

PROBLEMATIZING THE DEFICIT DISCOURSES OF PEOPLE WITH AUTISM AND
AUTISM PARENTS: A POSTSTRUCTURAL ANALYSIS OF SUBJECTIVITY AND
POWER/KNOWLEDGE

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by
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Abstract

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Through an interweaving of analysis and personal narrative, this postqualitative inquiry uses Foucauldian concepts of power/knowledge and subjectivity as method, thinking with the theory at all stages of research. Both medical and educational discourses of autism are problematized for their focus on disability as a deficit in comparison to normative standards. In each discourse, people with autism and their families are positioned as being in need of repair. Discourse analysis reveals the relations of power/knowledge and subjectivity for people with autism and their parents before, during, and after receiving an autism diagnosis in early childhood based on a chronological retelling of the author's experiences with her son. Key themes that emerge from the analysis are the relations of power based on surveillance, counting, and control; the production of docile bodies and productive

citizens; the privileging and measurement of certain types of knowledge; and the limiting of subjectivities as embodiments of compliance or resistance. Interludes offer space for thinking with affirmative difference and reimagining knowledge and learning with autistic perception in mind. Possibilities are opened for educational leaders and the Individualized Education Plan (IEP) process to foster spaces, interactions, and processes from a mindset of affirmative difference rather than one of reducing or eliminating abnormalities.

Keywords: autism, special education, affirmative difference, Foucault, Deleuze, Manning, power/knowledge, subjectivity, autism parents

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Dedication

This work is dedicated to:

Dean and Patsy Wilson, whose faithfulness and love have guided me, whose help and support have sustained me, and whose work ethic and compassion have inspired me.

Alicia Wilson, who is the smartest and strongest woman I know, both my sister and my life-long friend.

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Barrett Shoaf, my son and God's greatest gift in my life, who makes me a better person every day and has taught me more already than I will ever teach him.

Any parent whose child has been given a label marking them as deficient. May you have the tenacity to advocate, peace within yourself, and unbounded love for the unique and beautiful human your child is *becoming*.

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CHAPTER ONE: INTRODUCTION

Parenting is accompanied by worry, hopes, uncertainty, dreams, challenges, frustrations, and immeasurable joy. The journey of parenting a child with special needs can be even more complex, especially when the child's diagnosis is one like autism, which is not as outwardly visible as other diagnosed disabilities. Autism parents navigate through a sea of information from the medical and research communities, government agencies offering resources and services, and educational or therapeutic service providers. These parents act as caregivers, playmates, scientists, contract negotiators, secretaries, and advocates in trying to determine the best resources to pursue for their child. Because they serve as the common denominator among all service providers, doctors, insurance companies, and teachers, autism parents face the daunting task of piecing together all of the separate components into one cohesive picture that best aligns with the needs of their child. Along the way, autism parents are confronted with the ways in which their child is not typical: how he or she is falling behind and not measuring up to society's norms.

My dissertation study seeks to trouble the landscape, or discourse, surrounding autism in the medical/research community and in education, particularly as it applies to parents and families. The purpose of my study is to use poststructural theory to problematize normative assumptions about people with autism and to critique the positioning of autism parents within relations of power and discourse. In this poststructural study, I will weave theory and reflexivity with poststructural problematization in order to deconstruct the discourses of autism diagnosis, intervention, and education – paying particular attention to the subjectivities of autism parents. Three analytic questions that guide this inquiry are:

1. What is the problem represented to be regarding autism across medical and educational discourses?
2. What is the interplay among subjectivity, power, and knowledge for autism parents within these discourses? What does this interplay produce?
3. How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their families?

My approach is important and significant because I am writing from within my own role as an autism parent instead of conducting “neutral” or “objective” research about autism parents as an outsider. My study will work across discourses to offer readers a critical deconstruction of the messaging that autism parents receive about their child at various stages.

Before proceeding, it is important to clarify a few terms that will feature heavily in this analysis. First, I use the term *autism* throughout this work because it simultaneously serves as a rejection of the deficit-centered diagnostic language of Autism Spectrum Disorder (ASD) and works as a descriptor of a different way of encountering the world. The definition of Autism Spectrum Disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition), more commonly referred to as *DSM-5* (American Psychiatric Association, 2013) reveals how deficit-centered framing within the medical community creates fixed identities and subjectivities for individuals that can have far-reaching effects on their lives. Just within the two sentences of the *DSM-5*’s definition, there are seven uses of deficit-centered language. The condition of autism itself is labeled as a “disorder,” implying something inherently *wrong or dysfunctional* about any individual who will fall into this category. Autism Spectrum Disorder is characterized by “deficits” in social communication

skills, emphasized as being “persistent,” and this deficiency in social communication is repeated twice to further clarify exactly what is *lacking*. Additionally, the diagnosis of Autism Spectrum Disorder requires that an individual also exhibit “restricted” and “repetitive” behaviors or interests, which signals a *comparison* between the behaviors of a person with autism and those of an individual who is considered to be *normal*. Therefore, I will use ASD only when I am referring to its inclusion in policies and other documents. The term *autism*, on the other hand, has been embraced by members of the autistic community as an expression of the unique beauty and joy that come with a different way of embodying and thinking the world (Bascom, 2011; Shore, 2003; Sinclair, 2012/1993). At the same time, *autism* is widely recognizable by much of the general public, allowing for at least a basic level of shared understanding and a starting point for conversation and exploration.

Also, I recognize and value the diversity of forms a family can take, and honor the contributions and experiences of all types of caregivers. The terms *parent* and *family* are used somewhat interchangeably in my writing to strengthen the connotations of personal connection and emotional ties in relation to caring for a child with autism. These terms are also the most accurate reflection of my personal journey with autism, which will bring continuity as I insert vignettes of personal experiences alongside my analysis as a researcher. It is my hope that the use of these terms will serve to make the joys and frustrations associated with being a caregiver of a child with autism more palpable rather than being exclusionary.

Context

A Brief History of Autism

Although the autism community benefits from increased awareness in the general population over the last few decades, its history as a recognized medical diagnosis is fairly new. Introduced by Leo Kanner in 1943 as a phenomenon not previously identified elsewhere, autism was originally believed to be a form of childhood schizophrenia (Kanner, 1943). While classifications and diagnostic criteria have changed over time, Kanner identified “autistic” behaviors in this early work, such as echolalic speech (the repetition of sounds and phrases that have been heard in the environment), fixation on objects over people, and a tendency to retreat to an inner world that isolates the individual from his or her surroundings. Major symptoms of autism associated with Kanner’s work remain in the current language of diagnosis with the focus being on social and communication limitations and repetitive behaviors (Rosen et al., 2021). Kanner’s (1943) reporting of these cases involving patients referred to him from various medical institutions combined clinical observations of children with autism with communications from their parents.

Although the contributions of parents were considered equally with clinical observations in Kanner’s writing about what seemed to be a new diagnosis, he also noted “the contributory effects of parental lack of warmth on constitutionally predisposed children” (Wolff, 2004, p. 204). With little understanding of the causes of autism, the tendency to evaluate parental characteristics alongside those of the person with autism has been part of autism diagnosis and research from its inception. The idea that parents caused, or at least exacerbated, autism in their children was emphasized in the “refrigerator mother” theory of autism put forward by Bettelheim (1967). Bettelheim asserted that the challenges with social

and communication skills facing children with autism are a direct result of cold and uncaring parenting, particularly on the part of the mother. Parent blaming and shaming contributed to the creation of stigmas surrounding autism and other intellectual disabilities that members of the autism community are still trying to combat today (Dolnick, 1998; Rank, 1949).

By the late 1970s, the medical community began to expand their search for causes of autism beyond parental behaviors, seeking proof that autism was genetic, tying it to other diseases and conditions, and working to distinguish it from other childhood mental disorders, which would eventually remove its link to schizophrenia (Wolff, 2004). Autism's inclusion in the *Diagnostic and Statistical Manual of Mental Disorders* (3rd edition), or DSM-III (American Psychiatric Association, 1980), as a separate diagnosis set the stage for expanding research and debating classifications, with 1,500 to 2,000 papers on autism published annually as of 2014 (Volkmar & McPartland, 2014). In 1981, Lorna Wing reintroduced the work of Hans Asperger from 1944 that described a more high-functioning form of autism (Wing, 1981). Asperger's syndrome became a separate diagnosis describing individuals who lack social skills and exhibit certain stereotypic behaviors of autism, yet are believed to be *gifted* in particular academic areas with creative ways of thinking (Wolff, 2004). Much of the discourse in popular culture surrounding autism focuses on those individuals with Asperger's syndrome, or at least those who have been classified as higher functioning, because those individuals are more able to participate "normally" in society and are thus more visible. Organizations like AutismSpeaks (2021) and the Autism Society of America (2020) have worked to increase awareness about the full spectrum of autism and the acceptance of individuals with autism in mainstream society.

Neurodiversity

Concurrently, the neurodiversity movement within the autism community has relied on the idea of a spectrum of abilities and neurological expression to dismantle the idea of neurotypicality. Instead of contrasting autism with neurotypicality, which sets people with autism up to be viewed as abnormal, neurodiversity sees autism as a completely different way of being. As Sinclair (2012/1993) explains, “Autism isn't something a person has, or a “shell” that a person is trapped inside. There’s no normal child hidden behind the autism. Autism is a way of being” (p. 1). Sinclair goes on to say that “it is not possible to separate the autism from the person--and if it were possible, the person you’d have left would not be the same person you started with” (p. 1). The neurodiversity movement pushes back against the tendency to label the world with binary oppositions such as able/disabled and normal/abnormal by advocating for the recognition of a spectrum of ways to be fully human.

First appearing in print in an article in *The Atlantic* by Harvey Blume (1998), the term “neurodiversity” was originally coined by Judy Singer, the parent of a child diagnosed with Asperger’s syndrome (Armstrong, 2010) and has sparked an international movement to embrace neurological differences as part of a continuum rather than evidence of deficiency. Only through a more expansive framework like that of neurodiversity can we seek to explore new possibilities for people with autism. Within the neurodiversity framework, the focus moves from curing and treating autism as a means of helping the individual function more normally in society to embracing *all the ways to be fully human*.

Embracing the full spectrum of ways to be human moves beyond a simple awareness of autism as a difference. It calls for recognizing autism as a unique way of being in the world. Manning and Massumi (2014) write that “it is a question of the diversity of modes of

existence, and of the modes of thought they enact, and of the varieties of expressive outcomes they compose, and of the differing determinations of experience those outcomes instantiate in the world” (p. 22). This “diversity of modes of existence” cannot be encapsulated in categorizations like autistic or non-autistic, neurotypical or neurodiverse. Instead, the mode of existence for each person, especially for those people with autism, lies somewhere on a spectrum of capabilities. Yet, it is important to remember that the concept of neurodiversity, while inextricably linked with and critical to a study of autism, includes other conditions like dyslexia, attention deficit/hyperactivity disorder, and Tourette’s syndrome (Lerman, 2022). Therefore, my dissertation will foreground the use of the term *autism* as a means for clarifying the discourse and my own thinking.

Ways Autism Is Currently Experienced By Parents

According to the most recent estimates based on a study conducted in 2016 in 11 communities across multiple states, one out of every 54 eight-year-old children is diagnosed with Autism Spectrum Disorder, representing roughly 1.85% of the population of the same age (Autism and Developmental Disabilities Monitoring Network, 2020). Autism is widely studied yet its causes are still relatively unknown and there is disagreement about the most effective treatments and interventions. Even the act of diagnosing autism poses challenges as it is largely based on observation in contrast to other physical or developmental differences that can be detected through blood tests or other DNA sampling. The wide range of symptoms and severity of autism further complicates its diagnosis, preventing the application of a universal medical test (Mayo Foundation for Medical Education and Research, 2018). Making the diagnostic process more difficult is the wide range of comorbidities that may present alongside Autism Spectrum Disorder, including physical conditions like

gastrointestinal dysfunction, sleep irregularities, metabolic disorders, and hormonal imbalances (Bauman, 2010) and mental health conditions such as Attention Deficit Hyperactivity Disorder (ADHD), depression, anxiety, and conduct disorder/challenging behaviors (Matson & Williams, 2013). An additional barrier to diagnosis is that a child's pediatrician cannot diagnose autism, but rather has to make a referral to a specialist such as a child psychologist or psychiatrist, developmental pediatrician, or pediatric neurologist for an evaluation. (Mayo Foundation for Medical Education and Research, 2018).

Families encounter this lack of clarity prior to and upon receiving a diagnosis of Autism Spectrum Disorder while simultaneously feeling pressured to make decisions and access services for their child quickly. As the Centers for Disease Control and Prevention (2020b) cautions, "By the time [children with ASD] are identified, significant delays may have occurred and opportunities for intervention might have been missed. Getting services as early as possible can make a difference in the development of a child with ASD" (n.p.). During the critical period for intervention, the onus for recognizing signs of difference in a child and accessing recommended services falls almost exclusively on the shoulders of the parents, a daunting task made only more complicated if the family faces a lack of resources, education, or access to care. Parents often receive information about clinical service providers, advocacy organizations, support groups, parent training materials, how to access funding, and strategies for interacting with their child all within the same conversation where they receive the autism diagnosis (Carolina Institute for Developmental Disabilities, personal communication, March 20, 2019). At the same time that they are sifting through the overwhelming mass of information in the discourse about autism, parents are also coming to

terms with the implications of their new role as an autism parent for themselves, their child with autism, and their other family members.

Problem and Purpose

Because of the enormous role they play in the identification of autism in their child and the level of support that their child receives following diagnosis, autism parents are frequently sought after as research participants. In traditional autism research studies, parents are asked to complete surveys or questionnaires about their stress levels (Cachia et al., 2016; Shamash & Hinman, 2021; Shepherd et al., 2018;), participate in semi-structured interviews on a variety of topics (Bowling et al., 2019; Rabba et al., 2019; Smith et al., 2020), and even to submit saliva samples for DNA testing (Simons Foundation, 2021). A commonality across all of these formats is that they take something tangible or intangible from parents and report it back through the lens of the researcher. This research is designed to meet the needs of the researcher first by answering the research question and yielding publishable, and possibly actionable, results. Although the results and recommendations of such research may work toward better diagnostic procedures and treatment options for the autism community at large, they do not typically provide direct benefits for the parents and families who participate outside of the parameters of the study.

What is necessary is an analysis of the systems, processes, and published information that form the discourse about autism and the ways that this discourse positions people with autism and their families. Discourse is “more than simply a group of statements or a stretch of text on paper, discourse can be characterized as a dynamic constellation of words and images that legitimate and produce a certain reality” (Allan, 2003, p. 37). What the discourse legitimates then shapes what is considered to be normal, positioning people and ideas within

or outside of the dominant discourse. According to Preston and Hoffman (2015), “Discourse, in its role as forming frames of knowledge and reference, also creates an understanding of individual identity. It allows people to understand and take up identities” (p. 64). Therefore, people with autism and autism parents will experience their own sense of self as part of the larger discourse.

As a departure from traditional means of research, my analysis will trouble this larger discourse of autism, looking at what is offered to parents alongside what is expected from them, while exploring the interplay of my own positionalities as an autism parent, educator, and researcher. Traditional research studies work toward causes, treatments, and cures for autism as a disease or disorder, or they seek to observe patterns and trends in the thoughts and behaviors of individuals affected by autism (Interagency Autism Coordinating Committee, 2021). Although researchers may have a vested and benevolent interest in studying autism as medical, therapeutic, or educational service providers, they are usually working from an outsider status because they are not individuals with autism or autism parents themselves (Pellicano et al., 2014). Previous research hones in on one aspect of autism or one sample of the population of the autism community (Organization for Autism Research, 2021). This limiting and narrow view may produce statistically valid results and raise awareness or understanding, but it prevents the researcher from taking a broader, systems-level view of the discourse. Also, participants in traditional research studies rarely receive information about the findings of the research, leaving them with little benefit from participation (Simons Foundation, 2021).

The purpose of my analysis is to examine the discourse surrounding individuals with autism and autism parents at the institutional, systemic level. By interweaving personal

experiences into my writing, I will build on my subjectivity as an autism parent to reflect on my own positioning within the discourse. My approach will be one of questioning rather than finding solutions, with the ultimate goal of opening new possibilities for people with autism and their families. My claim is that, across discourses, there will be a noticeable depiction of autism and people with autism as a problem to be solved with a focus on the ways that these individuals deviate from what is “normal.” By deconstructing the diagnostic criteria and process, resources available to parents, and special education services, I will be revealing a different perspective on knowledge that has become widely accepted.

Significance

Existing research on autism is experimental or qualitative and seeks specific solutions. My study is significant for its use of discourse analysis and its questioning of existing systems, processes, and knowledge. Instead of seeking to further define autism and to find ways to help people with autism adapt more normally in society, my analysis will question why certain ideas have become dominant and normalized. Disrupting what has become taken-for-granted creates new questions and knowledge. Additionally, because most autism research is done by outsiders, the inclusion of my voice as an autism parent is significant for its addition of the lived impact of the discourse surrounding autism.

Personal Connection to the Topic

The entirety of my career in education, both as a teacher and learner, has existed within the discourse of accountability and standardization. Students in my classes and I have been evaluated, labeled, and measured by test scores. Graduate school courses taught me to consult quantitative data and research to make informed decisions, as well as to engage in action research as a reflective practitioner in order to solve problems in my classroom, my

school, and my district. A normative assumption typical to such educational research is that students, teachers, schools, districts, and states are problems to be solved; undesirable test results or other performance measures would be eliminated if we, as educators and researchers, could only find the right intervention or solution. These processes revealed, and continue to reveal, systemic inequities time and again with little promise of lasting change, giving the impression that the system is broken, but that all we can do is continue to measure its brokenness.

One specific area of education that tends to mirror this image of measured brokenness is the Individualized Education Program (IEP) process. In this highly formulaic and federally regulated process, special education teachers try to map out the most effective services and instructional modifications for each student on their caseload. Guided by their heart for students and dedicated passion to see them succeed, special education teachers are often restricted by the legislation, funding, and parameters set on their services from federal, state, and district levels. I served as the “regular education” teacher in countless IEP meetings, empathizing with parents and special education teachers as I shared anecdotal, observational, and testing documentation of a student's progress and needs, along with my own classroom modifications or accommodations for that student. My heart ached for many of my students because of glaring inequities in the educational system, which propelled me toward opportunities for advocacy and social justice. Yet, these efforts seemed to make little progress, so I continued to seek ways to have a greater impact by moving out of the classroom and continuing my education. Looking back, I realize that my intentions were honorable, but my work was misguided. I was working from within a normative framework, railing against the system, but asking the wrong questions.

Although continued personal and professional growth as an educator is an important aspect of my career, nothing in my life has changed my ability to see from a different perspective more than becoming an autism parent. Reflecting back on the last three years since my son's diagnosis reveals how much my interactions with him have reframed my subjectivities within and across discourses, but also my awareness of normative assumptions at work. Many experiences in helping my son to deal with the world are positive as society's awareness of autism increases; however, there are still countless examples of situations where normative assumptions place limitations on our family's ability to fully engage and participate. One normative assumption within the educational discourse is that students who receive special education services cannot also be academically gifted. My son breaks this mold since he is already a very proficient reader at age 6, but he needs significant special education support for social and functional skills. As he enters kindergarten and we contemplate the best placement and services for him to thrive in an educational environment, we will face decisions that may pigeonhole him in a setting that is supportive, but not academically challenging, or one that is academically appropriate, but not inclusive of the supports he needs. Expanding my own thinking (and hopefully the thinking of others regarding autism) will help me to open more possibilities for my son and our family, but also to extend the "field of possibles" within the discourses of education at large (Greene, 1987-88).

My analysis of the educational discourse of disability works to uncover the normative assumptions within special education processes and services, especially the ways in which parents are set up to comply with or resist recommendations for their child's education. Mirroring the problematizations of the medical discourse surrounding autism diagnosis,

federal legislation regarding special education also produces a deficit-centered discourse, one that operates on taken-for-granted assumptions about normativity, about learning, and about intelligence. Systems and processes are in place that create hierarchies and categorizations within the attempt to create an IEP for a child's individual needs. Exploring how power, knowledge, and subjectivity interrelate within the discourse of special education for autism parents can open up new questions and considerations for educational leaders.

Overview of the Methodology

The purpose of my study is to use poststructural theory to problematize normative assumptions about people with autism and to critique the positioning (or subjectivity) of autism parents within relations of power/knowledge and discourse. Three analytic questions that guide this inquiry are:

1. What is the problem represented to be regarding autism across medical and educational discourses?
2. What is the interplay among subjectivity, power, and knowledge for autism parents within these discourses? What does this interplay produce?
3. How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their families?

Using techniques of postqualitative inquiry within a poststructural framework, my dissertation will trouble normative assumptions in the medical and educational discourses regarding children with autism and their parents. To do this, I engage in a discourse analysis of both documents and processes, determining ways in which people with autism and their families are set up as a problem to be solved. Personal experiences as an autism parent merge with the theory to expose the interplay of power, knowledge, and subjectivity within the

discourses of autism. My methodology is an interweaving of the procedural, the theoretical, and the personal. While a traditional Chapter 2 in a dissertation typically reviews the literature, my method of inquiry foregrounds the literature throughout the entire analysis instead of just providing an initial background for the work. Therefore, my Chapter 2 sets the stage for the use of the literature in analysis by establishing poststructuralism as a framework and outlining my approach to postqualitative inquiry.

The first section of analysis follows the journey of autism parents (and my own journey specifically) to and through receiving a diagnosis of ASD for their child. In Chapter 3, “The Path to Diagnosis,” I reveal the binary opposition of normal/abnormal that is reproduced by developmental milestones, creating a sense of urgency for parents to act quickly when their child falls behind. Chapter 3 also outlines the different steps parents may take, as well as the potential barriers they face, as they move toward a diagnostic evaluation. Chapter 4, “The Day of Diagnosis,” draws from my family’s experiences during our full diagnostic evaluation appointment while problematizing the questionnaires, standardized assessments, interviews, and processes used to make a diagnostic determination about my son as my analytic sources. Finally, I outline underlying assumptions within Chapter 5, “Diagnostic Criteria and Processes;” the assumptions align with the official medical definition of ASD in the *DSM-5* (American Psychiatric Association, 2013). Chapter 5 also includes an analysis of the analytic question: How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their families? In each of these three chapters regarding the process by which a diagnosis of ASD is secured, my overarching question is: What is the problem represented to be regarding people with autism in the medical discourse of disability? In other words, how are

children with autism and their parents represented as problems to be solved? In Chapter 6, “The Aftermath,” my analysis addresses the research question: What is the interplay between subjectivity and power/knowledge for autism parents as they first encounter and engage with the discourse of autism and what does this interplay produce? In Chapter 6, I problematize the messaging our family received alongside our son's diagnosis as well as refer to the literature and its prevailing theories and models for how parents cope with a new diagnosis for their child.

The final section of analysis troubles the taken-for-granted assumptions within the educational discourse of disability, returning to the analytic question: What is the problem represented to be regarding people with autism in the special education discourse? Chapter 7, “Special Education and Evaluation” reviews the history of federal legislation and its current application, particularly in how individuals with a suspected disability are evaluated by school personnel. Chapter 8, “The Individualized Education Program (IEP)” examines the sections within an IEP document, problematizing the assumptions and questions explicitly or implicitly stated when determining a child’s eligibility for and placement in special education services. Chapter 9, “An Alternative Approach to the IEP Process” examines applied behavior analysis (ABA) therapy as one of the most widely recommended interventions for people with autism and how it has been used at one autism school and clinic to reshape the IEP process. Rather than being offered as the preferred solution for IEP reform, the alternative IEP process is also problematized, although it is acknowledged for asking different questions about individuals with autism and their families. Chapters 8 and 9 examine the analytic question: What is the interplay between subjectivity and power/knowledge for autism parents as they encounter and engage with the special education

discourse and what does this interplay produce? The analysis in Chapters 7, 8, and 9 analyzes the analytic question: How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their families?

The concluding chapter of my dissertation revisits the thinking and claims produced throughout the previous chapters. I seek to situate my inquiry within the larger contexts of autism research and educational research, offering implications of this work for educational leaders and posing questions for further lines of inquiry.

I also utilize interludes in my writing, continuing my theoretical analysis through a different lens. The purpose of the interludes is to move from problematization to possibility. Serving as a break from the analysis of power, knowledge, and subjectivity in the main chapters, the interludes move the analysis from *what is* to *what could be*. The first interlude appears after Chapter 5 and introduces the Deleuzian concepts of immanence and difference as they relate to the medical discourse of autism. It explores the small openings within the current definitions of autism and argues for a perspective of difference as possibility rather than deficiency. A second interlude revisits immanence, difference, and possibility in educational discourse by questioning what counts as knowledge and learning in relation to Manning's concept of autistic perception. Both interludes expand the definitions and thinking of autism beyond the current discourse, embracing difference, neurodiversity, and a spectrum of abilities and experiences.

This dissertation study is not born out of a specific educational context, but rather from the very core of my heart. My only son received his diagnosis of ASD at the age of three following a lengthy and intense time period of medical and developmental testing. The

path leading up to his diagnosis and every day since has felt like the act of putting together a large jigsaw puzzle with no idea of what the final image is supposed to be. At every step of the process, I have wondered what was happening with families that had less time or financial resources to devote to ensuring that their child accessed the most helpful supports. It is my hope that, by pursuing this topic and analyzing the discourse of autism, I have combined my subjectivities of parent, educator, and researcher to expose problematic assumptions and openings for new possibilities for children with autism and their families.

CHAPTER TWO: THEORY AND METHODOLOGY

Most existing research about autism and the people within the autism community falls into two categories. One aligns with positivism, quantitative measures, and the scientific method. Researchers in this framework seek causes, treatments, and cures for identified problems and measure outcomes through statistics and experimental design. The second category of research is qualitative, seeking to understand the experiences of people with autism and their families through surveys and interviews. Although varied in their methods, both approaches observe and interpret autism as it exists within the current discourse, usually without questioning normative assumptions. This type of research often works to (re)produce the dominant discourse by addressing predictable questions about gaps in the literature; for example, investigations into gene variants that are linked to autism (Simons Foundation, 2021) or the perceived effects of the child's autism on the sexual lives of the parents (Aylaz et al., 2012). Manning (2007) argues that critique and learning are often “framed and deadened through the crafting of questions that already have answers, or whose answers are close at hand, contained within preexisting academic discourse” (p. 9). Predictable questions flow logically from the existing and prevailing literature rather than opening up a pathway to reframing the discourse as a whole. What is needed is a move beyond the feedback loop of traditional autism research.

Woods, Milton, Arnold, and Graby (2018) call for a more inclusive interpretation of critical autism studies, one that opens a pathway for new inquiry and thought. This expanded view of autism research does not seek solutions but rather creates new questions and perspectives, opening up the possibilities for divergent discourse (Arnold, 2013). It enlivens the research discourse to the full embodiment of autism rather than being limited to naming

causes, treatments, cures, and effects. My analysis falls within this expanded criticality by “investigating power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce ‘disability’” (Waltz, 2014, p. 1337). I did not set out to offer any templates for change, but instead have approached the analysis with an open mind to see what the discourse of autism reveals when viewed through a different lens. As Manning (2007) suggests, “speech that is political must involve an argument that is neither pre-established nor regurgitated” (p. 14). My analysis poses questions, troubles what has become taken for granted about autism, and explores openings for possibility.

This chapter lays the groundwork for my analysis by outlining poststructuralism as the overarching framework for my dissertation. Ascribing to the principles of postqualitative inquiry, I think with theory (Jackson & Mazzei, 2017), thinking with concepts from Foucault, Deleuze, and Manning in tandem with the techniques of discourse analysis, problematization, and reflexivity. Following a description of this process within postqualitative inquiry (St. Pierre, 2019), the chapter concludes with the standards for refusal and answerability to which I have tried to hold myself accountable during this work.

Poststructuralism as a Theoretical Framework

Representing a break with other epistemologies, poststructuralism assumes that the complex subjectivities and discourses of humans, both individually and collectively, cannot be constrained by social constructs, hierarchical classifications, and binary thinking. Poststructuralism falls within the larger epistemology of subjectivism, in which meaning is imported from “somewhere else” (Crotty, 1998, p. 9). Unlike objectivism, which believes that meaning lies within the object itself, or constructionism, which asserts that meaning is

created through the interaction of subject and object, subjectivism posits that meaning is derived from the context surrounding the subject and object. Poststructuralism operates under the assumption that all knowledge is subjective (Esterberg, 2002). Subjectivity is shaped and either normalized or marginalized within specific historical, political, ideological, organizational, and social discourses – through a process of power relations.

Contesting Binaries and Normativity

Poststructuralist theory works to destabilize and disrupt normalizations, binaries, and other socially-constructed categories, allowing for an analysis of discourse. Discourse consists of “the very material, statements, documents, and archives shaping thoughts,” but it is more than just a collection of ideas expressed in language (Moghtader, 2016, p. 49). Discourse also includes a field of relations in which subjects and objects are named and classified, in which certain statements become possible and others unthinkable. Discourse establishes what becomes acceptable and taken for granted as knowledge; it defines what is knowable, as well as what is unknowable and unthinkable within a system. Poststructuralist researchers examine discourse for the processes that create subjectivities that are commonly accepted, while also interrogating processes that serve to maintain the privileging of dominant discourse and the marginalization of others. Some discourses become mainstream and are highly visible while others are relegated to invisibility and otherness. For example, in autism studies, the discourse of autism as a fixed and inherent deficit within the individual is mainstream, but the discourse of autism as a unique and valuable way of engaging with the world is silenced.

Filax, Sumara, Davis, and Shogan (2011) note how poststructuralism “conceptualizes subjectivity and discourse” by questioning fixed categories and binaries that have become

normalized in a given context (p. 87). A fixed category, one like *disabled*, lumps all individuals within a group into one classification, presumably associated with an essential part of the person's identity and experiences. Such a classification creates a binary opposition of able/disabled where "able" is privileged as being normal and "disabled" is othered as being deficient and in need of repair. By defining an individual through their placement on either side of the able/disabled binary opposition, fixed categories sanction some individuals (those who are able) as worthy – and others (those who are disabled) as problematic. Defining a person as being disabled not only limits their possible actions and outcomes, but it also affects the discourse through making certain types of knowledge and statements about people with disabilities possible and acceptable. Those taken-for-granted assumptions dominate the discourse while marginalizing other potential statements and knowledges.

Poststructuralist research works to trouble or contest categories, binaries, and generalizations (Merriam, 2002), opening up new possibilities by looking at the past, present, and future of classifications simultaneously. As Lather (2006) puts it, "we become both protean and plastic, constantly on our way to becoming due to the contingencies of history and our transformations, both conscious and unconscious, across conditions of repetitions that proliferate multiple differences" (p. 43). Poststructuralism is ripe with possibility for expanding beyond binaries and categories regarding fixed identity, allowing each individual a degree of freedom to determine exactly who they choose to be (Atkins, 2005), experienced as an iterative and continual process. Unlike a fixed identity, subjectivity is fluid and changing across time, space, and discourse.

Within the paradigm of poststructuralism, discourse continuously shapes and redefines individual realities (Bolton, 2012). The assumptions and knowledge within a given

discourse allows for certain statements to be made, but not others, which produces the subjectivities available for individuals within that discourse. Poststructuralists put forward the term subjectivity because “the word *identity* is a humanist signifier in that it evinces an essential nature that stabilizes meaning about people who belong to a particular identity category, such as woman” (Jackson & Mazzei, 2012, p. 69). In terms of my study, essentialism stabilizes people with autism as deficient and in need of treatment or cure to become more “normal.” Essentialism also categorizes autism parents as perpetually grieving and negatively impacted by their child’s autism. By rejecting essentialism, poststructuralism recognizes the fluidity of subjectivity that can be experienced by the same individual across discourses, putting the individual into a relationship of reciprocity and exchange with discourse instead of being defined by some essential quality or characteristic. Jackson and Mazzei (2012) emphasize subjectivity as a *doing* rather than a *being*, noting that “the agency of the subject in a poststructural paradigm is an enactment, not something that an individual possesses” (p. 69). For people with autism, such agency means moving beyond a defining label of disability as they engage within and against the medical and educational discourses, expanding the possibilities for choosing how they experience themselves and others in relation to the discourse at large.

Power/Knowledge

The range of possible actions and subjectivities for an individual within a particular discourse is largely determined by the discursive flows of power and knowledge. Power and knowledge are in relation with one another and are malleable. They are not fixed objects that can be possessed or made permanent. Knowledge functions in the form of statements and objects that humans “produce, manipulate, use, transform, exchange, combine, decompose

and recompose, and possibly destroy” (Foucault, 1972, p. 105). Power operates through techniques like classification, the creation of a normative ideal, the privileging of dominant assumptions, and the marginalization of others who fall outside of the norm.

My dissertation uses resistance as a starting point, following Foucault’s (1982) call to “bring to light power relations, locate their position, and find out their point of application and the methods used” (p. 780). Using the materials, documents, statements and processes of the medical and educational discourses surrounding autism as analytical sources, I reveal the techniques of power used to set up people with autism as being abnormal and deficient. My analysis outlines the ways that people with autism and their parents are framed as problems to be solved. Throughout my analysis, I examine how “knowledge circulates and functions, its relations to power” (Foucault, 1982, p. 781). I uncover the taken-for-granted assumptions about people with autism and how that privileged knowledge works to limit possibilities. Unraveling the power/knowledge relations in the medical and educational discourses of autism also exposes the lack of agency for autism parents in official processes, during which their possible actions and subjectivities are limited to that of compliance or resistance. My dissertation study troubles the flows of power and knowledge in the dominant discourses related to autism while opening up a space for new questions and possibilities.

Docile Bodies

Relations of power/knowledge are not overt methods of dominance by one group over another. Instead, techniques of power work to limit the possible actions of individuals, thereby making them more manageable and malleable. According to Hull (2017), this occurs “through a process of careful behavioral conditioning, [in which] subjects take compliance with regulatory demands upon themselves” (p. 416). Foucault refers to this concept as *docile*

bodies whose behavior has been shaped into compliance. The goal of creating docile bodies is “to discipline individuals and to optimize the productivity of populations” (Hull, 2017, p. 412). Some techniques of power that are employed to create and maintain a population of docile bodies are classification, normative standards, and the privileging of dominant assumptions in the discourse.

Populations that hold to normative standards with few individual outliers are more easily governed. My dissertation explores the concept of docile bodies in relation to both the person with autism and the autism parent. Using my analytic sources and personal experiences, I reveal how strategies that (re)produce docile bodies rely on a singular, normative ideal. As such, people with autism are encouraged to “be like everyone else and deny the reality of their experience” (Surbaugh, 2010, p. 113). Individuals with autism are categorized and experience their subjectivities in relation to how severely they deviate from the norm. Autism parents are confronted with complex decisions to be compliant and docile – or to take up a subjectivity of resistance. In pursuing therapies and services for their child with autism, autism parents are being complicit in the production of their child as a *docile body* and in bringing the child more in line with normative expectations.

Poststructuralism in Educational Inquiry

Using theories of poststructuralism in educational inquiry seems impractical, if not absurd, given the current penchant for proof and results. Every learner is supposed to measure up to the same standard and any deviation signals the necessity for interventions. “Conformity is the anticipated outcome, a compulsion that regulates and governs the norms of identity formation and intelligibility” (Jackson & Mazzei, 2012, p. 74). Yet, after almost four decades of national panic about our “failing” schools and a fear of falling behind other

nations in the global economy, a situation first articulated by the April 1983 report, *A Nation at Risk* (United States Department of Education), the widely-discussed and researched achievement gap has not disappeared. Neither have other systemic inequities in our schools. Reiterative cycling through problem identification, intervention, research, and policy-making has proven itself to be mostly fruitless because the test results and list of problems in schools remain largely unchanged. Therefore, it is precisely the poststructuralist questioning and problematizing of processes and discourse that is needed to address the flows of institutional and relational power, to upset the normative system, to produce new possibilities.

Systemic change can only be brought about by thinking differently, by approaching an entrenched set of normative assumptions in a new and uncomfortable way. Gowlett (2015) describes this process as *thinking otherwise*, which is “important since it draws attention to alternative ontological possibilities. “‘Thinking otherwise’ unsettles ideas that have seemingly become obvious and grants space to alternative and/or subjugated knowledges” (p. 161). Instead of reviewing products, programs, and policies or solving problems in the immediate context, poststructuralist educational inquiry exposes and dismantles the discourses that make up the educational environment, as well as the interplay between knowledge, power, and subjectivity within those discourses. Schools are viewed as “a type of location of bodies in space, of distribution of individuals in relation to one another, of hierarchical organization, of disposition of centres and channels of power, of definition of the instruments and modes of intervention of power” (Foucault, 2008/1977/1975, p. 9). Poststructuralist educational inquiry can ask questions about these flows of power and knowledge, about how subjectivity is (re)formed and embodied physically within educational

discourses. Inquiry can compel us to think about difference, not as a deviation from the norm or failure to meet an accountability standard, but as the impetus of possibility.

When normative assumptions set an expectation that every student can and should achieve at a particular level on a standardized assessment, binaries are created that separate those who meet the standard from those who do (or can) not. Educational discourses set the stage for the stabilization of identities based on a binary system of pass/fail, at standard/at risk, able/disabled, among other dichotomous pairings. Students with dominant, normative identities move through this discourse with ease assuming that their success is of their own making, while marginalized students experience schooling as the site of mental, physical, and emotional constraint, and possibly, a sense of unbelonging. A group of individuals who experience their educational identity as one of marginalization includes those students on the autism spectrum and those with other neurological differences, who may struggle socially as well as academically.

Poststructuralism as a Framework for Understanding Autism

Putting poststructuralist thought to work in the educational context of students on the autism spectrum opens a space for revolutionizing education for all students by troubling the current discourse. Specific to my study, I argue that the way that neurotypical individuals view autism through the recognition of many ways to be fully human rather than relying on labels and classifications is an important first step to disrupting normative assumptions. Through poststructural inquiry, I problematize the accountability model that is prevalent in current educational policy and practice, challenging the reliance on normative measurement. Poststructural theory allows me to question the normative assumption that interventions must be applied to help move students with autism or other learning differences closer to the

academic standard. Thus, I am able to analyze the possibilities for new ways to frame academic success. My work in a poststructural frame argues that instead of being positioned as abnormal, students with autism can be viewed as uniquely positioned to bring new perspectives and textures to learning.

By exploring the interplay between knowledge, power, and subjectivity in special education processes and services, and in education as a whole, my analysis deconstructs those policies and procedures in education that are not working to serve the best interests of students. Poststructuralism does not offer practical solutions to specific problems – most poststructuralist thinkers would reject the attempt to do so outright. Instead, my employing poststructuralism in educational inquiry, particularly in regards to autism, begins to sow seeds in the “field of possibles” (Greene, 1987-88), resisting standardization and accountability while opening the door for more complex and provoking conversations.

In my poststructural study, I reach beyond a need to quantify or to critique. I expose the interplay between knowledge, power, and subjectivity within and across discourses; I problematize and dismantle what has become normative; and I explore alternative possibilities. When policies are problematized from a poststructuralist vantage point as in my dissertation, normative assumptions that have become invisible and ingrained in the system and in its subjectivities are laid bare for examination and reconsideration, creating fodder for impactful change without proposing specific practical solutions. Opening up the educational discourse beyond what has become taken for granted offers new ways of thinking about knowledge, especially for students with neurological differences like autism, by problematizing assumptions, examining discourse, and asking new – possibly better – questions. In particular, my analysis prompts the question: What would education look like if

we moved from a framework of deficit to one of affirmative difference? Employing poststructuralism in educational inquiry and in relation to autism sets the stage for the conversation to break free from limitations and impossibilities, even within the parameters of the research itself.

Postqualitative Inquiry: An Anti-Method Approach

Poststructuralism sets forth the goal of uncovering and then troubling the dominant and normative assumptions within a discourse. Such a goal cannot be achieved by working within the parameters set by traditional research methods and questions, which inherently limit the questions researchers can ask and how they go about doing their work. Disrupting knowledge that has become deeply ingrained in the dominant discourse is incompatible with research methods that relies on identifying and studying significant gaps in the existing literature. Therefore, poststructuralist thinkers reject traditional research methods as a pre-given path for constructing knowledge, and instead start with theory and allow method to emerge. St Pierre (2011) coined the term *postqualitative inquiry* for this transgressive and anti-method approach to research.

Postqualitative inquiry shares with traditional qualitative research the belief that knowledge is constructed and a dependence on the researcher as the vessel for encountering and contemplating data, while rejecting much of the form and function of traditional qualitative research. Within postqualitative inquiry, there is “an explicit disavowal of method as generator of knowledge” (Manning, 2016, p. 12). One major departure from traditional qualitative research is that postqualitative inquiry uses theory as a compass, or lens, throughout all aspects of the research process. Everything about the research is connected to,

and guided by the theory (Jackson & Mazzei, 2012). The theory does not emerge from the research; it does not serve as a starting point to be verified. The theory *is* the research.

In its departure from traditional qualitative research methodology, postqualitative inquiry begins with theory instead of method. Postqualitative inquiry does not go through the motions of a methodology and wait for themes to emerge, as in grounded theory. Instead, it begins with a theory and follows that theory through the twists and turns of what is not yet known (St. Pierre, 2019). A postqualitative researcher reads and thinks with a theory or theorist to the point that she lives the theory, until it is part of all that she sees and does, until she notices it everywhere (St. Pierre, 2017). Recognizing her own subjectivity within discourse, a postqualitative inquirer does not put up a façade of neutrality, nor does she employ tactics to prove the validity of her work. The result of postqualitative inquiry yields a problematization of what-is and the openings of what-could-be.

Poststructuralism and postqualitative inquiry disallow the basic tenets of traditional qualitative research because they reject the idea of a static and knowable reality that can be measured, captured, or described. Although my analysis is presented somewhat chronologically, my dissertation study did not proceed in a linear fashion based around the collection or synthesis of traditional data. As a postqualitative researcher, I had to recognize that I am always already in the interconnectedness, or *assemblage*, within a discourse rather than trying to create an artificial distance or neutrality between myself and the constructs under study. This is why I chose to interweave my personal experiences with other analytic sources. Postqualitative inquiry deals with complexity, uncertainty, and infinite possibilities; it is incapable of encapsulating itself into reportable “findings” that can be generalized to other settings or worked into practical solutions (St. Pierre, 2017). It is unpredictable--always

growing and changing without ever really arriving at any particular destination. Such an approach to research is particularly challenging in the field of educational leadership, which is always looking for the next and best program or solution to implement, but allowing my research to emerge out of uncertainty created unanticipated connections and questions.

Concept as Method

Postqualitative inquiry looks to the creation of the new instead of documenting the “real.” It is *rhizomatic*, a non-linear process that involves the entangling and interweaving of thought and theory. There is no outline or methodology to follow because “no one can predict in advance how/when/why/where a philosophical concept or the world itself might interrupt and reorient our thinking...what happens is neither intentional nor the product of an enforced systematicity” (Lenz Taguchi & St. Pierre, 2017, p. 644). Rather than adhering to the steps and strictures of a particular methodology, postqualitative inquiry uses a concept or theory as method. This approach sets the stage for creative thinking instead of producing “answers to questions with a predetermined field of answers,” as is the case with many traditional qualitative research studies (Lenz Taguchi & St. Pierre, 2017, p. 646). Similarly, St. Pierre (2019) has argued that “a thinker with a method has already decided how to proceed and is simply a functionary of the method, not a thinker” (p. 2). I began my dissertation study knowing that I wanted to address both the medical and educational discourses of autism, that I wanted to include parts of my personal journey as an autism parent, and a few ideas for analytical sources. My analytic questions were created based on the key theories from the poststructuralist thinkers I had begun to read. Otherwise, I had no idea what direction

this study would take. Where I arrived emerged from somewhere in the middle and has very little in common with what I originally anticipated.

Thinking with Theory

In postqualitative inquiry, it is precisely this need for a way to “go about” research that is to be avoided. Looking for a prescribed path to follow is to start by asking the wrong questions. In their collaborative work, Jackson and Mazzei (2017) emphasize that the theory *is* the research, requiring thought, not procedures. “Describing ‘how’ to think with theory—or what it ‘is’—is ruined from the start;” rather, the rejection and refusal of traditional qualitative research “attempts to loosen a grip on stable structures and endeavors to shake off exhaustive and exhausting habits of method” (Jackson & Mazzei, 2017, p. 717). Theory was not something I could start with and then put on the shelf. I read the theory, then re-read it in light of my analytic sources, and then re-read it as I crafted my own critique.

Thinking with theory should not be thought of as a substitution for traditional qualitative inquiry or as a simple change in terminology or procedures. As Jackson and Mazzei (2017) explain: “This work does not occur as a stage in a process but is rather the process methodology itself” (p. 729). Thinking with theory is not an action; it is a completely different way of approaching inquiry. My dissertation study did not start with a specific question, hypothesis, or possible solution. Instead, I began with a lived understanding that some ideas and practices surrounding people with autism and their families are problematic, that the summation of a person with autism in the medical and educational discourses is limited and limiting. Thinking with theory “does not seek to answer questions...[but rather] to pose problems, to open up thought, to seek newness”

(Jackson & Mazzei, 2017, p. 732). As a parent, I would have preferred to have found a magical solution to offer on behalf of my son and our family to the autism community; however, my analysis may prompt other researchers to look at autism, which has been studied ad infinitum in a new and different way. According to Jackson and Mazzei (2017), thinking with theory “eschews a use of concepts for what they *mean* and instead puts to use concepts to show how they *work*, what they *do*, what they *allow*, and perhaps what they *hide*” (p. 732, emphasis in original). As a postqualitative researcher, I engaged in complexity of thought, finding the interweavings of a variety of texts and subjectivities within a discourse, in the hopes of yielding more interesting and expansive ranges of possibility than the simple answering of a question or clarification of meaning.

Postqualitative inquiry does not set out with a hypothesis to be confirmed or a standard methodology from which themes will emerge. Therefore, my analytical process was my own creation, one that emerged from within the act of doing the inquiry. I approached the work and outlined the writing chronologically according to the order of processes experienced by our family, but that was the only linear or sequential component of my analysis. I read Foucault, Deleuze, Manning, and secondary sources about poststructuralist theory and its use for disability studies. I revisited and reflected on our family’s experiences and reactions to the processes and assumptions we faced. I pored over documents that constitute the dominant medical and educational discourses, searching for both problematizations and possibilities.

Reading, writing, reflecting, journaling, remembering, and reliving all flowed in and out of each other in an interconnected web that eventually morphed into an analysis. In crafting a chapter of analysis, I typically began with the documentation and procedures of the

dominant discourse, interspersed with my personal story, to set the context and flow of the analysis. This work was deeply emotional, as my most raw and challenging experiences as a parent were revisited as transgressive data (St. Pierre, 2017) and placed on equal footing with the documents and procedures of the dominant discourse. It was only after some time away and re-reading of Foucault, Deleuze, or Manning that I returned to a particular chapter, settling into the theory and plugging it into what had already emerged.

Postqualitative Inquiry in Educational Research

Carrying out postqualitative inquiry in the field of educational research can be particularly challenging. Postqualitative inquiry is ethereal and rhizomatic, neither of which is a desirable characteristic of research in the current educational context. It does not seek to produce new knowledge, but rather to open new possibilities. It does not work to offer “practical” solutions to “real” problems and does little to substantiate decisions regarding education at the local, state, or federal levels. Postqualitative inquiry is not measured and does not seek validity or generalizability. It does not produce data sets and statistics; it cannot be captured in school report card grades or per-pupil spending.

Quantitative and traditional qualitative research are ubiquitous in educational research, almost to the point of saturation. The cycle of problem identification, intervention, evaluation/measurement, and reporting is repeated ad nauseum. Every effort is made to increase proficiency, to guarantee that students acquire the necessary knowledge and skills to become productive citizens and to keep the country globally competitive. But the focus on proficiency in clearly-defined skill sets ignores many other types of knowledge about what it is to be a human. As Deligny (2015) explains, “a tiny child, a future representative of the elite thought-out project of autonomy, must not be mistaken for a larva that has to be stuffed

with the acquired learning of the human-that-we-are.” (p. 49). Contrary to the current emphasis on accountability, education is about more than content standards and test scores; it is the system by which society indoctrinates individuals into the cultural landscape, into the normative assumptions of the dominant discourse. Education is about formation as much as information.

