IT'S GOING TO BE DIFFERENT, BUT IT'S GOING TO BE OKAY: CAREGIVER PERSPECTIVES ON AUTISM, CULTURE AND ACCESSING CARE

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Through ethnography influenced by public health and anthropological theory, I explored the cultural perceptions of autism among eight caregivers whose children received services from a local Dallas-Fort Worth (DFW) autism treatment organization. Participant observations and semi-structured interviews with caregivers and program employees provided a rich and nuanced view into the state of care currently available in the DFW area while also highlighting areas for improvement. This research will be used to not only identify the barriers faced by North Texas families while seeking out care for autism, but also the strategies the organization uses when connecting with families from different backgrounds.

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CHAPTER 1

INTRODUCTION

1.1 Background

In 2012, I moved to San Antonio, Texas to serve with the AmeriCorps program Public Allies. I was matched with Respite Care of San Antonio as a medical liaison and activities coordinator. At that time (and I believe currently), Respite Care was the only emergency shelter in the state of Texas for children with special needs. This experience was my introduction to autism. I spent almost two years interacting with children with varying disabilities from different backgrounds from all over the state of Texas. Towards the end of my time there I was given the opportunity to work directly with parents through their weekend respite program. This opportunity allowed me to see how families from different social and ethnic backgrounds handled their child's autism diagnosis, their behaviors and also caregivers' hopes and dreams for their children's futures. My interest in studying autism from a cultural perspective was further compounded while serving a second AmeriCorps term with an immigration office. The initial planning for my thesis began in early 2015 after a discussion with my head advisor about my interests. I was connected to my client site through my head advisor who previously served at organization as a consultant. The organization is also associated with the Applied Behavior Analysis program at the University of North Texas, and UNT ABA students often complete internships or work within the organization as ABA coaches. Most of the coaches I interacted with were either current or former ABA students (both undergraduate and graduate).

I aimed for the following with this research study:

1. An understanding of how families use cultural practices and beliefs when considering treatment options

2. An understanding of the trajectories that families have experienced in finding autism care before The Client and if they encountered any barriers.

3. The identification of the strategies staff members use to connect to clients and their families, and how these strategies aid in recruitment and retention.

This is accomplished using anthropological and public health frameworks and a phenomenological approach to research. Parents' discovery and understanding of autism and their subsequent response is the focus of the project. The thesis provides the Client with an overview of the perceptions of autism held by clients and the current practices used to identify how different communities utilize the organization's resources. Additionally, the project identifies practical ways to address disparities in use of services by different community groups.

1.2 Justification for Research

In the last decade, the incidence and prevalence rate of autism have risen steadily. This rise has been attributed to better screening measures for families from different backgrounds. Though there has been an increase in diagnoses, there are still disparities present not only in screening/diagnosis but also in accessing interventions.

1.3 The Client

The client is a non-profit organization that aids individuals with disabilities. Their scope is across the lifespan, and they provide services to people ranging from toddlers to elderly adults. They provide elder care, employment assistance for those with disabilities, early childhood intervention for children with autism and caregiver support. While the organization is located throughout the United States and internationally, my research took place at two of the organization’s early childhood intervention autism treatment programs located in the North Texas region. The two autism treatment centers provide ABA therapy to children between the ages of 3 to 16, and serve a diverse group of children from all over the North Texas area. The organization originally had three early childhood intervention autism treatment centers, but their South Dallas location closed in early 2016 due to staff shortages; a few families from the South Dallas location relocated to the other two locations to avoid a lapse in services. In addition to providing ABA therapy, the organization also provides an inclusion preschool in Grapevine, and offers speech therapy and occupational therapy on site at their North Dallas location. Speech and occupational therapy is accessible to families and children who are not enrolled in the Client’s comprehensive preschool or their comprehensive and after school autism treatment programs.

It is important to add that during this thesis project, dramatic changes to Medicaid funding at the State and National level affected both individual clients and the organization. In 2016, the Texas Senate passed legislation that greatly limited the reimbursement practices for organizations that relied on Medicare funding. This resulted in reduced access in certain areas and a lapse in care for families who relied on Medicare-funded treatment and could not afford out-of-pocket costs for treatment.

1.4 Deliverables

This project provides an ethnographic look into the experiences of clients and also an overview of the tools employees use when engaging with families from different backgrounds. The findings from this project will be presented to The Client through an oral and visual presentation. This presentation will provide an overview of the strategies used by employees, and how that translates to families receiving services. A discussion of common themes and unique perspectives learned through family interviews and program recommendations aimed at recruitment and retention of underserved communities within the DFW area will be provided as well.

CHAPTER 2

LITERATURE REVIEW

2.1 Background

Research on the ways that anthropology contributes to the study of autism is growing and shines a light on the practicality of an interdisciplinary approach; the social sciences contain a wealth of information on the sociocultural issues of autism treatment, the effects on families, and how autism is understood across cultures. There are intersections within current research that can be linked to both anthropological and public health theory. This growing area of study along with increased public health surveillance on health disparities faced by people with developmental disabilities creates a richer understanding of how to address complex health issues children with ASD face in childhood and how to effectively serve this demographic across the life span.

Healthy People 2020, a 10-year evidence-based set of goals and objectives aimed "improving health of all Americans", includes goals aimed at improving health outcomes for those with disabilities (About Healthy People, 2017). There are several goals and objectives focused on ASD, and they deal primarily with improving access to early intervention measures through increased screening, diagnosis, and connection to appropriate services (About Healthy People, 2017). The focus of these objectives is across the life span, starting with increasing the number of children screened based on CDC age-recommended guidelines, to improving healthcare access and preventing unnecessary illness and death among adults with disabilities.

Both children and families are affected by an ASD diagnosis, and both face unique challenges when trying to navigate the healthcare system and receiving care. When compared to children without ASD, children with ASD face lack of access to quality healthcare which can be attributed to a lack of adequate insurance coverage, issues with referral services, and higher out-of-pocket costs for parents. Adults with developmental and intellectual disabilities face worse health outcomes when compared to the general population, making the need for effective early intervention services imperative. With a growing and diversifying population in the United States, making sure that support and treatment services are accessible and culturally relevant is important. A review of relevant literature is presented by subject area to provide an overview of social and health disparities children and their families face while seeking health services for autism, the ways in which families from different cultural backgrounds understand ASD, and choose care based on their understanding.

The following section provides a brief discussion of Autism, relevant screening measures and treatment. I then examine disparities in screening and care, socioecological issues faced by families, and how organizations help bridge the gap and provide culturally relevant support. Lastly, I discuss contemporary examples of cultural competency within the field of applied behavior analysis, and how intersecting anthropological and public health theory and methods can be used to enhance current practices.

2.2 Defining Autism

Within the *Diagnostic and Statistical Manual of Mental Disorders*, autism is defined as “pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behavior” (American Psychiatric Association, 2013). Autism is classified as a neurodevelopment condition characterized by developmental delays in speech, motor skills and “social communication” (Lai, 2014, p. 896). The etiology of autism is currently unknown, but studies focused on examining both environmental and biological factors are underway. Autism is more prevalent in males. Almost 70% of those diagnosed with autism also have a comorbid condition (Lai, 2014, p. 897). Screening for ASD is a two-step process that begins with an initial developmental screening that checks to see if the child is hitting age-appropriate milestones and a comprehensive diagnostic evaluation that further investigates behavioral and developmental progress. (CDC, 2017). The CDC suggests that children be screened for developmental delays starting at 9 months, 18 months, and either 24 or 30 months (CDC, 2017). It is recommended that children be screened specifically for autism at either 18 or 24 months-old, and children with preexisting issues, such as pre-mature birth, have additional screenings for delays.

