (p. 31) necessary for government action to be effective. Manna asserted that although government action is often portrayed as either bottom-up or top-down, these perspectives are incomplete. He argued that at any point in federal education policymaking, interactions among policy entrepreneurs at the federal and state levels are occurring in both directions simultaneously. He also wrote that it is rare for one level of government

to have high levels of both the license and the capacity to act to conclude policy negotiations successfully. Rather, Manna explained, one level of government often holds the capacity to act, whereas the license belongs to another. Manna concluded that in the vast majority of government policymaking successes, the federal, state, and local governments lend license and capacity to one another and together legislate policies that represent the interests of all involved parties (Manna, 2006).

For example, Manna (2006) noted that in the case of NCLB, policy entrepreneurs at the federal level wanted uniform accountability and standards, but the Constitution limits the federal license to act on education policy. At the same time, Manna pointed out, many state governors had made campaign promises to develop accountability at the state level but had no capacity to act because of opposition party majorities in the state legislatures. Therefore, Manna argued, the federal government lent capacity to the states in the form of both political will and funding, and subsequently many state governments lent their constitutional license to act to the federal policy entrepreneurs. Manna concluded that although federalism can and does limit the power of government, it also provides ways for creative policy entrepreneurs to work around federalism (Manna, 2006).

**Implications of policymaking models.** In their case study about the passage of the original ESEA in 1964, Eidenberg and Morey (1969) portrayed the particular details within a timeless and unchanging framework of legislative processes and pointed to specific political conditions as the drivers of success or failure for a piece of proposed legislation. However, Manna (2006) pointed out that Madison's "compound republic" (Federalist 51; Hamilton, Madison, & Jay, 2006, p. 290) was intended to prevent radical

change, protect the individual rights of the people, and to establish a federal government capable of executing the power and the duties ceded to it by the states and the people (see also, Skousen, 2007). Although he developed the borrowing strength model from his observations of the passage of ESEA, Manna also used the perspective of its many reauthorizations, by which he identified an evolution in how policy entrepreneurs work within federalism. Manna incorporated the feedback mechanisms identified by Eidenberg and Morey to show how policy entrepreneurs at various levels leverage their license and capacity so that feedback increases their power to move their agendas to successful conclusions. In Manna's system, not only does politics make policy, but policy makes politics, and further, policy shifts paradigms (see also, McDonnell, 2012; Mehta, 2013). Even prior to the passage of the ESEA in 1965, the separation between the state and federal governments often ascribed to federalism was incomplete (Itkonen, 2007; Kessinger, 2011). This has been apparent in federal influences on the states and state invitations for federal assistance related to post-Civil War and Depression Era issues (Eidenberg & Morey, 1969; Manna, 2006). However, civil rights and access-to-education issues at many levels opened the door to federal involvement in public education in ways that have shifted what federalism means for education policy across the many reauthorizations of ESEA (Eidenberg & Morey, 1969; Kessinger, 2011; King, 1987; Manna, 2006; Rosenthal, 1987; Spring, 2005).

### **Critical Theory and Disability**

A family of critical theories and theorists arose out of the Frankfurt School, a group of philosophers and social researchers who built their ideas on Marxist theory in the years following WWI (Held, 1980; Tar, 1977). Their project was to develop a social

theory that did away with the separation of the researcher from what was studied and that was “explanatory, practical, and normative, all at the same time”(Bohman, as cited in Hosking, 2004 p. 3). The Frankfurt School is historically interesting, because its members in Germany were betrayed by the rise of Nazism and some had to flee Europe during WWII (Tar, 1977). Tar described how some returned to Frankfurt well after the war, whereas others remained refugees. He noted that those who survived the war had great difficulty confronting the fascistic and totalitarian socialist ideologies of the Nazis and the Soviet Communists. Those who fled to the United States also confronted an extremely flexible society that had “the capacity to neutralize all real opposition and absorb all countertrends,” (Tar, 1977, p. 116). These experiences led to a modified theory and critique, as well as a sociology associated with the Frankfurt School (Held, 1980; Jay, 1996; Tar, 1977). It is clear from its history up through the New Left period in the United States, that the Frankfurt School’s first generation did not easily give up on Marxism (Held, 1980; Horowitz, 2014). However, philosophers who adhered to orthodox Marxist thought rejected critical theory, and its second and third generation philosophers, calling them revisionists (Jay, 1996; Tar, 1977). Jay wrote that from its beginnings, critical theory was “the gadfly of other systems,” (Jay, 1996, p. 41). The second-generation critical theorist Habermas rejected modernism, because of its totalitarian and fascist socialisms that contradicted the enlightenment values of freedom and liberty (Outhwaite, 2009).

Postmodern modifications of critical theory led to different forms of critique, all of which make the researcher the instrument of the research (Hosking, 2004), and all of which are concerned with power (Glesne, 2011). There are a number of such postmodern

critiques, such as critical legal studies, critical ethnography, critical feminism, and critical race theory (Corker & Shakespeare, 2002; Hosking, 2004). CDT centers its critique on the ways in which liberal values and norms do not match the everyday experience of people with disabilities (Hosking, 2004).

**Critical disability theory.** In its beginnings, CDT embraced the naïve social model of disability, which was founded on the idea that impairment is a natural category, whereas disability is a social construction (Hosking, 2004). However, others critiqued the idea that impairment is a natural kind (see Hyman, 2010), and described it as a complex construction (Corker & Shakespeare, 2002; Devlin & Pothier, 2006). Using Foucault's concepts of *governmentality* (Foucault, 1995) and *dividing practices* (Foucault, 1994), Tremain argued that "impairment and its materiality are naturalized effects of disciplinary knowledge/power" (Tremain, 2002, p. 34). This argument reframes the conceptual framework for CDT from the social model of disability to the social construction of disability (Corker & Shakespeare, 2002; Tremain, 2005). Tremain observed that the underlying realities of impairment and disability are both subject to *bio-power*, Foucault's name for state power that is used to manage and control the social circumstances of individuals marked by disability (Corker & Shakespeare, 2002; Tremain, 2002; 2005).

Unlike the social model, the social construction of disability recognizes the biological nature of impairment, an individual's lived experience of impairment, and the social environment external to the individual where disability is constructed (Jones, 1996). Jones argued further that the biological fact of an impairment is real, but separate from the social values and mores that reify assumptions about individuals with conditions

that are labeled as disabling. She wrote that the “biological fact [of impairment] cannot be meaningfully understood outside the contexts, relationships, institutions, or situations that define and shape the meaning of disability,” (Jones, 1996, *Social Construction*, para. 2). In Jones’ definition, disability does not reside only within the individual as it does in the medical model, but exists within the spaces between the individual so labeled and the social environment. Thus, the social construction of disability has become a fundamental assumption of CDT (Devlin & Pothier, 2006; Jones, 1996; Tremain, 2002; 2005).

**CDT and disability policy.** A number of policy analysts have begun to use critical theory frameworks to understand educational policy, policymaking, and success and failure in the process of policy implementation (Diem & Young, 2015; McDonnell, 2012; Winton, 2013). Critical policy analysis in education challenges the assumptions of positivist methods for examining policy (Diem & Young, 2015). This collection of analytic methods all share the recognition that policy is shaped by the different values, interests, knowledge, politics and powers of various individuals and groups that assemble together with practices, events, conflicts and compromises in complex ways (Diem & Young, 2015; Winton, 2013). This kind of policy analysis is critical in that it addresses how power moves and works within the discourse of educational policy and policymaking (Diem & Young, 2015), and researchers use it to examine the voices and the silences that exist during policy construction and in the policy itself (Diem & Young, 2015; McDonnell, 2012). Critical policy analysts operate on the assumption that not only do problems create policy, but that policy also creates policy problems, as well as paradigms that guide those enacting the policy (Edwards, 2012; Fenwick, 2012; Hamilton, 2012; Winton, 2013). The critical policy analysts in education begin from a

variety of critical theories and are eclectic in their approaches to questions (Diem & Young, 2015).

**CDT in special education.** Research in the field of special education is primarily positivist in nature (Connor, 2013; Kauffman, 1987; Kauffman & Konold, 2007), and research and intervention generally rely on the medical model (Connor, 2013; Mercer, 1992; Sleeter, 1986). The philosophy behind these constructs leads to the division of the human world into those who are disabled and those who are not (Devlin & Pothier, 2006; Hosking, 2004; Jones, 1996) and is responsible for the narrow construction of the normal in American education (Annamma et al., 2013; Baker, 2002; Devlin & Pothier, 2006; Goodley, 2013; Simpson, 2005; 2013). The traditional view of research in special education relies narrowly on the numbers, and as we have seen, the policy of using only randomized, blinded trials with treatment and control groups (see, for example, Hardman & Dawson, 2008; McLaughlin, 2010; Simpson, 2005). There are also problems related to the social outcomes for students assigned to special education, such as poor academic skills, low graduation rates, poor employability, and elevated rates of incarceration (Gallagher, 2006; Gliona, Gonzales & Jacobson, 2005; Kauffman & Konold, 2007; McLaughlin, 2010). These issues and concerns not only raised the philosophical divide among special educators, academics, parents and policymakers as I described in Chapter 1; they also made room for a small but growing number of critical theorists to examine the problems in a qualitative way (Connor, 2013; Gallagher, 2006; Gorur, 2009; Hosking, 2004; Mercer, 1992; Sleeter, 1986).

Three years after the release of *A Nation at Risk* (Kessinger, 2011; Vinovskis, 2009), Christine Sleeter (1986) published a paper in which she asserted that the special



education category of learning disabilities (LD) was socially constructed. In it she stated that although most special education policy professionals lauded *A Nation at Risk*, they protested that it did not address the needs of special education students. However, Sleeter argued that educational reforms precipitated by *A Nation at Risk* “help create handicapped children” (p. 47) through the LD special education category. Using the history of educational reform, Sleeter asserted that when politicians, educators and the public view “children as raw material for international competition” (p. 52) and students experience heightened standards and standardized testing, educators tend to respond by labeling failing children with disabilities and segregating them from the general education curriculum (Sleeter, 1986).

In a later paper, Connor (2013) maintained that the reliance on the medical model to diagnose and treat individuals labeled with disabilities causes special educators to focus narrowly on the problem within the person. He argued further that special educators then miss the dynamic nature of the disability construct and they place the blame for failure on the student rather than on the learning environment. He argued that these discourses are influenced by and influence social knowledge about disability, and they create the “professionalization of school failure” (p. 497). He concluded that qualitative leaning scholars and teachers in special education, though few and far between, ought to work toward changing these discourses thereby broadening them to include models that locate the disabling conditions in the shared social environment (Connor, 2013).

There have been a few books and papers about special education that incorporate a CDT framework and are associated with New Mexico (Keefe, Moore & Duff, 2006; Ware, 2000; de Valenzuela, Copeland, Qi & Park, 2006). Ware (2000) included New

Mexico in her critical reflections on the research she has done regarding inclusion. She noted that during the 1990s, the New Mexico State Department of Education (now the PED) promulgated an inclusion policy that appeared to be one of the more just and progressive in the United States. However, as Ware pointed out, “policy is enacted in ways that, on the surface, may align with the original intent of the law, but it can be argued that the spirit of the law remains elusive and unrealized” (p. 45). From her research she learned that although the New Mexico State Department of Education promoted the idea that New Mexico was working hard on inclusion, the special education program at the state’s flagship university ignored inclusion altogether, or gave some students the impression that inclusion could not work. However, Ware also observed that at the classroom and school levels, teachers and students showed “a willingness to probe and explore the everyday acts of exclusion in schools that preclude progress toward inclusion”(p. 50). At the time she wrote her reflection, Ware’s research in New Mexico was ongoing, and so she was not able to know whether the state policy was successful in the “transformation” of special education in New Mexico classrooms (Ware, 2000).

**CDT and the social construction of autism.** The medical model of disability that informs the diagnosis and identification of disabilities in society and in education also informs the understanding of ASD (Allred, 2009; Corker & Shakespeare, 2002; Fenton & Krahn, 2002; Molloy & Vasil, 2003). Theorists and researchers using CDT query the dominant paradigm, asking whether ASD are disabilities or differences (Allred, 2009; Baron-Cohen, 2002; Fenton & Krahn, 2002; Molloy & Vasil, 2003). Although this is particularly true of Asperger Syndrome and other forms of high-functioning ASD (Allred, 2009; Bagatell, 2007; Connor, 2013), Fenton and Krahn (2002) concluded that

all forms of ASD need to be understood at least partly as differences. They wrote that “naturally occurring cognitive diversity, and the accompanying neurological diversity, coupled with a robust understanding of functionality make it impossible to maintain the current view that HFA [high-functioning ASD] is pathological” (p. 4). They argued that although the lower functioning forms of ASD are often comorbid with ID and are more disabling, they still ought to be part of a reexamination of how human societies view disability and how we define “functional” (Fenton & Krahn, 2002).

In two other papers on Asperger Syndrome, the authors argued that the social construction of the condition as a series of impairments rather than as neurodiversity, benefits the professional field of special education in much the same way Sleeter (1986) described for Learning Disabilities (Allred, 2009; Molloy & Vasil, 2003). Using a satirical approach to the deadly serious business of pathologizing high-functioning ASD, both Attwood (1999) and Connor (2013) played on the tendency of Asperger self-advocates to label those without neurodiverse conditions as “neurotypical.” Attwood imagined how Asperger Syndrome might look if defined by the diverse and unusual thought patterns and talents such individuals possess. On the other hand, Connor provided an informant’s “Diagnostic criteria for 666.00 (Neurotypic Disorder)” (p. 116) that defines all of the vaunted strengths of neurotypical functioning as disordered by contrasting them to the DSM characteristics for HF-ASD. Critical theorists point to such examples of a playful and yet pointed “turning of the table of knowledge” (Connor, 2013, p. 111) as ways that Aspergian/Aspie self-advocates resist the labels that pathologize and “other” them (Allred, 2009; Attwood, 1999; Connor, 2013).

***Autism identity construction.*** In an ethnographic of discourse analysis of ASD identity, Bagatell (2007) investigated the ways in which different discourses contributed to the identity construction of an individual labeled with ASD. She pointed out that from a social constructivist standpoint, people create “multiple, changing identities that are expressed in specific, though fluid social relationships” (p. 413), and Foucault argued that discourses and categories from the dominant society are ‘inscribed’ on an individual in the course of social interactions. Her study involved the ways in which her participant, a young man labeled with Asperger Syndrome, developed multiple identities through interactions with the therapeutic, medicalized ASD structures as well as through Aspergian self-advocacy groups online. Bagatell concluded that by shifting the social construction of Asperger Syndrome away from the medical model to an understanding of it as “neurodiverse,” her participant would have had a more fulfilling experience of identity construction (Bagatell, 2007).

***Autism policy construction.*** Dana Baker (2006) described how disability policy in Canada and the United States hews to a median theoretical strategy, wherein disability resides both in the individual and in the social spaces comprising interactions between the individual, his or her impairment, other people and the public policies of the society. Her work demonstrated that disability policies in Canadian and American societies are composed of three parts: civic education policy, rights-based policy, and public services policy (Baker, 2006). Civic education is the use of calendared awareness days and months, as well as public service campaigns aimed at raising awareness about ASD. Furthermore, as Baker noted, “Americans are forever forming associations” (p. 182) for benevolent purposes. She pointed out that in the United States associations dedicated to

autism advocacy and self-advocacy task themselves with raising both awareness and money for various projects related to ASD. Baker continued that in both Canada and the United States, the respective governments tie rights-based policies to the charters of individual rights written in founding documents. In her discussion of public service policies in both countries, Baker commented that it is the concept of the social safety net that is most problematic in the United States, because of the clear assertion of government limits in the United States Constitution. She noted further that despite this, public education has been an exception throughout the history of the United States, but that healthcare safety nets are more controversial. Baker described how through the creative use of federalism, states manage federal waivers, such as the DD Waiver, that provide federal block grants for services to citizens who qualify for them. Baker argued that the use of these uniquely Western ways of managing ASD represents a paradigm shift in the social construction of ASD. She wrote that shifts in ASD policy results in changes to the social contract, which “allows for a negotiation between two loci of power, rights and responsibilities” (p. 192). This in turn shifts the social standing of individuals labeled with ASD from a subordinate position as charity cases, to that of citizens who have the dignity of risk and opportunity (Baker D. L., 2006).

**Summary of the theoretical framework.** My theoretical framework for research is CDT. The literature about CDT outlined above shows how a researcher using this framework can access the complexity of policymaking, as well as the multiplicity of policymakers, who each use power to make policy reflect their own values and beliefs (Diem & Young, 2015; Winton, 2013). My theoretical framework, and my assumption that disability is socially constructed, opens a way for me to examine how power operates

in New Mexico ASD policymaking assemblages. My use of CDT will enable me to notice the ways that policy constructs ASD in New Mexico, and conversely, how the social construction of disability influences policy, as well as the new social paradigms that value the diversity and the genius of “Autists” and “Aspergians,” (Attwood, 1999; Dekker, 1999; Mehta, 2013; Mercer, 1992).

## **Conclusion**

In this literature review, I have discussed the various levels of educational and related ASD policymaking in the United States. There is a robust literature about the public education policy created within federalism through the reciprocal interactions between the federal government and the states. Policies enacted in this way resulted in laws and regulation that govern and mandate funding for educational reform and civil rights for children with disabilities. At a different level of government, federal and state bureaucracies combine the intent of different legislation and regulation in order to comply with the mandates of Congress and the state legislatures on matters of disability rights and the providence of services to people with disabilities. There is also a substantial literature on how individuals with disabilities and their families have used the courts to make and enforce public policy related to the education and civil rights that disability policy has promised to them. From other bodies of literature I reviewed here, I also discussed how the translation of the science of diagnosis and identification of ASD also influences policy and constructs certain models and social understandings of it as a medical disorder.

In this review, I also included a small number of papers about public policy work, special education policy, and the use of CDT in policymaking. There were very few

sources about the enactment and use of public policies in New Mexico. Finally, I could find few papers about special education policy in New Mexico, and only one that used CDT. There is a gap in the literature about special education and ASD policy in New Mexico. There is also a gap related to the use of CDT to examine ASD policy. My proposed research would fill small parts of these gaps. I intended to do a qualitative research study investigating the construction of ASD policy in New Mexico. I planned to analyze my data through the lens of a Foucauldian analysis of CDT and the social construction of disability.

## **Chapter 3**

### **Methods**

In this study, I investigated the social construction of autism as a disability through the making of ASD policy in New Mexico. My purpose for this dissertation was to critically examine the decision-making process of key stakeholders in New Mexico in the development of disability policy around ASD in light of their knowledge, assumptions and values. In this study, I addressed the follow question with four sub-questions:

How is ASD policy in New Mexico constructed?

1. Who are the key decision-makers in ASD policy in New Mexico?
2. What information do they use to inform their decision-making process?
3. What are their assumptions and values about disability and ASD, and how do these operate in their decision making?
4. To what extent does ASD policy take into account current perspectives in the neurobiology and neuropsychology of ASD?

### **Research Design**

For this research, I conducted an ethnographic case study to understand the people, organizations, legislation, and regulations in the middle that comprise the government of ASD in New Mexico. I focused on ASD policy because ASD prevalence worldwide is growing at a very fast rate (Autism Spectrum Disorder Data and Statistics, 2014), and the social construction of this condition as disability is highly visible. It affects the people labeled with ASD, as well as the educators, schools, advocacy organizations and institutions who make/use such policy.



**Description of the Methodology.** In an essay entitled *Anthropology in the Middle*, Knauft (2006) argued that recent forms of ethnography have developed that focus on more local and regional analyses that bypass the debates over grand theories that divide the field. Knauft asserted that although this ethnography in the middle is theoretical, its practitioners do not engage in battles over “Theory;” rather they employ “critical stances on social issues and institutional policies” (p. 411), and do not argue that their critique is universal or essential. Knauft noted that anthropologists in the middle recognize theoretical constructs such as culture, structure, hegemony, and agency more as plural modifiers than as solid objects. In so doing, they identify a middle place where they can explore applications and combinations of theory and practice in the sociocultural setting they are exploring (Knauft, 2006). Ethnographers have different definitions for the field (Ferguson & Gupta, 2002; Geertz, 1973; Madison, 2012; Malinowski, 2012; Marcus, 1995; Smith, 1999). However, they agree that ethnography includes the study of sociocultural interactions from the point of view of the group of people living them (Geertz, 1973; Knauft, 2006; Malinowski, 2012), which requires intensive participant-observation in the field (Gupta & Ferguson, 1997; Knauft, 2006; Malinowski, 2012). Ethnography, once traditionally conducted by the extensive study of one case in one location (Malinowski, 1984; 2012), can now take place in multiple sites (Gupta & Ferguson, 1997; Madison, 2012; Marcus, 1995). It occurs in places and virtual spaces where various participants enact a constantly shifting social reality (Ferguson & Gupta, 2002; Gupta & Ferguson, 1997; Latour, 1983; 2005; Marcus, 1995).

This study was an ethnographic case study in the middle. I investigated the development of a social construction of ASD as disability, influenced by the cultural

associations created during policymaking in New Mexico. I studied the interactions among individuals, organizations, scientific discourses, and the technologies of policymaking to see how this particular social construct is developing in the state.

In her book on qualitative research, Merriam (2009) defined case study as “an in-depth description and analysis of a bounded system” which is “the single most defining characteristic of case study research” (p. 40). Merriam continued that a case is the “unit of analysis, not the topic of investigation” (p. 41) but a specific example “of some process, issue or concern” (p. 41). Thus, she emphasized that the case study focuses on *what* is studied, which distinguishes it from methods that focus on *how* a phenomenon is studied. According to Merriam, a qualitative case study is different from a quantitative case study in that it is “particularistic, descriptive and heuristic” (p. 43). That is, the case study is about a specific example of a phenomenon, the researcher uses thick, rich description in data gathering and analysis, and case study provides new interpretations of the phenomenon under study (Merriam, 2009). Qualitative case study is often the approach used for basic and applied research in education because educational places, people and practices frequently assemble as parts of bounded systems (Bogdan & Biklin, 2007). In this study, the bounds of the case are the people and spaces that interact to construct ASD education policy in New Mexico.

**Description of the case.** The bounded system—that is the case—for this study was the State of New Mexico, and in particular, the people and organizations concerned with ASD there. However, the government and the people of New Mexico create and work within New Mexico’s history and unique cultural makeup (Wiegler, Levine, & Stiver, 2015). This also affects the relationships between local and state institutions and

the federal bureaucracy, and it influences how diverse New Mexican communities understand, implement, and resist such policies (Mondragon & Stapleton, 2005). For these reasons, the demographics, settlement patterns, and history that influence the politics and the people are important to discuss.

*Demographics, settlement and regional cultures.* As of the 2010 count, the US Census Bureau (2010) reported that the State of New Mexico had a population of 2,059,179 persons, composed of 83% White Americans (of which 40.5% answered non-Hispanic), 10.2% American Indian or Alaskan Native, 2.4% Black or African American, 1.6% Asian, and 0.02% Native Hawaiian or Pacific Islander. Of these, 2.4% reported being of mixed race.<sup>2</sup> The 2010 Census data also indicated that 47% of New Mexicans of any race reported Hispanic ethnicity, and interestingly, another 15% reported their race/ethnicity as “Other,” (U.S. Census Bureau, 2010). These figures indicate that although the majority of the population’s race is White American, they divide themselves between Hispanics and non-Hispanics of various ethnicities. The 2010 census collected other ethnic group/country of origin data separately from race. Those data indicated that most “native New Mexicans” (born in New Mexico) who reported Hispanic ethnicity identified their ancestors’ country of origin as Spain. Non-Hispanics reporting ancestries of origin collected in the 2000 census claimed Mexican (~16%), American Indian (~10%), German (~10%), Spanish (~9%), and English (~7%) descent (Brittingham & de la Cruz, 2004).

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<sup>2</sup> The US Office of Management and Budget sets the definitions for the racial categories. The government defines “White” as those people “having origins in any of the original peoples of Europe, the Middle East, or North Africa.” Those who are culturally Hispanic are not a race, but may be White or of mixed race (CDC Populations Definitions, 2014).

The population density and regions of settlement give context to the census data. Although New Mexico has a mean population density of 17 people/square mile (U.S. Census Bureau, 2012), this population is not evenly distributed. More than half the population lives along the Rio Grande, especially along a small stretch running from Santa Fe south to Valencia County, and in Doña Ana County (Las Cruces) near the southern border with Texas and Mexico (New Mexico Population per square mile, 2010 by County). This pattern reflects both the geography of the state and the waves of settlement (Wiegler et al., 2015; Woodward, 2011).

The prehistoric settlement of the current Native American populations occurred before first contact with Europeans, in major pueblos along the Rio Grande, and the Navajo Nation in the Four Corners region (Wiegler et al., 2015). The Spanish settlement followed the Rio Grande north from New Spain (now Mexico), making Santa Fe the oldest continuously used capitol city in the United States (Wiegler et al., 2015; Woodward, 2011). Spanish settlers spread out from there into other parts of the state, although the bulk of the population stayed along the Rio Grande (Wiegler, Levine, & Stiver, 2015). Settlement by various ethnic populations from the United States and Europe followed the 1848 treaty of Guadalupe-Hidalgo (Wiegler et al., 2015). These settlers first followed the Santa Fe Trail into Taos, Santa Fe and Albuquerque, or came through Texas to create ranches and homesteads in the eastern part of the state (Woodward, 2011). Woodward also traced the development of the southeastern part of the state by ethnic Scots-Irish from Texas and Appalachia. These settlers pushed on through to the still sparsely settled southwestern mountains and west-central plateau where homesteading and ranching continue in remote areas to this day (Wiegler et al.,

2015; Woodward, 2011). Woodward (2011) wrote that settlement patterns from the American colonial period until the present are the basis for the development in New Mexico of four of 11 larger, regional cultures present in North America, each of which has its own values, principles and social norms. New Mexico shares four of them:

1. *El Norte* is composed of the southwestern most counties, and those along the course of the Rio Grande, its tributaries, and the central mountain chains from where the river enters New Mexico in the north to where it leaves the state in the south.
2. *The Midlands* is present only in far northeastern Union County.
3. *Greater Appalachia* is in the far eastern counties along the Texas and Oklahoma borders.
4. *The Far West* is composed of the four most sparsely populated frontier counties along the western border with Arizona. (Woodward, 2011).

These settlement patterns and regional cultures are important because they influence how people in the different areas of the state respond to public policy from Santa Fe and the federal government (Holtby, 2012; Woodward, 2011).

***Statehood and government.*** The first colonial name for New Mexico, *Nuevo México*, does not come from the country and culture of Mexico, which ruled New Mexico for only 12 years prior to the 1848 Treaty of Guadalupe-Hidalgo (Weber, 1992). Rather, the place was named for the culture and folkways of *El Norte*, the northern states of Mexico, and the southern portions and the Rio Grande regions of New Mexico (Woodward, 2011). New Mexican culture developed from Spanish and Native American influences in the region (Weber, 1992), whereas the various North American regional

cultures from the East have only lately influenced the state (Wiegler et al., 2015; Woodward, 2011).

The terms of the Treaty of Guadalupe-Hidalgo, which ended the US-Mexican War (1846-1848), included the transfer of most of New Mexico Territory to the United States (Wiegler et al., 2015). As Wiegler et al. pointed out, the New Mexico Constitution included provisions intended to protect the legal, religious, and cultural heritage of New Mexico's Native American population and the Spanish settlements and land grants in unique ways.

New Mexico's quest for statehood was the most protracted in American history and took 64 years to accomplish (Holtby, 2012). Holtby documented that powerful partisan politics at the federal level played a role as Democrats and Republicans continued a political struggle to influence the West following the Civil War. The barrier to statehood was composed of racism, corruption, and cronyism at both the federal and territorial levels, and also included concerns about population growth, education, and economic development in New Mexico (Holtby, 2012). New Mexico was finally admitted to the Union as its 47<sup>th</sup> State on January 6<sup>th</sup>, 1912, by President Taft's signature (Holtby, 2012; Mondragon & Stapleton, 2005; Wiegler et al., 2015). The legacy of the battle for statehood continues to affect New Mexico politics, the state's culture, and its relationship to the federal government in the present (Holtby, 2012).

With statehood, New Mexico set up a divided government based on the US federal model, including an executive branch headed by the governor, a bicameral legislative branch, and a state judiciary. Like all states that entered the Union after 1791, the New Mexico Constitution recognized the United States Constitution as the law of the

land and provided an expanded Bill of Rights (N.M. Const. art. II § 1.). Uniquely, New Mexico also included a section in the Bill of Rights alluding to the Treaty of Guadalupe-Hidalgo that reads:

Sec. 5.

[Rights under Treaty of Guadalupe Hidalgo preserved.]

The rights, privileges and immunities, civil, political and religious guaranteed to the people of New Mexico by the Treaty of Guadalupe Hidalgo shall be preserved inviolate. (N.M. Const. art. II § 5)

This was important to the ratification of New Mexico statehood because although the Treaty of Guadalupe-Hidalgo is the oldest treaty between the United States and Mexico still in effect, the United States had not always honored these provisions for New Mexicans (Correia, 2004; Holtby, 2012). Furthermore, these provisions have affected New Mexico's relationship to the federal government and the disposition of its peoples regarding land and property rights, religious expression, and certain civil rights (Correia, 2004; Holtby, 2012; The Economist, 1996; The Impact of Federal Regulations in Western U.S., 2012).

*Education in New Mexico.* Education in New Mexico has roots extending through all of the major historical eras of New Mexican development over 400 years: the Spanish, Mexican and American periods of governance and the current “imposing presence of ‘federalism,’” (Mondragon & Stapleton, 2005, p. xii). Mondragon and Stapleton (2005) pointed out that the major influences over New Mexico education have included “the endemic multicultural diversity” (p. xii) of the state, its strongly religious character, “Catholic, Protestant, Jewish and Native American” (p. xii), and its settlement

patterns and economic bases. Furthermore, these authors maintained that the nature and character of education in New Mexico, public and private, has been an important point of concern for the various governing entities that have ruled over New Mexico, including Spain, Mexico, and the United States. For example, key federal legislators delayed statehood in part by decrying the “backwards” character of New Mexican education (Holtby, 2012; Mondragon & Stapleton, 2005).

In New Mexico, education is a responsibility of the state and local governments, with inputs from stakeholders such as teachers, business interests and the public (Mondragon & Stapleton, 2005). These authors noted that the state constitution empowered the governor to appoint a state superintendent of education, who was responsible to a state school board until 1993, when a constitutional amendment dissolved it. Mondragon and Stapleton continued that currently, the state superintendent governs and takes advice from the New Mexico Public Education Department, an executive department answerable to the governor. Although local districts and their boards theoretically represent the American principle of local governance in schools, these entities must often bow to state and federal mandates tied to various funding initiatives and grants (Mondragon & Stapleton). However, as Mondragon and Stapleton also emphasized, New Mexico is on the receiving end of a great deal of federal largesse because of its poverty, its rural nature, and the federal government’s direct control of nearly 38% of New Mexico land<sup>3</sup> (Gorty, Vincent, Hansen, & Rosenblum, 2012). Nevertheless, Mondragon and Stapleton contended that federal control of New Mexico lands poses a significant challenge to the state’s finance of education, because New

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<sup>3</sup> This does not include federal control of Native American lands by the Bureau of Indian affairs (Gorty, Vincent, Hansen, & Rosenblum, 2012).