As postqualitative inquiry is pursued in educational research, it works to expose the ways in which the current structures and policies of education are restrictive, normative, and limiting. My analysis explored what is privileged and what is marginalized within the educational discourse. Postqualitative inquiry allowed me to dismantle and problematize current educational practices and to pose new questions. One goal of my dissertation has been to open conversations and possibilities for new ways of caring for and supporting students in fulfilling their potential. Manning and Massumi (2014) describe this type of environment in the following way: “care organized itself not around the common but around *the irreducibly singular*. It concerned being-different-together and becoming-together as an expression of those differences, as part of a shared process participated in differentially.” (p. 108). Postqualitative inquiry allows for difference as it reveals what has become taken for granted and what has been made invisible within educational discourse. In troubling the educational discourse, my dissertation works to reimagine education by the posing of new problems and questions.

My Process for Analysis

Although the only definable characteristic of postqualitative inquiry is its emphasis on theory or concept rather than method, a postqualitative researcher has to proceed using some form of technique in order to engage in the work of analysis. Manning and Massumi

(2014) caution that “techniques are not descriptive devices—they are springboards. They are not framing devices—they activate a practice from within. They set in motion” (p. ix).

Techniques do not dictate the work, but rather make the work possible. There are no techniques that are sanctioned by postqualitative researchers over others, but some techniques by their very nature lend themselves more readily to thinking with theory. My dissertation includes discourse analysis and problematization as techniques. I thought with theory, documents, regulations, the literature, and my own experiences to explore the primary analytic questions of my study:

1. What is the problem represented to be regarding autism across medical and educational discourses?
2. What is the interplay among subjectivity, power, and knowledge for autism parents within these discourses? What do they produce?
3. How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their parents and families?

These questions emerged from my reading of and thinking with the theory. The first analytic question began with my reading of Foucault’s (1972) *Archaeology of Knowledge*, Tremain (2017), Gillies (2013), and Moghtader (2016). Foucault’s writings and lectures on the subject and power (1980, 1982, 2008b) prompted the second analytic question, along with Hacking (1999) and Hull (2017). The third analytic question came from my reading of Deleuze (1994), May (2005), Deligny (2015), and Manning and Massumi (2014). Every return to the theory in conjunction with other poststructuralist writings, my analytic sources,

and personal experiences opened a new way of thinking about these questions, which in turn prompted more reading and writing.

Discourse Analysis

Identity and subjectivity are the products of an ongoing interplay between societal structures, social interactions, and individual proclivities--a process through which discourse analysis seeks to name the status quo and to offer areas of potential resistance. Discourse analysis offers insight into which discourses are normalized, and thus rendered acceptable, within a particular context by examining the use of language (Fairclough, 2004/2014). Discourse analysis assumes that all language, or text, is embedded within a larger contextual discourse that represents both societal and personal perspectives.

My use of discourse analysis proceeded by first recognizing what language and knowledge is considered to be normative or ideal within the discourses of autism. In “excavat[ing] the underlying principles and taken-for-granted” (Patel, 2016, p. 88) of the medical and educational discourses of autism, my analysis brings awareness to the ways in which normative discourse works to marginalize or *other* certain groups and perspectives. In the dominant discourse, people with autism are classified as abnormal and deficient. Referring to the work of Foucault, Locke (2004) describes this type of analysis as revelatory in that it seeks to “reveal the nature of systems of rules, principles and values as historically situated bases for critique” (p. 27). Discourse analysis enabled me to expose the discourse of the medical and educational systems for what they advance and what they background.

Moreover, discourse analysis seeks to open possibilities for individual agency through resistance of dominant discourse and engagement with alternate discourses. By operating within the framework of discourse analysis, my dissertation seeks to facilitate

social transformation through the openings and problems posed by my research. Working toward that end, I employed discourse analysis to destabilize and disrupt the dominant discourse (Davies & Gannon, 2011). My use of discourse analysis with analytic sources that traverse both past and present, in an effort to discover how subjectivities are shaped over time for people with autism and their families while enabling those individuals to re-invent themselves by claiming alternative possibilities.

Problematization

In addition to posing new problems and questions, my dissertation reveals the ways in which problems are created, defined, and governed through problematization. For poststructuralist thinkers, “problematizations are deeply ingrained ways of thinking” that have the capacity to shape our subjectivities and agency within a discourse (Bacchi, 2015, p. 5). These problematizations are the taken-for-granted assumptions that impact how we think about ourselves and others. As poststructuralist research, my dissertation dismantles these assumptions and prioritizes the “need to *scrutinize and question meanings that are in place*” (Bacchi, 2015, p. 5, emphasis in original). To this end, Carol Bacchi developed the What’s the Problem Represented to Be? (WPR) technique as an approach to policy analysis. The goal of WPR is to “stand back from taken-for-granted objects and concepts to determine how they have come to be through studying the heterogeneous strategic relations—the politics—that have gone into their making” (Bacchi, 2012, p. 5). The WPR technique problematizes, or dismantles, concepts that have become normative assumptions by examining both their creation and how they are regulated. The way that policies are framed expose the normative thinking around an issue, as well as what has been made invisible. Bacchi (2016) suggests that “what we propose to do about something indicates what we think needs to change and

hence what we think is problematic—that is, what the “problem” is represented or constituted to be” (p. 8).

My analysis engaged in problematization of the discourse of autism and disability (as a whole) through the troubling of information, evaluation instruments and procedures, and legislation regarding people with autism. I began with our family’s journey in mostly chronological order, and my research questions emerged from thinking with poststructural theory. As analytic sources, I combined documents, regulations, and processes with my own experience. For example, in Chapter 6, “The Aftermath,” I explore the flows of power and knowledge for autism parents as they first receive their child’s diagnosis, revealing a dominant discourse that privileges normativity. I began by reviewing the one-page handout our family was given alongside my son’s official diagnosis and remembering what that day felt like. I thought with Foucault’s concept of *power/knowledge*, showing that this document reproduces a sense of urgency that parents should act quickly to address their child’s deficits and creates a relation of expert knowledge being privileged over parental knowledge. I realized that very little support was offered to us as parents in terms of clear next steps or counseling. I turned to the literature on medical models and theories regarding autism parents, which largely focus on grief and sorrow and follow sequential stages toward acceptance. Thinking with poststructuralist theories of subjectivity, I considered how these models normalize parental reactions and create binary oppositions of parents who are either progressing through or stagnant in their grief over having a child with autism. Beyond dismantling the dominant discourse, poststructuralist theory seeks to pose new questions, so I also included my thinking about potential openings and possibilities for parents in the wake of their child’s diagnosis.

For each analytic source that I used in my thinking with theory and the medical and educational discourses of autism, I asked the following questions:

1. What does it claim?
2. How does it categorize (creating binaries and/or hierarchies)? What is privileged or silenced?
3. What does it (re)produce?

By interweaving these questions in my process of thinking with a concept from poststructuralist theory, I analyzed what the current definitions, representations, and recommendations are *doing* instead of just critiquing what is said in policies and documents. These questions helped me to frame my analysis of the subjectivities and lived effects of current discourses surrounding autism on people with autism and autism parents.

Remembering that the postqualitative researcher is always already within the interconnectedness of an assemblage, WPR “incorporates a recommendation for a practice of self-problematization” (Bacchi, 2015, p. 8). Throughout my analysis, I considered the ways in which my thinking with theory worked to “either reproduce or disrupt modes of governing that install forms of marginalization and domination” (Bacchi, 2016, p. 12). The interweaving of reflexivity into my theoretical analysis offered opportunities for me to engage in self-problematization, exploring how I am compliant with normative thought and how I offer resistance to that normativity.

Reflexivity/*Parrēsia*

One such technique of the self that Foucault (2019/1982) commends is *parrēsia*, which he defines as the “set of characteristics that grounds and renders effective the discourse of the other in the practice of care of self” (p. 15). *Parrēsia* is identified by its

contradictory relationship to flattery, its freedom from the rules of rhetoric and philosophical argumentation, and its dependence on a partnership between two actors, the speaker and the listener (Foucault, 2019/1982). Working together the speaker must demonstrate a willingness to speak the truth and to be receptive of it from the listener, thus granting the listener the ability to receive and reflect truth in response, all of which falls under the act of *parrēsia*. Rather than remain encapsulated in a single exchange of discourse, however, Foucault (2019/1983) encourages individuals to take up *parrēsia* as a mode of living, seeking to exchange truth with one another as it is lived in that moment and context. *Parrēsia* approaches self-critique and societal critique in a way that is bold and unafraid.

In the spirit of *parrēsia*, I include my experiences as an autism parent in my analysis through personal vignettes that are interwoven with discourse analysis and problematization. These glimpses into my life and that of my family serve various purposes. At times, they offer contextual background knowledge to aid the reader in understanding the analysis that follows. In other spaces, these narratives operate as transgressive data (St. Pierre, 1997), revealing the embodiment of the discourse in my own lived experience. A final functioning of the autobiographical snapshots is to force the work of self-critique and self-problematization, to expose where I have been compliant with the dominant discourse and where I have offered resistance.

Refusal/Answerability

In its departure from traditional research practices, I adopted Bacchi's strategies of self-problematization, working to reveal my own normative assumptions. Responsible research, however, necessitates additional reflexive moves since a researcher is always already operating within the assemblage and constructs under study. Patel (2016) urges

researchers to ponder the question, “Why me?”, which should “prompt a humble pause and reflection on the specifics of individuals’ experiences that make them appropriately able to craft, contribute, and even question knowledges” (p. 58). As I examine the discourses surrounding autism and the interplay of my own subjectivities within those discourses, I had to continue to draw myself back to that question and the recognition that my work is relational to my *doing* and *becoming* within the assemblage of autism. It cannot be generalized or be seen as representative of other people. I may be uniquely situated at an intersection between parent, educator, and researcher, but that does not make me qualified above others, nor should it privilege my voice and experiences over those of others. Therefore, my analysis is unapologetic in its specificity to my own situation. It cannot be generalized into a commentary on the entire autism community.

Beyond the act of self-reflection, I have the responsibility to be answerable for what my work does or does not do, as well as for what it includes or does not include. Patel (2016) describes answerability in research as the researcher being responsible, or answerable, to learning, knowledge, and context. The acts of problematization and thinking with theory open the door for new possibilities while dismantling preconceived assumptions. Bearing the idea of answerability in mind, the design of this study is grounded in an important refusal--the refusal to traffic in the pain of others (hooks, 1989). Recognizing that autism parents are constantly propositioned with opportunities to participate in traditional research with little promise of direct benefit to themselves, their children, or the autism community at large, I refuse to take their words for my own academic purposes. This is the reason that I did not incorporate interviews, surveys, or questionnaires as supplements to my efforts at problematization and discourse analysis. Although I hope that other autism parents would see

their hopes and struggles reflected in the sharing of my own story, the focus of the work will remain on unsettling normativity in the discourses surrounding autism instead of constructing meaning from their shared pain.

Above all else, my analysis is answerable to my son, both now and in the future. I have tried to walk a fine line between sharing my story and sharing his, to honor his dignity and respect his right to determine his own subjectivities within the discourse of autism as he grows and develops. I have shared generalities about medical and educational evaluations, but not any specific scores or classifications. Specific schools and service providers remain anonymous. My aim with this dissertation is to expose the systems and normativity of the dominant discourse surrounding autism and disability as what is broken, not my son or any other person in the autism community. Therefore, I must remain mindful of the knowledge that is created, privileged, or undone by my work and what it may mean for my son and others with autism as a result.

Conclusion

My dissertation is a postqualitative inquiry based on discourse analysis, problematization, and thinking with theory. I think poststructuralist concepts like power/knowledge and subjectivity with an array of personal experiences alongside the documents and processes that dominate the medical and educational discourses of autism. This process for inquiry reveals techniques and relations of power/knowledge within the discourse, shows how people with autism and their parents are framed as problems to be solved, and opens up possibilities for new questions, frameworks, and subjectivities for the autism community. Because autism is not diagnosable at birth, my analysis begins in the next chapter with the steps families encounter in their path toward an autism diagnosis.

CHAPTER THREE: THE PATH TO DIAGNOSIS

One chilly morning in March of 2019, my husband, my son, and I entered a nationally-acclaimed, research university-connected autism clinic. This day was the culmination of almost eighteen months of continuous medical, developmental, and psychological screenings, accompanied by mountains of paperwork and parent questionnaires. At seventeen months of age, after previously developing according to, or often ahead of, typical milestones of all kinds, my son began to lose skills. He quit speaking, laughing, waving, clapping, making eye contact, responding to his name, or engaging in play with us. We had become desperate in our search for guidance in how to help him. Because the clinic was over two hours away from our home, we had traveled to that city the night before and stayed in a hotel—an experience that does not always go smoothly with my son. Our appointment was at 9:00 a.m. and included interviews with my husband and myself by several different therapists, along with a battery of play-based assessments with my son, some with us in the room but most with us being separated. Over the lunch break, we were asked to complete even more paperwork and questionnaires, and by 2:00 (only five hours from our arrival), we had a diagnosis of Autism Spectrum Disorder (ASD) and were on our way back home. We had never seen that building or those people before and have not seen them since. This was one of those moments when life pivots, when life is caught between what is possible and what is no longer possible, on the precipice of becoming something else.

Our family's trajectory changed drastically on that day. We cannot escape autism; it has become part of our story, but we struggle with what it actually represents for us. Will my son be able to attend a traditional school? Will he ever make friends and be invited to birthday parties? Will he be able to drive, have a job, and be self-sufficient? The label we

were given that day at the diagnostic clinic stands as one of the few “certainties” in our lives, so I am continually drawn back to the definitions and criteria that were used to define our family during the journey leading up to those five hours.

This section of analysis focuses on the analytic question: What is the interplay of subjectivity, power, and knowledge for autism parents within the medical discourse and what does it produce? In poststructuralist theory, subjectivity is not a fixed quality of a person’s identity, but rather a changeable and complex way of engaging with the other subjects and objects within a discourse. Power is a series of relations and techniques that privilege the dominant discourse rather than a possession that a person either has or lacks. Dominant and accepted knowledge becomes ingrained assumptions while other types of knowledge are marginalized. Uncovering what the problem is represented to be regarding autism through the interplay of subjectivity and power/knowledge within a medical discourse reveals normative assumptions about typical and atypical child development. For this analysis, and to deconstruct the medical discourse, I rely on documents, instruments, and policies such as the Centers for Disease Control and Prevention’s developmental milestones (2020), the pathway of referrals to medical and service providers needed to obtain an autism diagnosis, and the application documents for a full diagnostic appointment. Also, I share a portion of my family’s journey to illustrate how subjectivities of autism parents with young children are shaped by the instruments used, information disseminated, and judgments made through evaluative processes.

The Path to Diagnosis

Even though autism is “is a neurodevelopmental disorder that scientists believe has a strong genetic component,” there is no definitive medical measure like a blood test or brain

scan that can diagnose autism (Therapeutic Pathways, 2021). Therefore, autism must be diagnosed behaviorally, which makes the path to diagnosis a long and winding journey for most families. Along the way, parents encounter established systems and patterns of thought regarding autism that shape the discourse surrounding autism, frame it as a problem to be solved, and have direct effects on the way autism parents experience their new subjectivities with the discourse. Established systems and patterns of thought are those such as the idea that human development follows a predictable and sequential pattern (Piaget, 1964), or that human characteristics like intelligence can be quantified and fall on a normal curve (Binet & Simon, 1915). These patterns of thought are produced by and reproduce the reliance on positivism and measurement across medical and governmental discourses. As a result, other dynamics that impact early childhood development but are not as easily quantifiable, such as religion, a family's general approach to childcare, and opportunities to interact with same-age peers, are subjugated.

During each step on this path to diagnosis, families encounter systems that are complex and challenging. The processes and information that constitute the medical discourse about childhood development emphasizes normative assumptions, suggesting that any deviation from predictable, normal development represents an exceptionality that must be addressed. Abnormal development becomes a problem to be solved, leading to a series of specialists and evaluations. As children with autism and their parents traverse the steps on this diagnostic journey, they constitute and are constituted by new subjectivities connected to a discourse of disability, delay, and deficit.

To illustrate the path to diagnosis, I will recount our family's experiences with measuring developmental milestones and entering the medical discourse of disability. As

well, I will linearly present the steps necessary to secure a formal diagnosis of autism, noting the normative assumptions of the processes used and the way in which autism is problematized.

Monitoring the Milestones

The first step on the path to diagnosis, according to the Centers for Disease Control and Prevention (CDC), is *developmental monitoring* whereby parents are instructed to observe “how your child grows and changes over time and whether your child meets the *typical* developmental milestones in playing, learning, speaking, behaving, and moving” (CDC, 2020, emphasis added). Information in this section of the CDC website includes a link to a “brief checklist of milestones” divided into sections at different ages ranging from two months to five years (CDC, 2020). This list of developmental milestones is also conveniently available through the CDC’s *Milestone Tracker* mobile app (CDC, 2021). Skills that are typically reached at each age range are categorized under the labels: Social and Emotional, Language/Communication, Cognitive (learning, thinking, problem-solving), or Movement/Physical Development (CDC, 2020). For example, skills listed for the age of eighteen months include pretending to feed a doll, saying several single words, walking unassisted, and eating with a spoon (CDC, 2020).

For parents, particularly mothers, these milestones are a logical continuation of the myriad of metrics and recommendations during pregnancy, surrounding childbirth, and in assessing newborn health. Guidelines like developmental milestones “prescribe norms, adjust differentials to an equilibrium, maintain an average, and compensate for variations within the ‘general population’” (Tremain, 2017, pp. 54-55). These guidelines and measures of normality set a standard of behavior and development that is acceptable at each age range

versus that which should be addressed as quickly as possible. Parents are advised to “act early” and talk to their pediatrician if their child starts to fall behind the average (CDC, 2020). A separate section at the end of the milestone checklist for each age range urges parents to talk to their child’s doctor if certain highlighted skills or behaviors are absent, reinforcing a deficit discourse. At eighteen months, some of these highlighted milestone deficits are “doesn’t point to show things to others,” “doesn’t gain new words,” and “loses skills he once had” (CDC, 2020).

According to Hacking (1990), the word *normal* emerged in the late 18th century and became increasingly indispensable across the 19th and 20th centuries as a way to be “objective” about human beings, separating the normal from the pathological. The CDC’s app literally allows parents to “track” their child’s progress in comparison to these norms, automatically creating a binary of normal/abnormal. Parenting includes moments of uncertainty mixed with a fear of failure, so parents may rely on the advice of their child’s doctor and trusted sources of information like the CDC website for guidance. Normative ideals like the developmental milestones become the authoritative and objective voice on measuring the normalness (and acceptability) of a child’s overall well-being. Any deviation from these norms becomes a cause for concern, or rather a problem to be solved.

I fell under the spell of (my son) meeting developmental milestones in his first year -- mostly as an extension of my own conditioned need to “make an A.” His meeting a milestone at the prescribed time seemed like justification that I was doing something right and that he was on a track for success. When he achieved physical milestones early and exhibited physical strength, my husband nicknamed him, “The Specimen,” and we began to talk about the ways he might excel at sports. A very normative, ideal picture of his future began to

emerge in my mind according to my own subjectivities and expectations -- friends, ball games, good grades, awards, dates, going to college, and so on. At this point in his life, my only concern for my son was that he was below the 25% line on the growth chart (another normative measure) that I was given at each visit to our pediatrician. The ways that I thought about and interacted with my son were dramatically shaped by how he met these standardized recommendations and by comparing his “performance” to how other children we knew met these standards. My subjectivity as a parent was completely wrapped up in the normative discourse of ideal child development without questioning how those standards of typicality became so authoritative.

Beyond constituting parental and child subjectivities (at least in the mind of the parent), these developmental milestones are so instrumental in measuring the appropriateness of a child’s development in comparison to a normative ideal that they constitute almost the entirety of the conversation and procedures encountered at every well-child visit to a pediatrician in a child’s first two years of life. This involvement of a pediatrician is the second step on the path to diagnosis. This screening performed by a pediatrician is a continuation of developmental monitoring using the CDC's milestones – which I discuss next.

Pediatricians as Means to Referrals

As a second level to the diagnostic process for autism, the American Academy of Pediatrics recommends *developmental and behavioral screenings* at well-check visits for children at 9 months, 18 months, and 30 months, with additional autism-specific screenings at 18 months and 24 months (CDC, 2020). Autism is rarely evident from birth, and the emphasis on screening around 18 months is in response to what Shore (2003) calls “the

autism bomb.” This term describes children, like my son, who meet developmental milestones on time or early until around 18 months, when they begin to regress. Noting sudden changes in developmental patterns or such regressions in skills is often the first indicator for a parent and pediatrician that a child may have autism. Although they follow a child’s development over the course of their young life, pediatricians are not able to diagnose autism, through these brief screenings or any other measures, but they can determine whether or not to refer a child to other specialists for further evaluation. Hull (2017) emphasizes the importance of understanding such “social norms and institutions and how they operate to directly shape the clinical encounter” (p. 412). Policies that take the ability to diagnose autism out of the hands of the pediatrician shape the flows of power/knowledge regarding autism. Recognizing autism becomes the realm of the specialist, which in turn, justifies the specialist’s right to intervene (Foucault, 1980). The expert knowledge of the specialist is privileged over that of the pediatrician, who encounters the child over the course of the entire childhood, and that of the parent who engages with the most closely and in everyday living. To receive a diagnosis, families must move away from the familiar and into the realm of the specialist, whose expertise and status within their field position their findings as authoritative and official.

Sheldrick, Schlichting, Berger, Clyne, Ni, Perrin, and Vivier (2019) note that “pediatric surveillance” through developmental screenings is commonly based on a provider’s assessment of the child’s progress based on the CDC’s developmental milestones discussed above (p. 1). The impetus behind their study is the lack of normative data to support the averages and age ranges represented by the CDC’s milestones. The CDC milestones are based on the age ranges at which the majority of children pass each specific

skill, but the threshold of majority is never defined – is it 50% or 99%? Additionally, the CDC never cites the data sources used to set the normative criteria of the milestones. To address this gap, Sheldrick et al. (2019) sought to build new normative data to guide the assessment of milestones by analyzing survey data from over 40,000 developmental screenings across three states.

According to their analysis of the developmental milestones, Sheldrick et al. (2019) revealed other limitations beyond those I discussed above, including a lack of specificity in what constitutes a “pass” for a particular milestone and in the way each milestone is defined. They note that each CDC milestone describes an observable behavior, but none are accompanied by a specific question or guidance for consideration by the parent or the pediatrician (Sheldrick et. al., 2019). Conversations between parents and pediatricians and subsequent determinations about a child’s development boil down to each adult’s best guess about, and individual interpretation of, the developmental milestones. Any number of social constructs like parent education level, socioeconomic status, ethnicity, and religious beliefs would influence what counts as knowledge, whose “voice” is most authoritative, and how parents view themselves within these conversations. Yet, the developmental milestones define what is normal or abnormal about early childhood development without regard to any cultural considerations, reinforcing the reliance on what is quantifiable and observable within the discourses of child development and autism.

Not only are the developmental milestones possibly somewhat arbitrary, but this study directly questions their overall usefulness. Sheldrick et al. (2019) argue that “the CDC’s campaign has been shown to increase parents’ reported knowledge of and engagement with child development, yet evidence suggests that parents are often unclear

about how to act early, and effects of early detection have not been demonstrated” (n.p.). Lack of specificity and clarity does not diminish positioning the CDC developmental milestones as *the* authoritative voice on normal child development, as they are taken for granted as the only (or at least the best) way to measure a child’s progress.

Conversations based on the developmental milestones constitute the (interplay of) subjectivities of parents and their young children and influence the direction of their medical care. Information that used to be encountered as one component of a well-child visit to the pediatrician is now omnipresent in the parent’s lives, encouraging parents to assume a posture of surveillance and of tracking their child’s development. Passing or not passing a milestone at the prescribed age range forms a subjectivity of normal/abnormal. Abnormality necessitates action on the part of the parent to address the apparent deficiency. Parents’ recognition of and response to their child’s abnormality (or lack thereof) reinforces a subjectivity of being engaged/disengaged in their child’s development and growth.

The gaps identified by the Sheldrick et al. 2019 study create questions around the possible arbitrary nature of the normative guidelines that dominate the discourse of early childhood development. These normative guidelines affect the flows of power/knowledge within the discourse of early childhood development. The CDC’s developmental milestones are foregrounded as the most authoritative source of knowledge about a child’s early development, driving conversations between parents and medical or service providers and framing a child as either progressing normally or abnormally. Concurrently, power/knowledge flows in a complex web of relations as parents are encouraged to surveil their child’s development, pediatricians are expected to recognize warning signs while being unable to provide a diagnosis, and specialists are required to officially label autism. The “act

early” campaign and the creation of the *Milestone Tracker* mobile app have increased awareness and the availability of developmental milestones for parents. Communicated by a widely-recognized government institution and as factual statements, the developmental milestones become taken for granted as an unquestionable truth. The lack of normative data as a foundation for the developmental milestones is concerning given their authoritative status in the early childhood development discourse.

Therefore, parents are having conversations about their child’s development with their pediatrician and have access to several approved resources, but they may be uncertain about what these developmental milestones mean and about what they should do if they detect that their child is “falling behind.” There are institutional systems in place, however, to take action when a child experiences “developmental delays:” the current term in common use for any negative deviation from the norms set by the developmental milestones.

Accessing Early Intervention Services

Children with developmental delays and disabilities under three years of age in the United States are eligible for early intervention services, even without a specific diagnosis. These early intervention programs are managed at the state level, with each state program operating a little differently (CDC, 2019). At this stage of evaluation, specialists like child psychologists, occupational therapists, speech and language pathologists, and developmental pediatricians assess a child’s development through observation, structured tests, parent interviews, and parent questionnaires (CDC, 2020). Eligibility is based on detecting problems to be solved in the form of specific skill deficits and overall developmental delays. If the early intervention program determines that a child is eligible to receive services, a case worker is assigned to the family to secure appropriate therapies and services with local

providers (CDC, 2019). In most cases, a physician refers a child to the early intervention program, or at least counsels the family on how to get started, but families are able to refer their child for an evaluation themselves (CDC, 2019). A similar *developmental evaluation* can be conducted by the local public school system for children over the age of three. Regardless of the age of the child, the purposes of these evaluations are to determine eligibility for services, not to offer a diagnosis. Developmental evaluations often precede a full diagnostic evaluation. Therapies and services recommended by the developmental evaluation can occur in tandem with and beyond the full diagnostic evaluation.

Full Diagnostic Evaluation

Only certain kinds of medical practitioners are qualified to diagnose autism in children, including developmental-behavioral pediatricians, child psychologists, child psychiatrists, and pediatric neurologists (Therapeutic Pathways, 2021). These professionals have a higher level of expertise and specialization than those who are usually involved in the developmental evaluation for determining eligibility for early intervention services. They can be part of a specialty clinic, a research institute, or be in private practice. At this final stage of the path, diagnosis is based on patient history and monitoring of patient behavior through measures like patient observation, patient interviews (when possible given a patient's expressive language abilities), cognitive and language ability tests, and interviews or questionnaires from parents, teachers, and other adults (Therapeutic Pathways, 2021). Since a full diagnostic evaluation requires such a high level of specialization and expertise, appointment availability is often low with wait lists of several months to over a year (The Carolina Institute for Developmental Disabilities, 2021). Given the charge for parents to “act early,” a tension is created between the long wait for a diagnostic evaluation appointment and

the urgency to address the developmental delays as the child continues to fall behind their peers according to normative measures.

In November of 2018, after nine months of early intervention services, the child psychologist assigned to us by the local Children's Developmental Services Agency office recommended my son for a full diagnostic evaluation with the TEACCH® Autism Program's regional center nearest our home. In the same month, my son's nine-month span of enduring neurological and hearing evaluations with conflicting results led us to a more specialized hearing evaluation at the University of North Carolina hospitals. When hearing concerns were officially ruled out, that team of physicians referred us for a full diagnostic evaluation for autism at the Carolina Institute for Developmental Disabilities (CIDD) in December of 2018. We completed the application process for both organizations, deciding to go forward with the CIDD when an appointment opened up there first.

Our wait was shortened to three months because of our referral directly from another provider within the same healthcare system and through the emergence of my subjectivity of parent as advocate within this new discourse of autism. My weekly phone calls to the offices of both organizations, starting from the day receipt of our application materials was verified, made us the first family notified when an appointment opened up because of a cancellation. I have struggled with guilt over the families who may have been overlooked as we skipped to the front of the line, but that has been coupled with a fierce determination to do whatever it takes to get answers and support for my son as quickly as possible. Upon reflection, much of this early advocacy stemmed from fears and concerns about delays and deviations from the norms set up by the developmental milestones. My subjectivity as a parent was constituted

by the urgency to act early to rectify my son's deficits in comparison to the normative assumptions of developmental milestones and measures.

Parent Questionnaire

Thinking with theory in the analysis of this discourse requires an exploration of “which questions are prioritized, how they get asked, what kinds of answers are sought, and what methods of investigation are employed” (Tremain, 2017, p. 37). Both TEACCH® and CIDD are under the University of North Carolina umbrella, but they require separate and extensive applications. All paperwork has to be fully completed and approved before a child can be placed on the waiting list, creating a barrier for parents with less education, those whose native language is not English, and those whose socioeconomic status prevents them from having excess time to complete paperwork. One element of each application is a parent questionnaire asking for information about the child's demographic information, personal medical history, family medical history, development, therapies and services received, and current skills (CIDD, 2012). These questionnaires also gather basic information about parents including parental age, educational background, employment, and income, in addition to concerns or referral questions (CIDD, 2012). If autism is believed to have a “strong genetic component” (Therapeutic Pathways, 2021), why is it necessary to collect information about parent education, employment, and income? Ogilvie (2015, p. 16) attributes this necessity to a certain point where hope (on the part of parents) runs parallel to control (on the part of institutions): to know so as to anticipate, to anticipate so as to act. Prevention, diagnosis, cure, or improvement, adaptation, would depend on knowing, finally, what is the cause.”

With no definitive cause associated with autism, the medical field continues to look for patterns across people with autism and their families that would reveal an answer.

One element of the parent questionnaire that was particularly disturbing for me was that questions about pregnancy and childbirth appeared in three separate sections of an eleven-page questionnaire (CIDD, 2012). This emphasis on pregnancy reinforces a discourse of biological determinism by assuming that disadvantages and deficits are “reproduced in the bodies, especially the wombs” (Tremain, 2017) and continues a trend of parent blaming or shaming. The first section titled “Pregnancy Information” asks about maternal age, number of previous pregnancies, and whether or not any of the following occurred: alcohol, tobacco, medication, or drug use; unusual physical or emotional strain; major illness; or abnormal weight gain (CIDD, 2012). A separate table asks about birth weight, length of pregnancy, length of labor, problems at birth, and subsequent developmental problems for all of the mother’s pregnancies in chronological order, including any miscarriages or stillbirths (CIDD, 2012). A final mention of pregnancy and childbirth starts the “Child’s Medical Information” section of the questionnaire by asking about birth weight, length of pregnancy, whether delivered vaginally or by Cesarean section, and if the baby needed medical assistance to start to breathe or an incubator (CIDD, 2012). This emphasis on pregnancy and childbirth reveals the normative assumptions of medicalized discourse that works to determine “which questions are prioritized, how they get asked, what kinds of answers are sought, and what methods of investigation are employed” (Tremain, 2017). This discourse makes possible the subjectivity of the mother as being at least partially to blame for the abnormality of her child because of some decision or circumstance occurring during pregnancy. There were no accompanying statements about possible links found in research (or the absence of any such

links) between any of these pieces of information about pregnancy and childbirth and the occurrence of autism.

Parent Rating Scale

Beyond the parent questionnaire, the application process included completion of the *Behavior Assessment System for Children: Parent rating scales for preschool ages 2-5* (3rd ed.), or *BASC-3*, instrument (Reynolds & Kamphaus, 2015). In this instrument, parents are presented with a list of 139 behaviors and asked to mark each individual item as occurring never, sometimes, often, or almost always in the last several months prior to completing the assessment (Reynolds & Kamphaus, 2015). There are no guidelines given for how to gauge the frequency of these behaviors or for distinguishing between the different answer choices, leaving ample space for interpretation and confusion. These items range from “pouts” to “has seizures” (Reynolds & Kamphaus, 2015). No descriptions, examples, or indicators are provided to further define the individual items. Additionally, there is no information in the copy given to parents about the overall purpose of the assessment or what it is designed to measure. This lack of specificity and clarity mirrors that of the developmental milestones discussed earlier in this chapter.

What the Path to Diagnosis Produces

My analysis of the developmental milestones, the path to diagnosis, and the application materials for a full diagnostic evaluation has revealed the privileging of normative standards for development, along with an urgency to act quickly to rectify deficits. Power/knowledge relations engage parents directly in the surveillance of their child’s development while reserving the right to diagnose autism for certain specialists. Parents are asked to provide information about themselves, their family, and their child, often without

much guidance or even an understanding of the purpose for collecting that information. As a reminder, the main analytical question for this chapter is: What is the interplay of subjectivity, power, and knowledge for autism parents within the medical discourse, and what does it produce? I have been thinking with Foucault's concepts of power/knowledge and subjectivity (1980; 1982) to make visible the normative. Now, I go on to reveal what is produced for and by parents in the medical discourse on the path to diagnosis.

The path to diagnosis articulates the steps through which a family must journey to reach an official diagnosis of ASD. In engaging with the discourse of early childhood development, parents encounter a reliance on positivism and normative measurement, even when those measures are unclearly defined and explained. Their child's well-being is discussed in terms of normal/abnormal development, creating a binary opposition in which "typical" is produced as the normative ideal, within a discourse of deficit and delay. Deviation from established norms becomes a problem to be solved. A repeated urgency to "act early" produces a need for parents to continually seek the next step as quickly as possible within a system encumbered by lengthy wait times. As parents navigate this new discourse, normative assumptions about child development and the recommendations of government entities and medical specialists take over as the authority on what is best. This discourse is enabled by the workings of power/knowledge: "the simultaneous individualization and totalization of modern power structures" (Foucault, 1982, p. 785). The authority of government and medical recommendations is ubiquitous and thus *totalizes*, but each parent applies those recommendations to an *individual* child's development, tracking that child as developing normally or abnormally. Knowledge is a function of power and discourse because parents are receivers of information and expected to take quick action, but

experience a shift in their own subjectivity as experts about their own child. Within measurement scales and observational protocols, parents function as impersonal sources of data that are extracted from their cultural contexts and family's values.

In this medical discourse, power/knowledge shapes parents' subjectivity by subordinating parents' knowledge about their child to expert knowledge about typical child development. Foucault (1982) writes that power/knowledge "applies itself to everyday life which categorizes the individual" (p. 781). With the application of the developmental milestones to everyday life, parents are encouraged to take up a subjectivity of constant surveillance regarding their child and to act with urgency to remedy any deviations from the normative ideal. In the flows of power/knowledge, a subject is "either divided inside himself or divided from others. This process objectivizes him" (Foucault, 1982, pp. 777-778). A "good" parent is one who recognizes deviations from normal development and seeks next steps for correcting those deficits quickly, one who can complete the necessary paperwork and whose answers to questions on application materials do not indicate poor choices during pregnancy. Conversely, a "bad" parent is one who does not engage with the developmental milestones, one who delays in seeking help for their child, or one who is unable to provide sufficient information for application materials.

In this analysis of the path to diagnosis, I have focused on the interplay of subjectivity and power/knowledge within the discourse of early childhood development. I have also shown how the information and processes at each step set up a discourse of normal/abnormal and deficit-centered thinking. The next chapter of analysis considers the ways in which autism is problematized during the full diagnostic evaluation appointment.

CHAPTER FOUR: THE DAY OF DIAGNOSIS

Right before we were dismissed for a lunch break on our day of diagnosis, my husband and I were asked to watch one of the assessments of my son from an observation room with a one-way mirror. Three adult females stood in a room with my son, each holding a separate clipboard. They alternated in trying to engage him in various forms of play, while he played contentedly and ignored them completely. I could tell from their facial expressions and body language that they were marking him down on their checklists for lack of skills. Finally, in exasperation, they asked me to join them in the room. The first thing I was asked was, “Can you get him to smile?” He smiled almost instantly, and within ten minutes, he had also engaged in many of their activities by following along with me.

Although this short encounter describes only a small segment of what we experienced that day, it opens a space for examining the ways that autism is problematized and the significance of those problematizations for people with autism and their families. As a reminder, a problematization is a “deeply ingrained way of thinking” that contributes to the shaping of “who we are and how we live,” (Bacchi, 2015, p. 5). This section of analysis will investigate the research question: What is the interplay of subjectivity and power/knowledge for people with autism and their parents within the discourse, and what does that interplay produce? In thinking with power/knowledge and subjectivity, my problematization of the full diagnostic evaluation will rely on the instruments and processes used during our appointment, the evaluation summary report given to our family by the evaluation team, and our family’s experiences during the appointment. My analysis will reveal that people with autism are problematized as abnormal and deficient while their parents are framed as being either compliant or resistant.

Evaluation Structure and Personnel

My husband and I went to the diagnostic evaluation appointment with a sense of hope. Our son had experienced a regression in skills and had almost no language. We had been through a battery of medical and psychological testing over the last seventeen months and just wanted answers. This clinic was internationally recognized as one of the best, so we hoped they would have answers. We felt like having a diagnosis would empower us to advocate better on our son's behalf and would open the door to more therapies and services for him in addition to increased support once he started school.

The full diagnostic evaluation appointment occurred over two hours away from our home, requiring an overnight stay at a nearby hotel the night before. As a reminder from the previous chapter, my son does not do well in hotel rooms and it took us until close to midnight to get him settled and asleep, but that still seemed preferable to leaving our home before 6:00 a.m. in order to make it to the appointment on time. Upon arriving at a strange building on the day of our appointment, we were greeted by a kind, but unfamiliar receptionist and escorted to a small waiting room with unfamiliar toys, books, and furniture. My husband, son, and I were taken to an observation room for an initial greeting and interview time, after which my son was moved to a third location for observation and assessment.

The evaluation consisted of four components: a developmental/behavioral assessment, a speech language/communication assessment, an occupational therapy assessment, and an interdisciplinary autism diagnostic evaluation (CIDD, personal communication, March 20, 2019). Seven unfamiliar adults comprised the interdisciplinary team that evaluated my son. They rotated between conducting observations and evaluations

of my son in a separate setting and interviewing my husband and me. The initial introductory interview and the short time period described in the opening vignette were the only portions of the assessment that my husband and I were allowed to watch or participate in. Our exclusion from some of the evaluation processes reproduced the “fundamental asymmetry of the clinical encounter. This is an asymmetry of vulnerability and of knowledge; in short, it is a relationship of power” (Hull, 2017, p. 412). The evaluation team were in their familiar environment, held the expert knowledge on autism, and had exclusive access to my son during testing. As parents, we watched our child get taken away by strangers to complete unknown high-stakes tasks that would determine his diagnosis, which would put us at disadvantage later when we were presented with the evaluation results. Because we were absent from most of the evaluation process, this asymmetrical power relation forced us into a choice of accepting or rejecting the team’s findings without being able to intelligently discuss or question those results. In sum, we were vulnerable subjects in the clinical encounter.

The diagnostic evaluation took approximately three hours before our family was dismissed for a lunch break. During the hour that we were eating, the interdisciplinary team met to “consolidate findings and generate initial recommendations” (CIDD, personal communication, March 20, 2019). When we returned, we were taken back to the same observation room where we were initially interviewed for an “interpretive conference,” a euphemistic term for delivering a diagnosis (CIDD, personal communication, March 20, 2019).

Several issues for consideration emerge in thinking about the evaluation structure as constituting and being constituted by the discourse of autism. My son, like many other people with autism, thrives on consistency and routine. I would argue that most people, especially

most three-year-olds, autistic or not, prefer to be in situations where things are familiar and somewhat predictable. Being so far removed from his natural surroundings and schedule, the diagnostic evaluation appointment violated every routine my son had at that point in his life *at the same time*. He was also removed from his parents by unfamiliar adults who kept rotating in and out of the room. Not only was this unsettling for him as exhibited by his reported need for sensory input throughout the examination, a behavior that he shows when distressed, but it also prevented my husband and me from knowing specifically what behaviors had or had not been observed.

In his poststructural critiques, Foucault (1982) questions “the way in which knowledge circulates and functions, its relations to power” (p. 781) and we experienced this interplay of power/knowledge. For example, we were prevented from knowing and observing, which resulted in the subordination of our knowledge to that of the “experts” and diminished our ability to ask informed questions at the interpretive conference later. Knowledge was the domain of the evaluation team, creating a subjectivity of compliance for us as parents, experienced as not knowing and perceived helplessness. We were positioned as docile and compliant consumers of information, trusting what we were told without question and largely without our participation.

Instruments Used

Each of the four components of the evaluation (a developmental/behavioral assessment, a speech language/communication assessment, an occupational therapy assessment, and an interdisciplinary autism diagnostic evaluation) began with a review of my son’s medical chart and records of prior assessments with other doctors, therapists, and organizations (CIDD, personal communication, March 20, 2019). Given their short

timeframe for evaluation of my son, it makes sense that the evaluators would want to use any information available to make a diagnosis; however, I wonder if their review of assessments completed as much as a full year prior to our appointment might have formed preconceived notions of my son and his (im)possibilities before we even arrived on their campus. I suspected this because according to her feminist philosophy of disability, Tremain (2017) notes that the current medical model assumes disability to be a “prediscursive, transcultural, and transhistorical disadvantage” (p. 2). If the diagnostic evaluation team shared this assumption of disability as a fixed and inherent trait, then they would be likely to judge my son based on what a different medical or service provider noticed about him many months prior rather than focusing on his skill set at the time of evaluation. Operating from the viewpoint that disability is a fixed characteristic, the diagnostic process relies on the ability to neutrally observe disability as an objective and inherent quality that will present similarly over time and across settings. This process sustains the medical discourse of positivism, where knowledge is produced as quantifiable truth through measurement and expert observation.

Direct observations of my son’s behaviors by the clinical evaluators occurred across all four components of the diagnostic appointment, although they are described slightly differently in the official reporting (CIDD, personal communication, March 20, 2019). For the psychological portion, the observation is considered to be “behavioral”; for speech and language, it is “informal”; for occupational therapy, the descriptor is “play-based”; and the interdisciplinary observation relied on Module 1 of the *Autism Diagnostic Observation Schedule*[™], 2nd edition, or *ADOS-2* (Lord et al., 2012), which is a standardized and coded diagnostic measure.

Members of the evaluation team also completed two formal evaluative scales during their assessments of my son (CIDD, personal communication, March 20, 2019). The psychological component of the evaluation included two areas of the *Mullen Scales of Early Learning* (Mullen, 1995): Visual Reception and Fine Motor Skills. The Visual Reception area focuses on skills like matching objects, matching pictures, matching letters, and sorting objects by category while the Fine Motor area involves stacking blocks, imitating line drawings, and stringing beads, among other tasks (CIDD, personal communication, March 20, 2019). The speech and language component of the evaluation also incorporated a formal evaluative scale completed by the clinical evaluation team, the *Preschool Language Scales, 5th edition*, or *PLS-5* (Zimmerman, Steiner, & Pond, 2011). This instrument yields standard scores for both auditory comprehension and expressive communication (CIDD, personal communication, March 20, 2019).

In addition to the *BASC-3* that was submitted as part of our application packet and has been discussed above, my husband and I were asked to complete two parent scales on the day of our appointment—one in the office and one over our lunch break. The *Adaptive Behavior Assessment System, Third Edition (ABAS-3)* was part of the psychological component of the evaluation (Harrison & Oakland, 2015). The *ABAS-3* yields an overall score for adaptive functioning using domain scores for level of functioning in conceptual, social, and practical skills (CIDD, personal communication, March 20, 2019). The *Toddler Sensory Profile, 2nd Edition* was the only formal measure for the occupational therapy component of the evaluation (Dunn, 2014). This assessment is designed to “document a child’s sensory processing patterns and...assist in determining the extent to which those patterns interfere with participation in home, school, and community settings” (CIDD, personal

communication, March 20, 2019). Our family did not receive a copy of our responses or the scoring process for scales completed by the evaluation team, the *ABAS-3*, or the *Toddler Sensory Profile-2*.

A final instrument used in the full diagnostic evaluation appointment is the parent interview. My husband and I were interviewed for approximately two hours by varying personnel from the clinical evaluation team, each with a different focus. Interestingly, the only component that did not include a parent interview as one of its measures was the psychological component. Although some would think that an interview of the parents would be especially helpful in a psychological evaluation given the field's focus on behavioral and emotional functioning, it was the only area of the diagnostic evaluation that relied solely on standardized measures, existing medical records, and the expertise of the clinical evaluation team in performing a behavioral observation (CIDD, personal communication, March 20, 2019).

Problematizations in the Diagnostic Evaluation Appointment

My analysis in this chapter is addressing the analytic question: What is the interplay of subjectivity and power/knowledge for people with autism and their parents within the discourse, and what does that interplay produce? In doing the work of problematization, Bacchi (2016) emphasizes the need to trouble both what is privileged and what is silenced, to think about what is made (im)possible by both inclusion and omission of information. In other words, to problematize is to reveal what has become taken for granted and how it (re)produces power/knowledge relations within the discourse. Following the descriptions of the diagnostic evaluation appointment process and the instruments used above, my analysis of the language and areas of emphasis in the official evaluation appointment summary report

reveals problematizations of children with autism and their parents. These problematizations expose assumptions of the medical experts and the systems in which they practice. For example, assumptions such as that a child's development is measurable against a statistical average and that deviations must be addressed quickly producing and reproducing normative discourse surrounding normal and abnormal child development. The relations of power/knowledge in the diagnostic evaluation process make the assumptions of disability as an inherent and fixed trait of an individual associated with these problematizations both thinkable and possible. Problematizations are so deeply ingrained that their "status as independent phenomena requiring intervention is unquestioned" (Bacchi, 2016, p. 2). As a result, the ways that the diagnostic evaluation process represents autism as a problem to be solved set the stage for how individuals with autism and their families constitute and are constituted by the larger autism discourse. That is, people with autism and their families are always in relationship with the belief that they are inherently flawed and in need of repair within the medical discourse of autism.

Blaming the Individual for Noncompliance

As early as the first paragraph summarizing the observations and findings from the diagnostic evaluation process, the clinical evaluation team casts a small shadow of doubt on the reliability of their process through an introductory disclaimer that "scores from developmental testing may provide underestimates of his true abilities" (CIDD, personal communication, March 20, 2019). This chink in the diagnostic armor is not presented as an indictment of the evaluation design or claims made by the formal evaluation tools. Rather, any uncertainty is derived from my son's lack of compliance and engagement with the evaluation process. Any "underestimates" or inaccuracies in the evaluation results are "due to

[his] preference for playing with items in his own way and his difficulty pointing to depicted objects in test books” (CIDD, personal communication, March 20, 2019), a theme which is repeated throughout the report. In reporting the scores from the *Mullen Scales of Early Learning*, we are reminded that “these scores may underestimate [his] current developmental functioning” and again in the psychological component write-up that “interfering behaviors may have negatively impacted these scores” (CIDD, personal communication, March 20, 2019).

Beyond the negative impact on the reliability of instrument scores, my son’s deficient performance and engagement during the evaluation created other issues for the clinical evaluation team. Major speech functions such as articulation, voice, fluency, and oral-motor abilities “could not be formally assessed due to limited vocal output” (CIDD, personal communication, March 20, 2019), causing the team to eliminate an entire portion of their routine diagnostic process. A final concern caused by my son’s noncompliance was evident in his lack of interaction with the evaluation team. The report notes that “the overall quality of rapport was frequently one-sided due to [his] inconsistent engagement in the activities and the examiner” (CIDD, personal communication, March 20, 2019). One specific example was given regarding his disengagement. During the occupational therapy evaluation, he put together several Duplo blocks, which was a desired task for this assessment, but was reported to have “abandoned the task when the [Occupational Therapist] made attempts to engage with him or encouraged him to request more blocks from her” (CIDD, personal communication, March 20, 2019). He was perceived as being disengaged because he didn’t engage in the right (*normal*) way.