If a pediatrician notices serious delays, a comprehensive diagnostic evaluation will be recommended (CDC, 2017). The comprehensive diagnostic evaluation should include interviews with caregivers concerning the child’s health and behavior history from birth to present and questions focused on “family medical and psychiatric history”

(Lai, 2014, p. 900). During the evaluation, the medical professional observes interactions between:

1. the child and caregiver
2. the child and medical professional and,
3. the child and their environment.

The focus of the evaluation is on understanding “the development of social, emotional, language and communication, cognitive, motor, and self-help skills; the sensory profile; and unusual behaviors and interests” of the child (Lai, 2014, p. 900).

2.2.1 Autism Treatment

When a child receives an official autism diagnosis, their caregiver is encouraged to seek out behavioral and health treatments relevant to their child’s needs. There are 4 treatment categories recognized by the CDC. They include behavior analytic approaches, dietary approaches, medication, and complementary and alternative medicine (CDC, 2017). For my literature review I focus on evidence-based behavior analytic, specifically the main research based approach to autism, applied behavior analysis. Applied behavior analysis is an applied science that has produced a body of evidence supporting effective interventions. At times, this can mean identifying challenging behaviors and replacing them with appropriate behaviors. It can also mean interventions directed at increasing social, communication and adaptive skills. Intervention is accomplished through different behavior modeling methods that can occur in naturalistic or educational settings. Therapists use a combination of methods based on observations of children in different settings and insight provided by caregivers. Early intervention methods oftentimes take a family-focused approach and include interventions focused on strengthening social skills, communication and self-care (Autism Speaks, 2017). Axelrod, McElrath and Wine (2012) discuss the role of ABA in adding to disability-focused research and assert that the discipline has been instrumental in providing evidenced-based research focused both on the issues faced by people with ASD, and aid in improving health and life outcomes (p. 2). Roane, Fisher and Carr (2016) validate the role of ABA in autism treatment, and go a step further to urge pediatricians and other healthcare providers "familiarize themselves with local ABA providers and the behaviorally based interventions that may help their patients with ASD" (p. 30). Using ABA, therapists help individuals learn "adaptive living skills" including behavior management, "independent living and hygiene", developing healthy feeding habits, and relevant self-help and self-care tips (Matson et al., 2011, p. 273.)

2.2.2 Reasons for Delayed Diagnosis

A requirement to receive treatment in most early intervention programs is an official ASD diagnosis, which can be attributed to funding regulations. Studies have shown that despite the guidelines for screening children between the ages of 18 to 24 months, in the United States, less "than half of the children with ASD in the United States receive a diagnosis before the age of five" (Matheis and Matson, 2015, p. 756). Children who receive a late diagnosis miss a critical opportunity to "to maximize opportunity for specialized early intervention" (Matheis and Matson, 2015, p. 756).

Reasons for a delayed diagnosis can be attributed to a myriad of structural issues including a lack of access to health services, discrimination, distrust of medical institutions, and an initial misdiagnosis. Daniels and Mandell (2014) found that parental concern also affected time of diagnosis, and parents who attributed atypical delays in their children to behavioral problems were more likely to receive a later diagnosis; Contrarily, parents that expressed concern about atypical behaviors were more likely to have earlier diagnoses (p. 592). Emerson et al. (2016) also note that children who do not have access to consistent medical care where a pediatrician can track developmental changes are more likely to be diagnosed at an older age. Additionally, the researchers identified “birth cohort, birth order, poverty level, parental education, health insurance, race, ASD severity and CSC, and the interactions between race” as potential predictors for a later diagnosis (Emerson et al., 2016, p. 132).

Shattuck et. al (2009) identify a present and very consistent gap in the age recommended for screening and diagnosis, and the median age that most children receive an autism diagnosis. Shattuck et al. (2009) details some of the causes of a delayed diagnosis, and discusses the effects that it can have on both children and their families. They assert that a “timely start of intervention is contingent on early identification" and this can aid families and caregivers in choosing appropriate treatments in a timely manner (Shattuck, 2009, p. 475). Itzchak and Zachor (2011) discuss the importance of early intervention and attribute the increased effectiveness of treatment among younger children to “better the response in the cognitive domain” (p. 349). From the clinician perspective, Rutherford et al. (2016) found that unclear care pathways, unstandardized screening practices, and prioritization of other issues (e.g. adult screening services) were often listed as causes for delayed diagnosis (pp. 61-62).

School-based autism identification is another opportunity for screening and diagnosis. School-based identification can vary by state or community depending on how autism is defined in guidelines and the resources available to conduct screenings. Sullivan (2013) examined the prevalence of autism diagnoses in school systems, similarities and differences in assessment tools used among states, and responses to racial disparities present in identification. Sullivan (2013) stresses the importance of both general and special education professionals being aware of ASD symptoms, and the need for special attention to socioeconomic factors that may affect access to early screening and treatment measures (p. 312). Identification of autism in the school setting can vary depending on the financial resources available to the school district. Overton et al. (2007) state that the geographical area that children live in and the resources available effect when a child is diagnosed, whether it is in a clinical or school setting (p. 1997). Additionally, the researchers found that even though children in public schools may fit the criteria of an ASD diagnosis in a medical setting, they may still need to go through additional testing and “meet the criteria of federal regulations for receiving services in IDEA before receiving educational interventions” (Overton, Fielding and Garcia de Alba, 2007, p. 1996).

2.2.3 Disparities in Screening and Diagnosis

Socioeconomic, racial, gender and ethnic disparities as well as wide-spread structural issues have been identified as reasons for lower ASD prevalence and incidence rates among non-White children. Refusal rates for autism screening vary by racial or ethnic identity, socioeconomic status, where the screening recommendation occurs (e.g. in a clinical or social program setting) and a family history of autism or other developmental or intellectual disabilities.

Jo et. al (2015) studied the age of diagnosis based on several factors including race, socioeconomic status, immigration status and the language spoken primarily at home and found that children from families who lived at or below the “federal poverty level were more likely to have a later diagnosis than those from higher income households” (p. 1692). Additionally, children from Hispanic immigrant families had a lower rate of diagnosis when compared to non-immigrant families, and Jo et al. (2015) mention how “cultural and language barriers” may prevent immigrant families from seeking out mainstream healthcare options (p. 1695). Janvier et. al (2016) suggest the use of early childcare facilities as potential hubs for screening for children at risk for ASD in underrepresented and underserved communities. Using early childcare facilities as possible screening centers was identified to reduce the issue of under-diagnosis for ASD among underrepresented populations. Their study took place in Head Start programs located in areas with “predominantly low-income, high racial/ethnic minority populations” (Janvier, 2016, p. 365). In the study, families with children enrolled in Head Start programs were also more likely to be “to be Black and less likely to be

Hispanic” and “more likely to be insured through Medicaid and less likely to have private insurance” (Janvier 2016 p.367).

Childcare providers were trained to use two screening tools: The Modified Checklist for Autism in Toddlers (M-Chat) and the Social Communication Questionnaire (SCQ); the tool used was dependent on the age of the child. If a child tested positively using the screening tools, a follow up interview was completed and the child was referred for a more in-depth evaluation with a specialist. Within their study, the researchers cited issues with participant retention and with follow-up for clients who tested positive during screenings; 25% of participants who were offered follow up services declined the offer (Janvier, 2016). The researchers cited for lack of participation and retention issues included mistrust, cultural factors, and a lack of knowledge of what to do and where to go to receive services in the case of a positive screening as possible barriers to screening; cited reasons were based on evidence presented in the literature (Janvier, 2016, p. 371).