Mexico does not have the power to tax the federal government. For this reason, New Mexico attempts to provide equality of school funding from state taxes on extracted commodities (minerals, oil and gas), as well as through taxes on privately owned agricultural lands (Mondragon & Stapleton, 2005).

*Summary of case description.* New Mexico, as a case for the study on ASD policy development, has similarities to other US states and its own unique character. Like most of the United States, increasing federal influence and control by political and economic means are the consequences of educational reform, as I discussed in Chapter 2. At the same time, the nature of New Mexico's population, land distribution, and economic bases combine to create unique challenges and opportunities for educational excellence and innovation in the state (Mondragon & Stapleton, 2005). Although I chose New Mexico as the case because I live and work here, I also see it as an atypical case because of its unique history, make-up, and culture. New Mexico adds rich dimensions to my ethnographic case study methodology.

### **Study Design**

In this ethnographic case study, I focused on ASD policymaking in New Mexico. I examined how policymakers' identities, information used, assumptions, beliefs, and the use of science influenced their understandings and decisions. Therefore, I used a number of data sources: Archival data and artifacts, demographic/contextual information, field notes, interviews, observations, and researcher journal. As an individual with numerous ties to the New Mexico autism community, I used my knowledge of it to interact in various ways with the people and organizations within it. I did the fieldwork for the study from March 2016 – July 2017. I completed almost all of the interviews and observations

over the summer and fall of 2016. I worked on the member-checks and completed archival data gathering through July 2017. As is customary for this type of research, I did data analysis throughout the fieldwork period.

**Participants.** For the interview portion of my data gathering, I recruited 20 individuals from six stakeholder organizations. Participants from five organizations agreed to take part in interviews. Members of the sixth organization agreed to provide technical information due to organizational time constraints. In Chapter 4, I provided detailed information about the participants.

For the participant-observation part of the study, I observed two public meetings each for two different organizations. They were the New Mexico legislature's Interim Sub-committee on Disability Concerns (DCS) and the Developmental Disability Planning Council's (DDPC) board. All four meetings were open, public meetings and I was not required to seek consents of those actively participating by testimony or public comment.

**Recruitment procedures.** I recruited organizations for observation by composing a list of groups engaged in the writing, making or influencing of ASD policy in New Mexico. In composing this list, I considered organizations I identified from my experience of the community, my archival search, and from individuals I knew who were involved in policy activities. I contacted key individuals in these organizations to gain access, using approved in-person, telephone and e-mail scripts. Several of the groups I contacted did not have open or public meetings scheduled during the period of data collection, and/or they were not conducting business germane to this study during that time.

I began interview recruitment by composing a list of individuals who were engaged in ASD policy, professional organizations, advocacy, and/or self-advocates. In composing this list, I considered contacts from my knowledge of state advocacy efforts resulting from my work as an educator, advocate, and doctoral student in special education. I also contacted individuals whose names appeared in the archival data search part of this project. Finally, I asked early interview participants for the names of possible participants in a snowball strategy. Using approved in-person, telephone and e-mail scripts, I contacted people of interest and asked them to participate in this study. After 10 interviews, the snowball was complete and later participants repeated names that I had gotten from earlier ones.

**Selection of participants.** From among the prospective observation and interview participants I found, I selected participants according to the following inclusion/exclusion criteria.

***Inclusion criteria.*** Only adults (age 18 or over), with or without a disability label, who met the following criteria were invited to participate:

1. Engaged with or influenced policy and/or policymaking around ASD in New Mexico;
2. Worked with or in politics, political think tanks, ASD-related professional organizations, ASD-specific professional and parent advocacy organizations; or
3. Were engaged in disability rights advocacy related to ASD policy; or
4. Who were self-advocates who have identified themselves with ASD/disability labels.

***Exclusion criteria.*** The following criteria were used to ensure individuals who would not be appropriate did not participate in this project. They were excluded if they:

1. Did not engage or advocate for or against ASD policy/policymaking;
2. Were self-advocates who did not choose to identify themselves as a person labeled with ASD/disability; or
3. Did not wish to participate in a study or wished to withdraw participation before any interviews or observations.

All of the participants I recruited completed the interview, 11 responded in some way to the follow-up member check, and 10 completed it. I stopped actively recruiting when I reached 20 participants because I found no more leads or suggestions using the snowball method. At that point, I had saturated the pool of willing and qualified participants.

***Consent procedures.*** I provided all potential participants with information on the nature and purpose of the study during recruitment and at the time of consent according to IRB regulations and standards.

***Consent for interviews.*** I provided IRB-approved consent forms for each interview participant at the time of the interview, read the consent form with the person, and invited and responded to questions and concerns. I made it clear to all participants that they could decline any particular question, request the deletion of responses from the transcript, or stop participation at any time during the study. I reminded participants of these rights as needed during the interviews.

***Participant-observation.*** All participant-observations took place during public meetings as defined by the New Mexico Open Meetings Act (NMSA 1978). The Act ensures that the public may monitor all public business in the State of New Mexico,

including government business meetings, meetings of the State Legislature, and its committees and interim committees (Office of the Attorney General, State of New Mexico, 2015). The New Mexico State Legislature provided live webcasts and podcasts of floor debate, committee-of-the-whole and legislative committee meetings, as well as audio podcasts of remote interim committee meetings (Bienvenidos! Welcome to the New Mexico Legislature! Home Portal, 2015). Participation at open public meetings does not require consent, and no meetings I observed were closed according to the rules of the Open Meetings Act (Office of the Attorney General, State of New Mexico, 2015).

*Withdrawal of participation.* One of the rights of study participants in human behavioral research is the right to withdraw from a study at any time (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). No participants chose to withdraw from the study after they had consented to participate.

### **Data Collection and Recording**

I collected different kinds of data for this study and I designed specific procedures for gathering and recording each data type. Here, I will describe the data types and how I collected it and where I kept it. In the section on data management, I will describe how I stored and protected data.

**Archival data.** These were data taken from public records found in libraries, on the internet and in other collections. They included written policies, information sheets, and written legislation that influenced policy. This data also included papers and information sheets provided by participants and organizations involved in ASD policymaking. All of this data was available to the public. I used this data to find out how

ASD policy in New Mexico had been evolving, and what ASD policy issues were important to the stakeholders and public before and during the 2016 and 2017 legislative sessions. I recorded this data by photocopy and/or downloaded it to numbered and dated files on my laptop computer for the data analysis.

**Demographic and contextual information.** I gathered demographic information by creating a demographic form for participants to fill out as they chose at the beginning of the primary interview. The form asked questions about the participants' race, ethnic group, location and length of residence in New Mexico, and entry points into work on ASD policy. I stored these hard-copy forms in a locked, fireproof cabinet in my office in Sandia Park, New Mexico. I also entered the demographic data into the Dedoose online data analysis program to make statistical charts after I separated it from the identifying information of those who chose a pseudonym.

I passively observed the public context of the study as I traveled around the state for interviews and other business. I noted the people, places, spaces, and the landscape in the areas I traveled. I was interested in the broad sense of life and did not record names, faces, or conversations. I did most of these observations in the Albuquerque-Santa Fe corridor, but I also went to Clovis and Rio Rancho during my travel. Again, I addressed the details in Chapter 4. I recorded these observations in my field journal on my iPad computer. I wrote up these notes as soon as possible following the observations, and transferred the resulting memos to a secure location on my laptop. I also placed them on a password-protected external drive that I secured in my office.

**Public meeting data.** I made observations of a legislative interim committee and the DDPC board during the summer and fall of 2016. I typed descriptive field-notes into

my iPad notebook. At the end of each observation, I wrote a field observation memo in which I completed my descriptions and recorded impressions and questions on the iPad notebook. I transferred these files immediately and directly to a password protected location on my personal computer and removed them from the iPad. These memos were stored in numbered files for efficient retrieval. I also uploaded the files to the secure Dedoose data analysis online program that was accessible by my dissertation advisor and me.

**Interview and member-check data.** I planned to conduct an interview and a follow-up member-check with participants who consented to interviews. All interviews took place at times and places agreed upon by the participants. I asked grand-tour type interview questions that are available in an appendix to this dissertation. Of the 20 participants who gave the first interview, 11 accepted the invitation for clarification and member-check. Of those who accepted, seven agreed to an in-person member-check and four agreed to e-mailed member-checks. One participant did not respond to the e-mailed member check. Shortly after each primary interview, I wrote up field notes for it, and fully transcribed the interview. For five of the in-person member-checks, I wrote up abbreviated transcripts that included only new information relevant to the data analysis.

At the time of each interview, I provided participants with an IRB-approved demographic form to fill out, which included the option to choose a pseudonym to protect their privacy. I went over the consent form as I described in the section on consent above, collected the demographic form, and handed each participant my card to contact me with questions and concerns.

I audio-recorded each interview using a hand-held, digital recorder. I reminded participants that they did not have to answer any question, that they could request that I stop recording any part of the interview, and that they could stop the interview or leave the study at any time with no consequences to themselves. I kept track of the time so that the participant did not experience any inconvenience.

As soon after each interview as possible, I wrote up my field notes about the interview, and included any thoughts or questions I had that could contribute to further analysis. I transcribed the digital recording as soon as possible after the interview. I stored the field notes and interview transcripts in numbered files electronically.

**Researcher Journal.** I kept a researcher journal over the period of data collection and analysis in order to assist my thinking about aspects of the research (Emerson, Fretz, & Shaw, 2011; Glesne, 2011). First, I used the researcher journal to maintain a record of what I did during that period. I maintained my calendar there, and uploaded spreadsheets related to participant contacts, appointments, and requests. In another section, I recorded my thoughts about the process. I wrote about what I thought was happening in the field, questions to consider, and ideas to come back to during coding and data interpretation. Lastly, I kept track of decisions that I was making as I applied the methodology and methods during the study. In this part, I included much of what I learned about method in my doctoral group and presentations I made that helped me clarify my methodological decisions. Although I sometimes took notes for the researcher journal on my iPad, I maintained it all on a protected part of my laptop computer. I also updated a copy of it that I kept on a password-protected thumb drive.

### **Data Management and Analysis**



For a research project of this magnitude, it was important to have a plan for managing the many forms of data throughout their collection and analysis (Miles, Huberman & Saldaña, 2014). Most of the data I managed during the course of this investigation was electronic in form. That included all the data generated by me: field notes, researcher memos, researcher journal, and interview transcripts. However, some forms required by the IRB or generated by the participants were in hard-copy form. They included consent documents, demographic forms, and certain archival data and artifacts. My data management plan included ways to secure and use both forms of data.

Qualitative data analysis differs from the methods typical for quantitative data analysis and depends on the particular methodologies and methods the researcher uses (Corbin & Strauss, 2008; Maxwell, *A realist approach for qualitative research*, 2012; Merriam, 2009). However, Miles et al. (2014) outlined some common analytic strategies that qualitative researchers use across methods. They included coding; identification of patterns and themes in codes; isolating such patterns and processes as a focus for future data collection; the use of jottings, journals and analytic memos; elaboration of assertions and propositions that reflect consistencies in the data; and comparison of generalized propositions to develop theory. These authors suggested that qualitative researchers begin data analysis as soon as they begin gathering data in order to follow up on data clues about what might be going on in the research context. This advice is commonly shared by most experienced qualitative researchers (Miles et al., 2014; see also Glesne, 2011; Merriam, 2009).

I began data analysis as I collected the data, which means that data management, and analysis continued throughout my dissertation research. This recursive use of the data made data management all the more necessary to my work.

**Data management.** As I described above, most of my data was in the form of various documents, and most of it was electronic, although some was not. Although I put most of the hard-copy data into digital form, some remained in paper form to satisfy the requirements of the IRB for maintaining records. Therefore, my management plan included ways to secure and appropriately use both forms of data.

**Hard copy data.** Hard copy records and data included signed consent forms, demographic forms, research project descriptions and any other form that I handed to participants as hard copies. I also collected information sheets, meeting agendas, flyers and other artifacts of stakeholder work regarding ASD policy in New Mexico. Although I digitized most of the forms, I kept any hard copies in my files.

I filed hard copy data in numbered files sequenced by the date received, in a series starting at 3000. I kept a hard copy and an electronic-copy of a file-catalogue with the file number, a numbered link to the source, and the collection date for ease of filing and access. I maintained the catalogue and the files in a locked, fireproof file cabinet at my office in Sandia Park, New Mexico.

**Electronic data.** I collected, managed, analyzed and maintained most of the data in electronic form. I used an iPad to write field notes and field observation memos. I used a hand-held digital audio recorder for interviews. I wrote my researcher journal and some first-order analytic memos on my laptop computer. I uploaded some of this data to the

Dedoose on-line program for qualitative data analysis and sometimes downloaded, linked, and organized higher-order memos and notes back to my computer.

I transferred all electronically collected data (field notes, field observation memos, transcripts, researcher journal, etc.) to a series of external thumb drives through my laptop computer. I stored these data in numbered files sequenced by the date received, in a series starting at 4000. I kept a hard copy and an electronic-copy of a file-catalogue with the file number, numeric link to source, and the date for ease of filing and later access. I kept copies of all electronic data files on a series of other external drives, stored in locked, fireproof file cabinets at my office in Sandia Park, New Mexico and at my home in Catron County, New Mexico. I used the thumb drives to bring the data I was analyzing onto my computer for that work. I encrypted all data I put on thumb drives and secured them with complex passwords. I did not use public computers for data management or analysis.

I developed a special procedure for the voice recordings I made of interviews and some of the follow-up member checks. I used a Sony digital recorder during these interviews. As soon as possible following the interview, I transferred the digital voice data from the digital recorder to Sony Sound Organizer™, a program compatible with the voice data that I placed at a secure location on my laptop computer. Once I had transferred the sound files to the computer, I erased the original voice recording from the recording device. I also copied the sound files to a password-protected thumb drive that I kept in a locked file drawer in my office. I then transcribed the interviews using Sound Organizer. When I completed and secured drafts of Chapters 4 and 5 of this dissertation, I erased the voice recordings from Sound Organizer and then from the thumb drives. I

moved each voice file to the trash basket of my computer. Then I immediately emptied the trash. I did this for each file, so that no voice file remained on my computer.

**Data analysis.** Maxwell (2012) argued that data and evidence are not the same thing, although data may well become evidence. He defined evidence as information used to ascertain the truth-value of a proposition. He wrote that facts become evidence only in relationship to the researcher's questions, making evidence context-dependent and inextricably linked to the claims it supports<sup>4</sup>. Maxwell continued that qualitative research centers on process and events, and its primary purpose is to find out what is going on in particular contexts. He asserted that researchers use qualitative evidence to support claims about meaning, intention, belief, and perspective as understood by their participants. Therefore, he concluded that data analysis is about turning qualitative data into evidence about the researcher's questions (Maxwell, 2012). Merriam (2011) simply called it "making sense out of the data," (p. 175).

Qualitative researchers analyze data through the lens their guiding theory (Glesne, 2011). As I discussed at length in Chapter 2, I see the world through the eye of Critical Theory, which is concerned with how power operates in social systems and networks (Hosking, 2004). Stripped of its political connotations, power is simply the ability to act or to do, to make or to accomplish desired outcomes individually and/or together with others (Barnes & Noble, 2003). As I noted in Chapter 2, public policy is the process by which a polity, body, or agency uses power to achieve the goals of constituent groups (see Gallagher, 2006). Therefore, power is a part of the public policymaking process by definition. Through my use of Critical Theory, I looked specifically for the footprints of

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<sup>4</sup> Here Maxwell draws heavily upon the work of the philosopher Peter Achinstein about evidence: Achinstein, P. (2001). *The Book of evidence*. Oxford, England. Oxford University Press.

power in my analysis of ASD policymaking in New Mexico. Because my theoretical framework for this study was CDT, I looked for how various stakeholders used power in ASD public policymaking, and how that policy constructs ASD as a disability in the social context of New Mexico.

*Coding.* Qualitative researchers often use the word “coding” to denote data analysis (Merriam, 2009). Codes are labels that are attached to pieces or ‘chunks’ of data that invite reflection on its meaning and provide connection with other such chunks, so that the data is condensed into meaningful, usable units (Corbin & Strauss, 2008; Miles et al., 2014). In their discussion of the grounded theory method, Corbin and Strauss (2008) wrote, “analysis involves what is commonly termed **coding**, taking raw data and raising it to a conceptual level” (p. 66, emphasis in original). They stated further that coding requires researcher interaction with the data in order to develop conceptualizations of it (Corbin & Strauss, 2008).

Miles et al. (2014) provided a schematic that divides coding into two major stages: ‘First Cycle codes’ are the labels placed on raw data chunks, and ‘Second Cycle coding’ involves the discernment of relationships and higher-level meanings among the First Cycle codes themselves. Merriam (2009) constructed an overview of how coding spirals recursively from raw data to greater levels of abstraction. She wrote that the logic of data analysis moves from discovery through a process of discovering and verifying, to a phase of testing and confirming. Data analysis is at first completely inductive, but becomes both inductive and deductive, and ends with primarily deductive thinking (see Merriam, p. 184). This process is recursive because the researcher probes the data repeatedly, using different analytical thought processes to move from description to

stepped levels of conceptualization and evaluation, and ends at synthesis and/or theory development (Corbin & Strauss, 2008; Glesne, 2011; Maxwell, 2013; Merriam, 2009; Willig, 2008).

I began coding with my first field notes and field observation memos so that data analysis was ongoing throughout the data collection period. I coded excerpts from interview transcripts, observations, archival data, and field notes. My first cycle codes were handles, as Miles et al. (2014) suggested, and I tried to find similarities in the data. I developed a large set of categories under which I placed data excerpts. At that point, I began to see patterns among the excerpts, and as I went back and forth between the categories and the excerpts, I began to see meaningful relationships emerge among the codes that pointed to theory (Glesne, 2011). From these, I developed broad themes that tied codes together and related them to theory. Then I studied the primary codes, and by broadening them, merging them, and nesting them, I saw significant ideas related to my questions emerge from the data. Merriam (2011) defined themes as relationships among the chunks of data that are responsive to the research questions. She continued that this involves a sorting process based on what the researcher wants to learn from the data. I applied my theory to the patterns, and named my themes for critical ideas that expressed them. Going back and forth from the first themes I developed to excerpts, I identified more themes and populated them with the primary and secondary codes. I used analytical memos to relate chunks of data, codes, and themes in order to describe the findings. I developed a nested code tree for the themes and their related child and grandchild codes. I was then able to visualize the relationships among the themes and to capture how the

patterns worked together to create a model of what is going on in ASD policymaking in New Mexico.

*Evidence, validity and evaluation.* Qualitative researchers understand the phenomena they study through contextual data represented verbally and visually rather than numerically through measurements (Bogdan & Biklin, 2007). Researchers cannot judge the value of such work using numbers and statistics (Mayan, 2009; Willig, 2008). Instead of using truth tests, goodness-of-fit statistics and p-values, qualitative researchers often talk about verification of findings and conclusions as an approach to rigor (Mayan, 2009). Rigor, as defined qualitatively, begs the question: What kind of knowledge can we expect from different methodologies (Willig, 2008)? The diverse ontologies and epistemologies that inform qualitative methodologies make it difficult to develop one set of criteria for assessing the quality of qualitative studies (Corbin & Strauss, 2008; Maxwell, 2013; Mayan, 2009; Willig, 2008).

Willig (2008) argued for two different systems of evaluation, one for critical realist and contextual constructivist methodologies, and another for radical constructivist methodologies. She suggested that researchers should judge realist and contextual constructivist studies according to external criteria (objectivity and reliability), and that they should recognize that ‘objectivity’ in this context is the assumption that meanings have not been imposed from outside the data. (Willig, 2008).

Maxwell (2012) pointed out that although the advocates of subjective methodologies reject the concept of validity, it is ironic that they are in agreement with positivist approaches to quality, trustworthiness and validity. He asserted that both positivist/quantitative and constructivist/qualitative researchers tend to judge validity

only by methods used, such as triangulation of data, member checks and peer agreement in coding. However, he argued that procedural checks could guarantee neither good data nor accurate conclusions, because validity pertains not to methods, but to findings and conclusions. Maxwell related findings and conclusions to the research questions and purposes. For this reason, he defended a realist approach that “sees the validity of an account as inherent, not in the procedures used to produce and validate it, but in its relationship to those things that it is intended to be an account of” (p. 130). Maxwell stated that although there is no checklist of procedures available, researchers should ask themselves if the conclusions follow from the data, and should discuss arguments for and against particular conclusions. Asking this question and being clear about the answer assures the reader that the conclusions of the study are credible (Maxwell, 2012).

In order to assemble the most complete data set I could, I triangulated it by using different types of evidence. As described above, I collected four kinds of data, and I kept a researcher journal in which I described their internal connections. In order to attain Willig’s (2008) measure of internal objectivity, I also used member-checks throughout early analysis. A member-check is a way of validating my preliminary interpretations by asking the participant(s) involved to look them over and give feedback about them (Yen & Mao, 2011). I got responses to member checks from 10 participants, and although they generally agreed with the analysis, they made clarifications and suggestions that improved my understanding of the data. In order to begin to achieve Maxwell’s (2012) concept of validity, I frequently discussed my higher-order data analysis and conclusions with members of my ‘Doc Group’ and with my advisor. The Doc Group was composed of other doctoral students working at various levels toward their degrees, who have



various areas of expertise in qualitative research, and who all had the necessary training to protect the rights of the participants in this study. My advisor and the group provided peer debriefing and lent an outside eye and check on the data analysis. These activities aided in ensuring that the conclusions followed from the data in a credible way.

Payne and Williams (2005) stated that qualitative researchers should address the issue of generalizability. They wrote that early qualitative authors thought qualitative work was not generalizable, although it could be transferable in limited circumstances. Conversely, Payne and Williams pointed to undiscussed generalizations they found in qualitative work. For this reason, these authors suggested that moderate, inductive generalizations are often applied to social research in order to strengthen external variability. However, they also required that such generalizations must take into account more than thick, rich description on the part of the original author. Rather, the original researcher ought to consider generalizability in the research proposal and in the results (Payne & Williams, 2005). The dissertation research I report in later chapters likely has limited generalizability according to Payne and Williams' (2005) criteria. I did not plan for a generalizable study and I focused narrowly on a particular case, which is a state that has a unique history and culture even among the southwestern states. Nevertheless, moderating generalizations treated as hypotheses open to verification are possible (Payne & Williams, 2005). I have provided a good description of the unique features of this case that constrain its comparison to future research sites.

### **Ethical Considerations**

Ethical considerations about gathering data from participants in research is also an important issue for qualitative researchers. The Belmont Report (The National

Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) outlined three principles that govern researchers who obtain information from human participants:

1. Respect for persons: Researchers should treat individuals as autonomous agents, and should protect individuals who are not autonomous;
2. Beneficence: Researchers are obligated to secure the well-being of participants; and
3. Justice: Researchers should not deprive participants of demonstrably effective treatment and researchers should not involve participants from groups unlikely to benefit from future applications of it. (National Commission for Protection of Human Subjects, Part B).

Institutional Review Boards (IRB) associated with universities, hospitals and other agencies where researchers engage in medical and social research generally oversee policy and procedural guidelines for human participation in research, and provide training and guidance to researchers (Maxwell, 2013; Merriam, 2009).

Miles et al. (2014) identified a number of ethical considerations that are important to qualitative researchers who obtain data from human participants, including issues of informed consent; cost, benefits, and reciprocity; risk of harm; honesty and trust; and privacy, confidentiality and anonymity. I discussed how I obtained informed consent in the research design section above. Here I will discuss the issue of honesty and trust, as well as how I protected the privacy, confidentiality, and anonymity of my participants. I will also discuss the risks and benefits they may have experienced from their participation in this research.

**Honesty and trust.** In some types of research involving vulnerable participants, deception is part of the research design (Glesne, 2011; Yen & Mao, 2011). This type of research requires a higher level of scrutiny by both the researcher and the IRB (Yen & Mao, 2011). However, my research questions involve how people approach their work in policymaking, and this does not require a protocol of deception. At the same time, as Miles et al. (2014) pointed out, when researchers probe for the meaning behind the words in an interaction or interview, a certain kind of “symbolic violence” (p. 62) is done, and this affects the outcomes of the encounter. I followed their advice that ‘honesty is the best policy,’ and when ethical dilemmas arose, I sought out the counsel of my advisor and/or the Doc Group, in order to minimize harm to my participants. In several cases, I consulted my advisor or the Doc Group, and in one case, I consulted the institutional review board to protect participants.

**Privacy and anonymity.** Privacy means that individuals have the right to control who has access to information about themselves and to limit the giving and receiving of sensitive or unwanted information (Miles et al., 2014). Miles et al. (2014) defined anonymity as the lack of any identifiers that link persons or organizations to specific data. To protect the privacy and anonymity of my participants, I gave all participants the opportunity to provide a pseudonym for interviews. About one-fourth of the participants chose this option. Those who did not use a pseudonym initialed a box on the consent form stating that they were specifically consenting to use their real names. I required that self-advocates already known as such in the autism community initial a box on the consent form specifically for that purpose. In a case in which several people shared the

same first name, one of them wished to use a pseudonym. With the permission of the others, I used a different name for each person.

I was the only person with access to the link between the anonymous individuals' identity and their data. I stored this link on a password protected thumb drive that I kept in a locked file drawer separate from their data. I destroyed these links by erasing the thumb drive after completing data analysis. I did so by deleting each link on the thumb drive after placing it in the trash on my computer. I then emptied the trash after I deleted each link.

I also limited private information discussed by limiting my interview questions to those needed to answer my research questions. However, because I used grand tour questions, I also stopped audio recording when a participant discussed off-topic information or shared private information that was not germane to the research. I did not transcribe any such information that escaped my notice in the interview. To protect the privacy of my participants further, I transferred all recordings to an encrypted, password protected file on a thumb drive and maintained them in a locked, fireproof file cabinet in my locked office in Sandia Park. I erased all interview recordings from my digital recorder immediately after the transfer and before I interview anyone else. I destroyed all recording files after completed data analysis, and maintained only the transcripts.

I collected all of the participant observations during four public meetings, at which participants had no expectations of privacy or anonymity. Two of these public sessions were podcasted on the internet in real time. Nevertheless, I confined my field notes and observation memos to those details that were relevant to my research.

**Confidentiality.** Confidentiality means that researchers must let their participants know how their personal data is handled, who has access to it, and how it will be protected (Miles et al., 2014). The IRB-approved consent form for this research contained the details of data management and destruction. I provided all interview participants with the opportunity to choose a pseudonym, and I was the only one with access to a link between the pseudonym and an individual's actual identity and protected that information as described above. I conducted all interviews in places chosen by participants, and they were either private or public. When a participant chose a public place, I chose a location within that minimized noise and traffic wherever possible. I did this in order to enhance the quality of recording and to protect the confidentiality of the participant. It is possible that individuals were recognized talking to me at locations they chose. If I was concerned about that, I asked about their comfort with the location before proceeding with the interview.

As I stated above, the participant observations were all in venues where the individuals involved had no expectation of confidentiality. Nevertheless, I protected the data (field notes, memos, researcher journal) in the same way I protected interview data and handled it as described in the data management section above.

I got a portion of the data from document reviews. Because my interest is in public policy, most of these documents were published notes and minutes, letters and reports. The authors and subjects of such documents had no expectation of confidentiality. However, I managed all such data in the same way that I described in the data management section above.

Finally, I uploaded the data to the Dedoose Website for management and analysis during my study. The company uses state-of-the-art encryption, including a patent-pending encryption system that allowed me to encrypt each project separately (Dedoose, 2015). Although the encrypted data was stored in the cloud and backed up nightly, the program allowed one individual to control access to the data and determine what others may see (Dedoose, 2015). I was that person, and I shared limited data only with my doctoral advisor and with members of the Doc Group. I did not share the actual identities of those participants who chose to use a pseudonym. All of those who saw limited data were part of the IRB-approved team members for this dissertation project and I submitted their training certifications to the IRB.

**Data storage and deletion.** I discussed data storage at length in the data management section above. I made every effort to ensure data security as outlined there. As stated previously, I deleted all interview recordings from the digital recorder as soon as possible after transferring the data files to a secured and encrypted thumb drive. I destroyed all interview recordings when I completed data analysis. I destroyed the lists that linked the identities of my data sources to their pseudonyms after I completed Chapters 4 and 5 of this dissertation. I will maintain only non-linked researcher notes, memos and the researcher journal in a secure location following the publication of the dissertation.

**Risks to participants.** The autism community in New Mexico is small and close. Everyone seems to know almost every other member. It would not be difficult for other researchers or involved members of the community to discern who was involved in this research and what they said. This was complicated by the fact that many participants

chose not to use a pseudonym. The participants in this study undertook a risk of loss of privacy and anonymity. However, the IRB granted this study an exempt status because all of the participants were adults capable of understanding these risks. Furthermore, the positive nature of my questions minimized such risks to the participants. I was diligent in protecting participants during interviews, and when I had concerns, I consulted with the proper authorities and took the recommended actions. I also protected the resulting data as I described in detail in the data management section above. For all of these reasons, I believe that risks to the informants were minimal and that they remain unlikely to suffer physical, emotional, or financial harm resulting from their participation in this study.

**Benefits and reciprocity.** Many of the participants were eager to participate in this study. Some called or e-mailed to ask to be included. They talked to me about the importance of participation. Some said that discussing their goals, work, and experience helped them understand the vital nature of their work. Some recognized that their participation helped them understand ASD and policymaking in new ways. Others said that they were concerned about the future of ASD policy in New Mexico and wanted to describe their hopes and dreams for it. Every participant wanted to contribute their unique knowledge in order to highlight the importance of policymaking to people labeled with ASD in New Mexico. They experienced immaterial benefits to themselves and saw them as benefits to the cause to which they had already devoted substantial monetary and opportunity costs.

Although I did not pay my interview participants for their time, I offered them a \$5 gift card to a local coffee shop as a token of my appreciation for their efforts on my behalf. More than half of the participants refused the offer for various reasons. I will also

make my results and conclusions available to them after publication of this dissertation if they request it. Although I am responsible for the results and conclusions here, this study's social value is really due to all those who contributed their experiences as participants. All of them shared their thoughts and their hearts for the purposes of this work.



## Chapter 4

### Findings

My purpose for this study was to critically examine the decision-making process of key stakeholders in New Mexico in the development of disability policy around ASD in light of their knowledge, assumptions, and values. In this study, I addressed the following question, with four sub-questions:

How is ASD policy in New Mexico constructed?

1. Who are the key decision makers for ASD policy in New Mexico?
2. What information do they use to inform their decision-making process?
3. What are their assumptions and values about disability, and about ASD in particular, and how do these operate in their decision-making?
4. To what extent does ASD policy take into account current perspectives in the neurobiology and neuropsychology of ASD?

In this chapter, I will present my research findings, which I organized into themes (parent codes) and sub-themes (child, grandchild and great-grandchild codes).