The positivist and scientific approach to diagnosis assumes that disability is an essential and fixed quality of an individual, and therefore any deviance or nonconformity is “routinely discredited, ignored, vilified, and stigmatized” (Tremain, 2017, pp. 40-41). The privileging of quantifiable and normative measures (re)produces a discourse in which such deviance and noncompliance cannot be primarily connected to the unfamiliarity of the environment, people, and procedures. Therefore, any uncertainty in the process was deemed unrelated to the incredibly high demand of a three-year-old being examined and assessed for three consecutive hours with no break for preferred activities or time with his parents.

Because the diagnostic process is evidence-based and highly-calibrated, it does not leave space to recognize the amount of language thrown at a child who exhibits low language skills and that every comment or prompt was an interruption that caused my son to have difficulty in processing. The report we were given problematizes the child with autism as the reason for any inaccuracies in the process because he is uncooperative, noncompliant, and deficient, but confidently states that the reliability and validity of the instruments and processes used in diagnosis compensate for any uncertainty on the evaluation scales created by my son’s reticence. As Hacking (1990) notes, “By covering opinion with a veneer of objectivity, [the diagnostic evaluation team replaces] judgment by computation” (p. 4). The report assures us of the reliability of the diagnosis since the “observations of [his] social communication and behavioral functioning provide an accurate representation of his current and habitual functioning in these areas” (CIDD, personal communication, March 20, 2019). This statement serves to reproduce the power/knowledge relations within the medical discourse by which the expert knowledge is privileged and measurements of the child’s abilities are perceived as “the real.”

Focus on the Mother

In Kanner's foundational writing about autism as a separate diagnosis, he noted "the contributory effects of parental lack of warmth on constitutionally predisposed children" (Wolff, 2004, p. 204). Kanner (1943) combined clinical observations of children with autism with communications from their parents, which is the model used in present-day diagnostic evaluations. My husband and I completed all application materials and attended all parts of the diagnostic evaluation appointment for our son together. Several times throughout the summary report from our diagnostic evaluation appointment, this partnership is acknowledged through references to my husband and me as "both parents," "the Shoafs," "Mr. and Mrs. Shoaf," or "the Shoaf family" (CIDD, personal communication, March 20, 2019). Although we were both actively engaged in the parent interviews, there is only one instance of a comment coming from just "Mr. Shoaf" in the entire 23-page report, referencing a nighttime routine that my son enjoyed at the time.

Multiple areas in the report that draw from parental input are attributed solely to "Mrs. Shoaf," as if I were the only one responsible for answering the questions. Also, the occupational therapy component report states that "[his] mother completed the *Toddler Sensory Profile-2*" even though my husband and I completed that report collaboratively (CIDD, personal communication, March 20, 2019). This practice reproduces the discourse that focuses on the mother from the multiple questions about pregnancy and childbirth in the application packet discussed above. As the mother, I was supposed to be the one with all of the answers, and all conclusions drawn about our family structure and routines seemed to be connected primarily back to me. Additionally, the discourse of focus on the mother harkens back to Bettelheim's "refrigerator mother" theory of autism (1967), in which he asserted that

the challenges with social and communication skills facing children with autism are a direct result of cold and uncaring parenting, particularly on the part of the mother. This discourse makes it possible to think of the parent as a potential cause of the child's autism, or at least a hindrance to the child's development.

Another interesting piece of analysis is in regards to the moments where we were directly quoted in the report. The majority of the report is written from the perspective of a neutral observer and in a friendly, but clinical style. There are a few examples of words appearing in quotation marks in the report because they represent our family's way of describing one of my son's behaviors. For example, we refer to the way his body tenses, his arms flail, and he kicks his legs in excitement as "cranking it up," and the report repeats that phrase. There is only one place in the entire report where a comment that one of us made in the interview was captured verbatim in a direct quote. In a discussion of feeding during the occupational therapy evaluation, it was noted that my son was eating a variety of foods, but that most of those foods did not require the use of a utensil. The report states, "Mrs. Shoaf explained that utensil use is not a major priority right now and that they 'don't want to fight the fight'" (CIDD, personal communication, March 20, 2019).

The flows of power/knowledge within the discourse of diagnosis enable the evaluation team to choose when our family's input was privileged and when it was silenced. Not only does the emphasis on my input over my husband's problematize autism as a concern for (and possibly the fault of?) the mother, but the inclusion of this sentiment as the only direct quote problematizes me as avoiding work on a functional skill for my child because I have chosen not to engage in something that would be a struggle. It implicitly attributes some of my son's developmental delays to my refusals or reticence, again

reinforcing the subjectivity of an autism parent as an obstacle to their child's development, or potentially the cause of the autism. By not prioritizing this particular feeding skill, I was positioned as noncompliant.

Also marginalized from the diagnostic evaluation processes and report is the agency that I exhibited in response to the discourse of my son's abnormality and deficits. I had constituted and been constituted by a need to advocate for him and to push forward toward knowledge and support. In this subjectivity as an advocate for my son, I experienced a liminal space in which I flowed from compliant to resistant, pushing back against the discourse while trying to navigate through it effectively. According to Foucault (1982), my various responses and actions upon entering the medical discourse of autism are examples of "the way a human being turns [herself] into a subject" (p. 778). I had been actively seeking answers for the changes in his development and working with various therapists and doctors for over a year. My son and I worked constantly on the strategies recommended by these service providers, trying to set him up for success. The power relations of the discourse "impose a law of truth on [the individual] which he must recognize and which others have to recognize in him" (Foucault, 1982, p. 781). Yet my efforts and those of my son were largely ignored and even unrecognizable within the discourse of diagnosis. I may care deeply about my son and passionately pursue his best interests, but in the minds of the diagnostic evaluation team, I was resistant to doing the work of shaping desired behaviors. I had not fully "submitted to a set of very specific patterns" (Foucault, 1982, p. 783) for being a "good" autism parent, and as such was not yet integrated into the apparatus of autism. What my directly-quoted comment was meant to convey was that using a fork did not seem to be as pressing of a need at that time as helping him to communicate his wants, needs, and

feelings, but instead it offered an opportunity to reproduce the discourse that blames the parents for the manifestations of a child's difference within the larger discourse of autism.

Deficit-Centered Descriptions of Abnormality

All members of the clinical evaluation team were friendly and positive in their personal interactions with our family during the diagnostic evaluation appointment, possibly in an effort to offset the high-stakes, stressful, and standardized nature of the process. We appreciated the warm welcome on a difficult day, but the normative framework within which the examiners operate remains glaringly evident throughout the report. My son is described in the report as “an affectionate, fun, and happy boy who was a pleasure to evaluate” and also as being “sweet” (CIDD, personal communication, March 20, 2019). He is definitely all of those things, and it is nice to hear positive sentiments about my child, but the small mentions of his pleasant personality were offset by pages and pages of descriptions of limitations in his abilities. There were no specific skills pointed out as strengths, nor were any of his scores on the evaluation scales positive. The emphasis on his happy disposition as his only strength served to underscore the chasm between his abilities and what a *normal* child would be doing at that developmental stage: a deficit-centered trend that continues throughout the report.

Deficit-centered discourse reinforces the normal/abnormal binary opposition whereby deviations from what is considered to be “normal” are assumed to be negative. According to Tremain (2017), this deficit-centered approach mirrors the dominant conceptualization and discourse of disability outside of the medical community. In this dominant discourse of disability, Tremain argues, “Disability is a deficit, a personal misfortune, or pathology that necessarily reduces the quality and worth of disabled people's lives and inevitably leads to the social and economic disadvantages that disabled people confront” (p. 19). Such a limited

and limiting view of difference produces impossibilities for people with autism and their families. The discourse privileges what a person with autism *cannot* do – while silencing, or at least ignoring, potential areas of strength.

For example, the initial summary of the clinical evaluation team’s findings includes this sentence before announcing a diagnosis of ASD: “Direct observation of [his] behavior during this evaluation was notable for *limited nonverbal* communication, *atypical* speech patterns, self-stimulatory behavior, sensory seeking behavior, *repetitive* play, and *limited* social engagement” (CIDD, personal communication, March 20, 2019, emphasis added). Each emphasized word in this statement describes a departure from the normal that is assumed to create a limitation of possibility for current and future functioning. A similar description appears in the summary at the end of the report. The team notes that my son “demonstrates some social strengths” and cites one specific behavior as an example before reporting that he “also exhibits numerous challenges” and citing six specific skills or behaviors in which he is deficient (CIDD, personal communication, March 20, 2019). In holding perceived deficiencies against normative assumptions, the discourse of autism reproduces the deficits of abnormality. It also perpetuates the reliance on positivism in its quest to quantify, evaluate, and observe normal and abnormal behavior. Moghtader (2016) describes this normative process as one by which “natural separations can be grounded based on observations of differences then these differences articulate and operate a set of ideals for individuals” (p. 25).

The deficit-centered approach to describing an individual with autism is not a collective character flaw of the clinical evaluation team. Rather, it is a continuation of the discourse surrounding autism in the medical field that problematizes individuals with autism

as abnormal, deficient, and in need of intervention, as can be seen in the structure of the evaluation scale instruments. In the psychological component of the evaluation, the *BASC-3* produces T-scores and percentile ranks in the following areas: *externalizing problems*, defined as hyperactivity and aggression; *internalizing problems*, defined as anxiety, depression, and somatization; *behavioral symptoms*, defined as atypicality, withdrawal, and attention problems; and *adaptive skills*, including adaptability, social skills, functional communication, and activities of daily living (Reynolds & Kamphaus, 2015). Out of the four categories, only the adaptive skills language reads as neutral with the other three categories labels themselves carrying negative connotations, along with their accompanying lists of problems. Results in each category and subcategory are assigned a descriptive range based on the T-score and percentile rank. Descriptive ranges included in our report were “within normal limits,” “at-risk,” and “clinically significant” (CIDD, personal communication, March 20, 2019), each pointing out adherence to or deviation from what is considered normal. Discourse is “more than simply a group of statements or a stretch of text on paper, discourse can be characterized as a dynamic constellation of words and images that legitimate and produce a certain reality” (Allan, 2003, p. 37). What the discourse legitimates – then shapes – determines what is considered to be normal, positioning people and ideas within or outside of the dominant discourse.

The emphasis on quantifying and explaining my son’s abnormality through deficit-centered language continued across other formal evaluation instruments, thus continuing a discourse of abnormality. The *PLS-5* score report includes “normative standard scores, age equivalents, and growth scale values (evidence-based scores, which can be used to track progress over time)” (CIDD, personal communication, March 20, 2019). In the case of the

PLS-5, percentile ranks do not function alone in helping a parent to grasp the severity of their child's deficits. Age equivalents in months are also included to indicate at what age a *normal* child would have exhibited the same skills (Zimmerman et al., 2011). The *Toddler Sensory Profile-2* also converts raw scores into normative classification ranges as follows: “much less than others,” “less than others,” “just like the majority of others,” “more than others,” and “much more than others” (Dunn, 2014), reinforcing the dichotomy between what is normal and what is deficient. Foucault (1982) labels this process of classification as a “dividing practice,” one which “objectivizes” the subject by causing divisions within the self or divisions from others (pp. 777-778). As a technique of power, a dividing practice creates subject positions that reflect binary oppositions like normal/abnormal or typical/atypical, whereby the first term in each pair is dominant and privileged while the second is othered and silenced. In so doing, classifications (re)produce the deficit-centered discourse of autism. Classifications also sustain parental subjectivity as compliant or resistant by forcing the acceptance or rejection of such labels by parents as part of their immediate and ongoing response to diagnosis.

As is discussed above, our experience as a family on the day of my son's diagnosis reflects the ways that young children with autism are problematized and placed in a binary of normal/abnormal. The full diagnostic evaluation process sheds light on the abiding faith placed on positivism, quantifications, observation, and expertise within the medical community. The medical discourse of disability and its accompanying flows of power and knowledge make possible a “process of careful behavioral conditioning” through which “subjects take compliance with regulatory demands upon themselves” (Hull, 2017, p. 416). My initial positionality was one of resigned compliance. There were so many deficits

identified by the “experts” throughout the diagnostic evaluation. I wanted to do everything I could for my son, and the path forward seemed to be one of acceptance and actively engaging in seeking help for him quickly. At the same time, I resisted the idea that a quantitative instrument or observations captured on a single day could or should define my son for the rest of his life. I knew that he was so much more than the numbers in the report. Through the diagnostic evaluation, our family officially entered a new discourse, the deficit-centered discourse of autism, as active participants with the agency to constitute our subjectivities of compliance or resistance therein.

In the Foucauldian concept of power/knowledge, power is not something that one group or individual “has” and can use to control another. Instead, power is a relation in which the dominant discourse and taken-for-granted assumptions are privileged and encourage compliance while marginalized knowledge and subjectivities offer resistance. Foucault (1982) takes the “forms of resistance against different forms of power as a starting point” for his analysis. Resistance can take the form of a refusal to accept ingrained assumptions as “truth.” Foucault (1972) encourages the questioning of “those ready-made syntheses, those groupings that we normally accept before any examination, those links whose validity is recognized from the outset” (p. 22). Resistance can also move beyond what is accepted as true to trouble the relations of power/knowledge and subjectivity. Foucault (2007) cautions us to critically examine “what we are willing to accept in our world – to accept, to refuse, and to change both in ourselves and in our circumstances” (p. 152). As an autism parent, my subjectivity is a complex mix of docile compliance and resistance with the way the discourse seeks to classify my son and shape our family’s behavior.

Working both within and against the dominant discourse of autism, my refusal to define my son in terms of his perceived deficits marked the emergence of my own subjectivity of *autism parent as advocate* exhibited through engaged resistance, a disruption or “fold” that has marked every part of my life ever since. In questioning, problematizing, and critiquing the techniques of power within the discourse of autism, “truth” and “facts” about individuals with autism and their families are reframed as being “discursively formed, contingent, fragile, and contestable” (Gillies, 2013, p. 26). For example, throughout this analysis, I have demonstrated the ways in which each component of the diagnostic evaluation and its (re)producing of the discourse of autism is fragile and contestable. The setting for the evaluation was unfamiliar and unnatural, taking my son out of his routines. The team used previous medical information, some of which came from appointments almost a year before this evaluation. Observations were conducted without our participation and without knowledge of the ways our family interacts with each other and the language we typically use. My husband and I completed questionnaires and instruments without much guidance or context for what was being asked. Most importantly, the entire process tried to make far-reaching determinations about my son within the space of a few hours. Recognition of all of these limitations in the diagnostic evaluation process make resistance possible within the medical discourses of disability, evaluation, and autism.

Taking on a subjectivity of resistance does not necessitate a sense of negativity or destruction. Although critique is often viewed as deconstructive, the act of problematization is largely positive as it “makes the status quo untenable and forces people to consider alternative approaches, beliefs, or strategies” (Gillies, 2013, pp. 23-24). If faith in the empirical “truth” and “facts” within the discourse of autism can be weakened, then new

possibilities and complex subjectivities open up for those subjects within the discourse. It might be possible for parents to take up a subjectivity of active and informed engagement with the diagnostic process rather than being forced into a dichotomy of compliance/resistance. Knowledge and power could flow through the discourse of diagnosis in a way that privileges the knowledge that parents bring to the conversation as the experts on their individual child. Removing unhelpful quantifications and classifications would open up the possibility for diagnosing a child with autism as a whole individual, recognizing the entire realm of social constructs that impact an individual human life.

CHAPTER FIVE: DIAGNOSTIC CRITERIA AND PROCESSES

The results of the diagnostic process are critical for families because they are applied in determining eligibility for therapies, services, and insurance coverage, among other factors. Ultimately, parents are hoping to locate and secure the supports and placements that will enable their child to flourish and reach their full potential, and the diagnostic criteria serves as a gatekeeper for many of those processes. This section of analysis explores the ways in which the language of the diagnostic criteria (re)produces a deficit discourse about autism and sets up people with autism as a *problem to be solved*. My analysis of the ways in which autism is problematized in the diagnostic criteria for ASD will address the research question: What is the problem represented to be regarding autism in the medical discourse?

In order to problematize the diagnostic criteria for ASD, I will first examine how the language of the diagnostic criteria compares people with autism to normative standards, thus (re)producing the normal/abnormal binary opposition discussed in the previous analysis sections. Statistical averages and ideals about what is normal for human development and behavior privileges individuals who fall within the normative framework while positioning others as deviant and deficient like with the CDC's developmental milestones. This normalization is achieved through techniques of power such as classification and ranking as in the evaluation measures used in a full diagnostic evaluation for autism. The analysis in this section will continue with a problematization of the reliance on positivism throughout the diagnostic criteria and processes. A final component of this problematization will reveal the taken-for-granted assumptions about people with autism that are reinforced by the diagnostic criteria. The assumptions are that ASD represents deficits that can be assigned a level of severity, that people with autism require support to correct those deficits to move closer to

the normative ideal, and that these abnormalities are part of an inherent set of flaws in the individual that will present across time and circumstance. This problematization is significant because these assumptions impact the possibilities for how those people shape their own subjectivities within the medical discourse of autism. To begin, I look at the most recent medical definition of autism, which is widely recognized as the authoritative description of autism given current knowledge and research. Throughout the analysis, I think with the medical definition of autism and poststructural concepts of subjectivity in order to problematize how people with autism are positioned by the diagnostic criteria.

Autism Spectrum Disorder in the *DSM-5*

According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition), more commonly referred to as *DSM-5*, Autism Spectrum Disorder is now an umbrella term that encompasses what would previously have been diagnosed separately as autistic disorder, Asperger's disorder, or pervasive developmental disorder (American Psychiatric Association, 2013). Rather than delineate between different diagnoses, the current manual clarifies the broader diagnosis of Autism Spectrum Disorder by specifying whether it is accompanied by intellectual or language impairments or is associated with other conditions, disorders, or environmental factors (American Psychiatric Association, 2013).

The *DSM-5* describes autism spectrum disorder as follows:

Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to

the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities (n.p.). A diagnosis of Autism Spectrum Disorder no longer refers to individuals as high-functioning or low-functioning, but assigns separate severity levels for the domains of social communication and restricted, repetitive behaviors. These severity levels are defined as “requiring support (Level 1), requiring substantial support (Level 2), and requiring very substantial support (Level 3)” (American Psychiatric Association, 2013, n.p.).

Deficit-Centered Definitions

The definitions and criteria for Autism Spectrum Disorder established in the *DSM-5* are considered to be the ultimate medical authority on autism and are employed beyond the diagnostic process, producing a discourse that affects decisions regarding insurance coverage, eligibility for services, and educational placement for individuals with autism. Alexander and Coveney (2013) posit that “examining discourse illustrates how a certain way of thinking imposes itself on a particular domain” (p. 354). Therefore, this section of my analysis interrogates the deficit-centered discourse associated with Autism Spectrum Disorder in the *DSM-5*, problematizing its normative assumptions to open up possibilities for “thinking otherwise” about individuals with autism (Gowlett, 2015, p. 161).

Problematizing the diagnostic criteria requires first the examination and interrogation of the ways in which identities are produced and assumed to be fixed or essential to an individual by the discourses and politics in which that individual lives. In taking a step back from what has become taken for granted as *knowledge*, limited and limiting representations are called into question. The definition of Autism Spectrum Disorder in the *DSM-5* is a prime example of how deficit-centered framing within the medical community creates fixed

identities for individuals that can have far-reaching effects on their lives. Just within the two sentences of the *DSM-5*'s definition, there are seven uses of deficit-centered language. The condition of autism itself is labeled as a “disorder,” implying something inherently wrong or dysfunctional about any individual who will fall into this category. Autism Spectrum Disorder is characterized by “deficits” in social communication skills, emphasized as being “persistent,” and this deficiency in social communication is repeated twice to further emphasize what is lacking. Additionally, the diagnosis of Autism Spectrum Disorder requires that an individual also exhibit “restricted” and “repetitive” behaviors or interests, which signals a comparison between the behaviors of a person with autism and those of an individual who is considered to be normal. May (2005) notes that “there are specific sexual, psychological, cognitive, and emotional lives that are characteristically human. To fail to live in accordance with these characteristically human lives is to fail to be fully human. It is to be abnormal” (p. 14). Within this normative framework, the individual with autism is labeled as “abnormal” because their interests do fall within the acceptable range of intensity or categories, and such “restricted” interests prevent the person with autism from being viewed as engaging in the full human experience.

In direct response to the normal/abnormal binary that is perpetuated by the diagnostic criteria, many individuals within the autism community have rejected the normative language of the medical discourse. The neurodiversity movement pushes back against the idea of a typical human being, against the very concept of *normal* cognitive, social, and communicative functioning (Tougaw, 2020). The focus of the neurodiversity movement has been acknowledging the shared humanity across the neurological spectrum (Tougaw, 2020). A neurodiverse perspective disallows the use of the words “disorder” or “deficit” within a

diagnosis, terms which automatically insinuate abnormality, dysfunction, marginalization, outsider status.

Deficit-centered language in the *DSM-5* is understandably unacceptable to many people within the autism community, but what are the alternatives? What new wording would make the diagnostic criteria more palatable? Raising awareness and promoting the use of more inclusive language is a worthy goal, but does it address the perceptions and politics behind the framing of the diagnostic criteria? Attempts at “political correctness and linguistic correction” are not enough (Tuck, 2009, p. 419). With a focus on language, an analysis of the diagnostic criteria only allows for a substitution of terms. What is needed is a closer look at how the “problem” of autism is being framed, the underlying assumptions of such a framing, and the effects that are produced as a result within the autism community.

Problematization and Positivism

One overarching and significant assumption reproduced by the *DSM-5* is the reliance on positivism and quantitative research within the medical community. “Generally positivism remains the dominant paradigm within medical research, relying upon an assumption that independent (objective) scholars can access information, or evidence, about “the real,”” writes Bacchi (2016, p. 2). Diagnosing an individual with autism depends on the ability of the expert evaluators to determine the “facts” about that individual’s capabilities and to compare those “facts” against what is statistically typical. Moghtader (2016) describes this positivist approach as the process by which “natural separations can be grounded based on observations and differences” (p. 25). Highly-trained clinicians, leaning heavily on their own expert observation and standardized materials, diagnose an individual with autism through a series of tests and measures, often in an unfamiliar setting and within hours of meeting that

individual. Human qualities and behaviors are quantified, tabulated, and compared to the statistical mean, which represents the “normal.”

Behind the façade of truth and objectivity, the positivist framework of medical discourse problematizes people with autism as atypical and deficient for not falling within the statistical mean. The definitions and classifications of the diagnostic criteria become binding and overarching labels that play a role in determining the future outcomes for people with autism and their families. Philosopher Ian Hacking (1990) warns that “defining new classes of people for the purposes of statistics has consequences for the ways in which we conceive others and think of our own possibilities and potentialities” (p. 6). Such labels may directly impact the way that autism parents think about their child and the future as parents take up a subjectivity of compliance within this positivist discourse. A subject position of compliance may be the only one available at this juncture because of the inaccessibility of the process and information involved in an autism diagnosis. The diagnostic process and criteria for autism involve an “intricate manipulation of impenetrable data” (St. Pierre and Jackson, 2014, p. 715) whereby the diagnostic evaluators are positioned as experts who must interpret the data collected for autism parents to understand. The medical discourse of diagnosis is laden with jargon and quantifications shared without context, preventing access and understanding for many parents, thus hindering their ability to engage in conversation and advocate for their child. As the neutral keepers of the “facts” about the child, the evaluators become the experts. This power/knowledge dynamic produces parental compliance. In many cases, parents are neither given the opportunity to determine what information they provide to the evaluators about their child and family nor how that information is considered during the evaluation.

Additionally, the reliance on positivism within the medical discourse of diagnosis privileges quantitative knowledge and the judgments of experts above other forms of knowledge. Parent input, when sought by the diagnostic process, consists of answering specific questions that will enable the evaluators to more clearly sort the child into the correct categories and classifications. Many responses are in the form of Likert scales or constructed responses with little opportunity for elaboration. As a parent going through the diagnostic process, I was never asked questions like “What does your family like to do together?” or “What is most important to your family?” The lack of such questions exhibits how a discourse can produce a “domain of *normativity* for itself (according to what criteria one may exclude certain statements as being irrelevant to discourse, or as inessential and marginal, or as non-scientific)” (Foucault, 1972, p. 61, emphasis in original). Family values and preferences simply do not matter in the diagnostic process because they are irrelevant and unscientific.

A final assumption that underlies the positivist framing of the discourse of diagnosis is its reliance on specificity within a given moment. Within the positivist discourse of diagnosis, “impairments are . . . the intrinsic characteristics (pathologies or abnormalities) of individuals that manifest in remarkably uniform kinds of ‘disabilities’ (construed as abnormal functioning)” (Tremain, 2017, p. 86). Because these characteristics are intrinsic, fixed, and uniform, what can be observed and quantified at a given moment in an individual with autism’s life can be generalized into statements about that person’s present and future. To put it differently, the measurements and observations of the day or period of diagnostic evaluation work to define who or what the individual with autism is right now and who or

what that individual may become. This assumption largely ignores the full complexity of a person's interactions and subjectivities, as well as how those may fluctuate over time.

Problematizing the Diagnostic Criteria

The diagnostic criteria for Autism Spectrum Disorder in the *DSM-5* is produced by and reproduces the reliance on positivism and the accompanying focus on deficits and dysfunction within the medical community as discussed above. However, the diagnostic criteria exhibits its own problematizations that are unique to autism. According to Bacchi (2015), "Problematizations are deeply ingrained ways of thinking (conceptual schema) that shape (to different degrees) who we are and how we live" (p. 5). To that end, what "deeply ingrained ways of thinking" are promoted in the *DSM-5*? How are individuals with autism, their families, and their lives impacted by these underlying assumptions? How does the discourse of the diagnostic criteria (re)produce the binary opposition of normal/abnormal?

Developmental Milestones

By emphasizing the "persistent deficits" in social communication present in individuals with autism, the diagnostic criteria implicitly endorses the idea that human psychosocial development proceeds in predictable stages, as described in the work of Piaget (1954) and Erikson (1966), among others. These "deficits" are made evident when an individual fails to meet, or is significantly delayed in meeting, generally accepted developmental milestones, such as those published by government agencies (US Department of Health and Human Services, 2020) or groups within the medical community. The American Academy of Pediatrics (2020) echoes the reliance on developmental milestones and using deficits as evidence in its recommendation to parents that "only when a baby or preschooler lags far behind, or fails altogether to reach the developmental milestones, or

loses a previously acquired skill, is there reason to suspect a mental or physical problem serious enough to be considered a developmental disability” (n.p.). The typical stages of psychosocial development are held up as normative, which produces binaries of able/disabled and typical/atypical while reinforcing delays, deficits, and abnormalities as essential characteristics of autism.

Emphasis on Verbal Communication Skills

Verbal communication skills are typically divided into two classifications: receptive and expressive language. Receptive language is associated with listening skills including comprehension, following directions, and gaining clues about one’s surroundings. Expressive language, “our ability to communicate our thoughts and feelings through words, gestures, signs, and/or symbols,” is usually most associated with talking (Reyes, 2020). The definition of Autism Spectrum Disorder in the *DSM-5* does not specifically mention verbal communication, either receptive or expressive, but its emphasis on deficits in comparison to normative social communication reveals the assumed relationship between autism and verbal communication difficulties. This assumption is underscored by the clarifying phrase “with language impairments” that can be attached to the diagnosis. The few assessments of my son that I was able to observe during the diagnostic process involved verbal one-step directions, verbal questioning, and verbal prompts. His reliance on non-verbal language cues to complete the tasks, if he paid the assessors any attention at all, reinforced his abnormality. Lack of engagement or compliance on his part were perceived as lack of ability, a classification that would necessitate increased levels of support to counteract the deficiencies in his receptive and expressive language skill set.

Assumptions of Social Motivation

The first characteristic that must be met for an individual to be diagnosed with Autism Spectrum Disorder according to the *DSM-5* is the presence of “persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013). The diagnostic criteria goes further by delineating specific types of deficits that are common to Autism Spectrum Disorder: lack of reciprocity, difficulties with nonverbal communication, and challenges with creating and sustaining relationships. The underlying assumption behind this deficit-centered emphasis on social communication is that normative human behavior is socially motivated (Burger, 2001). By experiencing these difficulties in social situations, people with autism are presented as abnormal and unlikely to have meaningful friendships (Petrina et al., 2014), family bonds (Beurkens et al., 2013), or romantic relationships (Hancock et al., 2020). There are a large number of neurotypical individuals who are introverted and only socialize when it seems necessary for a job or to function successfully in their environment (Liu & Csikszentmihalyi, 2020). Yet the reticence or challenge faced by individuals with autism in social interactions is problematized as an example of abnormality or dysfunction.

“Restricted” and “Repetitive” Abnormalities

Bacchi (2012) draws the focus of analysis to “the mechanisms involved in collecting together things, actions, gestures, behaviours, words that are to make up ‘the real’” (p. 3). Categorizations of human individuals require the “collecting together” of observable characteristics that Bacchi describes above to make the distinctive classification “real.” Once these characteristics, or behaviors, are brought together, experts can begin to identify and diagnose individuals that fall into the newly-defined category in comparison to what is

considered normal behavior or functioning. Tremain (2017) describes this process as one by which “ostensibly natural and objective characteristics are rendered as “abnormal” and “defective,” are regarded as *naturally disadvantaged*, and are signified as either less than fully human, or as fully human, but *in need of repair*” (p. 201, emphasis added). Such a process is derived from deviations from the norm, and these behaviors are an example of deficiency that must be lessened or eliminated. Problematizing repetitive behaviors works to create or reinforce the normal/abnormal binary as fixed identities that limit an individual with autism’s capacity for meaningful socialization.

According to the diagnostic criteria for ASD in the *DSM-5*, deficits in social communication are coupled with the presence of “restricted, repetitive patterns of behavior, interests, or activities” (American Psychiatric Association, 2013). “Patterns of behavior” is a euphemism for sensory aversions and self-soothing movements. Many individuals with autism are hypersensitive or hyposensitive in comparison to most neurotypical individuals and can become physically and emotionally dysregulated (Boyd et al., 2010). For example, an individual with autism may have to wear headphones to deaden the noises in a crowd or may be overwhelmed by the sensation of playing on a swing. To cope with the sensations of dysregulation, individuals with autism often engage in self-soothing behaviors like rocking, hand-flapping, spinning, or my son’s personal favorite -- rolling the skin of someone else’s elbow between his fingers.

To the average observer, these behaviors may seem odd and repetitive, but neurotypical people in times of distress will find themselves rocking or hugging themselves, twiddling their thumbs, or biting their fingernails in an unconscious effort at self-regulation. Additionally, many individuals outside the classification of autism become overwhelmed and

overstimulated during certain sensory experiences (e.g., riding a roller coaster, walking through a Las Vegas casino, attending a rock concert). Despite similar sensations for neurotypical individuals, self-soothing behaviors and their frequency may draw unfavorable attention to an individual with autism, highlighting a visible difference between that individual and what is “normal.” The emphasis on the “repetitive” nature of these patterns of behavior constructs individuals with autism as engaging in them more frequently than is normatively acceptable. In short, these individuals and their behaviors become a problem to be solved.

“Restricted . . . interests or activities” are another consideration in this portion of the diagnostic requirements. In subsequent material from the *DSM-5* meant to elaborate on the indicators included in the diagnostic criteria for ASD, restricted interests are defined as “abnormal in intensity or focus” (APA, 2013). The discourse of deficiency and abnormality that continues across all components of the diagnostic criteria places limits on individuals with autism and their families. The diagnostic criteria and its resultant problematizations “structure the possible field of action” of autism parents and their children (Foucault, 1982, p. 790). The “possible field of action” is positioned in response to the “abnormality” of the intensity and focus of the interests or activities. Parents can choose to encourage, ignore, or correct the child’s interests, but always with the knowledge that their choices may impact the child’s future self-perception and the perception of the child by others in comparison to normative and “acceptable” behaviors. As Tremain (2017) explains,

Concepts, classifications, and descriptions are never “merely” words and representations that precede what they come to represent, but rather are imbricated in the constitution of (among other things) institutional practices, social policy,

intersubjective relations, and medical instruments in ways that structure, that is, *limit*, the field of possible action for humans, including what possible self-perceptions, behavior, and habits become available to them in any given historical moment. (p. 112, emphasis in original)

To be included in society and approximate a “normal” existence, individuals with autism will have to find ways to eliminate or accommodate their restricted interests. A failure to approximate more “normal” interests and ranges of intensity imposes a stigma on the person with autism as being unable to participate fully in society. Listing restricted interests as one of only two defining factors in an autism diagnosis foregrounds it in the discourse as what is recognizable about autism. The repeated call for early intervention to correct any deviations from normal functioning makes possible the subjectivity of compliance, as parents are encouraged to reshape their child’s interests and behaviors.

The category of “restricted interests” play a major role in the flows of power/knowledge within the discourse of autism because they are one of the most recognizable characteristics of autism to people outside of the autism community. Connecting back to Tremain’s (2017) argument, the presence of restricted interests becomes a taken-for-granted assumption about people with autism, limiting the “field of possibility” for their subjectivity and interactions with people who are not on the autism spectrum. In fact, the two most common questions that I am asked when someone finds out that my son has autism are, “So, does he really like trains?” and “What’s his *thing*?” These well-meaning people are referring to the tendency of some people with autism to be highly interested in and motivated by a certain object or activity, such as trains, elevators, or appliances. In some cases, the person with autism may only want to talk about this interest and refuse to engage

with anything else. This association is problematic for two reasons: it assumes that *all* individuals with autism have interests that are “restricted” and limiting in some way and that these interests are somehow different from more normative interests.

My son does not have a *thing*. He is interested in books, music, and Youtube videos, and the content he chooses in each format varies widely from week to week or sometimes daily. Even if he were highly interested in trains, how would his reading about them and visiting museums or train stations on the weekends be any more limiting or “restricted” than the child who practices baseball several times a week and plays in travel tournaments every weekend? As Smerbeck (2017) notes, “while there is considerable evidence that these interests have maladaptive consequences, they also provide a range of benefits” (p. 247). Operating from a stance of what is possible, “restricted interests” can be cultivated rather than limiting. Individuals with autism can lean into their areas of interest to promote social interaction with those who share their interests (Muller et al., 2008), to find gainful employment (Grandin & Duffy, 2004), and to build self-confidence (Winter-Messiers, 2007).

Where Do We Go from Here?

The diagnostic criteria for Autism Spectrum Disorder in the *DSM-5* (re)produces normative assumptions that emphasize the binary relationship between individuals with autism and their neurotypical peers. These normative assumptions narrow the possibilities for individuals with autism to be accepted and valued as contributing members of society who can be perceived for more than their deficits and limitations. Yet my analysis consistently maintains that simply substituting the framework or terminology is not enough, so where do we go from here? Deacon (2000) writes that analysis does not seek to

solve an issue, but rather to reveal ways that issue is “questioned, analysed, classified and regulated” at “specific times and under specific circumstances” (p. 127). In problematizing the *DSM-5* outside of its previous versions, this analysis reveals how autism is perceived, produced, enacted, and embodied within and outside of the autism community of this moment. Moving forward will require more than analysis; it will demand an exploration of what is possible by opening the door to difference.

INTERLUDE ONE: IMMANENCE, DIFFERENCE, AND WHAT IS POSSIBLE

In my analysis throughout the previous sections, I have shown how the discourse of autism diagnosis relies on descriptions of normal and abnormal development, creating a binary opposition in which “typical” is produced as the normative ideal, within a discourse of deficit and delay. Deviation from established norms becomes a problem to be solved. Parents are positioned as acting within a range of compliance or resistance in response to the conclusions being drawn about their child and about the overall discourse of diagnosis. Difference is placed in opposition to what is normative, and result in the marginalization or othering of those who are non-conforming, limiting their possibilities to be engaged in their community. Speaking of this way of defining difference in a framework of *different from*, May (2005) states that “difference is subordinated to identity; difference is what is not identical. This is difference seen as lack: difference is the lack of identity, the privation of sameness” (p. 125).

In this interlude, I take a pause in order to consider where there may be openings within and beyond the binary oppositions and normalizations discussed in the preceding analysis. I think with the Deleuzian concepts of *immanence* and *affirmative difference* to reveal (im)possibilities for people with autism and their families on the journey to and through diagnosis. Immanence reaches beyond the subjectivities and normalizations of a particular discourse. It calls us to recognize that-which-is-not-yet-known, to stand on the edge of the past, present, and future simultaneously, to consider what may lie outside of our current thinking and doing. Immanence is a force at work, a *doing*, a *becoming*. In thinking with the concept of immanence, “Deleuze never stops asking the question of what other possibilities life holds open to us, or, more specifically, of how we might think about things

in ways that would open up new regions for living” (May, 2005, p. 3). Therefore, it is from the plane of immanence that new possibilities may open for individuals with autism; it is from the plane of immanence that we can change the current deficit-centered medical discourse of diagnosis. I conclude this Interlude by addressing questions such as: How can a new way of conceptualizing difference emerge? How can difference become synonymous with possibility? How does difference *affirm*, rather than negate?

What Counts as Life?

In light of the often grim prognosis for future social engagement and acceptance of individuals with autism, coupled with the emphasis on deficit-centered language within the medical community, the neurodiversity movement has emerged as a way for individuals with autism, their families, and other advocates to “think otherwise” (Gowlett, 2015) and push back against the ways that people with autism are labeled and stereotyped. The philosophy of Gilles Deleuze (1994) supports the thinking behind the neurodiversity movement as he describes life as existing on the *plane of immanence* and incorporating “at the same time, that which must be thought and that which cannot be thought. It is the non-thought within thought” (p. 59). Following this line of thinking, an individual is not a defined subject characterized by categorizations, subjectivities, and descriptors. Rather, the individual is a *doing* or a *becoming*, not a *being*, which requires a recognition that the individual is not a separate entity but the sum of all forces, discourses, and experiences of life in combination with actions that those forces call forth.

Deleuze’s philosophy opens the realm of possibilities through the rejection of fixed identities and normative assumptions. Reflecting on Deleuze’s concept of immanence, Agamben (2003) notes that “a genealogical inquiry into the term “life”... will demonstrate

that "life" is not a medical and scientific notion but a philosophical, political and theological concept and that many of the categories of our philosophical tradition must therefore be rethought accordingly" (p. 168). Life is more than what can be observed and quantified. It is not bound by or limited to biology. If life is within the plane of immanence, then so are all of its cuts and flows – all of its wanderings, disruptions, and pivotal moments. Life is – all at once – what has been, what is possible, the not-yet.

As Manning and Massumi (2014) explain, "Potential is abstract by nature, in the sense of not yet being this or that, here nor there . . . potential is allied to *what-if*" (p. 41, emphasis in original). Immanence allows autism to be more than a diagnostic label or medical condition. Autism expands into another way of seeing, doing, and becoming in the world. With immanence, people with autism are people *of potential*. The limited and limiting views of the past are questioned, are expanded to include more of the infinite and less of the fixed points that medical discourse has inserted into life.

Thinking immanently, previous conceptions and distinctions are rethought and reimagined – including the labels surrounding autism and neurodiversity. As Prado (2003) suggests, "To think is to throw oneself against the limits of representation and to subvert it, and, again, to free the flow of life and expand its sphere" (p. 25). Only through a more expanded view of what counts as "life" can we work to trouble the deficit-centered mindset of the medical community and to explore new possibilities for people with autism.

Openings in the Diagnostic Criteria

What might happen if our view of difference moves from the realm of constraint and conformity into that of complexity and immanence? Relinquishing quantifications and categorizations allows for an opening to the nuances and flows of how we experience

difference as affirmative and non-oppositional. Khalfa (2003) describes this viewing as follows: “What I see are layers of meaning that I have received from other subjectivities, in particular through language, and which cover the phenomena” (p. 70). People with autism are more than a label or set of classifications, and the spectrum of ways in which autism is embodied creates complex webs of meaning. Understanding a person with autism is a sifting through the layers of meaning and language that have been ascribed to individuals with autism from the outside, but which tend to cover the phenomenon of autism itself. For example, autism is frequently symbolized by a puzzle piece. The experience of parenting a young child with autism feels like a constant puzzle –a desperate effort to (re)arrange pieces of information into something coherent and tangible. The puzzle is an endless loop of (re)searching, questioning, (un)making meaning, fighting, peacemaking—all with the understanding that the puzzle will never be fully re/solved. Yet none of these ways that autism is lived by individuals and families within its community are reflected in the current medical and diagnostic definitions. Embracing this complexity might revolutionize the diagnostic criteria in the *DSM-5*, opening up possibilities for new associations, subjectivities, and flows for individuals with autism.

Returning to the diagnostic criteria for Autism Spectrum Disorder in the *DSM-5* (American Psychiatric Association, 2013) with the Deleuzian concepts of immanence and affirmative difference in mind, there are a few openings to new possibilities present in the changes from previous versions of the *DSM* noted in the previous chapter. First, the fifth edition eliminates associated diagnoses like Asperger’s syndrome and Pervasive Developmental Disorder, lumping previously distinct diagnoses under the common umbrella term, Autism Spectrum Disorder. By removing further categorizations, the *DSM-5* is more

inclusive of the full spectrum of how autism is embodied, a first step in seeing difference as complexity. Although the deficit-laden term “disorder” remains in the diagnostic criteria for autism in the *DSM-5*, the removal of previous sub-categorizations allows for the possibility of neurodiversity, for infinite (re)iterations of what autism might signify beyond four or five defining labels.

Instead of separate diagnostic sub-labels, the *DSM-5* specifies whether or not the Autism Spectrum Disorder is accompanied by intellectual or language impairments and whether or not it is associated with other conditions, disorders, or environmental factors. The discourse is still one of deficit and abnormality, yet it includes an affirmation of the vast complexity and interplay of factors that preclude a clear and tidy encapsulation of individuals with autism into a diagnosis. As such, there is an implicit admission of the general lack of certainty within the medical community regarding causes, treatments, or cures for autism. Autism *may* be an intellectual disability, *may* manifest in language differences, *may* stem from and/or be impacted by myriad other physical and environmental considerations. Although subtle, this admission of uncertainty works to undermine the authority and perceived truth of the diagnostic criteria.

Stepping away from positivism, however unwillingly, allows for a more nuanced and complex understanding of individual differences. The *DSM-5* no longer refers to individuals with autism as high- or low-functioning, which serves to remove some of the stigma surrounding autism and moves away from predicting the future capability of an individual at the moment of diagnosis (although the tendency toward prediction reappears in the application of levels of severity).

Openings for Individuals and Families

These openings are small but significant in what they affirm for individuals with autism as they shift the discourse from one of limitations and impossibilities to that which is possible. Instead of framing individuals with autism as fixed *beings*, defined forever by their characteristics at the moment of diagnosis, these openings allow individuals with autism and their families to *do* and to *become*, shifting power, knowledge, and agency ever so slightly toward the individual and family – and away from the diagnostic experts. Autism can be experienced as one component within the complex web of subjectivities, knowledge, and encounters that make up a life rather than a defining diagnosis.

In stepping away from the medical discourse of diagnosis, it becomes both thinkable and possible to remove the need to solve or fix the (individual with) autism through identification, labeling, and treatment. Families might still seek out therapies and services for their child with autism, but the focus of the relationships with providers might be more about the potential of the child instead of overcoming deficits. The language and thinking surrounding therapies and support services would shift *from normalization to possibility*. Such a move would allow individuals and families to experience autism as a perpetual act of discovery. Such a move would create space to honor the values and culture of the family in tandem with supporting the unique gifts of the individual with autism.

Implications of (Im)possibilities

What if human behavior and being did not have to be measured statistically? What if difference did not have to carry the term “disorder” everywhere it appeared? What if recognizing and labeling difference were more descriptive than diagnostic? The philosopher Todd May (2005) imagines, “Suppose the world is indeed a world of difference. Then the

individual, the state, the economy would be particular actualizations of a difference that need not be actualized in these particular ways, or that may be actualized in these ways but in many different ones as well” (p. 129). The normative ideal put forth by developmental milestones and diagnostic evaluations is one particular actualization, but there is potential for many different actualizations, including those associated with autism. My analysis of the medical discourse of diagnosis has worked to seek openings for possibilities as a starting point for re-imagining autism with the concepts of difference and immanence. In light of increasingly widespread representation and awareness of autism in the mainstream media, the current moment offers opportunities for reimagining autism. The neurodiversity movement can affirm difference as complexity and immanence to move beyond offering more palatable terminology and representations to establishing meaningful goals that will shape how autism is (re)produced. Thinking with the theories of affirmative difference and immanence have opened possibilities, and we can no longer accept the limitations of normative thinking.

Changing the framework and thinking with immanence does not seek to eliminate difference or to create a new normal. This is not a journey to force autism’s way into normativity or to act like *everything* is suddenly possible for an individual with autism simply because we started to think differently. In writing about possibility, May (2005) claims, “But, since we do not know of what a body is capable, it would be better to say, not that anything can happen, but that so much can happen that we do not know about. The world’s possibilities are beyond us” (p. 116). Immanence challenges constructs that are limiting and definitive while seeking openings to the not-yet.

CHAPTER SIX: THE AFTERMATH

The first hour of our car ride home from the diagnostic evaluation appointment was silent. My son had fallen asleep, and my husband and I were both too exhausted and shell-shocked to speak. On my lap, I held the two-inch binder that contained the records and paperwork collected from all of my son's appointments, therapies, and evaluations over the last seventeen months. That binder offered a sense of grounding in a moment of swirling thoughts and emotions. It had accompanied me throughout the journey of trying to find answers for what was happening with my son, and it felt like an anchor in a liminal space, like the only connector between our life before that day and the new life we would start to imagine now that we had a diagnosis. Everything seemed to be spiraling out of control, and that binder provided a tangible reminder that we had already survived a lot. We would get through this moment, too.

As we tentatively began to speak, my husband and I both felt a sense of floundering about in completely new territory. Our son was the same person that he was when we woke up that morning, but an entirely different set of terminology and clinical recommendations now hover over his existence. As of that day, he has a label. He has a disability. He needs interventions to be successful in finding his way in the world. According to the experts, he is deficient, and we needed to work hard to get him help — and quickly. We were hurting because what we heard that day seemed to shut down a lot of possibilities for his future. At the same time, we expressed disagreement with some of the diagnostic process, for many of the reasons discussed in previous sections of my analysis. Even in that time of raw emotion, we experienced spaces of resistance, knowing that our precious son was and is more than a

diagnosis. More than anything, we were frustrated and overwhelmed because we had no idea what to do next.

Upon receiving a diagnosis of autism for their child, families are inundated with recommendations for gathering more information about autism, for learning to be an advocate for their child, and about evidence-based interventions. There is an increased sense of urgency to put these recommendations into action quickly for younger children who do not yet have access to services through public schools. Because there is no centralized care management of the various medical providers, therapies, and services recommended for young children with autism, the capacity to locate and secure the most appropriate services for their child lies predominantly with the parent at this stage. The ways in which parents engage with (and develop their own subjectivities within) the discourses of autism and disability directly shape the treatments and care their child receives. Parents are the experts on their individual child, but others are experts on autism. In the aftermath of receiving a diagnosis, parents are navigating a well-established apparatus of disability along with their own reactions to it.

Thinking with Foucault's concept of *power/knowledge*, my analysis in this chapter will explore the responses and shifting relations of power that parents experience as they enter the discourse of autism (Jackson & Mazzei, 2012). This chapter will address the research question: What is the interplay between subjectivity and power/knowledge for autism parents as they first encounter and engage with the discourse of autism and what does this interplay produce? I begin with a review of the handout our family was given as a companion to the diagnosis, which reproduces a sense of urgency to act quickly to address the child with autism's deficits and privileges expert knowledge over that of the parents. My

analysis continues with an examination of the literature on medical theories and models offered to categorize parental reactions to their child's diagnosis of disability since autism became identified as a separate diagnosis. These models reinforce a reliance on normativity that creates binary oppositions like normal/abnormal and progressing/stagnant. Finally, I suggest some possible openings for supporting parents through and beyond receiving an autism diagnosis for their child.

Initial Recommendations and Reactions

As we returned from a lunch break on the day of our diagnostic evaluation appointment, we were ushered back into an observation room to wait while the interdisciplinary team reviewed the parent evaluation scale we had just completed and prepared to discuss their findings with us. The diagnostic evaluation process concluded with an interpretive conference, which offered the clinical evaluation team an opportunity to “share team findings, answer specific questions, and discuss initial recommendations” (Carolina Institute for Developmental Disabilities, personal communication, March 20, 2019). We were given a diagnosis of Autism Spectrum Disorder with accompanying language impairment, along with levels of severity for social and communication functioning and restricted, repetitive behaviors. There was an additional diagnosis of Global Developmental Delay. My first impression was that my son didn't just have autism, he had *really bad* autism with a side of other problems. I could feel my heart and stomach constrict as I envisioned all the doors of possibility that were closing on his life before he reached the age of three.

