

PARENT PERSPECTIVES OF AUTISTIC STUDENTS ON FACTORS OF DENIAL
FROM SPECIAL EDUCATION IN TEXAS:
A MULTIPLE CASE STUDY

by

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A dissertation submitted to the Graduate Council of
Texas State University in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
with a Major in School Improvement
August 2023

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DEDICATION

I dedicate this study to my son, Carter Joplin Ota, whose story of struggle, strife, and victories is a part of the narratives as much as the participants'. Without his autism, I would not have changed course in my career and personal life, which has led me to a path of advocacy, enlightenment, and discovery of my own diagnosis. He is my world, and the moment he was born, I fell in love and grow more amazed by him every day. I relish in the memories of his awesomeness, and I look forward to seeing the good he will bring to the world.

ACKNOWLEDGEMENTS

Collectively, I have been in college for 21 years, which includes two bachelor's degrees, two master's degrees, and now one doctorate. These certificates of completion were accomplished by a kid who couldn't read in the third grade, who finished just above the 50th percentile in high school, and was told by a math professor that if I needed accommodations for upper level courses, then I shouldn't be in college. One might easily say that I was successful because I had perseverance, dedication, and self-reliance; one would be wrong. It took a whole community to get where I am at today, both professionally and personally, and what follows is my best way to thank them.

Penny Smeltzer and Mike Kristan were high school teachers who not only taught me how to be a good teacher, but they also showed me how to be a compassionate person and researcher. Terry Falcomata, Mark O'Reilly, and Andrea Flower are professors who instilled in me the importance of critical research, sometimes at their own expense, and helped me sharpen my quantitative tools in search of better solutions for students with special needs. Keri Douglas, Trissa Williams, and Christine Stanton supported and encouraged me—including spending countless hours listening to me proof essays for applications to doctoral programs—to pursue my passion for autism research and advocacy even if that meant leaving the teaching profession. Rep. John Bucy and staff, the Autism Society of Texas Board of Directors and staff, and committee members of the policy group from TxABA guided me in how to become a research activist. Most recently, I appreciate all my professors at Texas State University—including Hilary Lustick—who encouraged me to study autism, helped me become the researcher I am today, and showed me how social justice and community are integral parts of validity in studying special education.

I would also like to thank my committee members—Drs. Larry Price, Miguel Guajardo, and David DeMatthews—for all your support and guidance in pursuing such an important and timely study. Above all, though, I would like to thank my chair, Melissa Martinez, for your guidance, patience, encouragement, kindness, and faith in me even at times when it was at its lowest. I am truly indebted to you for taking me on as a mentee, including me in projects, allowing me to TA your class, and for many more favors I am sure to come. I would be in dereliction of duty if I did not also include the members of my writing group, especially Christina Gomez-Hernandez and Kelley Glover, who invited and included me into the “family,” partnered with me in research, and I hope will be lifelong resources for me and me for them.

Most importantly, I would like to thank my family. I was able to accomplish something that alluded my father due to the racism against Japanese Americans in the 1960s. In their own way, both my mother and father expected nothing less and encouraged me to pursue any path I set my mind to. My sons and stepdaughter have been there for 13 years of “gradual” school, and I thank them for their understanding and patience for the times I was present at their games and concerts with a laptop or book. Thank you to my in laws, Mark and Sue Wieland, for stepping in and being present after my parents passed. And finally, but not least, to my wife, Amy, who has been a partner and critical analyst in all my work. You are my best friend and partner in crime, and there is no way whatsoever I could have gotten to this point, both professionally and personally, without you.

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LIST OF ABBREVIATIONS

Abbreviation	Description
504	Section 504 of the Americans with Disabilities Act
ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
ADOS-2	The Autism Diagnostic Observation Schedule, 2 nd Ed.
AP	Assistant Principal
ARD	Annual Review and Dismissal
ASD	Autism Spectrum Disorder
BASC	Behavior Assessment System for Children
BCBA	Board Certified Behavior Analyst
BIP	Behavioral Intervention Plan
CAPS	Clinical Assessment of Pragmatics
CARS-2	Childhood Autism Rating Scale, 2 nd Ed.
CDC	Centers for Disease Control and Prevention
CDT	Critical Disability Theory
DOE	U.S. Department of Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECI	Early Childhood Intervention
EL	English Learners
ESC	Educational Service Center
ESSA	Every Student Succeeds Act

FAPE	Free Appropriate Public Education
FBA	Functional Behavior Assessment
HFA	High Functioning Autism
ID/IDD	Intellectual Disability and Developmental Disability
IDEIA	Individuals with Disabilities Education Improvement Act
IDEA	Individuals with Disabilities Education Act (now IDEIA)
IEE	Independent Educational Evaluation
IEP	Individualized Education Program
LSSP	Licensed Specialist in School Psychology
MIGDAS-2	Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, 2 nd Ed.
OHI	Other Health Impairment
ISD	Independent School District
OSEP	Office of Special Education Programs
OT	Occupational Therapy or Therapist
PBMAS	Performance Based Monitoring Analysis System
PDD	Pervasive Developmental Disorders
PE	Physical Education
PPCD/ECSE	Early Childhood Special Education
PTSD	Post-Traumatic Stress Disorder
RBT	Registered Behavior Technician
RTI	Responsive to Intervention
SEB	Social, Emotional, and Behavioral Learning

SEEP	The Special Education Expenditure Project
SPED	Special Education
SRS-2	Social Responsiveness Scale, 2 nd Ed.
SWIFT	Schoolwide Integrated Framework for Transformation
TEA	Texas Education Agency

ABSTRACT

In 2005, the Texas Education Agency implemented a new accountability measure for school districts that penalized those that had more than 8.5% special education enrollment. The policy that lasted for over a decade and its implications, which continue to this day, created inequitable access to services for students with disabilities of all socioeconomic and racial/ethnic backgrounds as school leaders struggled to keep percentages down. Researchers and advocates provided ample evidence that Texas was artificially suppressing special education enrollment using narratives and statistical analysis by arguing that the state had an 8.7% enrollment compared to a national average of 14%. The evidence got the attention of the U.S. Department of Education, which issued a report in 2018 confirming the agency's multiple violations and including corrective actions. Most compelling was that the policy resulted in some estimates to be around 25,000 students with disabilities not receiving a free appropriate public education.

One of the fastest growing segments of special education is autism; yet, as many as 36% of those with an eligible autism disability are not receiving services, which may have been exacerbated by the special education cap policy. Current research is clear on why this happens: poor evaluator training; inappropriate assessment tools; and insufficient funding. However, many of these barriers to services could be resolved by implementing the inclusion mandate, which includes community resource involvement and collaboration in the eligibility process.

The purpose of this study was to examine how the Texas special education cap policy affected families with autism, in particular the student with a medical diagnosis of autism enrolled in a public school, in receiving services and their perspectives of school administration as agents of oppression, which may be continuing today. Themes were analyzed against a community model framework based on critical disability theory, including collateral costs of

eligibility denial, lack of quality evaluators and training as a major factor, and a pervasive “culture of denial” that appears to exist today. Recommendations were provided so that school administrators and district leaders can take immediate corrective action. In doing so, I hope to change the systemic factors that created and continue to propagate inequities for families with autism.

1. INTRODUCTION

In Texas, special education (SPED) services had been limited like other social services were managed at the turn of the 20th Century with deep spending cuts (Isensee, 2019; Needham & Houck, 2020; Swaby, 2019; Webb, 2019). In 2018, the U.S. Department of Education (DOE) found that the Texas Education Agency (TEA) had encouraged school districts across the state to artificially limit the percentage of students receiving special education services, including that the: “TEA failed to ensure that all children with disabilities residing in the State who are in need of special education and related services were identified, located, and evaluated, regardless of the severity of their disability, as required by IDEA...;” “TEA failed to ensure that FAPE was made available to all children with disabilities...;” and “TEA failed to fulfill its general supervisory and monitoring responsibilities...” (Ryder, 2018, p. 4). Around 2005, the TEA set a policy that cited or “dinged” districts in their annual accountability score who qualified more than 8.5% of its student population for special education (DeMatthews & Knight, 2019). This policy set off a wave of dismissals and denials that remained constant for over a decade, preventing underserved students access to a free appropriate public education (FAPE). Among those affected were students with less severe disabilities (e.g., high functioning autism or HFA, dyslexia, and ADHD), like my son, who were funneled into accommodations with no specialized instruction; to balance the demand of special education services and the cap by the state, many school districts encouraged staff in lieu of special education to use Response to Intervention (RTI) or only accommodations through Section 504 of the Americans with Disabilities Act (504) to address the needs of students who were suspected to have a disability (Ryder, 2018).

This result pitted parents and advocates against the very schools that were supposed to help their children be successful in a general education environment with accommodations

and/or modifications to the greatest degree possible (DeMatthews & Knight, 2019; Isensee, 2019; Webb, 2019). Most damaging (i.e., resulting in corrective action and monetary penalties by the DOE) was how TEA officials did not properly supervise, monitor, and act on known violations (Ryder, 2018). This affected individuals with disabilities relatively equally across the state, regardless of rural or urban locale, ethnically diverse populations, or socioeconomic status (Isensee, 2019; U.S. Department of Education, 2018; Webb, 2019). The study that follows are narratives of the parents of students with autism who experienced denial of SPED services in Texas during this time, including my own story from the perspectives as a parent, teacher, advocate, researcher, and now activist.

Kojin Teki Na Keiken: My Personal Journey

Following the tenets of Anzaldúa's (1999) “accounting” of all cultural influences in the exploration of the self, it is important to disclose those influences on my own self-identity and perspectives. I was born to a White mother (i.e., European-mixed ethnicities primarily of Italian descent) and a Japanese father, both first generation born in the United States. Although both cultures were present in my upbringing (e.g., I clearly remember at a young age visiting family in California and noticing the differences in customs and interactions within each clan), the Japanese culture was predominant and most influential on my view of the world. In fact, growing up I was never regarded as White but Asian by peers; the family Samurai sword was a major point of contention when my father died as my elder half-sister (i.e., my mother had remarried to my father) contested the “law” being followed to bestow the heirloom to the eldest son (i.e., me). However, I struggled reconciling cultural differences more so than my father when navigating the outside world. He stuck to the teachings of listening before talking, avoiding eye contact unless in conflict, and drawing from the ancient pool of belief in superiority. Meanwhile, I lived

in two worlds where my body and mind conflicted with the input of every contradictory cultural norm as many diverse children of the 1980s similarly experienced. This trifecta of cultures (i.e., White, Japanese, and 1980s United States) continued into adulthood and played out in my relationships, career, and fatherhood.

In 2011, I had just returned to teaching math at a middle school after a five-year stint in the “real world” as an e-learning developer when Carter, my five-year-old son, began Kindergarten at our local public elementary school. Immediately, he received “oops” notes sent home, referrals, and even in-school suspension from being “out of control” and hitting peers. Thus, I began my personal journey into the world of special education in search of solutions. These experiences left me emotionally traumatized and professionally altered with a deep sense of the social injustice that happens to individuals and their families with autism because of the decades of *getokipingu* or gatekeeping by district leaders. What is equally impactful was my Japanese and Italian upbringing, and how both cultures guided and gate-kept how I processed disability, labels, and needs/wants both personally and professionally.

Too Exhausted to Contemplate the Future

Carter was born on November 29, 2006, and as I like to tell him, “You didn’t come out of mommy’s tummy as much as run out.” He was a very active baby and toddler, and he had extraordinarily developed gross motor skills; in the nursery, his grandmother and the nurse watched him repeatedly use his arm to detach the multiple sensors attached to his upper body on his first day of life. Carter continued his advanced development: flipping over at weeks old; climbing out of his crib only a few months old; learning to walk at seven months; and speaking his first words around nine months. He was also very affectionate, giving hugs constantly, asking “up” to be held or be on my shoulders, and saying “I love you” in words or sign language.

However, these astounding early benchmarks were overshadowed by our constant chasing after him for which his aunt gave him the nickname “Flash Gordon.” I was convinced that he had attention deficit hyperactivity disorder (ADHD) since I was diagnosed at age three. So, when a friend asked me if fatherhood had met my expectations, I told him, “I’m too tired to think about what I had hoped in the past and too exhausted to worry about the future.”

What I thought was hindsight when researching personal narratives for this paper, differences from my development began around Carter’s first birthday, beginning with losing the handful of words he had been confidently using for months. The theme of his first birthday party was of all the things he liked to do, which were activities set up in our living room, and when our neighbors’ toddler boys joined the festivities, he froze, stared blankly, and hardly engaged until most of them had left. At the playground, he no longer jumped in with peers but had to be coached and given a script of what to do to engage play, which subsequently happened by his directives or alongside a “friend” without any active exchanges. When I would hold him face-to-face to look at his eyes, smile, and give kisses, he now averted eye contact with his entire body sometimes leaping out of my arms. He rarely asked to be picked up and he only gave hugs when he wanted them, screaming at times if anyone else initiated. In preschool, he often bit the other children, randomly ran out of the classroom, or refused to practice his ABCs because—as he explained at a later age—he had already learned them once. The remains of his words were nonsensical sounds and gestures, often resulting in tantrums lasting hours after he was unable to get what he wanted in a sense of basic needs. His “negative” behaviors resulted in hours of teaching, practice, and assessing, which was me following my mother’s advice on how she solved “the puzzle problem;” when I was two or three years old, my mother addressed my tantrums with puzzles and frustrations with vertical stacking of building blocks by using “floor

time” and sequentially teaching me how to accomplish each task learning step-by-step. Nothing seemed to help manage and improve Carter’s behaviors, and they only seemed to be getting worse.

Doctors Dealing with Neither a Square nor Circle

Each child wellness check through age four resulted in no recommendation or referral; Carter’s pediatrician placed him on the left tail of the development chart and consistently advised to wait another six months. He was behind his peers with speech, social engagement, emotion regulation, and behavior, but his advanced reading skills, gross and fine motor skills, and activeness always led to the conclusion that he had ADHD. All the while, he would experience bouts of growth with long periods of regression culminating in the summer before starting Kindergarten when I realized I was living the Mrs. Holland’s journey from the movie *Mr. Holland’s Opus*; my wife and I had challenging and contentious discussions about changing doctors and having Carter evaluated for something more than ADHD. I wanted a label that described Carter’s uniqueness, provided answers to why he was exceptional in some areas yet had challenges in basic skills, and guided us to the right kind of help. My mother insisted he was just like me, and I emphatically replied, “But not like this!” I was active, yes, but I was social, empathetic, loving, and very, very talkative. School took focus, explicit teaching, and lots of practice for me, which seemed to come naturally to Carter with little to no challenge. It was also clear that something was different when comparing Carter’s development to the typical development of his younger brother, Marley. One argument came to a head when my wife, Amy, said, “Why is a label so important to you?” I had nearly the same response as did Mrs. Holland:

I don’t know what he wants. I don’t understand what he’s trying to tell me... I can’t talk to my son! I don’t know what he wants or what he thinks or what he feels. I can’t tell him

that I love him. I can't tell him who I am. I want to talk to my son. I don't care what it costs. I don't care what some stupid doctor says is right or wrong. I WANT TO TALK TO MY SON! (Herek, 1996, 1:05)

That summer we changed pediatricians and met with a specialist for children experiencing developmental delay.

After the evaluation by the neurologist, Carter was diagnosed with PDD or pervasive developmental delay, a label I later learned from colleagues was given to children who did not exactly fit other diagnoses like autism. He was also officially given the ADHD label, coming from the same assessments I was given in college to reaffirm my own diagnosis. With labels and prescriptions given, I had high hopes that we were finally going to see improvements; instead, we saw different, weird, and odd behaviors appear. In the very first week on medication, the activeness succumbed to hyper-focusing on a few preferred topics, rigidity with routine, comments on sounds or smells that no one could note, and singing song lyrics or reciting movie lines repetitively. Play with the neighbors' boys turned into Carter demanding leadership and often resulted in fighting or arguments to the point that he rarely got asked to play. On his fourth sport (i.e., having been uninvited to return after each behavior-challenging season), Carter also developed an unnatural reaction to injured players in his sports games—appearing to fly to them like a hawk with his arms spread out and open, jostling his feet left then right, and circling and assessing, which would frighten the young player into getting up off the field. One morning was especially quiet when I could hear a faint “help” coming from the boys' bedroom. I rushed there and flung open the door to find Marley backed in a corner with Carter holding a built lego set and talking incessantly in a robotic, monotone voice. Marley peered around Carter and said, “Daddy, please make him stop. He's been talking about Legos forever!” We were so alarmed by

the changes in his behaviors and personality that we stopped the medication right before school started.

In the first semester of Kindergarten, we were on the phone with his teacher almost daily hearing her pleas for help on his latest antics: disrupting class lessons by calling out answers incessantly; profusely refusing to learn topics he had already been taught; demanding that students play his way or not at all at recess; running on top of the student desks during “quiet” time; and punching peers as they walked in line to specials or lunch. Carter received five office referrals and spent three days in in-school suspension that first semester. It got so bad that by Christmas some of the parents of classmates were demanding that their children be assigned to a different class because of Carter’s behaviors. We agreed to visit with his neurologist during the break to explore non-medicated solutions, during which Carter hid in the examination table’s under-cabinet. The doctor would slide open the cabinet door and Carter would crawl over to the closed portion, not speaking, fidgeting with his fingers, and not engaging in the doctor’s attempts to make the hiding into a game. He also observed Carter’s multiple bald spots, of which I informed the doctor had developed that school year from him pulling on his hair. “I think Carter is very intelligent, and he should be evaluated by a specialist who can tell us how smart he is,” the doctor concluded. I always knew Carter was bright, but could this be the reason for his behavior?

After the spring semester began, we scheduled the week-long assessment for January; however, after the first day, the neuropsychologist said that she was seeing some other issues and asked if she could do additional testing in February, for which we agreed. Meanwhile, the problems at school continued and having re-entered teaching in a school that practiced positive behavior supports, we set up a reward system for good behaviors tracked by smiley faces on his

daily charts—90% smileys at the end of the week earned him a Skylander figure for his video game. Living off my teacher salary alone, I thought maybe he would earn one or two of the figures that started at \$20 each; instead, he earned a Skylander for each week starting with the week we began till the end of the year costing us approximately \$1800! The hitting continued, though, and when I asked him in a rare moment of back-and-forth conversation, he revealed that while he held the classroom door open as line leader, peers would pat his head as they walked by, and he hated that. So, his response was to punch back to the level that he perceived he was being touched. We shared that revelation with the neuropsychologist who finally provided a diagnosis in April: autism.

Family and School Gatekeeping

The news of autism did not hit my wife and I like a ton of bricks, but more like a puzzle with an unexpected portrait. It made sense at the same time being incongruent with our professional experience with autism: Carter wanted to be social; he was verbal, albeit mute at times; and he acted hyperactive. But it was curious when I told my mom that she did not seem surprised at all and responded with, “They thought you were autistic at first.” I was floored—I had been diagnosed with autism?! (During my records review for my family’s narrative with autism, I came across a box of educational paperwork my mother had saved, which included a diagnostic report of autism from the University of Chicago from 1975.) Before there was the label of ADHD, there was no place in psychological disorders for hyperactive, verbal, and sensory-sensitive children like me. She often remarked at how Carter was just like me as a child, but that she had “cured” me of my hyperkinetic behavior by participating in a rigorous skill building study—what would later be known as applied behavior analysis (ABA)—and the Feingold diet. She later revealed that she did not tell the school about my diagnosis because

“back then they were still sending kids with special needs away.” My dad, on the other hand, had a typical Japanese response: “Why you’d go and do that? There’s nothing wrong with him. He just needs discipline.” Amy’s family asked why labels were so important to me and that challenges in the family should stay within the family.

Despite the lukewarm support from our families, we met with Carter’s assistant principal (AP), the school’s licensed specialist in school psychology (LSSP), and his teacher in May to provide a copy of the “outside diagnosis” and find a solution for the coming year. The response was immediate and intense—“Carter doesn’t have autism,” the AP stated while tossing back the neuropsychologist’s report back at us. “He doesn’t flap his arms!” The LSSP also reported that she had observed him and saw a bright, active, verbal, and social boy who would not qualify for special education. His teacher, who had provided information for the report, remained silent as the administrators said that the report was invalid because it did not include a school observation even though it did include his teacher’s input on rating scales. Carter would not qualify for assessment because his behaviors did not demonstrate an educational need—his grades were mostly of the highest possible marks, and by far Carter’s behaviors were not the worse of his class. That is when Amy broke her usual stoic and quiet demeanor and stated, “We’re not here to talk about other students. We’re here to talk about my child!” When we pushed for an evaluation, the AP said that intervention needed to be attempted first, and so we agreed to Section 504 accommodations for the following year. I remarked to Amy after we were exiting the building, “I didn’t realize how far behind the school was in understanding autism.”

First grade began like the last year with overactive behavior, daily physical aggression towards peers, and social isolation. Within the first weeks of school in a rare show of emotion other than anger, Carter fell to the floor after school at home, crying and rocking, “This is like

last year all over again!” That is when the warrior in me came out and I decided to share Carter’s story via Facebook, noting the struggles we were having with the school in getting help. Friends, neighbors, and strangers replied with their own stories of gatekeeping from our same school, across the state, and throughout the country. However, a common thread seemed to exist with Texas families: requests made for special education evaluation were met with 504 accommodations, especially for those with high functioning autism. This is a label that I was unfamiliar with and learned that it closely matched the now retired Asperger’s diagnosis, describing children with autism who were verbal and academically at par with their peers but often needed help with social and behavioral skills.

We did see some improvement with challenging behaviors reducing to a couple of incidents weekly instead of daily that I attribute to at-home, private ABA, but Carter seemed more autistic with a new medication (e.g., he only engaged in military play and painted repeatedly a portrait by Ellsworth Kelly), had no friends nor birthday party invites, neighbor kids either bullied or avoided him, he got kicked off an after-school karate team, and he made mutual enemies of some teachers. The Physical Education (PE) teacher openly disliked Carter, and vice versa; during the Fall Harvest Festival, Carter spent his own money for a chance to dunk the coach in a water tank and had to be pulled away from the booth having a tantrum over not being able to use his last chance after being successful on the second throw. After a semester of these continued behavior issues—he lost interest in Skylanders and only wanted to work for something from his narrow areas of interest, a gun—we verbally requested, again, that a special education evaluation be done. It took the entire second semester to obtain an agreement for a special education assessment. Thus, he was not initially tested until the beginning of second grade by the same LSSP who previously said he would not qualify; she found that he was not eligible.

Warning Signs

During this two-year period, I became the math department chair of the middle school where I had been teaching and part of my duties was to observe, model, and assist teachers with academic intervention. I observed a pattern almost immediately where teachers would send academically obstinate students in the hall for most of the class period. After repeatedly being cast out with no improvement, they would be written up for defiance and serve suspension; after nine days in suspension, they would hold a meeting to transfer the student to the alternative learning center or the behavioral school for those in special education. One student in particular, Frank, had high functioning autism, and I worked with him extensively throughout the year, so much so that he would come to my classroom during his math class to do homework. I found that he responded to interventions like Carter: choices worked better than demands; if he got the concept within the first five problems, there was no need to torture him for an additional 25; if he had an emotional outburst, it always was preceded by an unexpected change; and any kind of touch resulted in aggression. Then, suddenly, he was gone; surprisingly it took several weeks to find out what happened—he had been sent to the behavior school for hitting a teacher. I immediately set up a visitation to see Frank, but also to find out why so many of our students ended up there to never come back. What I encountered was a school straight out of the textbooks, one that exemplified the dignity of the individual student as well as gently pushing them towards adulthood and independence. With only 25 students served by five teachers, four paraprofessionals, and two administrative staff, I thought I had warped into an alternate universe where all the best practices were used to address behavior by emphasizing alternative behaviors, build social, emotional, and academic skills, and address the needs of those with autism instead of forcing the individual to meet the needs of the school. I was so impressed with the program

that I left my leadership position at the middle school to become a special education teacher at that school.