Before I present my findings, I will describe the context in which I conducted the research. First, I will address the present financial condition of the State of New Mexico, so that the socio-economic situation within which the participants move and work provides background for the data that I collected. Readers can find an overview of the State of New Mexico, its origins, people, and forms of government in Chapter 3. Here, I will begin by describing the fiscal state of the State of New Mexico, because it was present throughout the research process and continues to overshadow the policymakers and their work. I will also describe relevant court cases, legal issues and regulations that

fill in context. I will then describe the autism community in New Mexico and its institutions. I will end the context section by describing the research and the participants.

### **The State of the State: New Mexico's Ongoing Fiscal Condition**

A variety of measures demonstrates that New Mexico is currently one of the most economically depressed states in the U.S. (U.S. Census Bureau, 2017). The origins of New Mexico's fiscal troubles go back to the circumstances of New Mexico's fight for statehood (Holtby, 2012; Wiegler, Levine, & Stiver, 2015). However, New Mexico's budgetary problems are most likely due to its current fiscal policies and its unique tax structure, as well as demographic problems common to most of the developed world (Mitchell & Stansel, 2016). A complete causal description of the state's current fiscal woes is beyond the scope of this dissertation. However, there is general agreement that federal ownership of nearly half of New Mexico's lands (The Impact of Federal Regulations in Western U.S., 2012), the state's heavy dependence on oil and gas taxes for revenue (Peach, Delgado, & Starbuck, 2009), and the pyramidal nature of the gross receipts tax (Clifford, 2010), all contribute to New Mexico's current fiscal troubles (Coleman, 2017).

According to the U.S. Census Bureau (2017) estimates, 20.4% of New Mexico's residents lived in poverty in 2016. The New Mexico Department of Health (2017) estimated that 27.2% of New Mexico children lived under the poverty level in 2016 as well. New Mexico ranked as the third worst state for child poverty in 2016, just above Louisiana and Mississippi (New Mexico Department of Health, 2017). New Mexico residents' poverty puts them at risk for a number of serious health and education outcomes that contribute to generational poverty (New Mexico Department of Health,

2017). Almost every informant to this dissertation expressed concern about the impact of New Mexico's current fiscal situation given the generational poverty that affects many of the state's families and children.

During LEND seminars and in individual interviews, members of the ASD community and participants to this study expressed particular concern about Centennial Care, New Mexico's name for the federal Affordable Care Act (ACA) Medicaid expansion (see also Cahill, 2016). Traditional Medicaid is a joint federal/state program that has financed healthcare for the poor (elders, pregnant women, and children) in the several states and provided for people with disabilities (Kiewiet & McCubbins, 2014). In New Mexico, the Medicaid program has paid for a menu of services needed by individuals with disabilities with medical diagnoses (Cahill, 2016). In a 2016 presentation to New Mexico LEND, Cahill pointed out that regular Medicaid covers 30% of the costs of the traditional Medicaid services for enrollees in New Mexico and the federal government provides the remaining 70% of the coverage. In 2012, Governor Martinez chose to implement the ACA Medicaid expansion that provides medical coverage to adults up to 138% of poverty and children up to 240% of poverty (Health Insurance dot org, LLC, 2017). The federal government paid 100% of the costs for the expanded enrollees for the first two years (2014-2016), and the state is required to pick up 5% of the cost in 2017, 6% in 2018, 7% in 2019, and 10% in 2020 and beyond (Cahill, 2016). However, the state government estimated that about 80,000 people would enroll in Centennial Care, whereas the actual number in 2016 was 240,000 and is expected to rise in 2017 and beyond (Cahill, 2016). This translates to a total cost estimate of 5.5 billion dollars on the Medicaid expansion in 2017, of which the State of New Mexico will pay

between 85 and 90 million and cover 48% of New Mexicans (Cahill, 2016; Gessing, 2016). These new costs are increasing New Mexico's budget deficit and may also translate to lower payments toward the care of existing Medicaid recipients, including those with disability/ASD (Gessing, 2017), and reduce their access to timely care (Cahill, 2016).

The poorly predicted cost of the Medicaid Expansion in New Mexico contributes to an increasing deficit (Baldwin, 2015) that is already impacted by aging populations, public employee pension obligations, and the state government's taxation and revenue policies (Baldwin, 2012; Kiewiet & McCubbins, 2014; Mitchell & Stansel, 2016). In conditions like these, a state government's attempt to avoid bankruptcy by raising taxes and cutting services usually drives small businesses and private industry out of state (Mitchell & Stansel, 2016). The loss of these businesses triggers the migration of the working population who build them, staff them, and pay taxes (Baldwin, 2015; Kiewiet & McCubbins, 2014). Because younger workers looking for opportunities are often the first to leave, this increases the demographic shift to an aging population who pay fewer or no taxes, which in turn causes an exponentially increasing deficit (Baldwin, 2012; Mitchell & Stansel, 2016). New Mexico is currently experiencing the emigration of New Mexico- educated entrepreneurs and business owners, experienced workers, and their children (Coleman, 2017; Marks, 2017). As both Coleman (2017) and Marks (2017) pointed out, this means New Mexico is losing its investment in the educations of the emigrants, and also the expected revenues from business and personal taxes they would have paid.

The sense of fiscal crisis expressed by the informants is an important part of the context of this dissertation. The very real prospect of state insolvency makes it difficult for them to imagine future growth and improvement in ASD policy and programs in New Mexico. Over the 10 months of data collection, I heard participants talk about how much harder it became to advocate for increased public financing to meet the needs of New Mexicans with ASD. This context of fiscal uncertainty framed the responses of the study participants, and provided for some unexpectedly creative solutions.

### **The Autism Community and its Institutions**

I conducted this study primarily within the “autism community” in New Mexico. The autism community is the term that most people who live with, work with, or advocate for ASD readily use and recognize. I defined the autism community for the purposes of this description as the networks of people involved with ASD in New Mexico, who operate within and use its institutions in order to govern, advocate for, or provide/benefit from its services. I defined New Mexico as the bounded system within which I conducted this research. However, for the most part, the individuals who participated in the study identified themselves as New Mexicans who are part of the autism community.

The autism community in New Mexico is statewide, because even people in the sparsely populated rural and frontier<sup>5</sup> counties of New Mexico encounter it and participate inside of it. However, the community appears to be concentrated in the towns and cities of the Rio Grande Valley, where half of the population of New Mexico resides

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<sup>5</sup> The term “frontier county” is a designation of the US Department of Health. It indicates a county that has small population-to-area ratios, few or no hospitals, clinics, and pharmacies, and primitive infrastructure.

(U.S. Census Bureau, 2017). Albuquerque, which is the state's largest city, is the center of the autism community. That is where most of the institutions that provide research, services, and support are located. However, there are also satellite groups and organizations in Taos, Santa Fe, Las Cruces, and Farmington.

**Institutions.** Here, I will describe the governmental institutions and Non-Governmental Organizations (NGOs) and their respective missions. Individual members of the autism community are often associated with many of these organizations at the same time, and over time, they move in, within, and out of the government of the different institutions as their respective interests grow and develop.

I connected directly with seven different institutions that are part of the autism community or that intersect it, in order to develop background information, recruit participants, and/or make observations. They included:

- The ARC of New Mexico (The ARC NM). The ARC of New Mexico is an affiliate of the national ARC, which describes its mission as advocacy and service for individuals with ID and/or DD, and their families. Autism NOW is a research and information center within the ARC for the use of people with ASD, their families, and key stakeholders who work in advocacy and research. A national board of directors guides Autism NOW and its state affiliates. The ARC of New Mexico employs a policy director who is responsible for all the duties associated with writing, advocating for and passing legislation to benefit New Mexicans with ASD, DD, and/or ID and their families.
- The Center for Development and Disability (CDD). Affiliated with the University of New Mexico and University Hospitals, the CDD is a federally designated

“University Center of Excellence in Developmental Disabilities Education, Research and Service” (Center for Development and Disability, n.d.) authorized through the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act, PL 106-402). The CDD is also a member of the Association of University Centers on Disability Education, Research, and Service (AUCD) and works in partnership with 14 other national and state institutions and organizations. The CDD houses the Autism Programs, through which faculty and staff conduct research, provide professional training, provide diagnostic services to children, and provide information services about ASD and other disabilities throughout the state. It also houses New Mexico LEND, which is a nationally recognized leadership development and training for graduate level students in disciplines related to neurodevelopmental disabilities. The CDD also sponsors New Mexico Partners in Policymaking, an internationally recognized training designed “to teach parents and self-advocates the power of advocacy to change the way people with disabilities are supported, viewed, taught, live and work” (The ARC of New Mexico , 2012).

- The Developmental Disabilities Planning Council (DDPC). The DDPC is a state council mandated by the federal DD Act (PL 106-402). The mission of the DDPC is to “engage in advocacy, capacity building and systemic change activities that are consistent with the purpose of the DD Act” (New Mexico DDPC, 2017). Council members are appointed by the governor, and the council must consist of 60% self-advocates and family members. The DDPC houses three programs: the Federal Program, in which the council develops and tracks detailed 5-year plans

related to its mission; the Center for Self-Advocacy, which provides self-advocacy training and opportunities for individuals with DD; and the Guardianship Program, which provides publicly-funded guardians-of-last-resort for individuals with DD when there are no less restrictive options for the individual.

- **Disability Rights New Mexico (DRNM):** DRNM is a non-governmental, non-profit organization that manages federally mandated programs as well as other advocacy for the rights of individuals with disability in New Mexico. On its website, DRNM states its mission as “to protect, promote and expand the legal and civil rights of persons with disabilities” (Disability Rights New Mexico, 2014). DRNM operates the following programs: information and referral related to services and civil rights; individual case advocacy; advocacy designed to improve services, systems, and to promote the rights of individuals with disabilities; and training services to effect change in the area of rights for individuals with disabilities.
- **The New Mexico Autism Society.** NMAS is a non-governmental, non-profit organization affiliated with the Autism Society of America (Autism Society, 2016). Local and state autism societies share the mission of the national organization, which is to increase awareness, advocate for services, provide information, and raise funds for ASD research. The Executive Director of NMAS, Sarah Baca, advocates for legislation at the state and national levels.
- **The New Mexico State Legislature.** Some members of the legislature ran for office specifically to advocate for the legal and program needs of individuals with



ASD and other DD, or more broadly, for people with disabilities (E. Thomson, personal communication, January 9, 2015). Certain members work with policy makers and advocates from the ARC, the CDD, the DDPC, Disability Rights New Mexico, NMAS, and the New Mexico university system, to write, advocate for and pass legislation related to ASD and DD. These individuals make up an informal but well-known ASD/DD caucus at the legislature (C. Hardin, personal communication, August 4, 2016).

- The University of New Mexico Department of Special Education (UNM Special Ed). The department website states its mission as “Teaching, research, service” with the goal to “prepare educators, leaders, and policy-makers who strive to assist individuals with exceptionalities and their families create personally satisfying lives across a variety of school and community settings” (The UNM College of Education, n.d.). The UNM Department of Special Education has majors, concentrations and certificate programs related to ASD and DD, including certificate programs in ABA and in ASD.

Table 1

*Autism Community Institutions’ Participation in this Study*

Institution	Type	Mandate	Participation Types
The ARC NM	NGO	Non-profit	Interviews/Technical Info.
CDD	University	DD Act	Interviews/Technical Info.
DDPC	State	DD Act	Interviews/Observations/ Technical Info.
DRNM	NGO/ State	Private/ADA	Technical Info.
NMAS	NGO	Non-profit	Interviews/Technical Info.
NM Legislature	State	NM Constitution	Interviews/ Observations/ Technical Info.
UNM Special Ed	University	State	Interviews/Technical Info.

These institutions and individual members of the autism community can and do interact with other local, state, regional, national, and international governmental agencies, NGOs, non-profits, and activist organizations. However, the seven institutions listed above are the most central or most immediately associated with ASD in New Mexico and its government.

### **New Mexico Disability Waivers**

An important part of federal/state financed Medicaid disability services are the different disability waivers that states purchase on behalf of citizens who have need of them (NM-LEND, course notes, October 2015). The federal government administers these waivers through the Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), and the purchasing states manage them through various departments (CMS, n.d.; New Mexico Human Services Department, n.d.).

Through waivers, states can get federal financing for members of special populations who would not otherwise qualify for Medicaid services (CMS, n.d.).

Although some states have purchased Medicaid autism waivers, New Mexico has not yet done so. Members of the state legislature's Disability Concerns Interim Subcommittee discussed the option during meetings in 2016 (DCS Subcommittee Minutes, 2016).

However, individuals with ASD can obtain waiver services under the traditional DD Waiver (New Mexico Human Services Department, n.d.) or under the newer self-directed Home and Community Based Services Waiver, called Mi Via, developed by the Centers for Medicare and Medicaid Services (CMS) for New Mexico in 1999 (New Mexico Department of Health, 2017). The traditional DD Waiver is managed by the New Mexico Department of Health's Developmental Disabilities Services Division (DDSD), whereas

Mi Via is administrated through a partnership between the New Mexico Department of Health and the state's Human Services Department (New Mexico Department of Health, n.d.). Furthermore, the DD waiver covers only individuals labeled with ID/DD, whereas Mi Via covers those with either ID/DD or Medically Fragile labels. Individuals who wish to qualify for either waiver must register with the New Mexico Department of Health's Intake and Eligibility Division (New Mexico Department of Health, n.d.), and those who want to switch from one waiver to another must apply to do so, although they do not have to requalify for waiver services (New Mexico Human Services Department, n.d.).

Lastly, states share the funding burden for Medicaid waivers with the federal government, and therefore have the right to limit the number of people receiving waiver services at any given time (CMS, n.d.), and can apply means testing so that individuals may clinically qualify for a waiver, but may not qualify financially (Medicaid Waiver.Org, n.d.). Using data from the New Mexico Department of Health, the Medical Waiver.Org website estimated that there are about 3,500 people being served through New Mexico's disability waivers, there are another 6,300 people currently on the wait list, and the wait time for waiver services is at least 10 years from application. The state legislature has allocated funds from the state general fund to assist those who either do not qualify or who are on the wait list for services (Medicaid Waiver.Org, n.d.; New Mexico Department of Health, n.d.).

Members of the autism community and its institutions share concerns with the larger disability advocacy community about the ability of the state to transition to unsegregated home and community based services and supports as required by CMS (CMS, n.d.). Advocates have brought two lawsuits related to the DD waiver to federal

district court in New Mexico on behalf of their relatives labeled with DD that have marked a change in how the state governs DD/ASD (J. Jackson, DRNM, personal communication, November 7, 2016). Some DD/ASD advocates are also concerned about the CMS Final Rule, which requires a sea change in policy for individuals and organizations that receive money through the Medicaid disability waivers and services (CMS, n.d.).

**Jackson v. Fort Stanton.** The families and friends of 21 individuals labeled with DD who resided at Fort Stanton Hospital and Training School and Los Lunas Hospital and Training School filed suit in United States District Court in New Mexico in April 1987 (*Jackson v. Fort Stanton*, 1990). The defendants included the Los Lunas and Fort Stanton training schools, the New Mexico Health and Environment Department, the New Mexico Department of Human Services, the New Mexico Department of Education, and the New Mexico State Board of Education, all represented by named administrators, secretaries and board chairs (*Jackson v. Fort Stanton*, 1990). U.S. District Court Judge Parker wrote in the 1990 decision that:

This litigation centers on the area of developing law concerning the rights of the developmentally disabled. It also concerns the constitutional powers of and constraints on federal courts that are asked to grant relief when political branches of state government are perceived as moving too slowly to improve the welfare of the developmentally disabled. (p. 12)

In May of 1989, Judge Parker defined the Jackson Class as follows: 1) all residents of the two institutions at the time of filing, 2) all new residents placed through the duration of the lawsuit, and 3) all residents transferred to other care facilities at the

expense of the state during the proceedings (*Jackson v. Fort Stanton*, 1990). In December 1990, the court ruled that the defendants had violated the civil rights of people with severe disabilities “by unnecessarily segregating them and by subjecting them to institutional conditions which were unconstitutional in eighteen discrete areas” (Rucker, 2017). Rucker also wrote that although the parties attempted to cooperate on the remediation of those conditions, the state has been unable to accomplish that goal. Rucker concluded that although there have been other motions in 1997 and 2004, there remain “a series of systemic obstacles” and “structural problems that fundamentally impede the service system” (p. 2) so that the Jackson Class is still not receiving adequate services (Rucker, 2017). However, a Stipulated Order of Disengagement in 2016 for one of the remaining objectives indicates some progress toward the final resolution of this 30-year-old lawsuit (University of Michigan Law School, 2017).

**Waldrop v. New Mexico Human Services Department (HSD).** In January 2014, The ARC NM and DRNM, together with seven individual plaintiffs and their legal guardians, brought a suit in federal district court alleging that loss of services provoked by an overhaul of the DD waiver system criteria was a violation of their civil rights (The ARC of New Mexico, 2015). The lawsuit centered on the use of the Supports Intensity Scale assessment as the basis for a grading system to help the state reduce the per client costs of the waiver (The National Association for Homecare and Hospice, 2014). The plaintiffs argued that the grading system was arbitrary in that it treated all members of a graded group as the same, regardless of differences among them and that it lacked transparency because clients had no way to know how the grade decisions were made (DRNM, 2015; The National Association for Homecare and Hospice, 2014). In January

2015, the plaintiffs successfully obtained a preliminary injunction to stop cuts to the budgets of clients in the Supports Intensity Scale groups A and B, and an agreement that the state would hear appeals from clients assigned to all other groups based on immediate danger to their health and safety (The ARC of New Mexico, 2015). On May 29, 2015, Judge Herrera approved a settlement agreement but also maintained jurisdiction over the process until May 2017 (DRNM, 2015). By agreement, HSD is continuing the use of Supports Intensity Scale -graded groups. However, instead of a one-size-fits-all approach, a suggested range of services is now provided to the client's interdisciplinary team, which makes the final determination on budget and services (DRNM, 2015).

**The CMS final rule.** On January 16, 2014, CMS published its "Final Rule" in the Federal Register and described its intent as:

to ensure that individuals receiving long-term services and supports through home and community based service (HCBS) programs under the 1915(c), 1915(i), and 1915(k) Medicaid authorities have full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate.

And to enhance the quality of HCBS and provide protections to participants.

(CMS Disabled and Elderly Health Programs Group, n.d., p. 1)

The CMS Final Rule makes it possible for states to combine different service populations under one waiver, allows a five-year renewal so that states can innovate, and allows states to switch providers more easily (CMS Disabled and Elderly Health Programs Group, n.d.).

The area of greatest concern about the Final Rule among advocates is the Home and Community Based Settings Requirements (DCS Subcommittee Minutes, 2016). The

purpose of the settings requirement is to integrate CMS waiver and program clients more naturally into the community for all their needs: work, social life, and services (CMS Disabled and Elderly Health Programs Group, n.d.). The practical result of applying the settings requirements in the states will do away with institutions designed to cater specifically to the elderly and people labeled with disabilities such as sheltered workshops, day habilitation centers, and group homes (National Association of Councils on Developmental Disability, 2016). My observations in various national and local conferences and training sessions is that various stakeholders, interest groups, and advocates are meeting these changes with some trepidation, expressing concern about loss of services and supports.

### **Description of the Research**

I conducted this research in the State of New Mexico, in the southwestern United States. I centered the research on the New Mexico autism community and its associations with other agencies and organizations within the state. I collected the data from March 2016-April 2017. I collected three kinds of data for analysis: individual interviews, observations, and documentary evidence.

**Interviews:** I conducted 20 interviews with participants associated with the New Mexico autism community. They took place in a variety of environments in Albuquerque, Santa Fe, Rio Rancho, and Clovis. I audio recorded all of the interviews with the permission of each interview participant. I used open-ended questions to encourage the participants to talk about their experiences, and although some of them were not used to this kind of interview, they all eventually provided very individually detailed discussions of disability and ASD.

**Observations.** I completed two types of observations during the course of data collection. The first type consisted of community observations, where I took note of the structure and function of the New Mexico autism community and its moving parts. I did these observations as I interacted with the community, and documented them by picking up flyers and reading institutional webpages. I did not contact or question individuals as part of this overall community observation.

I also observed public meetings from two institutions governed by the New Mexico sunshine law. I observed two quarterly meetings of the DDPC and two interim session meetings of the New Mexico Legislature Disability Concerns sub-committee. At these meetings, I took notes and listened to the procedures and testimonies. All four of the meetings were open meetings, and I did not need to get permission to observe them.

**Documentary evidence:** I collected documentary evidence primarily from the New Mexico Legislature's website, from which I accessed bills and memorials from the 2016 52<sup>nd</sup> Legislature and the 2017 53<sup>rd</sup> legislature. I also collected information sheets and flyers from institutions that I visited in the course of this research.

### **Description of the Participants**

Twenty individuals participated in this research. Some chose to use their own names and others decided to remain anonymous. In order to use their real name or to be identified as a self-advocate, participants checked and initialed separate boxes on the IRB-approved consent form. Please see chapter 3 for a more in-depth description of the consent procedures and anonymity protections.

As I began data analysis, I realized that although all but two participants identified multiple entry points into the New Mexico autism community (e.g., self-advocate,



policymaker), each one had a preferred identification that was evident from the scope and tone of the interview itself. Therefore, I assigned each participant to a primary identification group based on my assessment of their interviews. This assigned category is useful for data analysis and may assist interested readers to keep track of the informants and excerpts. I will define and describe these groups below.

**Advocate.** Advocates primarily speak on behalf of individuals with DD/ASD. The people they advocate for may be their children, relatives, students, and/or clients. They work on policy from the perspective of their particular advocacy group. I identified four advocates: Katie, Phyllis, Sarah, and Lauriann.

**Educator.** Educators are professionals involved with the education of people who carry the ASD label. Educators may also teach general and special education teachers who directly educate individuals with ASD in the public or private schools. Educators may also, administrate, develop/promote interventions, and/or develop policy specifically related to schooling and education. I identified four educators: Alex, Blu, Lee, and Maryann.

**Policymaker:** Policymakers are volunteers or professionals involved in making, promoting, and instituting policy. They participate in politics primarily to promote specific policy. Their goal is to construct systems that create access for all individuals with ASD/disability. I identified four participants who are policymakers: Doris, Gay, Pat, and Paul.

**Politician:** Politicians are elected officials who participate in politics primarily to pass legislation conducive to their political and social agendas. They develop, promote,

haggle over, compromise, and vote on legislation to institute ASD policy as a matter of law. I identified two participants who are primarily politicians: Clint and Liz.

**Autism professional:** Autism professionals are individuals who have educational degrees and training in specific skills related to the identification, diagnosis, and treatment/intervention for ASD and related conditions. Their interest in policy relates to the promotion of specific goals for individuals or groups of people under the broad ASD umbrella. I identified two autism professionals: Chris and Sandy.

**Self-Advocate.** Self-advocates are individuals with ASD/disability who identified themselves as such. They develop and promote policy primarily to extend individual and civil rights to individuals with disabilities and to achieve access to citizenship for all. I identified four self-advocates: Cynthia, Daniel, Jesse, and Ross.

Table 2

*Number of Participants by Primary Identification Group*

Primary Association	Number
Advocate	4
Educator	4
Policymaker	4
Politician	2
Autism Professional	2
Self-Advocate	4

*Note. All identified self-advocates gave express permission to be identified as such under their real or assumed names.*

**Participant demographics.** I asked all of the participants in this research to fill out a participant demographic form at the beginning of the interview. On the form, there were options for participant's race, ethnic group, generation (by age ranges provided), how long they have lived in New Mexico, where they live and/or work within the state, and their entry points into the autism community. I encouraged respondents to check all answers that apply to them for demographic questions with a multitude of categories. All

of the participants completed the form, although some did not answer every question, or did not answer every part of the question. For example, some people responded to the question about race, but left the question about ethnic group blank and vice versa. Interestingly, everyone answered the question about gender, even though some informants requested that I assign them a gender-neutral pseudonym. I included their data in the statistics, but removed it from the Dedoose data analysis program.

**Gender.** All of the respondents indicated their gender. There were 15 female participants and five males, a ratio of three females for every male. These numbers strongly suggest that the grassroots make-up of the autism community is predominately female. There are likely a number of factors influencing this gender gap. For example, I noticed from the entry point data that many of the volunteers in the ASD community are also mothers of children with ASD. For many of those mothers their first entry point was as a parent, and that led to other entry points, in which they acted first as volunteers and then as professionals. I also noticed that in the interviews, every respondent who identified herself as a mother of a child with ASD discussed the expectations that professionals assumed to be hers as a mother, regarding the care, treatment, and educational responsibilities for her children. It is likely that societal assumptions about gender roles are still operative and may have some influence on which gender takes responsibility for the autism community in greater numbers.

**Generation.** I used Strauss and Howe's (1991; 1997) generational theory. Their theory ties generational characteristics and identities to the cycles of history, and they posit that certain generational patterns relate to the ways a society responds to events (Strauss & Howe, 1991). I identified participants' generation by asking them to indicate

an age range. All but one participant responded, giving 19 out of 20 possible data points.

I have summarized the generational data in the table below.

Table 3

*Number and Percentages of Respondents' Strauss and Howe Generation*

Generation	Birth Years	# of Participants	Participant %
Silent	1925-1942	0	0
Boomer	1943-1960	9	47.4
Gen X	1961-1981	8	42.1
Millennial	1982-2004	2	10.5

*Note.* The Strauss and Howe generation being born now (2005-?) has yet to develop an identity of its own and its members are not yet adults.

These results may indicate that individuals who are working and volunteering in the autism community are primarily Boomers and Generation X, and that the Millennial generation is just beginning to embark on careers in the ASD fields and/or have children who have been identified with ASD.

***Race.*** I used the federal government's definitions of races: White, Black/African American, Asian, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander. Two of the informants did not respond to this question, and all of the remaining 18 indicated they are White. This suggests that individuals working/volunteering in the field are predominantly White. However, the separation between race and ethnicity in the federal system means that a person who claims Hispanic ethnicity may also identify as White.

***Ethnicity.*** Again, I used the federal government's definitions of ethnicity: Hispanic, European non-Hispanic, and Other. All but two of the participants answered the ethnicity question. Of the 18 respondents, 14 reported they are European non-Hispanic, and four indicated that they are Hispanic. One participant responded as both European non-Hispanic and Other. This data may indicate that the number of European

non-Hispanic individuals engaged in ASD policy in New Mexico is out of proportion to the actual population percentages of these ethnic groups within the state (See Chapter 3, for New Mexico demographics).

*How long in New Mexico.* For this question, I provided two responses: one asking if the respondent is a New Mexico native (born here) and the other asked for how long the respondent has lived in the state if not born here. There were 19 responses to the first question; 13 said they were not born here and six claimed native New Mexican status. There were 14 responses to the question: how long have you lived in New Mexico. The highest number of years lived in New Mexico was 50 and the lowest was 2 years. The median number of years lived in New Mexico was 33.5 and the mean was 28.4. These statistics may reflect the higher average age of the respondents.

*Entry points.* All but two of the participants to this study identified multiple entry points into the ASD community. On the demographic form that they completed, participants had the choice of up to four entry points into the community. All 20 participants had at least one involvement, 17 participants had two, 13 participants had three, and five participants had four involvements. As I talked to the participants, I realized that almost all of them had multiple entries into the autism community and this agreed with the demographic data. I noticed that most of the participants have worked at different institutions and organizations over the time of their involvement. They also described attending the same workshops, conferences, and trainings sponsored by the same agencies. All of this demonstrated the tight-knit nature of the autism community. It also points to the depth of involvement and the extraordinary amount of time most of the participants have devoted to ASD advocacy and to the community itself. It is noteworthy

that the participants who have the smallest number of involvements are those who said they had been in New Mexico for a shorter period.

### Findings of the Thematic Analysis

Through a recursive process of data analysis, I identified themes present across the data set. I based the names of the themes on CDT to understand what is going on in the world of ASD policy in New Mexico. At the same time, I began to recognize patterns and repetitions across the interviews, observations, and documentary evidence I was gathering, and these I organized into a nested series of coded excerpts, most of which have labels that come directly from the data. In this fashion, I identified 1930 excerpts and I applied codes to them 4518 times. I identified six themes (parent codes) under which I organized sub-themes (child codes). Grandchild codes are only associated with three child-codes under one theme. I have summarized the organization of themes, child, and grandchild codes in Table 4 below.

Table 4  
*Summary of Themes and Codes*

Themes	Tension in Discursive Field	Dividing Practices	Reifying Autism	The Use of Force	Government of Autism	Policy Paradigm Shift
Child Codes	<i>Discourses</i> Normalizing Scientific Counter Coopted voice Dangerous, difficult & strange	Master status Othering Passport to services	Diagnosis The spectrum Difference or disability There & back again	Symbolic violence Concrete violence Power in formal process	The establishment The community The movement	The Gap Dreams of good policy Shifting the infrastructure Access to Citizenship
Government of Autism:	The Establishment		The Community		The Movement	
	At the Round House Bureaucracy rules		Mutual support Advocacy		Resistance & Rebellion Empowerment	

Grandchild Codes	Real money School matters Power of Science The civil society At the table	Concerns & Controversies	Self-advocacy
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The six themes I identified represent critical perspectives on the information that I found in the participant interviews, the observations, and the documentary evidence I gathered. I ordered the first five themes to tell a story about how people involved in ASD policy in New Mexico understand, categorize, realize, socialize and govern disability and ASD. Although I described the first five themes in terms from the literature of critical disability theory, the ideas they represent emerged from the data. The last theme, Autism Tsunami Policy Paradigm Shift is my description of the shift in thinking that people in the autism community are recognizing as necessary, and are dreaming of and planning for, as they realize that policy and politics as usual can only go so far to realize aspirations of full citizenship for all people marked with disability.

In the sections below, I describe the themes and their associated child and grandchild codes. I provide example excerpts from the interviews, observations, and documentary data to illustrate the themes and codes. I have chosen the excerpts that best represent each underlying child and grandchild code. I have linked each excerpt to the participant's primary identification, and sometimes their name/pseudonym. At other times, I simply refer the participant's primary identification, particularly for topics or statements that are controversial or sensitive for members of the autism community.

**Naming convention for hierarchical themes and codes.** For the convenience of readers, I will use the following naming convention for themes and codes throughout this

dissertation in order to facilitate recognition of the hierarchy. In the body of the text, I will always present the six major themes in upper-and-lower case italics. For example, *Tension in the Discursive Field*. I will label child and grandchild codes as such, and present them in the text in upper-and-lower case plain type inside single quotation marks. For example, child code ‘Normalizing Discourses,’ and grandchild code ‘At the Roundhouse.’

### **Tension in the Discursive Field: Who’s Will to Truth**

This theme emerged from the ways that the participants talked about disability and ASD. They answered questions about how they think about the words disability and ASD. They told me their stories about how they became involved in the autism community and their concerns and struggles in their work with ASD. I named the theme for Foucault’s notion of discourse, which he defined as the total environment and content of public discussion on a subject (Foucault, 2010). The discourses I found appear to represent several different paradigms that are juxtaposed inside the participants’ thinking, as well as in conversations about ASD that take place in the autism community and in the public sphere. Five child codes emerged under the theme *Tension in the Discursive Field*. They are ‘Normalizing Discourses’, ‘Scientific Discourses’, ‘Counter Discourses’, ‘The Co-opted Voice’, and ‘Dangerous, Difficult and Strange’. I will describe these child codes in the following paragraphs.