2.2.4 Issues with Autism Screening and Treatment

Matheis and Matson (2015) examined the characteristics of families who refused optional ASD screening suggestions at a State of Louisiana early intervention program. The researchers point out that offering screening and identification at early intervention programs would be imperative due to the age requirements for children in the programs, and screened and diagnosed children would then have access to intervention methods at an earlier age (Matheis and Matson, 2015, p. 756). The researchers noted significant differences in refusal rates depending on the child’s gender, and families with female children were more likely to refuse ASD screenings compared to those with male children. Female children are also more likely to receive a ASD diagnosis later compared male children, and the researchers identify refusal of screenings at younger ages as a possible contributing factor (Matheis and Matson, 2015, p. 765). The age of the child at the time of screening was also significant, and researchers found that caregivers of younger children were less likely to consent to ASD screenings. Additionally, the idea that a child was too young for screening or would grow out of certain behaviors or delays was cited as a reason for refusal (Matheis and Matson, 2015, p. 765).

Parents of children with previous diagnoses of intellectual or physical disabilities such as “down syndrome, cerebral palsy, or a seizure disorder” were more likely to refuse screening (Matheis and Matson, 2015, p. 766). Caregivers were noted to not believe it was necessary to screen since their child had already received a diagnosis for a separate condition and rationalized that they were not at risk for ASD (Matheis and Matson, 2015, p. 766). Within the study, African American children were more likely to be screened, however this did not necessarily lead to an official diagnosis and access to early intervention programs. African American children required more specialist visits before receiving a diagnosis and were more likely to be misdiagnosed with a behavioral issue first before receiving an ASD diagnosis (Matson, 2015, p. 765; Mandell, et al., 2007). Magana, Lopez, Aquinaga and Morton (2013) found that Latino children were diagnosed almost a year later than their white counterparts, had higher reports of unmet needs and received less assistance and treatment.

2.3 Structural Issues

Berg et. al (2016) conducted a population-based study that looked at adverse childhood experiences (ACEs) and worked to identify causes for health disparities faced by children with autism as opposed to children that did not have a disability. Questions about adverse childhood experiences included topics such as family income, the family structure (whether the parents were together, separated or divorced), if the child had ever been a witness to domestic or neighborhood violence, whether they lived with a someone with mental illness, and if they had ever been treated poorly due to their race or ethnicity (Berg et. al, 2016, p. 1125). Berg et al. (2016) found that children with ASD were more likely to experience ACEs compared to children without ASD; children with ASD were also more likely to live in neighborhoods with poor support, or be a part of families dealing with economic difficulties (p. 1128). Caregivers of children with ASD oftentimes "reduce or stop employment in order to care for their child", resulting in limited incomes and more financial stressors. (Tregnago and Cheak-Zamora, 2012, p. 1027). Additionally, research examining parental stress among caregivers has found that caregivers of children with ASD were more likely to report higher levels of stress than their counterparts caring for children who did not have ASD; increased behavioral problems among children with ASD was also noted among parents who self-reported higher levels of stress (Baker, et al., 2003; Davis and Carter, 2008).

2.4 Impact on Family

Tincani et al. (2009) suggests that families from different cultural backgrounds approach the subject of ASD differently; how a family responds and copes with a diagnosis can be culturally specific, and families' culture shapes their beliefs regarding what constitutes best outcomes of intervention" (Tincani et al., 2009, p. 85). Tincani et al. (2009) also discusses how family systems can help families cope with a diagnosis through support via sibling or extended family interactions (e.g. grandparents). Dyches et al. (2004) concur and note the importance of extended family in multicultural groups as a form of support; depending on how the family is structured in multicultural groups, the entire family can be involved in raising and caring for a disabled family member (p. 213, 220).

Gourdine et al (2011) examined the effects of autism on African American families" and detailed the issues that a family faced as they tried navigating both the healthcare and education system to seek care for their child. Profiled parents discussed "issues of respect and a [lack of a] sense of comfort" when interacting with healthcare providers. How clinicians interact with families can influence care, and Gourdine et al. (2011) present a case study in which an African American family details the issues they faced in receiving an accurate diagnosis for ASD, and sympathy and understanding from the healthcare providers they interacted with:

> The parents sensed and received several negative assumptions from the clinicians. For example, there seem to be the assumption that the parents were uneducated and should not put much hope in this child. One clinician, at the full-day evaluation session, came in the office gleeful stating to the parents that the clinic might have found a cause for a disability; but the good news was that their son would probably not survive. The parents were stunned by this cavalier attitude and complained to the pediatrician, who reprimanded the clinician for

> insensitivity. Yet the insensitive behavior toward the parents continued when the psychologist, after her evaluation, told the parents that they should not have any expectations for the child and perhaps William should be institutionalized. (Gourdine et al. 2011, p. 462)

Families may be wary of seeking out needed care in clinics where they have had negative experiences, and this is especially dangerous if they live within an area where medical services are limited. Mello, Urbano, Goldman, and Hodapp (2016) note that families living in rural areas have a harder time accessing appropriate medical and diagnostic services, behavior management services, and specialized assistance in schools when compared to families living in non-rural areas. The researchers also note that even when rural families could access services they still had lower rates of successful implementation (Goldman et al., 2016).

Understanding the intersecting socioecological factors that influence how families address their children's ASD diagnosis and choose appropriate treatment is important (Hock and Ahmedani, 2012, p. 302). These factors can include socioeconomic issues, access to healthcare resources, geography, positive and negative experiences with medical or treatment staff, and family cultural perceptions of ASD. Caregivers' assessment of their child's diagnosis and how they think treatment should be approached is an important thing for clinicians and therapists to consider and can also aid in a positive relationship between caregiver and staff. Dubbin, Chang and Shim (2013) discuss the idea of Cultural Capital Health (CCH), which is a "specialized set of cultural skills, behaviors and interactional styles that are valued and leveraged as assets by both patients and providers in clinical encounters" (p. 114). Dubbin et al. stress the need for considering patient's CCH when developing the patient-provider relationship and trying to understand how disease and illness is conceptualized (p. 115). Cultural background can influence how families deal with their child's ASD diagnosis, and what they believe is the cause of the diagnosis. Dyches et al. (2004) studied the effects of autism and the associated stress on different multicultural groups. In their study, the researchers found that different groups approached and conceptualized their children's' diagnosis in ways that were inclusive of their cultural and spiritual backgrounds (P. 218). Likewise, it is key to examine how structural issues within mainstream culture can influence parents' and caregivers' perceptions of their ability to take care of a child with unique needs. Gourdine et al. (2011) describes how families from minority groups who often face racial discrimination are more likely to "feel personally inadequate, incompetent, and powerless in the helping process" (p. 460). A lack of self-efficacy regarding their children's care may lead caregivers to not seek out care or believe that finding adequate care is beyond their knowledge or ability.

Zuckerman et al. (2014) examines how the financial impact and the employment status of parents of children with autism can affect access to healthcare and health outcomes. The researchers found that parents with children on the spectrum "are at increased risk of under- or unemployment, financial stress, family burden, poor health-related quality of life, worse physical and mental health, and poorer psychological well-being" (Zuckerman, 2014, p. 398). This highlights that an autism diagnosis can have impact on the family unit which in turn can affect how families access care. Limited access to healthcare or poor-quality healthcare was also linked to higher levels of stress and poorer health outcomes for children and caregivers.

2.5 Caregiver Perceptions of Autism

Within the United States, Ennis-Cole et al. (2013) generally found that parents of varying backgrounds believed that “genetics, environmental factors, and events related to childbirth [were] contributing factors” to their child’s ASD diagnosis (p. 280). However, when looking specifically at the etiological beliefs held by different ethnic and racial groups there were marked differences (Hilton et al, 2010, p. 2). Hilton et al. (2010) found that African American mothers were more likely to “perceive lower levels of negative impact from having a child with ASD” when compared to white mothers; the researchers believe that this perception can affect how care plans are followed or what a parent may deem necessary (p. 2).