My new boss at the behavior school, Mr. Tyler, was the one who encouraged me to become a board certified behavior analyst (BCBA) and to use my graduate school theory in practice at the school. Together, we systematically enhanced the program to better serve those with autism by inviting outside and district services in the school including speech and counseling. We also transformed the transition planning process by incorporating cultural interviews so that we were respecting the individual student and their family's unique needs and wants for the future. He also taught me how to treat parents with respect and approach the individualized education program (IEP) process collaboratively. So, when Carter was denied special education services based on the ineligibility for autism, Mr. Tyler coached me through the process of requesting an independent educational evaluation (IEE) and hiring an advocate. At the meeting to discuss the findings of Carter's IEE, we were met with not only the school staff of five but also three additional district administrators all there to refute the findings of the IEE and who interrupted any staff that brought up an alternative route. At one point, the LSSP suggested considering ADHD under the "other health impairment" (OHI) option, only to be met with legal terminology by the district's lead assessment coordinator. Borrowing money from Amy's parents, we hired a lawyer and came to an agreement with the district for Carter to receive special education services under OHI beginning in third grade.

This chapter would appear to be over, but my experience in fighting for Carter's services revealed the inequities in the system. I had observed IEP meetings at the middle school with students as interpreters for parents who were not fluent in English; I struggled to change some of the archaic practices at the behavior school, like "look me in the eyes;" I helped LSSPs at the

high school that I subsequently taught at as the behavior specialist to see the need to re-evaluate female students for autism whom I suspected had been misdiagnosed as emotionally disturbed; and I worked tirelessly to change a system from within that favored discipline over positive behavior supports, victim blaming rather than examining systemic reasons for behavior, and an adversarial approach to handling parent disagreement. I also noticed a pattern at the district level of bending to the will of parents from affluent neighborhoods when they hired a lawyer, but when students of color were denied, the district fought any legal challenge called due process. I witnessed friends of district leaders or school board members have no issue with private evaluations being accepted for eligibility determinations. This pushed me to become an advocate and activist for new and changed policies that would affect access to services for families of color and with limited means. I also joined the board of the Autism Society of Texas, collecting informal data on how widespread the problem of autism ineligibility was across the state. The seemingly common theme to denial was the Texas cap on the percentage of students that could be admitted to special education.

The warning signs were there: advocates across the state testified and sued based on denials of eligibility; state funding for special education hit record lows; and dramatic increases in 504 accommodations, especially for ADHD and autism, left schools scrambling for solutions and personnel. I had participated in systematic review and denial of SPED as early as 2004 as a teacher; as an interventionist at two different schools, I had been instructed by administration to “keep kids out of SPED” by working with them as much as possible to address failing testing scores and keep our SPED numbers low; I encountered IEP facilitators who refused to add some students in classes with specialized instruction because it countered the narrative of dismissal. As the literature review to follow shows, and as the work of Knight and DeMatthews (2020)

specifically pointed out, larger districts were able to meet the TEA’s 8.5% policy while hiding with larger quantities of students in SPED as proof of FAPE (free appropriate public education) than smaller districts could; however, these researchers used statistical analysis to show how these larger districts were the furthest away from national averages of SPED enrollment. In addition, the DOE found that such a policy indoctrinated denial in district administration culture, justifying such violations as over-ruling ARD decisions, falsifying data, and using gatekeeping tactics such as RTI to steer families away from special education. Parents could only accept and follow the school directives or for those with privilege hire advocates and attorneys to fight for eligibility; historically, circuit courts of appeal favor districts and the Supreme Court rarely hears cases on special education, which leaves parents with no real legal recourse (Karanxha & Zirkel, 2014; Zirkel, 2011).

Following the footsteps of Kendi (2019) and Reindal (2008)—who combined advocacy for the individual to examine how they are affected from the systemic oppression to dismantle the structures in which its agents exist—I have recognized how much privilege plays in the access to special education. After three separate “outside” diagnoses of autism and thousands of dollars spent in legal and private ABA services, Carter was finally made eligible for services under the autism label in seventh grade. Mr. Tyler, who left the behavioral school was now Carter’s AP at his middle school; when the LSSP commented at his re-evaluation that Carter would not be eligible because his grades were all A’s, a new LSSP who had recently graduated replaced the old one and found that Carter was a bright, isolated young man who related to adults better than peers, had poor emotion regulation, and was hypersensitive to environmental stimuli, affecting his access to a social, emotional, and behavioral education. Was my relationship with the AP a factor? Had our past legal and present resources kept the district from meddling? Or

was my and Amy’s combined education in psychology, behavior analysis, and special education, in addition to our advocacy for more transparency from district leadership, influential in getting Carter what we felt he needed and deserved? Privilege and the fact that the newly trained LSSP used the medical criteria instead of the botched state requirements (Pennington et al., 2014; Rubenstein et al., 2018) in the assessment could all be reasons for Carter’s autism eligibility. What is clear, though, is that the process was collaborative and considered all stakeholders without a predetermined outcome, and both Amy and I came from it with a feeling of being served and treated with respect. Was this conclusion to our journey the result of teachers, administrators, and district leadership fulfilling their role as public servants tasked to educate and support *all* children in and for the community?

Problem Statement: Developing Responsiveness to Warning Signs

Although corrective actions were issued in response to the cap set on special education enrollment in Texas—which the Office of Special Education Programs (OSEP) found that the TEA failed to comply with all (VanderPloeg, 2020)—recent media reporting has shown that Texas is significantly below the national average (14%) of students in special education, having only recently increased the state percentage to 11.6% in 2021 (“Children and youth with disabilities,” 2019; DeMatthews & Knight, 2019; Isensee, 2019; Texas Education Agency, 2022a; Webb, 2019). *The Houston Chronicle* recently reported that denial continues in schools even though the policy has been lifted at the state and district levels (Isensee, 2019; Webb, 2019). What may be a reason is the fact that school administrators, diagnosticians/LSSPs, and special education teachers are undertrained both in special education law and best practices. For example, while there are specific criteria for autism in TEA’s code for eligibility, multiple denials have been linked to the fact that LSSPs read “verbal and nonverbal” deficits as needing

both to qualify when the medical criteria used “verbal or nonverbal” challenges (Pennington et al., 2014; Rubenstein et al., 2018). These structural, organizational, and human resource barriers to eligibility have yet to be studied in conjunction with the experiences of families with denial (Ota et al., 2020). What the literature does not show is how the cap specifically affected families with autism in Texas, whether gatekeeping continued to happen even though the cap has been discontinued (Isensee, 2019; Webb, 2019), and what factors at the district level may have attributed to denial of eligibility even though their student had a private diagnosis of autism.

Purpose of Study

This study highlights the social injustice of the Texas cap for those with autism, and what factors at the district and state levels continue to gatekeep families with autism from accessing special education, even after federal corrective mandates. By engaging in a case study to examine the narratives of families who have been denied special education services for autism across Texas, I provide recommendations for district leaders, legislators, and regulatory agencies so that the process for eligibility in special education for all individuals with disabilities is substantially more inclusive, collaborative, community-focused, and equitable.

Research Questions

Thus, the following questions were explored in this case study:

- What are the personal experiences (i.e., observations and interactions) of parents of students with autism when they are denied special education services?
- What are the systemic perspectives of parents of autistic children on how processes, interactions, and methods of determining eligibility for special education contribute to denial of services for students with autism?

- What do parents recommend that educational administrators, leaders, and policymakers do to provide a more equitable process of eligibility for autism in Texas?

Brief Overview of Methods

Building from the work of Knight and DeMatthews (2020) and DeMatthews and Knight (2019) in which they expose systemic oppression and inequalities in special education, this case study included a qualitative analysis of data that employed a new framework, the community model of inclusion. The methods included the collection and analysis of interviews to center the voices of parents of students with autism who were denied services from 2005–2021 (Merriam, 1998). See more details, rationale, and discussion in Chapter 3.

Theoretical Framework

The first known case of an individual with autism in the United States, as described by Donovan and Zucker (2016), was Donald Triplett (born in 1933 in Mississippi), who despite many challenges—disjointed social interaction, narrow interests, and fixated on objects and memorization—thrived in an era with little to no support or services from the medical field, who had recommended institutionalization in 1937 and diagnosed him by this new disorder similar to schizophrenia called autism in 1943. Instead, what occurred for Donald, from a young age beginning in 1947 through his adulthood, was that his family and community banded together so that Donald could receive the help that he needed. Furthermore, his parents did not follow the advice of the doctors to continue institutionalization because they knew that was not what they or their son wanted. High school friends, community members, and his parents supported him, worked on his social skills, and even worked at the family bank in Jackson, Mississippi after earning his bachelor’s degree in 1958.

Without this community model, Donald could have become just another statistic of those left behind in high school graduation, post-secondary education, and employment (e.g., those with autism have higher rates of involvement with criminal justice, lower rates of post-secondary completion, and higher rates of unemployment or underemployment when compared to typically developing peers) (Autism Society, 2015; Mehling & Tassé, 2015; National Center for Education Statistics, 2019; Shattuck et al., 2012; Siegel et al., 2015; U.S. Bureau of Labor Statistics, 2019; Wilczynski et al., 2013). This remarkable first diagnosed case of autism is an exemplar of how a community model of inclusion can not only be successful, but also be the bar to which all interventions for differences should be held (Donvan & Zucker, 2016). Nevertheless, there continues to be a mixture of frameworks in research, policy, and practice for special education and disability ranging from deficit-identification (Brantlinger, et al., 2005; Kapp et al., 2013), supports and services based on the individual's needs (Watson & Vehmas, 2020), to systemic analysis in the identification of environmental barriers that should be removed regardless of the individual's wants or needs (Reindal, 2008; Watson & Vehmas, 2020). As shown in the following section, none of these models or frameworks use the lens of inclusion based on the dignity of the individual, family, and community that was used to help and honor Donald Triplett as a person and not a burden to his family and society (Donvan & Zucker, 2016).

Medical Model vs. Social Model of Disability

There is ample evidence that disability in the public-school setting is treated under the medical model, which purports a need to correct differences in academic performance and social, emotional, and behavioral functioning when compared to a normed sample of peers. This is what is called a deficit model of disability where students' differences are identified and interventions, accommodations, or modifications are put into place with measurable goals (Brantlinger, et al.,

2005; Kapp et al., 2013). This model of schooling, especially in special education, strips the individual student's needs and wants (let alone their families' cultural norms) based on a predetermined set of social norms and expectations (Cooper et al., 2015). In contrast, the social model of disability puts the individual at the center of a team of stakeholders who plan educational programming to the needs and wants for academic and life goals of the individual and their family. From that plan, school personnel become facilitators of support and services in and outside of the school building that include mental health professionals, social workers, law enforcement, advocates, and other applicable state and federal agencies (Watson & Vehmas, 2020). The main difference between the medical model and the social model of disability is that the individual has the ultimate right and say in what interventions and goals should be used. In addition, the latter model also does not subscribe to a terminal criterion; rather, once special supports are provided in the school setting, those supports continue throughout the individual's life via social services (Eber et al., 2011; Eber et al., 2002; Fallon & Mueller, 2017; Watson & Vehmas, 2020).

Critical Disability Theory and the Social Relational Model

Within the last decade of special education research, there has been a great deal of progress in critical disability theory (CDT) (Watson & Vehmas, 2020)—which originated from critical race theory—and the social relational model of disability. Instead of focusing on who decides the services, CDT takes a critical examination of the systemic barriers to identify the inequities in services. These barriers may include the use of the term disability, the understanding of cognitive and biological development based on social constructs as opposed to natural human development, intersectionality, neurodiversity, human rights, individual rights, and social conformity. The results of these systemic oppressions may include denial of special

education services, the use of excessive force when implementing interventions, inadequate or improper accommodations and modifications to an educational plan, and overuse of deficit-oriented and culturally biased assessment tools (Reindal, 2008; Watson & Vehmas, 2020).

A Community Model of Inclusion

So, what frameworks could possibly help explain why the inequity of autism eligibility for special education services may be occurring in Texas? Those using the social model of disability framework would point to the disparities and de-humanization experienced by individuals under the medical model of disability. Instead of viewing differences from the norm as deficits to be corrected, a social model would examine the barriers to accessibility, embracing disability as an identity, and systemically teaching all students awareness and acceptance (Brantlinger, et al., 2005; Kapp et al., 2013; Lalvani & Bacon, 2019). Thus, as is seen with the eligibility requirements for autism in Texas, students like Carter do not have enough deficits to qualify per the social model (Diagnostic criteria, 2019; Disability criteria, 2019); meanwhile, lack of social skills, emotion regulation, and rigid thinking could be isolating him from peers. The social relational model of disability, on the other hand, shines a light on the ill-use of the term *disability* as a form of oppression and how the system separates and labels students with disability, like that of race (Reindal, 2008). Under this model, advocates might consider Carter not to be disabled and that the environment should change to meet his needs, like customizing assignments to his interests of guns, army men, and Legos. CDT takes both previously stated frameworks to the next level to show how race and ableism, especially in special education, are interrelated and systemic (Watson & Vehmas, 2020). This is true in how students were denied eligibility in Texas; Knight and DeMatthews (2020) found if a district had a greater proportion of students receiving free or reduced lunch, then those districts had a lower total percentage of

students in special education. Anecdotally, Carter’s district is large, spending an undisclosed amount on legal challenges to autism denials including many students in our neighborhood who qualify for financial assistance and many who are of Asian ethnicity like him.

These frameworks help provide some explanation as to why denial of services is happening at both a macro and micro level, but what lacks is effective activism and rectification. These frameworks suggest “Carter is autistic,” “Carter is fine, it’s you who needs to change,” or “Carter is being discriminated against!” (Watson & Vehmas, 2020). These perspectives are informative on how he and students like him may be *seen* by the system in their denial, but it does not help explain *why* he is being denied and how to keep others from being denied when it is obvious services are needed. What these frameworks do not tap into are the policy and tools in the hands of current educators that can lead to restoration and school improvement from, in particular, ESSA or Every Student Succeeds Act and IDEIA or Individuals with Disabilities Education Improvement Act—originally known as IDEA. This federal legislation already mandates districts to transform their special education programs from label/deficit-driven policies/practices/placement to one of inclusivity with peer students, collaboration with stakeholders, and community-based supports that have been shown to increase eligibility. For example, a transformed district would include parents/family, outside professionals, caregivers, and community members in the process for determining if a student with autism is eligible for special education—not just accommodations, but specialized instruction to meet all stakeholders’ needs and wants; this is in opposition to the most predominant practice of qualifying a student through medical-deficit driven assessments by only a school evaluator based solely on “educational need” that proves a gap between achievement and ability large enough to justify services (Smith et al., 2020). Hence, a new framework may be needed to pave the way for both

critical analysis and effective, corrective activism: the community model of inclusion (Ota, 2021a).

By following the footsteps of critical disability, social model of disability, and social relational model of disability while elevating in earnest students, parents, and community members to an equal and equitable level as district representatives, the community model of inclusion can not only address the agents of oppression, like district administrators and evaluators, but also critically focus on the active dismantling of systemic barriers to special education, like eligibility regulations, at both macro and micro levels (Ota, 2021a). Nonetheless, this framework should not be conflated with inertia, as some advocates of disabilities argue that students should be accepted “as is” and it is the job of the system to accommodate and modify the environment to meet their needs (Grinker, 2020); rather, the relationship between the student, family, community, and school should be configured with a growth mindset so that school becomes an inclusive environment where all stakeholders, including the student, have a voice *and* responsibility to ensure educational programming meets wants and needs (Lupart & Webber, 2012; Smith et al., 2020). A community model of inclusion would address access and oppression by recalibrating the individual student, family, and community at the center and redefine special educators as public resources to help grow the individual into the best person they can be (Ota, 2021a).

Significance

This study provides a research-based perspective (rather than one in popular media) of students with autism who were and continue to be denied special education (and their families), and the recommendations that state and district leaders can follow so that policies can be implemented immediately for corrective action. These aims are achieved by examining the

narratives from the families who were denied and shed light on the systemic factors that led (through thematic analysis) to the denial. By showing proof of gatekeeping that continues presently, this study provides the roadmap to action and remedy in policy and practice to cease denials from services. For instance, using the term “educational need” (i.e., a student that is performing within the average academically does not qualify for special education service) is code for denial and a way for school administrators to avoid the responsibility to teach the child holistically not just academically, which—as shown in this and following chapters—practices are the antithesis to SPED policy and law. These findings could lead to change in eligibility requirements, like removing the mandatory school evaluation allowing for acceptance of private, medical diagnoses, and encourage schools to be more inclusive who seem to hold all the power in the decision (Cooper et al., 2015; Smith et al., 2020).

Layout of the Dissertation

My personal journey is not unlike many parents of students with autism who were denied special education during the TEA’s SPED cap policy since 2005. However, my own perspective as a teacher is unique because I was able to see the policies of systematic denial in practice, hidden behind the veil of brick-and-mortar to which many other parents do not have access. I continue to observe these denials as I interact with agents of the educational system as a behavior analyst, as many clients with an autism diagnosis and who receive supports and services through insurance are denied specialized educational goals. There are many reasons understood by parents and advocates why this happened and continues to happen, but there is little understanding and research both in quantitative and qualitative measures how the SPED cap affected students with autism.

What follows in Chapter 2, I examine the literature that exists to provide some scaffolding to better understanding in how and why students with autism are denied eligibility. In Chapter 3, I explore the frameworks and methodologies that expand and fill in gaps in the literature. In Chapter 4, data that is methodically analyzed for differences in SPED enrollment for students with autism followed by a discussion on the systemic factors that may have contributed to denial. Finally, Chapter 5 includes recommendations how school leadership can take immediate, corrective action in making the eligibility process more inclusive and individual/family/community centered.

2. LITERATURE REVIEW

In 1975, Congress passed the Education for All Handicapped Children Act to address the systemic segregation and exclusion of children with disabilities from public education. Now known as Individuals with Disabilities Education Improvement Act (IDEIA) from 2004, the law provides six principles of “rights” for accessing state-funded education: a free appropriate public education (FAPE); appropriate evaluations; an individualized education program (IEP); least restrictive environment (LRE); parent participation; and procedural safeguards (Cooper et al., 2015; Yell, 2016). The Office of Special Education Programs (OSEP) conducted an audit of several Texas school districts in 2018 and found that the TEA violated several principles of IDEIA: child find; development of interagency agreements; and effective monitoring and enforcement of compliance with IDEIA (Ryder, 2018). In 2020, OSEP also found that the TEA continued to violate the mandated corrective actions by not referring students suspected of having a disability and instead referring them to 504 accommodations (VanderPloeg, 2020).

The law and subsequent regulations are set up to allow anyone—teacher, parent, or even the student themselves—to refer, in writing, a student to a special education evaluation. The district can accept the request, which then they must conduct within 45 school days and then meet to discuss eligibility within 30 calendar days, or they can reject the request because it does not suspect a disability; however, the school district must provide written reasons why the student is not eligible for testing or an IEP (Cooper et al., 2015; Yell, 2016). Although procedural safeguards, child find, and oversight can be factors in gatekeeping, a more specific issue lies within the eligibility requirements for autism; since 2004, the understanding of autism as a pervasive developmental disability has transformed in leaps and bounds. Once thought of as an intellectual disability, popularized by movies like *Rain Man*, ASD is now understood as a

neurological difference in social communication, social interaction, restricted/repetitive behaviors/interests, and learning and attention, exemplified by individuals like Elon Musk (Rubenstein et al., 2018). Thus, what once was a very rare condition affecting less than 1 in 100 with the vast majority at level 3 or severe levels, autism is now more common at a prevalence of 1 in 36 with nearly 75% of school-aged children at level 1 or 2 who are served in the general education classroom (Centers for Disease Control and Prevention, 2023), which districts and the state have been slow to reflect in eligibility criteria (Swaby, 2019).

In 2018, the DOE found that Texas since 2005 had arbitrarily set a cap on the percentage of students in special education based on their total enrollment. If districts were found to have a rate greater than 8.5% of special education students, then their Performance Based Monitoring Analysis System (PBMAS)—a data-based accountability system used by the TEA to monitor four areas including special education to report a score at district, region, and state levels (Texas Education Agency, 2018)—would be noted and the TEA could audit the district’s IEP records. As a result, thousands of students with special needs, including my own son, were either dismissed from SPED or denied eligibility; even though the DOE found this to be pervasive across settings (urban and rural) and socioeconomic status, inequities of underrepresentation developed for students of color, students in poverty, and those with “high functioning” disabilities (DeMatthews & Knight, 2019; Knight & DeMatthews, 2020).

In this literature review, I first examine how the most current research and data quantitatively provides some evidence of underservice for students with autism. Then I provide a brief historical perspective on special education in part to understand the underservice and denial. Finally, I report on the national, state, and local factors in systematic terms—including school finance, practices in assessment for eligibility, and political and power structures at

district levels—that perpetuate a culture of denial for students with autism. The review also provides a roadmap to substantiate the appropriateness of an inclusion model based on community, family, and the individual to advocate, activate, and rectify inequities in the system of special education.

Higher Percentages in Autism Do Not Equate to Adequate Numbers

Advocates and activists, who were the first to ring the alarm to the injustice of denial for specialized education for students within the school setting, have called out district leadership in using gatekeeping in exploiting families’ cultural and socioeconomic statuses as disadvantages to deny services (Isensee, 2019; Webb, 2019). For example, Latino families faced questionable practices such as having their children act as translators in IEP meetings, trusted authority to keep their child’s best interests at the forefront, and had cultural hesitation in not speaking against an administrator’s recommendation; meanwhile, White, affluent families were able to hire lawyers and typically received services, creating inequities in the system between the intersectionality of color and disability (Isensee, 2019; Knight & DeMatthews, 2020; Webb, 2019). Knight and DeMatthews (2020) found that districts in Texas with the highest poverty and/or proportions receiving free-or-reduced lunch had the lowest proportions of students in special education; they also found that the school districts with the largest student bodies had the lowest percentages of students in special education in Texas.

The frustrations and feelings of injustice by families with less means, who were simply applying the principles of a social model of disability to obtain services that are not readily available in their communities (Reindal, 2008), were met with months or years of delay to experience results—and then only if they could afford the expense of lawyers and advocates (DeMatthews & Knight, 2019). I believe that this injustice was very profound for those with

autism spectrum disorder (ASD), especially high-functioning autism that accounted for 67% of all autism diagnoses and where their “functioning” characteristics have been deemed ineligible for special education (Autism Society, 2015). The special education eligibility cap set by TEA and the change in district behavior in determining eligibility that followed it became ingrained, negatively reinforced, and justified by policy to use response to intervention as an alternative to special education, and ultimately created a culture of denial of services that prevails today; parents have watched the TEA appoint conservators to whole districts (e.g., Houston ISD) or programs in districts (e.g., Austin ISD) because of the failures of special education services following the gatekeeping and dismissal practiced encouraged by the state’s policies (Austin ISD, 2023; Benthall, 2020). In my own preliminary research, we directly identified factors to systemic denial towards those with autism, including district, school and special education leadership, organization, and adversarial perspective towards the community that runs along the lines of privilege (Ota et al., 2020).