**Normalizing discourses.** In the context of this dissertation, the term “normalizing” refers to the Foucauldian understanding of normalization, which is the construction of an idealized social norm that controls the discourse and conduct of individuals who operate within it (Tremain, 2005). My use of the child code



‘Normalizing Discourses’ is not the same as the normalization principle (Wolfensberger & Tullman, 1973) that is prevalent in research and intervention in the field of intellectual disability.

Normalizing discourses allow participants to place boundaries around the disability and ASD topics and make it possible for them to manage how they understand and talk about them in a conventional way. This allows them to establish a sense of control over the topic, and to frame and re-frame ASD without directly challenging the medical model. For example, when talking about the term *disability*, Ross, a self-advocate, stated, “the medical model is what disability came out of. . . . It’s a deficits-based model. So what are these deficits that make these people not whole, right? Like, what makes them not complete or not normal?” Liz, a politician, also voiced concerns, “So, you know, disability is a better word than handicapped. . . . It’s not a good word per se because . . . it’s negative. But I can’t think of a better word. . . . It’s convenient.” When asked about the word *autism* or the acronym ASD, participants also began by framing it conventionally. For example, Sandy, one of the professionals, said, “It’s a social-communication deficit. And it’s restrictive-repetitive patterns of behavior.” Normalizing discourse is also apparent in the language of the law. In one piece of documentary evidence I collected, House Memorial 51 stated:

Autism spectrum disorder is the name for a group of serious neurodevelopmental disorders that impair a person's ability to communicate and interact with others . . . . Autism spectrum disorder also includes restricted, repetitive behaviors, interests and activities, and these issues cause significant impairment in social, occupational and other areas of functioning.

Here, the authors used the normalizing discourse of ASD as a disability with terms like “impair” and “restricted” and “disorder.”

**Scientific discourses.** Some participants also used the language of science when talking about ASD. Participants’ knowledgeable use of scientific and medical jargon signals membership as professionals in the scientific and medical fields. Knowledgeable lay people may also use scientific discourses to make it easier to access information and services for themselves or others. When asked about the behavioral science behind ABA, one of the professional participants used the language of science:

You have the philosophical domain where we . . . talk about what . . . we should study, and why and how. . . . We have the experimental branch where it’s all about rigid controls and finding the laws of behavior. . . . In the applied realm . . . we’re trying to take those laws and move them away from the laboratories . . . and put them in the situations that allow for social significance.

Some participants also used the language and prestige of science to support their arguments for particular interventions. For example, one of the educators asserted: “You gotta do it. . . It’s the science. . . . It’s like saying: I don’t believe in astronomy. . . . I don’t believe in physics. There are certain laws. . . . In terms of ABA it’s the same thing. . . Reinforcement produces different behaviors.”

Others used scientific discourse to explain how categorizing people works, and how that can lead to negative effects. For example, a self-advocate said. “Schema theory. . . . Our minds want to systematize. Our minds want procedural records. They want to build models. . . . Our inclination is . . . to systematize and simplify. . . . We build schema . . . . That’s where racism comes from, that’s where bigotry comes from.”

Finally, sometimes the technical jargon of science became an excuse to avoid answering a question in plain language. In one of my observations, I heard a state employee respond to a question from an advocate. She turned toward the self-advocates and said, “The posting is several hundred pages. It’s technical language. And not every page is relevant to your purposes.” Although the state official’s turn toward the self-advocates may have been unconscious on her part, some of them commented that it seemed directed at them.

**Dangerous, difficult, and strange.** Using these discourses, people inside and outside the autism community begin to *other* individuals labeled with ASD. Sometimes, participants with a depth of knowledge about ASD said that they wondered about people they encountered casually. For example, one educator who spent time in Los Alamos, told me: “There are some folks there. . . I think . . . Could be. . . . They were highly intelligent, and those people also have social skills deficits, but . . . there were some people that had some pretty specific deficits that I wondered about.” A similar pastime is the game of guessing which historical figures might have had ASD. In my observation notes from one of the state legislature interim committee meetings, I noted that one legislator told the audience that he had “read that Thomas Jefferson had ASD.”

Parents and other relatives of children with ASD also experience this discourse when they take their children out to stores and restaurants. Clint, a legislator, said: “You take your child shopping at Walmart. You know? Can’t you control your kid? No! I can’t. This is autism. Spank him! Or hold him! Or take him and get the hell out of here!” In this instance, both parent and child were othered. The parent was treated as incapable of disciplining the child, and the child was treated as a nuisance.

These discourses reportedly create concern in the autism community because of what one self-advocate called “the Adam Lanza effect.” Participants noted that when there is a mass shooting, the mainstream media sometimes starts to speculate that the shooter “must have had ASD” because, as the self-advocate said, “they think autists don’t have empathy.” Another self-advocate pointed out that “adults with autism . . . have . . . difficulty interacting . . . with emergency services when they need help. . . . If they act a certain way, are people going to assume that they’re doing something wrong? Or that they might be dangerous?” This framing of individuals with ASD as dangerous, difficult, and strange was explicitly noted by self-advocates. It was also obvious in the discourse of other informants.

**The co-opted voice.** This child code describes situations in which participants softened their criticisms or excused attitudes, practices, and uses of force that maintain the differences in power among people who are labeled with ASD and those who are not. Most examples of this discourse were part of discussions about the lack of the self-advocate voice at the policy table. For example, one self-advocate reframed a criticism, “As a self-advocate, I have to acknowledge that they do a very good job of building up a large group and making their issues heard.”

**Counter discourses.** Counter discourses are those that challenge the dominant, deficit models of disability/ASD, and introduce counter-examples and arguments from alternative models. Ross, who is a self-advocate, said “the Autistic Self-Advocacy Network [*sic*]. . . . [*is*] part of society. . . . That challenges . . . the deficit model these days. It’s showing the ways that . . . deficits don’t . . . matter, in ways that neurotypicals can relate to. Having jobs. Having families. Owning real estate.” Daniel, speaking about

his work for the Center for Self-Advocacy, stated, “There is no such thing as the perfectly normal person. . . . When . . . we go to schools and do presentations . . . we point out that . . . people do things differently. . . . That does not mean that there is necessarily a problem with them.” Blu, who is an educator, also challenged the concept of normality: “I don’t think anybody’s normal. . . . If everybody could deal with the world . . . we wouldn’t have all the drug and alcohol abuse . . . Neurotypical people just find other ways . . . compared to how somebody with autism deals with it.” Another educator developed a counter-discourse about a very different perception of the term *normal*:

Disability. . . . It’s an expansion of the notion of normalcy to include all types. . . . So, rather than treating people in particular ways because of how we name them . . . we expand the tent, right? . . . Normalcy is just a huge category of people. There isn’t an abnormal.

Jesse, a self-advocate, provided a counter-discourse about the loss of Asperger Syndrome as a diagnostic category: “Who am I to say . . . Asperger’s doesn’t exist anymore? When somebody has . . . that diagnosis . . . and developed an identity with it . . . I think it’s disempowering, and frankly kind of rude, to strip that from somebody.”

Many of the participants provided counter discourses about various policies that they thought might limit people labeled with ASD or other disabilities. For example, Lauriann, an advocate, had this to say about transition: “It’s all the words. It’s ‘guardianship’ . . . ‘SSI!’ . . . ‘Employment!’ . . . What about the word ‘self-determination?’ And what about taking your own life into your own hands? . . . What about getting supported to do that?” In the same vein, Representative Gail Armstrong

challenged state hiring policies in this exchange at one of the Disability Concerns Subcommittee meetings I observed:

Armstrong: This is a total shift in the culture of how we provide services. I am hopeful, but watchful. We are not well known as a state to be inclusive. Do you have staff at HSC who have disability?"

Melanie: We can't discriminate in hiring practices.

Armstrong: In all due respect, you may be missing a lot! We need priority in hiring.

### **Dividing Practices: The Power to Name**

I identified the second theme as *Dividing Practices: The Power to Name*. I noticed that most participants attached labels to people who are marked by a diagnosis. They would then give a number of reasons why such labels are natural and necessary. These dividing practices hearken back to Foucault's conceptualization of bio-power, which he defined as the use of scientific examination and measurement to divide and govern a population as a population (Foucault, 1994). Through these dividing practices, those who govern ASD place individuals into dichotomous groups, *the norm* and *other* (Tremain, 2005). I found three child codes that fit under *Dividing Practices*. They are 'Master Status', 'Othering', and 'Passport to Services'.

**Master status.** Rosenblum and Travis (2006) define master status as social divisions expressed dichotomously that act to define a person regardless of their own, unique characteristics. I applied the child code 'Master Status' to capture instances where participants dichotomously labeled or described the labelling of individuals with

DD/ASD. Such labelling collectivizes people and makes their individual characteristics unimportant. Thus, everything an individual is or does becomes about the label.

Alex, an educator, described master status. “We choose to create that as ‘disabled,’ ‘less than,’ ‘other than,’ and in this case, it’s somebody who may not need support, right? Who can do just fine.” Advocate Lauriann recognized ASD as a master status in a conversation about how to think differently about people: “You’re not . . . saying: This person has autism. So this is what we do. Instead, it’s getting to know that person. . . . Who are they? . . . . Not just: This person has autism.” Another educator, Lee, pointed out the consequences of assigning people a master status: “People react to you in a particular way. Having limited . . . opportunities . . . to be in control of your own life. . . . Being able to learn skills that you’re . . . capable of learning, but not being given the opportunity.”

**Othering.** I used the child code *Othering* to capture the way participants separated out individuals who do not fit the social norm and marginalized them or reported this process occurring (Rosenblum & Travis, 2006). Self-advocate Daniel talked about how the puzzle piece symbol for ASD can produce othering. “I think the reason why the puzzle piece was chosen is because most people . . . think . . . They don’t fit. They don’t fit in to . . . whatever we’re gonna try to do.” In a historical discussion of special education, policymaker Paul described how early educators like Montessori marginalized people with disabilities. “She said let’s have special education classes separate but equal. Separate, but trying to target these various groups. So she actually believed that they could be educated, albeit separately from the main group.”

Otherring can also occur when people become uncomfortable with differences in social situations. Clint, a politician, talked about how people labeled with ASD get othered at the grocery store: “People would go to a checkout stand where . . . one of these special kids’ sacking groceries . . . They’ll go to another line. They don’t want to see that. It’s embarrassing . . . if they have to be corrected by the checker.” Participants also reported that parents get othered-by-proxy in public situations, which leads to social isolation. A self-advocate said, “Their child goes into a supermarket . . . they have a tantrum and . . . it’s immediately: The person’s . . . a bad parent. One parent . . . explained that their child had autism. . . . The response . . . was . . . . They shouldn’t be out in the community.” Otherring and marginalization also figured into participants’ discussion of when and how to disclose the presence of ASD. Sarah, an advocate, explained: “The isolation, but also the fear of speaking out. Or of seeking help. Because the child would be labeled different.”

Finally, participants talked about how othering and the isolation it produces affects their well-being. A self-advocate said: “When social engagement . . . is so difficult? . . . That’s when a lot of comorbid diagnoses come to the surface . . . . That is related to being isolated. To feeling a sense of otherness and shame. . . . Like: I’m not measuring up.” Participants described othering as a method of isolation that placed individuals labeled with ASD outside of the social norm.

**Passport to services.** This child code represents participants’ descriptions of the use of dividing practices as only justified to qualify an individual for services. Almost every participant mentioned that the reason for labelling was access to services. Chris, an autism professional, explained: “Number one, again, a diagnosis serves as the gate keeper



and in opening the gates to services and funds. So you have to go through a diagnostic process to open the gate.” Doris, a policymaker, pointed out that limitations are part of the labeling process: “An insurance company could . . . say: They have a diagnosis. It’s covered. Or they can say: They may look and act like they have autism, but they don’t have the diagnosis, so we don’t have to cover them.”

Pat, a policymaker, pointed out that these limitations exclude more people: “The problem with the DD Waiver is that you have to have an intellectual disability . . . Autism doesn’t cut it. . . . About half of individuals now do not have an intellectual disability . . . The gray area of ASD.”

However, self-advocate Ross pointed out that these dividing practices have personal consequences. “The medical model . . . it’s a passport to services . . . . I can’t get rehab or habilitation . . . without medical documentation. For the DD Waiver . . . I need . . . a medical person who says that I am deficient as a human in these ways.” These excerpts show the double-edge to the passport to services. Participants pointed out that although individuals must be labeled to get services, the label itself divides them from the social norm and others them.

### **Reifying Autism: The Power to Define**

When I asked participants what they thought about ASD, they described it with terms taken from the DSM and from the experts in the field. They described in detail what they were supposed to see, and how their own ideas dovetailed or differed from the expert descriptions. Nosologists such as Hyman (2007, 2010) call this the problem of reification. They frame ASD dimensionally, and write about the diagnosis as phenomenological and dynamically changing with variable characteristics across the full

house. However, participants tended to discuss ASD as one dimensional, bounded, and static. They talked about it as a diagnosis that is discontinuous from health or normality. From the ways that participants talked about the diagnosis, I developed four child codes for *Reifying Autism*. They are ‘Diagnosis: The Procrustean Petard’, ‘The Spectrum’, ‘Difference or Disability’, and ‘There and Back Again’.

**Diagnosis: The procrustean petard.** Procrustes was a bandit in Greek mythology who forced his guests to conform to his iron bed by stretching them if they were too short, or amputating their limbs if they were too long. The Procrustean bed has become a metaphor for fitting individuals to arbitrary standards. Participants pointed out those successive iterations of the DSM that govern the diagnosis of ASD. These required them to fit the person to the diagnostic criteria in order to get and maintain services. Many participants also described diagnosis as a discontinuous moment in time, a point where everything changed. For some, it was like a small bomb (petard) that breached their understanding of their child and/or their world. Phyllis, an advocate, recounted a phone call from a parent seeking help. “He said: They dropped the bomb! They dropped the bomb! It was a diagnosis. He thought it was similar to a bomb being dropped on him and his family.” Phyllis continued, “It puts you down a pathway. And it may or may not be a pathway somebody wants to go down or even chooses to go down, for that matter. I think diagnosis is a catalyst.”

Several participants brought up the change from the *DSM-IV* to the *DSM-5* diagnostic criteria. Lauriann, an advocate, discussed what the changes meant for services. “When someone was diagnosed with PDD-NOS from the *DSM-IV* . . . or Asperger’s . . . they’ve been denied different services. . . . In the new *DSM* . . . it would be ASD, and it

would give a certain level of support needed.” Ross, a self-advocate who works with families to get services, said:

For the waiver. . . I . . . tell parents . . . to make your kid more disabled. . . . On the worst day, what does your kid look like? I . . . say: We’re not gonna fib. You’re gonna have to have the documentation. She also pointed out, “the schools don’t accept the medical diagnosis anymore. . . They want their own tests. It really behooves a person to do both. But . . . the requirement for the documentation falls on the family.

Finally, ASD affects the labeled individual over the lifespan. However, the criteria for diagnosis are childhood characteristics. A policymaker, Pat, pointed out that this can be a problem for adults seeking services: “When we are diagnosing children we are getting information from moms, right? If we’re working with a forty-year-old, we’re getting the information . . . from them. . . . We’re asking them to go back and remember.” Pat also pointed out that increased incidence of co-morbidities in adulthood can confound adult diagnoses: “There is a high co-morbid incident with older individuals. . . . We see anxiety . . . depression . . . . When we see somebody who’s had . . . impatient treatment . . . somewhere in their file will be PDD . . . . These people come to us with a laundry list of diagnoses.”

**The spectrum.** Participants tended to frame and reframe their discourses and definitions of ASD, saying that the condition differs from one person to the next. Rather, they described ASD as a spectrum of characteristics that manifest uniquely in each marked individual. In this way, participants maintained that ASD was one, reified condition and acknowledged the variation across the population. When asked what they

thought about ASD, a majority of the participants responded as Clint, a politician, did. He said he sees people with ASD “individually. I don’t think about a broad group . . . I’ve come to the conclusion that . . . ‘if you’ve seen one child with autism, you’ve seen one child with autism.’” A majority of the participants used variations of the phrase ‘if you’ve met one person with autism, you’ve met one person with autism.’ After making such a statement, Doris, one of the policymakers, went on to point out how difficult it is to explain ASD. She said that when she thinks of ASD, “Some of the stuff is there, and some . . . is not there. . . . How do you find how limiting it is to somebody? . . . How do you explain that? That’s even harder to explain to Joe Blow politician.”

Gay, a policymaker, pointed out a problem with subdividing individuals into high- and low-functioning groups: “The labels just aren’t making sense. . . . It used to be that high functioning meant that you had language . . . you were verbal . . . I think it ebbs and flows. How somebody’s functioning is.” Many participants expressed concern that the high-low functioning division mischaracterizes ASD. For example, Daniel, a self-advocate, said, “High-functioning, low-functioning . . . doesn’t seem . . . specific enough. If . . . someone is high-functioning . . . they don’t need any . . . help, they’re just using their disability as a crutch. . . . With low-functioning . . . the opposite can happen. We think . . . they need remedial help in everything.” A few participants expressed doubts about the reification of the ASD spectrum altogether. For example, Lee, an educator, said, “What we call autism? . . . It allows people to get services and supports to have that label. . . . There are so many different underlying reasons for what we call autism. Maybe it should not all be lumped.”

**Difference or disability?** Many participants also questioned the dominant construct of ASD as it is understood in their various social circles. Is it a difference? Is it a disability? Is it both? Neither? For example, Jesse, who is a self-advocate, said, “Autism is just a . . . unique way of being in the world. . . .It’s just a different way of seeing. Of experiencing the world. It’s not better or worse. It’s not more or less.”

Moreover, the first introduction to ASD that some participants had made them think it was cool. For example, policymaker Paul said, “The famous Rain Man movie? . . . That’s a special kind of autism, but I thought that was autism . . . . How cool of a problem? You can go to Las Vegas and count cards. . . You have these unique talents.” Many of the parents and professionals talked about catching a glimpse of extraordinary talent in people with ASD who seemed otherwise very severely affected by it. For example, Liz told me:

One of my favorite kids ever . . . was totally non-verbal. . . . He . . . figured out that the thousand-piece puzzles . . . were all cut with the same die. He would take . . . five of those puzzles and . . . put them together upside down so that the pictures were not distracting.

A few participants pointed out that the issue of difference or disability has become polarized when it need not be. For example, Daniel pointed out: “People are very polarized on it. There are people who say that it’s just a difference. . . The other side would say . . . autism is a crippling problem.” Later in the interview, Daniel continued: “Maybe it is just a difference, but . . . they’re having a difficult time dealing with it . . . . They have a difference but now they’re also in need of a service to assist them.”

**There and back again.** Throughout the interviews, the participants constructed word-pictures that would spiral and narrow toward the point they were making. In these stories, participants described their journeys and their idiosyncratic reifications of ASD. They told of going from questioning to knowing to understanding and then back again. Sarah, an advocate, shared the beginning of her journey: “I didn’t know what it was. Just because I never had any experience with autism or knew anybody with autism . . . . Hearing the word was overwhelming . . . . It was kind of like, I had that overwhelming feeling.” Many family members shared the dismay that comes with the diagnosis of a relative. A family member described it this way: “It’s just hard for me to deal with the trauma associated . . . the environment associated with that. . . . The mother is a really bright, ambitious, charming lady. . . . She’s lost all of that. Because this job is 24/7.” Some participants told of being surprised as their family members with ASD grew and matured. Blu said, “Oh, my god. Puberty. Holy shit! Does anybody ever warn you about that? No! . . . I had this . . . OK! I got this autism thing . . . . but at 12, I was like, what happened now?” Many family members also noted that as their relatives with ASD grew up, their sense of their responsibilities changed. An advocate put it this way: “I was on this journey of . . . how can I help? . . . But now, I’m in a place where . . . I love that kid! . . . Now I’m like . . . how can we change the world?”

Professionals also noted the different emphases between the needs of children and adults with ASD. Pat, a policymaker told me:

Maybe the thirty year old would not be where they are had their mother not pushed that intervention . . . We don’t have a crystal ball. But . . . we start getting

at odds with adults with autism who say . . . . We don't want to be changed . . .

But a three year old who is falling apart . . . that's a different reality.

Participants also told me that part of the there-and-back-again journey was about recognizing the fear that the diagnosis of ASD can invoke. An educator spoke about this as the unknown quantity of ASD: "With autism, it's not that simple . . . . About what supports need to be put in place for a human youngster with autism. It's a journey . . . . I think that's why it scares people." Participants' stories of learning about ASD and accepting it showed a continuing, winding journey rather than a definite end.

### **The Use of Force: Who Imposes Power?**

Some of the most difficult parts of the interviews were those moments when participants told of the use of force against them by people with the power to do so. Individuals and groups can initiate force on others covertly through speech and positioning (Bourdieu & Passeron, 2000). Force becomes overt when threats and physical force are used (Colaguori, 2010). The resort to violence always results in the violation of the individual's liberty to make decisions (Colaguori, 2010; Rothbard, 1982). I identified three child codes under *The Use of Force*. They are 'Symbolic Violence', 'Concrete Violence', and 'Power in Formal Process'.

**Symbolic violence.** This code captures participants' descriptions of the imposition of force against them by the words and actions of people with greater authority and social capital. Bourdieu (2000) described symbolic violence as the subordinating effect of covert structures of power reproduced by differences in social capital among individuals and groups. Individuals who have been othered and marginalized for various reasons tend to give up their power to social rules and standards

that are unexplained and unquestioned (Bourdieu & Passeron, 2000). Using the institutions and ideologies of the society, individuals with more power can coerce individuals with less to give their sanction to force (Colaguori, 2010; Rand, 1967). In one form of symbolic violence, the actor with power ignores the voice or desires of the marginalized person. For example, a self-advocate remembered, “People had a hard time understanding what [relative] was saying . . . . There was a lot of talking about [pronoun] around [pronoun] without talking directly to [pronoun].” Daniel, another self-advocate, shared his discomfort with legislative sessions in which the public comment of people with disability seemed superfluous. He asked, “How are they being used? For example, is it coming up and testifying after . . . four or five other people already said something and they’re just . . . the rubber stamp?”

Another form of symbolic violence are the assumptions that typically developing people make about a person’s abilities and intelligence for reasons that have nothing to do with intellect. Ross, a self-advocate, said, “I have to wear Irlen lenses if I’m under fluorescents . . . . It’s an odd thing . . . that’s segregated me because people . . . conflate differences of the sensory system with a lack of intelligence.” Symbolic violence can also contribute to the fear of speaking one’s mind. People worry that they will be punished for contradicting the dominant discourses. For example, Katie, an advocate, pointed out that “teachers are . . . afraid of speaking out . . . about the abuse they’ve seen in their schools, and the instructions they’ve had from their leadership to continue these policies . . . known to be damaging to children.” Other participants also expressed worries about sharing a potentially unorthodox opinion. I heard the following in different interviews: “I want to fight it. But they might punish my child.”



“There’s a lot of factors probably driving it. Uh, programs, money, families. Different people have louder voices than others.”

“I worry about anything that’s all things to all people . . . You know, all my autism peers are probably gonna shoot me for even thinking this.”

“The jury’s still out. I know that the psychologists . . . would have my head if they knew that I was telling you that!”

“I thought that nobody wanted to hear it, and so I just couldn’t talk about it. I didn’t feel comfortable with it.”

Almost all of the participants expressed similar fears in the course of the interviews. Even greater than their fear, was the profound silencing people reported experiencing when their ideas contradicted those of the people perceived to be in power.

Low expectations and withheld opportunities are another form of symbolic violence. Lee, an educator, pointed to “the lack of opportunities . . . because of disability . . . being denied things . . . being pigeonholed . . . being segregated because of their disability.” One of the self-advocates was told that “I might not talk, I might not . . . think critically . . . ‘If your kid goes to college consider yourself very lucky.’ . . . Now I have a master’s degree.”

Withholding information so that individuals cannot make informed decisions is another form of symbolic violence. Participants said that parents were often told less than the truth about segregated classrooms in some New Mexico school districts. One of the educators stated: “You’re telling parents: You’re gonna get better services if you’re pulled out, but what you’re doing is more of the same . . . . You’re not providing anything that’s any more individualized.” Another educator said, “The families were told . . . this is the

placement that we're considering because this teacher has additional training and expertise . . . . It's just not true. The teachers may have skills or may not." Here, the educators appeared to have the national shortage of special education teachers in mind. They discussed the reality that inexperienced teachers with an intern license or as long-term substitutes often staff special education classrooms in New Mexico.

Lastly, the bureaucracy and its policies enact symbolic violence and the violation of rights quite apart from the good intentions of those who staff them. As one advocate pointed out: "To access the system, you have to prove your incompetence . . . . It's very hard . . . when you have those assessments every year, and you have to match . . . that evaluation." Furthermore, bureaucrats sometimes silence advocates and self-advocates who complain about their treatment during the evaluation. One advocate said, "The person from DD Waiver is going . . . 'we have a lot of individuals who get upset from that. I'm sorry it's so hard. He doesn't have to be here, you know.'" Advocates and self-advocates reported that people in power told them that they are taking advantage of other people's money if they ask for services to which they are entitled by law. Blu told of a DDPC meeting where "somebody stood up and said they thought they should cut all therapies for people on the DD Waiver . . . . That we were just taking advantage . . . because people were just not working and were just living on that now." Bureaucrats also justified the symbolic violence that individuals and their families experienced as necessary to help them, fix them, or make them more like the putative norm. As one of the advocates stated: "We want them . . . to behave like us. Because when somebody behaves differently, it makes us feel uncomfortable. As opposed to realizing that what we try to do to them is making them uncomfortable."

**Concrete violence.** Unfortunately, participants also described policies that condoned physical violence. This problem was particularly prominent in public education settings. The definitions and language of House Bill 190, proposed during the 53<sup>rd</sup> Legislature, makes clear the level of concrete violence allowed in New Mexico schools:

Restraint, when not otherwise modified, means chemical, mechanical or physical restraint; and seclusion means the confinement of a student alone in a room from which the student is physically prevented from leaving. Physical restraint means the use of physical force without the use of any device or material that restricts the free movement of all or a portion of a student's body.

This bill was passed in both chambers and was signed by Governor Susana Martinez on April 3, 2017.

Parent and other advocates described how school personnel restrained and secluded their children without telling them. One participant told this story: “My child . . . was afraid of [a school employee] . . . and . . . would run and hide under the desk. The school would respond by sending a four-person de-escalation team to pull [child] out from under the desk . . . and . . . lock [child] in a closet. . . . It happened 17 times.” One of the participants has been a strong advocate for the regulation of restraints and seclusion in New Mexico for approximately 20 years. Katie pointed out the consequences of officially sanctioned violence on a child’s future:

We look at the restraints and seclusion . . . as the . . . beginning of the school-to-prison pipeline. It starts with restraining a student. Once a student is restrained, they are likely to be restrained again. Once a student is suspended, they’re twice

as likely to drop out of school . . . . We see how the trajectory is very dark for those kids.

Katie also pointed out that restraints and seclusion “disproportionately affects students with disabilities . . . the same thing about students of color. . . . Black boys with disabilities are restrained at a rate of 46 times their white, non-disabled peers.” Clint, a legislator, described how school officials enlist law enforcement to restrain students, “Why do we have—you know—police, in grade schools? [snorts]. Where did that come from?” Another parent-advocate described how her child was bullied in school. It culminated in a physical attack: “High schoolers always hug each other . . . . Two kids jumped on [child]’s back. They ran up and said, “Hugs!” and jumped and [name] crumpled to the ground and it ended up breaking a bone in [name]’s foot.”

Although much of the concrete violence that the participants described happened in schools, they also talked about violence used during ABA interventions. Ross, a self-advocate, said, “Adults with autism that believe that it was cruel and unusual punishment. They don’t think it was helpful, they think it was forcing them into the medical model, and gave them strong tendencies toward depression and self-loathing.” Lee, one of the educators, shared similar thoughts: “ABA . . . has been misused. People have been hurt. All in the name of . . . we're going to cure them. We're going to fix them . . . . We're gonna use punishers.”

**Power in formal process.** During my observations of legislative committees and meetings of the DDPC, I noticed the projection of power by the formal rules and the physical arrangement of the spaces where meetings take place. For example, there is a

visible projection of power in the committee meeting rooms at the state capital, the Roundhouse, in Santa Fe. I wrote in part:

This is a large, rectangular room with a press corral at the back and seating for observers set up . . . with a middle aisle and . . . folding seats . . . . About 12 feet in front of the aisle of the observer's seating was a testimony table, with room for three . . . to sit while giving testimony to the committee. Behind a low courtroom bar with a gate in the middle was a half-circle bench table on a raised dais with tall, upholstered leather chairs for the legislators.

Here, the raised dais, the strong, square leather chairs, and the bar-and-gate between the legislators and the people and the press very clearly marked the power and importance of the legislators.

Conversely, the way that the room was set up for the DDPC quarterly meetings was less formal, although the seating arrangements still projected power differences. I observed:

The meeting table was six tables arranged to make a rectangle . . . One . . . end was clearly the top, because informal, tent-style paper name-plates were placed across it, identifying the DDPC executive committee by name and function . . . . State officials on the agenda to provide testimony seated themselves . . . just adjacent to the officers. Members of the council and guests seated themselves . . . at the bottom-half of the meeting table, with the self-advocates at the [far end].

In the legislative committee setting, the rules of testimony, questioning and comment also projected power. The committee summoned state officials and/or active board members of various NGOs to testify on topics of interest. I noted:

Those testifying approached the table in front of the gate by invitation of the committee chair. When giving testimony and answering questions, there was a formal rule of address: “Madam/Mr. Chair and members of the committee. . .” or, in answer to a question by a committee member: “Madam/Mr. Chair, and Representative/Senator [Name] . . . .” The chair would sharply correct the unfortunate officials if they did not follow protocol. The chair enforced these protocols upon public testimony/comment, but corrected the public much more gently than those giving official testimony.

At the DDPC meetings, members used Robert’s Rules of Order with less formality. I observed that:

The chair introduced officials giving testimony, but they remained seated. The executive and board members frequently interrupted testimony to ask and answer questions without addressing the chair. Side conversations sometimes broke out, requiring the chair to call the table back to order. However, the chair did remind the group of the process and did actively manage the meetings.

Another projection of power in formal meetings was the way that legislators and board members questioned those giving testimony, or interrupted them to make a point regardless of the topic under discussion. For example, at a Disability Concerns Subcommittee hearing, Representative Garcia interrupted a discussion on DDSD compliance, with a complaint about the governor: “We are having trouble with this administration, and I don’t want this to end up in the courts . . . . The . . . situation is with the budget and the philosophical position of the executive, who is not inclined to [raise taxes].” After a few more sentences of testimony, the exchange continued:

Garcia: What worries me is that the Department of Health is not stable financially. Then it gets . . . the special session cut 3 million . . . . The executive . . . should support the department and its personnel.

Stevenson: Madam Chair, Representative Garcia, I am non-partisan staff and cannot comment on the partisan issues in the legislature.