This pained concern must have been evident in my voice and face as I asked some cursory and clarifying questions about his diagnoses. The team assured me that, *given his*

young age and with the right interventions, my son could make excellent progress (CIDD, personal communication, March 20, 2019, emphasis added). Our ability as parents to act quickly and establish the right therapies and services for our son would have a direct impact on the (im)possibilities for his future. Then, they gave us a one-page handout that summarized four different agencies in our state that provide support, resources, and training for parents of children with autism. As they reviewed the handout with us, I frantically scribbled notes in the margins of this handout to capture any information I could during our one day with these experts, doing my best to process this information quickly enough to ask relevant and helpful questions amid the mental fog of receiving a potentially life-altering diagnosis for my only child.

Helpful Organizations

The first organization listed on the handout was TEACCH, a program under the umbrella of the University of North Carolina at Chapel Hill, where we had also sent application materials for a diagnostic evaluation. TEACCH provides “clinical services such as . . . parent training and parent support groups, social play and recreation groups” (CIDD, personal communication, March 20, 2019). The emphasis is on training the parent to do the recommended interventions with their child rather than providing those intervention services as an organization. Implicit in this emphasis is the power relation that there is knowledge about autism that must be imparted from the expert to the parent for the child’s benefit. As McKenzie (2009) explains, “decision-making and child rearing with the support of professionals is given more validity than that of parents/caregivers alone” (p. 188). In other words, the parent must be taught how to interact with their child correctly. Parents must also be taught how to provide the right social experiences and interactions for their child, so

TEACCH offers clinically-supervised socialization groups and activities. We were told to call the TEACCH office within the next few days to get transferred from the diagnostic evaluation waiting list to the early intervention services waiting list since the wait time is typically at least six months for an initial appointment. Again, a sense of urgency to secure the *best* resources quickly juxtaposes with the unavailability of those resources, creating a liminal space of tension and feelings of powerlessness for the parent.

Next on the list of organizations was The Autism Society of North Carolina (ASNC), a subgroup of The Autism Society of America for our home state. Following a summary of the organization's overall mission, the handout directed us to a webinar workshop called "After the Diagnosis" with the suggestion that it "might be helpful in understanding autism spectrum disorder" (CIDD, personal communication, March 20, 2019). The title "After the Diagnosis" signals a shift into a new discourse that produces a sense in the parent that knowledge about their child is ephemeral and just out of reach. Diagnosis becomes a life event with an aftermath that must be explained by the experts so that parents can understand. My handwritten notes show a brief discussion of the existence of other "online resources and toolkits" on the ASNC website (CIDD, personal communication, March 20, 2019). Within the discourse of autism, the dominant way of thinking suggests that knowledge is measured in volume of resources instead of actionability. An assumption is also made that parents have the time, resources, and ability to access the resources and then put them into practice. Those who can do so will provide more effective support for their child, thus "separating 'good parents' from 'bad parents'" based on their ability to advocate and manage their child's care (McKay & Garratt, 2013, p. 737). Embedded in the one-paragraph description of the organization is a mention of local chapters and support groups and "the world's largest

autism spectrum-specific bookstore” (CIDD, personal communication, March 20, 2019). The repeated suggestion across organizations for parents to join support groups privileges socialization with other autism families over integration into community activities with parents of neurotypical children, producing a segregated community of outliers. Encouragement to join autism support groups is prevalent in the dominant discourse, signifying both a potential coping mechanism for the parent and the formal entrance into the autism community as a separate entity. Therefore, a parent’s refusal to engage with autism-specific support groups becomes an act of resistance, which “may be viewed as unacceptable, as socially deviant and, by association, regarded as ineffective parenting” (McKay & Garratt, 2013, p. 737). After all, are parents really doing all that they can for their children with autism if they do not make use of every resource available?

Less information was provided on the handout about the advocacy organization, Autism Speaks, but we were directed to three specific areas of the organization’s website. There were detailed instructions about how to navigate from the website homepage to a resources area where parents can “find centers near you” (CIDD, personal communication, March 20, 2019). Another resource that was highlighted on the handout was “The 100 Day Kit,” which was “created specifically for newly diagnosed families to make the *best possible* use of the 100 days following their child’s diagnosis of an autism spectrum disorder” (CIDD, personal communication, March 20, 2019, emphasis added). This “best possible use” was not directly related to my son or any of the information the diagnostic evaluation team had gathered about him. Rather, The 100 Day Kit was designed to impart expert knowledge to guide *all* autism families (regardless of their culture, their values, and their child’s specific needs) in the most desirable path following their diagnosis. The admonition to act quickly

continued as the team noted that my son would turn three in less than two months, the age at which the state's coordination of his care transitioned from the early intervention program with the Child Developmental Services Agency, or CDSA, to the local public school system. This reproduction of urgency meant that we didn't have the luxury of 100 days to process our diagnosis and leap into action, so we were also directed to a website on the Autism Speaks website entitled "Getting an IEP," which would help us begin to navigate the process for obtaining services through the local public schools (CIDD, personal communication, March 20, 2019).

The final organization listed on the handout was the Exceptional Children's Assistance Center, or ECAC, described as a "private non-profit parent organization" designed with "a special emphasis on children with disabilities" (CIDD, personal communication, March 20, 2019). The description of this organization on this particular handout was the first time the word *disability* had been associated with my son, creating the second new classification for my son on that day which would impact his future (im)possibilities. Included in the ECAC programming is the Parent Training Information Center, "which offers a variety of support and education to caretakers, which helps them navigate special education services and the individual education process (IEP)" (CIDD, personal communication, March 20, 2019). The ECAC also offers the Family to Family Healthcare Information Center, "which assists caregivers in becoming their child's *best* healthcare advocate" (CIDD, personal communication, March 20, 2019, emphasis added). Complying with the recommendations of the experts signals a "good parent" who works toward the "best" for their child. Rejection of expert knowledge and resistance through independent action or choosing a different path is seen as bad parenting. Foucault (1980)

describes this as “the point where power reaches into the very grain of individuals, touches their bodies, and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives” (p. 39). “Good” parents who seek and follow expert advice, sift through and understand information about autism quickly, and put that knowledge into action through advocacy and gaining access to systems and services. They are privileged in the discourse because their docile acceptance of dominant forms of knowledge and integration into established systems for people with autism allow them and their children to be more easily surveilled and managed.

The clinical evaluation team briefly mentioned that the ECAC employs Parent Advocates who can accompany families to IEP meetings and other appointments as support, but no details about names or contact information were provided. Once again, we were teased with incomplete offers of help that were like elusive shadows to be discovered amid a sea of new information. Even gaining support for advocacy in making determination about the child with autism’s educational future placed the onus on the parent. In short, the parents who feel least comfortable navigating the educational system still have to navigate a system to access a Parent Advocate.

Additional Recommendations

The descriptions of, and specific recommendations regarding, the four organizations listed above comprise the entirety of the parent communication presented to us by the clinical evaluation team as they delivered our diagnoses. My handwritten notes, however, captured several other recommendations from the team that were only shared orally and in response to our questions. The first recommendation was to get on the waiting list for an Innovations Waiver as soon as possible since the wait time at the time of our appointment was *seven to*

ten years from the point of application to receiving financial support. Here again the sense of urgency to secure resources quickly is in tension with unbelievable delays and wait lists. Our state's Innovations Waiver program is “a federally approved 1915 C Medicaid Home and Community-Based Services Waiver (HCBS Waiver) designed to meet the needs of Individuals with Intellectual or Development [sic] Disabilities (I/DD) who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting” (North Carolina Department of Health and Human Services, n.d.). Services included in the program are managed by local managed care organizations. We were not given any contact information, websites, or application materials for our local organization. The implication is that “good parents” will pursue and find these necessary resources, further marginalizing those families whose parents cannot.

Based on the severity levels of my son's ASD diagnosis, the clinical evaluation team recommended that he receive 20-25 hours of direct services each week, including time spent at school and in engaged play. The team emphasized to us the importance of pursuing applied behavior analysis (ABA) therapy, an evidence-based intervention that has been used to treat people with autism for decades (CIDD, personal communication, March 20, 2019). We asked about organizations that provide ABA therapy, who to contact, and how to get started. The evaluation team's policy is not to refer to specific ABA providers, so we were told to check with The Autism Society of North Carolina and our insurance company to find ABA therapists in our area. ABA therapy would be very helpful for our son's progress, according to the team, however they cautioned us that it would not be productive for improving his communication skills (CIDD, personal communication, March 20, 2019).

Given our concerns about my son's lack of speech and the addition of language impairment to his diagnosis, it was frustrating to be recommended a therapy that would not address his communication needs. In addition to securing ABA services, we would need to continue speech therapy. Even though we loved our speech therapist, this process would not be straightforward. My son would transition out of early intervention services at the age of three (two months from our diagnostic evaluation appointment), and his services would transition to a speech therapist in our local public school system at that point. He needed occupational therapy, but again we were in a liminal space between early intervention providers and the local public school system. Physical therapy was also suggested, but sorting through and securing services for the other recommendations would ultimately delay us from pursuing physical therapy for almost a year.

Initial Reactions

Although it was intended to be helpful, the interpretive conference between the clinical evaluation team and our family was overwhelming. We were heartbroken by the list of our son's deficits communicated by the clinical evaluation team, both the skills he lacked and the quantifiable gaps between his abilities and those of *normal* children his age. We felt inundated with new terminology and tasks to be completed. According to the recommendations, we needed to get on the waiting list for TEACCH; get on the waiting list for state funding; read through all of the online information, resources, and toolkits; secure ABA therapy, speech therapy, occupational therapy, and physical therapy providers; and join a parent support group — all as quickly as possible. The team projected a sense of urgency, but they did not provide one clear next step or even a specific person or agency to contact. It felt like putting together a jigsaw puzzle with half the pieces missing.

The doublet of power/knowledge from Foucault's work was palpable in this moment. Foucault defines power as "a more-or-less organised, hierarchical, co-ordinated cluster of relations" (1980, p. 198). In the case of the interpretive conference, every recommendation reinforced the others with its sense of urgency. Within the discourse of autism, parents are encouraged to engage quickly with a variety of organizations, systems, interventions, and expert knowledge to address their child's deficits. Here again, power is operating through comparisons to normative standards. Children with autism whose parents are able to access the *right* information and services quickly have a better chance of a more "normal" existence in the future. As noted previously, power is both individualizing and totalizing (Foucault, 1982). Expert recommendations are presented as being beneficial for *all* children with autism, but it is up to the individual parent to put the accepted information and services into action for their child. Another "co-ordinated cluster of relations" was evident in the repeated use of the phrase *best* or *best possible* in describing potential parental actions on behalf of their child. This phrasing insinuated a hierarchy of parental responses to their child's diagnosis, implying that only the *best* ones (the ones that followed the recommendations most closely) would yield the *best possible* results for the child's future. A binary opposition is created between "good" and "bad" parents based on how compliant (or docile) they are with the expert knowledge about autism writ large, which is privileged over their own knowledge of their child. Thus, power/knowledge works to limit the field of possible action for autism parents to a range of compliance (docility) – or resistance – regarding expert recommendations. How parents shape their own subjectivity within the dominant discourse becomes directly connected to how the discourse itself constrains or produces how they enact the recommendations of autism experts.

Compliance is coupled with urgency as parents are repeatedly warned to make decisions and access services for their child quickly. For example, the Centers for Disease Control and Prevention (2020) cautions, “By the time [children with ASD] are identified, significant delays may have occurred and opportunities for intervention might have been missed. Getting services as early as possible can make a difference in the development of a child with ASD” (n.p.). Not only is deficit-centered language used to compare the child with autism to normative standards, but the parents are also viewed as deficient if they are unable to secure the appropriate services and interventions quickly enough. The success of the child with autism’s development (in alignment with the dominant discourse of autism and corresponding expert knowledge) is entirely up to the parent. During the critical period for intervention, the onus for recognizing signs of difference in a child and accessing recommended services falls almost exclusively on the shoulders of the parents, a daunting task made only more complicated if the family faces a lack of resources, education, or access to care.

Parents often receive information about clinical service providers, advocacy organizations, support groups, parent training materials, how to access funding, and strategies for interacting with their child all within the same conversation where they receive the autism diagnosis (CIDD, personal communication, March 20, 2019). Their own knowledge, competencies, and experiences of parenting are subjugated as they are inundated with the medical terminology, acronyms, and professional resources of the experts. At the same time that they are sifting through the overwhelming mass of information in the discourse about autism, parents are also coming to terms with the implications of their new role as an autism parent for themselves, their child with autism, and their other family

members. As Foote and Frank (1999) argue, “people have their stories set in place for them by a society that is structured through the availability of ‘tellable’ stories. The social availability of preferred stories, and the assimilation of experience to these narratives is how power works” (p. 177). Parents take up subjectivities within the discourse of autism through an iterative process of selecting from or refusing the preferred narratives of autism parenting.

According to Foucault, an apparatus like that of autism or disability consists of “strategies of relations of forces supporting, and supported by, types of knowledge” (1980, p. 196). When we were completing the application for the evaluation appointment and the various diagnostic questionnaires, or being interviewed by the clinical evaluation team, my husband and I expressed knowledge about our son. We were able to contribute knowledge that was viewed as significant by the clinical evaluation team to the evaluation process. That power/knowledge relation shifted during the interpretive conference. The tidal wave of the apparatus of autism shifted the sands beneath us. Our knowledge about our son was no longer as useful and had been subordinated to the knowledge of the autism experts. Because of our son’s deficits, we were no longer recognized as “capable” within the dominant discourse that privileges intervention and experts. A dearth of clarity within a sea of new information merged with a desperation to jump into action quickly—a paradox layered over the complex processing of emotions that accompanies a new diagnosis.

Parental Adjustments in the Aftermath of a Diagnosis

Upon entering a new discourse, individuals begin a process of becoming something different, of experiencing themselves within a complex new web of interactions, thoughts, and emotional responses – or, shaping their subjectivities. When parents receive a diagnosis of ASD for their young child, they enter both the discourse of the autism community and the

discourse of disability. As discussed in previous chapters, the discourse of disability produces the child with autism as atypical, deficient, and in need of direct intervention to become closer to the normative ideal. The discourse of the autism community includes the medical perspective of interventions, therapies, and services as well as neurodiversity efforts toward acceptance and the honoring of difference. Several different psychological models or theories have been offered to explain the processes by which parents of children with autism come to terms with their child's diagnosis and the ways in which those processes shape their own subjectivities (Beddie & Osmond, 1955; Broski & Dunn, 2018; Kübler-Ross, 1969; Kübler-Ross & Kessler, 2005; Olshanky, 1962; Scorgie & Sobsey, 2000; Seligman & Csikszentmihalyi, 2000; Solnit & Stark, 1961). Traditional models in the field of psychology focus on concepts of grief, sorrow, and mourning, and are the most widely recognizable within and across discourses. Positive psychology and family-centered practice models emphasize the strengths and capabilities of individuals and families. Transformational perspectives recognize that having a child with a disability may transform the parent in desirable ways that would not have happened otherwise. These perspectives assume a phased and linear response to diagnosis and reproduce binary oppositions of the dominant discourses of autism and disability, oppositions such as typical/atypical and ideal/imperfect. In this section, I will examine how power/knowledge interacts with the subjectivities of autism parents as they react to receiving their child's diagnosis.

Sorrow and Grief Perspectives

Early publications about parental reactions to their child's diagnosis derived from the deficit-centered, normalized medical discourse of disability with a significant focus on a sense of grief or loss on the part of the autism parent. Beddie and Osmond's writing (1955)

gave rise to the assumption that mothers grieve over the birth of a child with disabilities. Solnit and Stark (1961) and Olshansky (1962) focused on the concepts of *mourning* and *chronic sorrow* to explain parental emotional responses. These theories understand transition and disability through the lens of pathology and limitations (Broski, 2019). Allred and Hancock (2012) note that traditional conceptions “presume that parents experience the ‘death of a perfect child’ when they learn that their child has a disability: the child hoped and planned for no longer exists” (n.p.). During the 1950s and 1960s, society at large viewed the birth of a child with a disability as a tragedy (Allred & Hancock, 2012), reinforcing the normative ideals of the medical model of disability. Similarities exist between the discourse of parental adjustments and the discourse of diagnosis discussed in previous sections of this analysis, especially in the emphasis on the binary oppositions of normal/deficient and able/disabled.

The remainder of the 20th century continued the trend of mourning as the assumed and appropriate response to parenting a child with a disability, but with a more complex and well-defined process to explain that sense of loss and grief. The Stages of Grief Model was introduced by Kübler-Ross in her book, *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families* (1969), and includes five stages: denial, anger, bargaining, depression, and acceptance. In the denial stage, “the world becomes meaningless and overwhelming . . . we try to find a way to simply get through each day” (Kübler-Ross and Kessler, 2005, p. 10). As an individual emerges from the stage of denial, Kübler-Ross and Kessler theorize that there will be a move to anger “at this unexpected, undeserved, and unwanted situation” (p. 12). The third stage of the Kübler-Ross model involves a bargaining process, in which “the mind alters past events while exploring all those ‘what ifs’ and ‘if

only' statements" (Kübler-Ross & Kessler, 2005, p. 20). Once the individual fully recognizes the situation as something that cannot change, a deeper emotional response usually follows. According to Kübler-Ross and Kessler (2005), in the depression stage, "we withdraw from life, left in a fog of intense sadness, wondering" (p. 20). The final stage of Kübler-Ross and Kessler's model (2005) is acceptance, defined more as a new state of normal than a sense that everything is alright. Acceptance is explained as the realization that life "has been forever changed and we must readjust. We must learn to reorganize roles, reassign them to others or take them on ourselves" (p. 25).

Originally written to describe the process by which a dying individual comes to terms with the approach of his or her own death, Kübler-Ross's model has been applied to emotional responses people may experience when faced with a wide range of life changes or other events and has become ingrained in popular culture. In the subsequent update of the Stages of Grief Model, Kübler-Ross and Kessler (2005) focus more on the grief experienced by the loved ones who remain than on the dying individual, but the stages remain the same as with the previous publication. Although a comprehensive review of research on parental reactions showed little substantiation for its application (Blacher, 1984), the Kübler-Ross model has become the standard explanation for parental reactions when receiving a diagnosis of autism for their child. Autism self-advocate Stephen Shore (2003) references the Kübler-Ross model when describing how he thinks parents cope with their child's autism, noting that "after going through the stages of shock, denial and anger, there seems to be an acceptance and appreciation for what people who are wired differently can bring into their lives" (p. 105).

The Stages of Grief model is similarly embedded in the culture of many schools because it has been “sustained through a dominant paradigm, professional publications, and practitioner guides” in addressing, supporting, and communicating with parents of children with autism (Allred & Hancock, 2012, n.p.). The model has become institutionalized to the point that “perhaps the single most common ‘script’ that professionals impose on parents is the Kübler-Ross stage theory” (Ferguson & Ferguson, 2006, p. 221). Allred and Hancock’s (2012) review of special education textbooks confirms a heavy reliance on the Kübler-Ross model. As a result, decades worth of teacher inductees “perceptions of parental response may be negatively skewed or limited by stereotypical thinking” (n.p.). Counterproductive labels and negative perceptions (re)produced largely from the Stages of Grief model detract from the development of healthy parent-professional relationships (Sonnenschein, 1981). Well-meaning professionals embody the existing base of institutional knowledge, many without encountering enough parent experiences to push their understanding beyond the dominant deficit-centered model (Allred & Hancock, 2012). According to Foote and Frank (1999), “grief invokes relations of power that create the bereaved as (a) objects of knowledge, and (b) minds and bodies to be shaped by the practical application of that knowledge,” thus making parents who experience grief in this way more pliable and compliant (p. 163). Parents in Kearney and Griffin’s (2001) study felt “defiant” in their sense of hope and optimistic outlook regarding their children with disabilities because it seemed to be in opposition to the perceptions of professionals and the discourse of disability in general (p. 586). The parents noted that they were often categorized as being *in denial* or unaccepting of their child’s limitations, or as having unrealistic expectations for their child if they remained positive (Kearney & Griffin, 2001).

The Stages of Grief model has become institutionalized as the dominant discourse for parental reactions to their child's diagnosis, partly because it does accurately describe the experiences of some parents and families. Many parents describe the diagnosis of their child with disabilities as being stressful and challenging, often more so than they anticipated (Klein, 1984). Given the incredible amount of information and non-specific recommendations presented alongside an ASD diagnosis, a sense of denial and overwhelm seems like a logical first reaction for parents as they enter the new discourses of autism and disability. Some parents may resent the challenges they face in securing services for their child or the limitations now placed on their child's future possibilities, especially when they compare their family's situation to neurotypical families around them. It is important to note that negative parental reactions derive from interacting with the apparatus of disability – with the systems, the institutions, the expectations, and the stereotypes. They may be less about their lived experiences with, or feelings about their child, but the two cannot be separated. They are inextricably linked within the discourse of disability.

Although useful in describing the emotional reactions of some autism parents, the major assumption of this stage model is that having a child with a disability has a life-long adverse impact on the parent (Allred & Hancock, 2012). Its application is deficit-centered, focusing on negative emotions and comparisons between the child-that-is and the imagined child-that-could-have-been. Linking a child's diagnosis to grief and sorrow produces a discourse in which autism parents have little hope of experiencing positive outcomes beyond the final stage of acceptance. The stage model takes for granted that there are normal and abnormal responses to a diagnosis where "*normal* is defined in terms of *progress* and abnormal is its opposite" (Foote & Frank, 1999, p. 164). In taking up the dominant

subjectivity of grieving parent, the parent must comply with the assumption that a diagnosis of autism should be the cause of sorrow before traveling a linear path from maladjustment to recovery. The end goal is not one of happiness and pride but reaching a place of palatable acceptance of the less-than-desirable circumstances.

Positive Psychology and Family-Centered Practice

Most traditional models of transition focus on negative emotions and feelings of overwhelm rather than emphasizing the strengths of the individual. Broski notes that in her 2019 study, “while parents described aspects of sadness they did not describe a loss of quality of life” (p. 106). The positive psychology movement, led by Seligman and Csikszentmihalyi (2000), opened a space in the discourse for something beneficial for parents to come from their child’s diagnosis, including enhanced growth and development (Naidoo, 2006). Allred and Hancock (2012) define the major tenet of positive psychology as the presumption that “people either possess or can be supported in acquiring knowledge, skills, and attributes that permit them to overcome crisis, significant hardships, and other challenging experiences” (p. 5). Although positive psychology opens the door to positive outcomes from having a child with a disability, it remains inextricably linked to the negative with its focus on coping, adaptation, and overcoming in the face of undesirable circumstances (Scorgie & Sobsey, 2000).

One way for providers to move away from a negative framing of parental reactions is to engage in family-centered practice. Broski (2019) lists the core principles of family-centered practice as balanced relationships between families and providers, family choice, individualized services, and emphasizing the strengths of families and individuals. The Family-Centered Positive Psychology Model (Sheridan et al., 2004) builds on a family’s

strengths as well as its capability to access resources. Dunst and Trivette's (2009) model for "capacity-building family-systems" intervention infers a direct relationship between providers' perceptions of parents and parents' experiences of empowerment. Allred and Hancock (2012) assert that providers who "recognize parents' transformative experiences as potential family strengths, empower parents by accepting their current level of understanding regarding disability, and honor each family's unique experiences" contribute to a provider-parent relationship that is based on mutual trust and respect (p. 13). Family-centered practices offer a more positive and individualized approach to supporting parents, yet they retain a focus on parents' ability to access appropriate resources for their child. These models seek to honor what the family brings to the relationship while supporting the parents in attaining the *best possible* outcomes, thus reinforcing the hierarchical evaluation of how well parents are doing for their child. The best possible outcomes and the strengths of the family are determined by the provider's assessment in alignment with their expert knowledge and the dominant discourse, not necessarily by what the family articulates as being valued.

Transformational Perspectives

Beyond having the strength and capability to access resources and overcome adverse situations, many parents find that their lives have been changed for the better because of their child with disabilities. Scorgie and Sobsey (2000) studied transformations, which they define as changes that are both significant and positive, in parents of children with disabilities. Their work developed the Parent Transformational Process Model, which categorized parental transformations in three areas: "(a) personal growth, (b) improved relations with others, and (c) changes in philosophical or spiritual values" (Scorgie & Sobsey, 2000, p. 195). According to a transformational perspective, parents "release old assumptions and self definitions that

no longer work and actively construct a new self-identity and assumptive views following diagnosis” (Scorgie et al., 2004, p. 91). For example, some parents claim that parenting a child with disabilities has made them “stronger and more compassionate, caring, patient, self-assured, confident, outgoing, spiritual, and self-defined” (Scorgie et al., 1999, as cited in Scorgie et al., 2004, p. 97). These studies are largely focused on the questions and reactions of parents in the face of their child’s diagnosis rather than on their personal progression through stages. Parents experiencing transformations take up a subjectivity that is resistant to the dominant discourse of disability as something to be mourned and then accepted. They find their own stories to tell instead of choosing from the preferred narratives of expert knowledge.

Broski and Dunn (2018) introduced the Strengths-Based Theory of Parental Transformation (STPT) as a phased model to explain parental responses to their child’s diagnosis from a transformational perspective. The STPT model suggests that parents begin in an initial phase of awareness in which they notice differences and disconnect from others. The rites of passage phase is largely a liminal space in which parents focus on their concerns about their child and isolate themselves from others as they experiment with their new roles. Finally, parents enter a transformational phase in which they notice their child’s possibilities, connect or reconnect to others, and demonstrate confidence in their abilities (Broski & Dunn, 2018). In the transformational phase, study participants indicated that parenting their child with disabilities has helped them to “gain insights about themselves, have a better sense of humor, and make new friends” (Broski, 2019, p. 42). According to Broski (2019), the incidents that moved parents forward from one phase to the next were using and allocating resources, along with seeing possibilities. Incidents that hindered parents’ forward progress

through the phases include feelings of uncertainty and finding the edges of what they can tolerate. As with more traditional models, the STPT model assumes linear progression through stages and focuses on the parents' ability to access and use resources. Therefore, normal is aligned with progress through the stages while abnormal is linked to deficits in the parents' abilities.

What do existing theories produce?

Traditional perspectives that focus on grief and sorrow set up several binary oppositions in their assumptions about parental emotional responses to a child's diagnosis. In describing grief over the loss of the normal child that could have been, these theories create a binary opposition of the ideal child/imperfect child. According to these models, parents experience chronic sorrow or slowly work their way to acceptance in stark contrast to the happiness that they would have experienced in parenting a child without disabilities. Binary oppositions are also (re)produced in assumptions about parents' actual emotional responses. Parental responses are typical if they follow the prescribed pattern. Atypical responses, like those of the parents in Kearney and Griffin's (2001) study who felt "defiant" in their hope and positive outlook are largely dismissed by many providers and educators as being delusional. Additionally, a stage model sets parents up to be defined as progressing through the stages in a typical manner or as being stagnant in their processing of grief.

All of the models presented above rely on a linear quality that refuses a return to sorrow, denial, anger, or any other emotion. Once the parent experiences a new stage, the previous one is assumed to be complete, and the parent proceeds on through the hierarchy of emotions. The pinnacle of emotional response is acceptance or transformation, which indicates a new normal. As Foote and Frank (1999) explain, the assumption is that "grieving

is a task to be mastered and finally accomplished, that such accomplishment is productive” (p. 168). Parents who exhibit negative emotions after seeming to reach the final stages of these models would be viewed as having regressed or as not being fully accepting of their child’s diagnosis. Yet the processing of emotions is rhizomatic and complex. It can’t be compartmentalized into linear and definable stages, regardless of whether they are deficit-centered or strengths-based. Kübler-Ross and Kessler (2005) addressed the misunderstanding and misuse of the Stages of Grief model since its introduction saying the stages

were never meant to tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives. (p. 7)

The apparatus of disability relies on the classification of individuals in comparison to a normative ideal, so the dominant discourse continues to label parental responses as typical/atypical in accordance with clearly-defined stages.

The birth and/or diagnosis of a child with a disability is typically a profound, life-altering experience that is not totally comprehensible to those who have not gone through it personally (Snow, 2001). Reactions to a diagnosis or other life event are highly individualized and at the same time a product of the discourses and subjectivities in which that individual is *becoming*. Upon receiving their child’s diagnosis, parents enter the apparatus of autism and disability and begin to take up subjectivities therein. Foucault (1982) argues that an individual can only become integrated into an apparatus under the condition that their “individuality would be shaped in a new form and submitted to a set of very specific patterns” (p. 783). In the case of parental emotional reactions to a diagnosis, the prevalence of the Stages of Grief Model within and across discourses as the expectation for

how grief is enacted may impact how individuals grieve or whether grief is even an appropriate response for a diagnosis of autism.

Openings for Supporting Parental Responses

Given the correlation between diagnosis and loss within the dominant discourse of disability, it is surprising that our family was never given a reference for counseling, nor was an encouragement to seek counseling even mentioned in the diagnostic evaluation report. Additionally, family counseling in the aftermath of a child's diagnosis of a disability was not covered by most major insurance plans at the time of our diagnostic evaluation. Counseling would not have to focus on grief or loss, but rather it could help parents to process their emotions, identify their priorities for their family and their child moving forward, and to lean into their strengths and relationships as they navigate their subjectivities within these new discourses of autism and disability.

In the interpretive conference, we were given lots of recommendations from experts on what actions we should take to secure the *best possible* outcomes for our son. The judgment of what was *best* came solely from the clinical evaluation team by way of the discourses of autism and disability. There was no discussion of our family's values and priorities for our son. Providers might take into account the cultural, social, religious, and individual beliefs of a family when working with their child or when supporting the parents in accessing resources. Some families may not desire the typical, standardized, and normative ideal for their child, regardless of whether or not that child has a disability. Additionally, there may be certain symptoms or behaviors related to autism that some families treasure in their child and do not want to have treated. Practitioners might also reinforce and develop an individual or family's strengths and abilities to support them in

reaching *their* fullest potential and sense of well-being (Naidoo, 2006, emphasis added). That potential cannot be predetermined solely by a clinical definition of success for people with autism.

CHAPTER SEVEN: SPECIAL EDUCATION AND EVALUATION

Two weeks after our full diagnostic evaluation appointment, we arrived at an elementary school in our local school district for a play-based assessment to determine my son's eligibility for an Individualized Education Program (IEP) and special education services. I could not believe that after everything we had been through so far, including going to an internationally-recognized clinic for a full diagnostic evaluation, that we needed to do more assessments. What was left to measure? He had a diagnosis. Wasn't that good enough?

Overall, the play-based assessment process was positive. I was relieved that the school system personnel were pleasant and optimistic about my son and that, unlike with the full diagnostic evaluation, I was allowed to participate in the assessment environment. The evaluators wanted to gain a clear picture of my son's capabilities and asked for my input. Based on this information, they created several functional goals that would allow his skills to move forward across multiple domains. Their assessments mentioned delays, but did not include scores, ranks, or percentiles. Ultimately, he was deemed eligible for special education services under the category of developmental delay.

A few weeks later, his first IEP was developed with the following placement: he would continue at his church-based preschool in the mornings for three weeks and attend preschool special education classes every afternoon for four weeks until both organizations were dismissed for the summer. He was not eligible for an extended school year, so he would receive no support (unless we paid for private therapies) until school began again over two months later. That prevailing discourse of urgency crept in again. If my son's development was so delayed, how could he go over two months without any support? I was caught up in a liminal space between compliance and resistance, one of the binary oppositions within the

dominant discourse of disability. As we complied with the IEP recommendations for the following month, I was also actively seeking other avenues of support during that time frame.

According to the IEP team, with one additional year of support in the preschool special education setting, he would be ready to enter the regular education environment for kindergarten at the age of 5 in the 2021-2022 school year. Looking back, I realize the IEP team told me what I wanted to hear at that moment: my son would start kindergarten *on time* and in a *normal* classroom, erasing that feeling of his being behind and deficient. Their recommendations seemed to soften the grim prognosis of the full diagnostic evaluation process. My son could learn. He could have a *normal* school experience. Maybe everything would not always have to feel so hard. Those recommendations matched my emotional needs as I still grappled with my new subjectivities within the discourses of autism and disability. But they did not match the needs of my son. We got busy looking for an alternative setting that could provide more specialized support. He would need the opportunity to learn and grow at his own pace, free from anyone else's (including my own) desired timetable.

As discussed in the previous chapter, receiving a diagnosis of autism is a beginning step that catapults families into a new discourse of therapies, services, and interventions. Once a child reaches the age of three, this process is compounded by the entry into supervision by the local education agency, introducing yet another new discourse – that of special education. This chapter addresses two possible entry points into the discourse of special education. The first appears in the vignette above depicting the transition from early childhood services to local school system support at the age of three. The second entry point comes later in this chapter and the chapter that follows as I analyze our experiences with the

IEP process as a family whose child has a diagnosed disability and is ready to enter kindergarten.

This chapter begins with a context of foundational special education laws and reporting requirements. As Peters (2007) asserts, “every written policy document deploys a particular discourse as both tactic and theory in a web of power relations” (p. 100). Therefore, my analysis problematizes the “web of power relations” within government and educational discourses that (re)produce and create strategies for dealing with disability. My analysis will review the special education and the IEP evaluation process, addressing the research question: What is the problem represented to be regarding children with autism and their parents within the educational discourse of disability? Foucault’s central concern was not with the actions or intentions of individuals, but rather “the manner in which a field of actions is defined and dispersed” (Surbaugh, 2010, p. 115). I will think with Foucault’s concept of *power/knowledge* regarding what the special education evaluation processes produce, how their flows of power and knowledge systematically privilege some actions over others. This analysis addresses the research question: How do the processes that are used in dissemination of information and intervention reveal (im)possibilities for people with autism and their parents and families?

Special education personnel within public schools systems are charged with providing appropriate accommodations for students with disabilities. They may desire to provide what is best for each child, but they are also required to work within highly-regulated systems. Although well-intentioned, the IEP process continues a dominant discourse of normativity and deficit. It is designed to create classifications, hierarchies, and binary oppositions. The tie to federal funding and fill-in-the-blank structure combine to limit the opportunities and

supports available to many students with autism and their families. But before analyzing what is produced when regulations are put into practice, it is important to gain a basic understanding of the policies in place regarding the education of students with disabilities.

The Legal Landscape for Special Education

State and local public school systems rely on federal funding within a highly-regulated process to provide special education services to students in their area. Several key pieces of legislation have been passed over the last 50 years to define special education and to ensure equitable access to opportunities for students with disabilities. Policy shapes every decision made regarding public education, including which children can participate in which programs, which services are provided and by what type of personnel, and the allocation of resources such as time, space, and money (Abeson & Zettel, 1977). My discussion in these next sections highlights the purpose and aims of each piece of legislation to establish a general landscape for special education services in public schools. As a note, outdated nomenclature such as “handicapped” is present in this section as it appeared in historical policies and publications.

The Education for All Handicapped Children Act of 1975 (EAHCA)

The Education for All Handicapped Children Act (EAHCA) of 1975 (P. L. 94-142 § 89-773) was enacted to serve four major purposes. The EAHCA ensured that all children with disabilities were given access to free and appropriate public education, emphasizing special education services designed to meet the unique needs of the individual student. Rights of children with disabilities and their parents or guardians were to be protected. States and local governments would receive federal funding and support to provide appropriate services for students with disabilities. Finally, government oversight would “assess and assure the

effectiveness of efforts to educate handicapped children” (Sec. 3.c), creating a link between state or local compliance and federal funding. At the time the EAHCA was passed, statistics showed that at least one of every eight children with disabilities was completely excluded from public schools, and at least half of those within public schools were not fully served in ways that would meet their needs (Sec. 3.b). By bringing all children with disabilities under the surveillance of the federal government via the state and local public school systems, the EAHCA produced a discourse of inclusion, as well as one of protection. Implicit in the need to provide public education for all children with disabilities is the assumption that the care they were receiving from their families, hospitals, and other institutions was both separate and inadequate. Additionally, the EAHCA mandated that all children with disabilities be evaluated, resulting in the creation of an IEP document for each child that meets their needs in a way that *correlates to the education of their nondisabled peers* (University of Massachusetts Global, 2020, emphasis added). Efforts at inclusion and protection would be coupled with normalization from the beginning.

Although a landmark piece of legislation regarding the rights of children with disabilities and their families, the EAHCA provides general requirements more than specific guidelines for implementation and programming at the local level. No clear standard was set for how comprehensive in nature evaluations of children with disabilities should be prior to placement, nor is there clarity in what type of educational services should be deemed to be appropriate (The Harvard Law Review Association, 1979). This lack of clarity indicates that the EAHCA may have been more about the surveillance, counting, and control of children with disabilities and their families instead of enacting real and specific change. Protecting the interests of the family features prominently in the EAHCA as the “heart of the federal control

mechanism is a system of procedural safeguards which provides for parental involvement in educational placement decisions” (The Harvard Law Review Association, 1979, p. 1103).

Yet, the vague language of the EAHCA may have limited parents’ ability to access the complaint system (The Harvard Law Review Association, 1979, p. 1127). Whether or not the system for parental inclusion functioned effectively was subordinate to the fact that it was given a place of prominence in the written policy. As Foucault (1988) argued, “there cannot be relations of power unless the subjects are free” (p. 12). Parents must have a certain liberty to engage with the system and have decision-making opportunities for the flows of power within the special education discourse to function.

Given the murky nature of the EAHCA requirements, it is surprising that states seemed mostly uniform in their responses to the federal mandates regarding transportation, homebound and year-round services, and reimbursing families for unilateral placement in settings outside of public schools (Duke University School of Law, 1985). States also seemed heavily supportive of “mainstreaming” students, which is the preference toward including students with special needs into the regular education classroom whenever possible (Duke University School of Law, 1985).

The Individuals with Disabilities Education Act of 1990 (IDEA)

The Individuals with Disabilities Education Act (IDEA) of 1990 (P. L. 101-476 § 104-1103) was passed as an update to the EAHCA and was reauthorized in 2004. Special education is defined in the IDEA as “specially designed instruction at no cost to the parents, to meet the unique needs of a student with a disability” (Sec. 300.39.a.1). Expanding on the basic tenets of the EAHCA, special education law under IDEA embodies eight core principles: child find/zero reject, nondiscriminatory evaluation, individualized education

program (IEP), free appropriate public education, least restrictive environment, related services, parent participation, and confidentiality (Bateman & Cline, 2016). School districts are required to find and identify every eligible student with a disability, and no student deemed eligible may be refused services. Again, surveillance, counting, and control coincide with efforts at inclusion and protection. Eligibility for special education services must be based on nondiscriminatory and relevant evaluation, completed by knowledgeable personnel, to advise a determination made by a team. Special education services should be provided at no cost to the family and alongside same aged peers without disabilities whenever possible, continuing the emphasis on inclusion or “mainstreaming” from the EAHCA. Related services may include: “transportation, speech pathology, audiology, physical therapy, occupational therapy, therapeutic recreation, social work, medical services, counseling, and recreational services” (Bateman & Cline, 2016, p. 12). Overarching each of these components is the participation of parents in decisions about their child, from helping to develop the IEP document to accessing their child’s records. Parental permission is required to evaluate a child, and parents must agree with their child’s placement. If there is disagreement, parents can request a due process hearing (Bateman & Cline, 2016). Confidentiality is also critical to protect the privacy of the student with disabilities and their family, so personal information should not be shared beyond the work of the IEP team.

Coinciding with the passage of the Americans with Disabilities Act of 1990 (P. L. 101-336 § 104-327), IDEA made substantive changes in language and classification to that found in the EAHCA. The word “handicapped” was changed to “disabled,” and autism now had its own category, along with “traumatic brain injury.” Autism had previously been classified under the category of “other health impaired.” The House of Representatives report

notes that “this inclusion of autism is meant to establish autism definitively as a developmental disability and not as a form of mental illness” (H.R. Rep. 101-544, at 4, as cited in Colker, 2013, p. 88). This definitive classification of autism as a developmental disability within and across government and educational discourses lies in stark contrast to the maintenance of autism as a diagnosable mental disorder as recently as 2013 in the *DSM-5* that I discussed in previous chapters of my analysis.

The EAHCA was a response to a challenge of educational access, one that produces a discourse of inclusion and protection while working to bring children with disabilities under government surveillance, counting, and control. The legislation was enacted in response to problems that “lay mainly in an imaginary future and had to be prevented through proper education and upbringing” (Axelsson, 2016, p. 29). Prior to its enactment, most students with disabilities were excluded from public schools. Those who were educated within the public school system did not usually receive accommodations and support related to their individual needs. In the decades since, the challenge has become one of excellence (Katsiyannis et al., 2001). Subsequent amendments, including the substantive changes brought about by the passing of the IDEA, emphasize educational opportunity through increased effectiveness of special education services (Yell & Drasgow, 2000). The new goal has become a quality education for each student with disabilities (Eyer, 1999) as related to normative standards for their peers without disabilities.

The Every Student Succeeds Act of 2015 (ESSA)

Most recently, the Every Student Succeeds Act (ESSA) of 2015, P. L. 114-95 § 129-1802 was passed to “provide all children significant opportunity to receive a fair, equitable, and high-quality education, and to close educational achievement gaps” (Sec. 1001).

Although the ESSA does not address students with disabilities specifically, its oversight of the educational opportunities for all children directly impacts and must work in tandem with the IDEA (Sec. 1111.a.1.B). One particular area of the ESSA with implications for students with disabilities calls for a reduction in aversive behavioral interventions, including seclusion and restraint that compromise student health and safety (Sec. 1111.g.1.C.iii). During the 2013-2014 school year, 70,000 students with disabilities were subjected to seclusion and restraint, and students with disabilities had more than double the suspension rate of students without disabilities (United States Department of Education, Office of Civil Rights, 2014, as cited in National Council on Disability, 2018). Other guidance offered by the ESSA is more general and focused on student academic progress, but the continued language of inclusion and protection is prevalent.

Ideally, the ESSA and the IDEA combine to provide assessments of student progress for students with disabilities that are based on the same academic standards as those of general education students, as well as supports to foster their success (Bateman and Cline, 2016). States may develop alternative academic achievement standards and assessments for students with significant disabilities, but those standards and assessments must align with college and career readiness (National Council on Disability, 2018). Additionally, states must annually test and report results on 95 percent of all children, including 95 percent of all subgroups such as students with disabilities (Sec. 1111.c.4E.i). The ESSA's requirement that all students be prepared to enter postsecondary education or competitive vocational placement upon graduation offsets the argument by some that "the deference given to states will lead to lower standards set in order to achieve better results and avoid intervention of the federal government" (El Moussaoui, 2017, p. 410). That same requirement to be college- or

career-ready upon graduation (re)produces the mindset that “through training, [students with disabilities] could be brought up to become competent citizens who could support themselves” (Axelsson, 2016, p. 30). Such a statement reveals another problematization of the special education discourse: students with disabilities must be altered through the intervention of the government to become productive members of society rather than a drain on its resources.

Yet, the authority of the states to determine their own plans for implementation of the ESSA may allow for less than desirable outcomes. Adler-Greene (2019) argues that “no matter what terms are proposed in ESSA, students would have to trust that states would legitimately, without the oversight of the federal government, abide by the reforms initiated by ESSA” (p. 20). The National Center for Learning Disabilities found that 33 states do not separate out the performance of students with disabilities in their school rating systems; only 10 states have detailed descriptions of interventions for students with disabilities; and more than half of states will not intervene until schools have shown three or more years of low performance with a particular subgroup like students with disabilities (Turner, Kubatzky & Jones, 2018). Research shows that states have implemented evidence-based strategies such as multi-tiered systems of support (MTSS), universal design for learning (UDL), and specialized learning and literacy interventions (Turner et al., 2018). More work must be done, however, to ensure that the ESSA promotes equity for all students. Critically, states must “guarantee that underperforming schools will receive targeted interventions to improve educational outcomes” (McCabe & Nye-Lengerman, 2021). In short, the policy language of inclusion and protection does not translate into the goal of “high-quality education” for all students in reality.

Accountability and Reporting

Federal oversight of states' compliance with and implementation of the IDEA and ESSA relies on systems of accountability through annual data collection and reporting. Based on reports collected from each state, the Office of Special Education and Rehabilitative Services authors an annual report to the United States Congress on the implementation of the IDEA. This annual report includes a summary and data analysis at both the national and state levels, findings and determinations from a review of state-level implementation, and a summary of research, studies, and evaluations conducted (Office of Special Education and Rehabilitative Services, 2021). Key indicators in the report include the percentage of students receiving their IDEA services within the regular education setting, graduation rates, reasons for exiting IDEA services, student performance on assessments, and the percentage of students with disabilities involved in regular or alternate assessments (Office of Special Education and Rehabilitative Services, 2021).

States are responsible for developing and maintaining their own systems for monitoring IDEA implementation within their jurisdiction in accordance with federal guidelines. To that end, the North Carolina Department of Public Instruction created the Every Child Accountability & Tracking System, or ECATS, to collect and monitor IDEA implementation data. The North Carolina Department of Public Instruction's Exceptional Children Division is charged with ensuring that "all students with disabilities develop intellectually, physically, emotionally, and vocationally through the provision of an appropriate individualized education program in the least restrictive environment"(North Carolina Department of Public Instruction, n.d.). ECATS contains three integrated modules: Special Education, Service Documentation, and Multi-Tiered Systems of Support (MTSS),

along with a combined set of data or Operational Data Store (ODS) from the three modules. The ECATS interfaces directly with PowerSchool, the state's student information system (North Carolina Department of Public Instruction, n.d.). ECATS serves NCDPI and all current and future North Carolina Local Education Agencies (LEAs), Charter Schools, Regional Schools, Educational Services for the Deaf and Blind Schools (ESDB), and other public schools and entities under their purview as the need may arise (North Carolina Department of Public Instruction, n.d.). ECATS is the system used in developing and monitoring a student's IEP.

Power/Knowledge and the Legal Landscape

The language of the policies listed above is that of inclusion and protection. Each law enacted states as its purpose the betterment of educational opportunities for students and protecting the rights of those students and their families. However, when implemented, laws regarding special education can be reduced to counting and control. This is an effort by which the federal government and its educational apparatus has “centralized its power, standardized its knowledge, and coordinated the care under its auspices” using “methods of surveillance and classification” (Tremain, 2017, p. 54). As was indicated in the statement of purpose for the EAHCA, prior to its passing, children with disabilities were largely excluded from participation in public education or were underserved. The EAHCA created systems for including children with disabilities in public education, but only within the parameters for, and under the supervision of, the federal government by way of state and local reporting.

Productive/Burdensome Citizens

Bringing the education of children with disabilities into the purview of public education, and thus the federal government, allowed for the “assimilation of a floating

population found to be burdensome for an essentially mercantilist economy” (Foucault, 1980, p. 195). From 1975 onward, all children with disabilities were to be counted, classified, and monitored as special education services worked to eliminate their deficits, bringing them ever closer to the normative ideal of a productive citizen. In addition to reproducing the binary oppositions of normal/abnormal and able/disabled, a new division is emphasized: productive/burdensome. Special education legislation and processes operate within a “‘business discourse’ that is concerned with cost-effectiveness that drives toward self-sufficiency of the objects of the policy in an attempt to reduce the fiscal burden that they pose in their dependent state” (McKenzie, 2009, p. 100). In this business-like discourse of disability, the inherent worth of an individual with disabilities is in direct correlation to the ratio of their personal contributions to the economy versus their financial dependence on their family and the government for care and protection.

Simply counting and including children with disabilities into public education was not enough to solve the productive/burdensome issue. As noted above, the EAHCA gave very little guidance on how to achieve the goals of inclusion and protection, leaving a lot of room for interpretation at the state and local levels, with varying results. Students with disabilities were included more within the mainstream educational environment, but there were still concerns about their assimilation and participation in *normal* life upon graduation. The remaining deficiencies of students with disabilities in comparison to their nondisabled peers, even after being included in public education with special education services, continued their status as a problem to be solved. After decades of verifying that students with disabilities were accounted for and included, a new problematization entered the central focus of the educational discourse: how to ensure a quality of services that would *maximize*

the potential for each child's future. This urgent need is present in legislation regarding all students, as in the ESSA, as well as in special education legislation like the IDEA.