Despite the mandates by the federal government for corrective action, Texas remained well under the national average of 14% of students receiving special education services at 9.8%, pre-pandemic (“Children and youth with disabilities,” 2019; DeMatthews & Knight, 2019; Isensee, 2019; Webb, 2019). For example, recent reporting has shown that the TEA has not provided resources so that parents can more easily understand the process for becoming special education qualified; it has not issued guidance for school districts to improve qualification processes and rectify services for those who were denied; and there are unconfirmed reports (i.e., these reports have been denied by the TEA) that school districts have been told to disregard compliance deadlines issued by the DOE on corrective actions, dampening improvements in identification and leaving parents and special education advocates, again, at odds with IEP

committee decisions of denial (Isensee, 2019; Webb, 2019). TEA officials cited that a one percentile increase in special education qualification equated to tens of thousands of students now receiving services (Isensee, 2019). Current percentages for individuals with disabilities qualifying for special education services of all students had increased in Texas from 8.7% in 2016 to 9.8% in 2019 (Isensee, 2019; Webb, 2019) and that Texas served students with autism at rates higher than the national average (i.e., 13% vs. 10.2% of all students with an IEP for 2017–2018). However, the state overlooked the fact that this was a proportion of an overall rate that was still over four percentage points below the national rate. A calculation of this slow progression of increasing the overall average percentage of special education students means that as many as 5,000 students with autism were still unidentified, denied, or dismissed (“Autism,” n.d.; “The NCES Fast Facts Tool,” 2019).

Brief Historical Perspectives of Special Education

Arguably, special education in the United States started out with community advocacy because students with disabilities were excluded from a system that grew from one-room schoolhouses to multi-billion-dollar social programs; advocates successfully sued for FAPE on the grounds that exclusion violated their students’ Constitutional rights (Cooper et al., 2015). However, special education as an ideal of inclusion has been the center of educational policy’s tug of war between advocates, politicians, industry leaders, and university/college agendas. The main support for special education as a school within a school (i.e., as a segregated unit) was fueled by the neoliberal policies of the 1980s when accountability in education transformed into a standardized approach, solidifying the perspective that the needs of special education students were deficits to be fixed (Lupart & Webber, 2012). Today, special education is mandated by ESSA and IDEIA to be inclusion- and strengths-based (e.g., growth mindset pedagogy), which

when applied with fidelity can transform the entire school system from label-driven placement to one of universal design with a continuum of accommodations and modifications (Smith, 2020).

The literature has well established the benefits for all students; for example, when special education students are fully included in the general education environment, their peers significantly develop social skills, tolerance, and acceptance (Haines et al., 2015; Loreman et al., 2016; Lupart & Webber, 2012). Yet, in the United States, there continued to exist many barriers to mainstreaming special education in the general education classroom in meaningful ways. As Lupart and Webber (2012) proposed, these barriers may be due to how schools have historically implemented special education as label- and placement-driven, which contradicted training and mandates for seamless integration of a student with a disability in a classroom. This dual system left stakeholders at odds with each other and either created, perpetuated, or faced the following obstacles to inclusion: (a) success measures based on standardized testing; (b) education sheltered from the community; (c) placing cost of service in priority; (d) low-quality training and curriculum; and (e) assumptions that the current accountability-based system of education has positive effects on student learning, economic opportunity, or social measures. However, an educational model based on inclusion and community is well supported by the literature (Cooper et al., 2015; Francis, 2016a; Gross et al., 2015; Haines et al., 2015; Lupart & Webber, 2012; Wehmeyer, 2020) and even though U.S. policy mandated this model, it was behind its international counterparts in the implementation (Francis et al., 2016a; Gross et al., 2015; Gross et al., 2018; Ota, 2021).

This history helps provide some explanation as to why denial of services happened at both a macro and micro level to students with autism. The educational system was predicated on the idea of mass achievement, and students who did not meet accountability measures were

labeled as needing intervention with corrective instruction rather than implementing changes to the environment so that the student was successful (i.e., inclusivity principles of modification and accommodations) (Francis et al., 2016a; Gross et al., 2015; Gross et al., 2018; Ota, 2021a). Another explanation may be hidden in the chronological history of acceptance of disability among the public and then in the school system: physical disabilities were the first to receive protections under the law through ADA, whereas cognitive disabilities took far longer to be recognized as a protected class in the courts (Cooper et al., 2015; Watson & Vehmas, 2020). The authors of IDEIA intended to value the perspectives of the individual student, their family, and community members like outside medical and mental health professionals; unfortunately, the eligibility process often disregarded those perspectives (Francis et al., 2016a; Gross et al., 2015; Gross et al., 2018; Ota, 2021a).

Following the exemplar of U.S. policy and legislation in special education, internationally schools transformed to be more inclusive of students, families, and community (Ota, 2021a). To achieve this transformation, an inclusion model that incorporates the values, norms, and needs of the community would also draw upon frameworks that value culture and family and provide a solution for corrective action. For example, a common practice in these schools was to appoint a transition coordinator who ensured that not only students were being readied for adulthood, but that IEP plans were truly inclusive and based on the perspectives and the wants/needs of the student, their family, and community input (Elder & Kuja, 2018; Francis et al., 2016a; Haines et al., 2015; Loreman et al., 2016; Ota, 2021a; Scheef & Mahfouz, 2020; Wehmeyer, 2020). Transition coordinators and a community model of inclusion could help students of color who have experienced systemic oppression with transition planning in special education, which can be seen in two separate studies where students were forced to make adult

decisions based on “Whiteness and normalization” or “ableism” (Cannon, 2019, p. 145) without regard to their own needs and wants nor their families’ (Fadyl, et al., 2019). All these studies affirmed the need for oppressive agents of the school to change how they approach students and families and to incorporate culture and family at the center of their service. Francis et al. (2016a), Francis et al. (2016b), Gross et al. (2018), Gross et al. (2015), and Haines et al. (2015) all found that when schools communicated positive messages and set the tone for parent-school partnerships, more students were identified for special education services, parents set high expectations for those services and were more satisfied, and families participated actively in school policy and programming, increasing successful implementation and respect for individual/family culture.

Local Frames Perpetuating State and National Deficiencies

Even though the epicenter of the problem in Texas lies with the TEA and its cap policy (Isensee, 2019; Webb, 2019), there is evidence that students with disabilities, especially those with autism, were denied services long before and after the cap due to structural, staffing, political, and cultural barriers at the school and district levels. Zirkel (2011) found that the number of lawsuits nationally from 1995 to 2008 against school districts on grounds of FAPE violations rose approximately 100%; most profound was that the number of cases involving autism increased by 550%, accounting for 39% of all cases disputed in court from 2005–2008, albeit data on this trend specifically for Texas was unreported. An additional factor for underserving the ASD population could be due to ethnic disparities in autism qualification, especially with overrepresentation of Native Americans and African Americans and underrepresentation of Hispanic students in Texas. Researchers have cited inadequate assessments and poor interpretations of the diagnostic criteria for varying levels of autism by

staff conducting the evaluations as possible reasons for the disparities as well (Morrier & Hess, 2012).

The way in which states have defined and districts have evaluated autism in educational terms was highly subjective and disconnected from medical criteria, which was the basis for the assessment tools used in education to identify and qualify students with autism (Pennington et al., 2014). The psychological field has transformed its assessment with a major rewriting of diagnostic criteria in 2013 expanding the definition, focusing social communication and relationships, and delineating criteria into a spectrum or levels of autism with traditional portrayals at level 3 and “high functioning,” PDD-NOS, or Asperger’s Syndrome at levels 1 or 2 (American Psychological Association, 2013). Yet, TEA regulations stated that a student with autism was eligible for special education services if they exhibited significant difficulties in verbal *and* nonverbal communication, socialization, restrictive behaviors, changes in routines, and sensory inputs—leaving out deficits in *social* communication; however, the TEA did not further define the topographies of these characteristics, provide guidelines on how to evaluate them for different levels of autism nor explain what it looked like to have an adverse educational effect (“Autism,” n.d.). Thus, a LSSP could have easily recommended denial of services for an individual with high functioning autism due to lack of speech deficits in “verbal communication,” which was contrary to the diagnostic criteria of “poorly integrated verbal and nonverbal communication” in socialization (American Psychological Association, 2013; “Diagnostic Criteria,” 2019). As Pennington et al. (2014) found nationally, the TEA omitted or ill-defined reciprocity in social interaction and relationships, flat affect in facial expressions, unusual eye gaze, and ritual verbal behavior (“Autism,” n.d.; “Diagnostic Criteria,” 2019).

The complexities of autism diagnoses and an understanding of legalese—i.e., a lack of training in—may have most influenced a school evaluator’s determination. Morrier and Hess (2012) found that educational diagnosis criteria were greatly disconnected from the medical criteria for ASD. Many families were told by the evaluator that a main reason for ineligibility was because their students were verbal (Ota et al., 2020). However, this was not the intent of the criteria; individuals with autism could have difficulties with nonverbal (e.g., body language, facial expressions, and behavior) or verbal communication (e.g., social pragmatics and perspective taking) that negatively affected social communication, interaction, relationships, and social-emotional reciprocity (“Diagnostic criteria,” 2019). Also, the requirement for “educational need” criteria per Texas guidelines and IDEIA (Bolourian et al., 2019; Smith, 2005) did not state that a student must demonstrate an educational need to be eligible for services (“Disability criteria,” 2019). Rather, “the initial evaluation must consist of procedures to determine: whether the child is a child with a disability; and the educational needs of the child” (“Autism,” n. d., para. 1), which did not rule out social, emotional, and behavioral skills.

In addition, Pennington et al. (2014) concluded that assessments used by schools were inadequate for the vast variety of symptoms and manifestations of a disorder that was considered a spectrum. In other words, the over-dependence on the “gold standard” of assessments, like the ADOS-2, has been found to be insensitive to the unique characteristics of high functioning autism, especially in girls (Rynkiewicz et al., 2016) and could have been the reason that as much as 36% of students with ASD were not qualifying for special education services (Rubenstein et al., 2018). Other assessment tools, such as CAPS (social pragmatics), CARS2-HF (high functioning autism diagnosis), SRS-2 (social communication), and the MIGDAS-2 (qualitative

and team approach to assessment) have been found to be much more effective in the diagnosis of ASD (Monteiro & Stegall, 2018).

Isensee (2019) and Webb (2019), in follow-up reports on the status of compliance by Texas schools to DOE directives, found that students with outside diagnoses continued to be denied services. The continuation of denial may have been due to a culture of denial stemming from the decades of directives from TEA to cap the number of students receiving special education services. Typical behavior by districts and school personnel (including IEP committees) after the 2004 memo by TEA was to dismiss applications for services, funnel students to accommodations or EL (English as a second language) programs and deny new admissions. This practice was further evidenced by the fact that Texas schools in 2019 (two years after the cap was lifted) were still behind the national average of serving students with ASD, which was about 92.8% of the number of students served nationally (Isensee, 2019; Ota, 2020; Webb, 2019). However, a large portion of the reason for denial may have been in how special education is funded.

The Devil is in the Calculations

In 2000, the Special Education Expenditure Project (SEEP) found that the \$6,556 and \$12,474 allotted for general education and special education students, respectively, was underfunding schools; these allotments have not increased since 2000 (Needham & Houck, 2020). As the TEA has cited, special education needs had decreased and, thus, expenditures had decreased; however, the courts found that the number of high-needs disabilities had increased, increasing the overall need for expenditures, and that Texas had underreported the needs of most students (Needham & Houck, 2020; Swaby, 2019). Perry and Hawthorne (2018) found this phenomenon as a possible reason why school districts that experienced increasing overall

enrollment may have been due to significant underfunding when compared to those districts with stable enrollments. And when those disparities occurred, they either became inequities from unanswered funding deficits or a burden on local districts to address in budgeting. Yet, even with a historic funding of public schools and special education by the 86th Legislature, addressing a \$223 million shortfall in SPED funding, Texas continued to fall short of fully funding the 264% increase in autism eligibility and 93% increase in other health impairment (i.e., where those with high functioning autism were often placed) when compared to national growth and funding averages in 2013 (Needham & Houck, 2020; Murphy, 2019; Ota, 2021b; Swaby, 2019).

Even though Texas's funding model for SPED is progressive using disability-specific allocations, those amounts were disproportionately small for the most identified disabilities (Needham & Houck, 2020). For example, a homebound student received five times the base allocation of \$6,160 for services, speech therapy was also five times the base allocation, resource room was three times, and even vocational training was 2.3 times, which accounted for less than 40% of the special education population; yet a majority of students who were supported in inclusion classes received just 1.15 times, translating to an extra \$924 a year and a small fraction of a special educator's salary (Ota, 2021b). This disproportionality and lack of growth in funding allotments created a funding gap and stagnation amid growing expenditures (Needham & Houck, 2020). However, these efforts did not address the root cause of underfunding: federal funding was short 40% of its promise in the original law mandating special education; Texas continued to short the funding for SPED students, citing a decrease in enrollment as justification; and local districts were able to funnel 45% of SPED funding to the general fund, adding expenditure stress to an already underfunded need (Riser-Kositsky, 2019; Ota, 2021b).

By examining state and national funding issues for special education, I have found that there was consistently an underfunding of 40% at the federal level, which states then passed down to local districts to address. However, a question remains: that is, how (and if) were local districts addressing these funding issues. For example, in the district in which my son attends, the allotments for its 5,225+ special education students at the time of this paper were \$36 million, calculating to \$6,889 per student above the base allotment (Ota, 2021b; Texas Education Agency, n.d.); however, as its Summary of Finances details, only 55% of that allotment was spent on special education, of which my son Carter's case manager received only \$568 towards his salary based on the multiplier (Ota, 2021b). Calculated in another way, the average cost of employment of the inclusion-only teacher in my son's district was \$72,581 (i.e., calculated with taxes and benefits was $\$57,352 \times 1.14 + \600×12)—at that rate, it took 128 students to fund his case manager's pay (i.e., $\$72,581/\568) (Ota, 2021b). Thus, districts like my son's tend to address underfunding by overloading the ratio of special education teacher to special education student.

The impact of underfunding and how Texas calculates the per student need for special education created and exacerbated the inequities in the system. The lack of transparency in rules and regulation, the complexity of how differing states and districts allocated funds, and sparse research on how all these factors impacted services for students like Carter may need a paradigm shift to untether special education eligibility.

Factors to Successful Special Education Inclusion: A Community Model

The results of a literature search in successful transformations of existing schools to one of inclusion revealed five themes. They included: 1) culture of community inclusion; 2) clear and inclusive leadership; 3) high-quality training; 4) high-quality curricula; and 5) progressive yet

equitable funding. As in the sections to follow, these themes have been shown to not only provide a more equitable education for students with disabilities, but by examining special education processes through a lens of a community model of inclusion at a district level, they can highlight the factors and agents contributing to denial, gatekeeping, and oppression from entitled supports, services, and specialized education (Reindal, 2008; Watson & Vehmas, 2020). Then corrective action can be taken—supporting the aims of advocacy and activism from the frameworks of CDT and social relational model of disability—for full and meaningful inclusion to be realized.

Culture of Community Inclusion

Research has shown for special education to be truly inclusive, a culture of inclusion—i.e., policies and goals meant to include community members, family, and the individuals in the qualification and implementation process of specialized instruction and universal design—must be described, implemented, and reinforced consistently and boldly from school leadership. To be successful, a shift from simply accommodating special education students to one where they were equally included in the general education classroom required explicit and transparent support (Smith et al., 2020). Smith et al. (2020) provided evidence when an administration used an inclusive mission or goal statement, teachers were attentive to both general education and special education students on their varying academic needs. Models of inclusivity when initiated and sustained by administrative supports has been shown to increase interactions between all students, the self-esteem of special education students, and acceptance by peers (Scharenberg et al., 2019). SWIFT schools¹ that adopted a culture of inclusivity in a similar top-down fashion “profoundly influenced how [community partners] perceived disability and how they used their

¹ SWIFT is a program initially funded by the U.S. Department of Education to assist districts in transforming their schools to an inclusion model for special education.

new knowledge in other settings” (Gross et al., 2015, p. 18). Loreman et al. (2016) found that when Ukrainian schools communicated inclusive language, “many participants also remarked that a positive attitude towards inclusion has also been evident in the community” (p. 33).

However, the initiatives by schools did not stop at messaging; schools also included community members in professional development, specifically trainings on inclusivity. Gross et al. (2015) found that community partnerships were essential in the success of an inclusion transformation, providing a mutually beneficial relationship and access to more resources and support. To maximize the affordances of such a partnership, administrators needed to go “above and beyond” traditional relationships with community stakeholders with an “open door policy.” Teachers also needed to take advantage of community resources, such as mentorships by business leaders, instructional coaching by universities, and tutoring by parents (Gross et al., 2015). Elder and Kuja (2019) found that Kenyan teachers gained the most success for including special education students (in schools historically open only to those without disabilities) when schools had a resilient partnership between teachers and community stakeholders; this included incorporating stakeholders in planning stages, listening to their perspectives on systemic barriers, and openness to reciprocal knowledge on what it means to have a disability; most impressive, when teachers used a critical lens of disability in the planning for inclusion, stakeholders demonstrated the greatest level of buy-in and concluded that full inclusion was the best model of schooling for all students. When collaboration with community stakeholders was absent, inclusion initiatives likely failed and students suffered on multiple measures, including academic progress (Dentith et al., 2013; Elder & Kuja, 2018; Gross et al., 2015).

The most important stakeholders from the literature were the families, beginning with positive communication on inclusivity by administration and, subsequently, teachers and other

stakeholders. Families were partners and fully included in daily schooling, curriculum and inclusion measures, and school policy; contrary to schools' expectations, parents of special education students often set higher expectations for all students than had been done with segregated special education. Overall, when parents and community members were welcomed by an open-door policy, included in the daily life of students in the school, and given the task of maintaining the inclusive model, all students experienced a greater quality of life in an iterative success loop of awareness, acceptance, and dignity (Francis et al., 2016a; Francis et al. 2016b; Gross et al., 2015; Gross et al., 2018; Haines et al., 2015).

Clear and Inclusive Leadership

Research also showed that communication must be clear in the mission of inclusion and that such a policy is a major shift in philosophy, not merely another program layered on top of existing systems/processes. The literature showed that effective and long-lasting transformation to an inclusive school system required leadership at both the district and school levels to provide clear and intentional planning and implementation, communication and transparency, and support (Haines et al., 2015). Schools that had extensive support rather than accountability from district leadership, which required reimagining the role of district administrators into one as a liaison and resource, had the greatest success and implemented inclusivity via an equity lens; "...in two schools that fostered collaboration among teachers and school principals in governance of the school, faculty stated that they made many of the decisions regarding students with special educational needs" (Dentith et al., 2013, p. 232). Teachers also needed to take on leadership roles, as was seen in Ukrainian schools where success depended on it for planning, implementation, and collaboration of inclusion (Loreman et al., 2016); again, this comes from the modeling and tone set by school and district administrators as in a parochial school provided

evidence that “once building leadership was able to show that best inclusionary practices aligned with the needs of the current student population, individual staff members were able to work with leadership and colleagues to create a vision for inclusion” (Smith et al., 2020, p. 73).

High-Quality Training

In addition, inclusion research showed that teachers should not be left to their own devices when it comes to educational programming to address the specialized instruction and curricula for students with disabilities; instead, leadership should seek out and provide research-based and high-quality professional development in partnership with trusted institutions like universities. Like schools with inclusion SPED in Zambia, high-quality training—meaning when university resources train and maintain preservice learning throughout the year—of staff, parents, and community members was a common theme in the literature (Mwamba, 2016). Gross et al. (2015) also found high-quality training common in successful inclusion initiatives:

University partnerships provided schools with student teachers, professional development and continuing education (e.g., master's degree programs) for in-service teachers, instructional support and training, and other support for students with disabilities. Schools benefitted from the support of student teachers, the universities' recognition of their teachers' innovative practices, and the ongoing training and support provided to them. (p. 19)

Moreover, Kenyan schools experienced success when staff participated in community-based research facilitated by university staff that implemented training focused on CDT (Elder & Kuja, 2019).

High-quality training was directly related to greater involvement of parents in the daily school life, including co-teaching, significant utilization of the assets from the community, and

increased enrollment of special education students; co-teaching was significant in overcoming barriers of deficit thinking with parents and community members initiating implementation of universally designed physical environments (Elder & Kuja, 2019). Universal design was also found in other exemplars when training focused on “need” not the “label” of disability, increasing the effectiveness of maintenance skills and practice of inclusion (Dentith et al., 2013). Researchers also provided evidence that all staff, including paraprofessionals, needed high-quality training (Haines et al., 2015) for greatest buy-in of inclusion (Francis et al., 2016a).

High-Quality Curricula

The research showed that high-quality training and high-quality curricula were not mutually exclusive (Mwamba, 2016; Smith et al., 2020). Although the definition of “high-quality” for instructional materials may have been debated, what researchers did agree on was that it needed to originate from the collaboration of regular and special education teachers (Lupart, 2012). Moreover, high-quality curricula (especially when first being implemented for inclusion transformation) should interrupt the status quo (Loreman et al., 2016) and be implemented system wide (Gross et al., 2015) where “a variety of curricular and pedagogical options are employed to maximise student learning in large group, small group and one-to-one teaching arrangements in environments which can be accessed by all learners, not just those with specific disabilities” (Dentith et al., 2013, p. 224). Less successful schools continued with general education teacher-driven curricula, which were considered as low quality and not inclusive by families and the community when seeing the pedagogy in the home with homework (Francis et al., 2016a).

Even though internationally there was abundant evidence of successful implementation of SPED inclusion, the United States was behind (Francis et al., 2016a; Gross et al., 2015; Gross et

al., 2018) mostly due to poor communication, implementation on top of existing systems, allowing stereotypes of disability to go unchecked, and district leadership continuing to act as agents of accountability (Dentith et al., 2013). When districts followed a culture of inclusion, clear leadership, and high-quality training and curricula, the systemic barriers to special education and inclusion were non-existent. These successes showed real results: students in special education were more social and interacted with general education students (Haines et al., 2015; Scharenberg et al., 2019); SPED students achieved more academically and on standardized tests than those not in inclusive schools (Dentith et al., 2013; Haines et al., 2015; Scharenberg et al., 2019); and general education students gained the social skills of awareness and acceptance of others (Haines et al., 2015; Loreman et al., 2016; Lupart, 2012).