Here, Ms. Stevenson, who was an appointee working in an executive agency, politely sidestepped the comments about her boss, Governor Martinez, and went on with her testimony. At the DDPC meetings, discussion was much more informal. For example, a discussion about the new five-year plan:

Joanna: My discussion targets Jim Jackson's requests for changes. On 2.1.1 . . . . that goal is not measurable.

Sandy: We have to work with 3-5 agencies as part of our mandate from the feds. We have to say that we are doing that.

At the DDPC meetings, members also feel free to respond directly to state officials who do not fully answer their questions. For example, when Christine, a state official, said, "Not everything is important," Joanne countered, "Please tell us—you said that not everything was important, please tell us about the things important to this council."

At the Disability Concerns Subcommittee meetings, citizens who come to observe have almost no role except to comment at designated times. In public comments, citizens have the opportunity to alert the committee to policy problems or to request action. For example, at the October 7 Disability Concerns Subcommittee meeting, a citizen expressed concerns about "spending on residential treatment . . . out of state. There are huge advantages to keeping that money in-state . . . We spend money unnecessarily for

waiver services rather than on independent living skills.” However, I noted that out of seven public comments taken at the end of the morning session, only one evolved into an exchange between the legislators and the citizen making comment. When there is an exchange, participants often say that they feel like they are actually being heard.

At the DDPC meetings, members of the public may also comment but there are often no comments made at the scheduled time. However, members of the public who are present often comment in the course of the meeting. For example, a member of the public commented in the middle of a discussion about the CMS Final Rule: “I have concerns that getting rid of day-habs will mean no services. What about the needs of clients for socialization?” To which a family-advocate committee member responded, “Don’t have any illusions. They are looking at cutting costs to providers of community services!” Another community member then said, “I have real concerns about my [family member] being expected to access the community alone. I worry about safety issues.” These comments illustrate that members of the public recognized the more informal nature of DDPC meetings.

### **The Government of Autism: Who Owns the Power?**

When I asked the participants how ASD affected their lives and work, they described how they had to learn “the system” and follow directives and protocols in order to qualify for, use and keep a menu of services governed by New Mexico law, state agencies, NGOs, and private businesses. Their descriptions resembled the Foucauldian definition of government in the enlightenment sense: That which “aims to shape, guide or affect the conduct of some person or persons” (Tremain, 2005, p. 8) in order to manage and provide for individuals with ASD. The government of ASD occurs through a network



of services and controls at the individual, familial, educational, medical, political, scientific, and social levels.

I identified three child codes under *The Government of Autism* theme: ‘The Establishment’, ‘The Community’, and ‘The Movement’. This is the only theme where I found it necessary to identify grandchild codes. All three of the child codes have grandchild codes, and I will describe them as I develop each child code.

**The establishment.** This code captures the participant’s descriptions of the policies, politics and people they encounter as they navigate the ASD system that presently operates in New Mexico. ‘The Establishment’ represents the current management of the ASD system. Under this child code, I identified seven grandchild codes, each of which captures a part of the establishment, and illustrates how it operates. They are ‘At the Round House’, ‘Bureaucracy Rules’, ‘Real Money’, ‘School Matters’, ‘The Power of Science’, ‘The Civil Society’, and ‘At the Table’.

***At the Round House.*** This grandchild code developed from the participants’ descriptions of the political and the legislative process where policy initiatives become law in New Mexico. At the Round House, political strategies are developed, and legislators, advocates, bureaucrats, and the people involved in disability policy bargain, wrangle, and compromise their way to legislation that governs ASD. The state of New Mexico has maintained a citizen’s legislature, which means that unelected citizens have extraordinary access to the legislative process. As former State Senator and participant, Clint Harden said about the New Mexico state senate, “We’re a citizen legislature . . . We don’t get paid. We don’t have staff . . . . Our senate is . . . close enough R and D . . . so that when the issue is one of moderation, that group will join with this one.”

Representative Liz Thomson also spoke to non-partisanship. Using the example of the recently passed Restraints and Seclusion bill, she pointed out, “this wasn’t political sides at all, it was more philosophical sides . . . . Some of it probably is . . . we can’t spend money. It’s probably more about thinking than political or even financial.”

Liz also explained how the nature of the New Mexico citizen’s legislature and its short sessions affects the introduction and movement of bills through the committee system. When I asked her why the senate memorial on adult ASD services did not pass, she responded: “I don’t think there was any opposition. I just think there wasn’t enough time . . . It was a 60 day session . . . . And it wasn’t a priority . . . the budget was a priority.”

Within the autism community, there are advocates and policymakers who make it their special vocation to learn the system at the Round House. An advocate stated, “I am very passionate about legislative issues—or legislation in general. Out of college, I worked in Santa Fe for the legislature. So I’m very familiar with how that all works.” The nature of the citizen’s legislature also affects the input advocates and policymakers have to the process. Legislators frequently ask ASD advocates and policymakers who have specialized knowledge to draft legislation for them. For example, Gay, a policymaker, said, “Linda Lopez . . . and Nancy Rodriguez asked us to write a funding bill. And . . . Liz, me, Pat, Katie, Sarah, and . . . Cynthia, all came together and wrote it.” Advocates and policymakers are also aware of problems and bring them to the attention of legislators. For example, Katie described educating legislators about the special education budget. She said that “for years, they just kept dropping the special education budget . . . And they didn’t know . . . because of the way special education looks in our state budget . . . . I sat down . . . with every single one, to help them understand.”

Funding a bill or getting one passed in times of financial scarcity can be very difficult, and policymakers develop stamina for the long term. As Gay, a policymaker, said, “In September, the projections looked good. And then . . . oil and gas went down. I knew . . . when we were introducing it that we were just . . . getting it out there . . . no expectations at all that they’d fund it.” Clint also pointed out that getting ASD programs passed requires a willingness to become unpopular. He did all of those things to pass the insurance mandate: “The insurance companies were supportin’ it . . . the insurance lobbyists were fightin’ it. . . . I said: “We’re not gonna accept this. Let’s cram it down their throats. We knew we have the votes . . . I just blew them up.” Some advocates and policymakers worried that the make-up of the legislature does not reflect the diversity of race, ethnic group, age, disability and family status in the state. For example, when talking about restraints and seclusion, Katie maintained that “the people in our state making this policy . . . are . . . white, non-disabled men. Or Hispanic, non-disabled men. With a few women thrown in . . . . And no one with disabilities.”

***Bureaucracy rules.*** With this grandchild code, I captured the ways that government bureaus and agencies write the rules and regulations for legislation passed at the Round House, and how they come to govern the lives of citizens marked with ASD and their families. One issue of concern to the participants is the CMS Final Rule. An advocate testified, “CMS has their . . . rule out. . . . Services . . . have to be community-based . . . . By 2018, they’re going to have to get rid of all the sheltered workshops and . . . all the institutions.” However, New Mexico has been slow to develop compliance measures for the Final Rule, in part due to funding issues. This is evident from my

observation of this exchange between Representative Garcia and Cathy Stevenson at the October 2017 Disability Concerns Subcommittee hearing in Albuquerque:

Representative Garcia: About the CMS Final Rule: What are the feds doing to assist states resource-wise for compliance?

Cathy Stevenson: We have no specific commitment from CMS other than technical support at this time.

Garcia: Is there some kind of time-frame?

Cathy Stevenson: The state must be in compliance by 2017. We had a slow start and are now dealing with corrective action.

Legislators and citizens also expressed concerns about what the final rule means for the health and safety of DDSD and Waiver clients. For example, during the same hearing, Senator Ortiz y Piño also asked Cathy Stevenson about the day habilitation centers:

Ortiz y Piño: Question. About the DSA, how do they define integration?

Stevenson: Models like DSA do not fit the final rule. Now the state could pay when the feds won't.

Ortiz y Piño: What about reverse integration?

Stevenson: Ohio wanted to know how reverse integration could work to fit the final rule. The feds said no. Perhaps you could have a regular Artists Community Center that artists with DD could go to, but it's for all artists.

Advocates and professionals also expressed concerns about the Final Rule at the July 2016 DDPC quarterly board meeting.

Kathleen: They are going forward with the community-centered policies.

Diane: I am calling it inclusion.

Kathleen: They want to end the sheltered workshops and day-habs. They will be writing regulations and if we want to have any say-so, we must take public comment opportunities seriously.

At the same public meeting, the Vice-Chair shared her thoughts: “I believe in inclusion . . . but I am worried about getting rid of the day-habs . . . . Ending those programs means no services for severely involved adults . . . . What about clients that have socialization . . . and safety needs?”

There were also concerns related about the implementation of the Waldrop lawsuit settlement. New rules—including the appointment of outside reviewers and fair hearings—have meant delays and confusion about the renewal of the DD waiver for clients and their families. At the August 4, 2016 Disability Concerns Subcommittee hearing, Senator Ortiz y Piño questioned DDSB bureaucrat Cathy Stevenson about the use of the Supports Intensity Scale. She replied that:

We only used the SIS—the Supports Intensity Scales—for the traditional DD Waiver. The assessment is the gateway to service plans . . . . The outside review process is . . . required by the Waldrop Settlement Agreement . . . This has been very challenging. There are significant issues on the state side as well as the case management/service provider side. Much of this has to do with technology . . . . We now have a 1-800 number. Also the DOH gave clients undergoing review a temporary case number to bill services to, so that providers can get paid.

However, a parent-advocate and president of the New Mexico Association for Parent Providers countered in her public testimony, “There are great ideas on paper . . . . Advocates are . . . saying that it is not working . . . . It would be nice if they actually

listened to people . . . . They call for public comment. But we aren't heard!" These bureaucratic problems adversely affect the people who use the services. Cynthia, a self-advocate, stated, "The health care system stinks . . . Filling out forms . . . I can't hardly read them. They're too small . . . too difficult to understand . . . . And also going through them every year . . . I get overwhelmed."

Legislators, policymakers, and professionals brought up another bureaucratic issue of concern. That is the question of which agencies and bureaus "own" what aspects of ASD policy and its implementation in New Mexico. They also wondered which overarching federal/state laws and policies govern them. Chris, a professional, said: "Again that's not easy. . . . You can't just say: Isn't this a violation of federal law? They have ways of interpreting and saying that . . . . these laws don't apply." Doris, a policymaker, talked about the confusion care organizations have around ASD as a long-term diagnosis. "It's written into their . . . plan . . . employment services are part of what they do . . . . Transportation is part of employment services . . . MCOs are having a harder time accepting that it's not a medical thing . . . . They're medical providers." Gay, another policymaker, spoke to the territorial nature of bureaucracies: "Sister agencies . . . don't always play well together . . . . Unless they're directed. Unless it was . . . people from CYFD . . . HSD . . . PED . . . DOH . . . and they are instructed: Work together! . . . . That's something nobody's wanted to invest in." Liz, a legislator, recognized the problem of ownership. She maintained, "There's silos like crazy. . . . Education people . . . say that's medical. . . . Medical people . . . say that's educational and . . . that's physical health. That's behavioral health . . . . Nobody wants to own autism."

**Real money.** U.S. Senator Everett Dirksen of Illinois is reputed to have said, “A billion here, a billion there. Soon you’re talking real money.” This grandchild code is about the real money that it takes to finance ASD policy in New Mexico and how to continue to pay for it in a time of financial stress. Money is a limiting factor for all policy. When I asked Clint, a legislator, how to implement policy change, he answered, “Money. Money behind policy. In our world . . . everything is about money.” Doris, a policymaker, pointed out that the legislature is concerned with the big picture when it comes to spending. She pointed out, “They have to balance. What about everybody else with needs? What about the road fund? What about . . . the public schools?” For this reason, advocates and policymakers must sell their programs to the legislature. They often do this by a cost-benefit analysis over time, as Clint illustrated:

If we spend . . . so people . . . become self-sufficient is cheaper than taking care of them . . . until they pass . . . The old Fram Oil Filter ad . . . . “Change the filter now, pay me six bucks. Or pay for a new engine later. That’s pay me now or pay me later.”

Part of the funding crisis in New Mexico also have to do with the Medicaid expansion deficit. A number of advocates and policymakers recommend that people with significant needs should consider leaving the state. As Paul suggested, “Somebody reliant on these programs . . . should be looking at a more prosperous economic environment. Texas . . . didn’t expand Medicaid. States that haven’t expanded Medicaid.” Liz also remarked, “I tell people who have children with significant needs not to come here.” Clint said, “I don’t know why anyone would come here.” Some legislators and policymakers also reported considering drawing down the state’s Land Grant Permanent Fund. Liz

suggested that “some of the . . . permanent funds can be used for early childhood autism . . . It’s the old pay me now, pay me later. We have to find the will . . . to invest in early childhood.” Other participants considered ways to conserve money over the long-term by investing in a system of capacity building. Gay opined:

I get . . . this flex funding program. But, I also think in a state where we haven’t built a system, just giving people money is maybe not the best use of the money. We need to direct funds for capacity building.

Paul, a policymaker, argued, “The block grant with Medicaid expansion . . . [is] the better option for the long-term future of the state’s economy. . . . If I could wave my magic wand . . . block granting is a start. The state could control money better.”

Finally, while waiting for better financial times, some participants are thinking ahead. For example, Pat, a policymaker, proposed, “These folks could be contributing members of society . . . if we could figure out the systems to support them. . . It would be so much less expensive for our society.” Liz also spoke to the future: “We have to start reshaping how our state funds itself. Basically. We’ve been too dependent on oil and gas . . . and the prices are too volatile . . . We need to diversify our economy.” These comments all referenced challenges to New Mexico’s economy and its impact on service provisions for individuals with ASD. Participants seemed to recognize that new ways of serving people were necessary.

*School matters.* This grandchild code reflects participants’ descriptions and experiences of the specialized bureaucracy in the public schools. Participants voiced their understanding of New Mexico’s relationship to federal special education law and policies, and those governed at the state level. They discussed these matters from the



perspective of their own personal experiences and those of the children with ASD that they love, care for, advocate for, and teach.

According to the participants, New Mexico has a history of resisting special education law and policies imposed from the federal government. Maryann, an educator, noted, “New Mexico was the first state in the Union . . . the only state in the Union to turn down the 94-142 funding for implementation of IDEA.” Another educator explained: “The argument . . . from the state was . . . we don’t want the IEP. We are providing a free appropriate public education . . . in the least restrictive environment. We don’t want to have those extra conditions.” Several participants noted that adopting IDEA does not translate to faithfully implementing it. For example, Katie said: “IDEA . . . relies upon parents . . . to be the teeth of the law . . . . When there is action by the Department of Education against a state like New Mexico . . . there’s no real consequence. . . . The policy problem is . . . enforcement.” Liz argued that a lack of respect for special education is also a problem at the state level: “The Special Ed bureau is kind of a stepchild . . . I don’t think it gets the gravity that it should . . . Maybe it’s that it’s an impossible job and no one can do it and stay!”

Advocates, educators, and policymakers all expressed concern about how the lack of coherent special education policy at the state level affects the status and performance of special education teachers at the school level. Maryann contrasted her experience as a young special education teacher with the present: “I think we had better skills, more passion . . . . That if we could teach these kids, that made us really good teachers. Whereas now: You’re a Special Ed teacher? You get the dumb kids.” Another educator, Lee, asserted, “the burden of work . . . The lack of respect. It changes who decides to

become a teacher . . . and who decides to stay . . . That effects the quality of services and supports.”

Another issue that concerned participants is the inattention to the inclusion mandate in the public schools. A number of participants voiced concerns about the growing trend toward isolated classrooms for students with ASD. For example, Sandy, a professional, said:

“Kids should be integrated into schools and regular education . . . I am concerned as a professional . . . Everything in autism has moved toward isolation . . . autism specific classrooms . . . a lack of integration of services.” On the other hand, a parent-advocate, Sarah, thought that autism-specific classrooms could be “great,” but then said, “Parents . . . think that their child’s getting put into this autism specific classroom, so they don’t put anything into the . . . IEP about accommodations . . . They just assume they’re gonna use autism strategies . . . It doesn’t end up being that way.” Nevertheless, some participants see segregation as a stepping-stone to access. For example, an educator argued: “Teach kids in segregated settings . . . getting them back in general ed to the maximum extent possible. I have no problem . . . pull kids out and . . . then . . . support them back into general ed.” Given these concerns, it is important to note that none of the participants discussed whether students were being moved back into general education classrooms.

***The Power of Science.*** Participants have concerns about evidence-based practices for interventions to improve the lives of individuals marked with ASD. The evidence base is supposed to provide educators and professionals with a list of practices that have demonstrated success for persons marked with ASD. However, many participants

complained that ABA has dominated the market for evidence-based practice because of the insurance mandate. Sandy, a professional, said: “ABA has done more research than some other approaches . . . but there’s a number of approaches that are also evidenced-based practices. But they’re not supported by Medicaid dollars.” Another advocate said: “But there’s a lot of things that are evidence based.” However, those who research the evidence base have a different perspective about it. As Chris, a professional, put it: “If you . . . say: All research adds something to the literature . . . . Evaluate the content and the quality of that information comparatively, then . . . there’s a lot of research in the realm of autism.” Maryann, an educator, added that “it’s . . . quasi-experimental and . . . a young field and [there’s] . . . the practitioner’s role in determining the evidence base. And the role of social validity . . . as well.”

Another concern that participants have is that in New Mexico only a small part of the population receives subsidies for ABA services. Liz, a legislator, pointed out, “That we’re only covering ABA is a disservice . . . . It’s covering it for . . . a select group that meet criteria. There’s a . . . big population that doesn’t meet that criteria. Whether it be financial or diagnostic.” Furthermore, Phyllis, an advocate, pointed out, “I had some concerns, cost concerns. Just the cost of it. Extremely outlandish.” In addition, the publicity that ABA receives as the autism-specific intervention that is covered by Medicaid means that people do not look to other possible interventions. For example, one professional said, “There are other types of services . . . I’m not saying that speech and OT is the right thing for everybody . . . but people are forgetting that there are other things out there.”

There was also some concern expressed by educators and advocates about the qualifications of those who deliver ABA services. For instance, an educator said, “I do not believe that BCBA’s . . . know enough about how language develops. They know Skinner’s theory. But they’re missing a whole lot of just human development.” Another professional added that “there are concerns about the quality of the services. And how they’re implemented.” However, Chris, a professional, had a different view. “Evidence-based practice is a starting point . . . to give you the highest rate of success . . . . One of the pieces is . . . how is this working for this individual? . . . Is it being effective?”

*The civil society.* Participants recognized the role of civil society entities in the government of ASD in New Mexico. They described how private sector and NGO organizations participate in the autism community. They have expectations for how the civil society ought to relate to the autism community. For example, legislators often direct civil society organizations to accomplish some task that is beyond the mandate of government. In House Memorial 51, legislators wrote, “BE IT RESOLVED . . . that the . . . University of New Mexico center for development and disability . . . convene a task force to study ways to develop and implement programs for older youth and adults with autism spectrum disorder.” Liz, a legislator, commented that the memorial did not pass, but “we’re going to do it anyway.”

Civil society organizations also work with government on research. Pat, a policymaker pointed out “Policy has pushed research. The state has been fortunate enough to . . . work with Sally Rogers . . . and her model programs . . . Policy has been instrumental in seeing that research happens.” Civil society organizations also make things happen in hard economic times. Pat continued, “In New Mexico . . . we’re

scrappy. Because we're poor . . . we ARE a creative gang. That scrappiness is gonna hold us up through . . . the next few years." An advocate pointed out, "Most of what we've done here has been grassroots by New Mexicans for New Mexicans. I will say that most of what we've done in New Mexico did not go through Washington, DC."

Some participants noted that civil society organizations sometimes have difficulties. Sarah pointed out that there is "the whole insurance mess . . . . Dealing with insurance, and dealing with whether or not your plan covers certain things . . . . Families are really frustrated with the whole insurance aspect of it." Paul, a policymaker, noted that different civil society organizations do not work well together. He said, "They file an ADA lawsuit saying . . . this business is not compliant . . . but the business is attempting to comply while also staying in business . . . There should be a way to collaborate."

Participants also discussed the evolution of government and civil society efforts to provide for those in need. Clint, a legislator, reflected, "Society took care of our own . . . . Then we relied on our churches . . . . Now we rely on government. It's an interesting evolution. And I've studied it . . . the relationship between society, government and church." A professional opined, "I don't believe it's the government's job to interfere in a lot of businesses . . . . But I do think that there are protections that are needed. I think we go too far one way or the other." Conversely, a policymaker said that a government "is easier than [the civil society] . . . . Whereas, charity or voluntarism . . . take a lot more work. They are more challenging paths to getting whatever . . . you need."

*At the table.* As they considered the government of ASD policy in New Mexico, participants were particularly concerned about who has a place at the policy table and who gets to speak and is heard. This concern starts with who participates in the

government of autism and who does not. Chris, a professional, discussed the political process: “There seems to be that disconnect between our representatives actually representing the people . . . . I would say, are we really at the table? As citizens? But within that citizen population, you have a lot of unrepresented folks.” Clint, a former state senator, discussed the way political decisions are often made: “Why are there a hundred and ten people back there when there are 15 or 20 people that make all the decisions? . . . That’s our habit.” Along the same lines, Representative Liz Thomson wondered if politically appointed task force recommendations are actually heard. She said that Governor Richardson “formed an autism task force that had community members, family members, self-advocates, agency people . . . We met for years . . . a lot of good ideas . . . But nothing ever came of it.”

Almost every participant had an opinion about who should be at the ASD policy table. When asked who is actually at the table now, Daniel stated, “Legislators are the main people . . . . They hold the power and I think it’s probably . . . the lobbyists from different disability advocacy groups.” An educator added, “Classroom teachers really aren’t heard . . . Because teachers? They’ll show up . . . but it is always under the umbrella of a larger group.” Pat, a policymaker, reflected, “I think the world of autism has always had a major emphasis on hearing from families” and “the people who probably aren’t included . . . are the actual individuals with autism.”

Daniel expressed concern that even if self-advocates testify, legislators do not see them as fully capable to represent themselves. He said, “With self-advocates, [legislators] are hesitant. Because . . . they don’t want to make them look bad . . . I wish they would ask more questions . . . . I really want to talk with them.” On the same

subject, a self-advocate asked, “Is it tokenism? Is it patronizing? Yeah. And how much of it is intentional?” From these comments, it is clear that participants were concerned that certain constituencies such as teachers and individuals who carry the ASD label are less likely to be heard.

**The community.** This child code focuses on the autism community that participants say has grown up around ASD in New Mexico. Every participant without exception discussed the role of the autism community and their place in it. They described the comfort, information, and help it provides them, as well as the controversies it sometimes provokes. I identified three grandchild codes for ‘The Community’. They are ‘Mutual Support’, ‘Advocacy’, and ‘Concerns and Controversies’.

***Mutual support.*** Many participants associated with the autism community soon after they received a diagnosis of ASD for themselves or a family member. For example, Sarah, an advocate, remembered, “I think what helped me turn that negativity and that overwhelming feeling? Was meeting. . . other families and meeting other people who . . . had been through it.” Some participants recalled receiving support from people who had been there longer. Phyllis, an advocate, said, “They taught me so much . . . Go on with your life . . . Here’s coping strategies . . . It’s more than a diagnosis. It’s a support network that each person has to figure out for themselves.” For a number of the participants, the support they received as new members of the autism community was impetus to pay it forward. As an advocate said, “My life’s work . . . has really been around mentoring families. Mentoring families to be as successful . . . as they want to be. Families that have a child . . . with a disability.”

*Advocacy.* Some members of the autism community grow into the world of ASD advocacy. Although interviewees stated they continue to support one another inside the community, they also reported wanting to make changes that will make the there-and-back-again journeys of the next generations more successful and more fulfilling. They want to, as Laurieann, an advocate, proclaimed, “Change the world.” Katie told me that her reasons for engaging in advocacy were profoundly personal: “I am not paid for my advocacy work. I was dragged into becoming an advocate with my own children. In experiencing many difficulties in accessing school and accessing equal school participation from the time they were really little.”

For others, advocacy was something they did together in the community. Phyllis explained, “It was a long time coming and people worked really hard to make changes. We wrote letters. I was part of telephone trees. I’ve called legislators and . . . I’ve been in Washington many times.” Others ran for office or became advocates on a professional basis. Liz, a state representative, remembered, “We said: Let them hear about this! So we had letter writing campaigns and phone calls and showing up at meetings . . . and they heard us loud and clear.” Doris’s advocacy started as personal and became professional. She described advocacy this way:

They hold those meetings . . . . People come, they talk directly, and they see. That changes attitudes . . . . The only way that gets influence is that people talk to them . . . . They don’t have to look at the newspaper, they don’t have to see that person over there.

It is clear from their statements that participants understood advocacy as an enormously challenging, and immensely satisfying part of their there-and-back-again experience.



*Concerns and Controversies.* Through mutual support and advocacy, participants are engaged in a free association with one another. They come from different walks of life, have different world views, and are at different places in their there-and-back-again ASD journey. For these reasons, concerns and controversies about ASD, its policies and politics arise among the participants from time to time. One of the most long-standing of controversies is that over interventions. Pat, a policymaker, recalled, “People . . . formed camps around autism interventions . . . strict discrete trial people and . . . naturalistic people . . . the TEACHH camp, the Son-rise<sup>6</sup> camp . . . . People were pretty desperate.” Currently, the insurance mandate for ABA as the only specifically ASD intervention, has brought a specific form of behavioral intervention into controversy. Phyllis, an advocate, said, “It seems cultish . . . There were the ABA parents, and oh, and they were going to cure their kids through . . . pounding the hammer. Or whatever it was that they were doing.”

Another area of concern that is rapidly becoming controversial is the divide between participants who support early intervention and participants who are demanding adult services. As one policymaker put it, “Because it’s a very . . . different voice when you are talking with a parent who has a three year old and when you’re talking to a 30 year old with autism.” Gay, a policymaker, explained, “Why isn’t there any adult money? Because we haven’t been able to get any from the legislature. I don’t think that the community understands . . . Everything is way more complicated than it should be.” Lee, an educator, was also concerned about the consequences of lack of funding. She said, “I

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<sup>6</sup> Son-rise is an at-home ASD treatment program developed by Barry Neil Kauffman and Samahria Lyte Kauffman for their son, Raun, whom they claim was fully recovered from the condition. See Kauffman, B.N. (1995). *Son-rise. The miracle continues.* Tiburon, California: H.J. Kramer.

see fragmentation . . . And I think that weakens the whole thing. And I think part of that . . . is the lack of funds in the state.” Gay concluded that there will continue to be controversy because “Autism parents . . . we’re just contentious folks. We’ve learned . . . to go to war for what we want . . . . Unfortunately, sometimes we go to war with each other instead of the system.” These statements indicated that participants had their own views about the community’s policy ideas and priorities. They also indicated that at least some of the controversies resulted from misunderstandings about where scarce funds come from and how the legislature controls the use of the money.

**The movement.** I chose this code name to capture participants’ descriptions of their movements away from the established government of ASD and its orthodoxies; and toward a more empowered advocacy and action. They appear to accomplish this through resistance, rebellion, and empowerment, and for some, self-advocacy. The interviews suggested that participants find themselves at different places in this process, and only a few described being radicalized into the Disability/ASD rights movement. Thus, I have identified these as the grandchild codes: ‘Extraordinary Resistance and Everyday Rebellions’, ‘Empowerment’, and ‘Self-Advocacy’.

*Extraordinary resistance and everyday rebellions.* Participants described how they regularly experienced maddening procedures and bureaucratic nightmares as they attempted to navigate the medical model and the established government of ASD in New Mexico. These experiences seemed to lead some into everyday rebellions and others into large acts of resistance. The interviews intimated that resistance led many participants to new ways of thinking about disability/ASD.

Parent-advocates and self-advocates were the primary people who spoke of resistance and rebellion in this study. They told of rebelling over what one advocate called “the tyranny of treatment.” For example, Blu, an advocate, said, “You know what? Maybe I just can’t use you in my house! So we stopped having physical therapy. It wasn’t really doing that much . . . now.” Sarah, another advocate, explained why she chose not to do ABA: “That’s somebody in your home 5 days a week, 2 hours a day. That’s intense . . . That’s only 10 hours. For that to be . . . 15-20 you would need people . . . seven days a week.” These families experienced the daily round of therapies and treatments as invasive and somewhat oppressive. The interviews revealed that as they rebelled against the regimen of therapies and interventions, participants developed a desire for a ‘normal’ life. Ross, a self-advocate and a parent, said, “I wanna be a mom . . . I’m gonna be more picky . . . . Getting to play with neurotypical kids is much more therapeutic than . . . putting cotton balls into a jar.” Blu declared, “We’re gonna become parents again. We’re not [therapists]. We’re parents. And kids just need some down time . . . If the kids wants to just veg, then good for them!”

Another avenue that sparked resistance was the yearly evaluation requirements for getting and keeping the DD Waiver. At a Disability Concerns Subcommittee hearing, an attendee contended, “SIS is not the appropriate tool. That is an understatement when people doing their re-enrollments say that it is like a prison intake form. We need a better assessment, where people are not treated this way every year.” Phyllis, an advocate, explained that she worked with an individual marked with ASD who decided to refuse the waiver. She said that they had worked on the SIS paperwork, and the self-advocate

said, “I will never do that again! I said . . . if you stay on these services, you would have to do it every year. [Self-advocate] said: I can’t do it!”

These personal rebellions against the system led some participants to sustained resistance over a period of years. For example, one advocate began to be concerned about “people doing what they’re told . . . I want them to learn how to problem solve . . .to figure things . . . . If all they do is what they’re told, that doesn’t make a grown-up who has enough coping skills.” This concern, shared among participating advocates and self-advocates, linked directly to advocacy against the use of restraints and seclusion in the schools. As Katie, an advocate, pointed out, the most common reason for restraining and secluding a child is “for refusing to comply with instructions from an adult . . . and while that’s really frustrating . . . that does not give another adult license to lay their hands on that child.” Katie recounted how this concern about restraints and seclusion led directly to a sustained and extraordinary resistance led by her and other advocates and self-advocates over the past 20 years. She continued, “I became determined to change the law . . . I would have probably been better off just suing the school. That would have solved [it] for [us] . . . but [not] . . . for other kids.”

Other participants experienced this transformation to sustained resistance by choosing to be the change they sought. For example, Phyllis declared, “I told the case manager. . . . I’m gonna go to school . . . I’m gonna become a social worker. I won’t . . . need you. . . . You’re all making me crazy and I don’t want to work with you anymore.” Another advocate, Blu, said that medical and educational professionals “Look down at us . . . they have no idea what we’re doing . . . . That’s annoying me. So my goal is to make people understand what life with [ASD] is really like.” And Gay, a policymaker,

organized community voices committed to getting ASD on the legislative agenda. She remembered telling Department of Health official Pam Hyde that, “You’re gonna hear . . . about autism. She said: No I won’t! . . . I thought: The hell you won’t! I . . . got on the phone and . . . called . . . families all over the state.”

***Empowerment.*** Through acts of resistance and rebellion, participants learned to trust their own experience and develop their own, evolving definitions of ASD. This process appeared to move them toward taking charge of their own power to influence others and change policy. Their interviews revealed their move from asking to action, and from dependence to independence. With empowerment, participants broadened the purpose of their advocacy and thought about how to empower others. For example, Katie, an advocate, said, “I began looking at advocacy . . . as it related to civil rights . . . Half of it was teaching families . . . in those situations . . . . The other half was seeing these . . . endemic social and policy problems in our state.”