A surface reading of this urgent need might be interpreted through a lens of goodwill and equity. The laws safeguard opportunities for students of all backgrounds and abilities through accountability to the federal government. At its core, the federal oversight of education at large and special education in particular carries the aim of yielding productive, useful citizens. Individuals with disabilities, seen as a potential burden on society, create a problem of “efficient management” for government institutions, one that “demands prevention, correction, elimination or, at least, some managed and manageable form of integration” (Tremain, 2017, p. 162). Here we see the reemergence of the idea of the *best* interventions that will *maximize the potential* of the child with disabilities that is so prevalent within the medical discourse of disability and that I discussed in previous chapters. The “quality of services that will maximize the potential” is in relation to the normative ideal of a self-sufficient and productive adult. As Fleming (2014) notes, governance by the neoliberal state “sees economic calculability permeate into our broader life projects, making human capital no different to any other resource” (p. 883). And so it is with special education. Accommodating and assimilating students with disabilities into public education allows for the management of those individuals and direct surveillance of their potential for useful functioning in the future. What will they contribute upon graduation?

Parental Compliance/Resistance

Beyond enhancing educational access and opportunities for students with disabilities, the legal landscape surrounding special education includes regulations and procedures designed for the protection of the rights of students with disabilities and their families. This is

mainly achieved through parental consent and participation, but also with a structure for appeals and due process hearings if there is disagreement between the IEP team and the parents. According to Foucault (1982), “to govern, in this sense, is to structure the possible field of action of others” (p. 790). The discourse of special education gives parents a limited set of options. Parents must consent to the evaluation and IEP development processes or their child will not be eligible for special education services. Parents must participate in making decisions about their child’s education or trust the school personnel to do so on their behalf. Parents must agree with the decisions of the IEP team or embark on a legal process of dissent. Parents must accept the final decisions about their child’s placement in public education or arrange (and pay) for their education in a private, home, or clinical setting.

This protection and reliance on parent choice reproduces the binary opposition of compliance/resistance for parents of students with disabilities. Compliance is produced “through a process of careful behavioral conditioning” toward docility and legislative language with the guise of benevolence (Hull, 2017, p. 416). The emphasis on inclusion and protection within the legislation sets up special education services as a panacea, as a way to ameliorate the abnormalities of the child with disabilities while offering both care and protection. The special education discourse privileges the belief that inclusion “will reduce stigma, it will increase community integration and that it is the human right of the [student with disabilities] to be placed within the mainstream” (McKenzie, 2009, p. 93). Such a belief creates relations of power where the government is seen to be intervening on behalf of the interest of the individual. As they engage with the discourse of special education, parents of students with disabilities either “take compliance with regulatory demands upon themselves,” or they must choose a pathway of direct resistance (Hull, 2017, p. 416). Most parents will

comply with the recommendations of the IEP team, trusting that the school and legislation has their child's *best* interests and educational needs in the forefront of decision making. This compliance is a function of power/knowledge because the *best* interests of the child are seen as a "matter of objective truth to which parents do not have access as they lack the deep knowledge of the professional" (McKenzie, 2009, p. 104). As with the diagnostic process, the knowledge of the expert is privileged over that of the parent.

Parental resistance to the classifications and determinations regarding their child during the evaluation and IEP processes is typically expressed either through a due process hearing (which can be arduous, expensive, and unfruitful) or in their voluntary removal of the student from public education services. If a parent places their child with disabilities in a private school, then that child is no longer entitled to an IEP or other rights granted to public school students (Wettach, 2017). Some states do offer tuition assistance and other funding for students with disabilities who attend a nonpublic school. For example, North Carolina offers annual scholarships, awarded through a lottery, to cover expenses related to educating a child with disabilities, including tuition and fees for participating schools and related services such as therapies, tutoring, curriculum, and educational technology (North Carolina State Education Assistance Authority, 2022). To be deemed eligible for the funding, however, a student must have a current IEP document that can be submitted with the scholarship application (North Carolina State Education Assistance Authority, 2022). This requirement retains the student with disabilities within the counting, control, and general oversight of the public school system, even though the student may never enter public education. To receive any type of special education funding or services through the state, families must still engage

with the IEP process for their child, maintaining their presence within the flows of power of the special education discourse.

Initiating the IEP Process (Again)

In the early spring of 2022, our family was once again engaged in the IEP process with the local public school system — this time for a full reevaluation. Much has changed with my son over the last three years. Thanks to the care and support of teachers, therapists, and medical providers, in conjunction with his own progress and our family's commitment to helping him develop new skills, he is now much more verbal and able to advocate for himself. His unique combination of advanced reading ability, somewhat limited expressive and receptive language skills, and struggles with functional and self-care skills has brought us to a crossroads in determining his school placement for the 2022-2023 school year. His cognitive and academic abilities suggest a general education setting might work best for kindergarten, but concerns about his social, functional and language development make an argument for keeping him in his current specialized separate setting. The IEP process would be critical in helping us to determine how to meet his educational needs going forward.

The IEP process has several steps, most of which require parental involvement either through giving consent or direct participation, setting the stage for parents to take up a subjectivity of compliance or resistance. To begin, a conference between the local education agency (LEA) and the parent is held to review the child's current placement, determine the need for evaluation, and to gain parental permission for evaluation. The LEA must have parental permission to test or evaluate a child for special education and related services for the first time, which is called an initial evaluation (Public Schools of North Carolina, 2016). Parents must willingly and voluntarily enter the discourse of special education through the

systems of action laid out by the federal regulations to secure services for their child. One goal of the pre-evaluation conference is to discuss prior screenings, evaluations, and other existing information. In our case, those documents included my son's prior IEP, the full diagnostic evaluation report, documentation from his current school and ABA therapy services, a recent well-child pediatrician visit report, and a private speech therapy evaluation. The parent helps to gather this information, but is not typically interviewed nor asked to provide their own knowledge about their child's learning and needs.

Based on the information that is available, the LEA determines what additional areas of testing are needed and requests parental permission for the reevaluation. By granting permission for evaluation, the parent consents to subjecting their child to a series of tests that will "collect collateral evidence to corroborate the truth" of the child's disabilities and how far they deviate from the norm (Moffatt, 1999, p. 222). Without parental participation in the initial conference and/or permission for evaluation, the child is not eligible to receive special education services. In subsequent reevaluations, the school can proceed with testing and evaluation if the parent does not respond to requests for permission (Public Schools of North Carolina, 2016). Refusal to grant permission for reevaluation serves as an implicit expression of compliance on the part of the parent. The government by way of the school personnel takes over the care and protection of the child's education in the absence of parental response, thus dividing the "good parents" as those who actively grant permission and are involved from the "bad parents" who are absent and unresponsive.

Evaluation

On the day of my son's reevaluation, we arrived at the closest elementary school to our home, a building my son had never entered before, and were escorted to a small room

that felt more like a glorified closet than an office or classroom. It was full of filing cabinets and shelving, but had two small tables and four chairs where the assessments would be conducted. I was allowed to sit in the room with him, but was told not to intervene in a way that would affect his performance of assessment tasks. He was also allowed to keep the stuffed animal that we had brought along from home since we were dealing with unfamiliar people in an unfamiliar setting. I was also told that he could take breaks as necessary. This testing environment was indicative of the ways in which special education makes accommodations for the student to successfully access the mainstream classroom rather than adjusting the educational environment to meet his unique and individual needs. For example, the testing could have been conducted in our home, or we could have been allowed to visit the school and that particular space a few days prior to build familiarity, both of which would have resulted in a minor inconvenience to the school personnel.

Occupational Therapy and Sensory Processing Evaluations

The first evaluation segment was administered by an occupational therapist to determine his “performance of fine motor, visual motor, visual perceptual, and self-help skills, as they are relevant to the student’s [normal] function in the classroom setting” (IEP documentation). The evaluation began with the Wide Range Assessment of Visual Motor Abilities (WRAVMA; Adams & Sheslow, 1995) that provides “a reliable, accurate evaluation of visual-motor skills of children and adolescents ages 3-17 years” using a drawing test, matching test, and pegboard test. Scores on each subtest are reported as standard scores normed to an average score of 100, percentile rank in comparison to other students evaluated, age equivalent (according to typical developmental milestones), and interpretation descriptions like average or significantly below average (Adams & Sheslow,

1995). These scores and labels reproduce a hierarchical comparison between normal/abnormal abilities. Although the WRAVMA claims to produce a “reliable, accurate evaluation,” my son was unable to complete one of the subtests because his receptive language difficulties prevented his execution of the required tasks. Therefore, the heavy language component of at least portions of the assessment may skew the results based on language ability or inability rather than visual motor abilities.

In addition to the standardized WRAVMA test, the occupational therapist observed the range of motion, strength, and muscle tone on both sides of my son’s upper extremities, noting whether they were “within normal limits, deficits, or not tested” (IEP documentation). A pattern was emerging that, within the special education discourse, “it is the professional who measures, grades and informs decisions of educational placement, which have far reaching effects for the individual so classified and placed” (McKenzie, 2009, p. 102). Fine motor skills and visual motor integration were also evaluated through observation and performance measures by asking my son to use a pencil to draw multiple lines, shapes, letters, and numbers; a crayon and marker to color simple pictures and make representational drawings; scissors to cut straight and curved lines; and glue to complete a sequence task. The occupational therapy evaluation concluded with a parent interview to gauge the extent to which his performance on the evaluation tasks matched what he was able to do in other settings.

Based on her observations during the evaluation tasks, the occupational therapist also provided an assessment of my son’s sensory processing skills as being either *functional* or a *concern* as they relate to the educational environment in two areas: transitions and structured tasks. These labels reproduce the binary opposition of normal/abnormal. They reproduce a

belief that a “child’s receptivity to education was considered to stand in relation to their intellectual ability” (Axelsson, 2016, p. 27). Behaviors that were noted as concerns included the need for my presence and that of a preferred toy for him to participate in the evaluation, his need to walk the hall and take breaks, his changing positions frequently in his chair, and the presence of self-stimulation and hand-flapping behaviors (IEP documentation). He would need to be “taught to embody and reproduce norms of acceptable behavior” to have a place in the mainstream learning environment (Holt et al., 2012, p. 2192).

The occupational therapist’s observations were combined with the Sensory Processing Measure-2: School Form Ages 5-12 (SPM-2) questionnaire that had been completed by the program supervisor in his current school. The SPM-2 “provides a complete picture of sensory integration and processing difficulties in multiple environments” by measuring functioning in relation to vision, hearing, touch, taste and smell, body awareness, balance and motion, sensory total, planning and ideas, and social participation (Parham et al., 2021). Results in each area create hierarchical classifications: “typical, moderate difficulties, or severe difficulties” (Parham et al., 2021). Again, these classifications reinforce the normative ideal and the degree of deficiency in comparison to that standard. As Gillies (2013) notes, “specific attention is paid to the body in relation to developing skills and maximizing force” (p. 52). They set up every sensory experience as being normal or abnormal and then classify any abnormality by how far it deviates from behavior that would be productive upon graduation.

Cognitive, Educational, and Communication Evaluations

The occupational therapy and sensory processing evaluations lasted around 45 minutes, after which we were given a short break and allowed to go for a walk. Upon our

return the school psychologist arrived to complete the rest of the performance assessments. The Wechsler Preschool and Primary Scale of Intelligence, 4th Edition (WPPSI-IV) was administered to assess my son's cognitive processing abilities. The WPPSI-IV provides a measure of intellectual ability known as the Full Scale IQ (Wechsler, 2012). It represents cognitive functioning across the domains of verbal comprehension, visual spatial, fluid reasoning, working memory, and processing speed (Wechsler, 2012). Standard scores for each subtest and for the Full Scale IQ have a mean of 100, and deficits are categorized according to severity by the labels "low average, borderline, and extremely low" (Wechsler, 2012). Percentile ranks are also provided for the Full Scale IQ as well as for each subtest to provide a comparison of the student's intellectual ability to that of their peers, reproducing the normative ideal and discourse of deficiency. Danforth (2000) notes that psychology's tradition of measuring intelligence has built in "social status and moral purpose over decades as it 'helps' define some individuals as lesser, defective, deficient" (p. 364). It has become a key tool in the discourse of disability and that of special education by reproducing the normal/abnormal binary opposition and creating classifications that allow for the more efficient separation and management of students who are seen as deficient.

After two hours of testing, my son was tired and was not being as cooperative. The psychologist decided to end testing and resume later to try to capture more accurate results. I agreed, sensing that my son had reached his limit for tolerating the demands of the evaluations and the discomfort of an unfamiliar setting for one day. Beyond the length of time taken, there was no acknowledgement that the testing environment was less than ideal. Instead, our inability to complete all evaluations on the same day was attributed to my son's noncompliance and lack of stamina. With efficiency as the priority for completing the

evaluations and subsequent IEP process, we were scheduled to return at the same time the next day. My desire to be done with the testing process outweighed my concerns about another day away from his current school and our daily routines; I took up the subjectivity of compliant parent as a result of exhaustion on my son's behalf, and my own, more than anything else.

Upon our return the next day, the psychologist administered the Kaufman Test of Educational Achievement (KTEA-3), which is an “individually administered battery that provides in-depth assessment and evaluation of key academic skills” (Kaufman & Kaufman, 2014). Composite scores are determined for Reading, using subtests for letter and word recognition and reading comprehension, and for Math, using subtests for math concepts and application and math computation (Kaufman & Kaufman, 2014). Standard scores have a mean of 90 and are reported alongside percentile ranks and classifications. Most student scores will fall in the average range with deficits labeled according to severity as “below average, low, or very low” (Kaufman & Kaufman, 2014). Again, this standardized test maintains the discourse of normal/deficient students and creates hierarchical classifications of the deficits of students with disabilities in comparison to their peers. In so doing, this measurement sets the child with disabilities up as “an object to be studied, known, and defined in an authoritative way” and allows for a path to be laid out for correcting these individual deviations (Danforth, 2000, p. 364). Additionally, the emphasis on Reading and Math also reproduces a focus on the areas of educational life that are easiest to quantify, as opposed to “educational aims which relate to happiness, citizenship, confidence, creativity, and so on, [which] are not easily susceptible to measurement” (Gillies, 2013, pp. 47-48). As such, types of knowledge that are considered to be useful, measurable, and resulting in

productivity are privileged while types of knowledge that might increase the quality of an individual life are subjugated.

Most of the information about my son's communication was derived from a recent evaluation completed by our private speech therapist. It included informal assessments of articulation, voice, and fluency, along with an administration of the Preschool Language Scales (PLS-5). The PLS-5 "offers a comprehensive developmental language assessment with items that range from pre-verbal, interaction-based skills to emerging language to early literacy" (Zimmerman et al., 2011). Yielding results for auditory comprehension, expressive communication, and total language, standard scores on the PLS-5 have a mean of 100 and are expressed in relation to the average range for chronological age (Zimmerman et al., 2011). During our two sessions together, the school psychologist also completed a functional communication checklist based on observations of my son's communication abilities. I was not provided with a copy of that checklist or its name, but the narrative summary of the psychologist's findings focuses on verbal language over pointing, gestures, or even short phrases. Of note, was my son's lack of response to his own name or to questions from the school psychologist. According to the report, my son "appears to comprehend others" but struggles "when demonstrating general knowledge through verbal language" (IEP documentation).

Problematizing the Evaluations

Across the span of two days and a battery of tests, the occupational therapist and school psychologist came to "know" my son through quantifiable measurements and the ways in which those measurements relate to a statistical average, or the normative ideal. Armed with that knowledge, they would be prepared to make recommendations about his

educational placement, having identified his areas of need and his (in)capability of entering a mainstream classroom. As Gillies (2013) explains

Assessment develops knowledge about subjects; it individualizes them by judging, measuring, and comparing them with others. It normalizes their identity by outlining what they need to be trained for, what they need to develop, and how they need to correct themselves. (p. 56)

According to their quantifications and classifications, my son was constructed as a problem to be solved, as an individual that must be corrected to successfully assimilate into the mainstream educational system.

Standardized assessments and informal observations associated with evaluation for special education services reproduce a reliance on positivism, much like that in the medical discourse of disability. The positivist discourse within education perpetuates the beliefs that intelligence can be quantified, that human behavior can be measured, and that an individual's capabilities are directly observable. Positivism sees merit in "telling how people respond to tests, presenting persons in numbers, charts and graphs and how/why the outliers stand on the margins of a normal curve" (Moghtader, 2016, p. 47). What can be measured can also be surveilled and controlled. Therefore, the discourse of special education privileges measurement, reporting, and accountability to more effectively manage children with disabilities within the public school system. Results on special education evaluation measures are reported through scale scores in comparison to the mean and in descriptive ranges that indicate typical or average functioning or degrees of deviation, creating a reliance on normative ideals and standards. There is a constant reproduction of the normal/abnormal binary opposition. Hacking (1990) warns that "by covering opinion with a veneer of

objectivity, we replace judgement [sic] by computation” (p. 4). That is, evaluation results are constructed as being “the truth” about the child with disabilities, privileging expert knowledge over that of the parents and measurable, productive skills over the rest of human experience and learning. Even in situations where they seemed to think the assessment results may not adequately reflect my son’s abilities, the evaluators continued with the standardized testing format and presented the resulting scores for the IEP team’s consideration because that is the requirement within which they work. The scores and rankings from the evaluations thus carry more weight in the relations of power/knowledge than professional judgment or parental input in the creation of an IEP, regardless of the effectiveness of the assessment.

Additionally, the standardized evaluation measures used to determine eligibility for special education services reproduce power relations within the discourse that only allow for sanctioned types of knowledge to count as measures of intelligence. Only certain types of knowledge that are connected to normative functioning with the school environment and eventual productivity in society are measured and considered. Normative ways of knowing are privileged while others are silenced or marginalized. But Tremain (2017) asserts that

An epistemology that does not take account of . . . what people learn; what they know; what knowledge and information they seek; whether they learn; what, whether, and why they remember; how they know; and the extent to which they can learn and know seems elitist and outdated. (p. 43)

As an example of power/knowledge at work within the discourse of special education, my son’s knowledge and learning only counted if they could be demonstrated according to the exact instructions on the assessment instrument. One example of this was in the Bug Search component of the WPPSI-IV, which is designed to measure processing speed. The task was

for him to look at an image of a bug and then to find that same image in a line of several other bugs as quickly as possible. Instead of completing the assigned task, my son named each bug in the line in sequence (ladybug, butterfly, bee) and talked about how a bug is an insect with six legs. His knowledge was not only dismissed, but he was marked down for wasting time. The relations of power within the discourse of special education privilege efficiency over creativity or elaboration. The only skill that mattered was the one being assessed, and his attempts to demonstrate knowledge in his own way were downplayed as being abnormal and irrelevant.

Thinking with Foucault's concept of power/knowledge, it becomes evident that the characteristics needed for a child to be successful on these evaluations include not only quickness, but also compliance. As indicated in the Bug Search subtest, many components of the evaluations are scored based on the child's compliance with the parameters and instructions of the activity. Nonnormative responses are considered distractions that are either not scored or result in a lower score. Because several of the tests were timed, compliance is not even enough; the quickness with which a child complies is also important in quantifying their ability. The school psychologist noted in his report that my son used "a significant amount of echolalia and rituals during certain tasks" and that this "response style caused him to lose time on time tasks and may have distracted him when choosing certain answers" (IEP documentation). This evaluator's report also included several admonitions that "these results should be interpreted with extreme caution" because of my son's noncompliant behaviors that interfered with the reliability of testing procedures and results (IEP documentation). Axelsson (2016) agrees that "there is reason to be cautious and to adopt a higher level of humility when dealing with test results" as they are often used to "define who

the individual is and what can be expected from him or her” (p. 32). Overall testing fatigue and noncompliant behaviors on my son’s part also caused the psychologist to extend his testing session across two consecutive days to try to gain more reliable results rather than continuing past the two-hour mark on the first day. Although this suggestion was made in an effort to be considerate to my son, it also worked to preserve the integrity of the testing process, thereby maintaining the results as the privileged source of knowledge about my son’s abilities and potential. It also maintained my son’s noncompliance with the testing procedure as problematic instead of the test or the procedure being flawed.

Another area of concern with the evaluations were their heavy reliance on verbal language for instructions, prompts, and expected responses. Given my son’s difficulties with verbal language, the language-dominant nature of the evaluations became a barrier for his successful completion of the tasks. In a parallel to the assessments used in the diagnostic process, the significant amount of receptive and expressive language skills required for a child to demonstrate knowledge and ability on an evaluation task makes those measures ineffective and inaccessible in the case of a child with language impairment. The evaluators reported that “difficulty using and understanding spoken language adversely impacts” my son’s ability to “use language to express knowledge learned . . . as well as understand concepts and directions” (IEP documentation). Yet the team persisted in using language-dominant examinations because those were the ones that had been approved to provide eligibility documentation. Through the lens of power/knowledge, this persistence reproduces the privileging of assessment results above other types of knowledge and maintains their dominant position in the flows of power regarding children with disabilities within the discourse of special education.

Not only that, but the standardized nature of the tests prevented evaluators from varying their instructions to match vocabulary that my son understood. For example, when given a sequence of numbers 4, 5, 6, 7, __, my son was asked “what comes after?” He has not yet attained an understanding of before and after, so he could not answer the question, no matter how many times the same wording was repeated. But he knows that the number 8 follows 7; in fact, he can count to 100 without assistance. If the question had been phrased, “what comes *next*?” he would have answered it quickly and correctly. This is one small example of how standardized testing reproduces normativity, presuming the same vocabulary and prior knowledge on the part of every child and family. Tremain (2017) reminds us that “any norm is an artifact of the discipline that measures it: it has no physical being or reality apart from that practice” (p. 64). Even so, my son’s nonresponse was interpreted as a deficit of intelligence while the test was actually measuring his language ability and not the selected math skill. According to the educational discourse of disability, however, the problem was in my son’s inability to perform and conform, not an indicator of failing within the test itself.

Conclusions

Special education laws and evaluations constitute and are constituted by the normative educational discourse of disability. This discourse is continually reproduced through the elemental modes of normalization, “comparison, differentiation, hierarchy, homogeneity, and exclusion,” with the aim that a homogenized population “can be more effectively utilized and modified” (Tremain, 2017, p. 57). The efforts of federal legislation to count, control, and classify students with disabilities through their inclusion in public education have created “guidelines and recommendations that prescribe norms, adjust differentials to an equilibrium, maintain an average, and compensate for variations within the

‘general population’” (Tremain, 2017, p. 54-55). The flows of power/knowledge within the educational discourse of disability ask the IEP team members to take on the role of “judging individuals, making administrative decisions, laying down the norms” of what constitutes education, knowledge, and learning (Foucault, 1972, p. 164). In response to the dominant discourse of disability in education, students with disabilities and their parents take up subjectivities of docile compliance or resistance regarding evaluation tasks, resulting scores, and special education services. The same discourse of normativity, compliance/resistance, and classification continues as evaluation results are used to produce an IEP document for a student with disabilities, a process which will be taken up in the next section of analysis.

CHAPTER EIGHT: THE INDIVIDUALIZED EDUCATION PROGRAM (IEP)

Over three weeks later, I arrived at the same elementary school for the IEP meeting. The receptionist greeted me and told me to head back to the meeting room. I was unfamiliar with that space and had to stop someone in the hallway for help in finding it. No one from the IEP team greeted me or escorted me to the right location. I arrived at a room with six adults already seated facing a screen, actively engaged in conversation. Their conversation continued and I was largely ignored until the meeting officially began and formal introductions were made. I also noticed that there were two openings in one wall of the room that were lightly covered by curtains, not with doors that could be closed. I wondered if our discussions might not be fully private and confidential. Mostly, I felt alienated because it seemed like they were all comfortable and on the same team while I was alone and in an unfamiliar setting. They were all polite and friendly once the meeting began, but a tone had been set that made me feel ill at ease. Could I trust that these people had my son's *best* interests at heart or were they simply checking necessary boxes?

Even though I have begun this chapter with a vignette of entering an IEP meeting, the purpose of this chapter is not to analyze people or their direct actions. Rather, my intent is to problematize a highly-regulated *process* with significant ramifications for the education of a child with disabilities. This will address the research question: What is the problem represented to be regarding autism (and disability) in educational discourses? My analysis will focus on the ways that the IEP process and documentation *reproduce normativity* within the educational discourse of disability, which is problematic in that it perpetuates the binary opposition of normal/abnormal children and seeks to correct deviations from the norm. I will examine the ways that relations of power/knowledge are embodied for parents and their child

with disabilities throughout this process, relating back to another research question: What is the interplay among subjectivity, power, and knowledge for autism parents within these discourses, and what does this interplay produce? Continuing the work of the previous chapter, my analysis will reveal that parents take up subjectivities of compliance or resistance within a field of possible actions that is limited by the discourse and processes of special education.

I will think with Foucault's concept of power/knowledge as I engage in discourse analysis of each section of my son's IEP documentation, which follows the standardized formatting for all IEP documents created within the same ECATS system for North Carolina. Thinking with Foucault will show that the IEP process constitutes and is constituted by the judgment of individuals and the making of educational decisions related to the need to manage those individuals who are abnormal. Out of respect for the members of the IEP team, the school system, the school at which the meeting took place, and the identities of the individuals involved will remain confidential in this analysis.

Eligibility Determination

Within 90 days of the parent or school referral letter for evaluation, the Eligibility Determination process and paperwork must be completed (Wettach, 2017). This process determines the initial or continued eligibility of the student in question to receive special education services and under which disabling condition the IEP will be categorized. Evaluation results from all assessments administered are reported including scale scores and descriptive ranges such as Average, Typical, Below Average, Low, and High, along with narrative summaries (IEP documentation). Normative comparisons and hierarchical classifications are present in the meeting before the team even begins to create the IEP, thus

reproducing the deficit discourse of disability within education. Then the team considers the question: “As a result of the required screenings, evaluations, and review of existing information, what do we know about the student?” (IEP documentation). That question is answered through a list of the student’s strengths and needs based on the evaluation results. The state of North Carolina has established criteria for 14 different categories of disabilities (Wettach, 2017). The disabling category of Autism Spectrum Disorder requires a separate eligibility worksheet and accompanying evaluations before an eligibility determination can be made.

Determination of Disabling Condition - Autism

Autism determination under IDEA requires “persistent *deficits* of social communication and social interaction across multiple contexts,” manifested in three areas: *deficits* in social-emotional reciprocity, *deficits* in nonverbal communicative behaviors, and *deficits* in developing, maintaining and understanding relationships (IEP documentation, emphasis added). Additionally, eligibility determination under the category of autism requires manifestation of *restricted, repetitive* patterns of behavior, interests or activities in one or more of the following: *stereotyped or repetitive* motor movements, use of objects or speech; insistence on sameness, *inflexible* adherence to routines, or ritualized patterns of verbal or nonverbal behavior; *highly restricted*, fixated interests that are *abnormal* in intensity or focus; *atypical* responses to sensory input or *atypical* interests in sensory aspects of the environment; and symptoms generally present in the early developmental period (IEP documentation, emphasis added). A direct parallel can be drawn from this list of requirements to the deficit-centered language and observable behaviors featured in the diagnostic criteria of the *DSM-5*. In the eligibility determination process for an IEP, applying

the disabling category of autism is directly dependent on the degree of deficiency of the child in question in relation to normative standards of typical development and same-age peers in the areas of communication, socialization, sensory processing, and behavioral patterns.

ABAS-3

The Adaptive Behavior Assessment System (3rd edition) or ABAS-3 is a behavior rating scale that “measures daily living skills—what people actually do, or can do, without assistance from others” (Harrison & Oakland, 2015). The ABAS-3 is completed by both parents and teachers, resulting in a general adaptive composite score, as well as scores for the conceptual, social, and practical domains. Scores are also reported for subdomains, including communication, functional academics, and self-direction under the conceptual domain; leisure and social under the social domain; and community use, home/school living, health and safety, and self-care under the practical domain. Each score at all levels is accompanied by a classification as either low, below average, average, above average, or high (IEP documentation).

Adaptive behaviors include “*real life skills* such as grooming, dressing, safety, safe food handling, school rules, *ability to work, money management*, cleaning, making friends, social skills, and *personal responsibility*” (IEP documentation, emphasis added). The ABAS-3 measures the typical performance of daily activities of a person with disabilities against normative functioning, with an emphasis on the individual’s independence and productivity. It reproduces the normal/abnormal binary opposition within the educational discourse where the normal is the “purified state to which we should strive, and to which our energies are tending” (Hacking, 1990, p. 168). The ABAS-3 assesses an individual’s “actual performance as opposed to his potential” (IEP documentation). Privileging the quantification of current

ability over the innate capabilities and potential of the student with disabilities prioritizes the correction and management of daily living skills. Shaping behavior in this way requires that the normative discourse “posit conceptions of the normal from which the possibility and probability of deviations are measured and classified in order to prevent and control their actualization” (Tremain, 2017, p. 169). This prevention and control reduces deviant and undesirable behavior while molding the individual into a more normal, productive, and useful citizen.

ASRS

Another measure used in determining eligibility for special education services under the disabling category of autism is The Autism Spectrum Rating Scales (ASRS) instrument (Goldstein & Naglieri, 2009). ASRS are “norm referenced rating forms used to quantify observations of children and adolescents from six to eighteen years of age that exhibit behaviors associated with Autism Spectrum Disorders” (IEP documentation). Parents and general education teachers respond to each item on the scales with ratings of never, rarely, occasionally, frequently, and very frequently (Goldstein & Naglieri, 2009). Scores are reported for peer socialization, adult socialization, social/emotional reciprocity, atypical language, stereotypy, behavioral rigidity, sensory sensitivity, and attention/self-regulation (Goldstein & Naglieri, 2009). These scales produce a *DSM-5* correlation score, overall scores for social/communication and *unusual* behaviors, as well as a total score (Goldstein & Naglieri, 2009). Deviations from the Average range are classified as elevated, slightly elevated, or very elevated because “higher T-scores are associated with a greater number and/or frequency of reported *problems*” (IEP documentation, emphasis added). ASRS continues the trend of quantification, classification into hierarchies, and the normal/abnormal

binary opposition within the educational discourse. It assumes that “natural separations can be grounded based on observations of differences” which then work to “articulate and operate a set of ideals for individuals” (Moghtader, 2016, p. 25). The relations of power and knowledge within the special education discourse privilege the shaping of normal behavior and social functioning in children with autism without questioning why that set of behaviors is ideal or whose interests they serve. Thinking with Foucault allows educators to ask “whether these scientific tests act independently from a set of social and economical values imposed in our culture” (Moghtader, 2016, p. 42). Does the child with autism retain agency within a discourse dominated by the need for assimilation and productivity?

Problematizing the Eligibility Determination Process

Problematization questions what appears to be natural and logical, revealing how it is interconnected with the dominant discourse and the techniques of power. The usefulness of evaluations and rating scales and their application in the IEP process are taken for granted as both appropriate and the way things are done. The following problematizations bring forth the power/knowledge relations embedded in the eligibility determination process. All components for determining the disabling category of autism were based on those two scales, departing from the “validity” and “reliability” of standardized testing and expert observation used elsewhere in the IEP process. Unlike every other area evaluated from cognitive ability to social and emotional functioning, the determination for eligibility under the disabling category of autism relies solely on rating scales completed by the parents and teachers. On the surface, this process appears to privilege the knowledge of those individuals who know the child best and work most closely to the child within and outside of the educational environment. Further reflection on this process reveals it as a technique of power that recruits

“the willing participation of individuals in the constitution of their identity” (Chambon, 1999, p. 68). As parents are allowed to offer their perception of their child’s abilities – albeit within the confines of a formalized questionnaire – they are positioned to be more docile and compliant with determinations made about their child’s eligibility for special education services under the category of autism within the IEP process.

Much like the parent rating scales included in the full diagnostic evaluation, parents and teachers are asked to complete these questionnaires with little to no explanation or clarification. I was given no contact information for someone who could answer questions I had about the language used in any of the questionnaire items or exactly which behaviors were being assessed. Not only does this lack of clarity affect the reliability of my and the teachers’ responses within this positivist environment of quantification and measurement, but it also produces insurmountable barriers and obstacles for parents whose native language is not English, who have a low literacy ability, or who also have a disability. McKay and Garratt (2013) cite lack of knowledge of how the system works and inability to understand medical and technical language as difficulties experienced by parents as they engage with the IEP process. As a technique of power, the standardized nature of the questionnaires, along with the assumption that *normal* and responsible parents can complete them successfully, locates “reasons for failure or non-participation in individual deficit” (McKenzie, 2009, p. 82). Parents who are unable to complete the rating scales correctly are seen as noncompliant and uninvolved.

Another problematization with the use of parent and teacher questionnaires as the sole means for determining the disabling condition of autism is that they are used in isolation to the exclusion of open-ended or semi-structured interview questions. Such questions might

yield more detailed and relevant information from the parents and teachers about the student's behaviors, abilities, and interactions with the educational environment, in the community, and at home. The privileging of the parent and teacher questionnaires also excluded the existing quantitative data from previous evaluations of my son's performance from early intervention services, the full diagnostic evaluation process, and the IEP and ABA therapy treatment plan documents from his current placement in a more specialized school setting for autism. We had a mountain of data and paperwork, yet the only assessments that seemed to matter were those used within the special education evaluation process. He had a diagnosis of ASD from an internationally-recognized clinic for developmental disabilities. How did we still need to determine that he had autism? The IEP team's response to my question was that we had not yet determined whether his autism had an adverse effect on his education. The refusal to consider other available information "bolsters the authority" of the IEP team over that of the parents such that they are "in possession not only of scientific and technical knowledge but they also carry ethical weight by virtue of their knowledge of the *best interests*" of the child in question (McKenzie, 2009, p. 102, emphasis added). It also limits the available subjectivities for parents to take up within the discourse to that of compliance with, or resistance to, the expertise of the IEP team.

Outside of the determination requisites for autism, there are problematic components of the overarching eligibility determination process for parents. After all of the evaluation and deficit-centered discussion of student ability and deficiency, a student can still be deemed ineligible, in which case there can be no guarantee or protection of services under IDEA (IEP documentation). This may happen if other factors like hearing or vision impairments are presumed to be the cause of the educational difficulty that could be

addressed outside of special education services within the IDEA. Another example of an ineligible student would be one whose difficulties are determined to come from being an English-language learner rather than having a disabling condition. Although these determinations make sense because eligibility has to be the result of a disabling condition, this can feel demoralizing for parents who are seeking help for their child only to be met with a new process to pursue.

Parents do have the right to disagree with the evaluations and the eligibility determination for their child. Under the IDEA, parents have the right to have an outside evaluator of their choice conduct independent testing if they disagree with the school district's findings, as long as that evaluator meets qualifications required by the school district (Wettach, 2017). The school district must either pay for the independent evaluation or file a due process petition to have a judge decide if the district's evaluation was appropriate, thereby making an independent evaluation unnecessary (Yell et al., 2022). Although considered to be a procedural safeguard that protects a parent's rights, the decision to agree or disagree with the results of the evaluations after they have all been completed and presented reproduces the compliant/resistant subjectivity, a binary opposition that divides parents who will conform to the processes and decisions of the IEP team and those who are resistant and problematic. Parents have access to a limited range of subject positions with the power relations of "the administrative apparatus (rules and expectations) that govern" the special education discourse and IEP process (McKay & Garratt, 2013, p. 742). The parent either goes along with the findings, often subjugating their own knowledge and experiences of their child, or takes on the additional burden of requesting and securing an independent evaluation. As McKay and Garratt point out, in the case of resistance, "while the parents'

decision ultimately held sway, they also ended up isolated and banished from the system” (p. 740). Resistance can also feel combative and impolite depending upon the social and cultural norms of the parent. “Parents often have to walk a thin line between the task of pursuing relevant information and fear of being ignored . . . there is a sense that parents can simply be too active, too keen, too vocal” (McKay & Garratt, 2013, p. 743). I constantly wonder if I am being (perceived as) adversarial or as an advocate in situations where I am questioning the taken-for-granted assumptions and findings about my son.

Unfortunately, many parents are ill-equipped to understand these determinations, let alone advocate for other evaluations to take place. Barriers to parental understanding can include unfamiliarity with educational jargon, limited English proficiency, illiteracy, or having a disability themselves. On top of that is the inordinate amount of information to be processed at one time. Typically, evaluation reports are given to the parent as they are reviewed in the eligibility determination meeting, with no time for deep reading and processing. Evaluators are familiar with both the tests and their reports while parents are seeing the documentation for the first time. Scores, percentiles, classifications, and descriptions are readily available, but there is little explanation of the statistical means for each assessment or the cutoffs for the different classifications. Information is all presented in written language without supplemental graphs or charts (IEP documentation). Even as a highly literate person with a doctoral-level education and almost two decades of experience in the field of education, I struggled to process all of the information about my son and his deficiencies in real time. And this was just the first portion of the meeting.

These problematizations have addressed the research question: What is the interplay among subjectivity, power, and knowledge for autism parents within this discourse, and what

does this interplay produce? My analysis has revealed techniques of power that serve to limit the field of possible actions on the part of autism parents within the eligibility determination process. The knowledge of the IEP team is granted authority and expertise over that of the parent, positioning the parent into a subjectivity of either compliance or resistance. The IEP team via the evaluation and eligibility determination processes becomes the “arbiter of normal” with the ability to determine which children are normal/abnormal and eligible/ineligible (Foote & Frank, 1999, p. 174). Supported by familiarity with the system, technical language, and formal measures of what constitutes normal versus abnormal, expert knowledge supersedes the knowledge of the parent. Within the discourse of special education, parents experience “a form of nominal participation, which in real terms amounts to little more than tolerating the system and hence, paradoxically contributing to their own subjection” (McKay & Garratt, 2013, p. 745). Parents may offer input, but only within the confines of formal assessment tools and the official checks and balances segments of the process that are designed to safeguard parental rights.

Another research question is attended to in this section of analysis: What is the problem represented to be regarding autism (and disability) in educational discourses? McKenzie (2009) points to the “construction of intellectual disability through broad social practices which constitute the (in)educable subject that presents a problem for the education system” (pp. 60-61). Children with disabilities are presented as abnormal and deficient, and as such must be corrected to bring them closer to the normative ideal and to enhance their capabilities for productive and useful work in the economy upon graduation. The discourse of special education locates the learning difficulty and abnormality “within the individual and not as a result of the expectations of the social contexts in which the individual exists”

(Vakirtzi & Bayliss, 2013, p. 367). It is the child who must assimilate to normal functioning in society rather than the educational environment, testing processes, or future work opportunities that should be adjusted in response to the child. Both research questions will feature in the analysis of the next section, which outlines the creation of the IEP document once a child is determined to be eligible for special education services.

Creation of the IEP Document

Although a critical step in the initial evaluation or reevaluation process, the determination of “the child’s disability, or category of eligibility, does not determine the special education that the child can receive” (Wettach, 2017, p. 44). The eligibility determination process can take place in a separate meeting, but it is often combined in the same meeting with the creation of the IEP document for the sake of convenience. After almost an hour of discussing evaluation results and deciding that my son did have autism and that his autism did have an adverse effect on his education, we were ready to begin the actual IEP process. McKay and Garratt (2013) point out that special education professionals “cannot be held exclusively responsible for any perceived imbalance of power. In some respects, they are as much entrapped in a process of governmentality as their perceived alleged ‘victims,’ the parents” (p. 746). As a result, there is a limited range of subject positions for all participants in the IEP process to take up. Special educators are positioned as either compliant or resistant with the fill-in-the-blank process, much like the parents with whom they are meeting. These professionals may have to choose between honoring their experiential knowledge about a student and following the process with fidelity. Within the highly-regulated process, the IEP team is required to follow the sequential steps of documentation in the ECATS system as the IEP document is created. One example of how

the IEP team experiences limits on the possible subject positions available to them is that subsequent sections of the document are not accessible or trigger error messages if information is missing from a previous section. There is no room for flexibility or modification within the system. Therefore, my analysis will follow the IEP sequence as documented and experienced by my family.

Student Profile

The IEP document begins with a brief Student Profile section that has three components. First, the IEP team provides a list of the student's "overall strengths that contribute to success in the educational environment" (IEP documentation). This list was in the form of a short paragraph that identified the three areas of evaluation in which my son had scored in the Average or High range. It also mentioned that he has communication strengths in articulation, fluency, and voice. Next, the parent is offered a chance to express any concerns about their "child's academic and functional performance in school" (IEP documentation). Finally, the parent and student (if old enough to participate in the meeting) have an opportunity to express their vision for the future, specifically beyond high school if possible. Beginning with this section allows the IEP team to start with something positive and to garner parental input from the beginning. However, the inclusion of parental concerns might immediately override the brief expression of positivity by realigning with the dominant discourse of deficits and abnormalities. Additionally, the requirement to express a vision for the student's future, sometime over a decade in advance, reinforces the need to intervene with special education services to ensure that the student will be a functioning, productive, and useful member of society after graduation. The discourse of special education reproduces the "thrust to integrate devalued individuals into society in *normal* jobs and education so as

to enable them to engage in *socially valued* activities and to develop a *positive* social role and image [as determined by the normative standards].” (McKenzie, 2009, p. 73, emphasis added).

Present Levels of Academic and Functional Performance

Even though we had just reviewed the evaluations for almost an hour, the IEP process requires that the team “complete the current descriptive information by using norm-referenced, criterion-referenced, or any other valid data sources, as well as descriptive information for each of the relevant areas” to indicate present levels of performance (IEP documentation). For each area addressed, a determination must be made as to whether the data indicates a need for specially designed instruction (IEP documentation). Areas addressed for my son included expressive language, receptive language, fine motor skills, math, reading, social-emotional, and behavior. Some of these areas were determined to be in need of specially designed instruction while others were not. The section concludes with descriptions of any relevant medical information and of “how the disability impacts involvement and progress in the general curriculum” (IEP documentation).

The continuation of the normal/abnormal binary opposition within the discourse of academic and functional performance relies on the conception of disability as “a functional limitation . . . whereby minor adjustments to a given environment, such as a workplace, are made that enable a given ‘person with a disability’ to be ‘accommodated’ into an environment that, itself, remains intact overall” (Tremain, 2017, p. 10). Therefore, the IEP maintains the general education environment in its current state, designed around taken-for-granted assumptions about what is normal regarding knowledge and learning. Small accommodations are made to support the assimilation of the abnormal child into the

mainstream environment rather than revisiting or reshaping what constitutes learning. Specially designed instruction addresses those deficits to ensure that the student with disabilities can be more fully integrated into the apparatus of education as presented through the general education classroom and curriculum. The deficit-centered approach of IEP processes and documents that focus more on challenges than strengths reproduces the idea that students with disabilities are inherently deficient and in need of correction. Boroson (2020) posits that “it would be easy for parents and guardians to believe that at school, their child has been reduced to a stapled packet of deficits” (p. 156). The present levels of performance continue the hierarchical classification of students with disabilities in comparison to the statistical average, highlighting the ways in which the student will (or does) struggle to function normally within the educational environment. As Axelsson (2016) writes, “the examining and separating practices identified students who were understood to be problematic and also revealed a view of what talent is and when it is absent” (p. 28). Parents are confronted in the IEP process with their child’s seemingly profound lack of talent.

Secondary Transition

If the student with disabilities will be fourteen years of age or older during the duration of the IEP, then the secondary transition section must be completed. Beginning at age fourteen or the eighth grade, the IEP must choose a course of study and update it annually.

Choosing a Course of Study

The choices are for the student to learn according to the Standard Course of Study, which includes the general education curriculum and assessments for all children, or the

Occupational Course of Study, a modified curriculum that teaches the core content areas at a lower level and slower pace than the general education curriculum (Wettach, 2017). The Occupational Course of Study also includes “subjects that prepare students for work instead of for college and requires that students work in the community during their high school years” (Wettach, 2017). Students learning according to the Occupational Course of Study can earn a high school diploma, but their diploma “does not indicate mastery of the standard high school curriculum and does not indicate readiness for a 4-year college” (Wettach, 2017, p. 103).

Students with “significant cognitive disabilities” who are taught the Occupational Course of Study may take the College and Career Readiness Alternate Assessment, but participation in the alternate assessment means that the student is not “learning the standard grade-level curriculum and is not on a track to get a regular high school diploma” (Wettach, 2017, p. 104). This limits the possibility of the student attending a postsecondary institution, so it should only be used for students who are not capable of learning with the general education curriculum, even with extensive special education support. Dividing students into a binary of standard curriculum/occupational curriculum again creates a hierarchical classification between those students who are capable of completing a normal (and thus more valuable) education and those who lack the capacity to do so. Such a discourse constitutes a situation where “the fixed and static nature of impairment underpinned practices of exclusion and imposed a limit on the possibilities open to those classified as ‘having impairment’” (McKenzie, 2009, p. 270). The impairment is seen as an inherent and fixed characteristic of the student rather than a product of the discourse within which the student learns.

Although the expert knowledge of the IEP team is privileged throughout the IEP process, power relations that safeguard parental participation place the onus on those whose knowledge and expertise has been previously subjugated. The decision about a course of study is ultimately up to the parent and the student. McKay and Garratt (2013) describe the IEP process as “a model that unproblematically compels the exercise of ‘voice’ and participation through the illusion of active democratic engagement” (p. 738). Wettach (2017) cautions that although the course of study can be reversed after the ninth grade, is a difficult process that may necessitate an extra year of high school. Parents are often frustrated by the gravity of the decision, which has lifelong implications, as well as by the lack of options. One parent bemoaned that “the options were always presented as binary—either life skills class at the expense of academics [and the regular classroom] or life skills get pushed aside for academics. Why can’t the child have both?” (National Council on Disability, 2018, p. 22). Under the guise of freewill, parents and students are basically left with two choices: Standard Course of Study or Occupational Course of Study; within this choice they may take up the subjectivity of docile compliance or resistance with the recommendations of the IEP team.

Postsecondary Goals and Supports

The other component of the Secondary Transition section of the IEP document establishes goals and supports for the student after high school. Postsecondary goals are “based upon age-appropriate transition assessments as described in the present levels of academic and functional performance” (IEP documentation). Goals are established in three different areas: education/training, employment, and independent living. Postsecondary supports are then detailed to transition the student’s progress away from the supervision of

the school system to other people and organizations. Support areas include: adult living skills, employment development, functional vocational evaluation, instruction, related services, community experiences, and daily living skills. These areas fall within the moral responsibility of special education personnel to facilitate the development of a student's knowledge and abilities essential for "(a) exercising rights, fulfilling responsibilities, and exemplifying ideals of membership in the American democratic body politic and (b) having a reasonable chance for success in seeking the basic human good of self-fulfillment" (Ladenson, 2020, p. 162). For each support area, the team must describe the transition activities involved and the person or agency responsible for implementing those activities (IEP documentation). Postsecondary goals and supports continue the need to produce useful and functioning citizens that is prevalent in educational discourse. These goals and supports combine with the course of study choice in "guiding the possibilities of conduct and putting in order the possible outcomes" (Tremain, 2017, p. 72). With an emphasis on independence, self-sufficiency, and productivity, parents and students are guided toward goals and supports that will allow for the closest approximation to *normal* adult functioning possible. The normal/abnormal binary opposition is supplemented by classifications of independent/dependent, productive/burdensome, functioning/non-functioning. In preparing for their life after graduation, students with disabilities (and their parents) are confronted with their perceived value in society and take up subjectivities of compliance with or resistance to the classifications and determinations set forth in their plan for goals and supports.

Measurable Goals

Returning to the process for all IEP meetings, regardless of the child's age, for every area determined to be in need of specially designed instruction in the Present Levels of

Academic and Functional Performance section, the team must create at least one goal. These goals should be “clearly defined and measurable” (IEP documentation), achieved by the listing of one observable skill or behavior, along with a criterion level for mastery and methods for measuring progress. The IEP document also notes whether or not assistive technology is needed to make progress on the selected goal, or if the goal is related to transition goals as described previously in the Secondary Transition section. Each goal should describe what would “represent good, meaningful progress in each of the areas of concern” one year from the starting date of the IEP (Wettach, 2017, p. 49). An example goal in my son’s IEP under the area of receptive language is that “given a literacy activity or story read aloud with picture cues, [the student] will answer simple who, what and where listening comprehension questions with 75% accuracy over at least 3 consecutive sessions” as measured by data sheets and therapy notes (IEP documentation). Progress on the IEP goals is shared quarterly coinciding with school report cards unless the team determines a need for more frequent communication.