Ennis-Cole et al. (2013) found that white Americans were more likely to believe that physical factors, such as vaccinations, were the cause of their child’s ASD diagnosis. African Americans were more likely to attribute their child’s diagnosis to “nontraditional issues like diet, food processing, and contamination”, Asian Americans were more likely to cite violations of “religious, ethical, or cultural code or disharmony between yin and yang forces”, and Latino mothers saw autism and other developmental disabilities as a “gift from God” that would allow them to serve their child in a larger and more sacrificial capacity (Ennis-Cole et al. 2013, p.280). However, the researchers caution against the use of generalizations of cultural beliefs in forming being used to create overarching cultural narratives regarding autism diagnoses because beliefs could vary greatly between members of a specific cultural or social group (p. 34).

The varying views of autism across cultures can be explained by examining how autism is conceptualized within one’s country of origin. Hyun Uk (2012) found that many developing countries did not have a working system to track prevalence or incidence rates of autism and this was attributed to how autism was defined and constructed within the country (Kim 2012, p. 535). The ways in which parents interpret the cause of their child’s diagnosis is also important. While the etiology of autism is currently unknown, parents and caregivers may go through several “awakenings” concerning their child’s diagnosis as they attempt to find an explanation that fits within their worldview. Parents often had to adapt to the cultures within their communities in ways that were beneficial to their children. If they lived in an area where disability support was low, they were oftentimes forced to move to areas that better supported their children and beliefs (Kim, 2012).

2.5.1 Perspectives of Autism Screening, Diagnoses and Treatment

Caregivers interact and raise their children within the context of their culture and may have “different developmental goals” that are unique to their cultural community (Keller et al. 2004, p. 26). Understanding these nuances is useful when working with families of different cultural backgrounds and can aid health providers in identifying appropriate health and behavior interventions. Keller et al. (2004) found that it is important to consider where much of its diagnosis process is predicated on seeing if a child is hitting specific developmental milestones. Children from different cultural backgrounds that place more emphasis on certain early childhood skills and less on others may appear to fit into certain diagnoses that may not even exist in their own cultural framework. For instance, a child that was raised in a culture that does not emphasize eye contact or verbal communication that was not initiated by adults may set off alarms when examined through a western context. Trembath, Balandin and Rossi (2005) discuss how caregiver's cultural background can influence the effectiveness of interventions and stress the importance of clinicians and therapists being well-versed in identifying cultural nuances and "careful negotiation must be undertaken in order to successfully accommodate and respond to parental preferences" (p. 241).

Additionally, primary caregivers may have alternative approaches that are specific to their cultural background. For instance, Jo et al. (2015) found that Hispanic immigrants were more likely to use "folk remedies rather than preventive care and mental health services" (p. 1695). Ravindran and Myers (2012) stress the importance of not assuming "that treatment approaches developed in the west can be blindly generalized to children (or adults) with disabilities across the world" (p. 311). Instead it is recommended that behavioral professionals have a responsibility to their clients to provide culturally competent and evidence-based treatments. Consideration of traditional practices allows for behavior professionals to be aware of any conflicting treatments and serves as an opportunity for communication and the suggestion of "acceptable substitutes" (Ravindran and Myers 2012, p. 317).

The goal of acknowledging these differences is not to change the parenting habits of those who do things differently, but it is important to consider different parenting styles when developing care and treatment plans for children with ASD. Solomon and Lawlor (2013) discuss the methods employed by parents from different backgrounds when approaching the issue of elopement and keeping their child safe. Elopement is defined as wandering away from caregivers, from home or leaving an area without permission (Solomon and Lawlor, 2013). The researchers use ethnography to construct narratives of the families’ experiences with elopement, how they defined it and the ways in which clinical staff can work with parents to address it. The inclusion of families’ experiences was beneficial to both clinicians and families, and allowed for the acknowledgment of intersubjective experiences and the need for them to be acknowledged in clinical and professional spaces (Solomon and Lawlor, 2013, p. 112).

Angell and Solomon (2014) profiled African American families’ in their study of the “social life” of health records and found that families’ interpreted their children’s diagnoses and health records within the context of their views and experiences. Demographic data collected, such as employment status or education level created a profile of parents that clinicians used when forming understandings or bias. Health records served as a tool for parents when learning more about their child’s diagnosis, negotiating care plans and marked parents’ assuming of the role of an “autism parent”; (Angell and Solomon 2014, p. 52). The role of an autism parent was significant as it required the “precarious task of engaging practitioners in narrative and moral reasoning related to framing” (Angell and Solomon 2014, pp. 52-53). The researchers discuss the importance of family-centered care which works by identifying “the expectations of families and practitioners, emphasizing collaborative relationships among them and recognizing families' unique cultural worlds” (Angell and Solomon 2014, p. 56).

2.6 ABA and Culture

The inclusion of culturally competent practices is an intentional practice that the field of ABA has stressed as of late. Sugai et al. (2012) discusses the inclusion of cultural awareness in the practice of behavioral professionals as a positive thing, and that behavior professionals, educators and families should work together to provide effective care. Fong et al. (2016) have similar analyses and suggestions, and discussed the benefits of “integrating cultural awareness practices into service delivery, supervision, and professional development” and how that allows for shared learning between both the clinician and the child (p. 2). Wang et. al (2007) acknowledge that behavior is significantly influenced by “culture and context”, and there may be times behavioral professionals encounter a behavior that is outside the norm of the mainstream culture (38). In these instances, it is important for behavior professionals to be aware and understand the cultural nuances of the families they are working with. Wang et. al (2007) identify “cross-cultural competence” as an effective and useful tool needed in engaging families from diverse backgrounds; cross-cultural competence is defined as “the ability to think, feel, and act in ways that acknowledge, respect and build upon ethnic, socio-cultural, and linguistic diversity”. (Wang, et. al, 2007, p. 38). The authors identified 3 key elements needed to cultivate and develop cross-cultural competency. They include:

1. “Understanding one’s own culture and heritage”
2. “Learning culture-specific information from families of other cultures” and,
3. “Applying knowledge and skills to work affectively with families”

Wang, McCart and Turnball (2007) discuss the importance of a collaborative partnerships between families and behavior professionals. They believe strong partnerships lead to stronger familial involvement in care and better outcomes for the child.

2.7 Intersections among Disciplines

Utilizing an interdisciplinary approach to autism, surveillance, screening and treatment is key. There are opportunities of collaboration available between applied behavior analysis, public health and anthropology. There is a growing area of research that has been conducted within the discipline of applied behavior analysis focused specifically on developing culturally competent practices within autism care. ABA based procedures are recognized as effective and evidenced-based autism treatment, and collaboration with ABA professionals is of paramount importance as ABA trained clinicians and researchers work directly with families and children with ASD. Finn and Watson (2017) highlight areas of crossings between ABA and disciplines focused on healthy behavior change. They note that ABA has served as a basis for many behavior interventions aimed at improving physical and mental health, and it is “uniquely situated to play a key role in designing behavior-change programs that address lifestyle choices and related behavioral risk factors” (Finn and Watson, 2017, p. 182). Public health and anthropology can be used to examine both macro level issues and the personal experiences of families as they navigate behavioral and healthcare systems. The use of anthropological theory and public health methods can be used in the study of autism, the effects on families, and families’ experiences seeking out care; relevant theory includes phenomenology, critical medical anthropology, and the socioecological model of health. These theories can be used to examine and understand the unique experiences of families, but also inequalities present in care.