Like a number of people who became empowered, Jesse, a self-advocate, credited Partners in Policymaking for teaching the participants to “think different” about their work and their lives: “Partners . . . was transformative for me . . . How empowering that was . . . . To think . . . why are we . . . chasing these services? What about our quality of life? . . . Is it something that an expert told us?” Lauriann, an advocate and leader in Partners in Policymaking, talked about how empowerment builds different kinds of power for advocacy. She stated, “Like Partners teaches . . . money is power but if you don’t have money, people is power. So bringing the people together is where the power comes from.” These participants described how questioning the status quo of the

government of ASD brought them to new ways of defining the condition and acting on their newfound knowledge to make change.

*Self-Advocacy.* Participants marked with ASD also described how they began to move from passive acceptance of disability toward claiming and honoring their power in the world. This grandchild code honors the beginning of that journey, because self-advocates say that theirs is still a nascent movement in New Mexico. According to Daniel, a self-advocate and director of the Center for Self-advocacy, “My role is . . . to help people . . . stand up for themselves . . . to get things accomplished . . . to really push back . . . My job is to put . . . people in a position where they can . . . make change.” When asked about her self-advocacy, Ross pointed to the generational conflict between advocates and self-advocates:

I’m . . . in this funny place . . . the mother of a child with [disability] . . . who’s also a self-advocate, navigating the parents fighting with the kids on a political level . . . and I actually find myself . . . on the side of the kids, the adult self-advocates,” because “the adult self-advocates . . . are my peers.”

Cynthia, another self-advocate also works at the Center for Self-advocacy. She is developing her advocacy around educating others. She said, “I do advocacy work. I teach people public speaking. I educate them about their human rights, self-advocacy, how to speak to the legislators. I have graduate students . . . We teach [them] and new advocates about self-advocacy.”

Jesse is also a self-advocate and professional, who uses these skills to teach “typically developing” people how to communicate with “autists” and others who do not speak. Jesse described her method, step-by-step:

You are asking that individual. [Pronoun] might not have the words to tell you what [pronoun] did. But this is part of what's expected here. You need to speak directly to [pronoun] . . . They would say: What did you do today? . . . [Pronoun] would take the object and hand it, and . . . we would be the bridge: What [pronoun] means . . . with goggles is that [pronoun] went swimming.

The self-advocates in this study recounted a number of ways in which they moved from self-empowerment to the work of empowering other individuals marked with ASD/disability. In this way, they appeared to be at the very beginning of a movement toward reclaiming their own power.

### **Autism Tsunami Policy Paradigm Shift**

Unlike all of the previous themes, the Autism Tsunami Policy Paradigm Shift is about the future of ASD policymaking in New Mexico. A substantial number of the participants described what they called the *Autism Tsunami* when asked about the future of ASD policy. The tsunami is that tidal wave of children who are being diagnosed in greater numbers and who are about to hit the shores of adulthood. The tsunami also includes adults who have not have been formally labeled and/or who are not receiving services (P. Osborne, personal communication, June 2016). Because of the expansion of the criteria for autism, this tidal wave of individuals have a diversity of needs that are already beginning to overwhelm the systems for ASD. Therefore, the tsunami may provide an opportunity to shift how New Mexico provides services and support for ASD toward a needs-based system. All of the participants in this study are aware of the tsunami, although how they referenced it revealed different understandings of this paradigm shift. While some were more explicit in terms of discussing this issue, others

appears to be just coming to terms with the necessary structural shifts in the systems of services and supports. Some of the visionaries among the participants are actively making change to bring the paradigm shift about. I have identified four child codes for the *Autism Tsunami Policy Paradigm Shift*. They are ‘The Gap’, ‘Dreams of Good Policy’, ‘Shifting the Infrastructure’, and ‘Access to Citizenship’.

**The gap.** This child code represents many participants’ recognition of fault lines and chasms in the current system of services and supports. They recognized that something must change because the ASD Tsunami is already upon us. The broadest gap they identified is the lack of a coherent ASD system. For example, Alex, an educator, pointed out, “Autism policy in New Mexico is reactive, not pro-active.” Gay, a policymaker agreed. “They look around and say . . . there’s no system here . . . We’re just making decisions . . . that’s just the DD Waiver world.” Liz, a legislator, stated, “We’ve made . . . I don’t know how many autism state plans . . . . We’ve done the children’s autism state plan, adult state autism plans . . . . Nothing ever comes of it.”

Participants said that the gap was particularly noticeable in light of adults who do not receive services because they have no official diagnosis and/or they do not qualify for waivers. Daniel, a self-advocate, thought that this gap begins with transition: “When people become adults . . . the system disappears . . . . People are left to figure things out for themselves . . . when they become adults. There’s nothing there!” Jesse, a self-advocate, said, “I think the support for transition really needs to be more thoughtful, more deliberate. And based on the real experiences that people with autism are sharing with us.” Pat, a policymaker, elaborated on the theme of adult services. “The big payer is the DD Waiver . . . . The problem? We have a 10-12 year waiting list . . . you have to have



intellectual disability . . . . Autism doesn't cut it." Another policymaker, added, "They decided it's more cost effective to put the money for kids . . . Adults are out in the cold for specialized services. They can get a diagnosis . . . . But there's no need . . . . There's no specialized services." In the same vein, Lauriann said that even if there were services for adults, "There are people who have not been evaluated . . . and where's the place to be evaluated? . . . There's few places, and long waiting lists."

The tsunami gap discussed by participants extends to the problem of employment. Doris, a policymaker, pointed out, "There's . . . fairly competent people, but not quite competent enough to go work independently. They don't have access to a job coach. They need help, but they don't qualify." Pat, also a policymaker, added, "The ASD population? There are barriers that aren't so obvious for . . . these really smart, young people. Who can't hold jobs . . . can't make it through college. Yet they have . . . the capacity." Here, the tsunami of people being labeled with ASD has made it plain to the participants that there is a gap in adult services.

The rural nature of the state has created another gap. As a professional, Sandy, pointed out, "People living in different parts of the state don't have the same access . . . depending on social determinants of health . . . . Race, ethnicity, poverty, health professional shortage areas." Clint, a legislator, talked about both the rural service gap and the funding gap. "We've got to figure out how to get dollars into our . . . rural communities, to take care of the needs in rural New Mexico." By identifying all of these gaps, participants were able to imagine and describe their policy dreams and the infrastructure needed to shift the paradigm toward access to citizenship for all.

**Dreams of good policy.** I asked the participants what good policy should look like and they provided me with broad, idealistic visions of good ASD policy. Clint, a legislator, began, “We got to take a look at public policy based on . . . what’ll it look like down the road . . . . That’s the whole needs wheel . . . . I think . . . that’s the vision that needs to be in place.” Ross is a self-advocate who is looking down that road. She said, “We’ve created a new population . . . we’re letting our people with disabilities get old. That’s awesome. But it means we are going to be having to move the work along to accommodate them.” Pat, a policymaker, mused, “What I’m thinking about . . . is wrap around supports to the extent that they’re needed for anyone who needs ‘em . . . I would broaden it beyond ASD.” Chris, a professional, suggested “a policy to address the lifespan. Even individuals who might not need a high level of care, need . . . opportunities.” Liz, a state representative, had a more specific dream. “I would love to see . . . an autism cabinet with people who were dedicated . . . interested, and in it for the long haul. Reasonable sized . . . with all of the stakeholders and decision makers . . . actually working to make things better.” Doris, a policymaker, narrowed her dream down further. She pointed out, “There’s no point person for adult autism . . . There’s no comprehensive look at the needs of adults with autism. . . . Give that office clout to make . . . everybody talk to them. There needs to be an autism council.” Gay, another policymaker, agreed. “I think that autism’s big enough. . . . I think we need a state office on autism. It’s big enough and it’s expensive enough, when it’s done wrong . . . that we need to act smarter.”

Others related dreams of influencing ASD policy from the outside, as part of the movement. Lauriann said, “I think in terms of systems. . . . I love that Partners has that

vocal combination of providers, family members, and self-advocates . . . . How can we bring together that voice . . . to inform policy?” Educator Alex had a question:

How do the set of expectations shift such that the systems and structures that we build—foundationally, philosophically—are inclusive in FACT? Not lip service. Not rhetoric. In fact. Designed to be able to wrap their arms around, and support, and meet the needs of more flavors of people?

Another educator, Lee, demanded, “Why do we have to tie appropriate supports and services to ASD? Or, pick a disability category. When a strategy works . . . it works. We have the research base . . . That's just inequitable.” Elsewhere, Lee said, “That is indeed my dream. That people get what they need in terms of supports without having to be categorized with a label.” As they related their dreams of good policy, participants positively addressed areas of concern that they described as problems earlier in their interviews.

**Shifting the infrastructure.** Almost every participant recognized the widening gaps that expose the weakness of ASD policy in New Mexico in the face of the coming autism tsunami. However, a minority of them also communicated that they are planning to shift the ASD infrastructure to improve its strength and resilience. They described the infrastructure as the policies, budgets, personnel, and supports for shifting the paradigm toward a less expensive, more inclusive policy in the state. Representative Liz discussed the ASD infrastructure for this work in the context of policy. She defined it as “human capital. We need trained providers. We need . . . more SLPs . . . more OTs . . . more PTs . . . more teachers . . . . Not more in number; we need more who . . . understand.” Later, she added, “The biggest thing in my mind is having the right people to train the right way

in the right places, and with the right availability.” Similarly, a self-advocate conveyed concern that “First . . . we have to have a system that . . . starts with early intervention and . . . goes throughout a person’s life. It can’t just stop when they’re 5 or 15.” Another self-advocate said, “We need . . . a safety net. We need . . . access to behavioral health services in all areas. There needs to be . . . providers . . . to work with a wide a range of people with autism.”

Part of shifting the infrastructure is managing the necessary parts and getting them into the necessary order. Liz said, “So that’s really a headache . . . the cart before the horse thing. Getting the money paid out to build infrastructure. But you can’t build the infrastructure until the money is there.” A self-advocate mused, “It’s vague. I do see . . . funding for things that support people integrating into the community. And educate those in the community about disability . . . That comes through policy change.”

Other participants are thinking about how to leverage federal initiatives to move the infrastructure for a variety of projects. An advocate said, “The ABLE act . . . passed in New Mexico . . . people can save their benefits . . . Use them towards starting a business . . . Buying a house. Maybe getting . . . an accessible vehicle.” Phyllis remarked that federal initiatives might push DVR forward. “The biggest predictor of somebody being successful in their adult life is if they had . . . jobs while in high school, why can you not do that? WIOVA<sup>7</sup> might help with that.”

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<sup>7</sup>The Workforce Innovation and Opportunity Act was supported by both houses of Congress and is intended to make American more competitive in the world market by employing individuals labeled with disability who have not previously had opportunities in the workforce. See WIOVA One-Page Summary at <https://www.help.senate.gov/imo/media/doc/WIOA%20One%20Page%20Summary%20May%202014.pdf>

Participants were also working to shift infrastructure in New Mexico's institutions. Ross asked, "How do we grow the medical, health professionals? How do we grow somebody who knows adult autism? Not kids autism." Maryann proposed that schools provide a "differential in pay . . . in accordance with the skills you have . . . . Teachers who teach kids with disabilities . . . have more knowledge and should have better pay for what they do. Like in any other professional field." Gay plans to work on a new institution. She said, "A few years ago I asked for . . . a hundred thousand dollars. To have an autism oversight team . . . to look at the kids with the high needs and . . . then to develop policy for everybody else."

**Access to citizenship.** Participants' concerns about the gaps in ASD policy in New Mexico, their dreams of good policy, and their work to shift the infrastructure, seem to have one goal in common. Some participants' stated goal is to make sure that all individuals—including individuals marked with disability/ASD—have access to citizenship. They described the aim of the Autism Policy Paradigm Shift in New Mexico as bringing people with ASD into the community as full citizens with all the rights and privileges thereof.

Pat, a policymaker, detailed the concept of access in her interview and in her member-check, and defined it as:

All about individual choice . . . . Optimizing potential. . . . No systems barriers. It should be about . . . choice . . . I choose not to go to college. Not I can't go to college . . . because I can't figure it all out. Because the teachers don't understand my disability. It should be a choice.

Chris, a professional, discussed access to citizenship in terms of the civil society. He asked:

What are the barriers to me employing folks? What am I doing to address those barriers? . . . Whether it's social, whether it's functional. . . . How am I helping to get them employed and to create a population to support my company? . . . Some of that is on our private industry . . . . We shouldn't need government regulation to do this for us.

Daniel, a self-advocate, framed access in terms of the community:

Everyone in a community would benefit, but that individual with autism . . . would benefit greatly. We need to find out what those services are in different communities and make the case for them . . . . How do we ensure that those things are in place because . . . they create opportunities not just for kids with autism, but for everybody. . . . That shows a community . . . with more resources, that's more inclusive, where more people succeed.

Self-advocate Jesse equated access to citizenship with the rights and privileges of adulthood, and asked, "What do any of us want . . . and expect as adults? We want meaningful work. We want relationships. We want choices. We want a sense of independence. We want to be able to take risks in our lives." Lee, an educator said:

It means being given the opportunity to fail . . . or to succeed. You're not pigeonholed because of your disability. Or your race. Or your socio-economic status. And . . . . we can't let that happen. Not . . . in a country that . . . is based on this idea that you . . . have this opportunity to be whatever . . . you want to be.

## Chapter 5

### Discussion

My purpose for this dissertation was to critically examine the decision-making process of key stakeholders in New Mexico in the development of disability policy around ASD in light of their knowledge, assumptions and values. In this study, I addressed the follow question with four sub-questions:

How is ASD policy in New Mexico constructed?

1. Who are the key decision-makers in ASD policy in New Mexico?
2. What information do they use to inform their decision-making process?
3. What are their assumptions and values about disability and ASD, and how do these operate in their decision making?
4. To what extent does ASD policy take into account current perspectives in the neurobiology and neuropsychology of ASD?

I addressed these questions by use of qualitative methods and framed it as an ethnographic case study. I collected data from a variety of sources, including individual interviews, observations, document review, field notes, researcher journal, member checks, contextual observations, and demographic information. I interviewed 20 individuals who were involved with autism in New Mexico and conducted two observations of public meetings of the New Mexico State Legislature's Disability Concerns Interim Subcommittee and two observations of the Developmental Disability Planning Council's board meetings.

The theoretical lens through which I interpreted the findings for this study is that of CDT. An overview of CDT can be found in Chapter 2. Tremain (2005) discussed the

governmentality of disability through philosopher Michel Foucault's concepts of governmentality and dividing practices that inform his theory of bio-power (Foucault, 1994). Bio-power refers to the power of the state to use population measures and statistics to define and divide its subjects, mark them and subject them to various forms of discipline and control (Tremain, 2005). Members of the society then *normalize* (see Chapter 1) these definitions and divisions as the ideal and natural way to think about, discuss, order, and govern individual subjects (Foucault, 1994; Tremain, 2005).

The focus of this study was to understand how ASD policy in New Mexico is made in light of the assumptions, knowledge, and values of the policymakers and those who influence them. I proposed that this theoretical framework created a foundation for understanding the process and results of ASD policymaking in New Mexico. As I summarize and discuss these findings, I will also relate them to the research questions, and discuss how they add to, support and challenge other research on the topic.

### **Summary of the Findings**

I provided an in-depth presentation of the research findings in Chapter 4. Here, I will make a summary, and link the themes and codes to the research questions. Following the summary, I will discuss the findings in depth. As I analyzed the data, six themes emerged that address various aspects of the research questions. These themes and the child and grandchild codes nested within them provide integrated answers to those questions. From this analysis, I developed a model of how the governmentality over ASD leads to the eruption of a clash of discourses, violence, and paradigm shift.

Before I summarize these themes, it is important that I discuss their integration into the research questions. I found very few codes that directly addressed one, and only



one, research question. Rather, the majority of the themes and codes juxtaposed and/or integrated the points from several questions. For example, I found that excerpts from some codes demonstrated a juxtaposition of the respondent's fund of information with their values. Some codes featured excerpts that demonstrated an integration of answers to three of the questions. I elaborate further on this phenomenon when I discuss the findings in depth. Here, I present a more micro-view of what themes and codes mainly addressed which questions.

I identified six themes: (a) *Tension in the Discursive Field: Who's Will to Truth?* (b) *Dividing Practices: Who's Power to Name?* (c) *Reifying Autism: Who's Power to Define?* (d) *The Use of Force: Who Imposes Power?* (e) *The Government of Autism: Who Owns the Power?* and (f) *Autism Tsunami Policy Paradigm Shift*. Each of these themes has child codes, and some have grandchild codes. I will discuss the codes as I summarize each theme.

In the first theme, *Tension in the Discursive Field*, I honored the different discursive elements prevalent in the autism community in New Mexico. I also recognized the tension of different discourses individuals encounter and use as they frame and reframe the meanings of disability and ASD. I found that *Tension in the Discursive Field* addressed three research questions through its codes. They were questions about who makes decisions, what information they use to make decisions, and what assumptions and values they have around disability/ASD.

I identified five child codes for *Tension in the Discursive Field*. The child code, 'Scientific Discourses', was one of the few in this dissertation that provided insight into research question four, about the extent to which current perspectives in science are used

in ASD policymaking in New Mexico. The other four codes, ‘Normalizing Discourses’, ‘Dangerous, Difficult, and Strange’, ‘The Co-opted Voice’, and ‘Counter-Discourses’, all provided excerpts that mingled who decides, what information they used to decide, and what values go into the decision-making process.

In the second theme, *Dividing Practices*, I recognized how Foucault’s notion of bio-power (Foucault, 1994) operates to govern disability/ASD in New Mexico policymaking. According to this theory, marking and labeling individuals with disability/ASD separates them from the more valued “us” and puts them in a marginalized “them” at the edges of society. I recognized three child codes for this theme. Excerpts in the first two, ‘Master Status’, and ‘Othering’, primarily addressed the assumptions and values that participants bring to their decision-making. However, excerpts in the third code, ‘Passport to Services’, almost exclusively addressed the question of what knowledge informs respondents’ decision making processes regarding these divisions.

The third theme I identified is *Reifying Autism*. There, I addressed how transforming fluid, research definitions of ASD into a codified, billable series of diagnoses also locates disability solely within the individual. That is the result of “the problem of reification,” (Hyman, 2010) in which a fluid concept is mistaken for a concrete thing that can be used to rank and order individuals’ value (Gould, 1996b). Four child codes emerged from the theme. Two, ‘Diagnosis’ and ‘The Spectrum’, primarily addressed what information the participants used for decision-making about these policies. The other two, ‘Difference or Disability?’ and ‘There and Back Again’, both

equally addressed what information participants use to make decisions and what are the values and assumptions of the decision-makers.

I recognized the fourth theme, *The Use of Force*, as a bridge between the first three themes and *The Government of Autism*. I saw that when policymakers use discourses and dividing practices to define and label individuals with a reified, marginalized identity, it becomes much easier to violate their rights in the name of helping them. I found three child codes for this theme. I identified them as ‘Symbolic Violence’, ‘Concrete Violence’, and ‘Power in Formal Processes’. All three of these codes involved interactions among who the decision-makers are, what information they use, and what assumptions and values inform their decisions.

I identified the fifth theme as *The Government of Autism*. This theme draws from Foucault’s concept of governmentality (Tremain, 2005), which addresses how the state and the civil society use normalizing discourses, dividing practices, and violence to manage and control subjects whose conditions have been reified as disability. *The Government of Autism* is the only theme for which I found child and grandchild codes. From the first child code, ‘The Establishment’, there emerged seven grandchild codes. Three, ‘At the Round House’, ‘Bureaucracy Rules’, and ‘At the Table’, showed interactions between questions of who decides and what values they use to decide. However, ‘At the Round House’ excerpts were more about who decides, and ‘At the Table’ was more about what values participants use to decide, whereas ‘Bureaucracy Rules’ appeared to be equally about both. The grandchild codes ‘School Matters’ and ‘The Civil Society’ addressed equal relationships among questions of who decides, what information they use to decide, what assumptions and values inform them. Lastly,

questions of who decides and to what extent current scientific perspectives are taken into account interacted for 'The Power of Science' grandchild code.

The second child code under *Government* is 'The Community'. Three grandchild codes emerged from it. They are 'Mutual Support', 'Advocacy', and 'Concerns and Controversies'. All three primarily addressed question two, what information participants use to make decisions, and question 3, what are the assumptions and values that assist in their decision-making.

'The Movement' is the last child code I found under *Government*. It also produced three grandchild codes. The first of these is 'Extraordinary Resistance and Everyday Rebellions'. This code addressed questions of what informs decision-making, and what are the assumptions and values of the decision-makers. The last grandchild codes, 'Empowerment' and 'Self-Advocacy', both addressed three questions: who decides, what information they use to decide, and what assumptions and values inform their decisions.

The last of the six themes is *Autism Tsunami Policy Paradigm Shift*. This theme is different from all of the others because it deals not with what is, but with what may yet come to be. The face of ASD in New Mexico is changing in terms of numbers and the diversity of people who have been marked with ASD. These changes are beginning to prompt policymakers to think anew about the future of ASD policy in New Mexico. I found four child codes under *Autism Policy Paradigm Shift*. Two, 'Dreams of Good Policy' and 'Access to Citizenship,' almost exclusively addressed how assumptions and values about disability/ASD informed participants decision-making. Excerpts from 'The Gap' addressed the information decision-makers used and their assumptions and values.

Finally, ‘Shifting the Infrastructure’ showed a complex interaction among three questions: the identity of the decision makers; what information they used to decide; and what assumptions and values they use to decide. Specific answers to the research questions can be found toward the end of this dissertation, just prior to the concluding statements.

### **Discussion of the Findings**

My analysis of the findings for this dissertation helped me recognize that ASD policy cannot be confined to a single discipline such as special education policy or children’s health policy. Rather, the data demonstrated that ASD policy encompasses every aspect of the government of disability in New Mexico. There is no way to restrict the breadth of the subject, because the findings showed that any discipline under discussion linked with every other discipline also governed by ASD policy. I learned a tremendous amount about ASD policy from the varied perspectives, concerns and dreams of the informants to this study. I based my model of the government of ASD in New Mexico on four meta-themes that emerged from the themes and codes I found in the data. They are: (a) governmentality, (b) clash of discourses, (c) violence, and (d) paradigm shift.

**Governmentality.** In his book, *Discipline and Punish* (1995), Foucault provided the substrate to his concept of governmentality through his descriptions of the power to discipline subjects based on a certain kind of knowledge, which he later called *bio-power*. He described these disciplinary techniques as ways in which individual behavior is observed, shaped and controlled inside “social and economic institutions” like “the school, the factory, and the prison,” (Gordon, 1991, p. 5). In a later series of lectures,

Foucault (1991a) fleshed out this concept to include three levels at which governmentality operates: (a) private relationships or self-government, (b) individual relationships in community and institutional settings, and (c) relationships involving political sovereignty (see also Gordon, 1991). In his historical *archaeology* of the development of governmentality, Foucault (1991a) focused on the influence of the French Enlightenment and the ways in which the pastoral power of government to care for families was wedded to the power of *police*<sup>8</sup> in order to create the modern statist triad of “sovereignty-discipline-governmentality” (p. 102). Foucault concluded that through this triad, modern Western governments do not concern themselves so much with questions of sovereignty and law as they do with “the institutions, procedures, analyses” and “the calculations and tactics that allow” the exercise of bio-power “which has as its target the population” being governed (Foucault, 1991a, p. 102).

The particulars of the evolution toward bio-power and governmentality differ from Continental Europe to Great Britain and to the U. S. due to the philosophical differences between the French Enlightenment and the Scottish Enlightenment (Hayek, 2011). In the U.S. in particular, there is still debate about and opposition to the government welfare state as the manager and caretaker of the population (Hayek F. A., 2007; Horowitz, 2014). However, due to social movements in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, an American version of modern governmentality has evolved in the U.S. (Hayek F. A., 2007; Pestritto & Atto, 2008).

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<sup>8</sup> According to Gordon (1991), this term is best translated to the English term *policy*. However, Gordon also acknowledged that Foucault did describe the sovereign’s desire for control of their subjects as similar to the modern police state without the various technologies of surveillance presently available.

At the turn of the 21<sup>st</sup> century, Shelley Tremain (2001) published an article linking Foucault's concept of governmentality to the concept of disability. She argued that the use of normalizing discourses and dividing practices "created, classified, managed, and controlled social anomalies" to "individualize people, who come to be understood scientifically" (p. 6) due to the power of the state to define them (Tremain, 2005). Tremain contended that the imposition of this definition by the state created a separate, social identity for individuals marked with disability (2005). She argued further that the concept that impairment is located in the person is a necessary step toward the legitimization of governmentality, and all of the impositions and controls that come with it (Tremain, 2002).

***Governmentality by dividing practices.*** In *Discipline and Punish* (1995), Foucault described dividing practices as the way governmentalities use bio-power to separate and mark individuals into groups that require special treatment. Rosenblum and Travis (2006) noted that individuals socially develop and maintain a myriad of identities that mediate their positions vis-à-vis the various social groups in which they interact. In the lexicon of sociology, these positions define a person's status (Rosenblum & Travis, 2006). They wrote that a society accords certain status designations great power to define and circumscribe the lives of marked individuals. Identities such as "race, sex, social class, sexual orientation and ability/disability" (Framework Essay, Section I para. 2) are master statuses that overshadow other social identities to become an individual's total identity (Rosenblum & Travis, 2006).

The master status serves to identify the marked individual as *other*, in an identification dichotomy between those labeled 'typical' or 'normal' and those who are

defined out of those categories (Rosenblum & Travis, 2006). Rosenblum and Travis stated further that such dichotomous differentiation constructs the othered population as a group that is alike in important ways, and at the same time, as profoundly different from the “us” to which it is compared (2006). Thus, the process of othering ignores individuality and marginalizes the marked individual to the periphery of society (Rosenblum & Travis, 2006).

In my research findings, I saw how individuals speaking for institutions of the civil society and government agencies operated to divide out a marked ASD identity. This identity overshadowed all others, thus maintaining it as the master status, the sum of all that is real and important about the individual. In order to receive services, individuals and family agents acting on their behalf were required to obtain a “passport to services” consisting of documentation and evaluations, and resulting in the acceptance of a diagnosis that followed the labeled individual in a permanent medical and educational record. What is remarkable is that almost every participant pointed out that the only purpose of this dividing practice was to obtain the necessary passport to services, and very few could imagine any other way to render such services.

Once labeled, members of the marked population were expected to accept surveillance and control by the governmentalities of family, the community, the civil society, and the state. Foucault called this form of bio-power the *carceral network* (Foucault, 1995), which subjects unruly bodies marked as other than the norm to various disciplines to render them docile and productive in society (Sullivan, 2005). The results of this dissertation research suggested that marked individuals and their families often not only accept these forms of disciplines as necessary and proper, but also internalize the



surveillance and impose the discipline upon themselves, seeing both as necessary to access to services. Advocates and self-advocates talked about how they subjected themselves and/or others to demeaning evaluations to maintain a regime of services because it took such effort to get the services in the first place. However, a number also questioned the intrinsic value and purpose of the evaluations and the services.

***Resistance to governmentality.*** In physics, power means the capacity to do work. Transferred to the social world, power is the capacity to do or to act effectively. Foucault described power as something ubiquitous in the environment that comes to be only through its use in a given situation (Tremain, 2005). He clarified that the difference between power and violence is that power occurs among individuals who have agency and are thus able to act freely (Foucault, 1983). This creates what Foucault called “strategic reversibility” so that when power is enacted through governmentality, a counter to that force will also be created (Gordon, 1991). In other words, if power is as ubiquitous as gravity, then resistance becomes as ubiquitous as the countering *normal force*<sup>9</sup>.

Many of the advocates and self-advocates in this study countered the disciplines and power of governmentality with resistance. That resistance was revealed in their reflections with a “why” question, such as: “Why am I chasing these services?” or “Why is therapy taking over our family life?” These beginning reflections quickly became active resistance, and participants planned and took steps to rectify the situation to their own satisfaction. These actions were as simple as stopping a therapy or as time consuming as serving on certain boards, running for office, or spending years getting legislation passed. Several self-advocates resisted the pull of power by refusing the

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<sup>9</sup> In physics, the normal force is a term for any force that counters gravity.

humiliating re-evaluation, thus going off the waivers and public assistance, and finding family and community-based solutions instead. Others countered the governmentality in the schools by changing schools, choosing private education, or homeschooling.

*The governmentality of money.* Money is an instrument of power and a limiting factor for ASD policy in New Mexico. Before I discuss the relationship between governmentality and money, it is important to define the term, because although almost everyone recognizes and uses money, very few people can actually define money and its functions. Money is any object or bank record that people use to manage the exchange of goods and services or to pay debts in a society or nation state (Mankiw, 2006). In modern societies, money is used as medium of exchange, a unit of account, a store of value, and a standard of deferred payment (Mankiw, 2006). Until relatively recently, money's value has been based on the value of a commodity such as gold that is held by the issuing institution (Greenspan, 1967). However, most currencies in the developed world are now fiat currencies, and their value is relative to other currencies, the market, and the good faith and credit of the people who use it (Mankiw, 2006). All of this means that money represents the goods and services that people produce and trade with one another (Brown, et al., 1975; Hazlitt, 1946, 1979). Governments do not produce goods and services; that is, they do not create wealth or make money (Brown, et al., 1975; Hayek F. A., 2007). Rather, they take money by force of legislation in the form of various kinds of taxes (Hazlitt, 1946, 1979) which they use to pay for government functions and to redistribute to private entities (Brown, et al., 1975; Hayek F. A., 2007; Hazlitt, 1946, 1979). Ultimately, money represents the combination of time, work, and property of the

individuals who created it, and since these things are finite, money is finite (Hazlitt, 1946, 1979).

As I described in some detail in Chapter 4, various levels of government finance the cost of CMS waivers, special education, and other legislated goods and services. The money to finance government mandates comes from taxation,<sup>10</sup> borrowing on future tax income, and printing fiat currency (Kiewiet & McCubbins, 2014). All of these methods of financing ASD (and all other government projects) have economic consequences that impact individuals, institutions, and their governments (Mitchell & Stansel, 2016). The origin and scarcity of the money that finances ASD in New Mexico combine to make it a governmentality that is used to manage and control individuals marked with ASD.

In this study, I found that money served as a gatekeeper used to divide out and limit marked individuals, and as a method of discipline and control over individuals and businesses in the civil society. The gatekeeping function of money is due to its scarcity. Because there is never enough of it to finance everyone's needs and wants, legislators and policymakers argue about and establish qualifying conditions and means testing to limit the amount of money spent. These qualifications and tests established a baseline set of conditions to sort individuals within the broad parameters of ASD as deserving or not deserving of government financial assistance. The scarcity of money and the need to monetize individual services combine to create the passport to services. Participants talked about how the gatekeeping requirement made it necessary for them to accept a lifelong disability label and demonstrate their incompetence and dependence on a yearly basis. Some participants told of experiencing public reproof for taking these benefits. For

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<sup>10</sup> This is often called *public money*, a euphemism that obscures where the money came from and why it is scarce.

example, one participant reported being told that people apply for the waiver so that they do not have to work.