Progressive Yet Equitable Funding

Almost paramount to all other factors was funding in special education programs and without fully funding training, staffing, materials, and school needs for inclusion of special education students, inequities were created between schools and needs were poorly met. States and local districts have had to get creative with special education financing to equitably meet the needs of their students. For example, Illinois utilizes tiers that prioritize those districts with the greatest funding gaps in receiving supplemental monies in addition to ranking them with 29 categories of inequity (Bloch et al., 2018). A Texas school district collaborated with community members, businesses, and social services for access of resources for SPED students during the pandemic (Tremmel et al., 2020). However, funding creativity needs to be analyzed with caution like in Texas where needs-based ratios are artificially low for the greatest number of students; California tried to address underfunding using capitation, which has added the financial share and burden to local districts (Dhuey & Lipscomb, 2011 & 2013). In addition, North Carolina

funding caps caused 62% of districts to be underfunded, which was addressed by a 37% use of local revenue (Needham & Houck, 2020). Any funding framework, including alternative funding created to address inequities, should be critically examined by policymakers and researchers to avoid increased inequities (Dhuey & Lipscomb, 2011 & 2013; Ota, 2021b).

Summary of the Literature

Even though the general education student to teacher ratio has been historically stable at 16 to 1, the special education student to teacher ratio is 17 to 1 (Samuels & Harwin, 2019). This example shows how low the actual funding was for students with special needs in Texas, the impact of allowing school districts to use 45% of the funding for other purposes, and artificially low multipliers for most of the need. Additional research is needed to examine whether these funding parameters are contributing to lower achievement of students with disabilities (e.g., special education students failed the STAAR at an average of 19 percentage points more than all students in freshman end of course exams) (Texas Education Agency, 2020) and a culture of denial continues (e.g., as of 2019, thousands of students with autism have been deemed ineligible for special education services) (Isensee, 2019; National Center for Education Statistics, 2019; Webb, 2019). Such research may be needed so that corrective action can be codified, and districts have incentive to properly fund the increasing needs of students with autism (Ota, 2021b).

Another factor of success to a repurposed educational system would be a redefined leadership role from one of accountability to one as a resource at all levels (i.e., federal, state, and district) *servicing* teachers, parents, community members, and students. For instance, many schools currently have an assistant principal in charge of the curriculum of a subject; instead, the “authority” of that oversight should be diffused amongst the faculty and students (Kennedy et al.,

2011; Leithwood et al., 2020; Leithwood et al., 2007). This shift from top-down leadership could be applied to special education, opening collaboration with leadership, community members, and families to develop eligibility criteria based on the strengths, needs, and wants of students with autism, dynamically responsive to their culture, and richly integrated with the assets of the community (Guajardo et al., 2016; McKnight & Block, 2012; Meier, 2017). Empowering those who are traditionally micromanaged by state and district authorities not only provides more authentic special education services, greater teacher satisfaction working with students with autism, and greater parent/community involvement to the betterment of students (Hargreaves & Fullan, 2020; Hargreaves & Shirley, 2012a; Hargreaves & Shirley, 2012b), but there is a level of emancipation from systemic oppression when done with “deliberative transformation” (Biesta, 2010, p. 98) and a level of social justice and restitution (Bogotch, 2002; Diem & Welton, 2020; Reindal, 2008).

Finally, a third tenet to successful school renewal is where each school—both in aesthetics and curricula—reflects the community, culture, and families it serves. When schools use the evaluation, eligibility, and IEP process as tools for denial, they are de-valuing the reality of what happens in the community for that student with autism. A student may receive many hours of behavioral, occupational, and speech therapies in the community, but is left to fend for themselves in the school setting, taxing teachers’ resources and creating a discontinuity of their autism by environments (Ota, 2020). As Guajardo et al. (2008) recounted of community schooling, “We understand ourselves better; we know the history more clearly; and we’re engaging in teaching and learning processes that build on the strengths and energies of local people, rather than focusing on the deficiencies and/or limitations” (p. 19). What right does a

school have in telling a child and their parent they do not deserve the supports and services they readily receive in the community or that they must pay for them?

Many critics of the community model and inclusion referred to them as “pie in the sky,” limited by the realities of the system (Guajardo et al., 2016; McKnight & Block, 2012; Ota, 2021a). Yet, the first documented case of autism in the U.S. is evidence of a community model of inclusion: Donald Triplett was diagnosed in 1938 and instead of being housed in a psychiatric hospital (as the medical professionals recommended), his parents and the community came together to help support, teach, and love him throughout his life (Donvan & Zucker, 2016). Thus, the ingredients are present for a renewal of our school system, educational leadership, and community involvement (Cooper et al., 2015). This transformation would require a retooling of what special education means in physical terms (i.e., the neighborhood vs. brick-and-mortar building) and mission of special education (i.e., inclusion with universally designed supports and services); administrators and policy makers would need to yield the role of oversight to more organic measures determined by local school stakeholders (i.e., no more gatekeeping and 100% individually-based eligibility determinations); inclusion would be rooted in the ontology of the community culture, perspectives, and equity/assets and the epistemology of “ability” determined by the collaboration between the teachers, students, parents, and community members (Biesta, 2010; Guajardo et al., 2016; Hernandez & Ota, 2020).

Furthermore, it has long been recognized that school support alone is not enough for successful and full transition from special education to adulthood for students with disabilities. Coordinating and collaborating with outside services (e.g., mental health) to integrate with special education services (Eber et al., 2011; Eber et al., 2002; Fallon & Mueller, 2017) taps into the community’s assets and provides for more equitable supports than those from a prescribed,

ethnocentric lens (Cooper et al., 2015; Guajardo et al., 2016; McKnight & Block, 2012; Ota, 2021a; Watson & Vehmas, 2020). A community model could help redefine what it means to qualify for special education services when not only the individual student and their family, but community members and outside caregivers are given equal voice in the eligibility process (Ota, 2021a).

3. METHODOLOGY

By using the framework of a community model of inclusion, I studied what interventions in school improvement might be effective in changing the culture of denial of special education for students and families with ASD. More specifically, this research was guided by the following questions:

- What are the experiences of parents of students with autism when they are denied special education services?
- What are parents' perspectives on how district and school processes, interactions, and methods of determining eligibility for special education contribute to denial of services for students with autism?

In reporting the inequities and themes of ASD denial, a call to action can be established for a correction in special educators' practice, district leadership, and government policy—especially at the state level—towards inclusion and creating equality for parents and community stakeholders in the IEP process (Ota, 2021).

My methodological approach was case study, which is bounded by the event of the policy for a special education cap in Texas and based on the concept that multiple families with ASD experienced and continue to experience a culture of denial (Creswell & Poth, 2018; DeMatthews & Knight, 2019; Merriam, 1998). The perspectives from school staff and district leadership, in a large part, were irrelevant since “the reality of an object is only perceived within the meaning of the experience of an individual” (Creswell & Poth, 2018, p. 76). I also utilized a reflexive journal centered on my own experience of eligibility denial for Carter to ensure that it did not sway the recorded experiences of others and identified biases that may influence analysis of the data (Creswell & Poth, 2018; Merriam, 1998). This included the process of discovering self through

the lens of multiple identities—my experience of having a stake in diametric cultures (acceptance and denial), professions (teacher and advocate), and ethnicities (Asian and White)—that is continuously reflective and consists of adjusting of perspectives and influential biases (Anzaldúa, 1999).

Research Design

This study followed the guiding principles of case study methodology as outlined by Sibbald et al. (2021), which include full disclosure of the beliefs and perspectives influencing the research, defined bounds of the case, justification for the study design, and utilization of multiple data sources and methods. Qualitative methods can provide common themes that highlight missing connections between quantitative data and narratives (Jackson & Mazzei, 2011); in other words, it can provide an explanation as to why autism is linked to a high proportion of SPED ineligibility. To explore those possibilities, a research method that is flexible in approach so that the complex web of factors leading to ineligibility is in place is warranted (Creswell & Poth, 2018). Moreover, there are moral and ethical elements to disability research that are key to addressing the disproportionate conditions in society for individuals with ASD (Reindal, 2008). These facets have the best possibility of revealing those devices of inequity and pathways to empowerment with a qualitative approach (Creswell & Poth, 2018; Lichtman, 2013; Merriam, 1998).

Philosophically, this research sought to address the inequities that individuals with ASD experience in schools and society by empowering them with the knowledge of disability, inclusion, and social justice. In my epistemological view, this empowerment can only be achieved by the reality founded on the perspectives of multiple individuals involved in the process of special education eligibility, which includes the influence of personal values and

beliefs on the participants' perspectives by my biases, and takes on the reality of events with equal importance to the exploration of the factors (i.e., the in between of "cause-and-effect;" Jackson & Mazzei, 2011). A case study method for this research appeared to be the best method; this approach afforded comprehensive analysis of multiple cases of ASD ineligibility in Texas public schools (Creswell & Poth, 2018; Gibbs, 2007; Merriam, 1998). Furthermore, using this method along with the framework allowed a greater possibility that the experiences of those students were revealed, and my own biases, influences, and perspectives did not sway the analytic process with continuous and purposeful reflection (Creswell & Poth, 2018; Merriam, 1998).

Black storytelling (Toliver, 2022) provides voice to both the participants and researcher in the process of data collection and analysis. Although not specifically written as a generalized framework, black storytelling is based on responsibility as researchers that "demands scholars be accountable to the people and communities with which we engage" (Toliver, 2022, p. xvii). The purpose is to balance the procedures for biasness in qualitative research without "drowning out" their narratives with a Eurocentric, hegemonic lens of "empirical" research methods. One way to do so would be fact checking claims by parents on how or why their children were denied special education; records review can be hegemonic, limiting, and placing one account above another. Thus, I use the principles of black storytelling (i.e., becoming a story listener and remembering the storyteller) sharing my story, facts and figures, or resources available to parents after the questions were answered; in data analysis, I used my story as part of the perspectives puzzle (i.e., to follow the threads and consider the patches) after open coding was conducted in several iterations. In addition, instead of ethnicity or socioeconomic status being collected from each participant (to not predetermine the color of their story), the common bond between them and me

was the special education community and our common experiences with having a child denied services even though we had “outside,” private diagnoses of autism. Without black storytelling, forms of communication, culture, and community are set aside for “researchers... restricted to gathering stories, not telling them” (p. xv), which ignores the fact that “the stories of my families keep me rooted to my past and present” (p. xv). By including my story, I was able to listen to the stories of the participants more effectively by becoming a “story listener,” follow the threads of their and my stories like a seemingly random patchwork quilt (something my mother literally taught me how to do), and view how the patches were interconnected. This lifted the voices of each child denied services including Carter, which would have been, arguably, omitted in traditional methods.

Data Sources and Data Collection Procedures

The process of collecting data for this dissertation study included multiple measures. Conducting interviews with parents who had been denied eligibility of their child with ASD were included to help identify the factors leading to ineligibility. Utilizing a researcher’s journal was key to identifying bias and maintaining the integrity of the participants’ perspectives.

Qualitative Data Sources

Qualitative data for this study included interviews with parents and a researcher’s journal. Participants included eight parents or guardians who had at least one child with autism—medically diagnosed—and had been denied either currently or in the past from special education services in a Texas public school during the period of 2005–present. This included parents who had been denied access at any point in the initial process of eligibility, but who eventually received services. Participants were recruited from across the state to represent the differing geographical areas of the state.

To recruit participants, an electronic advertisement was posted and/or sent via listserv through autism organizations (e.g., the Autism Society of Texas), autism community groups on social media, or through snowball methods via university, advocacy, or parent networks (see Appendix for recruitment materials). For anyone who expressed interest via a hyperlink to my email, a consent form was sent via email and then verbally signed before the interview began. Parents who meet the inclusion criteria were included in the study if they consented; the plan was once 20 parents had consented to participation, additional families would be placed on a waiting list.

I anticipated a wide range of individuals by gender, ethnicity, and age; however, historic data suggested that individuals with autism are primarily White and male, which is essentially the majority of the sample (deriving ethnicity based on participants' last names). Participants who are Spanish-only language speakers or who would prefer to be interviewed in Spanish were referred to the ongoing study on Spanish-speaking families with autism who were denied eligibility (Ota et al., 2020). Parents (adult age, English speaking, child had been enrolled in public/charter school) of a child diagnosed with autism who experienced denial from 2005 to present met eligibility; DeMatthews and Knight (2019) provided evidence that significant changes in eligibility began in 2005 when the SPED cap policy was implemented and even though corrective action was to take place by 2020, I wanted to explore whether or not it is still happening.

Informed Consent and Ethical Considerations

Informed consent documentation included descriptive language focusing on participants who were parents of students with autism denied or being denied special education services based on eligibility. See Appendix for Informed Consent form. I was available via telephone,

Zoom, or email to answer any questions or concerns. Only one parent per family was needed for consent to participate in the interview. Verbal consent was recorded on Zoom with audio and video, and then transcribed. In-person interviews were not conducted; instead, interviews were conducted via online video conference on Zoom to maximize geographic reach of potential participants and to ensure participant comfort given the on-going reality of the COVID-19 pandemic. All interviews were video recorded via Zoom, with the participants' consent.

Parent interview recordings were stored on the university's server. Each interview was anticipated to take no longer than 60 minutes (see Appendix for interview protocol). At any time, the interviewee could choose not to answer a question or prompt or stop the interview. They were also able to withdraw from the study at any time, before, during, or after the interview. Any time the interview was stopped, or the participant withdrew, the data was not included in the study and another family would be recruited from the waitlist; no participants asked to stop participating. I conducted Zoom interviews in a secured, private location (i.e., in a home office with a door lock, headphone, and white noise machine) and each participant family was provided pseudonyms to ensure their confidentiality. The transcription feature of Zoom was used and verified against the recording for each interview.

A digital format of a researcher's journal was also maintained and stored on the university's server as part of the full disclosure principle of case study methodology (Sibbald et al., 2021). The intent was to document my introspection after each interview, including my "ideas, fears, mistakes, confusion, and reactions" (Merriam, 1998, p. 110) that may contribute to bias in the analysis of the data and to help honor my narrative along with the culture and community of special education parents (Toliver, 2022). Journaling also helped identify

adjustments to methodologies that were needed to further eliminate barriers to accurate and inclusive interpretation of the participants' perspectives (Merriam, 1998). For example, after the second interview produced a shorter narrative, subsequent interviews followed more story telling with story listening and patchworking the participants' story with own son's, which produced richer answers, follow-up questions, and honored all experiences (Toliver, 2022).

Analysis

Using case study analysis with the qualitative data, I ensured that all transcribed interviews were accurate by first checking over each transcript thoroughly with the audio/video recording. Then for each transcript, I used parent and child coding to identify the themes revealed through the experiences of the parent participants (Gibbs, 2007; Merriam, 1998). Quotes from each datum were examined and coded; each interview visit triggered re-examination of previous data for coding consistency and alignment; and each transcript consisted of three rounds of coding review, especially when integrated with results from the researcher's journal, analysis with the literature and policy review, and own story (Carter & Little, 2007; Creswell & Poth, 2018; Gibbs, 2008; Lichtman, 2013; Machi & McEvoy, 2018; Merriam, 1998).

Open coding was done by using the comments feature of Microsoft's word processing software, which were converted into child codes on a spreadsheet using a macro or add-on program so that parent codes and evidence codes were identified. Those quotes identified by evidence codes were used to create a codebook of data across participants so that possible themes could be examined, coded, and re-examined. Themes from the data were identified from the analysis using systematic and iterative examination; inductive reasoning was used to provide conclusions on the most relevant themes as they relate to the community model of inclusion

(Carter & Little, 2007; Creswell & Poth, 2018; Gibbs, 2008; Lichtman, 2013; Machi & McEvoy, 2018; Merriam, 1998; Reindal, 2008).

Positionality

My own knowledge and beliefs on the data analysis were included, especially with respect to being an indigenous outsider as a former educator of, parent of, and legislative advocate for individuals with ASD who had been denied eligibility (Chavez, 2008; Merriam, 1998). Examination and disclosure of my influence on the data collection and analysis was carefully included with the process of coding and thematic emergence. This self-reflection was derived from written entries in my researcher's journal after each interview. These entries were also examined, coded, and re-examined so that themes of bias (e.g., behavior analytic, researcher, former educator, and advocacy lenses) emerged, which could be used to guard against bias in the participant analysis and the results (Creswell & Poth, 2018; Gibbs, 2008; Merriam, 1998).

Participant Profiles

After journaling, reflection, and digesting of the transcripts in three rounds, an analysis began of the narratives by highlighting block quotes by common experiences and labeling them with open codes. This process was conducted three times with adding/dropping codes, combining codes, and multi-coding. The results can be seen in Table 1, which show that a total of 254 quotes identified as common experiences or unique data points that warranted investigation. Twenty-four different codes were then analyzed for thematic grouping for overarching experiences by the participants, as seen in Table 2.

Table 1. Count of Data Points by Code

Codes	Cassarrah	Corrine	Dona	Haylie	Keira	Love	Nicola	Scarlette	Grand Total
504 or RTI or OHI	2		1	1	1	1	1	3	10
Advice for parents	2	2	4	1	1	1	1	1	13
Advice to policymakers			5		2	2	1		10
Advice to schools	4	1		3		1		1	10
Advocate		1	2		3	3	4	1	14
Bad evaluation	1	1							2
Complex profile			1		3		1		5
Denial of IEE		2	2		3	1			8
District intervention	2	3	3	1	2	4	2	3	20
Emotional toll	1	3	3	1	1	4	3	1	17
HFA	1	2	1	1	1	1			7
Incomplete evaluation	3					1	4		8
Limited observation	1	1		1				1	4
Make the change	1	2	5		2	1		5	16
Medical diagnosis	1	1	2	2	1	2	2	2	13
Missed evidence	3	1	5	7	1	6	7	4	34
No educational need	1	1		2	1	1	3		9

Codes	Cassarah	Corrine	Dona	Haylie	Keira	Love	Nicola	Scarlette	Grand Total
Predetermined denial		2	1	1	1	1	1		7
Procedural confusion	1	4	2	1			2		10
Procedural safeguards	1		2	1	1	1	1	1	8
Qualified evaluators	2	2		1	1	3	1		10
Retaliation		1	2						3
Understanding the process				1		4	1	1	7
Wait to fail	2	2	2	2			1		9
Grand Total	29	32	43	27	25	38	36	24	254

Thematic Results

During thematic analysis, some codes were collapsed into other related codes for a total of 18 child codes. These quotes were analyzed with a final reading of the transcripts to identify themes of common experiences from the narratives. As seen in Table 3, these themes answer the research questions of what parents experienced and what systemic factors they thought contributed to the denial of eligibility.

Table 2. Child Codes and Themes

Child	Theme
Advocate	Collateral Costs
Emotional toll	Collateral Costs
Make the change	Collateral Costs
Wait to fail	Collateral Costs
District intervention	Lack of CMI Culture
No educational need	Lack of CMI Culture
Predetermined denial	Lack of CMI Culture
Procedural confusion	Lack of CMI Culture
Retaliation	Lack of CMI Culture
Understanding the process	Lack of CMI Culture
Denial of IEE	Lack of CMI Culture
504 or RTI or OHI	Quality Programming & Training
Bad evaluation	Quality Programming & Training
Complex profile	Quality Programming & Training
Incomplete evaluation	Quality Programming & Training
Limited observation	Quality Programming & Training
Missed evidence	Quality Programming & Training
Qualified evaluators	Quality Programming & Training

The analysis provided a thematic narrative as to the inequities that continue to exist in receiving special education for students with ASD, the barriers families experience from school staff and district leadership, and the extent to which district and school leaders implore inclusion and community schooling in IEP decisions. Detailed exemplars are provided in Chapter 4 that follows.

4. FINDINGS

Narratives of Participants

Below are summaries of the interviews that were conducted from August 2022 through November 2022 in the order that they were interviewed; no follow-up interviews were deemed necessary. The average time spent with a participant was 53 minutes. Eight participants were included in the data sample representing a cross-sample of major regions of Texas: Central Texas, East Texas, El Paso, Houston, North Texas, Rio Grande Valley, San Antonio, and West Texas. All participants had children with a medical diagnosis of autism and denial of eligibility for special education under the autism label since 2015 to present. Here are some of the demographics collected from the interviews.

Table 3. Demographic Data of Participants (with pseudonyms listed here)

Parent & Child Name	Sex at Birth	Location	Type of Autism & Other Factors	Medical Diagnosis Timing w/ Denial	School Type	Education Stage at First Denial	Procedural Safeguards (Received at Denial & Understood)	Year of Denial
Cassarah & Tyson	Male	El Paso	HFA	Before	Public	K-5	Yes & No	2022
Corrine & Jarvis	Male	San Antonio	HFA, EL	Before	Public	K-5	N/A	2020
Dona & Alysa	Female	North Texas	HFA, Speech, Dyslexia	Before	Public	Pre-K	No & No	2017
Haylie & Vinny	Male	Rio Grande Valley	HFA	Before	Public	K-5	Yes & No	2021
Keira & Russ	Male	Houston	HFA, ID, Speech	Before	Public	K-5	Yes & No	2022
Love & Astor	Male	East Texas	HFA, ADHD	Before	Public	K-5	Maybe & No	2019

Parent & Child Name	Sex at Birth	Location	Type of Autism & Other Factors	Medical Diagnosis Timing w/ Denial	School Type	Education Stage at First Denial	Procedural Safeguards (Received at Denial & Understood)	Year of Denial
Nicola & Tamsin	Male	Central Texas	HFA	After	Public & Charter	Pre-K	Yes & No	2015
Scarlette & Don	Male	West Texas	HFA, Speech, ID	Before	Public	K-5	Yes & No	2015

Haylie and Vinny from the Rio Grande Valley

Haylie noticed differences in how Vinny, her three-year-old son, processed information, had sensory-seeking behaviors, and rigidity. It was her husband and Vinny’s father who first noticed these differences, but after consulting her pediatrician and aunt who had experience in childcare, they said “He’s just smart.” This was evidenced by occurrences like learning to walk and stacking boxes at ten months. However, an incident that happened with his aunt when Vinny was playing with his toy cars caught their attention; instead of “playing” with them the way neurotypical three-year-old children would do by driving them and making motor noises, he only quietly lined them up by color and size. When his aunt took one of the cars, placed it in a different place in the line he had created, and said, “Vinny, I think this car belongs here,” he became verbally aggressive and insisted that the car should remain where he had originally placed it.

Vinny is Haylie’s and her husband’s first child, and, at first, he did not speak many words. He communicated in other ways and did not show stereotypical behaviors like they had known about autism. He was smart, active, and social, so it made sense that check-up after check-up the pediatrician said there was no concern—first mom jitters. He was also somewhat isolated in the community of the Rio Grande Valley as Haylie reported there were few other

toddlers with which he could play. Their suspicions solidified to concern and action after Vinny's younger sister began talking, he did not significantly increase his vocabulary. And then there was an incident during pick-up at his daycare center.

And I was like, oh my God. And as I'm checking him, you could see handprints on his neck. And I was like, what happened? [Vinny said], "He bit me. And he choked me." And we said, "Buddy, like you didn't tell the teacher, like you didn't say nothing." He didn't, he stopped responding... The teacher, it was actually the assistant, she said, "What happened?" And we are showing her, and she said, "He didn't scream. He didn't yell. He didn't react. And if he would've reacted, us, ourselves, with a scream or anything, would've said, 'what's going on?'" And we said, "Nope, that's it." That right there, that tells me that he does have autism because he did not react the way a normal child should have in this type of situation.