As mentioned previously, the study of autism within public health is usually from an epidemiological standpoint that tracks the incidence and prevalence of autism within the population. Surveillance of autism using public health methods is not as simple as tracking a communicable disease, and until recently autism was considered a rare and "epidemiologically stable disease from the time the diagnosis was introduced in 1943" (Kaufman 2010, p. 11). A spike in autism diagnoses has been noted as testing measures have improved and diagnostic criteria has expanded. This spike can also be attributed to "a growing demand for services that can be accessed only through an ASD diagnosis" (Kaufman 2010, p. 11).

From the standpoint of community health, how to define the autism "community" can be tricky. Anthropology has been useful in the exploration of defining an autism community, and much of the ethnography that Kaufman (2010) collected focused mostly on those classified as high-functioning, or fit into the primarily male, white and middle-class demographic that could attend the conferences where most of her field work was conducted. Anthropology would also be useful in the identification of subgroups within or on the outskirts of those represented in the dominant autism community.

Public health and anthropology converge again when perceiving risk of having a child with an autism diagnosis. Kaufman (2010) explores how parents perceive risk when drawing connections between autism and vaccinations. While the connection and most of the confusion surrounding vaccines and their link to autism have been unfounded, Kaufman (2010) describes how cultural perceptions of autism can influence how they perceive risk and where they pull sources of knowledge that influence their treatment decisions and when they. Kaufman shares the story of one mother who chose to delay vaccinations based on perceived risk. The mother's understanding of this risk was largely influenced by her interactions with medical professionals as detailed below:

> When my son was born, we decided to wait before giving any vaccinations. There was lots of talk about vaccines in the mothers group I belonged to. That group has an annual conference on vaccines, a panel of parents and health care providers. I went to the panel for information. There was a great doctor there she gave information on which vaccines are more important. Parents want to space out the vaccines. There were questions on how to separate the combination vaccines, how far to space them apart. Some people on the panel were absolutely against giving vaccines I wasn't interested in this . . . Attending that panel reinforced my feeling that I should wait... but it didn't create that feeling. I was worried about subjecting an infant to all the stuff in vaccines so young. I learned about all the preservatives in that panel discussion. My intent was to do a delayed schedule of some of the vaccines. (Kaufman, 2010, p. 14)

This case study is an example of how culture and social knowledge can influence health behaviors. It is important for anthropologists and public health professionals to be aware of this as being mindful of what a parent believes to be the etiology of their child's condition could influence care and adherence to care plans.

Cascio (2015) also discusses the use of anthropology in understanding autism, and lists three major ways in which anthropology has contributed to autism studies:

"(1) Anthropology conceptualizes intersubjectivity and empathy in a practice based way, not assuming that the anthropologist preternaturally can think like the people he or she is trying to study, but rather stressing careful attention and observation;

(2) Anthropology takes a hermeneutic, interpretive stance focused on lived experience; and

(3) Anthropology's meaning-centered ethnographic methodology attends to everyday practices". (Cascio, 2015, p. 207).

Grinker (2015) believes that anthropology, specifically ethnography, is a good contribution to autism research, and he believes that anthropology can do more than just a providing a simple relativistic view that approaches “autism as just another form of being”, (Grinker 2015, p. 1). Ethnography allows for individuals who are most affected by ASD, to tell their story, including both children and caretakers. Grinker employs the use of “autistic sociality” as well, and stresses the importance of moving away from viewing autism through a strict biomedical lens, and instead encourages the study of the role “social context plays in the identification and treatment of autism” that can be influenced by biological descriptors (Grinker 2015, p. 2).

Promotion of early childhood intervention methods by public health officials is also another point of collaboration between the two disciplines. Anthropologists can collaborate with public health professionals and applied behavior analysis professionals to create culturally tailored health promotion materials that are created with the intention of reaching communities that are underrepresented in the literature as well as in biomedical research endeavors aimed at screening and treatment measures. DisCrit Theory, an intersection of Critical Race Theory and Disability Studies, works to not only identify and address the disparities in treatment and care faced by marginalized communities, but also notes areas of improvement in research of intersectional identities within health and other socioecological factors (Connor et al., 2013). Creating culturally-sensitive interdisciplinary interventions should be at the forefront.

2.8 Theoretical Frameworks

The theory of **phenomenology** is relevant to the social study of autism as families “discover” and learn more about their child’s diagnosis. Phenomenology is both a research method and a theoretical framework focused on the perceptions held by individuals and the journey to their understanding. It allows for the consideration of gained knowledge and how the individuals interpret and understand situation through their own lived experiences and cultural upbringing. Phenomenology is a useful tool in the field of anthropology, as the theory's methods allow for "inquiry, the focus on "life as lived" and human consciousness in all of it"" (Desjarlais and Throop, 2011, p. 92,). With a phenomenological approach, the focus is instead on participants' unique lived experiences and how they position them and allow them to move through the world. It is relevant to the study of autism from social and anthropological standpoints as it "attempts to understand people's perceptions, perspectives and understandings of a particular situation (or phenomenon)" (Phenomenology, n.d.). Kaufman (2010) profiled the experiences of 11 families as they formed a new understanding of their child's diagnosis that was different from their original belief that vaccinations may have causing agent. The families switched between what they believed to be the cause of the diagnosis, which was based on interactions with those within their social circles and knowledge sharing that at times may not be accurate; the parents worked to develop an understanding that was accommodating of their beliefs, current scientific research, their doubts and their understandings of risk. Kaufmann found that families largely based their understanding of their child's diagnosis on the things they learned both intentionally and passively, but with an openness that allowed for the synthesizing of information from different and opposing sources (Kaufman 2010).

Woodgate, Ateah, and Secco (2008) used a phenomenological approach to examine the lived experiences for parents of children with autism. The researchers focused on the ever-changing and evolving beliefs of parents of children with ASD as they learned about and coped their child’s diagnosis, and how it not only expanded their world view and understanding, but highlighted their divergence from their previous way of life. The researchers found that families critically examined their way of living before having a child with ASD to after, often describing life after receiving a diagnosis as isolating and requiring the use of vigilance when encountering unfamiliar situations (Woodgate, Ateah, and Secco, 2008, p. 1082).

Social Networking theory is relevant to when considering the role of social capital and support in caregivers’ search for appropriate care. Szreter and Woolcock (2004) describe how social capital allows individuals “to gain access to resources—ideas, information, money, services, favours” through interactions with others within their social network (p. 654). Caregivers may rely on help from family members, information sharing with other caregivers in traditional settings (e.g. educational or clinical settings) or through online means (e.g. online parent support groups or forums). Kim (2015) found that social networks among immigrant communities were an important aspect of connecting people to health information and resources. Trainor (2010) discusses how families from diverse backgrounds use social, cultural and economic capital to navigate care for their children and interact with the social environment around them.

Hock and Ahmedani (2012) make use of a **social ecological context** to examine perceptions about autism held by parents and how this information can be used to enhance care. The researchers found that examining the social and physical environment was important, and caregivers’ self-reported information about perceptions of autism and health could be used by clinicians to deliver treatments and interventions that were encompassing of contexts outside of a clinical space (Hock and Ahmedani, 2012, p. 303).

CHAPTER 3

METHODOLOGY

3.1 Initial Procedures and Observations

Prior to starting the study design and development of the interview questions, The Client required that I complete an intern/volunteer application, a standard drug test and background check before being observing the autism treatment program; these requirements were completed in mid-2015. Once I received notice that the paperwork was cleared, I spent approximately 30 hours observing the autism treatment program and talking with senior-level clinicians.