Money is also a means of discipline and control over individuals marked with ASD and their families. Participants who are parents and guardians of children who have qualified for funding described the multiplicity of paperwork that they were required to fill out on a weekly, monthly, and yearly basis in order to continue to receive funds. Different agencies required the same information on separate forms, each with unique and complicated filing requirements, and different deadlines. Advocates and self-advocates described keeping up with paperwork as a “full time job.” Others pointed out how unreasonable it was to need to document a life-long disability in order to maintain guardianship and continue to receive waiver services.

The discipline and control that individuals and their families experienced revealed the cost of the bureaucracies that administrate the funding and delivery of diagnostic and treatment services. Informants, whose primary identification for this study was as professionals, legislators, and educators, discussed the thousands of dollars spent on diagnosis only for the purpose of getting the passport to services. Others described the legislature’s insurance mandate, which forces insurance companies to cover a certain application of ABA exclusively for individuals with a diagnostic label of ASD. Although insurance companies can pay for other interventions under this medical diagnosis, they are not required to do so by law. Informants pointed out that the bill benefits certain businesses that lobbied for it and assisted in writing it. In this way, money became the mechanism to benefit a small group of people by funding a variant of ABA as practiced by a specific industry. Informants who are professionals in fields that use other

behavioral techniques said that they were excluded from the certifications and licensing required to be paid under the insurance mandate. In this case, taxpayer money is the catalyst for the growth of a separate industry with its own professional ranks, standards, and educational requirements. In New Mexico, that money is also directed toward the university programs that prepare their students for this industry.

It is important to place this discussion about the power of money around ASD policy within the context of New Mexico's financial crisis and poverty. Several of the informants talked about the politics surrounding the state's use of federal dollars, state funds, and the insurance mandate, to switch taxpayer financing of ABA and other services from local businesses to out-of-state businesses. This reflects the poverty and lack of business opportunities in the state as discussed in the context section of Chapter 4, and further limits local economic growth and control of taxpayer dollars.

In this section, I have detailed how dividing practices such as the imposition of master status, labeling, and othering sets up separate governmentalities to discipline and control individuals marked by ASD and their families. The government of ASD is empowered by the bio-politics (Foucault's bio-power) that deal in the statistical management of populations qua populations. In my model, the substrate of governmentality places increasing pressure on the population marked with ASD and the ASD community. Like the movement of magma in the earth's crust, these pressures appear in the responses and resistances among the individuals and institutions involved. Pressure creates counter-pressure and the eruptions of resistance elsewhere in the system. The first place I found evidence of counter-pressures and resistance was in the discursive field. Free speech naturally results in the examination, questioning, and development of

new ideas. Ideas spread through competing discourses. As the pressure of governmentality increases, so does the volume of the competing discourses.

**Clash of discourses.** In Foucault's interpretation of post-modern thought, discourse is the total environment of discussion on a subject, including the content and the context in which it is written or spoken (Foucault, 2010). Foucault described the content as the ongoing public discussion of the topic, enriched through the media used to propagate it, and the specific language and ideas it contains. He understood context to be the greater part of the discourse, which includes what words are allowed, who has the power to speak, on what topics, and in what time and place. Likewise, Foucault paid attention to who does not speak, who is actively silenced, what is not allowed, and who is the gatekeeper (Foucault, 2010).

For an example of context, I will problematize the notion of person-first language, which has become the required jargon in professional circles in many U.S. institutions (Ford, Acosta, & Sutcliffe, 2013). Person-first language is the practice of placing the person ahead of a disability label rather than naming a person as a disability. In using person-first language, one would say "she is a person with ASD," rather than "she's autistic." According to Ford, Acosta, and Sutcliffe, as well as Wolfensberger (2011), the purpose here is to dignify an individual as a person with multiple identities rather than collapse their identity into the one, master status of disability. This change is laudatory but limited. Context matters and may send a clearer message than the content alone.

One contextual problem is who determines what speech is allowed. Advocate and self-advocate participants in this study identified professionals as the gatekeepers of person-first language. They reported that professionals tended to focus on the words used

instead of on the intended message. Thus, professionals acted as gatekeepers by correcting the individual's speech. This subordinated and othered the advocate/self-advocate, and kept the power of the interaction in the hands of the professional. Another contextual problem is mistaking correct language for appropriate action. Self-advocates particularly reported that person-first language often does not translate into person-first treatment. Advocates and self-advocates experienced being othered, having their ideas discounted, and being expected to give up their power, all in person-first language. As Foucault insisted (1991b), context matters more than content.

Foucault was also interested in the plurality of discourses on a subject. In one of his lectures, he responded that he thought of himself as a pluralist because he had difficulty defining broad subjects as one discourse (Foucault, 1991b). Foucault went to say that he thought of them as a collection that is circumscribed by topic, time, space, and who owns the floor. Foucault characterized a discourse as a state of constant change because the speakers come and go, and develop and alter their ideas (Foucault, 2010). There are a multiplicity of smaller discourses within a broad discourse that represent different, often competing stances, that are going on simultaneously (Foucault, 1991b). Among those that are contested, this often results in a "clash of discourses" (Allan, 2005, p. 283), that represent different micro-regimes of governmentality (Foucault, 1991a). This meta-theme captures the clash of discourses in the data from *Tension in the Discursive Field: Who's Will to Truth?*

I named the theme *Tension in the Discursive Field* because I recognized a certain tension among the participants' different discourses around ASD. This tension not only existed among different participants, but also within the spoken thoughts of the same

participant. It not only existed among the responses to different questions, but also within the same response and even within the same train of thought and the same sentence.

Participants framed and re-framed their thoughts about what is ASD as if the grand tour interview questions I developed gave them the opportunity to delve into their own thoughts and beliefs about disability and ASD. Nevertheless, when asked what they thought when they heard the words ‘autism’ or ‘ASD,’ all but two participants began their responses from the medical model and the DSM definitions. That is, they used the normalizing discourse to frame their conversations around ASD.

*Normalizing discourse and the privileging of science.* The use of normalizing discourse allowed participants to define and reify ASD in a conventional way that constructs the medical model as the natural and scientifically sanctioned frame for ASD. Words like “impaired” and “deficit” located the condition in the individual, which began a process of othering them and marking them for a special governmentality through disciplines of therapy and intervention. As participants entered the autism community, learning and using the normalizing discourse gave them a sense of control over a mystifying set of terms like “pervasive,” “neurodevelopmental,” and “disorders.” This mastery of the normalizing discourse and its use by participants further reified and normalized the medical model even as it gave them a common language to understand ASD.

The normalizing discourse about ASD that participants used in this study privileged a scientific discourse that was narrowly concerned with one form of ABA and excluded other behavioral or naturalistic interventions. A majority of the informants said that ABA was the only officially recognized evidence-based practice sanctioned for



exclusive use for ASD in New Mexico. It is therefore important for me to discuss ABA, its grounding in science, and its applications in New Mexico.

ABA is a basketful of interventions based on the behavioral sciences and it is intended to achieve behavioral changes that are socially significant (Dillenberger & Keenan, 2009; Kazdin, 2013). Dillenberger and Keenan (2009) described ABA in terms of three domains: the broad scientific philosophy of behaviorism, the narrower experimental analysis of behavior, and ABA, which represents the application of the science to human problems in the social world. Behaviorism and the ABA interventions were derive from positivist science (Kazdin, 2013) and the medical model of disability (Shyman, 2016). The medical model locates the condition within the individual, and sets up a dichotomy between able/disabled (Corker & Shakespeare, 2002) and feeds into the normal/abnormal division that underlies master status (Tremain, 2001; 2005).

Behaviorism combined with the medical model contributes to the normalizing discourse that labels those marked with disability as abnormal and their conditions as in need of a cure (Shyman, 2016). The goal of behavioral interventions is therefore progress toward normality and the reduction of abnormal or ‘autistic’ characteristics (Shyman, 2016; Tremain, 2005). Achievement of these goals are the standard for marked individuals to earn inclusion and access to citizenship (Shyman, 2016).

Very few of the participants in this study recognized ABA as a broad label for a multitude of behavioral interventions. Most defined and discussed ABA narrowly and equated it only with a particular version of Discrete Trial Training (DTT). Their conversations were filled with comparisons between “ABA” and other behavioral interventions such as PECS, generalization training, and token economies. A majority of

the informants said that the latter interventions were naturalistic or humanistic interventions. In their discussions, several participants stated the belief that whereas ABA (DTT) is evidence based the behavioral assessments (FBA) and interventions (BAP) used in schools were not. Only a few educators and autism professionals situated DTT in the broader category of behavioral techniques that are used in schools and psychological therapy.

It appears that the narrow discourse around ABA may be due to the legislature's insurance mandate. Many participants supported their beliefs by describing legislation in New Mexico that forced Medicaid and private insurance to provide ABA services for individuals marked with ASD. One of the legislators said that the mandate instituted ABA not as a general set of treatments, but as a specific treatment model endorsed and provided by The Behavior Analyst Certification Board. He remarked that the bill defined ABA so narrowly that new bills would need to be introduced to broaden the mandate to other types of behavioral, naturalistic, or humanistic interventions.

Lastly, what was missing from the scientific discourse was any discussion of the neurobiological and neuropsychological research around ASD. This lack indicates a divide between the phenomenological, fluid, and dynamic understandings of ASD provided by brain-based scientific research, and the fixed and static definition of ASD reified in applications of the medical model. A scientific discourse that is missing such fundamental scientific knowledge narrows policymakers' understandings of the diversity among individuals marked with ASD, their strengths and needs, and limits their citizenship within the community.

*Counter-discourse as resistance*: Drawing on Foucault's ideas about discourse (Foucault, 1991b), Critical Discourse Analysis (CDA) is a method to examine competing discourses in the social environment (O'Brian & Placier, 2015; Shyman, 2016). Macgilchrist (2007) wrote that a discourse could only briefly achieve dominance in a given discursive environment. She argued that constant change among individuals and their ideas made it certain that counter-discourses would arise. This means that a counter-discourse changes with the changing dominant discourse (Macgilchrist, 2007). In this study, participants engaged in different counter-discourses that challenged the normalizing discourse based on the medical model of disability. These challenges arose from the increasing pressure of governmentality on the individuals and institutions of the autism community.

One way participants used counter-discourse was to challenge the prevailing idea that people labeled with ASD are fundamentally different from people who are not. These challenges took aim at the normal/abnormal dichotomy that underlies the medical model. In several instances, participants challenged the myth of the perfectly normal person. Others pointed out that the coping skills people use to deal with the world are different, but not necessarily wrong. Some self-advocates noted that pathological coping strategies such as drug and alcohol abuse are common across the population and affect people with and without labels. In this way, they located the problem outward to the social environment rather than inward to the individual.

Participants also used counter-discourse to challenge the power of the language used in the normalizing discourse. A number of advocates talked about the normalizing language used around transitions for individuals marked with ASD. Rather than framing

them as times of empowerment and growth toward citizenship, this language framed them as dangerous passages that required separate kinds of governmentality. This framing again reflects the normal/abnormal dichotomy. Such framing perpetuates low expectations for individuals marked with disability/ASD. For instance, many professionals do not expect them to negotiate the typical pathways to adulthood successfully. Participants used counter-discourses that emphasized the inherent danger of transition for everyone, regardless of master status. They used terms like “the dignity of risk” and “the right to fail” to assert the essential human need for growth and empowerment.

Other participants challenged normalizing discourse by pointing to the disability/ASD rights social movement. Several cited ASAN, an autism self-empowerment network run by people who identify themselves with autism. First, participants pointed out that these social networks demonstrate the power and competence of individuals across the spectrum to manage themselves and maintain social ties online and in person, regardless of the severity of their labels. Their counter-discourse demonstrated that people marked with ASD are not asocial, but experience a different kind of sociality. They asserted that ASAN produced a free association of people around a particular identity. Secondly, several self-advocates pointed out that through ASAN, people discussed developing their own lives. They argued that “autists” want what any person wants: a full life with work, relationships, and material comforts. They also asserted that individuals marked with ASD can obtain what they want like any other person, and that the vision of the good life is unique to each individual. Here, self-

advocates used counter-discourse to assert that there are as many kinds of “normal” as there are people.

This meta-theme captures how the pressure provided by the increasing power of governmentality on the system and its parts enables resistance in the discursive field. The pressure also reflects back to governmentality, which causes other movements and pressure points in the system. As the pressure grows, the use of force to counter it also grows, and erupts into various forms of violence.

**Violence.** The Oxford English Dictionary Online defined violence as:

The deliberate exercise of physical force against a person, property, etc.; physically violent behaviour or treatment; (Law) the unlawful exercise of physical force, intimidation by the exhibition of such force. Formerly also: the abuse of power or authority to persecute or oppress.

For an action to be violence, the primary, modern definition requires that it be intentional rather than accidental (deliberate) and that it be concrete (physical) rather than symbolic. For violence to be recognized in a legal context, it must also violate some statute or ordinance. However, this primary definition ends on a historical note. In the past, violence also meant symbolic acts of force against others by people who exercise power over them. This older usage is related to the classically liberal political philosophy in which violence was defined as a violation of an individual’s rights (Hayek, 2011).

Rothbard (1982) noted that although enlightenment philosophers posited different lists of rights, they generally settled on three that encompassed them all: life, liberty, and property. We can derive other individual rights from these three overarching rights. For example, the rights to life, liberty, and property would be mere privileges if others could

take them from a person who had no power to stop them (Hospers, 1971; Rand, 1967). Therefore, it is clear that individuals also have the right to defend these rights against the initiation of force by others (Hayek, 2011; Hospers, 1971; Rand, 1967; Rothbard, 1982). From this, we can derive the right to self-defense against those who would violate our lives, liberty or property. In other words, individuals have the right to answer the initiation of force with retaliatory force (Hayek, 2011; Rand, 1967). For this reason, classically liberal and libertarian philosophers define violence as the *initiation* of force against another human being (Hayek, 2011; Hospers, 1971; Rand, 1967).

As I pointed out in Chapter 1, my ethics and my critique are libertarian. For the purposes of this dissertation, violence means the initiation of force against other human beings that violate their rights by threat, fraud, or physical action. This definition covers the symbolic and concrete forms of violence described under the theme *The Use of Force: Who Imposes Power?* I discussed in Chapter 4.

***Symbolic violence.*** Almost all of the participants in this study described some form of symbolic violence that they either witnessed or experienced. However only a few indicated that they recognized it as a form of violence at the time it occurred or in the present. As Bourdieu and Passeron (2000) explained, symbolic violence occurs because of the unequal power relationships maintained by the accepted forms, rules, and constructed knowledge of a particular society.

Much of the symbolic violence that participants described took place in schools, medical facilities, and other institutions that reproduced unequal power relations between professionals and clients, teachers and students, doctors and nurses, and adults and children. Furthermore, the inequality of power in these relationships increased when they

were enacted around disability/ASD because of the marginalization that the normal/abnormal dichotomy created.

Many participants described symbolic violence that came disguised as assistance rendered without the consent of those helped. Such actions violated their liberty to decide for themselves how to navigate the world. It also damaged their liberty to act under their own power and othered them in front of their unmarked peers. Some self-advocates described a variant of this type of violation. People would ask to assist and make the excuse that they had a pathological need to control the environment. One self-advocate pointed out that when this kind of exchange occurred, the would-be helper almost never waited for an answer. The self-advocate was left wondering what would happen if the request was refused. Whereas the verbal message in this type of transaction gives the appearance of equalizing power, the actions themselves increase the power differential and signal the greater power of the one expecting compliance. Who gives orders and who complies with them is a clear demonstration of a power difference.

This behavior may also be a form of *virtue signaling* for the individual who is forcing assistance on others. The Oxford English Dictionary Online defined virtue signaling as "the action or practice of publicly expressing opinion or sentiments intended to demonstrate one's good character or the moral correctness of one's position on a particular issue." Signaling theory was developed by evolutionary biologists to explain aspects of sexual selection (Bradbury & Vehrencamp, 1998). In animal behavior, a signal is a physical feature or activity that communicates the presence of some hidden factor related to the animal's fitness for reproduction (Dawkins, 1995; Williams, 1996). In social species, such as humans, the public display of pro-social behaviors increases an

individual's status within the social group regardless of the honesty of the signal (Dawkins & Krebs, 1978). Forcing assistance on individuals marked with disability/ASD disguises the power inequality by the appearance of a virtuous act that actually violates another person's rights. However, the display of virtue is likely to increase the power and status of the signaler even though it is a dishonest signal (Dawkins & Krebs, 1978).

Outright deception is another form of symbolic violence. A number of participants described the deception that often accompanied the placement of students into ASD-specific classrooms in the public schools. Parents/guardians were asked to choose between an inclusive classroom in their neighborhood school and a segregated classroom that might be located outside their neighborhood. According to various professional, educator, and advocate informants, parents were told that specially trained teachers would teach their children, and that they would receive targeted instruction to meet their individual needs in the ASD specific classrooms. However, participants said that students in special education classrooms were more likely to be taught by teachers or substitutes with little to no ASD or special education training. Several educators maintained that students in the ASD specific classrooms were also not likely to receive an individualized education as required by IDEA. Rather, the ASD master status determined the curriculum in the segregated classrooms.

One participant explained that most of the school employees were not responsible for the deception because they often did not know the reality in the classroom. This informant argued that they followed the orders of more senior educators and administrators and had no power over the policy. In this case, a system that has no clear assignment of responsibility perpetuated symbolic violence. Nevertheless, those who



have the responsibility to serve the public have withheld important information from individuals who have a right to it. That deception deprived them of the freedom to make a choice for themselves and their children.

Participants also described the violence of low expectations and assumptions of incompetence. Every educator and many others told at least one story illustrating this problem and its negative effects on the futures of students labeled with disability/ASD. The assumption of incompetence for marked students deprived them of access to the general curriculum and thus denied them the preparation needed for access to citizenship. Low expectations and assumptions of incompetence generally stem from the master status designation associated with ASD that obscures an individual's unique suite of strengths, talents, skills, lacks, and needs.

Advocates who were also mothers of children marked with ASD described the low expectations and assumptions of incompetence aimed at them. They talked about how teachers, educational assistants, and professionals often gossiped and criticized their care for their children behind their backs. They said that professionals sometimes talked down to them or lectured them in the course of parent-teacher conferences, IEP meetings, and behavioral health appointments. Mothers described how they were often placed in double binds that made them wrong regardless of their choice. For example, in one session a mother was accused of being over-protective and in another, she was criticized for not being protective enough.

In their book *The Mother Blame Game*, Reimer and Sahagian (2015) described the patriarchal roots of mother blame rooted in the lower status of women. They pointed to a trend toward "intensive mothering" (Location 157, para. 2) that has put increasing

pressures on women to be consistently perfect mothers. Mothers are then held responsible for every problem a child or the family has when they fail to maintain perfection (Reimer & Sahagian, 2015). Mother blame is not a new phenomenon for mothers of individuals marked with ASD (Courcy & de Rivieres, 2017). In the middle of the 20<sup>th</sup> Century, mothers of individuals diagnosed with what was then called infantile autism were accused of being cold, uncaring parents who caused their children to withdraw into themselves (Douglas, 2014). Although that myth has been dispelled, the research of Courcy and de Rivieres (2017) suggested that contemporary mothers of children with ASD are now held responsible for doing interventions perfectly, and are blamed when the child does not show expected progress toward normality. Mothers are marked and found wanting, and their dignity of risk and right to fail are curtailed. The symbolic violence of mother-blame here intersects with sexism and combines to include mothers of marked individuals into their children's master status. This combination demonstrates how governmentalities that operate to control women's status and those that control ASD have combined to make the work of mothers that much more difficult.

*Concrete violence.* Left unsanctioned, symbolic violence becomes concrete violence. The threat of physical force is at the point of this transition. All of the concrete violence that participants shared in their interviews occurred in schools. A number of participants described witnessing concrete violence in the form of restraints and seclusion enacted upon a student. In the definition of violence from the Oxford English Dictionary Online above, witnesses are counted among the violated. Witnessing an act of violence limits the liberty of the onlookers because it is a threat of violence against them as well

(Hospers, 1971; Rothbard, 1982). Rothbard stated that it is always an unethical violation of individual rights and is sometimes contrary to the law.

In a paper from the U.S. Department of Justice, Finkelhorn, Turner, Ormrod, Hamby, and Krakke (2009) stated that there are lasting effects on children who witness violence that harms their power to act, their relationships, their sense of safety, their physical and emotional health, and their ability to protect themselves. These consequences continue well into adulthood (Finkelhorn et. al, 2009). As an activist participant for the reform of restraints and seclusion put it: “It harms children.” As the documentary evidence, observations, and participant interviews to this study made clear, restraining and secluding students in schools violates the individual rights of both the victim and the witnesses. The New Mexico state legislature passed a bill that limits restraints and seclusion during the 2017 regular session, but it has yet to end this violent practice.

Like the eruptions of resistance in response to the clash of discourses discussed above, the eruptions of violence also reflect pressure on the systems of governmentality that manage and control individuals and ASD policy in New Mexico. Through the model I propose here, I have illustrated how increasing pressure over time contributes to the development of cracks and fissures that increase resistance and violence. These pressures, in turn, reflect back on the substrate of the governmentalities themselves. There, gaps are widening due to increasing specificity of dividing practices, the increasing pressures of the the state’s financial problems, and the increasing resistance to the governmentalities’ power and control. All of these things put further pressure on the status quo of ASD policy in New Mexico. It is a classic positive feed-back loop. At some point, the pressure

on the system will become too great to contain, and the system will come apart at the fault lines and fissures. Many informants, particularly the policymakers, predicted that the tipping point will be triggered by the Autism Tsunami that I described in Chapter 4. Some concluded that the sheer number of people diagnosed with ASD, and the diversity of their needs, will push the system into a new paradigm. A few envisioned how this new paradigm would change the government of ASD/disability in New Mexico and beyond.

**Paradigm shift.** In 1962, Thomas Kuhn released *The Structure of Scientific Revolutions* (Hacking, 2012a), in which he described periods in history when the dominant paradigm of a science was overturned and a new one developed. Hacking stated that a *paradigm shift* is caused by anomalies that build up until a discontinuity occurs and changes the conceptualization of the science (Kuhn & Hacking, 2012). Hacking stressed that the ideas and even the words of the old paradigm are not comparable to those of the new one (2012a). Kuhn concluded that scientific revolutions are the product of changes in the worldview of a science, and that science does not progress to a unitary truth (Kuhn & Hacking, 2012). Rather, “it is progress away from less adequate conceptions of, and interactions with, the world” (Hacking, 2012a, p. xi). However, Kuhn had no patience with skeptics who later used *Structure* to argue that there is no truth. As Hacking wrote, “Kuhn was a fact lover and truth seeker” (Hacking, 2012a).

Although Kuhn applied the phrase *paradigm shift* narrowly to the physical sciences (Kuhn & Hacking, 2012), others have applied it to the life sciences, the social sciences, and the humanities (Cohen, 2015; Hacking, 2012a). Critics argue that the term has become banal with overuse (Cohen, 2015). However, I applied the term in this work

as Kuhn described in *Structure*: the development of fundamental problems that inevitably produce discontinuous and revolutionary changes in a system.

*Consequences of the gap*: All of the participants in this study described gaps in ASD policy in New Mexico. The most fundamental problem they identified is that the state does not have a pro-active system for governing ASD. Neither does it have a coherent policy to guide and maintain its systems. Rather, participants stressed the reactive nature of ASD policy in the state. They maintained that presently, policy initiatives aim to solve immediate problems, but they do not simultaneously address capacity building for the future.

Advocates, educators, professionals, and policymakers all pointed to the policy divides among different interests in the autism community, and between it and advocacy groups for other disabilities. They argued that this fragmentation signals a lack of coherence in disability policy in general. They maintained that this kind of fragmentation widens gaps in services, creates expensive duplications of effort, and causes ill will and rivalry among organizations and institutions that have the same fundamental concerns.

Politicians and policymakers expressed concern about the formal government's resistance to change. They said that although the composition of the legislature has changed dramatically over the past quarter-century, the power structures and political habits have remained as relicts of the past. They also shared concerns about the fragmentation of effort among the different government agencies, and the lack of power that inter-agency leaders have to enforce and sustain integrated policy efforts. Lastly, every participant shared their fears about how the ongoing fiscal crisis in the state would likely cause further disruption to their efforts to construct better ASD/disability policy.

The majority of the participants laid responsibility for the state's fiscal woes at the door of the legislature. However, a minority also pointed to pressures brought to bear by federal mandates and demographic changes across the U.S.

Almost all of the informants pointed to problems with public education. Educators were particularly concerned about the lack of an articulated education policy for ASD and disability in New Mexico. However, almost everyone stressed that students marked with disability do not have access to an integrated curriculum spanning K-12 that prepares them for citizenship upon graduation. Some educators promoted using segregated autism classrooms as a stepping-stone to integration into general education. Others argued that segregation continues the practices that produce low expectations for students marked with ASD.

Even as they expressed their concerns about the particular problems in the community, the state government, and the schools, participants all pointed to the same basic policy problems. Fragmentation in and among the different areas is a sign of the reactive, incoherent policy that has been governing ASD in New Mexico up to the present. However grim and difficult the fundamental problem appears, the pressures on the system that they represent are also pushing inevitable change. All of the participants described the rumblings of change, most dreamed and planned for the oncoming tsunami, and a visionary few anticipated the radical change that the new paradigm would bring.

*Seasonality and anticipating change.* In *The Fourth Turning*, Strauss and Howe (1997) developed a cyclical theory of American history and linked it to their generational theory from previous work. They based their theory on a cycle of saecular periods that corresponds to the movement through time of four generations that occurs over 80-90

years. The authors posited four turnings, or periods with distinct moods and social patterns that recur in the same order in each saeculum. They called these turnings the High, the Awakening, the Unraveling, and the Crisis. Strauss and Howe gave the last turning of each saecular period a special status as “a great gate in history” (p. 3), when civic order decays and is built anew, based on a values regime developed during earlier turnings. The Fourth Turning marks a crisis, “a decisive era of secular upheaval, when the values regime propels the replacement of the old civic order with a new one” (Strauss & Howe, 1997, p. 3). Strauss and Howe predicted that the crisis for the current saeculum would begin in the middle of the first decade of the 21<sup>st</sup> century (1997). Later, they proposed that the global market meltdown in October of 2008 was the likely beginning of the current saeculum’s fourth turning (Howe, n.d.).

Although Strauss and Howe backed up their generational saecular theory with historical research presented in their books (Strauss & Howe, 1991; 1997), it is speculative and can only be verified from the future. However, I found the theory useful for thinking about the *Autism Tsunami Policy Paradigm Shift* theme that emerged from the findings for this dissertation. I used the Strauss and Howe theory, names, and dates, to identify the participants’ generational identities. The demographic data (see Chapter 4) showed that Boomers and Generation X each composed about half the majority of participants in this study. The Millennials made up a small minority. Boomers almost exclusively held the positions of moral guidance and visionary power. Members of Generation X were doing the hands-on, get-it-done leadership and support work. The Millennial generation, which had just filled their adult turning, were starting to participate in the work of the New Mexico autism community. They were still taking guidance from

the older generations, but they also exhibited a new, group oriented focus that is beginning to change the attitudes and prejudices of their elders. For example, whereas Boomer participants tended to see puzzle-piece jewelry and wristbands as ways of raising awareness; and Generation X participants tended to be concerned that they might represent virtue signaling; the Millennials generally saw them as symbols of solidarity. These observations align with Strauss and Howe's predictions of the characteristics and positions of the generations in a fourth turning (Howe, n.d.; Strauss & Howe, 1991; 1997).

All of the participants recognized that the autism tsunami had arrived, and that the predicted crisis was upon them. Many had also anticipated problems and developed ideas for immediate and long-term policy changes to meet the oncoming wave. Their ideas included bills to solve some of the immediate problems they were experiencing in the gap, such as the need for adult diagnostic facilities, and the recruitment of more service providers. They also endorsed a memorial asking the legislature to set up a study committee to delineate the current and anticipated problems experienced by adults marked with ASD. A smaller group, composed mostly of Millennial advocates and self-advocates, discussed more radical ideas, such as developing a greater voice for self-advocates, promoting more inclusive communities, and eliminating the onerous and repetitive re-evaluation requirements for those on waivers. All of these activities involved shifting the existing infrastructure to prepare for the anticipated autism tsunami. In this way, they are seasonal. That is, their activities anticipate the coming paradigm shift but do not look beyond the immediate next steps needed to meet it.



*Visionaries across the discontinuity.* In their work on crisis periods in history, Strauss and Howe (1997) retold the story of Nathaniel Hawthorn's Gray Champion. The Gray Champion was the elder statesman, visionary, and moral authority who had the power to muster the living generations to bring a crisis to resolution. The autism community, too, has its Gray Champions. A handful of the participants who had a lifetime of experience could look across the discontinuity and envision a new paradigm.

The autism community's Gray Champions imagine future governmentalities of ASD/disability in ways that significantly diverge from the present reality. One imagining they shared is a policy that no longer attaches certain services to specific labels. These participants wondered why it was necessary to pass through the narrow and expensive gate of diagnosis in order to access basic services. They argued that there are ranges of conditions that respond to the same interventions, and that the multiplicity of labels has resulted in inefficient service delivery, fragmentation, and rivalry among the various advocacy groups.

The visionaries also suggested dispensing with labels altogether for individuals who "need opportunities" but not "a high level of care." They suggested making short-term, targeted services available to whomever needed them, regardless of any label. In this way, the needs-based services would become part of transition planning for all young people moving from school to life. Individuals now marked by specific labels could be integrated into what one visionary called "the big tent of *us*." These informants imagined that adults with specific needs for educational and soft employment skills could get them met without wasting their time and talents waiting for a diagnosis. Rather, people would be able to access short-term behavioral health and employment services as needed from

modified and consolidated state and federal agencies. As several participants pointed out, this would reduce the inefficiencies of providing similar services through a number of different agencies. In this way, affordable, wrap-around services could be made available to meet the needs of most individuals who are presently not receiving them. This transformation of services could easily include many people currently labeled with other disabilities, as well as those who presently struggle without help because they have no labels at all.

The autism community's visionary policymakers are working to develop a plan for the future of individuals with comprehensive or severe needs. Some of these people presently receive services in day-habilitation or sheltered workshops. Others require expensive out-of-state residential services. The CMS Final Rule (see Chapter 4), will soon require integrated, community-based services for these individuals. Visionary policymakers recommended that in the near future, the state should dedicate the bulk of its resources to build capacity toward these most difficult problems. This would require the development of specific goals and targeted funding in these areas. Presently, the reactive nature of policymaking in the state works against such a plan. Part of the problem lies with the short-term nature of political appointments to state agencies and boards. The fragmentation in the community and among the different interests also keeps the focus on the most visible needs of the moment. However, policymakers in this area continue to reason with and educate advocates about the long-term benefits of such a plan. They pointed out repeatedly that the dividends of the capacity built would benefit everyone involved with ASD and spread to other disability advocacies in the state.