Vinny did not cry, yell, or complain of being hurt from an obviously painful injury. Then they knew Vinny needed a specialist who diagnosed him autism.

Haylie's greatest concern comes from the school's denial of special education services for autism, which they pursued after the medical diagnosis. Even with a level 2 diagnosis, which indicates a moderate level of support, the school did not believe that Vinny's autism warranted an educational need. His intelligence and academic success masked difficulties with social interaction (i.e., having no friends), emotion regulation (i.e., having meltdowns), and safety (i.e., knowing what to do in a fire drill). When she brought that up in the denial meeting, the principal said he would look out for Vinny.

Technically the principal jumped in—who we do have a great relationship with the principal— and the principal jumped in. He said, "Look, [Vinny's mom and dad]," he

goes, “I can assure you that in the event, should anything happen, should we have a fire drill, etc., etc., that you know, now we know our issues. I will go make sure to check on him. Okay?” And I'm like, dude, I understand this. And mind you, my husband and I talked about this later, we were just like, “Okay.” ‘Cause we were so done with the meeting because it felt like they weren't truly listening to us. So, we were just, okay, fine. That's fine. Let that meeting go. And my husband and I were talking about it afterwards and I'm like this dude has three to 400 other students he's gotta worry about. But yet his reassurance is “I'll make sure to go.” That's not as comforting as I'm sure he was trying to make it seem.

That feeling of defeat turned into doubt. “Okay. Maybe, as parents we're overreacting or we're overanxious and overthinking things. Let's just see how this one school year goes, ‘cause this'll be his first full year in a classroom setting. So, we're like, let's just see what happens.”

The year did not go well, and school staff, especially the LSSP, continued to inform Haylie that Vinny would not qualify under the autism label. Her concern for the social, emotional, and behavioral skills he was lacking turned to safety of others. “What if he's the one who goes out there and leads the shooter to where his friends and classmates are, because he doesn't know what to do and he doesn't know how to act.” Being gaslighted about her own son made her feel like they were out of choices and on the outside of a system. When asked how it affected their family and how it made her feel, Haylie shared, “Yeah. Helpless honestly. And like ignored because it kind of felt like, well, because he's not disabled or, you know, because he doesn't meet our disability and needing help requirements. We can't help you.”

Corrine and Jarvis from San Antonio

Corrine (mother and originally from Sweden) and Jarvis lived in San Antonio, which is where they landed after moving from Florida in 2020. She expected a simple transition since Jarvis had been eligible for autism services in special education in his home state for many years. However, the pandemic delayed implementation of the Florida IEP, taking over a year and missing key services including those for autism. This lack of compliance with the law—federal statute requires the receiving district to implement an out-of-state IEP while a new evaluation is conducted to determine eligibility (Yell, 2016)—spurred Corrine to hire advocates and attorneys who requested an IEE in 2022 when the school finally got to implementing their own IEP, at which time autism was denied even though it had initially been listed. When asked, school staff said autism was taken off the IEP due to the IEE request. “When I came from Florida, I had a lot of services [for] my son. And when I came here, they denied [them]. They have a different IEP. They're not very [well] written here in Texas.”

At the center of the conflict over the IEP, according to Corrine, is that the programming was poorly written, the school had cherry picked the services, and left out language from the Florida IEP without evidence of data from Jarvis’ two years in Texas. “Based on the evaluation, no, they didn't gimme as much as I asked them what the evaluation said. No, they left a lot of services out that came out from the evaluation.” In addition, there were major concerns with the fidelity of the evaluation. “No, because you cannot see someone in one minute. You need to take time. I mean, sit one hour with my son and he'll run away from you.” There was district intervention, which she asked for, but was neither helpful nor explained even though she repeatedly asked questions for clarity. The school disagreed with the IEE, which did include

autism and relevant services, because there was an overall belief that Jarvis was not autistic with staff stating, “He's such a sweet boy. He doesn't have, we don't think he has autism.”

Notably, Corrine had trouble with advocates and lawyers, who said she was aggressive, knows more than all, and eventually withdrew services. “I did have an advocate from insurance. I had several advocates. I had like five advocates who didn't know how to talk in the ARD” (a Texas specific term for IEP meeting), which caused delays for agreement and implementation. “So, I waited to sign the paper because the lawyer withdrew because the school was harassing them.” District representatives said she was rude just for asking questions. “There was district [personnel] all the time... Then they changed to another one and she came in August 2020. And she was really rude. She was extreme. She wouldn't [tell] me anything on evaluations. She just came to [the] meeting.” Eventually, school staff wanted to know why mom was pushing for services when Jarvis was so smart. Corrine withdrew Jarvis from the school district and enrolled him in virtual school, where he's doing better and receiving autism services in special education, but at a cost.

[It] took two years before he got eligible for autism in Texas. He didn't [receive services], the delay was [due] to [the] evaluation. It took two years to evaluate him... Delay, he's delayed. I had to have [an] insurance company coming for OTs and speech... After when I came here to Texas, according to evaluation, he hasn't [qualified for] anything. He still [doesn't] know the developmental milestones, some of the sound and the words and stuff like that. I was very disappointed [for] him.

This experience has also taken an emotional toll on Corrine. “And frustrated and sad? I'm angry... I fought so much...I spent so many hours researching everything... I was crying, but I told them how rude they were.”

Dona and Alysa from North Texas

Alysa received an educational diagnosis before getting a medical diagnosis for autism. Her mom, Dona, said that she would score just under the threshold for a medical diagnosis and doctors told her to be on the watch for it.

But we had had previous evaluations and what they essentially said is that she's on the spectrum. There are signs of autism at the time. It wasn't enough. And she had other disabilities, and they just didn't have enough to say definitely, "This is a child with autism." But what they did say is that there was a responsibility because there were signs that people needed to keep an eye out. That didn't happen in our case.

Doctors were not the only obstacle to services; Alysa had been diagnosed with multiple other disabilities, like dyslexia and speech impairment, from the age of three, yet the school district she attended in North Texas sent a letter congratulating her for not having severe enough disabilities for PPCD (a preschool special education program that starts at age three). Thus, these denials led to deepening challenges in social, emotional, behavioral, and academic skills with little to no intervention.

One of the biggest obstacles to Alysa's services was the special education coordinator from the district who attended all their meetings, especially when Dona hired advocates and lawyers to attend ARDs. According to Dona, this one individual from the district was the sole decision maker for every aspect of the eligibility and services process. This was more than apparent when an IEE was conducted.

They each wrote their own reports. And the district paid one bill for this. Well, in the report, the IEE specialist for dysgraphia said, "This kid is dyslexic. This kid is dysgraphic," and that she suspects autism, and she gave five different reasons. She said

for the five following reasons, I think this child needs to be identified or evaluated for autism. And she also noted it looks differently in girls. Well, it was really interesting 'cause in the meeting they said that they agreed with her, they accepted her evaluation in full, they paid the evaluator, but then they refused to evaluate, and they refused to consider autism moving forward.

This adversarial approach, orchestrated by the district coordinator, led to confusion amongst the school staff on what services and supports were being implemented. Inappropriate midnight emails, changed agreements on paper from deliberations, reduced hours after being ordered by the TEA to implement autism services, no prior written notice on denial of evaluation, falsified documentation by the district on the determination of autism eligibility, and predetermined goals and services prior to ARDs were the “bullying tactics,” retaliation, and results of the district’s expenditure of \$60,000 in attorney’s fees. In 2017, the denial of eligibility for autism and the reduction of existing minutes of services that had already been agreed upon were the last straws. “They don't qualify for this program. Now we're age 11 and we're trying to catch her up. I wonder where she could have been if she could have got[ten] the interventions when she needed them.”

Dona filed multiple complaints with the TEA, which ended up in a due process hearing, which is a court proceeding decided by a hearing officer.

Actually, after being diagnosed it, they actually fought in court that she doesn't have autism. Which they wouldn't know. They never evaluated her. Does that make sense?... They actually paid, they paid two different medical doctors, who they admitted were not experts, who they admitted [they had] never worked with my daughter. They selected what documents to give them. And one of them, my attorney got [them] pretty well under

oath. That document where the IEE evaluator said, “I suspect this child has autism,” they didn't give her that document.

Most apparent was a lack of prior written notice, which the court found the district had violated on multiple occasions including why it had rejected the IEE for autism eligibility. When returning to ARD after one of the hearings, the district coordinator would not allow Dona to discuss the outcome and refused to implement the hearing officer's order for autism eligibility and services.

Alysa's family decided to move to a new home and had to pay for out-of-district tuition until their house was built. Even Alysa's new district in Texas testified against her former district, which they had immediately approved eligibility for autism. A more expensive house, longer commutes, and the overall disruption of leaving your community was all worth it since how they are treated now is very different and collaborative.

It was night and day. Okay. So, I will tell you, I let them know that I have disabilities. I need accommodations. They were great about those. I go into a meeting. We record every time. It's now to the point where the district just records. I don't have to bring my own tape recorder... So, we are using the same recordings... We all participate. We all get to ask questions. If there's something, I like how they use the deliberations. And I like that there have been a few times when we're not totally a hundred percent on the same page about something. I love when I'm like, “This is what I want,” and they can say, “What about this instead?” It's been beautiful.

However, the negative affects continued to linger even after Alysa's IEP was on track and they saw immediate results. Dona also picked up advocacy including speaking at legislative hearings and to the press. What she has learned by working with parents across the state has been eye-

opening. “My kids have also gone without appropriate services for years. Everyone tells you [that] your kids need early interventions. Here in Texas, it's impossible to get 'em.” What was even more evident to her in her advocacy was that denial of autism eligibility as predetermined practice is commonplace across the state. “The whole thing is just infuriating, and it feels like a battle. And I started out not knowing how to advocate and now it's something I lose sleep at night.”

Nicola and Tamsin from Central Texas

Tamsin had challenges from birth having been born prematurely, for which he received immediate intervention for various medical conditions through Easterseals. When he turned three years of age, Easterseals helped Nicola (Mom) to apply for services through the district. Tamsin experienced sensory processing disorder, gross and fine motor skill deficits, and emotional regulation issues. However, he was also twice exceptional (i.e., high intelligence with remarkable disabilities) and “wow’ed” the school evaluators with his “professorial speech.” The school district denied him PPCD services in a two-page report. At first, Nicola felt like it was good news that his deficits did not warrant continuing intervention. Her contentment changed once she witnessed firsthand as a parent volunteer in his Kindergarten class. She asked the teacher and other school staff if he needed testing. No one ever responded to her requests, and no one shared with her that she needed to request special education testing in writing.

By second grade, Tamsin was so overwhelmed with the school day that he was crying for hours at home and school, and he often was punished for missed work: he would have to take a “work bucket” to lunch and teachers often removed recess from his schedule. When he started at a new charter school, he continued to have social, emotional, and behavioral challenges with new element where Tamsin used the school’s calm room to escape the classroom frequently.

So [in the charter school], he was in second grade. He was crawling under the desk at like a group activity because he was getting overwhelmed. He was isolating by himself at PE.

They had a peace room, and he was going to the peace room a lot.

By now, Nicola knew there was something else going on and she had him tested in Dallas by two different centers who both diagnosed him medically with autism. When she brought the reports to the school, they did do an evaluation completed by a new-to-the-field speech therapist who recommended denying autism eligibility. Essentially, the special education director said there was no educational need because his grades were too good.

At first, the school said they could only provide accommodations. So, when we received the autism diagnosis, I submitted it to the school and [they] told me that he did not have an educational need for a school autism diagnosis. And they told me they could only put him in a 504.

That changed when she hired an advocate who “eviscerated” the school’s evaluation citing above all the evidence of autism provided in the speech pathologist’s own report. Tamsin began special education services for autism and continues to do so, which changed the trajectory of his educational experience.

Nicola shared that the whole experience was very traumatic, especially because she had to watch her son struggle in school for so long and they would not do anything to help. She had experience as an advocate for domestic abuse, but the world of special education advocacy was a completely different world and she had to learn an entirely new set of skills to help her son. All along she was feeling torn between the educational system that she had been raised to respect and the trauma of how it was not only ignoring the needs of Tamsin, but it was punishing him for those needs. Nicola felt that the system worked against families asking for help and the greatest

change needed should be the school's responsibility: when a parent asks for help, school staff should teach parents the process for referral, testing, and the requirements legally needed.

Scarlette and Don from West Texas

In 2015, Don was diagnosed with ADHD but his mom, Scarlette, took him off the medications because he turned into a "zombie." Subsequently, he was made eligible for PPCD because he was receiving speech through ECI (early childhood intervention). Don's behavioral challenges were immediate, and he was subjected to daily restraints resulting from his tantrums.

He was able to get in pre-kindergarten through our district because he was in speech.

Since that little age of five or six, he's always been [having] behavioral problems, like through school to the point where they would restrain him on a daily basis. And it was just out of control. I just did not know what we could do, and I didn't understand why this child was so angry and acting this way.

He hated school, and his mom asked the staff if he could possibly have autism since the interventions were not working for his ADHD. The school conducted a screener and told her that he would not qualify for autism since he made "eye contact."

Once he began general education classes (i.e., without special education eligibility) in 2018, Don continued to have behavioral issues that escalated to physical destruction of property. The school even told her to seek a mental health evaluation outside of school because of Don's suicidal ideation at age six; they tested for autism, which was not confirmed, but he was identified to have an intellectual disability, after which the school still did not evaluate for special education services. Meanwhile, Don spent more and more time in a behavioral program under 504 accommodations. "So, [they had him in], the back unit and it was more for behavioral issue children." It got to the point that he was spending up to 85% of his time away from his

peers and increasing his academic gap. In 2020, Scarlette went to another private center who diagnosed him with autism. This opened private services that made an immediate effect. This time armed with a second diagnosis, she hired an advocate and lawyer and included them in the next meeting.

What had begun in 2018 as an informal 504 meeting ballooned into a much more formal procedure by 2020 that seemed more adversarial with district staff, Don's family, district lawyers, Don's advocates and lawyers, district diagnosticians, and Don's caregivers including his BCBA.

And then I felt like it was all against him. So, then I would want to bring in his doctor and his therapist and his ABA people just so we could have more. And I always called it "Team Don," like just to have more people on his side to see the good in him. 'Cause he is a good kid.

Her lawyer pointed out the lack of due process and prior written notice when Scarlette requested multiple times for testing, the illegal use of alternate educational placement without special education, and the increased developmental delay of three grade levels. Instead of continuing to battle, Scarlette recounted, a change in tone occurred where district and school staff listened and collaborated with outside support like ABA. "When all those different people from Team Don were involved, it felt more evened out. It felt like they were actually listening to what we were saying now. It felt fair." He was deemed eligible for special education under autism, is getting back into the general education classroom one minute at a time and receives his academics in a special education classroom. Now in fifth grade, Don is happier, seeing that he is capable, and exhibiting a lot fewer behavioral challenges. This collaborative approach has also made an immediate change in all other aspects of their lives.

Cassarrah and Tyson from El Paso

Cassarrah knew she had an intelligent boy, Tyson, but it was apparent that something extraordinary was happening, especially when compared to her older child. “He's very bright, but emotionally he is very sensitive. So, he has a lot of meltdowns.” He was not social, refused to eat most foods, and had tantrums that escalated to the point that she could not take him to the grocery store anymore. By age three, Cassarah wanted an evaluation done by the school before enrolling in the district’s preschool program; her greatest worry was how Tyson would be able to function in a classroom with other peers, whom he “couldn’t care less about.” The district did conduct an evaluation and she simultaneously pursued a private diagnosis, which confirmed autism, delayed social pragmatic communication, and sensory processing disorder.

The district’s evaluation did include language/speech, behavioral, and OT, but it did not directly test for autism. Cassarah did provide the private evaluation, but the district’s report had an overall conclusion that Tyson did not qualify for special education because he had good verbal skills. District personnel also made the decision to not qualify because he did not need it academically. The diagnostician specifically stated that they needed to see a language delay to qualify for autism, which was not part of the social communication criteria in the DSM-5. (American Psychological Association, 2013) “And they wrote on the report that he's very functional. Yes. He's very functional. But in a class full with 20 kids, he's gonna be overwhelmed, overstimulated, and we're gonna have the same issues.” This decision for eligibility appeared to come from the diagnostician with the message for the school and mom to “wait and see” how Tyson performs in the general education classroom.

We had a Zoom meeting, <laugh>, and we went through that report. They told me their findings or their opinions, and at the end it states that he, at the moment, he does not

qualify for services... Any services, no speech. He will be put in a regular class with other children, and if they see that he needs a review, then they will do it.

Cassarrah reluctantly enrolled Tyson in the preschool program without a specialized educational program.

Once he began the program, Tyson needed extensive accommodations that the teacher and Cassarah worked out. They needed to address his movement needs and distracting others from learning. He also had food refusal and sensory complaints, resulting in reducing a full day of school to half and an isolated desk area. Even though these measures have decreased the behaviors, Cassarah was worried about the transition to Kindergarten in a few years. Working at the school, she saw the issues and gained skills; however, Tyson is not receiving specialized instruction.

Yes. And I'm scared that if I put him in, we are gonna have the same issues and I don't wanna wait for them to see or to have the time to think about it... And the other thing is that depending on how much it hinders his learning, they're only gonna take him out for let's say OT.

Cassarrah felt that schools need to look at the whole child, not just the academic. Tyson receives outside services like OT, feeding skills, and sensory training. These are intensive interventions, including ABA, but the school's response to those issues has been dismissive; for example, when she asked about his food refusal, the district said that Tyson was just a picky eater. "I told them, and what the occupational therapist said is that he was not a picky eater. He just knew what he wanted." Cassarah also believes schools should be ready to help anyone with a diagnosis of autism and neurodiversity, otherwise parents in desperate situations may feel there are no

alternatives but desperate measures. Cassarah also feels like she has had to fight and advocate for her son's needs, but that it should not have been that way.

Keira and Russ from Houston

Russ has “high functioning autism” with symptoms of being overly obsessive with routine and trusting of others. In 2022, the district diagnostician made him eligible for special education through ID and OHI but ruled out his medical diagnosis for autism. They stated Russ had no educational need for autism services. Keira, his mother, asked for an IEE in speech and autism, which two separate, independent evaluators found that he qualified for both. Yet, the district did not agree through both the diagnostician and special education coordinator who made the decision not to accept the IEE's result.

We petitioned the district for a, paid for by the district, third party evaluation through speech and a psychological evaluation. And both professionals agreed with us that he does have an educational diagnosis of autism, which the district then said that they did not agree with the findings.

Their main argument was that it did not include qualitative data, although the district used CARS-2 for an assessment of autism, which is a qualitative and subjective instrument (Monteiro & Stegall, 2018). “And so, when I reached out to the evaluator and I said, ‘They are disagreeing with your evaluation because they say it's not thorough enough.’ And she said, ‘I'm happy to come and do more evaluations if that's what they want.’ And they said no.”

Essentially, the district said there was no need to qualify for autism since he was already getting the services under IDD that he would receive with the ASD label.

It's just like any type of other medical condition. If your diabetes is causing your blood pressure interaction, you can't treat it the same way. I mean they wouldn't even evaluate

him for dyslexia because they said, “Oh, sorry, his IDD is the umbrella that covers everything.” And I'm like, you could have a reading disability and low IQ... You can have dysgraphia and you can be diabetic. It happens.

Keira strongly believes the autism supplement, a multiple page schedule of services and interventions included in the IEP of every student who is eligible for autism (Yell, 2016), was why the district would not recognize Russ's autism. “The only reason I ask is that if the autism supplement umbrella was in effect at that point or not because I fundamentally believe that the reason that I am being denied is because they don't wanna have to follow that.” Currently, they are considering filing due process with the TEA since Keira feels Russ deserves a complete and comprehensive IEP in case they move to another district.

Russ's family came to their current district because they thought he would have a greater chance of getting more and higher quality services.

I am part of a non-profit called Steel Magnolia Moms in here in Houston. And it's a group of about a thousand women in the west side of town who just know all kinds of [information], are very helpful about making recommendations and resources. So that's kind of a dashboard I can go to say, “Hey, I'm getting denied this or do you have a recommendation for an IEE evaluator?” So, I have that. And then I've used... Texas Disability Rights website just [for] their interpretations of what the TEA rules and regulations [are] has been helpful... My husband and I both have master's degrees, and this is still a fourth language.

They have been blocked just like many other families Keira knows in the district, a wealthier one than where they came from, who go to private, specialized schools because they can afford it, which Keira's family could not afford. The biggest issue for her was that she did not know what

services Russ was missing because he was not eligible for autism. She felt like the district just “waits them out” and provides incremental services to delay.

Love and Astor from East Texas

Astor, now age nine, was denied twice by his school district: first in 2019 when it said he had ADHD but not autism; second in 2020 when the LSSP stated he does not meet qualifications and was “too verbal.” Mom, Love, decided to hire an advocate, who prompted an IEE.

We got the ADHD diagnosis first, and that didn't explain it... He was borderline on a CARS, on like a parent survey. But we had a fair amount of denial about it within our family. We took him to be evaluated by the school district when he was four in 2019, and they said he does not have autism, he has ADHD, and denied him services. Then in 2020 we took him for an ADOS [privately] and he was diagnosed with autism.

Astor was curious, persistent, and very empathetic; however, socially, he experienced difficulties because he was overly curious, rigidly persistent, and oblivious. “He's persistent. <laugh> <laugh>. He can be fairly oblivious. He has a hard time picking up on emotions and social cues. His impulse control is pretty low. He's really rigid. He has a hard time with change.” He was overwhelmed in the classroom and often would miss class. He was off task, in need of very frequent prompts and often was held from recess as a consequence. “They text and they email me, and they call me, and they say, ‘Astor did this today. Astor did that today,’ but I don't know that they're taking any action in the classroom.” Most apparent were learning delays and “holes” in his academic skills.

Nevertheless, in 2020, Love seemed to watch a LSSP drive the second ARD meeting towards ineligibility. She verbally asked for an autism evaluation before the pandemic, but the diagnostician never got back to her after stating, “We’ll look into it.” The school staff also did

not inform Love that the request needed to be in writing. Love pursued a private evaluation from a psychologist who did use the ADOS to diagnose him with autism. When she turned over the report to the school, they re-evaluated him with the BASC-2 and other instruments meant for screening not evaluation (Bradstreet et al., 2017) and qualified him for OHI with no social skills support. Through an advocate, Love requested an IEE and FBA, which found that Astor was eligible for autism, speech, and a BIP. “We gave it some time. We weren't really sure what to do. And we had started ABA in the interim, and that was helping a lot. And we saw that he was continuing to really struggle in the classroom, and so we requested an independent educational evaluation.” Yet, the district rejected the IEE because they said there were “data conflicts” in the report.

Love was no longer working because she had to spend countless hours working on Astor’s special education battle. Staff had told her that the district rejects students with much worse conditions, and Love had noticed families leaving the district because their children were not receiving services. The denial had made her feel like a failure as a parent, experience burn out, question her son’s diagnosis, and have a constant level of frustration since he was age four. She was baffled by the district’s refusal to serve her son for autism for such a low-cost investment.

Oh, it's completely destroyed my trust in the education system. I'm so fed up and dismayed by it and horrified. And it's made us really seriously consider leaving Texas. It's just, we moved to this school district for the schools and it's appalling and it's horrifying to think that if this is how they're treating two college educated parents with a lot of resources, what are they doing to the other kids? In my off-the-record interviews with all of the teachers and the support staff, they say they don't qualify way worse kids.