3.1.1 Ethical Clearance

Permission and ethical clearance for the project was obtained from the Institutional Review Board of the University of North Texas in September 2016. An IRB modification was submitted in April 2016 to include the expansion of the participant pool to The Client's additional centers as well as the greater North Texas community. Due to the subject of the study and sensitivity of the subject matter, any identifying information about The Client and study participants was masked and pseudonyms were used. Interview and focus group participants were provided with an informed consent form; the researcher walked each participant through the document, explaining the study procedures, potential risks and how the information would be used. Each participant was provided with a copy of their signed informed consent form and the researcher made special note of the contact information section in the case the participant had questions or concerns about their involvement in the study. A requirement for participation in the study included being 18 years or older and a caregiver for a child currently receiving services at one of The Client's autism treatment centers. No children were interviewed during the study, and this decision was reached during discussion with the site sponsor, thesis committee head and the researcher. All three parties believed that the inclusion of children interviews would lead to complex issues with obtaining IRB clearance considering the vulnerability of conducting research with children, particularly children with special needs.

Once the IRB modification was approved, the researcher reached out to a couple support groups in the North Texas area in the hopes meeting to explain the project. I hoped to meet with representatives of autism support groups, explain the project and see if there would opportunities for me to meet with caregivers for recruitment. However, these attempts were unsuccessful and contacted organizations did not respond to meeting requests. I decided to focus my efforts exclusively on recruiting caregiver participants from The Client's two autism treatment centers.

3.2 In-Treatment Participant Observations

Before and during data collection I regularly engaged in participant observation at The Client's autism treatment centers. Participant observation is a tenet of anthropology and a critical tool when conducting ethnographic studies. I observed parent-child interactions during pick-up and drop-off times, employee-child interactions, employee-employee interactions, and employee-parent-child interactions during parent trainings. These observations and being present at the centers allowed me to build rapport and allowed potential participants and employees to connect my project with the center.

3.3 Parent Training Observations

After I completed participant interviews, I reached out to the director of the Client's autism treatment program to see if it would be possible for me to observe parent trainings. These training sessions serve as an opportunity for both caregivers and case managers to go over the child's progress, goal that both parties have, and allowed for the case manager to work with the caregiver on ways to address any behavioral concerns. This is accomplished through discussion and modeling of appropriate reactions by the case manager. These trainings take place either at home or in clinic.

3.4 Caregiver Recruitment

Recruitment and completion of participant interviews took place between March 2017 and July 2017. Participant recruitment involved a combination of methods, and all participants were intercepted in the lobby of the autism treatment centers during pick-up and drop-off times. A main concern of The Client was how potential participants were approached and requested that it be done in a way that was both respectful and not coercive. At the request of The Client, recruitment of participants was completed as such: Firstly, an initial introduction to potential participants was completed. The Client provided every enrolled family with a flier that included a brief description of the study as well as my contact information. During that time, I introduced myself and explained my purpose at the center as well as the focus of my project. I informed the potential participant that I would be around the center in the case they had questions about my project or if they were interested in participating in an interview. I would then provide them with my contact information and an overview of my project.

The next time that I was at the center I would reach out again and see if they were interested in participating in the study. If they showed interest, an interview was scheduled. If the potential participant mentioned that they needed time to think about it or to check with their spouse, I would follow-up the next time we met. If a potential participant did not show interest or stated that they did not want to participate, I did not approach them again.

Eight caregivers of children with ASD were interviewed. Five interviews were completed in person, with one interview taking place at a participant's home; the remaining four in-person interviews took place at on-site at one of the autism treatment centers. Three interviews were completed over the phone at the participant's request. All interviews took place while the caregiver’s child was in session at The Client’s centers. Several participants reported that they often used the time their child was in session to run errands, care for their other children, or rest. The interviews followed a semi-structured format, and lasted between 20 minutes and an hour and 45 minutes. The caregiver interview guide consisted of 31 questions broken up into five content sections: Demographics, Cultural/Initial Experiences with Autism, Experiences with Initial Diagnosis, Experiences with Seeking Care and Experiences with The Client.

3.5 Data Analysis

Interviews were audio recorded using either a handheld voice recorder or a phone-call recording application; the recording method used was dependent on the interview type (in-person or over the phone). The interviews were transcribed using either a traditional transcription method or echo-dictate method.

During the transcription process, the researcher made note of common themes across interviews. Once interview transcription was complete, the transcripts were coded and analyzed using MAXQDA. Grounded theory was used in the coding and analysis of the data and allows for the exploration of themes and data that present themselves during data collection and analysis. Grounded theory also allows for the identification of relevant theory that can be used to better understand social phenomena (Engward 2013).

3.6 Employee Focus Groups

I completed one employee group interview and one employee group focus group at the two autism treatment centers. Employees were asked about the strategies they used when interacting with families from diverse backgrounds and the structural issues that can affect access to care. Employees were informed of the focus groups by the director and were told that they could sign up to participate if interested. The focus group was not a required activity for employees. Focus groups took place on site before or after program hours so that it would not interfere with their caseloads.

CHAPTER 4

RESULTS

4.1 Participant Demographics

In this chapter I discuss the significant themes that arose during my analysis of caregiver interview and employee focus group transcripts. I first discuss caregiver interview results and then end with themes surrounding employee focus groups. Interview and focus group transcripts were coded and analyzed using MAXQDA which is a mixed methods data analysis tool. The narratives provided by participants were a large focus of this project, so quotes from participant interviews are shared in relevant sections. Participant observations were conducted mainly during pick-up and drop-off times so the interactions observed during this time are not necessarily reflective of the interactions caregiver-participants have with the children. I did have the opportunity to observe a parent-training during a clinic session, and that is discussed in the sectioned titled “Experiences with The Client. An overview of caregiver participant demographics is provided below. Pseudonyms were used to mask the identity of participants.

The caregivers that participated in this study were above 18 years old and had at least one child with an ASD diagnosis who was receiving ABA therapy from The Client. 88% (n=7) of participants were female, 4 participants identified as Hispanic, 3 identified as white, and 1 participant identified as Asian. All participants were either married or in a long-term relationship with their partner. Interestingly enough, half of the participants (n= 4) were the caregivers of female children with ASD. This was important to highlight as the prevalence rate of ASD is higher among male children, and past research and interventions were geared towards male children (Lai, 2014, p. 897; Halladay, 2013).

For employment status, the sample group was evenly split, with 4 participants employed outside the home and 4 participants who identified themselves as either unemployed or a stay-at-home parent. All participants (n=8) had more than one child, and for half of the participants (n=4), the child who received ABA therapy from The Client was their last-born child.

During the time of participant recruitment and interviews, there were 34 families who had children receiving services from The Client, including the 8 caregivers I interviewed for the study. The program demographic breakdown was similar to my participant pool, but differed slightly in some areas. 97% (n= 33) of the caregivers who filled out the intake application were female, the ethnic makeups for the families were 23% white (n= 8), 35% Hispanic (n= 12), 9% Asian (n= 3), 12% Black (n= 4), 12% Multiethnic or Multiracial (n= 4), and 9% did not disclose their race or ethnicity (n=3). 85% of caregivers were in long-term relationships or married (n= 29); for employment, 50% of caregivers classified themselves as stay-at-home parents (n=17), while the other 50% worked outside the home on a full-time or part-time basis.

Participant (Caregiver) Pseudonyms	Age	Gender	Ethnicity/Race (Self-reported)	Country of Origin	Marital Status	Employment Status	Number of Children in Home	Birth Order of Child Receiving Services
1. Reese		Female	White	USA	Married	Employed	2	Firstborn
2. Amanda		Female	White	USA	Married	Stay at home parent	3	Second-born
3. Irma		Female	White/Native American	USA	Married	Stay at home parent	3	Lastborn
4. Constance		Female	Hispanic	USA	Long-term Partner	Stay at home parent	2	Firstborn
5. Aanya		Female	Asian	India	Married	Employed on PRN basis	2	Lastborn
6. Elizabeth		Female	Hispanic	USA	Married	Stay at home parent	3	Firstborn (biological)
7. Robert		Male	Hispanic	USA	Married	Employed	2	Lastborn
8. Nora		Female	Hispanic	Mexico	Married	Employed	2	Lastborn

Table 1: Caregiver Participant Demographic

4.2 Caregiver Interview Themes

While the experiences of each family were unique as they navigated care, and learned to manage their child's diagnosis, there were major themes that arose across the interviews during the transcription and coding process. Major themes included understanding of autism, prior experience with autism and disability, cultural influences, experiences with family, parenting methods, effects on the family, experiences with providers, insurance, experiences with the school system, and experiences with the client. Within these themes, there were related sub-themes that provided an in-depth and more textured glimpse into caregivers' experiences with ASD. Sub-themes are discussed more under their respective theme.