Gray Champion educators, policymakers, politicians and professionals also have a vision for the changes necessary to meet the diversity of educational needs brought by the oncoming tsunami. They, too, spoke of a revolutionary change in the way that educators and citizens think about the breadth of normality. Several argued that in order for everyone to have access to citizenship, they must be educated together across the lifespan. In fact, inclusion is the educational policy in New Mexico. However, these participants stressed that the policy on paper does not match the reality in the classroom. They envisioned inclusion set within a structure in which teachers, professionals, para-professionals, and administrators have the supports they need to provide individualized education to all students.

As educator visionaries pointed out, this goal demands changes in the training, compensation, and status of educators. Some argued that the accountability movement in education (see Chapter 2) presently promotes top-down management and extensive testing that benefits textbook and testing companies rather than students and teachers. They envisioned a more locally managed special education system that still operates under federal guidelines. Some argued that such a system would provide teachers more power to make the teaching and curricular modifications necessary to meet each student's educational needs.

One visionary described a system developed by the U.S. Department of Education that taught state special education officials how to focus on specific practices and create measurable goals to improve local and district alignment with IDEA. Using this system, officials matched schools to levels of supervision and support to increase FAPE and inclusion. District officials were also encouraged to learn from master teachers about how

to meet the individual needs of all students in their schools. As local district and school personnel learned how to evaluate their own progress, they built on their successes and became pro-active in determining future goals and benchmarks. This program anticipated the paradigm shift because it met the needs of specific populations as a first step to meeting the needs of all students.

In order to enliven all of these policy dreams and plans in New Mexico, visionaries say that a less reactive and more enduring political structure needs to be built. A Gray Champion politician, together with policymakers, has begun to develop the idea of an executive agency in charge of ASD at the state level. This “Office of Autism” (as one visionary called it) would need the power and political clout necessary to work across the divisions among the extant state agencies that currently manage portions of ASD/disability policy. The participants envision a board large enough to represent a variety of needs and concerns, but small enough to make change happen. The visionaries persuaded the rest of the autism community to support this project. Although they did not get a legislative memorial passed in 2017 to direct them to do the planning work for this and other projects, they decided to start the committee themselves.

Those who have studied crises and paradigm shifts (Cohen, 2015; Hacking, 2012b; Kuhn & Hacking, 2012; Strauss & Howe, 1997) characterized them as difficult, exciting, and fearful passages. Strauss and Howe noted that when standing on the present side of radical changes, people often have difficulty seeing across the discontinuity to a resolution in the future. However, they noted that the generation that fully occupies elderhood in a crisis has the visionary power and moral strength to guide the midlife practical leaders and young adult team-workers across the discontinuity and into the new

paradigm (Strauss & Howe, 1997). In New Mexico, that seasoned leadership is available, and the visionary goal is access to citizenship for individuals marked with ASD/disability.

*Access to citizenship.* The question of what access to citizenship will look like on the other side of the discontinuity does not have a detailed answer because that work must take place during the paradigm shift. Nevertheless, all of the participants in this research had dreams of what it ought to look like. Participants imagined that individuals would have a multitude of choices about their futures, and that their choices would reflect their individual talents, skills, and desires, unconstrained by labeling and master status. Individuals could expect to pursue all of those things that anyone wants to attain upon reaching adulthood: satisfying work, independence from parents, and the vicissitudes of personal relationships and community involvement.

Participants also described basic rights guaranteed to all in theory, but that have often been denied to people who have been marked with disability. These included the natural rights the United States federal government exists to protect: rights to life, liberty, and property. They also described the fair treatment, respect, and equality expected by members of a free society. The dignity of risk, and the right to fail. Freedom from discrimination and prejudice. Freedom of association. The freedom to choose identities, roles, and relationships. The right to refuse treatment, assistance and aid. Access to public accommodations and right-of-way. These are the expectations that participants discussed for this study. There are other lists, most notably, the UN Convention on the Rights of Persons with Disabilities (United Nations Committee on the Rights of Persons with Disabilities, 2012). It is a political treaty that has been debated and contested in Congress

and in the civil society of the U.S. (Home Schooling Legal Defense Association, 2013; U.S. Department of Justice, 2012; United Nations Committee on the Rights of Persons with Disabilities, 2012). The U.S. Senate turned down ratification of the treaty in 2012, 2013, and 2014 (Home School Legal Defense Association, 2015).

The development of a policy paradigm shift that can bring access to citizenship to individuals marked with ASD/disability is a nascent possibility at this writing. To make it so, there must be opportunities to discuss and debate the innovations and challenges among the organizations and institutions of the autism community and other disability advocacies. Full applications of the idea will also require changes in the governmentalities that presently organize and control ASD/disability in New Mexico, the several states, the federal government and the various levels of the civil society. However, participants have told me in their interviews and member-checks that the idea and its possibilities brings them the hope and the energy to continue to advocate for it through this period of uncertainty and change.

### **Limitations**

This dissertation was a qualitative study that relied on individual interviews, observations, documentary evidence, and artifacts for analysis to draw out findings. These methods cannot produce the type of generalizations available for quantitative studies that rely on physical laws and deductive reasoning to draw conclusions. However, the findings might be generalized in the limited way that individuals make inductive generalizations that are open to modification in their everyday worlds (Payne & Williams, 2005). These findings might have limited transferability to the study of ASD policy in states with similar demographics, politics, institutions, and organizations. Some

of the policy situations might be similar because they deal with federal laws and mandates. However, the several states also vary in how they respond to federal law with their own policies and regulations. I believe that New Mexico's policy environment is unique to the point that generalizations to other times and places should be made with caution.

A second limitation arises from the nature of the data analysis. Due to the amount of evidence that I collected, I chose to conduct the analysis by developing broad themes that emerged across the data sources. Although I worked inward from those broad themes to capture more detail, I did not analyze small differences among individual participants. I did place individual participants into primary identification groups that I derived from their interviews. I then looked for different policy and practical viewpoints among these groups in order to get a sense of how participants' positionalities influenced their views about policy.

Lastly, I based my data analysis on a particular theory from which I drew my themes and organized my critique. I used a Foucauldian analysis of CDT to understand what was going on within the bounded system of ASD policy in New Mexico. CDT goes beyond what exists now to cast a critical eye on what might yet happen concerning questions of human freedom, justice, and the values of a society (see Glesne, 2011). In the discussion of my findings, I also used information from other theorists and ideas from a range of disciplines in order to draw conclusions around a model I constructed based on my critique. All of this means that my findings and my conclusions are irremediably tied to my positioning. Other qualitative researchers would surely look at the same data with a different eye and find other important results and implications.

## **Implications**

**Future research.** I intended this dissertation research to explore New Mexico's ASD policy in the middle (Knauff, 2006). That is, it was my goal to delve into the ways that ASD/disability policy in the state affect/are affected by Foucauldian critical constructs such as conflicting discourses, the power of governmentality, the use of force, and the unfolding relationships among them. Although I had intended to focus primarily on educational concerns, I quickly discovered that to remain in the middle I had to broaden my view, because ASD policy in New Mexico connects medical, political, educational, therapeutic, and social concerns together. All of these are important to the anthropology in the middle that I was attempting. Nevertheless, working from the middle meant that my findings are painted in broad strokes because of the amount of data generated using this approach. Future research based on this dissertation could go inward to the more personal, individual, or local relationships. It could also go outward, to the broadly regional, national, and international issues that occupy ASD/disability policymakers in more powerful positions.

Moving inward, one interesting topic for further research is the relationship between New Mexico's ASD policy and the knowledge that the neurological and psychological sciences are producing. In this research, I found very little connection between policy initiatives in the socio-political arena and the flood of scientific knowledge about ASD published every month. The only scientific application that a majority of informants to this study discussed was ABA. I think several studies that examine aspects of policy that involve applications of science would be interesting. One might be a more in-depth look at the science behind ABA and its policy applications.



Another study could entail an examination of translational barriers between ASD research and policy applications in social settings. Such studies could elucidate the relationship between science and governmentalities, and the uses of reification to alter power structures.

Moving outward, several studies could consider questions about federalism and its relationship to state and regional governmentalities for ASD/disability. One interesting study might be an examination of changes in the separation of powers and its effects on regional and state policy efforts. A similar study could look into the relationships involved with executive agencies, state governments, and regional intergovernmental agencies. Studies of this type could produce information about optimal balances of power in these systems, and their effect on the development of local, state, and regional policy innovations. They may also show where there are gaps in the system through which innovations might arise.

Finally, there is a need for information about the effect of current policy on certain segments of the population marked by ASD/disability. For example, a finding from this study is the lack of policy about adults with ASD who are past the age of transition. Unless such an individual qualifies for one of the waivers, there are few or no services available to them. It would be very valuable to study this population and the likely diversity of its characteristics. Questions about their numbers, where they live, and their socio-economic status would provide valuable information to translate into good policy for the population. It would also be interesting to learn about their identification or relationship to ASD and to the autism community. Further studies in this area might

focus on the state-to-state and regional differences in the identification and well-being of members of this population, and policy innovations that are valuable to them.

**Practical applications.** The findings from this research has produced applications useful for members of the autism community in their various roles. It has implications for their relationships to other advocacies and governmentalities. The autism community members and participants to this study expressed serious concern about the effects of the demographic and financial problems on autism policy in New Mexico, the several states, and the U.S. At the same time, the possibility of a paradigm shift in how we think about and act on ASD/disability policy provides an opportunity to make changes.

**For governmentalities.** Members of committees, boards, professional societies, advocacy organizations, and other governmentalities all serve by exercising power. Even outside the sitting board, individuals with such memberships have accrued social capital and status. So have those who have acquired licensing, titles, and other forms of sanctions from governmental entities. As discussed earlier in this chapter, there is nothing inherently good or bad about power. It is simply the ability to act, do, or make something happen. However, like everything else humans have or do; power is dangerous (Foucault, 1983). Furthermore, the power exercised in governing ASD is likely to be bio-power, which involves the use of population measures and statistics to divide and assign social status categories to individuals according to a master status that may devalue their individuality, marginalize them, and limit their rights. These concerns are amply evident from the findings in this study.

Participants in this study discussed concerns about how governmentalities manage and control individuals marked with ASD and their families. One area of great concern

was the “passport to services” and misunderstandings of the changes from the DSM-IV to DSM-5. Although the DSM-5 acknowledged that “well established” AS, ASD, and PDD diagnoses from the DSM-IV should be included in the DSM-5 diagnosis of ASD, there is still confusion among psychologists, providers, and the affected individuals and their families. Conversely, informants said that some psychologists and providers are still diagnosing from the DSM-IV, which causes individuals and their families lost time and great expense to get the required passport to services. Self-advocates have questioned the control that the American Psychiatric Association has over the lives of so many people, and psychologists themselves question the power of the DSM (Kirk & Kutchins, 1992, 2008). These gap issues will likely be rethought if the paradigm shifts. In the meantime, governmentalities for ASD in New Mexico might consider publicizing recommendations on this topic outside the autism community.

The surveillance state is another area where participants said that the governmentality of ASD negatively affected their lives. Their concerns centered on the discipline imposed through the expectations of therapists, educators, and service providers who demand that their lives center on the regime of therapy and services with little regard for family life. Some participants pointed out that this focus seemed to indicate that providers are pushing for a cure for ASD. The findings here demonstrated that individuals marked with ASD and their families often do not agree with such a project. The majority of participants in this study valued living their lives while getting some support, rather than “chasing services.” Mothers, in particular, shared their concerns about the unrealistic expectations and the mother-blame associated with ASD

(Courcy & de Rivieres, 2017). Service providers might consider the way that they talk to their clients and the families and think through the demands they might be making.

Another governmentality of ASD is that enforced by the public school system and special education. In the findings for this study, participants discussed problems with the high-low functioning dichotomy most often in relation to education. Self-advocates, advocates, and educators all pointed out that it does not capture the variations of functioning within an individual labeled with ASD. Although the DSM-5 has instituted scales that help professionals assess the severities of different marking behaviors (American Psychiatric Association, 2013), participants said that it has not yet permeated the school culture. Self-advocates pointed out that this has meant that schools and teachers ignore the real needs for those labeled “high-functioning” and the real abilities for those labeled “low-functioning.” The idea of the spectrum itself may have contributed to this problem. However, IDEA demands that schools provide an individualized education for each student placed in the special education governmentality.

Lastly, educator participants had concerns about LRE. All of the educators and many advocates supported inclusion, although they had different ideas about how to implement it. Some educators still argued that students labeled with ASD must earn inclusion by demonstrating progress toward normality. Others worried that students who are not included lose opportunities to grow together with peers and will not have access to citizenship in adulthood. LRE is at the center of IDEA and it is a moral imperative for a society that values freedom and equality. State education officials and school leaders ought to consider making inclusion a schoolwide project in each school. School leaders

should continue to move the culture of their schools to include everyone, and state officials ought to provide guidance and demand accountability.

*Negotiating the clash of discourses.* Language has power. In Western cultures, the power to name is associated with the human powers of order and dominion. In the Western creation story, the order of the world was summoned into existence by the power of the word (Genesis Rabbah 17:4). As I related earlier in this chapter, a discourse represents the body of discussion about a particular subject. The clash of discourses occurs on contested ground (Macgilchrist, 2007). Conflicts of discourse may arise when ways of knowing, thinking and behaving are themselves contested (Foucault, 1991b).

One contested area of discourse is the normal/abnormal dichotomy that is the basis for the dominant, medical model of ASD. There is ample evidence from the findings above that this dichotomy is the basis for master status, othering and marking individuals as abnormal and therefore in need of progress toward normality or a cure. At the same time, the science that manages the definition of ASD does not confirm such a clear-cut division. Characteristics identified as deviant among individuals marked with ASD are present across the full house of the human population (Constantino, 2016; Hyman, 2010). In this research, I found very little discourse on the fundamental scientific knowledge about ASD. This disconnect normalizes the reification of ASD and other DSM categorizations as natural kinds. To combat these divisions, scientists and policymakers could promote a much fuller translational discourse together.

Early in this chapter, I briefly problematized person-first language. I pointed out that although well intentioned, it is still planted firmly in the normal/abnormal dichotomy. In a study of professional journals, Gernsbacher (2017) noticed that authors

used person-first language only to identify disability, and they called people considered non-disabled, “persons.” As self-advocates pointed out, person-first language does not end condescending and controlling treatment of individuals on its own. Changing our language must go beyond person-first and take into account the individual identities people carry with the labels they have been assigned. As Hacking (1995) wrote, the reification of neurodevelopmental conditions has created a looping effect in which populations defined by the DSM (and other such schemata) become separate, human kinds and develop identities as such. The UNM College of Education, and especially the Special Education Department, would be a good place to continue to foster counter-and competing discourses about identifying language. The department could then more fully fulfill its mission to the wider community by bringing these discussions out of the academy and into scientific and professional spaces.

*Ending the violence.* In the model I developed above, I suggested that violence in the system is the result of the pressures our governmentalities place on all of us. I suggested that violence is a marker that systems are not working, that governmentalities have become oppressive, and that the people involved have no way to make change. If our goal is access to citizenship for individuals marked with ASD among all persons, then the violence must end. In her article *Inclusion as an Ethical Project*, Julie Allan (2005) wrote that reducing inclusion “to a technical matter or problem of resource distribution has deflected attention away from the radical changes” (p. 281) needed to make it happen. As Allan wrote of inclusion, so it is with violence. It is upon us to begin with ourselves. Therefore, I recommend that taking concrete measures to end violence as

an ethical project is incumbent on advocates, educators, policymakers, professionals, and self-advocates.

One of the first steps to ending violence is to recognize that symbolic violence is a violation of an individual's rights (Bourdieu & Passeron, 2000; Colaguori, 2010). It is important for everyone who deals with human beings to recognize the unalienable rights that everyone possesses by virtue of being born human. It is upon us to remember the humanity of the other and practice non-violence by recognizing personal boundaries, practicing honest disclosure, and paying attention to the intent of virtue signaling.

Sadly, the findings discussed here included concrete violence in the form of bullying, restraints, and seclusion in schools. Some of the participants in this research spent years working to change the law, regulations, and institutional policies that allow violence. One participant who worked to end restraints and seclusions in schools argued that teachers who got the proper supports did not need to use force against children. Making sure that people have the supports they need is part of the structural change that must occur to end violence. Another part is to honor and properly compensate the work of teachers and other service providers. Bourdieu and Passeron (2000) theorized that violence and issues of power, status, and social capital are closely related. Therefore, it is imperative to take care of the needs of the people who educate the next generation in order to end violence in New Mexico's schools.

*Self-advocates in a time paradigm shift.* In this discussion, I have argued that the forces of governmentality and reactions to it have brought ASD policy to edge of a paradigm shift. The qualities of such a shift are only now forming, and individuals marked with ASD have the opportunity to shape its result. In order for the resulting

paradigm to accommodate autism identities, it is upon us (autists, autistics, aspergians, people with ASD, self-advocates, no-label, human beings, fellow travelers, etc.) to query the various *knowings* about ASD. The purpose to this challenge is to identify and contest the discourses that created the dominant constructs of ASD. These suggestions for self-advocates comprise a modest proposal on how to begin.

The findings from this study confirmed that the medical model informs the dominant discourse around ASD within the autism community in New Mexico. In the English-speaking world, the prevailing construct defines it as a neurobiological disorder located in an individual's brain that produces social-communication deficits in functioning. Although I constructed this particular wording, similar definitions can be found in the introductions of any of the neuroscience papers cited in this dissertation. The definition locates ASD in the individual, who is marked as deficient and lacking, making it a classic medical model construct (Jones, 1996; Tremain, 2005). O'Dell et al. argued that ongoing research regarding ASD's etiology, defined biological markers, and its developmental emergence has not produced a coherent "brain-based explanation that fully accounts for autism" (p. 172). However, neurobiological accounts about ASD and other neurodevelopmental conditions have accrued great explanatory power and the cultural saliency to define human identity and citizenship (Rose & Novas, 2005).

The reduction of ASD to a purely brain-based phenomenon has inspired a counter discourse that uses the same neuroscience to frame it as one variation of neuro-function among many across the human race (O'Dell et al., 2016). The neurodiversity discourse counters the normal/abnormal dichotomy by framing ASD as a diverse variation to the neurotypical (NT) norm (Attwood, 1998; Broderick & Ne'eman, 2008). O'Dell et al.



concluded that neurodiversity challenges the concept of a unitary neuro-normal cognitive identity and therefore uncovers and names the governmentality that normalizes NT functioning and assigns ASD as a deficit status.

It is important for me to emphasize here that the neurodiversity movement does not reject the neurobiological basis of ASD, but frames the current research as supportive of the phenomenological nature of the designation and of the continuous nature of its traits across the normal curve. In our use of neurodiversity to challenge the normal/abnormal dichotomy, self-advocates are not rejecting ASD identities. Rather, we are rejecting the segregation, stigmatization, and othering that the medical model has produced.

This historical sketch provides valuable insights for autism self-advocates now riding the tsunami. The neurodiversity construct has its critics, but it does show us a way to reframe the prevailing deficit model of ASD. Furthermore, it provides a model for moving from an advocacy based on disability and need, to a self-advocacy based on diverse abilities and rights. As with the ethical project discussed above, this would allow us to see ourselves not as passive subjects, but as the main source of our own transformation and access to citizenship.

### **Answers to the Research Questions**

#### 1. Who are the key decision-makers in ASD policy in New Mexico?

The decision-makers around ASD policy in New Mexico are self-selected individuals involved in ASD policy through a variety of entry points as advocates, educators, policymakers, politicians, professionals, and/or self-advocates. Most of the

decision-makers affiliated with more than one of these identifications, but were primarily involved with one at the time of this research.

Furthermore, a mismatch exists between the backgrounds of the decision-makers who participated in the study and the population of New Mexico whom they serve. Whereas the state's population is majority Hispanic, only four participants identified as such. Almost three-fourths of the decision-makers were not native New Mexicans, although half of them had lived in the state for more than 27 years. These differences may represent disparities of power and access that the participants in the study did not discuss. They may rise from New Mexico's unique cultural context, the rural-urban divide, and the socio-economic disparities these differences highlight. More information on the decision-makers can be found in the description of the participants in Chapter 4.

2. What information do decision-makers use to inform their decision-making process?

The participants to this study primarily made their decisions based on their understanding of ASD/disability as defined by the prevailing medical model, their historical knowledge of ASD/disability policy in New Mexico, and the current legal mandates coming from the federal and state agencies that manage and finance that policy. Policymakers in the state are particularly concerned about compliance with federal mandates because of the high poverty rate among the people of the state, and the number of people who rely on federal programs such as Medicaid and the waivers to finance care and treatment for ASD/disability. As I pointed out in the context section of Chapter 4, the current fiscal crisis in New Mexico requires policymakers to obtain a great deal of knowledge about federal mandates and financial grants to the state.

3. What are the decision-makers' assumptions and values about disability and ASD, and how do these operate in their decision-making?

Although the decision-makers rely on the medical model for information, their assumptions and values about disability and ASD are more complex. For example, they do not necessarily assume that disability is located in the individual so labeled. Rather, many of them described an evolution in their thinking about disability and the relationship of the individual so labeled to the social context in New Mexico. The disparity between their assumptions and values and the information they rely on to make decisions was most apparent in their descriptions of their dreams for good policy going forward. Many of them described an evolutionary approach to policy, and wrestled with the question of how to move forward from the presently difficult state financial situation to a more comprehensive and inclusive ASD policy in the future. Detailed descriptions of participant values and beliefs can be found in the findings sections in Chapter 4.

4. To what extent does ASD policy take into account current perspectives in the neurobiology and neuropsychology of ASD?

The decision-makers I interviewed for this study did not discuss the current perspectives in neurobiology and neuropsychology at all. The only science they referred to related to ABA, and only two participants mentioned the science behind it. These participants and several others also described the institution of evidence-based practices when I asked about scientific understandings of ASD. However, evidence-based practices refer to research on the efficacy of interventions, and do not stem from the basic research that informs the evolving scientific understandings of ASD. This disconnect between the basic research that informs our scientific understandings of ASD and policy decisions in

New Mexico is unfortunate because evolving knowledge about the biological bases for ASD would add to our understanding of its diversity within Gould's full house (Gould, 1996a; Gould, 1996b).

### **Conclusion**

I began this study with the intention to research ASD policy related to public education in New Mexico from the perspective of CDT and the social construction of disability. With that in mind, I began with a short introduction of the social construction of disability and a discussion of the medical model of disability. I described the medical model as the prevailing construct of disability in the U.S. and discussed how it was used to identify, label, and qualify students for special education services. I then introduced special education policy and gave a brief, historical outline of its guiding philosophy and practice. I also described a philosophical divide among special educators about appropriate placements and practices, and I discussed how the controversies related to changes in special education policy and practices. I defined ASD, briefly discussed its basic characteristics, and some of the scientific consensus and controversies around it.

I then looked into literature concerning recent trends in special education policy in the U.S. That literature covered policy developed by the federal government and mandated to the several states. I found very little literature about policymaking at the state level. That literature was mostly concerned with state regulations and state governments' different interpretations of the federal laws and policy. I found only two documents that discussed New Mexico's response to these federal policy initiatives. They were not substantial, and neither covered some of our state's resistance to certain federal special education policies. I found no literature that described how policymaking was

done, nor any that described policymakers' identities, methods, values, and knowledge regarding educational policymaking in our state. I also found no literature about these qualities among ASD policymakers. I believed that this is a significant gap because policymakers would bring their passion for good ASD policy, their methodologies and methods, their political and professional connections, and their values and beliefs about ASD/disability to the policy table. I also believed that there were significant gaps between the goals ASD policymakers intended and the reality of their application in New Mexico schools, hospitals and service centers. I thought that large segments of the population with ASD were poorly served by the policies that existed in New Mexico at the time of this research. For these reasons, I argued that research was needed that provided an understanding of the ASD policymaking process; the knowledge, values, and beliefs of the politicians and policymakers; and those of the advocates, educators, professionals, and self-advocates involved in the process. I argued that such a contribution would fill a gap in the literature and serve the people involved in ASD policymaking in New Mexico.

My purpose when I proposed this study was to critically examine the relationships and networks that underlie ASD policymaking in New Mexico. My goal was to understand the identities, motivations, and knowledge people bring to the policy table, and what values and beliefs about disability and ASD influence their decisions. My primary question was: How is ASD policy in New Mexico constructed? I used a Foucauldian analysis of CDT with the social construction of disability to interpret my findings about how ASD policy is constructed.

For Chapter 2, I conducted an extensive review of the literature. I included: (a) a history of the evolution of federal education policy, including sections on special education and ASD policy, (b) an overview of models for policymaking, and (c) an overview of critical theory and CDT. In Chapter 3, I described my research design and methods for this work. My methodology was a case study, and the bounded system was the state of New Mexico. I provided an extensive description of the case. I gathered data from four sources: individual interviews, participant observations at public meetings, documentary evidence, and researcher journal. I submitted my research plan to the university's main campus Institutional Review Board on Human Subject Research and received an exempt approval. I collected interview data and member checks from 20 individuals, observed 4 day-long meetings of a legislative committee and an agency board, and reviewed 10 documents.

In Chapter 4, I provided a description of the context in which I collected the data and of the participants in the study. I presented findings that I derived from coding and analyzing data from the above-mentioned sources. I uncovered six major themes: *Tension in the Discursive Field: Who's Will to Truth? Dividing Practices: Who's Power to Name? Reifying Autism: Who's Power to Define? The Use of Force: Who Imposes Power? The Government of Autism: Who Owns the Power? Finally, Autism Tsunami Policy Paradigm Shift*. Through these themes, I addressed my research questions. *Tension in the Discursive Field, Violence, The Government of Autism, and Autism Policy Paradigm Shift* all addressed who are the key policy decision-makers. I found the information that participants used to make their decisions in *Tension in the Discursive Field, Dividing Practices, Reifying Autism, The Government of Autism, and Autism Policy Paradigm*

*Shift*. Through the themes *Tension in the Discursive Field*, *Dividing Practices*, *The Use of Force*, *The Government of Autism*, and *Autism Tsunami Policy Paradigm Shift*, I discerned the assumptions and values that participants held about ASD/disability. Only two themes addressed the question about the use of the neurosciences in decision-making, *Tension in the Discursive Field* and in *Dividing Practices*, and the extent of its use was very small.

During the time that I conducted this study, the autism community in New Mexico was experiencing the hopes, fears, and concerns that come in a time of changing expectations. These changes came from forces outside the community, but also from inside of it. From the outside came pressures from the state's financial crisis, which threatened hard-won funding for many of the programs for ASD and other disabilities. From afar came pressures that developed from America's political and sociocultural changes. From within, the community was experiencing conflicts related to the autism tsunami. Visionary members of the autism community had begun to think about the opportunity and danger that comes with the commitment to change the world. Through this research, I learned who the key decision-makers for ASD policy in New Mexico were. Some were the high-level policymakers that I had envisioned at the beginning of the study. Many were not. They were parents, teachers, service-providers, political organizers, activists, and self-advocates. Although they came into the community from different entry-points, they became decision-makers because they persevered. They developed the ability to sit for the hours required to make themselves experts in some aspect of ASD/disability policy. ASD policy in New Mexico is a do-it yourself project.

From the perspective of CDT, I found many ways to trouble the received knowledge, the definitions, constructs, and the practices around ASD in New Mexico. In this dissertation, I began to query the dichotomies autistic/non-autistic, disabled/abled, and abnormal/normal. The assumptions behind these dichotomies divide and marginalize the autistic world as the devalued other. Yet these assumptions undergird the governmentalities that discipline and control the unruly other, and make them governable. I noticed that as outside forces began to put pressure on the governmentalities, they responded by increasing pressures to contain and govern the other, to continue to shape the subject closer to normal. With the increasing pressure of governmentality came eruptions of clashing discourses, resistances, and violence. The positive feedback loop of pressure, eruptions, and the incoming autism tsunami are pushing the system toward change. The governmentalities that exist now are not sustainable. There must be something new under the sun. A paradigm shift.

In the *Genealogy of Ethics* (as cited in Tremain, 2005), Foucault said, “my point is not that everything is bad, but that everything is dangerous, which is not exactly the same thing as bad. If everything is dangerous, then we always have something to do.” The passage through a paradigm shift for ASD policy in New Mexico represents the regeneracy of a crisis. It is a point of maximum danger. We have much to do. I believe New Mexicans are up to it. I learned about the values and beliefs of the members of the autism community who contributed to this study. They are of the highest quality. As Pat Osborn, Director of Autism Services at the CDD maintained, “New Mexicans are scrappy!”



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## **Appendices**

### **Appendix A Acronyms**

#### **List of Acronyms and Terms**

APA: American Psychiatric Association

ASD: Autism Spectrum Disorders

AUCD Association of University Centers on Disability

Autism CARES: Autism Collaboration, Accountability, Research and Support Act

CDT: Critical Disability Theory

CMS: Centers for Medicare and Medicaid Services

DD: Developmental Disability (Act and Waiver)

DDSD: Developmental Disabilities Services Division

DSM: APA Diagnostic and Statistical Manual

ESEA: Elementary and Secondary Education Act

FAPE: Free Appropriate Public Education

HF-ASD: High-Functioning ASD

ID: Intellectual Disability

IDEA: Individuals with Disabilities Education Act

IEP: Individual Education Plan

IQ: Intelligence Quotient

LD: Learning Disability

LEND: Leadership Education in Neurodevelopmental and Other Disabilities

LRE: Least Restrictive Environment

MCH: (Federal Division of) Maternal-Child Health

NCLB: No Child Left Behind Act

NGO: Non-governmental Organization

PDD: Pervasive Developmental Disorder

PED: (New Mexico) Public Education Department

## Appendix B Questions

### Interview Questions

1. Tell me about disability. When I say the word “disability,” what comes to mind? If necessary, elaborate by asking: What role does disability play in your world? Your work? Your policy ideas?
2. Tell me what you think of when I say “autism” or “Autism Spectrum Disorder (ASD).” If necessary, elaborate by asking: What role does ASD play in your world? Your work? Your policy ideas?
3. Tell me about policymaking for disability/ASD. How should ASD policy be developed in New Mexico? Who should be involved? What are the characteristics of good disability/ASD policy?

## Appendix C Rules

### Transcription Rules

#### 1. Page set-up:

- a. Header: Interviewee name/pseudonym, institution code, date and file number.
- b. Body double-spaced, wide margins.

#### 2. Paragraphing, title rules:

- a. Interviewer: “EHL”
- b. Interviewee: name/pseudonym as determined by consent procedures.
- c. New paragraph for interviewer question, interviewee responses.

#### 3. Transcribe:

- a. Literally, as spoken by interviewee. Do not clean up grammar, pronunciation.
- b. Do separate words when interviewee blends them together.
- c. Unintelligible words in parentheses with question mark e.g. (xxxx?)
- d. Indicate speeding up, slowing down, whispers in parentheses e.g. (whispers).
- e. Use capitals for louder speech e.g. STOP, use **BOLD** for very emphatic speech.
- f. Use period for definitive sounding full stop even if statement is actually a question.
- g. Use question mark for rise at end of sentence, even when a question is not being asked.
- h. Use brackets to describe non-verbal cues e.g. [clear’s throat].
- i. Use ellipses to indicate pauses: short pause . . . medium pause . . . . long pause . . . . .
- j. Handle voice-over-voice using dashes. For example: EHL: So when they—

Interviewee: —but then I said . . .

k. Indicate interruptions by braces e.g. {phone rings}