And our campus is worse for it than other campuses in the district, but the district as a whole is pretty intensely terrible. I would say on average, one family a week leaves our district because they are so terrible at providing special education services. They just deny, deny, deny.

However, staffing may have been one reason: 20 special education students in one class, one LSSP for four schools, and annual diagnostician turnover. Her second son was denied autism eligibility in 2022 because they found no educational need and was too high functioning.

Thematic Analysis

Using thematic analysis, three main themes emerged from all the participants' data: lack of a community model of inclusion (CMI) culture; quality programming and training; and collateral costs. Even though IDEIA mandates a collaboration between parent and school staff, the following data shows a *lack of CMI culture*. Instead of inclusion and collaboration, participants often spoke of an adversarial process, exclusion, and confusion. They also included issues with the evaluations completed by the school and even misunderstanding, some supported by the court, of the criterion for quality assessments for autism. These accounts point to a *lack of quality programming* not just in the licensure and/or certification of school evaluators, but a lack of ongoing *training* as evidenced by multiple accounts of evaluators relying on outdated assessment tools and stereotyped characteristics of autism. Finally, all the participants spoke to the *collateral costs* of fighting the system that ranged from psychological effects to effects on marriage and the family.

Lack of CMI Culture

Three sub-themes emerged from the lack of CMI culture data: confusion from both parent and district on special education procedures; staff coming to the IEP with a predetermined

denial; and district intervention and direction of denial. As shown in Table 1, most of the participants identified with the sub-themes of a lack of CMI culture. Based off policy, regulations, and the law, there was ample evidence that procedures for evaluation in special education were not properly followed; in addition, there are several instances where parental ignorance was taken advantage by the district. And what is supposed to be a collaborative process between all stakeholders often was usurped by district personnel dictating decisions on eligibility.

Procedural Confusion. As noted in Table 1, all eight parents reported not understanding the procedural safeguards, if they were given, because of its lack of simple language and bulk. This may be a contributing factor as to why there were so many instances on both the parents' and districts' parts of non-compliance with the law. Prior written notice, verbal agreements not implemented, and not receiving a copy of the full evaluation were some of the many issues parents brought up. And in many cases, even though it is the responsibility of the school to explain and walk them through the special education eligibility process, the parents were at fault legally—or treated as such—which delayed the procedures even further.

Confusion about what constituted a request for evaluation was a common sub-theme in the data. Several parents reported verbally asking for an evaluation unaware they were not following protocol. Nicola asked teachers on multiple occasions with no action.

Sadly, they just told me verbally in the screening that this child [is so smart he] should be testing other children. And I didn't know that I needed to have requested in writing and to ask for a formal evaluation. And so, I just accepted that... And then in Kindergarten I kept saying my concerns and asking, I still didn't realize I needed to request it in writing. So, I was asking in informally. I would volunteer in the class, and I really thought if I was

really kind to the teacher and ask her for help, that they would help me. So, I asked maybe 20 times between Kindergarten and first grade, if he needed an assessment, if he needed more support, I would speak to the teachers about my concerns, but I didn't yet know that I had to do it formally in writing and no one shared that with me.

Love also improperly asked for an evaluation with no correction from the school.

Well, because he had started Kindergarten and I had requested it verbally through the school in the fall of his Kindergarten year, and they didn't do anything... She said, "Okay. We'll look into it..." And she didn't... They just kept taking advantage of me not knowing the system.

Not following the proper procedure was also experienced by Scarlette; in 2015, she suspected Don had autism, asked the school about it, they did a quick screener, and no prior written notice was provided whether they thought he had it or not. Although there was no proof of a conspiracy to delay services, the effects were the same. Additionally, there may have been a lack of training or knowledge on the part of staff in knowing the legal requirements.

Corrine said that the school had denied eligibility for autism because she asked for an IEE, which she had requested for other issues. Having come in from Florida with autism eligibility, she realized a year later that the school did not include autism in the IEP. "I said, 'Why don't you put autism there when you approved autism?' And she said, 'You asked for an IEE. So, we are not gonna put that in the IEP yet.'" This confusion continued during the pandemic when the district had Jarvis change schools, further delaying his services. "But then once you get in... they changed the ARD to different school. So that they said, 'Well, we are a different school. So, we are gonna... wait until we know your son.'" Six months later, Jarvis

changed to another school and the delay continued. Dona's North Texas district also had challenges with protocol when an IEP was in dispute.

Their own employees admitted, one person would say the IEP was implemented even though the mom disagreed. Another person would testify and say, "We couldn't implement the IEP because the mom didn't agree." So, their own staff members didn't know what IEP was in place. And you'd have staff members saying we couldn't implement it.

What might seem like a technical issue could have been an indication of a larger procedural issue.

Districts are required to provide prior written notice for practically everything pertaining to an IEP (i.e., changes, drafts, and denials) (Yell, 2016). Several of the parents cited never receiving notice including the request for evaluation, as was the case for Dona.

I will also say another thing that you haven't asked about, which a parent is supposed to have a right to a prior written notice. They were not providing those to us. It's something that got covered in court quite a bit... So, as an example, if I come in and say, "I want this service for my kid," and they say, "No, we're not gonna do that." They're supposed to give you a prior written notice saying, "Hey, so, you know, we're not doing this. This is our reasoning."

This lack of notice included the evaluation report. Haylie did not receive the "actual paperwork" for the denial, Love only got the report *at* the IEP meeting (not before) for Astor's denial, and Nicola had learned her lesson from previous missteps, stating, "But when they denied him, I hired a special education advocate."

Another procedural issue that many of the participants reported was alternatives to special education often offered before an evaluation is conducted, which is against federal statute. Schools cannot use 504 accommodations, RTI, or OHI as a replacement for assessment for eligibility in the suspected disability (Yell, 2016). Nicola was deflected from an evaluation and instead, “So when we received the autism diagnosis, I submitted it to the school and [they] told me that he did not have an educational need for a school autism diagnosis. And they told me they could only put him in a 504.” Scarlett talked about how Don was placed in a behavioral intervention program without her knowledge that it was an alternative.

That was something that we kind of did recognize from the very beginning... I wish I knew exactly what the back unit stood for ‘cause it's not really a program. Like now when I hear about it, all I can think about is just troubled bad kids. They just put all the problem children over there. So, I mean, we had our meeting, this is the best they could do. They said we will have so much time with him in this back unit. It wasn't special education. It was just like a different program. That they would pull him out and do the work with him there.

Her lawyer did later point out to the school that this was an illegal placement. Keira was told, “I will say their main focus of denial is that they say that he doesn't need any other resources that he's getting everything that would have been covered.” Haylie talked about how their principal said that he would personally intervene with Vinny when there was a fire drill or other triggering event in lieu of special education services. Cassarah and Dona both reported that they were not offered any alternative to eligibility. Tyson being placed in a general education classroom without support worried Cassarah and waiting to see what happened would “hinder his learning.”

Dona also was not provided alternatives for Alysa in terms of autism-specific services, even though she was receiving life skills training for her intellectual disability.

Predetermined Denial. Many of the parents expressed a feeling that the denial for eligibility under autism was predetermined. These were formal in proceedings (e.g., Haylie said, “But they did have the psychologist there. Other than that, I’m gonna assume it was just between them, the special education department and, you know, school administrators [are] what I’m assuming is who all decided.”) to informal comments (e.g., Corrine said school said answered her admission of evidence of autism with, “He’s such a sweet boy. We don’t think he has autism”).

However, most of the parents felt there was a concerted effort to deny results, whether privately obtained, from an IEE, or even in district data, despite overwhelming evidence to the contrary. Nicola recalled how Tamsin had been denied intervention through the district even though he had been receiving therapy since birth.

So, he was in early childhood intervention from really birth because he was a micro preemie, had just been released from the hospital. And then he stayed in ECI until he was three. But he did not receive an autism diagnosis during that time. And then I tried to get him into the PPCD program, and they denied him.

Dona also experienced early denial.

My daughter was first evaluated by [the district] before she turned three. Right at three years old she was completely nonverbal. I remember when we went to a meeting, they said that she didn’t even qualify for speech therapy and I’m like, “How can that be?” So, because I fought, we got a little bit of speech therapy...

In some cases, it could be an avoidance of work. Keira surmised, “The only reason I ask is that if the autism supplement umbrella was in effect at that point or not because I fundamentally believe that the reason that I am being denied is because they don't wanna have to follow that.” And in some cases, it is a lack of training; for instance, Love said that the school denied autism because of its misinterpretation of the medical diagnosis. “I just read that you couldn't be dual diagnosed with ADHD and autism until, like the latest DSM 5 or DSM V in like 2015, something like 2012.”

Almost universally, though, was a predetermination of “no educational need.” Even though the requirements in Texas did not require an education need but rather “adverse educational performance” (Disability criteria, 2019), several parents said they were denied eligibility and, thus, services because their child was performing academically. Cassarah recalled, “I think that's funny because I think that said their reason why they're denying him services <laugh>, and it is because he is smart,” and Corrine remembered how the district explained denial, “They said, my son is so smart, so he cannot get service.” Nicola also saw this connection with grades and autism from her district. “So, when we received the autism diagnosis, I submitted it to the school and [they] told me that he did not have an educational need for a school autism diagnosis... And they talked about his good grades.” This predetermination tactic was often used to stop any request for evaluation.

Keira said the school was less than willing to evaluate for autism despite the private diagnosis.

So, when they did their three-year evaluation, the second one, we asked for that to be him to be evaluated for autism. And they said that he didn't qualify under educational diagnosis. And so, we had an external evaluation done.

Love said that her district talked about levels of function. “They denied him any sort of support because he is quote unquote too functioning. He functions too well. They don't see an educational impact.” The result of poor understanding of autism, evaluation, and eligibility criteria was boiled down to a simple, subjective observation or judgement, according to Haylie.

You're testing for math. You're testing for science, but you're not testing for the other things. While yes, he may get along well with other kids. He also reacts differently in the event of, you know, an argument or a fight or he may get anxious in the classroom. I mean, you don't know how he's gonna react, but yet because he tests academically well, and he's giving you high scores that he doesn't need [special education].

While these are factors to denial, they are driven and influenced by the district’s intervention in the process.

District Intervention. All eight participants spoke about their district’s involvement in the decision-making process for evaluation, eligibility, and/or services. It has been well established by federal and state laws, regulations, and policy statements that the determination of (a) eligibility for special education and (b) the educational needs, goals, and services fell within the purview of the IEP committee (Yell, 2013). Although it was not uncommon nor illegal, district personnel acting in the role of advisor often directed the decision for the school representative (usually the building principal).

Cassarah recalled when decisions on eligibility were made by her son’s evaluators from the district who wanted to place a three-year-old with a disability in a preschool program with 30 other children. Keira saw multiple levels of decision making from the district including the diagnostician, who to her made the sole decision in denial and then disagreeing with the IEE with the support of the special education coordinator. Nicola also saw high-level administrators

making the decision for the IEP committee. “Involved in [the decision]? I believe there were a speech and language pathologist, maybe an educational diagnostician. There were district personnel there in that meeting.” Nicola also recalled who made the final decision of approval for SPED under autism eligibility. “I believe it was like their special education director of the person who handled it at the charter school.” And as Corrine explained, district personnel were involved from the beginning of the process circumventing any collaboration, discussion, or cooperation to find a solution to disagreement; in her opinion, they offered no help, were rude, and just listened in the meeting for no apparent purpose. And at times, it would devolve into what felt like retaliation, as Corrine further explained, “So I waited to sign the paper because the lawyer withdrew because the school was harassing them,” or to the detriment of the child, as Love recounted, “Oh, our district, our insurance will pay to have an ABA therapist, an RBT come to school with John, but our district doesn't allow him in.”

Some of the involvement became very adversarial and combative. Dona recalled how one particular district admin took the conflict to a personal level.

So, in almost all of my ARDs, they brought district representatives... There's one specific person who they called him a special ed coordinator. He is supposed to be above multiple campuses and he is supposed to be the person above the special education. I would say he's the reason I'm in court... So, I've had previous experiences with that man where I had filed grievances. I got inappropriate emails from him at midnight where I think he was drinking. We did not have a very good relationship. He would come to these meetings. It's supposed to be a team, we're supposed to collaborate and sit at around table. He refused to sit at the table. Often. He was on his phone, he's doing other things... He also did not know my daughter. He had no interaction with her. But he would be the

sole decision maker in these meetings. Other people were afraid to talk. If I asked a teacher a direct question, she would look at him like, "Can I answer?" It was not collaborative.

Even involving an advocate did not change the relationship or action by district personnel. When the attorney asked if the district was going to provide a particular service, the SPED coordinator refused; when they asked for compensatory services, he refused; "So, it was clear that the SPED coordinator was the sole decision maker. It was not a conversation. It was not [an] ARD." Once due process was ruled in Dona's favor, this decision did not sway district administrators at the next mandated IEP meeting.

Oh, no. He comes, I go into the meeting, and he says, "You're not allowed to talk about it." I'm like, "I can talk about whatever I wanna talk about." And he says, "No, we're gonna ask for a redo." He goes into the meeting, he went ahead and reduced my daughter's services, maybe down to 20% of what the IEP said she was supposed to receive. And that was significantly less than what we had verbally agreed to in that meeting that didn't get written down in the paper... There were never prior written notices. They just didn't do it. They wouldn't do it. And we were arguing about a lot of things. We had inappropriate extended school year services. They kept taking away goals. If a goal didn't progress, they would just take it away and delete it. They kept just taking away services.

For Dona, the question left was what to do next, especially when she has another son with an autism diagnosis or give up due to the district's involvement, negation of eligibility mandates, and risk of retaliation resulting in reduced services.

Quality Programming and Training

Three sub-themes emerged from the quality programming and training theme: challenges in assessing complex profiles of autism; incomplete assessments; and unqualified evaluators testing for autism. A few of the participants discussed how their child's complex profile (i.e., autism with a comorbid condition like intellectual disability) was used by the district to deny autism eligibility. All the participants discussed how school evaluators used an incongruent assessment tool, observed their child's behavior for only a short period of time, provided limited detail in the written report or no report at all, or missed evidence as seen in each parent's narrative on their child's behavioral health history; this also included denying IEE results confirming autism eligibility and defaulting to 504 accommodations, RTI, or qualifying under OHI with limited support, which most students were funneled towards. Finally, most of the participants cited the qualifications of the evaluators and their interpretations; e.g., diagnosticians used assessments not suited for high functioning autism or speech pathologists independently made the determination of eligibility.

Complex Profiles of Autism. Many of the denials of autism eligibility were due to compounding disabilities, which often shielded the school from addressing the autism-specific challenges. Dona explained how her daughter's other disabilities created confusion with the autism. "Alysa has a lot of other disabilities. Sometimes it's hard to decide which disability it is. Does that make sense? She has speech. She has OT needs. She gets counseling. She's dyslexic and... And then we have autism." Keira talked about how Russ's school used his intellectual disability and stereotypical characteristics as a shield for services for autism.

But he's very friendly and very outgoing and very affectionate. But that's what they say,

"Well, he doesn't flap his arms, or he doesn't stim, and he has such a good personality, [it]

can't be autism.” And autism was our first kind of formal diagnosis. But he's labeled as intellectually disabled, IDD, through school because of the IQ testing that they did. And he is in a life skills setting.

In past years, schools were allowed to deny autism eligibility when comorbid disabilities were present, which is no longer true but was still in practice in some cases (Cooper et al., 2015).

As seen in Table 1, most of the parents identified their children as having HFA. The research shows that evaluators tend to rely on stereotypical characteristics of autism observed in the 1940s to 1990s (Morrier & Hess, 2012; Rubenstein et al., 2018). Hence, our participants experienced many symptoms of HFA being missed by the assessment for eligibility. Dona, for instance, described her daughter as aloof and that her “challenges manifest in social, emotional, academic, all of those” that evaluators did not always take the time to detect as contrarily seen in one case. The private speech pathologist said that when “she first met Samantha, she could only understand probably 30% of what she said,” but at the conclusion, “Now I'm getting 80% of what she says,” which is not what school evaluators took time to observe. There was also historical context that was missed in the conclusion that a speech impairment was paramount over autism.

So, between four and five, I'll say we definitely did a lot of questions like, “Do you want an apple or an orange?” We didn't ask things like, “What do you want for lunch?” She wasn't gonna answer that. But she could point, she could show you if you [gave] her two choices... I would say that she had that speech explosion at probably age six.

Haylie talked about how evaluators did not consider her aunt's past observations with the lining up of the cars, and the district did not take current data of autistic behaviors.

He was like in a daze like lost. And so, we were like, “That's weird. Maybe something happened and he's, you know, processing it. Who knows?” Then he gets in line with his class, and he was in so much of a daze that he didn't even realize that me and my husband were standing right there waiting for him. He walked right past us. And we were like, “Okay, weird.”

Cassarah's Tyson had already been in private behavioral, speech, and occupational therapy, who assessed that he was behind peers for pragmatic language. Yet, the district did not consider Tyson's language and behavioral needs.

Yes, because I told them that while we were going through the process of getting him evaluated, he was enrolled at the private preschool. But I was looking for services for him because I know he was having a hard time in a regular bus setting. I told him that he had trouble sitting for a long, like, even short periods of time that he gets overstimulated, that he was hitting his friends, lots of meltdowns. I told them everything.

Surprisingly, Tyson received feeding therapy for sensory issues. But all this evidence was not enough for autism eligibility. Keira even understood Russ's complex profile often hid his autism tendencies.

He has really great emotional range, but he does kind of have some obsessive tendencies with schedule routine. He likes to do the same thing in the same way. And then he has a very difficult time with peer emotion, peer friendship. He gets too close to people. He has no real understanding. “Stranger danger...” he doesn't really understand that.

The data was not considered enough to sway eligibility in the evaluation.

Even when there were classic clues for autism, the evaluators missed it. For example, Nicola said that Tamsin would save up his tantrums at school for home, which the school staff

never observed. Most of his behaviors were based on anxiety, which is a common and pervasive symptom of autism (Centers for Disease Control and Prevention, 2023).

So, some of the challenges are rigidity, needing to have a really similar schedule, having trouble with social communication. So, he was really challenged. Like if it was structured at school, it was fine, but if it was a group activity or recess, he was really struggling. He had, really significant anxiety... He did well academically, although in first grade they had [to] pick five or something, like you go to five different stations and he was very challenged by that because it was so many different activities rather quickly and he wasn't able to do his assignment. The teacher got very upset with him and told him that he needed to take a work bucket with him to the lunchroom. So, he had to sit with the work bucket in front of him in the cafeteria during lunch and following lunch was recess and she removed his recess from him. So, he didn't do well on those assignments. And then his anxiety about school was very pronounced. He was crying at school. He just wasn't able to handle that.

Tamsin's behaviors regressed further in the next year, hiding under his desk during group activities, isolating during PE, and overuse of a "peace room." But, again, the district did not consider the evidence for eligibility even though they discussed maladaptive behaviors in groups and recess, his "overdeveloped sense of justice," and vocal, rigid rule following in class that upset him daily. Scarlett also provided simple evidence to the contrary of ineligibility. "Like, I don't know how his temper can go from zero to a 100 within those minutes where he's hurting people, supposedly gonna hurt people 'cause he is throwing objects or flipping furniture."

Reasons, though, for denial relied on stereotypical traits.

Each year that we kept getting into school, it just kept getting worse and worse. He was just getting restrained every single day. He hated to school. We were just trying to figure out different things. So, I was trying all types of different techniques. I brought it to the school's attention that I thought he [has] autism as well... They kind of did like a quick thing to see if he qualified for it. And they said, "No, he didn't [have it] 'cause he can make eye connection."

The DSM-5 was published in 2013 and used "abnormalities in eye contact" (American Psychiatric Association, 2013) (unlike previous versions like "marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze") (American Psychiatric Association, 1994) as one possible example of deficits in social communication, which was several years before Don's denial in special education.

These observations were ignored when an independent evaluator or advocate found differing evidence. Love talked about Astor's IEE.

It picked up on his pragmatic language deficits. He said 99th for vocabulary, but he's in the second percentile for pragmatic language. It picked up on his social or on his fine motor issues more intensely. It picked up on both. We had an FBA and a psychological evaluation, and they both said he qualifies for autism in all three areas, and they picked up on the errors that were made in the initial, or in the 2020 evaluation, and the school district still denied it.

She said that the independent evaluator found off-task and inappropriate behavior at a frequency of 50 per hour in all school environments, which was a significant level of maladaptive behavior. Corrine hypothesized on why the denials continued even after an outside evaluator found eligibility in autism.

They can see everything when you do IEE, they know everything, but the evaluator, I can tell you, I don't know how many times he's been evaluated by school. And they said, "No," when he was younger and you can clearly see that he has autism, you can actually see with your eye or everything that the autism does, you know? He was doing all this rocking and talking and lining up and everything. [It] was so clear, and they denied... I think there is something with a principal that says that 50% can't be approved. Like you tell me, "There's a cap. Don't approve. Don't say autism."

Evaluators may not have been thinking of caps or quotas for autism, but all the participants were perplexed why so much evidence was seemingly ignored in their children's determination of eligibility.

Incomplete Evaluations. Supported by the literature, poorly conducted evaluations are a common problem; incomplete, brief, or inappropriate observation measures were cited as likely causes (Rubenstein et al., 2018). Cassarah spoke about how her son's behavior was observed and that the evaluators made a conclusion from a brief duration.

So, on the day of the evaluation, even though he was very active, he gets distracted very easily, so he needs a lot of prompts to go back to task. But he's very fond and very happy. They said that he has very good skills and after they analyzed their observations, they told me that since he has very good skills and he doesn't need anyone accompanying him, that makes him not a qualifier for services.

In addition, there were unqualified evaluators and evaluation tools used for an autism diagnosis. Cassarah did not understand who was giving the autism evaluation: occupational therapist, speech pathologist, or psychologist. In the report, there was no evidence of an autism evaluation. "Not for autism, no. And I guess it was because they already had the [medical] diagnosis. I'm not

sure.” And she cited his overstimulation behavior when the report concluded “he’s very functional.” Nicola also was given a brief, incomplete report from a speech therapist who assessed for autism. “Verbal. They did give me a report. They did, it wasn't a report. It was like, I believe it was a couple of pages. But it did say that he was not admitted into PPCD.” Love pointed out that Astor was “too verbal” for the evaluators, yet they did not formally assess for verbal behavior or speech related to autism. Corrine recounted how poorly the evaluation report was written with unclear communication and consisted only a couple of pages.

Qualified Evaluators. Several parents reported inappropriate evaluators assessing autism with limited qualitative data. Haylie recalled that the evaluator only assessed in one day. “As far as I know, it was just the one day of the testing. If they did any more, I'm unaware of that. But as far as I know, it was just the day of the testing.” Cassarah said observations were not done. “They said that they wanted to go and observe him. But they never went.” And Corrine was frustrated with the amount of time spent with Jarvis, which did not add up to even an hour. “I spent hours, and you don't know how many hours I spent... It took my insurance for four, five hours [for the] psychologist to get the insurance part. These observations of evaluation duration highlighted the difference between a medical diagnosis and school evaluation, which may be a defining factor for denial.