4.3 Understanding of Autism

The first major theme was caregivers' understandings of autism; this theme encompassed how caregivers understood autism before and after their child's diagnosis' a relevant sub-theme includes prior experiences with autism and disability. Prior to having a child with an autism diagnosis, a few participants mentioned that they were not aware of what autism was or how it presented in people. Other participants mentioned that they were aware of autism prior to their child's diagnosis and cited reasons included educational, professional and personal experiences. Caregivers' experiences in the time leading up to seeking out autism screening was a major theme; sub-themes related to understandings of autism include cultural experiences, parenting methods and experiences with family. Caregivers were asked to discuss their understanding of their child's ASD diagnosis and what led them to seek out screening for autism. Caregivers discussed their child's symptoms from both a biomedical perspective and one that was representative of their experiences and what they observed. Almost all caregivers reported missed developmental milestones or regression in speech and social skills as "red flags" that caused concern. The order in which initial experiences with autism was told was similar across participants. It was often done sequentially starting with the participant describing how their child acted during infancy to toddlerhood and then when they first started to notice behavior they found concerning or would describe as “red flags”.

> She started talking by one and then she fully stopped and then it was like a little regression for talking. So, we saw that after one her words started going down and not increasing. By one and a half she stopped talking completely. No words. And then we were so concerned about it we took her to the physician for her 1-and-a-half-year appointment and by that time we were referred for an Autism assessment and started from there. (Aayna, caregiver)

> So, when I saw her start – she was 2 years old and she started doing like regression – I don't know what the word is. She was talking, everything was good when she was born and from when she was born to the age almost 2 years... but I don't know what happened she stop talking, she start crying a lot, she's waking up at midnight, something like that; she start put all her toys like in a line and I thought "I think something is wrong because why she doing that? (Nora, caregiver)

> Reading up on both sides of that I found that there are often early warning signs of autism that parents miss. It just becomes more noticeable at the 18-month mark so I was very aware of the early warning signs. And at 7 months I started to notice he wasn’t pointing and stuff like that – things that he should have been doing. And when he was 12 months he wasn’t waving hi and bye and people just kind of dismissed me like “he’s just going to grow out of it” or “you’re reading too much into this”. And everyone except for the pediatrician and my husband and… with my son it was always – there was enough to be concerning but it was not severe enough to say that he couldn’t grow out of it. It was kind of that range until he was 4. But really just a lot of those people telling me that I was just overreacting to things and… (Reese, caregiver)

4.3.1 Prior Experience with Autism and Disability

For one caregiver, her own autism diagnosis and working with children on the spectrum during her teenage and college years helped her identify with and understand the issues her son would face.

> When I was 13 I was trained to babysit children with disabilities by Camp Fire and one of the kids I started to babysit had autistic tendencies. When I was researching what autism was, I was going “this sounds a lot like me,” and well my mom goes “you were diagnosed with autistic tendencies.” (Reese, caregiver)

Prior experience with autism or a disability was a factor that affected participants’ understanding of autism. Participants shared how prior experiences with disability helped them better contextualize and identify the issues that their children faced. Irma reflected on how her own mother's struggles with her sister's disability helped her approach her daughter's diagnosis:

> Well, in my family I didn't really know some things... I knew my sister had – I though she just had seizures when she was younger, but – and dyslexia, she had a lot of developmental things going on and I know it was a real struggle for her whenever she was younger, elementary school age. I mean now you wouldn't be able to know, but talking with my mom that kinda helped me have some more hope because at one time they told my sister she'll probably never be able to live on her own, she won't be able to cross the street by herself, you know all these terrible things that they tell you that they don't really know. And she's married and she's got three kids and she's happy, but a lot of the things she went through when she was younger – bad teachers or whatever – they really had a bad impact on her, you know? On her confidence, especially. But I think just knowing that there are others that have had the similar diagnosis and how much progress they have made, that was something that gave me a lot of hope. (Irma, Caregiver)

Birth order also influenced how a caregiver reacted to red flags or noticed peculiarities. In instances where the child with ASD was not the firstborn child, caregivers compared the child to older siblings or other family members who were in the same age range. Participants who had prior experience with children mentioned how they noticed differences or similarities between their other children's development and the development of their child with ASD. Oftentimes the experiences that participants went through with their older children helped them better navigate the healthcare system, the school system and in identifying developmental delays.

> She's the second born. So, the first one we had we always compared the things that she wasn't doing with my oldest daughter. (Robert, caregiver)
>
> The oldest wasn't "normal" either. I hate using the word normal, but she was a preemie, she had severe medical issues as a young child: globally developmentally delayed; she was our crash course into speech/Occupational [therapy]. She didn't talk until she was over 3, and when she started talking she was hyperlexive. She could read, write and do math. It was one of those like "so, genius child, are you graduating from college at 10 (laughs)?" She was in speech/occupational therapy and physical therapy till 5. So, she was kind of our crash course into the therapy world. She was actually the one where we still look back and go "I don't know how you avoided an autism diagnosis". She was my one who would sit, stare at the wall and flap. (Amanda, caregiver)

Constance was a young first-time mother when she noticed concerning behavior from her son:

> Since he was my firstborn – I was turning 19 years old and when he was born I felt like everything was fine. The first thing that came in my head was, well I was thankful – he's perfect! He looks perfect. So then once he was a year old I noticed somethings were odd but I didn't pay too much mind to them because we're not – I'm not really that social so the only reason why I started like noticing something was wrong, something wasn't right was because he has cousins around the same age. So, I noticed the development and I noticed my son. At a year I started noticing his sleeping patterns. There would be times he would stay up late at night, he wouldn't really play with his toys correctly and then there was like certain behaviors. He would always so giggly and I was like he's just a happy baby, he's just a happy baby.

While Irma's had 3 children and her youngest is the only one with an ASD diagnosis

> I thought that might just be my daughter's temperament at first. Maybe she's just not much of a talker because a lot of people in my family – I didn't know it but my grandpa, my mom said he didn't even talk until he was about 5. And I was like really? She said, “Yeah, he was very introverted and he was very late speaking. Maybe she's just like he is."

For many of the caregivers, their child’s diagnosis was their first introduction to autism and disability in general. This was often true for their immediate and extended families as well, leaving caregivers without support and a clear guide on how to help their child while still filling professional and personal obligations. Caregivers who were parents before having a child with ASD were placed in situations where they had to learn new ways of connecting with their child and adapt the way they cared for their other children to prevent feelings of animosity or jealousy. First- time parents went through a slightly different journey as they based their parenting methods on what they observed from family and friends, and had to create a parenting method that was based on best addressing the needs and behaviors or their child with ASD. For all caregivers, the journey is marked by discovery as they learn more about their child, their child’s diagnosis and ways to approach it. Participants often talked about taking everything day-by-day and how everything they did revolved around how their child was feeling in that moment.