Foucault (1995/1975) argued that “a relation of surveillance is inscribed at the heart of the practice of teaching, not as an additional or adjacent part, but as a mechanism that is inherent to it and which increases its efficiency” (p. 176). A “relation of surveillance” also aligns with the main characteristics of special education: it is individualized, may provide modifications of teaching strategies or programs, and services are systematically monitored (Bateman & Cline, 2016). Setting and assessing progress on annual goals allows for accountability, reporting, surveillance, and control regarding students with disabilities and the effectiveness of the special education services. The requirement that annual goals be measurable and relate directly to an observable skill or behavior is a technique of power –

surveillance – that limits the types of knowledge and abilities that count within the framework of the IEP document. It reproduces the educational discourse’s reliance on positivism, assuming that “the more numbers we have, the more inductions we shall be able to make” (Hacking, 1990, p. 62). Such goals reduce education and learning to the quantifiable performance of one specific behavior or skill that is privileged within the discourse of special education as moving the student with disabilities closer to normal functioning within the educational environment. Surveilling discrete and measurable skills is problematic because it reproduces a subjectivity of compliance or resistance on the part of the student by measuring how often and how effectively the student responds to the instruction or intervention.

Placement Decisions

Once measurable goals have been created, the IEP development process is complete, and it can serve as the basis of placement decisions. Although technically not part of the IEP development process, placement decisions are typically made by the IEP team and included in the IEP documentation (Yell et al., 2022). Placement does not refer just to the location in which the student will receive special education services, but rather to the overall program that includes curriculum and services (Yell et al., 2022). What is problematic about placement is that it assigns educational labels to the student that make them visible as being abnormal, as needing to be educated in a qualitatively different way than normal students. Placement situates the student with disabilities “both within a field of surveillance and within a system of documentation. The various codes that are used for documentation are a means of formalizing the person within the power relation” (Moffatt, 1999, p. 223). In many cases, the student becomes defined by those labels and services, resulting in the lower of people’s

expectations for their educational attainment (Molloy & Vasil, 2002). The placement process operates under several taken-for-granted assumptions about students with disabilities and their parents, which will be problematized in my analysis.

Least Restrictive Environment: Idealizing Inclusion

Placement represents a point on a continuum of possible settings and services, but must create the least restrictive environment in which a student can participate successfully. This requirement means that students with disabilities should be educated with their same-age peers to the greatest extent possible, creating a power relation in which abnormal students should aspire to function within the normative educational environment, which typically means in the general education classroom (Bateman & Cline, 2016). In 2019, a total of 6,237,889, or 95.1 percent, of the 6,561,998 students ages 5 (school age) through 21 served under IDEA, Part B, were educated in regular classrooms for at least some portion of the school day (Office of Special Education and Rehabilitative Services, 2021). The majority of these students (82.2 percent) were educated inside the regular class 40% or more of the day (Office of Special Education and Rehabilitative Services, 2021). One taken-for-granted assumption is that the general education classroom is the best placement for students with disabilities unless they have significant cognitive deficits that would prevent their participation (Bateman & Cline, 2016; Ladenson, 2020; Katsiyannis et al., 2001; Yell et al., 2022). The prevailing wisdom about special education placement is that students with disabilities should be educated in the general education classroom “until all available methods to meet their needs in this environment are tried and deemed unsuccessful” (Bateman & Cline, 2016, p. 11). Therefore, many IEP team members will recommend initial

placement in the general education classroom with related services and supports until it can be proven that those measures do not work, a practice known as *mainstreaming*.

IEP teams should be aware of a different parent perspective, one that comes from knowing their child's struggles and the triggers that cause their child to become dysregulated. McKenzie's (2009) study revealed a "care and protection discourse" that is contradictory to mainstreaming and has been largely marginalized, whereby parents felt their children would not "receive the resources, care, and protection that they require" in a regular classroom or school (p. 255). Writing specifically about students with autism, Boroson (2020) offers the example of a student "who cannot cope in a large physical space with as many as 20 or more people in it, or whose behaviors are dysregulated enough to become a barrier to learning for others" as a candidate for education in a more restrictive environment (p. 161). I fell into the care and protection discourse, crafting my subjectivity as "resistance parent" to the IEP team's decision to place my son in the general education classroom for more than 80% of his day, albeit with special education, related, and supplemental services. Placing him in a kindergarten classroom with more than 25 students, one teacher, and one teacher's assistant shared across five classrooms seemed overwhelming and less than ideal in relation to his needs and triggers for dysregulation.

The push for inclusion in the general education classroom takes for granted that parents should want their child with disabilities to be educated in a setting that is *as close to normal* as possible. The special education discourse largely characterizes parents as pushing for the inclusion of their child in the general education classroom, even in some cases where it would not be warranted according to the data (Boroson, 2020; Yell et al., 2022). As I discussed above, it is important to recognize that "while inclusive education is for everyone,

placement in an inclusion classroom is not suitable for every student (Borosan, 2020, p. 161). Whether seen to be demanding inclusion in contradiction to the data or to be rejecting the emphasis on mainstreaming, parents are positioned in a subjectivity of resistance to the recommendations of the IEP team. They are seen as combative, uncooperative, and unaccepting of the expert knowledge that has been presented by the IEP team. Parents become “those who need to be persuaded” that the recommended placement is in the *best interest* of their child (Van Rooyen et al., 2003, as cited in McKenzie, 2009, p. 255). Parents may retain the legal right to make the ultimate determination about their child’s participation in special education services, but “the degree to which the voice of the parent is fully incorporated into decision-making [about placement] is largely contingent upon the extent to which what is being said actually conforms to the received discourse and normalising gaze of prevailing authorities and professionals” (McKay & Garratt, 2013, p. 743). The mandate for the least restrictive environment and the quantitative evidence presented in the IEP process trump the wishes of the parent in determining appropriate placement for the child. Again, parents take up a subjectivity of compliance or resistance regarding the prevailing discourse of disability and its power relations within the IEP process.

Least Restrictive Environment: Protecting the Collective Interests

As is noted above, most students with disabilities are mainstreamed and then monitored to see if they fail in the general education environment. Swart and Pettipher (2005) referred to this practice as *mainstreaming by default*, *mainstream dumping*, or a method of *dump and hope*. Not only is this practice in direct contradiction to the relations of urgency in the medical discourse of disability, but they set up a power relation in which “the limited progress was ascribed to the biological limitations of the child” (McKenzie, 2009, p.

64). If the IEP team determines that a student cannot be successful in the general education classroom, based on quantitative data and observations, then alternative placements such as special education classrooms, special schools or instruction in the home or a hospital may be considered (Yell et al., 2022). A least restrictive environment justification statement must be included in the IEP document to explain why the student will be removed from the general education classroom for any part of the day and why those services cannot be delivered through supplemental aids and services, accommodations, or modifications (IEP documentation).

Presumably, this justification is in place as a safeguard against the unnecessary separation and exclusion of students with disabilities, but its benevolent façade covers a power relation that desires the maintenance of the status quo that serves the school's best interests. Foucault (2008b) describes this as “the protection of the collective interest against individual interests,” especially in relation to the business discourse of costs and benefits (p. 65). General education is what the school is already doing. It is familiar, assumed to be functioning properly, and requires no extra costs or efforts. Mainstreaming is the path of least resistance for the school. In less well-resourced communities, where resources for alternative placements are not available, mainstreaming may be recommended even when the evidence from the IEP process would indicate a separate setting (McKenzie, 2009). When I advocated for at least part of my son's day to be spent in a separate classroom with a smaller group of students who also had disabilities, I was told that the school our neighborhood was assigned to attend did not have such a classroom. There was a vague reference back to the evidence justifying my son's placement with the assurance that, if he failed to perform satisfactorily in the general education classroom, he could be transferred to a nearby school that offered such

a separate class. Having our home located within the boundaries of the service area for a different school less than five miles away could have opened up different placement possibilities for my son.

Beyond questions about the placement decisions serving the interests and needs of the student with disabilities, there are overarching concerns regarding the full integration of students with disabilities into the general education classroom. There is some debate as to whether or not it is “educationally beneficial, with no exceptions whatsoever, for *all* students—both for students with disabilities and for nondisabled students (Ladenson, 2020, p. 86, emphasis in original). The interests of both the learning of nondisabled students and the functioning of the general educational environment as a whole raise concerns about the incorporation of students with disabilities into the general education classroom. With their abnormal behaviors and need for special attention, students with disabilities potentially distract from the educational experiences of their nondisabled peers. If that is the case, then the role of the classroom teacher becomes one of “reducing the ‘incompatibility’ of the [student with disabilities’] presence with the education of others” (Allan & Youdell, 2017, p. 78). The student with disabilities will have to be accommodated further to offset any abnormalities until it can be demonstrated that an alternative placement is required. As a consequence of the pressure to conform and appease the needs of others, the student with disabilities is forced to “be like everyone else and deny the reality of their experience” or take up a subjectivity of resistance that will be interpreted as a failure to adapt to the general education classroom and evidence of personal deficiencies (Surbaugh, 2010, p. 113).

Another assumption regarding placement in the least restrictive environment is that it is in the student’s *best* interest to receive the fewest special education services possible and

still retain successful academic and functional performance. This reproduces the need within the educational discourse to produce functioning, independent, and useful citizens and to bring the student ever closer to the normative ideal. In truth, special education has the goal of ultimately eliminating services for as many students as possible through their progress and increased abilities. This was evident in one IEP team member's comment that "our hope is to provide enough services and support so that he no longer needs an IEP down the road" (personal communication). Although put in place for the protection of student and parent rights as well as for equity, the IDEA's insistence on the least restrictive environment can cause situations where the parents must wait for their child's failure to show progress before they can be removed from the general education classroom or deemed eligible for extended school year services. This practice is counterintuitive with the sense of urgency that parents experience within the medical discourse of disability and may feel like a waste of precious time for their child's development (Boroson, 2020). Parents take up subjectivities of docile compliance with the IEP team's recommendations for placement, or they place themselves in a position of resistance. Resistance may be embodied through a posture of questioning and active participation during the IEP process, but ultimately resistance to a placement decision involves court proceedings or removal of the child from special education services in the public school.

Pathways of Resistance

Once the placement decision is made, the members of the IEP team sign and date the finalized document that serves as a contract for educational programming and services for the term of one year, unless members of the team agree that changes should be made earlier. In that case, there would be other meetings and reviews based on data and possibly other

evaluations. Though the IEP creation process may be complete, its implementation has significant impacts on the educational possibilities for the student with disabilities for the ensuing calendar year. Focusing on the least restrictive environment works to limit and “structure the possible field of action” for parents and IEP team members during that year of educational programming (Foucault, 1982, p. 790). As a reminder, a “possible field of action,” for Foucault, is one that is made thinkable within the dominant discourse. Working within the regulations regarding the least restrictive environment, only certain educational placements are acceptable for consideration by the IEP team, and the chosen placement must be continuously monitored for its effectiveness. Special education personnel are also in a limited possible field of action as they must provide services in alignment with the parameters of the IEP document and track its implementation. The progress of the student with disabilities will be subject to surveillance, defined by Danforth (2000) as “careful and total observation,” to determine the appropriateness and effectiveness of the IEP goals and placement. Minor adjustments can be made to personalize the learning for the child, but in general all parties are expected to comply with the IEP as written, leaving little room for creative collaboration between the teacher and parent as the learning is happening. If the placement turns out to be ineffective, the parent must take up a subjectivity of resistance by requesting for new meetings and a review of the IEP before the year is complete, a process that can be both lengthy and arduous. This is part of a power relation within the special education discourse where resistance on the part of the parent is met with a process designed to be long and difficult or the alternative of removing the child from special education services.

Parents experience the IEP process as counterintuitive from the discourse of urgency they encounter across other discourses of autism and disability, and they may also notice that the emphasis on quality decreases in the discourse of special education. From the messaging about developmental milestones in early childhood to an ASD diagnosis and beyond, autism parents are urged to act quickly to secure the *best possible* therapies and services to help their child. Yet, when the responsibility for academic and functional progress switches over to the state via the public schools, the standard lowers from *best possible* to *adequate*. Court cases have ruled that, in their implementation of IDEA, schools do not have to provide an *optimal* education that would maximize a student's potential, but instead must ensure that the student with an IEP is making *meaningful or reasonable* progress toward their annual goals (Bateman & Cline, 2016; Wettach, 2017). This concept is presented within the special education discourse as the "Cadillac versus Chevrolet" argument, meaning that a student is entitled to educational programming that meets their needs but not one that provides the highest-quality interventions, therapies, services, and equipment available (*Doe ex rel. Doe v. Bd. of Ed. of Tullahoma City Sch.*, 1993). Parents are placed in a binary of compliance/resistance when the IEP team's decisions about what is adequate conflict with the parent's vision of educational programming that would maximize their child's potential. The relations of power/knowledge within the special education discourse across the federal legislation, judicial rulings, and the public school system may cause parents to experience the IEP process as "deceptively promising reform, progress, or freedom but in actuality delivering subjugation" (Devine, 1999, p. 251). Parents are left with little recourse in the wake of such court rulings.

Adding to the potential discrepancy between desired and actual educational programming, the emphasis in the IDEA legislation on parental rights creates a burden of responsibility on parents to know about, understand, and participate in making critical decisions regarding their child's education. As a result "over time, the IDEA has increased the burden on parents to act as effective advocates in order for their children to receive adequate educational programs" (Colker, 2013, p. 107). Procedural safeguards create flows of power relations that seem to favor parents throughout the IEP process and in due process hearings. At the same time, power relations within the special education discourse operate "by guiding and limiting subjects in accordance with their capacity to choose from a highly circumscribed set of possible actions" (Tremain, 2017, p. 161). The IEP process is so highly regulated and monitored that meetings are often reduced to fill-in-the-blank and multiple-choice responses to the student's needs and goals as opposed to a wide open range of possibilities. As Moffatt (1999) argues "the forms are constructed to serve the logic of a particular political rationality . . . the forms also function as techniques of control, which create a dissonance in the relationship that protects against the creation of intersubjective meaning" between the IEP team and the parent (p. 227). Adding to this struggle are the challenges that arise when a district is not fully equipped to meet the needs of a student with disabilities. "In many cases, especially in poorly funded or overwhelmed districts, the appropriateness of a child's services is commensurate with the effectiveness of the advocacy of their parents or guardians" (Boroson, 2020, p. 147). With fewer resources available, those students whose parents can and will advocate (resist?) most relentlessly have greater access to the educational programming they need than those whose parents are not in a position to advocate as heavily. According to McKay and Garratt (2013), "parents with greater

knowledge and understanding of the system, and thus the ability to effect power, appeared able to engage more confidently” (p. 739). Couple the lack of resources with parents who are English-language learners, who live in poverty without the time or transportation to attend meetings, or those who themselves have disabilities which make understanding the IEP process difficult and there is tremendous potential for students with disabilities whose families are already marginalized in the educational discourse to receive less than adequate services.

Knowledge and Control

My analysis in this chapter has looked at the interplay among power, knowledge, and subjectivity within the discourse of special education and what it produces for parents. The IEP process replicates what counts as knowledge within the educational discourse and the flows of power relations related to surveillance and control. In examining the educational discourse of disability and special education, it is important to question

Who is speaking? Who, among the totality of speaking individuals, is accorded the right to use this sort of language? Who is qualified to do so? Who derives from it his own special quality, his prestige, and from whom, in return, does he receive, if not the assurance, at least the presumption that what he says is true? (Foucault, 1972, p. 50)

In other words, what types of knowledge and input are privileged and what are silenced or marginalized? The IEP process and educational discourse at large are deeply entrenched in positivism as evidenced by the reliance on quantitative data and the belief that behaviors and progress (that matter) are measurable. Behaviors that are not observable, quantifiable, and measurable have no place in the annual goals of the IEP (Bateman & Cline, 2016; Wettach, 2017; Yell et al., 2022). In the same way that the educational discourse of disability

privileges quantitative data, the power relations that position the school personnel as the experts on the student at school work to subjugate other types of knowledge, including anecdotal and experiential data, as well as parental input about the student at home. Boroson (2020) reminds school personnel to honor the wisdom that parents bring to their interactions, noting that

Parents are the historical and holistic experts. They know every trigger, every single preemptive or responsive intervention that has helped, and every single highly touted intervention that has made things worse. They can see a meltdown coming a mile away. They know it all too well. They know. (p. 156)

Relations of power/knowledge within the educational discourse of disability produce dynamics between school personnel that can be collaborative or combative depending upon the parent's taking up a subjectivity of compliance or resistance in any given interaction.

Those flows of power are always in the act of *becoming* within an apparatus of surveillance, classification, monitoring, and control. My analysis has shown how students with disabilities are problematized as a population that is abnormal and that must be managed under the auspices of the government. Tremain (2017) explains that strategies of power must operate to "maximize the efficiency of the state and minimize its political, economic, and social costs, while at the same time guiding, influencing, and limiting people's actions in ways that seem to enhance their capacity to be self-determining (Tremain, 2017, p. 74). With the passage of the EAHCA, the state brought students with disabilities under surveillance, and the enactment of the IDEA has continued systems of classification, monitoring, and control regarding students with disabilities and their families. Though benevolent in its

efforts to improve access and opportunities for education to students with disabilities, the IEP process and the legislation behind it are also always serving the interests of the state.

In considering the interests of the state, a question arises about the number of students served in special education. The EAHCA states that there were eight million handicapped children in the United States in 1975 (P. L. 94-142 § 89-773). In 2019, 6,374,498 were served in 49 States, the District of Columbia, and Bureau of Indian Education schools (Office of Special Education and Rehabilitative Services, 2021). How is it possible that fewer students received special education services in 2019 than the number of children identified in 1975 given the state's penchant for counting and surveillance? The statistics cause even more suspicion when one considers the focus on identification of students through child find and zero reject policies, the increase in special education professionals, and the increase in the total population of the United States over the last four decades. Although beyond the parameters of this dissertation, these questions bear further investigation into the flows of power and knowledge within the educational discourse via methods of counting, classification, and surveillance. Who is being left out? What policies and taken-for-granted assumptions are at work to explain the lower number four decades after the passage of the EAHCA?

CHAPTER NINE: AN ALTERNATIVE APPROACH TO THE IEP PROCESS

In the wake of my son's diagnosis, my husband and I reproduced, and were produced by, a discourse of urgency in the medicalization of autism. The diagnostic evaluation team had encouraged us to seek out applied behavior analysis (ABA) therapy for our son, but no organization in our home county provided these services. Adding to our worries was our displeasure with the initial IEP placement for our son in the local public school system in May of 2019. No one who would be working with him – including classroom teachers, special education teachers and related services providers – had received specific training for autism. We were also concerned about his not being deemed eligible for any services or support over the summer months.

Based on the recommendations of a family at our church and a preschool teacher, we scheduled a tour at a specialized school and ABA therapy clinical setting two counties away from our home that serves children with autism from preschool through high school year-round. For the sake of anonymity, during this analysis I will refer to this school as Barnfield. A spot in one of the preschool classrooms opened, and he began attending Barnfield in July of 2019. He has been enrolled in the school setting for the last three years, which includes one hour of one-on-one ABA therapy services within the classroom, but it took over fifteen months from our initial enrollment to get off of the waiting list to receive clinical ABA therapy services at the same location. The second IEP meeting described in Chapter Eight took place in March of 2022 as we contemplated our son's possible transition away from Barnfield and into a more traditional Kindergarten program.

Our family is fortunate that we were able to enroll our son in this type of program with limited openings, and we fully recognize that this is not an option for every parent of a

child with autism. Driving to a location that is 45 minutes away from home and working remotely while their child attends school is not feasible for many families. It requires a flexible schedule, reliable transportation, the ability to pay for gas, and having access to appropriate technology for work. Even though Barnfield receives early intervention funding from the state and many insurance carriers will cover at least a portion of the cost of ABA therapy services, there are still monthly tuition fees and any remaining ABA therapy service fees after insurance is applied, which could prove to be cost-prohibitive for some families.

Because Barnfield is a private, non-profit organization, it does not have to follow the same federal guidelines for IEP creation and documentation as public schools. Our family's experiences with IEP documents and meetings have been very different at Barnfield. Parent subjectivities are not reduced to that of compliance or resistance; rather, we have experienced IEP meetings in the role of collaborative partners in the conversation. Additionally, IEP proceedings at Barnfield focus only on the child in question, eliminating the hierarchical comparisons that reproduce the normal/abnormal binary opposition in public school settings. Barnfield's methods do work to shape the behaviors of a child with autism to help them adapt more successfully in their home and community environment, which reproduces the assumption from the dominant discourse of disability as deficit that there is something about the child with autism that needs to be corrected. However, the Barnfield approach to learning celebrates what the child *is* and what the child is *becoming*, which is both a disruption in the dominant discourse of producing useful citizens and a move toward a discourse of neurodiversity. In this chapter, I will show that Barnfield employs a strengths-based approach that is an improvement to the IEP process in public schools.

This chapter begins with foundational information about ABA therapy, which is one of the most widely-recommended interventions for people with autism and is the basis for the educational programming at Barnfield. My analysis explores the interplay among power, knowledge, and subjectivity in the methods used by Barnfield for its IEP process, in comparison to more traditional state-monitored IEPs. Finally, my analysis will examine Barnfield's alternative IEP process, addressing the research question: How do the processes that are used in the dissemination of information and intervention reveal (im)possibilities for people with autism and their parents and families? Barnfield's methods allow for personalization and collaboration in ways that could be adopted to improve traditional public school IEP processes, and their adaptation of Applied Behavioral Analysis therapy moves toward discourses of *becoming* and affirmative difference.

Applied Behavioral Analysis (ABA) Therapy

ABA therapy is based on the work of B. F. Skinner (1957) who proposed that our ability to understand verbal and social behavior is assessed by “the extent to which we can predict the occurrence of specific instances and, eventually, from the extent to which we can produce or control such behavior by altering the conditions under which it occurs” (p. 3). In other words, a behavior is only understood in relationship to both its antecedents and consequences, which follow predictable patterns and can be manipulated. According to Sauter and LeBlanc (2006), Skinner's work provides a “conceptual framework and taxonomy for the controlling variables of language that defined independent verbal operants by their functional relations to antecedents and consequences (rather than by topography or meaning)” (p. 35). Skinner identifies seven types of verbal operants—echoic, mand, tact, intraverbal, textual, transcriptive, and copying a text (Sundberg & Michael, 2001). Take, for

example, the verbal operant of mand, in which the “response is reinforced by a characteristic consequence and is therefore under the functional control of relevant conditions of deprivation or aversive stimulation” (Skinner, 1957, p. 35-36). Mands are requests, commands, or expressions of wants and needs like asking for a glass of water or saying the phrase, “Stop!” In ABA therapy, verbal and social behaviors, including mands, are modified or stimulated through reinforcers, which can be positive such as approval from others or negative like escape or withdrawal from aversive stimuli (Skinner, 1957). Gitimoghaddam et al. (2022) define ABA at its core as “the practice of utilizing the psychological principles of learning theory to enact change” on behavior. Freedman (2012) points out that behavioral modification is used by individuals outside of the autism community to address a wide range of health issues from addiction to weight loss, as well as in supporting other desired lifestyle changes. With smartphones and social media accountability groups, “we can train ourselves to lead healthier, safer, eco-friendlier, more financially secure, and more productive lives” (Freedman, 2012, p. 44).

Understanding and modifying verbal and social behaviors according to Skinner’s framework seems particularly relevant to the language and social difficulties experienced by many people with autism. For this reason, ABA therapy is the most widely recommended evidence-based intervention for people with autism (Peters-Scheffer et al., 2011), as was our experience at the diagnostic evaluation appointment. Interventions for children with autism based on Skinner’s work can lead to improvement in a wide range of verbal behaviors, including manding (Adami et al., 2017; Albert et al., 2012; Davis et al., 2012; Groskreutz et al., 2014; Kodak et al., 2012; Shillingsburg et al., 2013), labeling emotions (Conallen & Reed, 2016; Conallen & Reed, 2017; McHugh et al., 2011), and reducing challenging

behavior (Adami et al., 2017; Falcomata et al., 2012; Falcomata et al., 2013). ABA therapy yields positive outcomes for improvements in the following categories: cognitive, language, social and communication, problem behavior, adaptive behavior, emotional, and autism symptoms (Gitimoghaddam et al., 2022). Dixon et al. (2021) conducted a randomized-controlled trial evaluation study and found that ABA-based interventions may aid in an increase of IQ for individuals with autism. According to Sundberg and Michael (2001), ABA therapy may accelerate the acquisition of language by children with autism. Unfortunately, ABA therapy may be cost-prohibitive to families even with insurance or Medicaid coverage, and there may be other barriers for families as well including the location or accessibility of services in conjunction with a family's access to reliable transportation (Antill, 2020).

Despite the proliferation of research studies touting the benefits and effectiveness of ABA for individuals with autism, strong criticism can be found in the neurodiversity community and expressed by autism activists against the basic principles of ABA. Autistic self-advocate, Amy Sequenzia (2015) claims the goal of parents who place their children with autism in ABA services “force their children into molds that were not made for them,” accusing those parents and the ABA service providers of “stealing the childhood” of these children on the spectrum by complying with the industry-wide recommendation for 30 or more hours of ABA services per week for maximum effectiveness (n. p.). Many opponents of ABA claim that its interventions are only successful in teaching individuals with autism to “mask” their essential autistic nature in order to fit in with societal norms and expectations (Leaf et al, 2022). Masking is a concept introduced by Ekman (1972) in reference to the Japanese cultural practice of hiding emotions in facial expressions. Masking applies to members of the autism community much in the same way as people of color “passing” as

white throughout the history of the United States, foregoing their identity for enhanced access and opportunity (Hobbs, 2016). Masking is often “driven by stigma avoidance” as individuals with autism suppress their sensory differences or engage in social mimicry to fit into their environment (Miller et al., 2021, n. p.).

Some critics of ABA argue that it has the potential to teach children with autism that “there is something wrong with who they are, teaching them how to blend in rather than exercise their own unique capacities” (Wilkenfeld & McCarthy, 2020, p. 33). Behavior modification reinforces the normative ideal by correcting those behaviors that cause an individual to be abnormal and deficient. Expressing ethical concerns with ABA as a “treatment” for autism, Wilkenfeld and McCarthy (2020) find fault with ABA’s emphasis on “behavioral modification in lieu of more holistic, humanistic, or cognitive interventions” (p. 37). The behavior to be fixed supersedes the mental development, autonomy, and identity formation of the child with autism. The child with autism is objectified as an entity to be studied, managed, and improved. Continuing the critique, the methods used in ABA interventions are problematized by Wilkenfeld and McCarthy (2020) who argue that those practices act in a way that “overrides the child’s natural inclinations *and* does so via at least moderately coercive methods” (p. 37, emphasis in original). Attempts at assimilation may repress or diminish the child’s unique perspectives and abilities.

When we first enrolled my son in Barnfield, I had some major reservations about ABA therapy. We had been advised by the diagnostic evaluation team that ABA had been “found to be successful for *decreasing aberrant behavior* or *increasing prosocial behavior* for autistics/individuals diagnosed with ASD” (Leaf et al., 2022, p. 2840, emphasis added). All the talk about antecedents, consequences, and reinforcers felt like the production of

Foucault's *docile bodies*, the concept of power relations through which individuals take up subjectivities that make them more manageable and malleable according to the interests of the state. Danforth (2000) argues that systems of reward and punishment like that of ABA therapy "unite rituals of power/knowledge with specific techniques of social control to suppress and subjugate individuals" (p. 364). I worried that we were surveilling and shaping my son's behavior to bring it under control, setting him up to become a docile body. The principles of ABA seemed to go against much of my personal philosophy as an educator as well, but what my husband and I witnessed in touring the school and clinic facilities seemed much more personal and respectful of the individual than I expected. I took up a subjectivity of skeptical compliance since he would only receive one hour of ABA therapy per day within the structure of his four-hour long preschool class. We would give it a try, but I was determined to stay in constant contact with his teachers and ABA team about his goals, their methods, and his progress in case I needed to change to a subjectivity of resistance. After all, our field of possible actions was limited since his previous church preschool and recommended public school system placement opportunities would not meet his needs appropriately.

An Alternative IEP Structure

Although not subject to the same legal requirements as public schools regarding IEP development and documentation, Barnfield follows a similar sequential process. Enrollment substitutes for the initial referral or request for evaluation in the public school system and is followed by a series of evaluations that are used to determine goals and a treatment plan for services. These goals are reviewed periodically in a parent-teacher-service provider conference and adjusted as needed based on the progress monitoring data. I outline this

process for Barnfield before I compare it to that of the state-mandated IEP process that we encountered through our local public school system. The analysis that I offer will reveal the interplay among power, knowledge, and subjectivity within the Barnfield process as more collaborative and less normalizing than that of the state-mandated IEP process. In doing so, I will point out ways in which the Barnfield framework could be applied to the public school system's processes to pave the way for transformative change. I will also reveal the ways in which the Barnfield process moves toward a discourse of affirmative difference – rather than one of disability.

Evaluation

To design classroom and ABA therapy services for my son, the team at Barnfield reviewed his diagnostic paperwork and our enrollment information packet. Parent and teacher interviews were conducted after the first two weeks of instruction and services at Barnfield that had been adapted from the *Pictorial Infant Communication Scale* (Delgado et al., 2003) to rate the frequency of early communicative behaviors such as eye gaze, pointing, reaching, seeking help, and showing or giving objects (Barnfield communication). These behaviors comprise the social communication and developmental milestone of joint attention which can be a challenge for children with autism, and the *Pictorial Infant Communication Scale* has been validated as a tool for measuring joint attention in children with autism (Ghilain et al., 2017). Results were communicated on separate pages for parent and teacher scores showing a frequency rating for each of sixteen behaviors as “never, sometimes, or frequently” (Barnfield communication). There were no percentiles, rankings, or classifications in relation to normal behaviors. Interestingly, my husband and I rated my son much lower than the teachers in almost every category. Upon reflection, we realized that our

perceptions had been shaped by the dominant discourse of deficit regarding people with autism. We had taken up a subjectivity of compliance, conforming to a discourse of what is lacking while the teachers had been trained to look for what is demonstrated. This was a first signal to us that the discourse at Barnfield was different. The teachers were looking at my son's unique strengths. They were noticing what he could do instead of marking him down for what he could not do.

Natural Environment Play Assessment

Another measure used to establish a baseline for my son's behaviors and skills was a natural environment play assessment that Barnfield had adapted from the *Structured Play Assessment* (Ungerer & Sigman, 1981). Symbolic play has been related to language development (Kelly & Dale 1989; Laakso et al., 1999; McCune-Nicolich 1981; Sigman et al., 1999; Stone et al. 1990). Eisert and Lamorey (1996) report developmental level as a stronger predictor of play level than chronological age. Leslie (1987) identifies three forms of symbolic play: object substitution, the attribution of false properties, and the attribution of presence to imaginary objects. Functional play is defined as "the appropriate use of an object or the conventional association of two or more objects, such as a spoon to feed a doll, or placing a teacup on a saucer" (Ungerer & Sigman, 1981, p. 320). Children with autism may experience problems with functional play, in addition to their well-documented deficits in symbolic play (Williams et al., 2001).

Barnfield's adaptation of Ungerer and Sigman's (1981) *Structured Play Assessment* divides play skills into four different levels of increasing complexity: exploratory, relational, functional, and symbolic. Exploratory play is not defined beyond involving "indiscriminate actions" (Barnfield communication). Components of relational play include taking an object

apart, presentation and general combination of objects, and physical and conventional attributes of objects (Barnfield communication). Functional play is characterized as object-directed, self-directed, other-directed, doll-directed, or as a single scheme sequence (Barnfield communication). In symbolic play, the child uses a doll as an agent or engages in substitution, imaginary play, sequential play, sociodramatic play, or thematic/fantasy play (Barnfield communication). On the evaluation results, each play component is marked as being “absent, emerging, or mastered” (Barnfield communication). These results focused on my son’s present level of development rather than in a comparison to chronological peers. The inclusion of the label “emerging” indicated a sense of *becoming*, that these skills were attainable and part of a learning journey instead of a snapshot of what was performed on the day of evaluation. Because the labels were more of a progression of development than a fixed statement about ability, a skill being labeled as “absent” was considered to be a starting point rather than a description of my son as a human and his potential for the future.

Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP)

Finally, the Barnfield team administered the *Verbal Behavior Milestones Assessment and Placement Program*, or VB-MAPP (Sundberg, 2014) in the first two weeks of his enrollment to determine baseline information about his performance of verbal behaviors and to establish a way to track his progress in acquiring verbal behavior skills over time.

Sundberg (2020) describes the VB-MAPP as “a criterion-referenced assessment tool, curriculum guide, and skill tracking system that is designed for children with autism, and other individuals who demonstrate language delays” based on the work of Skinner, established developmental milestones, and existing research in the field of behavior analysis. According to Sundberg (2020), the VB-MAPP consists of “170 measurable learning and

language milestones that are sequenced and balanced across 3 developmental levels (0-18 months, 18-30 months, and 30-48 months).” Milestones range from “visually attends to faces and people 5 times” at Level 1 to “sits in a small group for 5 minutes without disruptive behavior or attempting to leave the group” at Level 3 (Sundberg, 2014). The VB-MAPP assesses skills in the following areas: mand, tact, echoic, intraverbal, listener, motor imitation, independent play, social and social play, visual perceptual and matching-to-sample, linguistic structure, group and classroom skills, and early academics (Sundberg, 2014).

Results from the administration of the VB-MAPP assessment “serve as a guide for the development of an effective individualized language, social skills and learning curriculum” (Sundberg, 2020). This assessment was always administered during his school day, so I was not present and cannot reflect directly on the evaluation experience.

Communication of the results noted the specific verbal behaviors my son already possessed and the next set of discrete skills in each area to be obtained through applied behavior analysis curriculum and services programming. Barnfield provided a bar chart for each verbal operant with boxes colored in for each skill my son demonstrated within the framework of that particular administration. Skills yet to be attained were left white, allowing for a clear visual representation of his ability to demonstrate different verbal behaviors. In subsequent administrations, his progress was tracked over time by coloring in the boxes for new skills attained with a different color for each time he was assessed. Again, the focus remained on his specific skills and not a statistical average or comparison to normal development.

The VB-MAPP is used by thousands of individuals worldwide to make decisions and develop treatment plans for children within their practice of behavior analysis (Padilla & Akers, 2020). Due to its sequential nature across the three developmental levels, the VB-MAPP “implies detailed assessment of a child’s skills, thorough selection of goals, planning of the learning process and monitoring the development of a child’s skills” (Nigmatullina & Nigmatullina, 2020, p. 1058). The multi-stage diagnostic technique of the VB-MAPP yields a functional assessment of speech skills of individuals without replicating a “topography of disorders” (Gryaznova & Vasina, 2020, n. p.). Gryaznova and Vasina (2020) also laud the broader goal of functional assessment that aids in the development of verbal behaviors as having the capacity to help children attain a better quality of life through improved communication skills. Such capacity reproduces a power relation within the discourse of disability that the professionals are “judiciously dispensing their expertise in the best interests of these individuals who need only to respond in the correct way to improve on themselves and attain a better quality of life” (McKenzie, 2009, p. 48). Barnfield does work toward the assimilation of the child with autism into normative society, but such assimilation is not treated as the only prerequisite for a well-lived life. At Barnfield, “quality of life” is viewed through the lens of the family’s values and the community settings in which the child lives. Assimilation is about learning skills to navigate the child’s world as opposed to living out a more normative existence.

One complication with Barnfield’s use of the VB-MAPP is the fact that “the reliability of the VB-MAPP has not been reported” (Montallana et al., 2019, p. 2016). In fact, a major limitation of the VB-MAPP according to current literature in the field of behavior analysis is that, although it is used widely, “its psychometric properties are not well

established” (Carlson et al. 2017). A study conducting an external factor analysis failed to show the independence of the verbal operant categories using the assessment items contained in the VB-MAPP (Belisle et al., 2021). Instead, Belisle et al. (2021) found that

As a learner’s performance on assessments such as the VB-MAPP improves, it may be the case that targeting single operants is less efficient than targeting multiple operants in order to build verbal complexity—as complexity appears to be the most consistent determinant of factor structure within now multiple assessments of verbal operant development. (n. p.)

Subject matter experts have called for greater availability of normative data to use alongside the VB-MAPP as a criterion for comparing children with autism to neurotypical children (Padilla & Akers, 2020). The lack of normative data available to use as a companion to the VB-MAPP is reminiscent of the limitations of the CDC’s developmental milestones discussed in the Path to Diagnosis section of this dissertation. Additional research is needed to determine if “the psychometric properties of the VB-MAPP make it an appropriate instrument for selecting goals for students with ASD and for evaluating the effects of interventions intended to attain those goals” (Montallana et al., 2019, p. 2022). Although given Barnfield’s application of the VB-MAPP to each individual child without normative comparisons, the lack of normative data is not as problematic.

Barnfield’s administration of the VB-MAPP yielded a comprehensive picture of the skills and language that my son possessed. It provided us with a starting point for his instruction and outlined reasonable next steps across multiple areas. Barnfield provided a visual representation of the results that were easy to understand and devoid of comparisons to any other child or to a statistical average for children his age. The conversation was about

where he was and what he was *becoming*, not about his deficiencies. There was also little quantification as the skills were either present or absent, which privileges mastery over measurement. Barnfield's focus was on the skills they could support my son in developing next, not on catching him up to some normative ideal.

The Assessment of Basic Language and Learning Skills-Revised (ABLLS-R)

For the first two years of his enrollment in Barnfield, my son's attainment of new skills on the VB-MAPP provided the basis for our IEP meetings, which will be discussed below. Once my son had shown mastery in the skills measured by the VB-MAPP, Barnfield switched to tracking his progress using the *Assessment of Basic Language and Learning Skills-Revised*, or ABLLS-R (Partington, 2010). The ABLLS-R is designed to provide a "comprehensive review of 544 skills from 25 skill areas including language, social interaction, self-help, academic and motor skills that *most typically developing children acquire prior to entering kindergarten*" (Partington, 2022, n. p., emphasis added). Within each skill area, tasks are arranged by increasing complexity (Partington, 2022) and each task is scored on either a three-point scale (0, 1, or 2) or a five-point scale (0 to 4) (Partington, 2010). For example, one of the receptive language tasks records if a child can "demonstrate a specified pretend action" such as crying or yawning upon the request of the assessor (Partington, 2010). To receive a score of 2, the child must demonstrate five such pretend actions without prompts while a score of 1 indicates can demonstrate at least two such pretend actions with only verbal or pointing prompts (Partington, 2010). A score of 0 is used when a skill is not yet demonstrated by the child.

As with the VB-MAPP, the ABLLS-R draws upon the work of Skinner in addressing language skills and behavior reinforcement (Partington, 2022). The ABLLS-R serves as "an

assessment tool, curriculum guide, and skills-tracking system used to help guide the instruction of language and critical learner skills for children with autism or other developmental disabilities” (Partington, 2022). Primarily, the ABLLS-R assesses *strengths and shortcomings of the curriculum* with the goal of adjusting and personalizing that curriculum to better meet the needs of the child (Goin-Kochel et al., 2007). Unlike other assessments presented throughout this dissertation, the ABLLS-R sets up a binary opposition for the *curriculum* as being effective/ineffective rather than the *child* as being normal/abnormal. Standardized evaluations reproduce the belief that “within the ambit of one number a child can be graded and normalized with respect to other children” (McKenzie, 2009, p. 88). The ABLLS-R notices what the child is doing and what the child is *becoming*, given effective instruction and the right environment. Mastery of a skill in an individual child may be marked as present or absent, but the responsibility shifts to the school or service provider to adjust the instruction and/or environment to better facilitate the development of that skill for that child. Rather than presenting a list of the child’s deficits in comparison to normal children as the fault or inherent lack of the child, which would produce subjectivities of either docile compliance or resistance on the part of the parents, presenting the strengths and shortcomings of the curriculum sets the stage for creative and collaborative problem solving between parents and the IEP team. It opens up possibilities for conversation that are closed when the IEP process centers around the child’s intrinsic deficiencies. Parents can take up a subjectivity of engaged participation.

IEP Communication and Documentation

Based on all available information about the child, including the assessments detailed above, the School team develops suggested goals to be incorporated into the child’s IEP

document. Our initial IEP meeting was held at Barnfield with the program supervisor and one of my son's teachers. The power relations already felt more intimate and conversational because there were two representatives from Barnfield who worked closely with my son daily and me at a round table. It was the opposite of my experience of walking into a room of strangers, some of whom had never even seen my son, and feeling outnumbered. Removing the fight or flight feeling from the physical environment and attendance of the meeting also worked to remove the compliance/resistance binary opposition that I encountered in the discourse of special education within public school IEP meetings. I was able to take up a subjectivity of engaged participation through less intimidating conversations.

The Barnfield team presented the results from the parent and teacher interviews, the play-based assessment, and the VB-MAPP, all with the focus on what my son was already able to do. There was no comparison to other children or to a statistical average. There was no discussion of what was normal or abnormal. The team suggested goals in relation to the next skills in each area of the VB-MAPP, but they also asked for our input on how meaningful the suggested goals were in relation to our family's values and my son's specific abilities and interests. Adjustments were made to prioritize what would be most beneficial for my son in our family's context. We brainstormed together some favorite activities and characters that could serve as motivation and reward for attaining those goals. The Barnfield team asked about any additional goals that we would like to see included based on our observed needs in the home and in community settings. I was relieved to add a goal about expressing frustration more productively, since my son had started to become physically aggressive when he was unable to communicate his wants and needs. Overall, my husband and I felt supported and welcomed to take up a subjectivity of engaged participation rather

than being limited to a state of compliance or resistance. We didn't walk away with the feeling that our son or our family was deficient and in need of correction.

On the IEP document, each short-term goal was listed with a description of the desired behavior, along with its corresponding code on the VB-MAPP or ABLLS-R (Barnfield IEP documentation). It is important to note that, other than sharing an assessment results graph immediately after its administration, this code was the only mention of formal assessments or results in subsequent IEP meetings. This made the IEP meeting more about my son and less about data from a standardized evaluation. For example, one of my son's goals was "SM 25 Modified: [My son's name] will ask for reasonable modifications or assistance in his environment verbally or with a visual" (Barnfield IEP documentation). Next, there was a baseline statement that described my son's current level of demonstrated skill in that area. If it was an entirely new skill, the baseline statement would say, "Not demonstrated at this time" (Barnfield IEP documentation). Again, this was not in comparison to other children or to a statistical norm. It was simply a starting point. Another statement detailed what mastery for that skill would look like, including the percentage of successful attempts or number of times the skill would be observed within a certain period of time (Barnfield IEP documentation). Goal status was listed as either "met" or "in progress;" if in progress, an anticipated mastery date was indicated, along with percent completion at the date of the progress report or IEP update (Barnfield IEP documentation). The document indicated who was responsible for implementing the goal, including classroom teachers, behavioral specialists, parents (with training), or other Barnfield personnel (Barnfield IEP documentation). By being included in the work on the goals with equal status to the Barnfield personnel, a power relation was created that given us space to take up a subjectivity of

engaged participation. Finally, progress on each goal was shared visually through a line graph that depicted change over time (Barnfield IEP documentation). The visual representation supported the language of the goal, making it more understandable for us. We had access to knowledge that allowed us to be informed participants in the conversation and prompted new questions when we did not understand a goal.

Officially, the Barnfield IEP is created once per calendar year with goals in skills areas like communication, social behavior and play, group instruction, academic areas (reading, writing, and math), and adaptive skills like toileting (Barnfield IEP documentation). Most IEP goals are short-term, meaning they would likely be mastered, amended, or rejected before the next official annual meeting. Barnfield met with our family quarterly to share progress updates, reassess the appropriateness of the IEP goals, and to add new goals based on Barnfield team observations and our input. These progress updates privileged knowledge about my son beyond just the VB-MAPP or ABLLS-R data. They were about sharing things my son enjoyed at school, funny and encouraging stories of progress at home, and new challenges that we and/or my son might be facing. Two of these quarterly meetings were held in our family's home, which allowed the Barnfield team to better understand our family's values and daily living to better support our family in generalizing skills mastered in the school environment to the home setting. One of Barnfield's main purposes was to enable our son to thrive in multiple settings, to be able to communicate and use his new skills at school, home, and in the community. This purpose communicated a focus on overall well-being rather than on measurable progress on standardized evaluations and mastering curriculum. Rather than reproducing the dominant discourse of shaping a child with disabilities into a

productive and useful citizen, Barnfield privileged the potential for the child with autism to live happily and engage with their environment.

Beyond the review of official goal documentation, the IEP meetings allowed space for sharing anecdotal data about my son's progress and experiences, both at home and at school. Teachers and behavior analysts shared videos of my son engaging in work on the goals and enjoying different activities within the classroom. They bragged about him and told funny stories about his interactions with them and with his peers. We did the same for what we were experiencing with my son at home. We were encouraged to ask questions and to partner with the Barnfield team in thinking about ways to help our child progress in the desired skills areas across different settings. If there was disagreement about goals or further discussion was needed to ensure mutual understanding, another meeting would be scheduled. We were also encouraged to contact the team for support via a meeting or phone call if we encountered challenging behavior that we were struggling to manage at home or in the community. If the Barnfield team and our family were in agreement and were ready to move forward, the Barnfield team would make revisions to the IEP document based on the content of the meeting and our input before sending it to us for a signature. There was no pressure to sign the IEP as written, and the expectation was that the process would be iterative instead of completed in one sitting for the entire year. As parents, we were not presented with a formal and binding annual agreement with which we had to choose to comply or resist.

Comparing the Barnfield IEP Process to Traditional IEPs

In many ways, Barnfield's IEP process parallels the structure of the IEP process in public schools: referral followed by evaluation, the creation of an IEP document with goals, and the annual revisiting of that document to review progress and make adjustments for

another year. As with public schools, Barnfield provides quarterly progress reports on IEP goals, although Barnfield does this in conjunction with in-person or virtual meetings rather than a written report sent home with the student's report card. Both structures require parental input and consent. In both systems, goals reference observable and measurable behaviors, and mastery is determined by a quantity of success over time. Most importantly, both processes involve groups of special education professionals who are working alongside parents to determine and support the needs of the child.

There are some critical differences between the two processes, however, that directly impact the ways in which they shape parents' subjectivity. In the state-mandated IEP process, assessment results feature heavily in both the eligibility determination meeting and in the Present Levels of Academic and Functional Performance section of the IEP document. These assessments reproduce the dominant discourse of disability that sees the child with disabilities as deficient and in need of correction to attain a normative ideal. They privilege quantitative, standardized measures of specific and observable skills, demonstrated in a "normal" and highly verbal manner. In the traditional public school IEP process, scores are reported in relation to a mean or as a percentile rank comparing the child in question to the general population of their same-age peers. The child's performance on the assessment is also given a hierarchical classification like "extremely low" or "below average." Such labels reproduce the normal/abnormal binary opposition, locate the fault for abnormality within inherent deficits of the child with disabilities, and limit the possible actions of parents to subjectivities of either docile compliance or resistance.

In Barnfield's IEP process, assessments are conducted to determine a baseline level of skill demonstration and results are shared with parents, but those results do not usually

reappear in the discussion during IEP creation or progress meetings. Barnfield reports assessment results in a non-normative way by silencing discussion of statistical norms and privileging a focus on the unique strengths of the child. Behaviors are expressed in terms of frequency using “never, sometimes, frequently” while skills are described as “absent” or “mastered,” sometimes with an intermediate category of “emerging.” There are no comparisons to other children or “typical” age-related performance, which effectively removes the normal/abnormal binary opposition from the discourse. By focusing on *that one child*, both how the child is now and what the child is *becoming*, the conversation opens up to one of learning and potential – not for future productivity but rather for enrichment of opportunities. Parents are able to take up a subjectivity of engaged participation as equal partners in the conversation who bring valuable insight about their family’s values, their community, and their child’s progress in other settings. The binary opposition of compliance/resistance regarding a highly-regulated and impersonal process is not produced in this discourse of *becoming*.

Another way that the School’s process removes the assumption of deficiency regarding a child with autism is through the strengths-based method of setting IEP goals. Goals are chosen based on the child’s readiness and interests, along with parent input. They focus on what the child can do and what they have not done *yet*, suggesting the next step for the child in a particular skills area. Instead of trying to catch the child up to grade level, the conversation is about what comes next. There is a space for *becoming* instead of a cavernous gap between the child with autism and the norm that emphasizes what is lacking. Barnfield uses the skills sequence in the VB-MAPP or ABLLS-R as a guide for suggesting goals, but there is no pressure to perform those skills in a specific way or according to a standardized

testing measure. The focus is on growth and mastery over measurement. Leaving a space for *becoming* embraces neurodiversity and opens the door to a discourse of difference.