At the heart of the assessment process were the qualifiers, level of training, and experience of the evaluator. Thus, practitioners understood that there was hierarchy and weight to these factors in an evaluation; for instance, a psychologist has many more years of training and qualifiers (i.e., Ph. D.) than a LSSP (M. A.) (Texas Behavioral Health Executive Council, n.d.), and a behavior analyst would have been more qualified to conduct an FBA than a diagnostician (Texas Department of Licensing & Regulation, n.d.). These tiers appeared to be

illusory for our participants and their children's school staff. Cassarah questioned the qualifications of the OT therapist assessing food sensitivity for autism. "I told them, and what the occupational therapist said is that he was not a picky eater. He just knew what he wanted." This same misreading of symptoms was found in Astor's district evaluation, which Love's IEE was able to show. "I just wanna note that when we had an independent evaluation done last year, they found that the diag had misread the results of the CARS-2." And Haylie considered the qualifications of the school's evaluator.

The whole process that would make a lot of sense considering. Considering, I mean, I didn't really look into who the school psychologist was to see what their qualifications were. 'Cause I assumed, "Oh, it's just like his doctor, like his psychologist."

But they were not of the highest quality in evaluation training and experience, which could have been another defining effect to the denial of eligibility.

Collateral Costs

Four sub-themes emerged from the collateral costs data: advocacy and legal action costs; the adverse effects of waiting to fail; the emotional toll on the parent and child; and the time and expense of making a change in programming. Most of the participants used the services of an advocate or legal representation at some point during the process of being denied and spoke to the costs, benefits, and even district retaliation seemingly connected to it. Most parents also said that their districts wanted to wait to see if the students regressed enough to qualify, which is explicitly prohibited by special education law (Yell, 2016). All the parents recounted the emotional toll that it took on them personally, on their family, on their child's development, and some even their marriage. And several parents had to make the positive change for their child at

a financial cost and/or personal sacrifice, whether through a different school or private providers, so that their children could receive the services for autism not provided by the school.

Advocate and Legal Action. For many of the parents after denial, the next step was to hire an advocate and/or pursue legal action against the school district. In and of itself, this was a daunting, time consuming, and costly move towards services; many of the parents had no resolution, and as one parent pointed out, the chances are stacked against them since “9 out of 10 times” the courts ruled in favor of the district. Love pointed out from her advocacy work.

Well, you've talked to some advocates and some lawyers, and they've said your only chance of getting them to provide services is to sue, but your chances of winning are like one and 10. It'll be dependent on judge or the hearing officer. But even then, you know?

And whether they'll actually then follow through and provide the services.

Nonetheless, all but one of the parents at least sought advice from an advocate, sometimes bringing multiple legal, behavioral, and psychological representatives for outside collaboration to the special education process. In six of our eight cases, bringing in an advocate was met with an adversarial move to include more district representatives, administrators, and lawyers in an IEP.

For some, they understood the districts' response to advocates. But as Scarlett stated, “But that's only because I had an attorney for his disability. I didn't like the way that it was getting handled.” It became a method of last resort when it began with parent versus all the district and school staff in an initial meeting. Nicola pointed out that getting legal involved was the only way to check the district's work.

So, they did their own evaluation. They had a speech therapist do part of it. I then attended a Partners Resource Network, parent support group. And I was very fortunate that there were some three excellent advocates, two of whom are attorneys. And they

practically eviscerated the evaluation that the school had done because in the same evaluation where they denied him, they also gave specific examples that were very telling of a student with autism: hiding under the desk, struggling in group activities, rigidity. So, then the advocate went with me to a meeting and said, “This evaluation is not complete. It wasn't legal. It wasn't a complete evaluation. And we're not signing it.” And then the school said, “Oh my goodness, we didn't realize this speech and language pathologist is new. And, of course, you wouldn't sign this, and now we understand.” And then they approved him.

And in some cases, like for Dona, other school districts were asked to defend Alysa’s rights. Her new district testified in court as witness for Alysa. “They straight up said, ‘We don't agree with what [the old district] did here. This is what we think the child needs.’” For Keira, though, this action created a continuing adversarial relationship to a point that any routine request was met with denial.

I requested an evaluation... [to] see if there's any type of electronic tools that might help him with [speech to text]. It's just an evaluation that's one of the supplements. But now we're at a point where we're still considering filing a complaint with TEA.

It was an ironic to her that each IEP meeting began with a statement that the parties involved should work collaboratively.

Wait to Fail. Special education law requires schools to proactively intervene with skill deficits rather than “wait to fail” (Yell, 2016) Several of the parent participants provided evidence that school staff had presented waiting to qualify as the only option. Cassarah said, “That even though he's not very fluent and he has still some grammatical errors, I should give him a year to wait how much he develops.” More so, though, were their concerns after waiting.

Dona talked about the impact of waiting and where her child could have been if the interventions were implemented earlier. In addition, a lack of intervention worried Haylie as well. “What if he's the one who goes out there and leads the shooter to where his friends and classmates are, because he doesn't know what to do and he doesn't know how to act.” Nicola reflected,

So, when I brought my son to PPCD to qualify, he kind of wowed them with his large vocabulary and they actually told me this child should be testing other children. And at the time I was relieved because I thought they were the experts in that maybe he doesn't have this diagnosis. Maybe things are okay. I didn't realize that that was really setting him up to not be able to be successful in school by not getting the help and support he needed.

Even Corrine could clearly see a need, but still no action from Jarvis’s school district. “When I came here to Texas, according to evaluation, he hasn't [qualified for] anything. He still [doesn't] know developmental milestones, some of the sounds and the words and stuff like that. I was very disappointed [for] him.” Delays in eligibility often came from a borderline result in a sub-category on the assessment when the preponderance of the evidence indicated autism. However, some parents felt that there was a barrier to autism services unique to Texas and that “wait to fail” was used as a tool of obstruction. Dona understood the need for early intervention, yet she had been denied after multiple attempts. “My kids have also gone without appropriate services for years. Everyone tells you [that] your kids need early interventions. Here in Texas, it's impossible to get 'em.”

Emotional Toll. What is not well documented in the literature is the emotional toll on parents, families, and the child denied services due to the subsequent “battle” with the district. The process can be taxing affecting personal mental health and even marital health. Scarlett

shared how the fight with the first district took affected her emotional wellbeing and how that changed once her child was getting the services needed in a second district.

I was very stressed out, you know? I basically quit my job so I could focus on him and figure out what was going on, what we needed to do. And it's better now. Now that he's going to school, he's doing it. We're just destressed. It was lifted off, you know? I'm back at work again. I was depressed. I was sad, bummed out. I just didn't know what else I could do to help my kid out. It was just very hard times, and it was stressful for the whole family. 'Cause I mean, I was just on edge and just real protective and I didn't know what I could do.

Cassarrah also experienced stress and strain in her marriage. "I have [my husband] getting all the stress and all that it affects. I think it affects me in the part that I wanna help him. And I don't want him to feel or to cause these feelings of frustration." So, essentially, she takes on the fight alone. Haylie expressed a helplessness with the lack of support. "Yeah. Helpless honestly. And like ignored because it kind of felt like, well, because he's not disabled or, you know, because he doesn't meet our disability and needing help requirements, 'We can't help you.'" Dona had a significant impact from the conflict with the district, including family.

I tell people very specifically, I have PTSD myself over these experiences... We've been negatively impacted in so many ways. My kids are both in counseling. My daughter now has ABA. She's doing equine therapy, which is for kids who've suffered trauma... And the cost of moving to [another town]. It was very expensive to move here. The homes are more expensive. The move was expensive. [The new district] initially charged us tuition. We had all of the expenses of traveling. My husband now has a commute to work when we used to live 10 minutes [away].

And Keira explained how the financial expense of taking legal action added undue stress by the district when she asked for an IEE.

We've spent thousands of dollars on advocates, over a hundred hours on Zoom in arguing about this when I was finally granted the IEE. They gave me a list of recommended evaluators and some of them were 45 miles away. What if I don't have a car? What if I had to take a bus to another county? It was an act of God to get that evaluation. And then all they have to say is, "We disagree." So, it's been hard because it's an emotional event to try to convince something that I live with every day.

She continued with a concern for those in her area that have been denied but lack the resources or speak English as a second language. The emotional toll came at a personal cost, but the frustration expressed by all the parents was from the fact it could all be avoided if the district did a better job at evaluating for eligibility of autism.

Love has had to endure an "intense" amount of collateral damage from taking on the fight against the school district. It has affected her son and marriage.

Well, it's been pretty intense. He's had a ton of testing and he's really anxious. He's not getting the support he needs. So, he's ostracized in his class. His class is disrupted. He's off task a lot of time, you know? So, he's reading a Kindergarten level, he's writing probably below a Kindergarten level, even though he's in third grade now. That's really affected his self-esteem, I would say. It's been problematic... Oh my God, it's been so intensely stressful [on the family]. I have not been able to go back to work because I spend 20 hours a week, probably, trying to sort all of this out and working on it... I mean, it's caused marital problems. It's caused problems for his younger sibling... Yeah, it's not fun.

It has also made her doubt Astor's disability and her responsibility in his failures at school.

It definitely made me question my judgment. You know, that made me think, "Well, maybe I'm not seeing things." And then it's just made me feel like my job is infinitely harder. 'Cause he's not getting support. And the majority of this time, it's made me feel like I'm failing him as a parent. It's definitely kept me up at night a lot worrying like, "What damage am I doing to him by having him continue to be in this education system?" But there's no good alternative in our area. Yeah, I'm burned out and frustrated.

That helplessness comes from living in a small community in East Texas where the school is the only resource for mental and behavioral health services.

Tamsin struggled a lot before receiving special education services years after Nicola suspected a disability in autism.

From first grade until the time I was able to get him admitted into special education, it was very common for him to cry in the morning on the way to school. He frequently would cry on the way home from school and at night before bed about things happening in school. I remember times when he would, in first grade, come home from school and lay on the ground crying about because he was just so overwhelmed, and he had homework to do. And he just couldn't do it at that stage.

Witnessing that decline in social, emotional, and behavioral skills was heartbreaking for her.

It was incredibly traumatic to watch him struggling so much in school and to discuss the struggles with the school and to not receive any support. It was very anxiety producing for him and for my family... I felt like I was ignored, like my child's needs were ignored. I honestly felt like I couldn't trust the school personnel. My grandmother was a teacher, and I was raised to be very respectful of teachers and educators. I have a lot of respect for

them in general and it was very sort of confusing because on one hand I really liked and respected them. And on the other hand, I kept politely asking over and over again for help, support and was continuously denied.

Now Tamsin gets services for autism, but the fight, expense, and time took the ultimate cost to her marriage when she and her husband divorced.

Make the Change. All the participants approached the special education process with collaboration in mind, especially since nine of the 10 had a medical diagnosis before requesting an evaluation. It was very surprising to them that the school rejected outside diagnoses, disagreed with independent evaluations, and/or wanted to wait for more severe symptoms. But once they were familiar with what they were up against, they explored ways to fix the problem outside of the micro-system in which they felt trapped. Corrine found schooling that works for Jarvis. “Now I can tell you, I just switched to an online school and the public online school. And I said, ‘It looks like [it’s] very good.’” Dona also changed school districts for the better. “So, we moved our kid to a new district that was expensive and farther away and inconvenient, but they’re known to have a better SPED program.” Alysa is now receiving autism services and doing much better in school; the school is even allowing mom to volunteer in Alysa’s class and her BCBA provides services during the school day. Keira said a move was necessary. “And we left one school district to come to what is literally I think the third or fourth wealthiest school district in the state to be able to have better services.”

More impressive, though, was how “Team Don” became a collaborative effort from all parties even after the legal battle. Scarlett reported that her son has made a complete turnaround behaviorally, which has made it possible for him to gain academic skills. At first, the school needed to see a change in what the family was wanting them to do.

So, that's when we went to the Dallas Institute, and they figured it out with him having [autism]. Finally getting the autism diagnosis, I was able to get him into ABA therapy [and] that was supposed to help with the aggression and the angriness. And since then, I mean, he was only in the program for about a year and a half and he's already making major improvements. He's staying in school the whole time. He's not running, he hasn't had any tantrums or anything.

This success and its relation to the outside ABA had opened the school staff's perspective and to possibilities to more inclusion with peers.

You've seen a change since everything's finally been classified to special ed now. We had our meeting the end of the school year. So, I guess like around April, May of last year and it was a complete 360. I finally feel like they're listening to what we have to say... I wanted him to try getting into general ed again and kind of just like spending more time there. And they were just like, "Absolutely. Will look into it."

Scarlette attributed the transformation to a collaborative model to attitude and mindset changes on the part of district leaders, evaluators, and school staff.

Summary of the Findings

All the participants encountered systemic barriers to their child's eligibility for special education based on autism. These barriers included misinterpretations to criterion like "educational need," unqualified evaluators using non-standardized instruments, district personnel over-ruling or influencing IEP committee decisions, stereotyped understanding of autism by staff, unclear guidance from school administrators on parental rights in special education, and missed evidence of social, emotional, and behavioral needs. These barriers came with a cost: emotionally, financially, marital, and developmentally. Additionally, similar challenges were

faced by families across Texas, consisting of from very young to older elementary children, from low to high socioeconomic status, non-college- and college-degree-holding parents, English learners, of European-decent and Hispanic families, male and female students, and “high functioning” and complex presentations of autism. Most striking is the fact that the data shows the practice of denying autism eligibility was present before and after the U.S. DOE’s corrective mandate in 2018.

The factors of denial that the eight families experienced were not unlike Carter’s journey. He was misdiagnosed as ADHD before receiving a medical diagnosis of autism, which was denied by his school based on stereotypical behaviors of autism. We were steered illegally towards 504 accommodations, which proved disastrous and spurred the school district to evaluate him. One of the instruments used was the ADOS, which we told the LSSP that Carter had been tested with it several times and would provide skewed results because he memorized the prompts. At the initial IEP, several district administrators were included in the meeting unannounced who took over the conversation to deny eligibility of autism. We did not agree and brought an advocate at the reconvened meeting, which included more district administrators all of whom were there to reiterate the ineligibility. An IEE was conducted and found pervasive developmental disorder and autistic tendencies, allowing the IEP committee to decide on eligibility, with which the district disagreed and rejected the recommendations of the IEE. Legal action was taken to secure some services for special education, but not under the autism label. The experience did drain our savings, made work stressful (I was still employed by the same district Carter attended), and resulted in obvious social deficits at home and school.

Despite the similarities and differences in my son’s story and the stories of the participants, we all have one observation in common: we had to make the change to achieve a

community model of inclusion. Once Carter entered middle school, having a principal that knew him and our family resulted in pre-IEP meetings for collaboration, shielding us from district involvement, and reasonable disagreements, negotiations, and answered calls for qualified evaluators. Moving districts, quitting jobs, and splitting families are the lengths to which these parents went to receive the services so many outside the educational system were clamoring. Most had to sacrifice so that we could achieve inclusion in the special education process, and once that was achieved our children thrived making massive gains academically, socially, emotionally, and behaviorally. The question remains: why does a collaborative system for eligibility of autism come at such a great cost?

5. DISCUSSION

Summary of Research Study

This study sought to explore the parent perspectives of autistic children who had been denied special education services based on eligibility criteria. By using critical disability theory as a framework, I focused on systemic issues that caused barriers to those services and supports (Watson & Vehmas, 2020); as a child framework, I also utilized the social relational model to examine the environmental factors that resulted in oppression of the student (Reindal, 2008); finally, I used the community model of inclusion (CMI) to reinsert the individual into the equation of the systemic gatekeeping on eligibility that had been reported by media and the U.S. DOE. Moreover, CMI attempts to level the field by honoring the individual while incorporating all stakeholders in the process of education, especially in specialized/ individualized services like special education (Ota, 2021a).

A qualitative methodology was implemented in the collection and analysis of the data, which is excellent for identifying the factors and agents of oppression that contribute to a societal problem or phenomenon (Creswell & Poth, 2018; Merriam, 1998). Parents were candidates for participation if their child had a medical diagnosis of autism, been denied eligibility for special education under the autism label anytime from 2005 to the present and attended a Texas public school at the time of ineligibility. In addition, I attempted to recruit one parent from each major region of Texas and major Texas city: Central Texas, East Texas, Rio Grande Valley, North Texas, Panhandle, West Texas, and Dallas/Fort Worth, El Paso, Houston, and San Antonio. Eight parents participated with children who had been first denied eligibility under autism from 2017 to 2022, representing all areas of Texas sought except for Dallas/Fort Worth and the Panhandle.

Bias is a major concern with this methodology and several steps were taken to ensure the greatest level possible in terms of reliability and validity: (a) a cross-section of parents in Texas were sampled; (b) triangulation of the data was established through the literature, a review of the historical data from policies, regulations, and statutes, and original data from parents; (c) interview protocols and practices were used to reduce the incidents of bias (e.g., confirmation, question-order, and leading questions/wording biases); and (d) research checks and balances were accomplished through interviewing, coding, journaling, reflection, and reevaluating systematically and when warranted (Creswell & Poth, 2018; Merriam, 1998). However, overreach of methods to eliminate bias can result in other types of biases, like colonization and ethnocentric lenses. Thus, black storytelling methods as an analysis tool helps incorporate the researcher's experience and positionality with the study while honoring the perspectives of the participants without eliminating viewpoints through an "objective lens," which can silence voices including the researcher's (Toliver, 2022). This method was used in both the interview process by disclosing positionality after interview question(s) were asked to honor and connect with participants and data analysis by incorporating my own experiences with denial in the coding and thematic analysis processes.

Statements of Research Efficacy

Validity and Reliability

Triangulation, data from the participants, and data from the researcher's journal increased the validity of the qualitative data in addition to follow-up interviews if needed and disclosure of researcher biases (Merriam, 1998). The qualitative data sources included journaling, multiple coding of interviews with plausible categories, consultation with my chair, and active analysis of

positionality with data collection, analysis, and multi-site design (i.e., picking one parent from each region in Texas) (Merriam, 1998).

Limitations and Delimitations

Limitations could stem from parent accounts being skewed by faults in memory, which has been established by research especially when emotionally charged (Kahneman, 2011; Pinker, 2018; Shaw, 2016). In addition, sampling was recruited and not randomly selected, which could lead to bias in the conclusions. Delimitations come from only interviewing parents and not school district personnel, which could contribute to missing key data important in understanding of the denial.

Funding Disclosure

No funding was received nor spent in the process of this study. Parents received no benefits from participating other than having their story heard and, in some cases, learning about advocacy and other resources available.

Answering the Research Questions

The following questions helped guide my data analysis:

- What are the personal experiences (i.e., observations and interactions) of parents of students with autism when they are denied special education services?
- What are the systemic perspectives of parents of autistic children on how processes, interactions, and methods of determining eligibility for special education contribute to denial of services for students with autism?
- What do parents recommend that educational administrators, leaders, and policymakers do to provide a more equitable process of eligibility for autism in Texas?

Overview of Thematic Findings

Parents reported issues with the eligibility process at the district and state levels. They experienced a lack of a *community model of inclusion* due to denials of IEEs or outside/medical diagnoses, predetermined denials, procedural confusion, or a lack of understanding of the process on both sides. District intervention would often supersede what school or IEP committee members desired, and many parents experienced indirect and direct retaliation. Parents gave explicit accounts of the *quality of evaluations* based on programming and training of staff from poorly conducted, short, or missed evidence to unqualified evaluators examining for autism. Complex profiles often led to denial of specialized services and “high functioning” or verbal with normal IQ profiles led to funneling into intervention or accommodations. Parents also talked about the *collateral costs* associated with fighting the system of denial including an emotional toll, financial costs, and watching their children fall further behind peers so the school could see a need. Some resigned to drastic changes like moving to an entirely different district, suing the district, or even going to media.

Making Sense of the Findings

Isensee (2019) and Webb (2019) alerted us to the problems with eligibility in special education in Texas, DeMatthews and Knight (2019) provided an empirical path to both quantitatively and qualitatively identify the social justice issues with district practices, and the U.S. DOE (2018) mandated corrective action, which included a collaborative IEP process. However, none of these studies, stories, and mandates specifically examined the effect of a culture of denial on families with autism, and they did not identify the factors and agents of oppression. Through thematic analysis of eight recent narratives from families of autism across the state of Texas, I was able to answer the first two research questions: the experiences of

parents of students denied autism eligibility were negative, complex, and highly impactful on the lives of the families; and according to the parents, a “culture of denial” exists currently related to the actions of school staff, how special education is funded and regulated in Texas, and legally stacked against those with challenges but not academically. I was also able to find systemic problems in special education due to the phenomenon of autism denial: the process of eligibility is not collaborative, the evaluators are often not qualified or use outdated assessment tools, and denial has collateral costs that could last a lifetime and be a multiple of the relatively low cost of early intervention.

The evidence from the participants is overwhelming in many of the sub-themes supporting the main themes of the study. As seen in Table 1, the majority of participants experienced a lack of CMI due to district intervention (8/8 or eight out of eight), sometimes acting as sole decision makers in autism eligibility, most encountered a predetermined denial (6/8) where the parents felt that their children did not have a chance from the start of the meeting, all parents had a private, medical diagnosis rejected by the IEP committee (8/8), and most were subjected to violations of procedural safeguards (5/8). Many of the parents spoke of the lack of quality of the assessments or evaluators to determine eligibility including unqualified evaluators (6/8) like speech pathologists screening for autism, making decisions based on limited observations (4/8), or missed evidence (8/8). When taken to an independent evaluator, the parents reported a confirmation of an educational diagnosis of autism, but that the IEE cited numerous errors in the school’s evaluation (4/8). In addition, six of the parents recounted how their children were illegally given RTI or 504 accommodations (8/8) including change of placement instead of having an evaluation done. Finally, but most impactful, were the stories of the collateral costs from pursuing rectification like the emotional toll (8/8) on the family and self,

the financial cost of making a positive change (6/8) like moving to a different district, and the greatest violation to IDEIA in waiting for their children to fail (5/8) or regress enough to meet the district's standard of educational need.

The findings in this study mirror what exists in the literature. There is a low proportion of autistics in special education (Needham & Houck, 2020), possibly since school evaluators and their training, including assessment tools used, have not caught up to the changing understanding of how autism manifests differently than in traditional terms. Recent data from the CDC suggests that the profile has evolved from one of nonverbal, severe cases to verbal, high functioning (i.e., nearly 75% of all school-aged children have level 1 or 2 autism) (Centers for Disease Control and Prevention, 2023), which would explain the missed evidence and contradictory diagnoses when compared to those obtained from the medical field. As Morrier and Hess (2012), Rubenstein et al. (2018), and Rynkiewicz et al. (2016) found, autism is too complex and dynamic from individual to individual for staff trained in diagnostics and specialties in school psychology, leading to inadequate assessments and poor interpretations of the results. Another factor may be how special education is funded in Texas; Needham and Houck (2020) and Swaby (2019) argued that the needs of autistic students were underreported in Texas due to how most of them are classified in funding categories with low multipliers of the base allotment; several parents experienced the effects of low staffing and restrictive allowances of services.