Special education teachers within the public school system are restricted by the fill-in-the-blank programming of the ECATS or other state-mandated tracking systems, as well as by the requirement that they prepare their students for performance on standardized tests. Free of such constraints, Barnfield's IEP process can be more fluid and organic. As a parent, I experienced Barnfield's IEP meetings as more of a conversation and less like completing a checklist than those meetings within the public school system's IEP process. Public schools are also constrained by the educational system itself, which is designed for the average learner and to produce useful and functioning citizens in the future. As such, special education professionals must provide substantial modifications and accommodations for children with autism to be able to participate in either the general education or special education classroom.

Accommodations are not discussed in Barnfield's IEP documentation because the teaching and learning environment was created and continues to evolve according to the needs of children with autism. The taken-for-granted assumption in the Barnfield model is that the curriculum is either effective or ineffective in supporting the growth of each child, not that the child is failing to adapt and be successful in the school environment. At Barnfield, schedules and materials are designed specifically for each child, a move toward embracing difference. The child is not abnormal, deficient, or failing. Instead, the child is working toward new skills, in the process of *becoming*. It is the responsibility of the Barnfield team to adapt their environment and practice to meet the unique needs of that child and to find fulfillment in the level of skill attainment that is appropriate for that one

individual rather than comparing progress across different students. Strengths, growth, and mastery are privileged at Barnfield while deficits, statistical gaps, and measurement are privileged in the public school IEP process. Such knowledge and power relations allow children to be more than data and accountability measures at Barnfield.

(Im)possibilities in Barnfield's IEP Process

Barnfield offers a unique educational environment designed specifically for children with autism and based on the principles of applied behavior analysis. Schedules, materials, and the environment itself can be tailored to the needs of the individual student's interests, needs, and goals in a way that is unlikely to be replicated in the public school classroom. Yet, my analysis must return to the research question: How do the processes that are used in the dissemination of information and intervention reveal (im)possibilities for people with autism and their parents and families?

Breaking down the normative/abnormal binary opposition that is so dominant within the discourse of disability through the refusal to include comparisons to other children or normative standards in assessments results reports or other communication measures is one way Barnfield opens up possibilities for children with autism. Tremain (2017) reminds us that discourse determines "what is said, how it is said, the social contexts in which statements are made, why they are made, whose communications are given authoritative status, and the historical conditions of possibility for topics to emerge" (p. 48). Barnfield's discourse of *becoming* allows for different statements to be made and "given authoritative status" than those within the special education discourse of the traditional IEP process. Incorporating anecdotal information and parental input about family values and priorities in setting goals for the child is another step toward individuation and possibility. More frequent meetings

with parents, especially those that can be conducted in the family's home, allow for new topics to emerge than within formal school-based meetings. Shifting the physical location of the meeting to a more familiar environment for the family also works to elevate the authoritative status of parental input by removing "certain forms of unequal social power" that are often present when a parent enters a less familiar school setting to meet with an entire team of school personnel and experts (Tremain, 2017, p. 40).

For all of its efforts at personalization and honoring parents and families, Barnfield may still limit possibilities for children with autism through its reliance on ABA. Barnfield's IEP process and educational programming reproduces the "need to develop individual correctional and educational programs for each child that would improve their socialization, increase the level of social adaptation, development and effective learning" (Nigmatullina & Nigmatullina, 2020, p. 1058). The child (and their behaviors) must be corrected through behavioral intervention to function successfully in society and to learn. Skills that will enable the child to produce more language (verbal and nonverbal), interact more with peers and adults, and complete more self-care tasks independently are the focus. This "work" is done for several hours each day, to the exclusion of more organic exploration by the child. Little room is left for balancing beauty with behavioral interventions. As noted above, Wilkenfeld and McCarthy (2020) criticize such ABA programs for their lack of "holistic, humanistic, or cognitive interventions" (p. 37). Children at Barnfield play on the playground and splash pad, but they spend very little time exploring nature, creating art, or listening to music outside of educational songs and videos.

Stimming

One specific set of behaviors with which Barnfield can either open or restrict possibilities for children with autism is in the area of *stimming*. Stimming is the term adopted by the neurodiversity community (Nolan & McBride, 2015) to describe self-stimulatory behaviors like hand flapping or rocking that are named as “stereotyped or repetitive motor movements” in the diagnostic criteria for ASD (American Psychiatric Association, 2013). Stim behaviors are often the target of behavioral modification through ABA because they are an obvious physical display of different, *abnormal* behavior. Occasionally there is a danger of a child with autism being injured by a stim behavior, but mostly the behavior is corrected because a neurotypical adult worries about that child being bullied or isolated. Masiran (2018) expresses concerns that stim behaviors “can undeniably be a source of distraction and fear to others” (p. 2). Repression of stim behaviors is one of the most common manifestations of masking in the autism community (Miller et al., 2021).

There are benefits to stim behaviors as well. Bakan (2015) argues that stimming could be “embraced as productive, communicative, pleasurable and even socially valuable for those who perform them—as manifestations of difference, not symptoms of deficit” (n. p.). Autistic adults have cited stimming as a helpful way to “soothe or communicate intense emotions or thoughts,” and have denounced treatments that work to decrease stim behaviors (Kapp et al., 2019, p. 1782). Additionally, stimming “can play an important role in empathic communicative exchanges between autistic persons and neurotypicals” (van Grunsven & Roeser, 2021, p. 95).

Given that most of the students at Barnfield are nonverbal or have limited verbal communication, and in keeping with their emphasis on honoring family values, the decision

to decrease stim behaviors through interventions or to allow those behaviors to be expressed by the child lies almost completely with the parents. Considering that many parents are not autism experts and that some may find their child's stimming to be concerning, they may choose to decrease or eliminate stim behaviors. As a result, ABA provided by Barnfield may work to limit possibilities for what bodily statements can be made by children with autism both now and in adulthood. Some autism self-advocates, including Amanda Baggs (2007), describe stimming as their "native language" and as their way of cognitively processing the world. One autistic adult shared that "emphasis on certain ways of coming to cognition has depleted her experience of autistic perception" (Manning, 2016, p. 148). There is an apparent tradeoff that requires the loss of a certain type of autistic neurological processing along with the repression of stim behaviors. By considering parental preference and family values, Barnfield enables parents to revert to the dominant discourse of disability, whereby their child and his or her *abnormal* behaviors must be corrected to avoid negative social stigma. The decision to decrease or eliminate stim behaviors returns to Foucault's (1995/1975) concept of *docile bodies* that are more manageable and malleable. Such bodies are more easily controlled and are more able to "mask" within social situations. They have been shaped to assimilate into normative expectations for human functioning. Removing stim behaviors may remove coping mechanisms that allow the child with autism to engage with the neurotypical world, or it could alter something unique, different, and full of possibility for that individual. Leaving the choice about addressing stim behaviors up to parents creates a power relation that privileges family knowledge, but is a departure from the discourses of *becoming* and affirmative difference that is present everywhere else at Barnfield.

Conclusion

During the writing of this dissertation, I had laryngitis for five consecutive days. Unable to make even a whisper, I relied on gesturing, writing thoughts on paper, and other people's ability to read lips to communicate, sometimes with extreme frustration. That experience caused me to reflect on how challenging life can be for a nonverbal individual who also may not possess the fine motor skills to point, gesture, or write. I recalled what my son was like when he enrolled in Barnfield. He had a vocabulary of about 25 words, most of which were not very functional like "stick," and his main method of communication was physically pulling an adult to something he wanted. I tried to be attuned to his interests and needs, but it was often a guessing game. When my guess was wrong, he would become frustrated and sometimes aggressive. In shaping his behavior through ABA at Barnfield, our family's main goals were that he not hurt himself or others, that he could self-advocate for help, and that he could express his wants, needs, and emotions.

After three years of intervention at Barnfield, my son talks constantly. He sings. He reads aloud. He expresses opinions and asks for help. He can tell us when something hurts. He can engage in social and verbal activities with us. He makes eye contact and responds to his name. He notices other children and often tries to engage in their play. He mimics favorite characters, commercials, and the way family members laugh or sneeze exactly. He can say, "I love you." Based on this progress, he is ready to transition to a more traditional school environment, one that is not specifically designed for children with autism. Although I celebrate his new skills and the possibilities they open for his future, part of me has to wonder what parts of him we have lost forever by shaping his behavior through ABA, by helping him to assimilate successfully into *normal* social relationships. I also wonder how

accepting and encouraging his new school will be of his unique set of strengths, challenges, and behaviors, as well as what subject positions my husband and I will be able to take up within a new discourse of learning and disability.

INTERLUDE TWO: KNOWLEDGE, LEARNING, AND AUTISTIC PERCEPTION

Across the previous chapters, my analysis has shown how the normal/abnormal binary opposition is reproduced within and across governmental and educational discourses regarding students with disabilities. Special education law and evaluation processes create hierarchical categorizations that label how far a student deviates from the norm. The IEP process continues efforts at surveillance, counting, and control while solidifying knowledge as something that can be measured and observed. ABA therapy seeks to shape the child's behavior toward normative social and verbal interactions. In each of these discourses, parents take up a subjectivity of compliance or resistance as they make decisions about their child's education. The system is established. It is up to the parents (and the IEP team) to determine how – and if – the child with autism can function within the system.

In this interlude, I will return to the concepts of immanence, difference, and possibility, particularly in regard to the educational discourse. Mirroring the question, “What counts as a life?” in the previous interlude, I begin my analysis by questioning what counts as knowledge and learning within current educational thought. I review how the dominant conceptions of knowledge and learning are limited and reproductive of neurotypicality before offering a more expansive view of knowledge and learning. I contrast neurotypical parsing of the environment with Manning's (2016) concept of *autistic perception* before thinking autistic perception with immanence to reveal possible implications for doing education differently.

What counts as knowledge and learning?

Federal and state legislation, along with the educational research landscape, set parameters around knowledge and learning, prioritizing accountability measures over a

broader range of experiences. Thus, education in the United States, as a whole, reproduces a discourse of normativity and taken-for-granted assumptions about what counts as knowledge and learning.

Knowledge

This normative approach derives from a neurotypical mindset, one that limits educational encounters, not only for learners on the autism spectrum, but for all learners. Manning (2016) explains that

Neurotypicality involves a hierarchization of knowledge . . . and segregates knowledge according to accepted ideas of what serves society best. Most accepted approaches to learning assume neurotypicality with regard to processing information, thereby segregating not only neurodiverse learners, but also predestining what counts as knowledge. (p. 9)

My analysis across previous chapters demonstrated the intense focus of special education on producing independence and useful citizens that will “serve society best.” The hierarchization of knowledge is evident through evaluation procedures that only acknowledge and reward a specific type of response. Recall that my son scored lower on one of the evaluation instruments because he wanted to label the bugs instead of identifying the matching bugs quickly. Neurotypicality is assumed in how knowledge is disseminated in the classroom, and students who are eligible for special education services are given documented accommodations to help them participate in their educational setting, rather than reshaping the setting to accommodate neurodiversity.

Content standards establish knowledge as certain observable “facts” or skills that a student must learn to have attained grade-level mastery. In the same way, the verbal

behaviors across levels of the VB-MAPPS and ABA therapy are concrete and sequential, mapping out desired actions and language to be shaped in a child during interventions. In both approaches, knowledge is narrowed to what is useful and appropriate in normative relations. Educational discourse assumes that knowledge is static and can be clearly defined. This assumption silences other types of knowledge. “The problem is that in this activity of assuming in advance that we know what constitutes knowledge, there is a danger of not hearing the voices that . . . lurk beneath the words” (Manning, 2016, p. 31). Neurotypicality privileges knowledge that can be quantified and expressed using language. In doing so, it backgrounds experiential knowledge, sensory knowledge, knowledge that can only be thought-felt.

Manning (2016) calls for a broader vision of knowledge that incorporates the fuller expanse of human experience. This view of knowledge “defies existing understandings of where knowledge is situated and what it can do” (p. 41-42). Viewed through a lens of immanence, knowledge cannot be captured. Rather, it is emergent and full of possibility. According to Patel (2016), “we must also learn to regard all knowledge as incomplete, partial, contextually created, and perspectival” (p. 79). Instead of seeing knowledge as something that we can obtain and possess—something we can measure and replicate, “knowledge should be seen as an entity, specific, mutable, and impermanent itself” (Patel, 2016, p. 79). Knowledge changes. It contracts and expands. It flows within and across discourse. Knowledge is *in relation*.

Learning

In the same way that educational discourse privileges knowledge that can be named and contained, learning takes place within a restricting environment. As Manning (2016) notes

Most of our education systems are based on starting from stillness. We learn in chairs. We associate concentration with being quiet. We discourage the movement of thought we call daydreaming, particularly in the context of “learning.” We are told not to fidget. Reason is aligned with keeping the body still. (p. 122)

This stillness is not natural. It must be explicitly taught to all children upon entering the school setting, neurotypical and neurodiverse learners alike. In setting up procedures that facilitate the stuffing of “knowledge” into young minds, much of the beauty and movement of childhood and human relation in the world is sacrificed. Critique and learning are often “framed and deadened through the crafting of questions that already have answers, or whose answers are close at hand, contained within preexisting academic discourse” (Manning, 2016, p. 9). Learning the right answers is a hollow version of engaging with others and the world. It limits creativity and possibility.

Manning (2016) poses the question, “What else could learning (and listening and attending) become?” (p. 122). Instead of the rigid structures of the current educational discourse, learning could be opened up beyond normative constraints. Schooling could be “hospitable to learning, to thinking, and to the collaborative gesture that feeds both . . . making it possible for us to engender a culture of affirmation” (p. 196). What if learning were opened up to exploration and experience rather than privileging factual knowledge and right answers? In a “culture of affirmation, possibility and rightness are not predetermined. They

unfold alongside the learning. Since there is no preview of what the learning can do, it neither predicts nor (de)values it in advance of its coming to be” (Manning, 2016, p. 201).

How different could learning be if allowed to unfold into its own *doing* and *becoming*?

Despite the desires of accountability measures, special education processes, and ABA therapy interventions, learning is not sequential, nor does it always proceed along the same path. Patel (2016) points out that “learning is fundamentally about transformation. It is coming into being and constantly altering that being; it is a subjective and often messy act” (p. 76). Learning is transactional and relational. It is collaborative and yet deeply personal, continually operating within the flows of the discourse. As Ellsworth (2004) describes it,

Learning never takes place in the absence of bodies, emotions, place, time, sound, image, self-experience, history. It always detours through memory, forgetting, desire, fear, pleasure, surprise, rewriting. And because learning takes place in relation, its detours take us up to and sometimes across the boundaries of habit, recognition, and the socially constructed identities within ourselves. (p. 55)

When freed from its constraints, learning shapes who we are and expands beyond what we can be. Learning becomes a process, constantly evolving, and not a product for demonstration.

Autistic Perception and Immanence

Children with autism are often perceived as being withdrawn and incapable of engaging in social play or relationships, accused of living in their own world as opposed to the neurotypical world (Manning, 2013). ABA therapy and special education services strive to bring children with autism into normative socialization and language through

interventions. Yet, the child's refusal to engage is not an absence or deficiency. Ogilvie (2015) explains:

Autistic children whose enigmatic agitation creates ripples and underlines their "invasive absence": absence from "themselves," absence from the collective project, and absence from normalized human life in general . . . on the contrary, it is not absence that is underlined but a presence, powerful, solitary, yet territorialized in the extreme. (p. 10)

As indicated earlier in my analysis, normativity presumes that humans are socially motivated. Viewed through this dominant lens, the child with autism's withdrawal from social interactions becomes "something profoundly lacking that must be rectified" within the educational discourse (Kedar, 2012, as cited in Manning, 2016). Measures must be taken to support the child in being more successful at school — at fitting into a neurotypical mold of being present with other humans.

Neurotypicality places the human and consciousness of the self at the center of the environment and interactions. The neurotypical brain perceives the subjects and objects within an event quickly and later notices other details through a process called parsing (Manning, 2016). The neurotypical brain is capable of prioritizing some sensory information while deadening other sensory input to perform tasks efficiently. This ability may have much to do with survival and adaptation of the human species over time, but it dominates to the exclusion of other levels of experience. Manning (2016) argues that "parsing [the conscious ordering of sensation], so allied with the neurotypical not only reduces our capacity to feel the complexity of the event in the event; it perpetuates the hierarchy of conscious experience over nonconscious experience, reason over affect" (p. 22). Parsing reproduces normativity,

allowing an individual to flow effortlessly within the dominant discourse, placing it in stark contrast to autistic perception.

Autistic perception experiences the entire field of complexity of an event simultaneously. Instead of clearly distinguishable subjects and objects, autistic perception pulses with “a mélange of fields of relation, fields composed of complex networks of sounds, colors, textures, of object-body environment composites” (Manning, 2013, p. 153). The individual is not engaged in conscious thought about self or in feeling a particular sensation. Instead, the entire field of relation is thought-felt by a body-in-relation, not by a human subject distinct from the event. Autistic perception is not in a rush to parse this mélange into manageable chunks, but rather it lingers in “the true fullness of attention, lured by infinite complexity” (Manning, 2016, p. 138). Autistic perception is not exclusive to individuals diagnosed with autism. According to Manning (2013), “autism is a *modality of becoming* before it is any kind of state” (p. 180, emphasis added). Individuals who naturally engage with the world in a more normative and neurotypical way may access autistic perception, but most often it is in small glimpses or moments of openness. Many neurotypical individuals find the relinquishing of dominant norms about thinking and feeling too difficult. Parsing is too useful and too ingrained. As Skott-Myrhe and Taylor (2011) describe it, “becoming autistic is equal to the immanent possibility of an impersonal subject extending finally beyond the bounded shell of humanity into an encounter with life itself” (p. 47). Becoming autistic involves a decentering of one’s self, a fuzziness around the edges of everything, a melding of sensation, a *doing* rather than a *being*.

Implications of Autistic Perception for Education

Fuzziness and melding of sensation seem acceptable for mindfulness practices like meditation or yoga, but they become jarring when considered within the educational discourse of accountability and measurable progress. Beyond providing a better understanding of how children with autism experience the world, what can autistic perception *do* within education? It starts with reframing the idea of “caring for” and “comprehending” children with autism. Deligny (2015) asks, “So what does it mean to ‘comprehend’ these children? Does it mean showing them a form of comprehension that would be like a well-intentioned embrace?” (p. 155). Such a comprehension would not seek to categorize, to label, to quantify, or to know. Such a comprehension would seek to *know-with* the child with autism, to truly be in relation with that child without predetermined aims or expectations.

Given such a comprehension, care would move beyond interventions and setting individual goals. Care would not start from a place of normativity or neurotypicality. It would not be centered on treatment, on cure, on correcting areas that are lacking. In describing an event of autistic perception by a group, Manning and Massumi (2014) write, “Care organized itself not around the common but around *the irreducibly singular*. It concerned being-different-together and becoming-together as an expression of those differences, as part of a shared process participated in differentially.” (p. 108). As *irreducibly singular*, autism is a mode of being, or subjective structure, that is inextricably linked to a person’s basic practices of existence (Brenner, 2020). Thus, following Manning and Massumi, care would then proceed from tending toward affirmative difference. Care would not just allow, but also be shaped by, difference and the potentiality of *becoming*. This type

of care might foster creativity and exploration, along with opportunities to privilege and benefit from experiences of autistic perception, for children across the entire spectrum of neurological processing.

Becoming from a place of immanence and difference is possible, but not within the current structures and strictures of educational discourse, especially within that of special education. It is only possible by moving away from quantification and rigid hierarchies. According to Manning (2016), “the unquantifiable within experience can only be taken into account if we begin with a mode of inquiry that refutes initial categorization” (p. 29). Openings for accepting children with autism as fully human and for embracing the unique beauty of autistic perception appear at the dissolution of normativity. Removing and changing labels or setting up an individualized education program is not enough.

“Potentiality, as the insertion of difference in a moment of certainty, is one way of speaking of the divergence between normativity and the interruption of accepted norms” (Manning, 2007, p. 6). Thus, potentiality refuses the ingrained and normative assumptions of the dominant discourse by opening up spaces for resistance and difference. Expansion of potentiality for children with autism (as well as for children across the entire neurological spectrum) would then be prefaced by a rejection of the statistical average as the normative ideal against which all human life is measured. Within an educational model that is more about *doing* and *becoming* – or potentiality – than about comparing, “there is still room for mutation, for difference, for an opening toward the as-yet-unseen, the as-yet-unthought, the as-yet-unfelt” (Manning, 2016, p. 23). Who makes room for the *as yet* in educational spaces for people with autism? It would be educational leaders, special education teachers, ABA therapists, parents, autism self-advocates, everyone working within and against the

educational discourse to start asking different questions, to continually return to a plane of immanence, of difference, of potentiality.

CHAPTER TEN: TOWARD A DISCOURSE OF DIFFERENCE

Autism self-advocate, Dr. Stephen Shore, was the guest speaker for the 2020 annual fundraiser lunch at Barnfield. He is famously quoted as saying, “If you’ve met one person with autism, you’ve met one person with autism.” On that day, he opened his presentation with this oft-repeated maxim before sharing with our group the importance of recognizing the unique beauty, complexity, and potential of each person with autism as an individual and not as a diagnostic label. By problematizing the processes of diagnosis, my dissertation has worked to trouble the ways in which people with autism are categorized as an entire group, and how they are classified as abnormal and deficient through limiting and taken-for-granted assumptions in medical and educational discourses. I have done this by deconstructing the literature surrounding developmental milestones, diagnosing autism, parental reactions to a diagnosis, special education legislation and processes, and ABA therapy. I have chronicled our family’s journey to and beyond receiving a diagnosis of autism for my son. In so doing, I have revealed (im)possibilities for parents trying to work through systems and institutions to secure support for their child as they take up their own subjectivities within and across discourses as autism parents. My goal has been to reveal openings to expand the field of possible actions within the current dominant discourses while suggesting a shift toward a discourse of difference rather than one of disability.

Methodological Approach

As a means to employ poststructural theories in transformative work regarding autism, I engaged in postqualitative inquiry. Postqualitative inquiry uses concept as method (Lenz Taguchi & St. Pierre, 2017), and every part of the research process is a technique of thinking with theory (Jackson & Mazzei, 2017). I thought with Foucault’s concepts of

power/knowledge, subjectivity, and discourse. Along with my personal experience, my analytic sources included the research literature on developmental milestones, diagnosing autism, parental reactions to a diagnosis, and ABA therapy, as well as documents, legislation, and processes related to autism within the medical and educational discourse. My analysis focused on the discourses surrounding people with autism who are diagnosed in early childhood and their parents. In my study, I used strategies of discourse analysis and problematization to analyze three questions, which I summarize how they are addressed across my dissertation here.

The first analytic question drove my technique of problematization: *What is the problem represented to be regarding autism across medical and educational discourses?* As a reminder, in problematizations, a problem is “represented” through the knowledge that comes to be ingrained as taken-for-granted assumptions. Across the dominant medical and educational discourses of autism, I revealed how people with autism and their families are represented as problems to be solved. Disability is represented to be an inherent and fixed trait within the individual that is in need of repair. Individuals with disabilities are labeled as deficient through evaluations that measure human behavior and capabilities against a statistical average. Comparison of individuals to the statistical mean, or “norm,” creates the deficit-centered language of labels, categories, and hierarchical classifications while producing the normal/abnormal binary opposition. A sense of urgency emerges to quickly address these abnormalities – or solve the problem of these individuals – to bring them closer to the “normal” and acceptable level of functioning. “Normal” use of language, social interaction, and interests are privileged, as well as the desire to shape people with disabilities into productive citizens in the future. Producing docile bodies that function more “normally”

and are easier to manage is also part of solving the problem that people with autism are represented to be, especially through interventions that decrease or eliminate undesired behaviors like stimming.

Guiding my use of discourse analysis was the second analytic question: *What is the interplay among subjectivity, power, and knowledge for autism parents within these discourses, and what do they produce?* Within the discourses of autism, power not only operates through the creation of the abnormal/normal binary opposition, but also through surveillance, counting, and control. Parents are encouraged to engage in the surveillance of their child by tracking progress on developmental milestones. Formal evaluative processes are designed to identify abnormal individuals and bring them into systems of intervention. ABA therapy works to modify and control the behaviors of people with autism. Expert knowledge is privileged over parental knowledge in determining what is *best* for or what would *maximize the potential* of a child with autism. A binary opposition of good/bad parents is (re)produced across medical and educational discourses whereby “good” parents are those who access and follow expert recommendations while “bad” parents do not. Parents take up their subjectivities within these relations of power/knowledge, navigating their subjectivities along a range of docile compliance and resistance. Noncompliance is positioned as a problem of the individual and not a flaw of the system. Parents are assumed to take up subjectivities of grieving and sorrow in reaction to their child’s diagnosis before progressing through predictable stages toward acceptance.

Finally, my study addresses the analytic question: *How do the processes that are used in diagnosis, dissemination of information, and intervention reveal (im)possibilities for people with autism and their parents and families?* My analysis reveals the ways that the

relations of power/knowledge and the availability of certain subject positions within the dominant medical and educational discourses of autism limit the field of possible action for parents (Chapters 3, 4, 5, 6, 7, and 8). I also argue that similar limits are placed on pediatricians (Chapter 3) and special education personnel (Chapters 7 and 8) due to the highly-regulated processes for diagnosing autism and determining eligibility for special education services. My analysis put forward openings for possibilities within the dominant medical and educational discourses of autism (Chapters 3, 4, 5, 6, 7, and 8). Chapter 9 offered substantially more openings toward discourses of *becoming* and of affirmative difference as Barnfield's IEP approach privileges mastery over measurement, makes adjustments to the curriculum instead of the child, and allows space for skills to be "emergent" or "not yet." Additionally, the Barnfield process – which sustains discourses of *becoming* – privileges family values and knowledge, along with anecdotal information from both the family and the Barnfield about the child, instead of a sole reliance on quantitative data. The comparison between the Barnfield approach and the traditional IEP process is significant for its illustration of competing discourses within the field. Because it is practices that shape discourse, my analysis with this question reveals how poststructural theory works in the world. Taking up different practices allows for the resistance of dominant discourses from within in order to shift it and to open up new potentiality.

Stepping away from the analytic questions, I thought with Deleuze's concepts of immanence and affirmative difference, as well as with Manning's work on autistic perception, to explore potentiality in the interlude sections. Beyond the troubling of the dominant discourse, my use of poststructural theory looks to open up new questions and possibilities for people with autism and autism parents. As Chambon (1999) writes, "because

power is productive, it is up to us to produce new forms, after seeing through that which is all too familiar” (p. 71). In suggesting a move toward a discourse of affirmative difference, I sought to celebrate the unique strengths and perception that individuals with autism provide.

In the remainder of this chapter, I offer a reminder of traditional approaches to autism research and detail how my research contributes to the literature. Next, I review the theoretical and methodological implications of my study to reassert my claims about taken-for-granted assumptions within the medical and educational discourses of disability. A section on the limitations of my research is followed by recommendations for future inquiry. Finally, I address the implications for this work specific to the field of educational leadership before sharing my concluding thoughts. I take up the move toward a discourse of affirmative difference in the recommendations and implications sections of this chapter.

Connections and Contributions to Literature

Current autism research assumes that autism is a distinct and definable disorder with clear-cut boundaries and characteristics. Through both quantitative and qualitative means, researchers search for the causes, treatments, and cures for autism. Autism is depicted as an abnormality – a disorder – that must be corrected to bring the afflicted individual closer to the normative ideal. In both the medical and educational discourses, this process is carried out by first naming the individual’s deficiencies and then prescribing appropriate interventions. Some research studies look for trends in the behavior and thoughts of people impacted by autism, especially parents (Cachia et al., 2016; Rabba et al., 2019; Shamash & Hinman, 2021; Smith et al., 2020). Parents have been reported to be contributing factors to their child’s autism (Bettelheim 1967; Kanner, 1943) and to be in perpetual states of mourning over their abnormal child in the decades since the label of autism first appeared

(Beddie & Osmond, 1955; Kübler-Ross, 1969; Kübler-Ross & Kessler, 2005; Olshansky, 1962; Solnit & Stark 1961). Existing research focuses on one specific manifestation of autism, such as the ability to make friends or form romantic relationships, or on a small sample group (Autism and Developmental Disabilities Monitoring Network, 2020; Beurkens et al., 2013; Hancock et al., 2020; Petrina et al., 2014;). Findings are often considered to be generalizable to the autism community at large. Some research is clearly self-serving, designed to promote a particular intervention, to reinforce systems of surveillance and control, or to “fix” the person with autism (Bruinsma et al., 2020; Rogers et al., 2012; Simons Foundation, 2021). Even with the most benevolent and well-intentioned research studies, there is typically little benefit to people with autism or autism parents for their participation. Most importantly, the current literature works to reproduce the dominant discourse of disability and the normal/abnormal binary.

My study contributes to the literature by simultaneously approaching the discourse of disability from the center and from the margins. My analysis is both systemic and deeply personal. I make visible what has become taken for granted by unraveling layers of institutional processes and discourse. By using poststructural theory and problematization, I expose the well-known “truths” about autism as techniques of power. In my research, autism is one quality of an individual, a difference that possesses challenges in navigating a neurotypical world as well as unique strengths and possibilities. I do not seek to solve autism, but rather to dismantle the deficit-laden normal/abnormal binary opposition. In telling my own story rather than gathering the words of others for my own purposes, I have refused trends and generalizations. My contribution to autism research has “both destructive and constructive objectives, which in this context are mutually constitutive” (Foley, 2016, p.

177). As I have worked to dismantle the dominant discourse of disability, I have also argued for a move toward potentiality. The goal of my analysis has not been to find solutions, but rather to generate new questions and knowledge that might provoke the opening of new possibilities for a discourse of difference rather than disability.

Significance of Poststructuralist Theory

My nontraditional approach to autism studies is based on poststructural theory, which can most easily be described as “*work that unsettles*” (Chambon, 1999, p. 53, emphasis original). Poststructuralist theory works to destabilize and disrupt normalizations, binaries, and other socially-constructed categories. Poststructuralist inquiry concerns itself with the interplay between power, knowledge, and subjectivity while revealing the taken-for-granted assumptions within the dominant discourse. In the main chapters of my analysis, I thought with Foucault’s concept of *power/knowledge* and explored its interplay with subjectivity for autism parents within and across the dominant medical and educational discourses. In the two interludes, I relied on the Deleuzian concept of *difference* as it relates to immanence and possibility, as well as to Manning’s work on autistic perception.

Power/Knowledge

The dominant discourse of disability perpetuates the comparison of individuals to the statistical average as the standard for what is *normal*. Any deviation from the norm is a deficiency, an inherent lack within the individual that must be corrected. The normal/abnormal binary opposition is a technique of power that sets up the person with disabilities as a problem to be identified, categorized, and solved. Institutions of the state define individuals through labels and bring them under systems of surveillance, counting, and

control. Once integrated into institutions and systems, the individual becomes a *docile body*, one that is more manageable and malleable.

In offering answers, interventions, and services, institutions are “deceptively promising reform, progress, or freedom but in actuality delivering subjugation” (Devine, 1999, p. 251). For example, special education services are presented as a way to provide a high-quality education to students with disabilities, and parents are afforded the freedom to exercise their rights throughout the development of the IEP. As shown above, however, such progress and freedom are severely limited by the field of possible action produced through the highly-regulated discourse of special education. Thus, another technique of power lies in the privileging of those types of knowledge that maintain the status quo and subjugate those that offer resistance to the dominant discourse. Deception occurs in the dominant discourse of disability when expert knowledge and data from qualitative, standardized evaluations are privileged, and touted as progress – while other types of knowledge (such as broader background and contextual information, anecdotal information, parental knowledge about their child, and cultural values) about an individual with disabilities are marginalized. Within evaluations, knowledge can only be demonstrated in acceptable, limited, and *normal* ways, further separating out the abnormal and deficient individuals.

Subjectivity

Within the dominant medical and educational discourses of disability, parents must take up their subjectivities based on the classification of their child with autism as being abnormal and in need of repair. Typically, this manifests in the limited subject positions embodied within a range of compliance and resistance, although those positions are temporary, fluid, and always contingently responsive to power/knowledge. In a subjectivity

of compliance, or docility, the parent subordinates the knowledge they possess about their child to the experts' privileged knowledge about autism and what is *best*. The docile and compliant parent (re)produces the power/knowledge relations within the discourse by cooperating with diagnostic or IEP processes, believing in the validity of the data collected about their child, asking few questions, and working diligently to secure the recommended services and interventions as quickly as possible. Parents take up a subjectivity of resistance when they assert their own knowledge, ask questions, disagree with assessments of their child, and refuse to follow expert recommendations. Because it pushes back against the dominant discourse, such resistance is often punished through isolation or the removal of eligibility for support. Parents may vary in how or when they take up subjectivities of docile compliance or of resistance at different times and across different circumstances within the dominant discourses. Subjectivity is a constant making and remaking – not one way of being in the world.

Affirmative Difference

Difference, in poststructural theory, is non-oppositional and affirmative. Difference starts from a place of immanence, a place of potentiality. Within the discourses of autism, affirmative difference is to consider the person with autism as *fully human* with or without services or interventions. Difference, in poststructural theory, privileges the living out of one's potential over the creation of a productive, docile, and useful citizen. Non-oppositional difference allows for a space of *becoming*, for emerging and growing into an as-yet-unknown future rather than being defined by limited classifications produced at one point in time. In a discourse of difference, mastery is prioritized over measurement. Difference does not compare or create hierarchies; it is not on a timeline. Difference is always multiple. Its

multiplicity is what produces possibility. Difference allows for engagement and creation. Difference opens up space for transformation.

Research Limitations

Although my dissertation does not seek to prove a hypothesis or offer any solutions (and as such the positivist language of “limitations” is not aligned with poststructuralist inquiry), I do recognize that there are other analytical moves that could have been made in the doing of this inquiry that would have generated different questions and other ways of thinking with theory.

First and foremost is the recognition that autism is not a single story but a spectrum. This analysis has problematized the assumption that every individual with autism can be defined by the same stereotyped set of behaviors and perceived failings. Therefore, every autism family cannot be defined by one journey or set of emotional responses to diagnosis. By sharing my family’s experiences, I am presenting only one possible path to diagnosis, one possible taking up of subjectivities within the discourse of autism, one possible series of encounters with IEP creation. Poststructuralism operates with the understanding that the researcher (whether or not she is also an autism parent) is always already within the discourse under analysis. Given my refusal to traffic in the pain of others, my story is the only one I can tell, but it does not allow for generalizations to other families in other situations. This is in line with poststructuralist thought and preserves openings for multiplicity and difference within the discourse.

I acknowledge that my story comes from a place of privilege, one of financial security, food security, extended family support, whiteness, and advanced educational opportunities. In addition to those advantages, I possess privileged knowledge that other

parents of children with autism may not. My educational level and professional background enable me to understand the technical jargon of the medical and educational discourses of disability, to process large quantities of data and language quickly, to know what questions to ask, and to feel confident in raising those questions in a room full of experts. Throughout my analysis, I have tried to point out where obstacles are created or access denied for parents of different backgrounds and circumstances; however this inquiry does not, nor is it intended to, represent the journeys of other families.

Finally, I made a deliberate decision to trace the entirety of my family's autism journey before, during, and after my son's diagnosis in this analysis. This approach allowed me to trouble the assumptions of the diagnostic process in connection to the ways in which they are reproduced in special education. Following a more significant portion of our story also engenders the feeling of seemingly unending struggle that autism parents face in navigating the medical and educational systems in seeking support for their child. This choice was one of breadth over depth. Any one of the topics addressed in the analytical chapters could have been explored in more depth as a separate inquiry, which would have yielded different problematizations, questions, and possibilities.

Recommendations for Future Inquiry

My hope is that my dissertation would inspire other autism parents and individuals with autism working as self-advocates to produce their own knowledge. There is a burgeoning genre of autism publications, including activist speech, autobiographies, memoirs, poems, video essays, blogs, and presentations. So far, these works have gone largely unnoticed by those in academia and are not afforded the status of research or relevant data. I would recommend the incorporation of innovative ways for research to be done *by* or

with people with autism and their parents rather than being done *on* or *to* them. Making space for different stories opens up the possibilities for seeing difference over disability.

Another avenue for thinking with theory about autism is to incorporate the experiences of those people whose employment works to reproduce the dominant discourse of disability. This might include pediatricians; diagnostic evaluators; providers of therapies, services, and interventions; general or special education teachers; school psychologists; or family counselors. In each case, it would be interesting to see how the techniques of power are at work and the subject positions that are available for those individuals to take up within the discourse of disability as a professional. Would those positions still be either compliance or resistance?

The above recommendations address the people involved in the inquiry, but there are also other parts of the discourse that could be examined instead of the topics chosen for this analysis. My inquiry did not include an analysis of the discourse of early intervention since our family had such a small window of time between diagnosis and the creation of an IEP. Yet, the emphasis on early intervention services continues the sense of urgency present in the diagnostic processes and reproduces the responsibility on the part of the parent for securing the *best possible* support for their child. Analysis in this area could problematize the provision of early intervention services through the state as a technique of power, or it could involve a discourse analysis of research-based interventions recommended for children with autism for their reproduction of the taken-for-granted assumptions about disability present in the dominant discourse. Finally, policy analysis would be an area where poststructural inquiry could begin to transform action.

Implications for Educational Leadership

Based on my analysis, there are some ways for educational leaders to engage in transformative action with and for students with disabilities and their families. An initial step would be for educational leaders to begin a process of reflexivity, by which they examine their own taken-for-granted assumptions about students with disabilities and their families. They could work to identify where they are taking up a subjectivity of compliance with the dominant discourse of disability and potential spaces of resistance. As is often the case, the commitment of educational leaders to introspection may spark a similar process in the professionals that they lead. Thereby, a school or district culture that is more accepting and accommodating of affirmative, non-oppositional difference may grow out of this reflexivity.

There are several ways to create a school or district culture that reproduces a discourse of difference rather than disability. First, school and district personnel could search for ways to open up new subject positions for parents beyond that of compliance or resistance. IEP teams in particular could reassess the ways in which they communicate with parents of students with disabilities, what and how information is presented about the student, and the power relations within the meeting and evaluation environments. Parents might be given more opportunities to actively engage in conversations about their child's learning and growth, rather than just signing off on official decisions or helping to fill in boxes on forms.

Another way that educational leaders could transform the discourse of disability into one of difference is by refusing the normal/abnormal binary opposition, as well as by refusing to engage in the comparative discourse that marks students with disabilities as deviant from the statistical average or their "typically developing" chronological peers.

Instead of discussing student progress in terms of scores, standard deviations, and rankings, conversations with parents could be about the unique strengths and challenges of that individual child. Much like the meetings at Barnfield, the discourse could become that of what the child can do now and what he or she cannot do *yet*. A discourse of *as yet* emphasizes emerging skills rather than deficits; a discourse of *as yet* underscores a space of potentiality, a space of *becoming*, and an avenue for embracing difference as possibility.

A final suggestion for educational leaders to embrace a discourse of affirmative difference over disability is to review how they evaluate the effectiveness of their teachers and how their teachers perceive their own effectiveness in terms of classroom management. Do the classroom, school, and district policies limit the possible subject positions for both adults and students to that of compliance or resistance? Brown and McIntyre (1993) found that teachers considered lessons to be successful if students acted in a certain way that maintained a sense of comfortable equilibrium and control and if they covered their content. In general, education has privileged classroom management, as defined by how docile the students' bodies are during instruction. Teachers whose classrooms are quiet and orderly with students mostly seated at their desks have been commended. Conversely, classrooms where students roam about and speak without raising their hands are often perceived as being chaotic. In this view, educational effectiveness becomes more a function of meeting the needs of the teacher or school than meeting the needs of individual students.

McGovern (2019) recommends that educational leaders “explore the wider complexity going on within the classroom environment” (p. 164) and flip the notion of docile bodies on its head. Classroom management could encompass setting procedures for a wide range of activities and movement, as well as empowering students to learn and use self-

regulating strategies when they are feeling frustrated, overwhelmed, or simply need to move. Simple environment adjustments like flexible seating, less abrasive lighting, and designated quiet areas would help with sensory regulation and behavior. One elementary school in our local public school district installed decals in the hallways that encourage students to hop from letter to letter or number to number and “high-five” handprints on the wall. Some adults in the building were skeptical about the decision, thinking it would lead to more disruptive behavior, but the school saw an 80% decrease in discipline incidents in the hallway and during transitions over the course of one semester (Shoaf, 2020). Such an approach privileges adjusting the instruction and environment to meet the needs of students rather than requiring students to conform to a normative ideal for classroom functioning that benefits adults more than students. This approach could remove obstacles to including students with disabilities more fully into the general education environment, but would probably also produce beneficial outcomes from students who do not receive special education services.

It is important that I acknowledge that these are not evidence-based solutions in the positivist sense, but rather suggestions out of my own thinking and professional experience. Also, I am aware that educational leaders are always already in the highly regulated assemblage of the educational system, and that there are different levels of availability for them to take up a subjectivity of reflexivity or resistance within their respective work settings.

Closing Thoughts

My analysis throughout this dissertation has troubled the dominant medical and educational discourses of disability. I have made visible taken-for-granted assumptions about individuals with autism as noncommunicative and antisocial, as being abnormal and

deficient, as being inherently flawed and in need of repair. I dismantled evaluations, classifications, normalizations, labels, descriptions, and limitations. I showed how the dominant discourse positions people with autism as problems to be solved and limits the subjectivities taken up by their parents to that of compliance and resistance. Some of the motivation for this work originally came from a place of personal anger and trauma. I realized during the writing of this dissertation that I had gone through a type of grieving process, but not one that was related to what my son is, has, does, or cannot do. Instead, these deep and complex emotions were the result of interacting with systems and discourses that were limiting for him and for me. These emotions were present because he was seen as a series of metrics and not a complete human, because the way he was defined by these processes did not match the child I know and love. I was never angry with individual people who were part of these processes, but the cumulative effect was a feeling of despair, frustration, and overwhelm.

Out of my thinking with theory, however, came the push for a discourse of affirmative difference. Openings to a different way of seeing my child and other people with autism became a ray of hope in this work. I am inspired by the possibility that my son might encounter a discourse where his difference is honored for its unique potential without being overshadowed by statistics about how he compares to other people. I hope that the questions and problematizations that have emerged from my analysis would provoke other parents, researchers, and educators to think reflexively about their own assumptions, to embrace difference, and to work toward the opening of new possibilities for children with and without autism to be celebrated for their unique potential. I also hope to inspire work around

reframing the idea of disability itself and around changing perspectives and environments rather than trying to fix people.

In closing, I offer an original poem on the following page. This poem is intended to be a call and response between the words of Maxine Greene (1987-88) in bold and the basic tenets of poststructuralism and the neurodiversity movement within the autism community. It is my deepest wish that my analysis will contribute to a “breaking free” from the discourse of disability and a striving toward a discourse of difference for my son and all people with autism.

Breaking Free

Look for alternative ways of being, openings

Exploring alternative possibilities

Consciousness, a moment of being

Self-awareness and subjectivity

Mediation between what impinges on one from without and on one's response

Finding an identity within a discourse

A world lived in common with others

Unique humanness of each individual

Surpassing of a constraining or deficient "reality"

From deficit language about autism

Field of possibles

Negotiating beyond negative stereotypes

The wall...as a personal challenge

Deconstructing, dismantling, troubling

A dialectical relation marking every human situation

Refusing traditional binaries, labels, categories

Provoked to reach beyond themselves, to wonder, to imagine

Strengths-based approach; building on enthusiasms

Transcend determinacy or surpass facticity

More than a diagnosis or disability

Pose questions to the world

Challenging what has become normalized

What might be, should be, is not yet

To a perspective of possibility and difference

References

- Abeson, A., & Zettel, J. (1977, October). The end of this quiet revolution: The Education for All Handicapped Children Act of 1975. *Exceptional Children*, 44(2), 114-128. <https://doi.org/10.1177%2F001440297704400205>
- Adami, S., Falcomata, T. S., Muething, C. S., & Hoffman, K. (2017). An evaluation of lag schedules of reinforcement during functional communication training: Effects on varied mand responding and challenging behavior. *Behavior Analysis in Practice*, 10, 209–213. <https://doi-org.proxy006.nclive.org/10.1007/s40617-017-0179-7>
- Adams, W., & Sheslow, D. (1995). *The wide range assessment of visual motor abilities (WRAVMA)*. Pearson.
https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Motor-Sensory/Wide-Range-Assessment-of-Visual-Motor-Abilities/p/100001723.html?gclid=Cj0KCQjwpv2TBhDoARIsALBnVnnBDOEnUajHCACX2ssit3zeYNiTz-9JssfTlr8BWh1-J3CjuB1BPrUaAmHVEALw_wcB
- Adler-Greene, L. (2019). Every Student Succeeds Act: Are schools making sure every student succeeds? *Touro Law Review*, 35(1), 11-23.
<https://heinonline.org/HOL/LandingPage?handle=hein.journals/touro35&div=6&id=&page=>
- Agamben, G. (2003). Absolute immanence. In J. Khalfa (Ed.), *Introduction to the philosophy of Gilles Deleuze* (pp. 151-169). Continuum. (Original work published 1999).
- Albert, K. M., Carbone, V. J., Murray, D. D., Hagerty, M., & Sweeney-Kerwin, E. J. (2012).

- Increasing the mand repertoire of children with autism through use of an interrupted chain procedure. *Behavior Analysis in Practice*, 5, 65–76. <https://doi-org.proxy006.nclive.org/10.1007/BF03391825>
- Allan, E. J. (2003). Constructing women's status: Policy discourses of university women's commissions. *Harvard Educational Review*, 73(1), 44–72. <https://doi-org.proxy006.nclive.org/10.17763/haer.73.1.f61t41j83025vwh7>
- Allan, J., & Youdell, D. (2017). Ghostings, materialisations, and flows in Britain's special education needs and disability assemblage. *Discourse: Studies in the Cultural Politics of Education*, 38(1), 70-82. Taylor & Francis. <http://dx.doi.org/10.1080/01596306.2015.1104853>
- Alexander, S.A., & Coveney, J. (2013). A critical discourse analysis of Canadian and Australian public health recommendations promoting physical activity to children. *Health Sociology Review*, 22(4), 353-364.
- Allred, K., & Hancock, C. (2012, Fall) On death and disability: Reframing educators' perceptions of parental response to disability. *Disability Studies Quarterly*, 32(4), 3. The Ohio State University Libraries. DOI: 10.18061/dsq.v32i4.1737. https://scholarworks.boisestate.edu/sped_facpubs/69/
- American Academy of Pediatrics. (2020). *Developmental disabilities*. <https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/default.aspx>
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). <https://dsm.psychiatryonline.org/doi/pdf/10.1176/appi.books.9780521315289.dsm-iii>

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.11776/appi.books.9780890425596>
- Antill, K. (2020). Family-centered applied behavior analysis for children with autism spectrum disorder. *Intervention in School and Clinic*, 55(3), 185-191. SAGE. <https://doi.org/10.1177%2F1053451219842240>
- Armstrong, T. (2010). *Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences*. DaCapo Press.
- Arnold, L. (2013). Autonomy, the critical journal of interdisciplinary autism studies. In S. K. Kapp (Ed.), *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* (pp. 211-220). Palgrave Macmillan.
- Atkins, K. (Ed.). (2004). *Self and subjectivity*. Blackwell Publishing. <https://doi.org/10.1002/9780470774847>
- Autism and Developmental Disabilities Monitoring Network. (2020). *Community report on autism 2020*. <https://www.cdc.gov/ncbddd/autism/addm-community-report/documents/addm-community-report-2020-h.pdf>
- Autism Society. (2020). *Autism Society homepage*. <https://www.autism-society.org/>
- Autism Speaks. (2021). *Autism Speaks homepage*. https://www.autismspeaks.org/?utm_source=portal&utm_medium=text-link&utm_campaign=global-nav&utm_term=autismspeaks
- Axelsson, T. (2016). Intelligence testing, ethnicity, and construction of the deviant child: Foucault and special education in Sweden. *Nordic Journal of Social Research*, 7, 22-35. <https://www.idunn.no/doi/full/10.7577/njsr.2093>

- Aylaz, R., Yilmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: A qualitative study. *Sexuality and disability*, 30, 395-406. Springer. <https://link.springer.com/article/10.1007/s11195-011-9251-3>
- Bacchi, C. (2012). Why study problematizations? Making politics visible. *Open Journal of Political Science*, 2(1), 1-8. <http://dx.doi.org/10.4236/ojps.2012.21001>
- Bacchi, C. (2015). The turn to problematization: Political implications of contrasting interpretive and poststructural adaptations. *Open Journal of Political Science*, 5, 1-12. <http://dx.doi.org/10.4236/ojps.2015.51001>
- Bacchi, C. (2016, April-June). Problematizations in health policy: Questioning how “problems” are constituted in policies. *SAGE Open*, 1-16. <https://doi.org/10.1177%2F2158244016653986>
- Baggs, A. (2007, January 14). *In my language* [Video]. YouTube. <https://www.youtube.com/watch?v=JnylM1hI2jc>
- Bakan, M. B. (2015). The musicality of stimming: Promoting neurodiversity in the ethnomusicology of autism. *MUSICultures*, 41(2). <https://journals.lib.unb.ca/index.php/MC/article/view/22914>
- Bascom, J. (2011, April 5). *The obsessive joy of autism*. Just stimming. <https://juststimming.wordpress.com/2011/04/05/the-obsessive-joy-of-autism/>
- Bateman, D. F., & Cline, J. L. (2016). *A teacher's guide to special education*. ASCD.
- Bauman, M. L. (2010) Medical comorbidities in autism: Challenges to diagnosis and treatment. *Neurotherapeutics*, 7, 320-237. <https://link.springer.com/article/10.1016/j.nurt.2010.06.001>
- Beddie, A., & Osmond, H. (1955). Mothers, mongols, and mores. *The Canadian Medical*

Association Journal, 73(3), 167-170.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1826049/>

Belisle, J., Dixon, M. R., Malkin, A., Hollie, J., & Stanley, C. R. (2021). Exploratory factor analysis of the VB-MAPP: Support for the interdependency of elementary verbal operants. *Journal of Behavioral Education*, 31, 503-523. Springer.

<https://doi.org/10.1007/s10864-020-09413-2>

Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self*. The Free Press.

Beurkens, N. M., Hobson, J. A., & Hobson, R. P. (2013). Autism severity and qualities of parent-child relations. *Journal of Autism and Developmental Disorders*, 43, 168-178. Springer.

<https://link.springer.com/article/10.1007/s10803-012-1562-4#Sec10>

Binet, A., & Simon, T. (1915). *A method of measuring the development of the intelligence of young children* (C. H. Town, Trans.). Chicago Medical Book. (Original work published 1911).

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *Mental Retardation*, 22(2), 55-68.

<https://www.proquest.com/openview/61b98a1f8f25495c4c8f783f9d8d838a/1?pq-origsite=gscholar&cbl=1976608>

Blume, H. (1998). Neurodiversity: On the neurological underpinnings of geekdom. *The Atlantic*, 30, 09-90.

<https://archive.ph/20130105003900/http://www.theatlantic.com/doc/199809u/neurodiversity>

Bolton, C. (2012). Animating poststructuralism [YouTube Video].

<https://www.youtube.com/watch?v=6a2dLVx8THA>

Boroson, B. (2020). *Decoding autism and leading the way to successful inclusion*. ASCD.

Bowling, A., Blaine, R. E., Kaur, R., & Davison, K. K. (2019). Shaping healthy habits in children with neurodevelopmental and mental health disorders: parent perceptions of barriers, facilitators and promising strategies. *The International Journal of Behavioral Nutrition and Physical Activity*, 16(1), 52. <https://doi-org.proxy006.nclive.org/10.1186/s12966-019-0813-6>

Boyd, B. A., Baranek, G. T., Sideris, J., Poe, M. D., Watson, L. R., Patten, E., & Miller, H. (2010, April). Sensory features and repetitive behaviors in children with autism and developmental delays. *Autism Research*, 3(2), 78-87. International Society for Autism Research. <https://doi.org/10.1002/aur.124>

Brenner, L. S. (2020). *The autistic subject: On the threshold of language*. Palgrave Macmillan.

Broski, J. A. (2019). Critical insights: Incidents that help and hinder parents' transition related to their child's developmental diagnosis [Doctoral dissertation, University of Kansas]. <https://kuscholarworks.ku.edu/handle/1808/30127>

Broski, J., & Dunn, W. (2018). Fostering insights: A strengths-based theory of parental transformation. *Journal of Child and Family Studies*, 27(4), 1275-86. <https://doi.org/10.1007/s10826-017-0964-5>.

Brown, S. A., & McIntyre, D. (1993) *Making sense of teaching*. Open University Press.

Bruinsma, Y., Minjarez, M., Schreibman, L., & Stahmer, A. (2020). *Naturalistic*

- developmental behavioral interventions for autism spectrum disorder*. Paul H. Brookes Publishing Co.
- Burger, J. M. (2001). Psychology of social influence. *International Encyclopedia of the Social and Behavioral Sciences*, 14320-14325. Elsevier.
<https://doi.org/10.1016/B0-08-043076-7/01805-2>
- Cachia, R., Anderson, A., & Moore, D. (2016). Mindfulness, stress and well-being in parents of children with Autism Spectrum Disorder: A systematic review. *Journal of Child & Family Studies*, 25(1), 1–14.
<https://doi-org.proxy006.nclive.org/10.1007/s10826-015-0193-8>
- Carlson, J. F., Geisinger, K. F., & Jonson, J. L. (Eds.). (2017). *The twentieth mental measurements yearbook*. Buros Center for Testing.
- Carolina Institute for Developmental Disabilities (2012, May). *Hearing and development team parent questionnaire*. University of North Carolina at Chapel Hill.
- Carolina Institute for Developmental Disabilities. (2021). *Request an appointment*.
<http://www.cidd.unc.edu/Appointment/>
- Centers for Disease Control and Prevention (2019, December 9). *What is “early intervention”?* <https://www.cdc.gov/ncbddd/actearly/parents/states.html>
- Centers for Disease Control and Prevention. (2020, March 13). *Screening and diagnosis of Autism Spectrum Disorder*. <https://www.cdc.gov/ncbddd/autism/screening.html>
- Centers for Disease Control and Prevention (2020, March 16). *Accessing services for Autism Spectrum Disorder*. <https://www.cdc.gov/ncbddd/autism/accessing-services-for-autism-spectrum-disorder.html>
- Centers for Disease Control and Prevention. (2021, January 22). CDC’s developmental

- milestones. <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>
- Chambon, A. S. (1999). Foucault's approach: Making the familiar visible. In A. S. Chambon, A. Irving, & L. Epstein (Eds.), *Reading Foucault for social work* (pp. 51-81). Columbia University Press.
- Colker, R. (2013). *Disabled education: A critical analysis of the Individuals with Disabilities Education Act*. New York University Press.
- <https://www-jstor-org.proxy006.nclive.org/stable/j.ctt9qfsz6>
- Conallen, K., & Reed, P. (2016). A teaching procedure to help children with autistic spectrum disorder to label emotions. *Research in Autism Spectrum Disorders*, 23, 63–72. <https://doi-org.proxy006.nclive.org/10.1016/j.rasd.2015.11.006>
- Conallen, K., & Reed, P. (2017). Children with autism spectrum disorder: Teaching conversation involving feelings about events. *Journal of Intellectual Disability Research*, 61, 279–291. <https://doi-org.proxy006.nclive.org/10.1111/jir.12339>
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. SAGE.
- Danforth, S. (2000). What can the field of developmental disabilities learn from Michel Foucault? *Mental Retardation*, 38(4), 364.
- Davies, B., & Gannon, S. (2011). Feminism/post-structuralism. In B. Somekh & C. Lewin (Eds.), *Theory and methods in social research* (2nd edition) (pp. 312-319). SAGE.
- Davis, B. J., Kahng, S., & Coryat, K. (2012). Manipulating motivating operations to facilitate the emergence of mands for a child with autism. *Analysis of Verbal Behavior*, 28, 145–150.
- <https://doi-org.proxy006.nclive.org/10.1007/BF03393116>

- Deacon, R. (2000). Theory as practice: Foucault's concept of problematization. *Telos* 118, 127-142.
- Deleuze, G. (1994). *What is philosophy?* H. Tomlinson & G. Burchell (Trans.). Columbia University Press.
- Delgado, C., Mundy, P., Venezia, M., & Block, J. (2003). *Pictorial infant communication scale*. University of California Davis MIND Institute.
- Deligny, F. (2015). *The arachnean and other texts*. D.S. Burk & C. Porter (Trans.). Univocal.
- Devine, J. (1999). Postmodernity, ethnography, and Foucault. In A. S. Chambon, A. Irving, & L. Epstein (Eds.), *Reading Foucault for social work* (pp. 247-257). Columbia University Press.
- Dixon, M. R., Palilunas, D., Barron, B. F., Schmick, A. M., & Stanley, C. R. (2021). Randomized controlled trial evaluation of ABA content on IQ gains in children with autism. *Journal of Behavioral Education*, 30, 455-477.
<https://doi.org/10.1007/s10864-019-09344-7>
- Doe ex rel. Doe v. Board of Education Tullahoma City Schools, 9 F.3d 455 (6th Cir. 1993).
<http://case-law.vlex.com/vid/9-f-3d-455-597928790>
- Dolnick, E. (1998). *Madness on the couch: Blaming the victim in the heyday of psychoanalysis*. Simon & Schuster.
- Duke University School of Law (1985, Spring). State response to the Education for All Handicapped Children of 1975. *Law and Contemporary Problems*, 48(2), 275-294.
<https://www.jstor.org/stable/1191573>
- Dunn, W. (2014). *Toddler Sensory Profile* (2nd Edition). Pearson.
- Dunst, C. J., & Trivette, C. M. (2009). Capacity-building family-systems intervention

- practices. *Journal of Family Social Work*, 12(2), 119-143.
<https://doi.org/10.1080/10522150802713322>
- Education for All Handicapped Children Act of 1975, P. L. 94-142 § 89-773. (1975, November 29).
<https://www.govinfo.gov/content/pkg/STATUTE-89/pdf/STATUTE-89-Pg773.pdf>
- Eisert, D., & Lamorey, S. (1996). Play as a window on child development: The relationship between play and other developmental domains. *Early Education & Development*, 7, 221–235.
https://doi.org/10.1207/s15566935eed0703_2
- El Moussaoui, S. (2017, Summer). The Every Student Succeeds Act and its impact on vulnerable children. *Journal of Law and Education*, 46(3), 407-414.
<https://heinonline.org/HOL/LandingPage?handle=hein.journals/jle46&div=32&id=&page=>
- Ellsworth, E. (2004). *Places of learning: Media, architecture, pedagogy*. Routledge.
- Ekman, P. (1972). Universals and cultural differences in facial expressions of emotion. In J. Cole (Ed.), *Nebraska Symposium on Motivation*, 19, 207–282. University of Nebraska Press.
- Enforcing the right to an “appropriate education”: The Education for All Handicapped Children of 1975. (1979, March). *Harvard Law Review*, 92(5), 1103-1127. The Harvard Law Review Association.
<https://www.jstor.org.proxy006.nclive.org/stable/1340453>
- Erikson, E. H. (1966). Eight ages of man. *International Journal of Psychiatry*, 2(3), 281–300.
- Esterberg, K. (2002). *Qualitative methods in social research*. McGraw-Hill.

Every Student Succeeds Act of 2015, P. L. 114-95 § 129-1802. (2015, December 10).

<https://www.congress.gov/114/plaws/publ95/PLAW-114publ95.pdf>

Eyer, T. L. (1999, April 1). Greater expectations: How the 1997 IDEA Amendments raise the basic floor of opportunity for children with disabilities. *Dickinson Law Review*, 103, 613.

Fairclough, N. (2014). Semiotic aspects of social transformation and learning. In J. Angermuller, D. Maingueneau, & R. Wodak (Eds.), *The discourse studies reader: Main currents in theory and analysis* (pp. 379-387). John Benjamins Publishing. (Reprinted from *An introduction to critical discourse analysis in education*, pp. 225-235, by R. Rogers, Ed., 2004, Lawrence Erlbaum).

Falcomata, T. S., Muething, C. S., Gainey, S., Hoffman, K., & Fragale, C. (2013). Further evaluations of functional communication training and chained schedules of reinforcement to treat multiple functions of challenging behavior. *Behavior Modification*, 37, 723–746.

<https://doi-org.proxy006.nclive.org/10.1177/0145445513500785>

Falcomata, T. S., White, P., Muething, C. S., & Fragale, C. (2012). A functional communication training and chained schedule procedure to treat challenging behavior with multiple functions. *Journal of Developmental and Physical Disabilities*, 24, 529–538.

<https://doi-org.proxy006.nclive.org/10.1007/s10882-012-9287-z>

Ferguson, P. M., & Ferguson, D. L. (2006). Finding the "proper attitude": The potential of

- disability studies to reframe family/school linkages. In S. Danforth & S. L. Gabel (Eds.), *Disability studies in education: Vital questions facing disability studies in education*, 2 (pp. 217-235). Peter Lang.
- Filax, G., Sumara, D., Davis, B., & Shogan, D. (2011). Queer theory/lesbian and gay approaches. In B. Somekh & C. Lewin (Eds.), *Theory and methods in social research* (2nd edition) (pp. 86-93). SAGE.
- Fleming, P. (2014). When “life itself” goes to work: Reviewing shifts in organizational life through the lens of biopower. *Human Relations*, 67(7), 875-901. SAGE.
<https://doi.org/10.1177%2F0018726713508142>
- Foley, S. (2016). Normalisation and its discontents: Continuing conceptual confusion over theory/praxis issues regarding the empowerment of people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 41(2), 177-185.
<https://doi.org/10.3109/13668250.2016.1153053>
- Foote, C. E., & Frank, A. W. (1999). Foucault and therapy: The disciplining of grief. In A. S. Chambon, A. Irving, & L. Epstein (Eds.), *Reading Foucault for social work* (pp. 157-187). Columbia University Press.
- Foucault, M. (1972). *The archaeology of knowledge*. Tavistock Publications Limited.
- Foucault, M. (1980). *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*. C. Gordon (Ed.). C. Gordon, L. Marshall, J. Mepham, & K. Soper (Trans.). Pantheon Books.
- Foucault, M. (1982, Summer). The subject and power. *Critical Inquiry*, 8(4), 777-795.
<http://www.jstor.org/stable/1343197>
- Foucault, M. (1988). *Politics, philosophy, culture: Interviews and other writings, 1977-84*. L.

- D. Kritzman (Ed.). Routledge.
- Foucault, M. (1995). *Discipline and punish: The birth of the prison* (A. Sheridan, Trans. 2nd ed.). Vintage. (Original work published in 1975).
- Foucault, M. (2007) *The politics of truth*. S. Lotringer (Ed.). Semiotext.
- Foucault, M. (2008, Autumn). Panopticism. *Race/Ethnicity: Multidisciplinary Global Contexts*, 2(1), 1-12. (Reprinted from *Discipline and Punish*, by A. Sheridan, Trans., 1977, Pantheon. Original work published 1975, Editions Gallimard).
- Foucault, M. (2008b). *The birth of biopolitics: Lectures at the College De France 1978–1979*. Palgrave Macmillan.
- Foucault, M. (2019). *Discourse and truth and parrēsia*. (H.-P. Fruchaud & D. Lorenzini, Eds.). (N. Luxon, Trans.). The University of Chicago Press. Original lectures in 1982 & 1983.
- Freedman, D. H., (2012, June). The perfected self: B.F. Skinner’s notorious theory of behavior modification was denounced by critics 50 years ago as a fascist, manipulative vehicle for government control. But Skinner's ideas are making an unlikely comeback today, powered by smartphone apps that are transforming us into thinner, richer, all-around-better versions of ourselves. The only thing we have to give up? Free will. *The Atlantic*, 309(5), 42-52.
- Ghilain, C. S., Parlade, M. V., McBee, M. T., Coman, D. C., Owen, T., Gutierrez, A., Boyd, B., Odom, S., & Alessandri, M. (2017). Validation of the Pictorial Infant Communication Scale for preschool-aged children with autism spectrum disorder. *Autism*, 21(2), 203-216. SAGE.
- <https://doi.org/10.1177%2F1362361316636757>

Gillies, D. (2013). *Educational Leadership and Michel Foucault*. Routledge.

Gitimoghaddam, M., Chichkine, N., McArthur, L., Sangha, S., & Symington, V. (2022).

Applied behavior analysis in children and youth with autism spectrum disorders: A scoping review. *Perspectives on Behavior Science*. Association for Behavior Analysis International. Springer.

<https://doi.org/10.1007/s40614-022-00338-x>

Goin-Kochel, R. P., Myers, B. J., Hendricks, D. R., Carr, S. E. & Wiley, S. B. (2007, June).

Early responsiveness to intensive behavioural intervention predicts outcomes among preschool children with autism. *International Journal of Disability, Development and Education*, 54(2), 151-175. Routledge.

<https://doi.org/10.1080/10349120701330404>

Goldstein, S., & Naglieri, J. A. (2009). *Autism spectrum rating scales*. Pearson.

Gowlett, C. (2015). Queer(y)ing new schooling accountabilities through *My School*: Using Butlerian tools to think differently about policy performativity. *Educational Philosophy and Theory*, 47(2), 159-172.

<http://dx.doi.org/10.1080/00131857.2013.793926>

Grandin, T., & Duffy, K. (2004) *Developing talents: Careers for individuals with Asperger Syndrome and High-Functioning Autism*. Autism Asperger Publishing Company.

Greene, M. (1987-88, Winter). Freedom, education, and public spaces. *Cross Currents*, 37(4), 442-455. Wiley.

<http://www.jstor.com/stable/24459371>

Groskreutz, N. C., Groskreutz, M. P., Bloom, S. E., & Slocum, T. A. (2014). Generalization

- of negatively reinforced mands in children with autism. *Journal of Applied Behavior Analysis*, 47, 560–579.
- <https://doi-org.proxy006.nclive.org/10.1002/jaba.151>
- Gryaznova, A. N., & Vasina, V. V. (2020). Assessment of the formation of communication skills using VB-MAPP in preschool children with ASD. *Autism and developmental disorders*, 18(4), 23-32.
- <https://doi.org/10.17759/autdd.2020180403>
- Hacking, I. (1990). *The Taming of Chance*. University of Cambridge Press.
- Hancock, G., Stokes, M. A., & Mesibov, G. (2020). Differences in romantic relationship experiences for individuals with an autism spectrum disorder. *Sexuality and Disability*, 38, 231-245. Springer.
- <https://link.springer.com/article/10.1007/s11195-019-09573-8>
- Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System* (3rd Edition). Western Psychological Services.
- Hobbs, A. (2016). *A chosen exile: A history of racial passing in American life*. Harvard University Press.
- Holt, L., Lea, J., & Bowlby, S. (2012). Special units for young people on the autistic spectrum in mainstream schools: Sites of normalisation, abnormalisation, inclusion, and exclusion. *Environment and Planning*, 44, 2191-2206.
- <https://doi.org/10.1068%2Fa44456>
- Hooks, B. (1989). Choosing the margin as a space of radical openness. *Framework: The Journal of Cinema and Media*, 36, 15-23. Wayne State University Press.
- <https://www.jstor.org/stable/44111660>

Hull, G. (2017). The subject and power of bioethics. *Ethics, Medicine, and Public Health*, 3, 410-419. Elsevier Masson SAS.

<http://dx.doi.org/10.1016/j.jemep.2017.08.001>

Individuals with Disabilities Education Act of 1990, P. L. 101-476 § 104-1103. (1990, October 30).

<https://www.govinfo.gov/content/pkg/STATUTE-104/pdf/STATUTE-104-Pg1103.pdf>

Interagency Autism Coordinating Committee (IACC). (2021, April). *2017-2018 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. United States Department of Health and Human Services Interagency Autism Coordinating Committee.

<https://iacc.hhs.gov/publications/portfolioanalysis/2018/>

Jackson, A. Y., & Mazzei, L. (2012). *Thinking with theory in qualitative research : Viewing data across multiple perspectives*. Taylor & Francis Group.

Jackson, A. Y., & Mazzei, L. A. (2017). Thinking with theory: A new analytic for qualitative inquiry. In Denzin, N. & Lincoln, Y. (Eds.). *The SAGE Handbook of Qualitative Research* (5th edition). SAGE.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2(3), 217-250.

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). "People should be allowed to do what they like": Autistic adults' views and experiences of stimming. *Autism*, 23(7), 1782-1792. SAGE.

<https://doi.org/10.1177%2F1362361319829628>

Katsiyannis, A., Yell, M. & Bradley, R. (2001, November/December). Reflections on the

- 25th anniversary of the Individuals with Disabilities Education Act. *Remedial and Special Education*, 22(6), 324-334.
- <https://journals.sagepub.com/doi/pdf/10.1177/074193250102200602>
- Kaufman, A. S., & Kaufman, N. L. (2014) *Kaufman test of educational achievement* (3rd ed.). Pearson.
- <https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Academic-Learning/Reading/Kaufman-Test-of-Educational-Achievement-%7C-Third-Edition/p/100000777.html>
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with a developmental disability. *Issues and Innovations in Nursing Practice*, 34(5), 582-592. <https://doi.org/10.1046/j.1365-2648.2001.01787.x>
- Kelly, C. A., & Dale, P. S. (1989). Cognitive skills associated with the onset of multiword utterances. *Journal of Speech Language Hearing Research*, 32, 645–656.
- <https://doi.org/10.1044/jshr.3203.645>
- Khalifa, J. (2003). An impersonal consciousness. In J. Khalifa (Ed.), *Introduction to the philosophy of Gilles Deleuze* (pp. 64-82). Continuum.
- Klein, B. L. (1984). Families of handicapped children: A personal account. In M. L. Henniger & E. M. Nesselroad (Eds.), *Working with parents of handicapped children: A book of readings for school personnel* (pp. 73-81). University Press of America.
- Kodak, T., Paden, A., & Dickes, N. (2012). Training and generalization of peer-directed mands with non-vocal children with autism. *Analysis of Verbal Behavior*, 28, 119–124. <https://doi-org.proxy006.nclive.org/10.1007/BF03393112>
- Koro-Ljungberg, M., MacLure, M., & Ulmer, J. (2017). D...a...t...a..., data++, data, and

- some problematics. In Denzin, N. & Lincoln, Y. (Eds.). *The SAGE Handbook of Qualitative Research* (5th edition) (pp. 462-484). SAGE.
- Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. Routledge.
- Kübler-Ross, E., & Kessler, D. (2005) *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Scribner.
- Laakso, M. L., Poikeus, A. M., Eklund, K., & Lyytinen, P. (1999). Social interactional behaviors and symbolic play competence as predictors of language development and their associations with maternal attention-directing strategies. *Infant Behavior and Development*, 22, 541–556.
[https://doi.org/10.1016/S0163-6383\(00\)00022-9](https://doi.org/10.1016/S0163-6383(00)00022-9)
- Ladenson, R. F. (2020). *Moral issues in special education: An inquiry into the basic rights, responsibilities, and ideals*. Rowman & Littlefield.
- Lather, P. (2006). Paradigm proliferation as a good thing to think with: Teaching research in education as a wild profusion. *International Journal of Qualitative Studies in Education*, 19(1), 35-57.
<https://doi.org/10.1080/09518390500450144>
- Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2022). Concerns about ABA-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*, 52, 2838-2853.
<https://doi.org/10.1007/s10803-021-05137-y>
- Lenz Taguchi, H., & St. Pierre, E. A. (2017). Using concept as method in educational and

- social science inquiry. *Qualitative Inquiry*, 23(9), 643-648. SAGE.
<https://doi.org/10.1177/10778004177326>
- Lerman, T. (2022, January 28). It's time we expand the neurodiversity conversation beyond autism. *Invisible Illness*.
<https://medium.com/invisible-illness/its-time-we-expand-the-neurodiversity-conversation-beyond-autism-a0b2d46d00f>
- Leslie, A. (1987) Pretence and representation in infancy: Origins of “theory of mind.” *Psychological Review*, 94, 84–106.
<https://psycnet.apa.org/doi/10.1037/0033-295X.94.4.412>
- Liu, T., & Csikszentmihalyi, M. (2020, December 1). Flow among introverts and extraverts in solitary and social activities. *Personality and Individual Differences*, 167, 110197. Elsevier.
<https://doi.org/10.1016/j.paid.2020.110197>
- Locke, T. (2004). *Critical discourse analysis*. Continuum.
- Lord, C., Rutter, M., Dilavore, P. C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism Diagnostic Observation Schedule* (2nd edition). Western Psychological Services.
- Manning, E. (2007). *Politics of touch: Sense, movement, and sovereignty*. University of Minnesota Press.
- Manning, E. (2013). *Always more than one*. Duke University Press.
- Manning, E. (2016). *The minor gesture*. Duke University Press.
- Manning, E. & Massumi, B. (2014). *Thought in the act: Passages in the ecology of experience*. University of Minnesota Press.
- Masiran, R. (2018, February 23). Stimming behavior in a 4-year-old girl with autism

- spectrum disorder. *BMJ Case Reports*.
<http://dx.doi.org/10.1136/bcr-2017-223671>
- Matson, J. L., & Williams, L. W. (2013, April). Differential diagnosis and comorbidity: distinguishing autism from other mental health issues. *Neuropsychiatry*, 3(2), 233-243.
<https://www.proquest.com/docview/1324573988?pq-origsite=gscholar&fromopenview=true>
- May, T. (2005). *Gilles Deleuze: An Introduction* (pp. 1-25; 114-153). Cambridge University Press.
- Mayo Foundation for Medical Education and Research (2018, January 06). *Autism Spectrum Disorder: Diagnosis and treatment*. Mayo Clinic.
<https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/diagnosis-treatment/drc-20352934>
- McCabe, M., & Nye-Lengerman, K. (2021, July). Putting policy into practice: Impact of the Every Student Succeeds Act on speech-language pathologists and students with disabilities. *Language, Speech, and Hearing Services in Schools*, 52, 949-954.
 American Speech-Language-Hearing Association.
https://doi.org/10.1044/2021_LSHSS-20-00139
- McCune-Nicolich, L. (1981). Toward symbolic functioning: Structure of early pretend games and potential parallels with language. *Child Development*, 52, 785–797.
<https://doi.org/10.2307/1129078>
- McGovern, T. (2019). *Using Rancière, Deleuze and Foucault to re-imagine research with*

- children on the Autism Spectrum in Scottish primary schools* [Doctoral Thesis, University of Stirling (Scotland)]. Stirling Online Research Repository.
<http://hdl.handle.net/1893/30543>
- McHugh, L., Bobarnac, A., & Reed, P. (2011). Brief report: Teaching situation-based emotions to children with autistic spectrum disorder. *Journal of Autism and Developmental Disorders*, 41, 1423–1428.
<https://doi-org.proxy006.nclive.org/10.1007/s10803-010-1152-2>
- McKay, J., & Garratt, D. (2013). Participation as governmentality? The effect of disciplinary technologies at the interface of service users and providers, families and the state. *Journal of Education Policy*, 28(6), 733-749. Taylor & Francis.
<https://doi.org/10.1080/02680939.2012.752869>
- McKenzie, J. A. (2009). Constructing the intellectually disabled person as a subject of education: A discourse analysis using Q-methodology [Thesis]. Rhodes University.
<https://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.630.7103>
- Merriam, S. (2002). *Qualitative research in practice*. Jossey-Bass.
- Miller, D., Rees, J., & Pearson, A. (2021, December 7). “Masking is life”: Experiences of masking in autistic and nonautistic adults. *Autism in Adulthood*, 3(4).
<https://doi.org/10.1089/aut.2020.0083>
- Moffatt, K. (1999). Surveillance and government of the welfare recipient. In A. S. Chambon, A. Irving, & L. Epstein (Eds.), *Reading Foucault for social work* (pp. 219-245). Columbia University Press.
- Moghtader, B. (2016). *Foucault and Educational Ethics*. Palgrave Macmillan.
- Molloy, H., & Vasil, K. (2002). The social construction of Asperger Syndrome: The

- pathologising of difference?. *Disability & Society*, 17(6), 659–669. Taylor & Francis.
<https://doi.org/10.1080/0968759022000010434>
- Montallana, K. L., Gard, B. M., Lotfizadeh, A. D., & Poling, A. (2019). Inter-rater agreement for the milestones and barriers assessments of the Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP). *Journal of Autism and Developmental Disorders*, 49, 2015–2023. Springer.
<https://doi.org/10.1007/s10803-019-03879-4>
- Mullen, E. M. (1995). *Mullen Scales of Early Learning*. Pearson.
- Muller, E., Schuler, A., Yates, G. B. (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, 12, 173–190.
<https://doi.org/10.1177/1362361307086664>
- Naidoo, P. (2006). Potential contributions to disability theorizing and research from positive psychology. *Disability and Rehabilitation*, 28(9), 595–602.
<https://doi.org/10.1080/00222930500219027>
- National Council on Disability (2018, February 7). *IDEA series: Every Student Succeeds Act and students with disabilities*.
https://permanent.fdlp.gov/gpo153961/NCD_ESSA-SWD_Accessible.pdf
- Nigmatullina, I. A., & Nigmatullina, A. A. (2020). VB-MAPP: Opportunities for differential diagnosis of verbal skills and social interaction of children with autism and hearing disorders. *International Journal of Pharmaceutical Research* 1, 1058–1067.
<https://doi-org.proxy006.nclive.org/10.31838/ijpr/2020.SP1.157>
- Nolan, J., & McBride, M. (2015). Embodied semiosis: Autistic "stimming" as sensory praxis.

- In P. Trifonas (Ed.), *International handbook of semiotics* (pp. 1069–1078). Springer.
- North Carolina Department of Health and Human Services. (n.d.). NC Innovations Waiver.
<https://medicaid.ncdhhs.gov/providers/programs-and-services/behavioral-health-idd/nc-innovations-waiver>
- North Carolina Department of Public Instruction. (n.d.) *Every Child Accountability & Tracking System (ECATS)*.
<https://www.dpi.nc.gov/districts-schools/classroom-resources/exceptional-children/every-child-accountability-tracking-system-ecats>
- North Carolina State Education Assistance Authority. (2022). *Education student accounts (ESA+) program*.
<https://www.ncseaa.edu/k12/esa/>
- Office of Special Education and Rehabilitative Services. (2021). *43rd annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2021*. United States Department of Education.
<https://sites.ed.gov/idea/files/43rd-arc-for-idea.pdf>
- Ogilvie, B. (2015). Living between the lines. In F. Deligny, *The arachnean and other texts* (pp. 9-19). D.S. Burk & C. Porter (Trans.). Univocal.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-193.
<https://doi.org/10.1177%2F104438946204300404>
- Organization for Autism Research. (2021). *Studies funded*.
<https://researchautism.org/research-grants/studies-funded/>
- Padilla, K. L., & Akers, J. S. (2021). Content validity evidence for the Verbal Behavior

- Milestones Assessment and Placement Program. *Journal of Autism and Developmental Disorders*, 51, 4054-4066. Springer.
<https://doi.org/10.1007/s10803-020-04864-y>
- Parham, L. D., Ecker, C. L., Kuhaneck, H., Henry, D. A., & Glennon, T. J. (2021). *Sensory processing measure* (2nd ed.). Western Psychological Services.
<https://www.wpspublish.com/spm-2>
- Partington, J. W. (2010, September). *The assessment of basic language and learning skills—revised: An assessment, curriculum guide, and skills tracking system for children with autism or other developmental disabilities*. Behavior Analysts.
- Partington, J. W. (2022). *ABLLS-R set*. Partington Behavior Analysts.
<https://partingtonbehavioranalysts.com/products/ablls-r-the-assessment-of-basic-language-and-learning-skills-revised>
- Patel, L. (2016). *Decolonizing educational research*. Routledge.
<https://doi.org.proxy006.nclive.org/10.4324/9781315658551>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756-770. DOI: 10.1177/1362361314529627
- Peters, S. (2007). Education for All? A historical analysis of international inclusive education policy and individuals with disabilities. *Journal of Disability Policy Studies*, 18(2), 98-108. SAGE.
<https://doi.org/10.1177%2F10442073070180020601>
- Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2011). A meta-analytic study

- on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 60–69.
- <https://doi.org/10.1016/j.rasd.2010.03.011>
- Petrina, N., Carter, M., & Stephenson, J. (2014, Feb). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 8(2), 111-126. Elsevier.
- <https://doi.org/10.1016/j.rasd.2013.10.016>
- Piaget, J. (1954). The development of object concept. (M. Cook, Trans.). In J. Piaget & M. Cook (Trans.), *The construction of reality in the child* (p. 3–96). Basic Books.
- <https://doi.org/10.1037/11168-001>
- Piaget, J. (1964). Development and learning. *Journal of Research in Science Teaching*, 2, 176-186.
- <https://doi-org.proxy006.nclive.org/10.1002/tea.3660020306>
- Prado, B. (2003). The plane of immanence and life. In J. Khalfa (Ed.), *Introduction to the philosophy of Gilles Deleuze* (pp. 9-25). Continuum.
- Preston, M. J., & Hoffman, G. D. (2015). Traditionally heterogendered institutions: Discourses surrounding LGBTQ college students. *Journal of LGBT Youth*, 12, 64–86.
- DOI: 10.1080/19361653.2014.935550
- Public Schools of North Carolina: Exceptional Children Division (2015, December). *Special education regulations and law* [PowerPoint].
- <https://files.nc.gov/dpi/documents/charterschools/planning/student-needs/ecregulationslaw.pdf>

- Public Schools of North Carolina: Exceptional Children Division (2016, July). *Parent rights and responsibilities in special education: Notice of procedural safeguards* [Booklet].
- Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, 66. <https://doi-org.proxy006.nclive.org/10.1016/j.rasd.2019.101415>
- Rank, B. (1949, January). Adaptation of the psychoanalytic technique for the treatment of children with atypical development. *American Journal of Orthopsychiatry*, 19, 130-139. <https://doi.org/10.1111/j.1939-0025.1949.tb06567.x>
- Reyes, A. (2020, May 16). *The difference between receptive and expressive language*. NAPA Center. <https://napacenter.org/receptive-vs-expressive-language/>
- Reynolds, C. R., & Kamphaus, R. W. (2015). *Behavior assessment system for children: Parent rating scales for preschool ages 2-5* (3rd ed.). Pearson.
- Rogers, S. J., Dawson, G., & Vismara, L. A. (2012). *An early start for your child with autism: Using everyday activities to help kids connect, communicate, and learn*. The Guilford Press.
- Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-V and beyond. *Journal of Autism and Developmental Disorders*, 51, 4253-4270. Springer. <https://doi.org/10.1007/s10803-021-04904-1>
- Sauter, R. A., & LeBlanc, L. A. (2006). Empirical applications of Skinner's analysis of verbal behavior with humans. *The Analysis of Verbal Behavior*, 22, 35-48. <https://doi.org/10.1007/BF03393025>
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting

- children who have disabilities. *Mental Retardation*, 38(3), 195-206.
[https://doi.org/10.1352/0047-6765\(2000\)038%3C0195:TOAWPC%3E2.0.CO;2](https://doi.org/10.1352/0047-6765(2000)038%3C0195:TOAWPC%3E2.0.CO;2)
- Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin*, 32(1), 84-110. Retrieved from
<https://eric.ed.gov/?id=EJ848193>
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55(1), 5-14. doi: 10.1037/0003-066X.55.1.5. Retrieved from
<https://liminalolutions.com/wp-content/uploads/2021/06/Positive-Psychology-An-Introduction-by-Martin-Seligman-and-Mihaly-Csikzentmihalyi.pdf>
- Sequenzia, A. (2015, February 11). My thoughts on ABA. *Autistic Women & Nonbinary Network*.
<https://awnnetwork.org/my-thoughts-on-aba/>
- Shamash, E. R., & Hinman, J. A. (2021). Assessing caregiver stress and coping at time of Autism Spectrum Disorder diagnosis. *Early Childhood Education Journal*, 1-10.
<https://doi-org.proxy006.nclive.org/10.1007/s10643-020-01145-2>
- Sheldrick, R. C., Schlichting, L. E., Berger, B., Clyne, A., Ni, P., Perrin, E. C., & Vivier, P. M. (2019, December). Establishing new norms for developmental milestones. *Pediatrics*, 144(6), e20190374. The American Academy of Pediatrics.
<https://doi.org/10.1542/peds.2019-0374>
- Shepherd, D., Landon, J., & Goedeke, S. (2018). Symptom severity, caregiver stress and intervention helpfulness assessed using ratings from parents caring for a child with autism. *Autism: The International Journal of Research and Practice*, 22(5), 585–596.

<https://doi.org/10.1177/1362361316688869>

Sheridan, S. M., Warnes, E. D., Cowan, R. J., Schemm, A. V., & Clarke, B. L. (2004).

Family-centered positive psychology: Focusing on strengths to build student success.

Psychology in the Schools, 41(1), 7-17.

<https://doi.org/10.1002/pits.10134>

Shillingsburg, M. A., Powell, N. M., & Bowen, C. N. (2013). Teaching children with autism spectrum disorders to mand for the removal of stimuli that prevent access to preferred items. *Analysis of Verbal Behavior*, 29, 51–57.

<https://doi-org.proxy006.nclive.org/10.1007/BF03393123>

Shoaf, G. (2020, February 27-28). *At-risk students and sensory decals: A study on school climate and discipline* [Poster session]. NCARE 2020 Conference, Greensboro, NC, United States.

Shore, S. M. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome* (2nd ed.). Autism Asperger Publishing.

Shore, S. M. (2020). *The four A's of autism* [Video Presentation]. ABC of NC Fundraiser.

https://issuu.com/abcofnc_autism/docs/abc_of_nc_gll_postcard_2020

Sigmana, M., Ruskin, E., Arbelle, S., Corona, R., Dissanayake, C., Espinosa, M., Kim, N.,

López, A., Zierhut, C., Mervis, C. B., & Robinson, B. F. (1999). Continuity and change in the social competence of children with autism, Down syndrome, and

developmental delays. *Monographs of the Society for Research in Child*

Development, 64(1). Wiley.

<https://www.jstor.org/stable/3181510>

Sigman, M., & Ungerer, J. A. (1984). Cognitive and language skills in autistic, mentally-

- retarded, and normal children. *Child Development*, 63, 796–807.
<https://psycnet.apa.org/doi/10.1037/0012-1649.20.2.293>
- Simons Foundation. (2021, March 12). Genetic analysis FAQ. *Simons Powering Autism Research for Knowledge (SPARK) for Autism*.
<https://sparkforautism.org/portal/page/genetic-analysis-faq/>
- Sinclair, J. (2012). Don't Mourn for Us. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1), 1-5. Autism Network International. Original work published 1993.
<http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/8>
- Skinner, B. F. (1957). *Verbal behavior*. Appleton-Century-Crofts.
<http://hdl.handle.net/2027/uc1.b4377057>
- Skott-Myrhe, H. A., & Taylor, C. (2011). Autism: Schizo of postmodern capital. *Deleuze Studies*, 5(1), 35-48. Edinburgh University Press.
<https://www.euppublishing.com/doi/abs/10.3366/dls.2011.0004>
- Smerbeck, A. (2019, January). The Survey of Favorite Interests and Autism: Assessing and understanding restricted interests in children with autism spectrum disorder. *Autism*, 23(1), 247-259.
<https://doi.org/10.1177/1362361317742140>
- Smith, C. A., Parton, C., King, M., & Gallego, G. (2020). Parents' experiences of information-seeking and decision-making regarding complementary medicine for children with autism spectrum disorder: a qualitative study. *BMC Complementary Medicine and Therapies*, 20(1).
<https://doi-org.proxy006.nclive.org/10.1186/s12906-019-2805-0>

- Snow, K. (2001). *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. Braveheart Press.
- Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, 16, 523-537.
<https://doi.org/10.1080/00797308.1961.11823222>
- Sonnenschein, P. (1981). Parents and professionals: An uneasy relationship. *Teaching Exceptional Children*, 14(2), 62-65.
<https://doi.org/10.1177%2F004005998101400205>
- Stone, W., Lemanek, K., Fishel, P., Fernandez, M., & Altemeier, W. (1990). Play and imitation skills in diagnosis of autism in young children. *Pediatrics*, 86, 267-272.
<https://doi.org/10.1542/peds.86.2.267>
- St. Pierre, E. A. (2011). Post qualitative research: The critique and the coming after. In N. K. Denzin & Y. S. Lincoln (Eds.), *SAGE handbook of qualitative inquiry* (4th ed., pp. 611-635). SAGE.
- St. Pierre, E. A. (2017). Writing post qualitative inquiry. *Qualitative Inquiry*, 24(9), 1-6. SAGE.
<https://doi.org/10.1177/1077800417734567>
- St. Pierre, E. A. (2019). Post qualitative inquiry, the refusal of method, and the risk of the new. *Qualitative Inquiry*, 27(1), 1-7. SAGE.
<https://doi.org/10.1177/1077800419863005>
- St. Pierre, E. A., & Jackson, A. Y. (2014). Qualitative data analysis after coding. *Qualitative Inquiry*, 20(6), 715-719.
<https://doi.org/10.1177%2F1077800414532435>

- Sundberg, M. L., (2014). *Verbal behavior milestones assessment and placement program: A language and social skills assessment program for children with autism or other developmental disabilities* (2nd ed.). AVB Press.
- Sundberg, M. L., (2020). *VB-MAPP*.
<https://marksundberg.com/vb-mapp/>
- Sundberg, M. L., & Michael, J. (2001). The benefits of Skinner's analysis of verbal behavior for children with autism. *Behavior Modification*, 25, 698–724.
<https://doi-org.proxy006.nclive.org/10.1177/0145445501255003>
- Surbaugh, M. (2010). Producing islands of self-mastery: The biopolitics of self-determination in special education. *Philosophy of Education Archive*, 108-116.
 University of Illinois.
<https://educationjournal.web.illinois.edu/archive/index.php/pes/article/view/3015.pdf>
- Swart, E., & Pettipher, R. (2005). A framework for understanding inclusion. In E. Landsberg, D. Kruger & N. Nel (Eds.), *Addressing barriers to learning: A South African perspective* (pp. 3-23). Van Schaik.
- Therapeutic Pathways (2021, March 9). *Who is qualified to diagnose autism?*
<https://www.tpathways.org/faqs/who-can-diagnose-autism/>
- Tougaw, J. (2020, April 18). Neurodiversity: The movement. *Psychology Today*.
<https://www.psychologytoday.com/us/blog/the-elusive-brain/202004/neurodiversity-the-movement>
- Tremain, S. L. (2017). *Foucault and feminist philosophy of disability*. University of Michigan Press.
- Tuck, E. (2009). Suspending damage: A letter to communities. *Harvard Educational Review*

79(3), 409–428.

<https://doi.org/10.17763/haer.79.3.n0016675661t3n15>

Turner, M., Kubatzky, L., & Jones, L. E. (2018). Assessing ESSA: Missed opportunities for students with disabilities. National Center for Learning Disabilities.

https://www.ncld.org/wp-content/uploads/2018/10/AssessingESSA_2018.pdf

Ungerer, J. A., & Sigman, M. (1981). Symbolic play and language comprehension in autistic children. *Journal of the American Academy of Child Psychiatry*, 20(2), 318-337. Elsevier.

[https://doi.org/10.1016/S0002-7138\(09\)60992-4](https://doi.org/10.1016/S0002-7138(09)60992-4)

United States Department of Education. (1983, April). Archived Information: *A Nation at Risk*.

<https://www2.ed.gov/pubs/NatAtRisk/risk.html>

United States Department of Health and Human Services. (2020, June 10). *Center for Disease Control and Prevention's developmental milestones*.

<https://www.cdc.gov/ncbddd/actearly/milestones/index.html>

University of Massachusetts Global (2020, January 3). *Four special education laws and policies every teacher should know* [Blog]. UMass Global Administration.

<https://www.umassglobal.edu/news-and-events/blog/special-education-laws>

van Grunsven, J., & Roeser, S. (2021). AAC technology, autism, and the empathic turn. *A Journal of Knowledge, Culture and Policy*, 36(1), 95-110.

<https://doi.org/10.1080/02691728.2021.1897189>

Vakirtzi, E., & Bayliss, P. (2013). Towards a Foucauldian methodology in the study of

- autism: Issues of archaeology, genealogy, and subjectification. *Journal of Philosophy of Education*, 47(3), 364-378.
- <https://doi.org/10.1111/1467-9752.12004>
- Volkmar, F. R., & McPartland, J. C., (2014). From Kanner to DSM-5: Autism as an evolving diagnostic concept. *Annual Review of Clinical Psychology*, 10, 193-212.
- <https://www.annualreviews.org/doi/abs/10.1146/annurev-clinpsy-032813-153710>
- Waltz, M. (2014). Worlds of autism: Across the spectrum of neurological difference. *Disability and Society*, 29(8), 1337-1338.
- <https://doi.org/10.1080/09687599.2014.934064>
- Wechsler, D. (2012). *Wechsler preschool and primary scale of intelligence* (4th ed.). Pearson.
- <https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Cognition-%26-Neuro/Gifted-%26-Talented/Wechsler-Preschool-and-Primary-Scale-of-Intelligence-%7C-Fourth-Edition/p/100000102.html?tab=overview>
- Wettach, J. (2017). *A Parent's Guide to Special Education in North Carolina*. Children's Law Clinic at Duke Law School.
- https://law.duke.edu/childedlaw/docs/Parents'_guide.pdf
- Williams, E., Reddy, V., & Costall, A. (2001). Taking a closer look at functional play in children with autism. *Journal of Autism and Developmental Disorders*, 31, 67-77.
- Springer.
- <https://link.springer.com/article/10.1023/A:1005665714197>
- Wilkenfeld, D. A., & McCarthy, A. M. (2020, March). Ethical concerns with applied

- behavior analysis for autism spectrum “disorder.” *Kennedy Institute of Ethics Journal*, 30(1), 31-69. John Hopkins University Press.
- <https://doi.org/10.1353/ken.2020.0000>
- Wing, L. (1981). Asperger’s syndrome: A clinical account. *Psychological Medicine*, 11(1), 115–129.
- <https://doi.org/10.1017/S0033291700053332>
- Winter-Messiers, M. A. (2007) From tarantulas to toilet brushes: Understanding the special interests of youth with Asperger syndrome. *Remedial and Special Education*, 28, 140–152. SAGE.
- <https://doi.org/10.1177%2F07419325070280030301>
- Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining critical autism studies: a more inclusive interpretation. *Disability and Society*, 33(6), 974-979.
- <https://doi.org/10.1080.09687599.2018.1454380>
- Wolff, S. (2004). The history of autism. *European Child and Adolescent Psychiatry*, 13(4), 201-208.
- <https://doi.org/10.1007/s00787-004-0363-5>
- Yell, M. L., Bateman, D. F., & Shriner, J. G. (2022). *Developing educationally meaningful and legally sound IEPs*. Rowman & Littlefield.
- Yell, M. L., & Drasgow, E. (2000). Litigating a free appropriate public education: The Lovaas hearings and cases. *Journal of Special Education*, 3(3), 206-215.
- <https://doi.org/10.1177%2F002246690003300403>
- Zimmerman, I. L., Steiner, V. G., & Pond, R. E. (2011). *Preschool Language Scales* (5th Edition). Pearson.

Vita

Gwynne Wilson Shoaf was born in Salisbury, North Carolina, to Dean and Patsy Wilson. She graduated from the University of South Carolina with both a Bachelor of Arts degree in Spanish and a Bachelor of Science degree in Business Administration in May 2003. Mrs. Shoaf earned a Master of Education degree in Curriculum and Instruction from the University of North Carolina Greensboro (2008) and National Board Certification (2011) while serving as a middle school Spanish and Language Arts teacher. While working as an instructional coach, Mrs. Shoaf completed a Master of School Administration Add-on Licensure program with the University of North Carolina Wilmington in 2014. Following the birth of her son, Mrs. Shoaf left full-time employment in public schools to pursue her Education Specialist degree at Appalachian State University, which was awarded in 2018. In Fall of 2019, she began work on her Doctorate of Education degree at Appalachian State University.

Mrs. Shoaf has held various positions in nonprofit organizations since leaving the classroom with a focus on college access, grant management, and teacher empowerment. She serves on the North Carolina Association for Research in Education Board and is an active member of her church. Mrs. Shoaf resides in Salisbury, North Carolina, with her husband, son, and cat, Checkers.