These accounts from parent experiences of being denied special education eligibility under the autism label are clearly in violation of the law. IDEIA (Cooper et al., 2015; Yell, 2016) requires that appropriate evaluations be conducted, procedural safeguards are followed, parents fully participate in the decisions of the IEP committee, and students are included in the general education classroom to the greatest extent possible *with* reasonable supports, services,

modifications, and accommodations so that they meet the criteria of their individualized goals. Additionally, the eligibility criteria in Texas for autism as a qualifying disability, as Pennington et al. (2014) also found, has not caught up with the changes of the DSM, relying on outdated stereotypes like eye contact instead of the holistic portrait of a student with social, emotional, and behavioral needs for intervention. Like Bolourian et al. (2019), this study shows a troubling and persistent use of the clause “educational need” to gatekeep services for autism, including using a narrow definition of academic achievement for need and coupling need and disability.

These themes, the literature, the evidence, and existing policy/law are proof that there continues to exist a culture of denial in Texas public schools even five years after the policy ended. These parents’ experiences highlight what arguably is happening to thousands of families with students of autism. District personnel continue to use the relics of gatekeeping for an apparent commitment of decreasing special education enrollment by discouraging collaboration with parents, outside experts, and community members; district administrators are often the sole decider of ineligibility even though school staff implicitly disagree; and evaluators frequently disagree or disregard medical and independent evaluations contrary to the ineligibility. This behavior also permeates how staff present themselves as experts in the field when licensure requirements, including education and training, are well below the standards of parallel professions in the medical community (Morrier & Hess, 2012); for example, requirements for a license as an LSSP in Texas is 1200 clinical hours in contrast to 3500 for a licensed psychologist who follow the same protocol for diagnosing autism (Texas Behavioral Health Executive Council, n.d.). Finally, the schools as an organization—from the parents’ experiences and citations—appear to count on exhausting the families financially, emotionally, and temporally so that they will give up the fight and leave the challenges of the students for the next school or

through private services. The systemic issues from a lack of a collaborative and inclusive process for determining eligibility, the lack of quality and sound practices for evaluating disability and educational need, and the costs endured by families as a delay tactic imposed upon them by the school system are ample in showing that the culture of denial, entrenched during the capping policy by the TEA for special education, continues to be major obstacles for students with autism in accessing their entitled individualized education program.

Recommendations from Parents

Parents had a lot to say when asked the last question, “What would you say to other parents facing denial, schools or districts or even policy makers, like lawmakers, what would you say to them? What advice would you give to them?” These questions were purposefully placed at the end of the interview so that recommendations from the data, literature, and me could be interwoven and supported by their words, feelings, and experiences. One important point: these emotions rooted in frustration are not the product of activism, political agenda, or retaliation; instead, they are a culmination of years of struggle against a system that openly disregarded the law as the parents watched their children suffer academically, socially, emotionally, and behaviorally.

Recommendations to Parents

They overwhelmingly, like Cassarah, wanted other parents to know that information of the legal process is imperative for access to fighting the barriers to special education.

I will say that we have to inform ourselves through our own research. I try to read a lot about not just autism, but in his case sensory processing disorder. If I, whatever challenge I see that he's facing, I'll go and do my research and I'll try to provide his teacher right now with the resources or the information that I find. ‘Cause they don't know either.

Haylie also had the sentiment that information on what works for her child helps teachers implement best practices for students with autism even in the face of denial. “Honestly, I think my biggest thing would be don't let it go on for as long as we did. Like, if we would've known what we know now and how to properly advocate for him...” Dona also advised because the legal process is stacked against parents and one misstep could negate years of progress.

There are some programs out there, like the Partners Resource Network, which I hate to plug certain organizations ‘cause people are real good about saying that they're helping and not actually helping. There are so many parents out there that don't know the difference between a 504 and an IEP.

“Knowledge is power, and I would say,” Love shared, “know your rights. Talk to others that have gone through it and don't give up.”

Sometimes, though, that takes advocacy, online support groups, and drastic changes. Cassarah told parents to move to a different state, and if you decide to stay, Keira said to prepare for the long haul.

Probably that this is a long game and not, “Oh, we're gonna get the diagnosis or we're gonna get the IEP and it's gonna win.” That it's the long game of whatever layer you're in the education. If you're in elementary school, you are gonna be doing this forever <laugh>, for the next 15 years... And then I would also just say, do not worry about offending the school district. Do not worry about offending your teacher. The gazelle is not worried about offending the crocodile. This is a zero-sum game that you have to push, and you have to be aggressive.

Nicola liked giving the school the benefit of the doubt, but not without verification and support.

“I think the most powerful thing you can do to help yourself and your child is to get support from

an agency like Partners Resource Network where [they] have free advocacy to educate parents on their child's rights.” Some parents, like Scarlett, have to create that support—emotional, legal, and community.

Always trust that mom that, like I said before, just that parent instinct. Like if it doesn't feel right and just to get support, it's just something little as just [as] a little group chat or Facebook page, just to say that it's okay. Because for the longest time, like we felt that we were on an island alone, like no one knew what we were going on, what was happening and how we felt, but there's a lot of families that feel that way. So, just kind of like leaning on each other to just support each other and say, “Yes, this does happen.”

For most of the parents who participated, advocacy, research, and support groups seemed to be the ingredients to endure the denial process that they wanted other parents to be knowledgeable about.

Recommendations to School/District Leadership

Parents had specific issues that they collectively faced when talking about school staff and the handling of the eligibility process. They talked about how the definition of autism, at least in the minds of school staff and administrators, is disjointed from what they experience outside of the school building. For example, Cassarah talked about how staff look for traits or stereotypes based on disability labels, especially when it is counter to academic performance.

I think they're outdated, as you said... ‘cause I think they're looking at the academic perspective. Either you have a learning disability, and if you don't, then you fit in the classroom. And they don't look at behaviors as a part of the spectrum or of the ADHD. And those also need to be treated because they're part of the diagnosis.

This lack of sophistication in diagnosis or evaluation was also observed by Haylie, who found it frustrating watching school staff insisting on all the “pegs” of autism fitting their predetermined or prescriptive criterion. “Actually, to everyone, I would like them to know that a diagnosis is not a square. Not everyone is gonna fit into the box of what you have pictured in your mind...” Yet, frequently with those parents of students with HFA, if the profile did not fit, then the evaluator saw no problem. But, as Haylie continued, “That doesn't negate the fact that he has other needs that need to be met educationally—because he's in your care for eight hours, not mine—that you're lacking and you're missing because he doesn't fit in your pretty box.”

Several parents felt that the kernel of the problem of misdiagnosis was a lack of quality training and the qualifications of the staff conducting the evaluations. Haylie also noted that evaluators, specifically LSSPs, speech pathologists, and diagnosticians, have a lack of understanding for how autism, especially HFA, operates within their own field and that extensive training is obviously needed.

Differences. Yeah. So, it would make more sense if they were to at least take some funding to get them professionally trained or send them to classes that actually help them so that they could better assist their students. It would make a lot more sense.

Corrine, who had a vastly different experience in obtaining special education services in Florida, was very critical of the evaluations her son received.

How can they deliver services to people when they poorly write evaluations... If they don't know how to write a plan...? First of all, they need to... study, they need to see a good evaluation in order to know what evaluation [to write], but they don't know what evaluation is probably because they write such a bad plan.

As the research states, quality training is key to success in a community model and these eight cases highlight the fact that proper training is missing for some evaluators.

Other parents were baffled by obvious—to them—empathetic steps school staff could take to improve collaboration and lessen the adversarial element to the process. Scarlett advised schools to acknowledge the problems instead of protecting the status quo.

There was just so many bumps in this road just for them to act like they care and listen to the parent. Just ‘cause I felt like I kept crying out to them and they were just like shutting it down. So, just showing compassion and that you're trying to do what's in the best interest for the child. It's ‘make the family feel like that you care’ about the kid and that you're trying to help them out, not just label them as a bad problem and just keep going about your day.

Love thought in the big picture using a cost-benefit analysis and asked schools to think beyond the short-term needs and plan for the long-term impacts.

These are such low-cost interventions. That's what I don't get. This is a low investment [in] a lot of respects, and early education or early childhood is the time where their brains are plastic. And you can have the biggest effect and you can create scaffolding that will give them lifelong skills. By underfunding it, now you're setting up thousands of kids for failure. So, they're not going to be productive citizens. Like you're shooting yourselves in the foot. What is it, “Penny wise, pound foolish?”

As Haylie mentioned above, Cassarah also pushed back on the “scapegoat” that social, emotional, and behavioral issues are not “educational needs” or just an issue at home. “Even teachers on their own... can look more into how to help their children ‘cause they're their children. I mean, they spend seven to eight hours a day with them.”

Recommendations to Policymakers

For policymakers, parents pinpointed public funds spent on legal fees, lack of transparency, and even what feels like a “conspiracy” against them with the student suffering throughout life. Dona spoke about her legal experiences with a school district that took the denial all the way to a due process hearing.

We did an interview one time with the local news station, and he didn't use it, but [the attorney] said... something that just really rode home to me. And she said that, “You know, in the state of Texas, there's maybe five or 10 attorneys that do special ed almost at all.” She said the school districts have probably 90 to 110 different law firms that are representing them... Those school districts, attorneys are getting their 450 an hour, every hour, all the time... I'm like, “Why do you think that they wanted to take this to court?”

Would you wanna settle out with the parent or would you wanna go to court and get \$450 an hour for 40 hours a week for the next four years?

Where the legal system may be rigged against parents, the legal protections are also stacked against parents. For example, as noted by several parents, if one verbally asks for an evaluation, then the school is not obligated to respond until it is put in writing. Most of the parents, like Nicola, shared how schools do not provide the procedural safeguards when a verbal request for evaluation is given and how to correct it.

I think the most critical thing is that when a parent asks for help, that they should then automatically be supplied with the information about the process to request an evaluation... Parents shouldn't have to know that they have to request it in writing. If a parent is asking for help in support, there's something going on.

Essentially, the responsibility to teach and guide the parent through the special education process should fall on school staff.

Keira saw it systematically where simple terminology is used to confuse parents out of their rights and that, according to her, schools manipulate the policies to delay eligibility to services.

That they are waiting us out. Their whole job is to kick the can down the road to the next grade, to the next school, to the next, until we're out of the system, everything will be fine. And it's also, you start the school year and you're like, "Alright, let's review the goal. Let's talk about regression. Well, let's ease into it." And then we're at the end here, we are six weeks before the end of the year, and we're just now implementing our goals for this year... You really think that there's some kind of conspiracy that they're like, "You win a gold medal if you don't do it right. They'll give in..." I think if anybody's gonna get a special education evaluation, that they need to have [a] very simple and clear written guide or what the process is, how it works, what's supposed to happen when. And then these stupid acronyms, the PLAAFP, the IEP, the Fifth, no one understands any of that besides the diagnostician. That's the only person that I understand that it needs to be, like, for example, prior written notice comes after the ARD, how it literally says, "prior written notice." I now understand what it means is prior written notice before the implementation. But, I mean, it's so confusing and it will, they need to create [it], and maybe that's something that the state could work on. And because I think that I've seen different schools and different diagnosticians do it different ways and it's supposed to be the same.

The result, as Love and all the parents pointed out, is a lost student, family member, and citizen that ultimately becomes a burden to the state and all of society. “By underfunding it, now you're setting up thousands of kids for failure. So, they're not going to be productive citizens.”

Research, Leadership, and Education Policy Implications

Although triangulation was attempted and limitations/delimitations were disclosed, the results of this study cannot be generalized to the entire school-aged, autistic population of Texas or in the United States. Therefore, more participants from Texas should be interviewed continuing the broad cross-section geographically. Researchers may consider a randomized selection of parents—both initially accepted or denied to special education—to establish experiential comparisons; in addition, quantitative methodology may be warranted to explore the prevalence of denial based on the experiences by parents. One area of interest may be in the intersection of school finance and special education staff shortages using quantitative and qualitative methods; following DeMatthews and Knight (2019), more research may be warranted in examining the experiences and perspectives of autistic students in urban versus rural districts, English as a second language programs, or differing regions of the state. However, given the limitations of the study and that some researchers or readers of this paper may cite the need for district personnel perspectives in the cases provided above, it is my position that whether it enlightens the whole story, it is not relevant to the experiences and impressions of the eligibility process for these parents, whose narratives provide ample evidence to the need for changes.

One area that could provide relief to parents facing denial is using an inclusive model of special education. Mandated by law, the policy of a collaborative process between family and school is not being followed with fidelity. Evidence shows a breakdown in the diagnostic protocol with respect to the complexity of autism, and a need for “outside” professionals to be

part of the process is warranted. Additionally, social services are not routinely utilized in the IEP process and district intervention impedes staff from providing necessary supports. Above all, the parent participants expressed a desire and need for collaboration in the process of eligibility, which could help them with understanding, satisfaction, and the emotional effects. Experimental research should test the use of CMI for special education using the SWIFT program to measure its impact on parent satisfaction, rates of denial, and overall outcomes for the students.

Policymakers, lawmakers, and regulators could provide relief by updating the eligibility requirements for autism to match the diagnostic manual, including the intended separation between “eligibility” and “education need”; instead, the criterion should be asking the school, “Does the student have a disability? If yes, what are the educational needs of the child?” which would be a major shift in the process of eligibility and could shift school staff’s view of social, emotional, and behavioral needs—e.g., executive functioning and communication—as valuable in education as academic performance. The process of evaluation should also be codified by TEA to include tools of best practice, especially for complex profiles of autism. Schools, districts, and educational service centers should be aware and honor the levels of expertise, education, and training of school personnel certification requirements, and they should be mindful of their limitations. For example, while LSSPs are qualified to assess students with autism, they are not qualified to assess the functions of behavior and are not required to successfully complete 21 credit hours in behavior analytics, 2000 hours of clinical practice, and the BACB exam (Texas Department of Licensing & Regulation, n.d.); however, LSSPs and many other school staff often conduct FBAs with or without a typical week-long professional development (Texas Education Agency, 2022b).

The evidence supports the conclusion that districts are failing at their obligation to properly train staff from diagnosticians to special education paraprofessionals. In all areas of special education, there are numerous reports across Texas of staff abuse of students, incorrect implementations of BIPs, and minimal or improper services, such as dyslexia. However, for autism, the misunderstanding and poorly applied interventions have been damaging and long lasting. As shown in the literature, use of high-quality training could help solve this malpractice; for instance, principals need training and practicum in SPED law, positive behavior supports, and restorative practices; teachers need to be critical agents of the system, have equal voice in the IEP process, and be taught to speak up when injustice in the SPED process occurs. Equally important, though, is that district leadership needs to change its role from enforcer/accountability agents to resource/facilitators of inclusion and to model how community—from school staff to social services to family partners—are used in earnest to serve the student.

Finally, a longer-term remedy may be in shifting the responsibility of evaluations and eligibility to the ESCs much like in Northern Ireland, elsewhere in the United Kingdom, and other educational systems worldwide where parents take their child to a regional/community education authority for evaluation and, if deemed eligible, receive a “prescription” or statement of needs for the school to provide special education supports in addition to community supports (NI Direct, n.d.). Another longer-term solution—almost goes without saying—is funding; not only does Texas need to change how it categorizes or levels the multipliers for different types of disabilities so that the minimal support is fully funding, but the overall amount of funding should be at the 60% state share originally promised by the inception of IDEA. Moreover, the federal government is derelict in its obligation to fund IDEA at 40% (Cooper et al., 2015; Yell, 2016), while both state and federal funding deficits end up being passed on to districts to fulfill.

Regulations could be updated so that RTI, 504, and general fund syphoning practices are stopped, which are stressing and draining staff allocations for special education.

Conclusion and My Storytelling

By using qualitative and black storytelling methods, the narratives of both the participants and the researcher were not lost. Most of the experiences of the participants' children followed the same path as Carter's: diagnosed at first with ADHD; difficulties in school, especially socially, emotionally, and behaviorally, led to a medical diagnosis of autism; school staff rejected the "outside" or non-educational diagnosis and delayed assessment by deflecting to 504 accommodations; and challenges continued over years and a legal battle was required to implement services. The collateral costs were also something my family experienced: legal fees in the thousands; martial strain over the struggles with Carter's behavior at school; countless hours researching and seeking advice from friends, family, and advocates; and a lingering emotional toll affecting sleep, anxiety, and the ability to work. Most of us also experienced denial based on "educational need," which is code for "academic achievement;" however, this reliance on academic performance as a litmus test of specialized instruction hides or discounts the SEB needs of the child, which impacts academic performance at some point.

During this study, Carter experienced a mental health episode directly related to the lack of services received in high school, compacted by years of minimal supports and a late acknowledgement of the autism diagnosis. His case manager, who was supposed to be meeting with him on a weekly basis helping him with executive functioning skills and checking in on his social functioning, reported compliance, but after failing most classes by the second progress reporting period, it was clear that she was not providing the instruction and intervention he needed. This led to suicidal ideation, elopement, threats to himself and others, and vandalism;

when the school levied disciplinary action in the spring semester, after hospitalization and intensive outpatient therapy, we hired an advocate and lawyer who filed a due process complaint against the school district. I was worried about retaliation, which felt like it when the school administration sought removal from campus after an incident with a toy grenade; however, after the lawyer spoke to district administrators, the school backed down and instead implemented procedures for a FBA and behavioral support services, the type of services and goals Carter should have been receiving since age five... The hope now is that his story and the stories of the children from this study are heard, corrective action is taken, and the next generation of families do not experience the trauma of systemically having their needs not being met and their desires for a brighter future not oppressed in lieu of a process that is collaborative, individualized, and based on community and inclusion.

APPENDIX SECTION

Recruitment Language

Are you parent or guardian of a child with autism? Has your child ever been denied special education services by a Texas public school?

I, Michael Ota, a PhD student at Texas State University, along with my faculty advisor, Dr. Melissa Martinez, are studying the story of denial for autism services and supports in Texas public schools. We are interested to see if there are any similarities or differences in how students with autism are denied assessment or eligibility for special education services. We are also interested to see what organizational factors may be contributing to the denial of services.

Participating in the study would include a 60-minute interview with me via Zoom. Interview questions will include topics of your child's history with special education, including disability eligibility, how ARD meetings are conducted, your observations of district and school personnel, and what steps you took after receiving a denial of services.

If you are interested in participating, please click on this link [hyperlink to pdf] to review the consent. If you have questions or would like to participate, please email Michael Ota at mto20@txstate.edu.

INFORMED CONSENT

Study Title: Advocating for the Autistic Child Despite the Hegemony of Special Education

Principal Investigator: Michael Ota
Email: mto20@txstate.edu
Phone: 512-944-2752

Faculty Advisor: Melissa Martinez
Email: mm224@txstate.edu
Phone: 512-245-4587

This consent form will give you the information you will need to understand why this multiple case study is being done and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form to keep.

PURPOSE AND BACKGROUND

You are invited to participate in a research study to learn more about how children with autism are denied special education services in Texas. The information gathered will be used to find themes around the organization of school leadership that contribute to decisions of denial. Information from this study could help inform educators, employers, mental health professionals, caregivers, and individuals with autism on how to access appropriate supports. You are being asked to participate because you indicated interest in participating.

PROCEDURES

If you agree to be in this study, you will participate in an online, remote interview. You will need access to a device, Internet, and Zoom. The interview will be recorded for the purpose of transcription and analysis. The topics of this interview will be: autism history and diagnosis of your child; history of referral or request for special education assessment; and the circumstances or story of denial by the school for assessment or eligibility to receive special education services. The interview will take approximately 60 minutes or less to complete. You must be at least 18 years old to take this interview and a parent or guardian of a child with autism who has been denied or is currently being denied special education services from a Texas public school.

RISKS/DISCOMFORTS

In the event that some of the interview questions make you uncomfortable or upset, you are always free to decline to answer or to stop your participation at any time. Should you feel discomfort after participating, you may contact the Principal Investigator for referral to counseling services.

BENEFITS/ALTERNATIVES

There will be no direct benefit to you from participating in this study. However, the information that you provide will help improve policies, procedures, and interventions in services for

individuals with autism.

EXTENT OF CONFIDENTIALITY

Reasonable efforts will be made to keep the personal information in your research record private and confidential. Any identifiable information obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. The members of the research team may access the data.

Data will be kept for three years after the study is completed and then destroyed. Video/audio recording of the interview will be kept on a secured university server until a transcription is completed. All recordings that have been transcribed will be deleted from university servers.

PAYMENT/COMPENSATION

You will not receive compensation for participating in this study.

PARTICIPATION IS VOLUNTARY

You do not have to be in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw from it at any time without consequences of any kind or loss of benefits to which you are otherwise entitled.

QUESTIONS

If you have any questions or concerns about your participation in this study, you may contact the Principal Investigator, Michael Ota: mto20@txstate.edu or 512-245-3658.

This project was approved by the Texas State IRB on [date]. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB Chair, Dr. Denise Gobert 512-716-2652 – (dgobert@txstate.edu) or to Monica Gonzales, IRB Regulatory Manager 512-245-2334 - (meg201@txstate.edu).

DOCUMENTATION OF CONSENT

Your participation in this research project may be recorded using video/audio recording devices. Recordings will assist with accurately documenting your responses. You must consent to being recorded in order to participate. Please initial one of the following options:

I consent to audio recording:

Yes _____ No _____

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks have been explained to my satisfaction. I understand I can withdraw at any time.

Printed Name of Study Participant

Email of Study Participant

Signature of Study Participant

Date

Signature of Person Obtaining Consent

Date

Interview Protocol and Questions

Protocol

- Start with my introduction and contact information, explain the purpose of the study, how the recording will be secured, that they may ask for a copy of the transcript, and when raw data will be disposed.
- Be sure to ask the participant not to use names, including but not limited to the school, their own name, names of colleagues, and names of students (whenever possible).
- Note the start of the interview session and start the recorder (and back-up).
- At the end, be sure to thank the participant, note the time, and stop recording.

Questions:

1. Please tell me about how your child was diagnosed with autism. [follow-up questions if not addressed] What are their strengths and challenges? How does autism affect their learning/education?
2. Explain how you first requested testing for autism eligibility in special education services. [follow-up questions if not addressed] How did you request it? How long did it take to get approval/agreement or denial from the school? If you were denied, was that solely from school personnel or were district administrators involved in the decision?
3. [If applicable] Describe how you received the final report and determination of eligibility. [follow-up questions if not addressed] Was the decision solely from school personnel or were district administrators involved in the decision?
4. Tell me about how the ARD committee meeting was conducted. [follow-up questions if not addressed] Who attended? Who made the final decision of denial? Were you provided the packet of procedural safeguards? If so, did you understand your rights?
5. Were you offered an alternative program, like individual counseling or social group, 504 accommodations, or response to intervention (i.e., RTI)?
6. What were the next steps that you took after being denied? [follow-up questions if not addressed] Did you seek legal advice or hire an advocate? If so, did that outside representation attend subsequent ARD meetings?
7. What is the current status of your child's case of denial?
8. How has this process impacted your son/daughter and your family?
 - a. Their education and your perspective of the education system?
9. How did you feel throughout this experience as a parent and stakeholder?
 - a. How did the school or other organizations support or advocate for you and your child, if at all?
10. What advice or suggestions would you like to share with other families?
 - a. What advice or suggestions would you give to schools, districts and policymakers?

[For everyone] Thank you for your time and thank you for sharing your family's story! Please contact me if you have anything else you'd like to add to our discussion today.

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