4.4 Cultural Influences

Caregivers described how their cultural background and upbringing influenced their understandings or autism, their parenting methods and how they adapted them to better serve their children. Culture was defined by caregivers as habits or behaviors they learned during childhood, traditions or expectations they observed among their ethnic group or family, and customs they engaged in during their day-to-day lives. Several participants mentioned how their child’s autism diagnosis was a “first” for both their immediate and extended families:

> Yeah, no one has anything like this; It's never been a family issue before. So, if we ever had a family member who had an issue like this, things will come up but everyone else is okay this is the first one in the family having autism. it never came up in the family before. (Aayna, caregiver)
>
> We never had any experience is autism. Yes, we never thought something like this would happen. I realized there was a movie in the 80s called Rain Man – okay so I was talking with my wife the other day and I said “since that time they knew about autism, they knew”. I saw the movie but I didn't pay attention to it; I didn't know what it was. So, before my daughter we didn't have any idea what it was even in the family, both families– my wife’s, myself… we didn’t have anybody who had it any problems so that that's why. We have people that are a little bit slower than some others or they have behavior problems but never that nonverbal and stuff like that. Our daughter was the first one and that's the thing that we knew. (Robert, caregiver)
>
> I didn’t know what autism was, you know? Everyone close to me, no one had autism. The friends that I had – I just never never heard of autism before so I didn’t know about it so I wasn’t aware of what the flags were. So, I noticed that, that he would stack up toys and he would be climbing and really active, jumping. He couldn’t, I guess contain – giggly and you just – it looked like he was somewhere else. I would talk to him but it would be really hard for me to get his attention. (Constance, caregiver)

4.5 Experiences with Family

For some participants, their child’s autism diagnosis was their immediate and extended families' first experience with autism or disability in general. Participants dealt with varying levels of support, with some participants describing full unwavering support from family members and others describing both disbelief and denial.

> I think just the way my family is in general – I’m the fifth of six kids and you know my dad – there’s six kids in his family. We have a really large extended family and just growing up, the way that we were, if someone was struggling with something we would all just come together and we would include and we would bring them you know, help them to do stuff. Especially all the women in my family; I was really blessed in that aspect of my life, you know to have someone say “You know you’re going to be okay. She’s going to be okay. We’ll all help. We’ll pray together. Let me teach you what I did." So I think, absolutely in my background I had that, but I may not have been able to recognize it as a cultural thing. (Irma, caregiver)

> My husband pretty much… “You’re the one with the psychology degree, so I’ll defer to you” and I think he was concerned by some of the things he was seeing; he was concerned that our son wasn’t talking and stuff like that… uh (loud sigh) … my husband’s family … his mother immigrated from the Philippines and she does not believe autism is a real thing. She still does not believe our son is autistic. And there’s a divide with the people who immigrated from the Philippines thinking that this isn’t a real thing versus his sister and cousins [the husband’s] who have been supportive; (laughs) even though it’s only been recently that they’ve acknowledged that he’s autistic. (Reese, caregiver)

Regardless of the level of support provided by family, participants still spoke of the isolation that they faced after their child was diagnosed. Participants mentioned feeling the need to withdraw from the public or friends and family who did not understand their child’s diagnosis and the behaviors associated with it. Participants discussed the fears they had of being judged or classified as a poor parent if their child engaged in what may be considered socially unacceptable behavior Participants revealed how they often tailored their day-to-day activities around their child’s comfortability in a situation. For example, if their child was easily overwhelmed by the commotion and busyness often associated with grocery stores, they would either avoid putting their child in those spaces or adjust the time spent in the store:

> More than anything, social. It affects socially. When you go to places – it all depends on him. If he feels comfortable – he’s nonverbal so I can tell by his behavior if he’s comfortable or not as comfortable. If he’s not, it’s just time to go. Grab something quick, let’s go. So yeah, it’s social. (Constance, caregiver)
>
> You don't go outside as much as we used to because the baby screams more. We try to select which places are better for our kid and which is not. And you have to be behind your kid more. (Aayna, caregiver)
>
> I'm a very very friendly person. My wife is also and my daughter, she has lot of friends. So, just to realize the little one can't play the same way like the other ones it hurts big time. Social relationships are harder because you can't go to places with her and like we used to do with her older sister or some other kids so that's the hardest thing to do. (Robert, caregiver)

Participants spoke candidly about personal effects of their child’s diagnosis on their physical and mental health, and shared that they went through a grieving process when they first learned of their child’s diagnosis. Participants used a variety of methods to get through that time including seeking out the support of friends and family, participating in therapy and trying to learn more about their child’s diagnosis to prepare themselves and their family for the future.

> Sad. I mean I went to a therapist after he was diagnosed because I was traumatized. It's just – is he going to get better? And that's what I tried to focus on, on him getting better. And my husband is like “No he's not going to get better. He's going to be with us the rest of his our lives.” And you know, that was his point of view and my point of view was trying to get him therapy to get him better to outgrow it or whatever. And now that he's going to be 10 – last year was really hard because he's not getting better – I mean he repeats things now, he can say somethings but he doesn't seem like he's going to get better like I thought he would get better. (Elizabeth, caregiver)

Even with the use of these coping methods, participants still found themselves constantly worrying about what the future held. Participants worried about finances, their child's health, their health and how care would be arranged for their child once they were no longer living. Several participants shared their fears of their children facing harm or abuse and not being there to protect them. Participant's concerns were valid as people with disabilities are at increased risk of experiencing different types of abuse (Mandell, Walrath, Maneteuffel, Sgro, and Pinto-Martin 2005):

> You can start thinking that you have an idea of what autism is and what it looks like, but until it's in your family you don't really get an understanding of how much she needs the different help or how you relate to her because you really take for granted things that – my other kids, you know they had a lot of verbal skills at a young age. And my daughter, she did and then hers kinda went away and then now she's starting to come back and talk more, but that's the biggest challenge I think. Having your child, and you're wondering what is she thinking, what does she need, is she hurting and to me the autism diagnosis… I don't know it made me kind of sad for her because – it made me sad and scared thinking, what is this world going to be like for her, you know? Who's going to keep her safe? [starts to cry] (Irma, caregiver)

Many caregivers expressed concerns about what the future held and the unknowns for their child in both the present and future. Caregivers had questions about if they were doing things right, whether they were the cause of their child's illness and if their child would ever get better.

> I had questions: what to do, where to go, who to ask. What's going on with her? Was it my fault? Was it my wife's fault? Was it something that we didn't do? I don't know. So many things. (Robert, caregiver)

For some parents, extended family not only assisted with childcare, but they were instrumental in noticing delays that the immediate family had missed.

> ... she [child's grandmother] was the first one to say – to mention it to us. She said, "Hey, your daughter has a bit of problems because when you talk to her, when you call her by name, by the age of 2 or 1 and 1/2 she should be able to - every time you say her name to turn around. Even though she doesn't listen or pay attention at least when you call her by name she should turn around." She didn't do that. We did it, we call her she still didn't respond. Once again, we always thought she was just a little bit – she was the type of kid where she doesn't like to talk or to be with other people. So, we thought it was her personality or whatever. So, that was the first touch that we had with that and my mom was the one to realize that. Once again, we didn't have any idea what autism was. (Robert, caregiver)

4.6 Parenting Methods

Cultural experiences with autism were closely linked to familial interactions which influenced parenting methods. For some caregivers, certain methods that worked with siblings were not effective when parenting their child with ASD. At times, new or adapted parenting methods were at odds with how they were raised or the expectation of other family members. One participant, Constance, described how she grappled with parenting method suggestions from family that were not in line with how she parented her child:

> I would say like – not normal but you know how parents are like the kid – if the kid doesn't want to listen don't – it's not even cultural now that I'm thinking about it. Don't let him have like free-time if he doesn't cooperate with what you asked him to. Don't let him play with his iPad or toys until he listens and things like that. Or he has to sitting down or things like that. You know it's just so hard because even until now when we go visit family, especially grandma, um they see everything wrong. And okay you don't understand. You don't understand. I can't do that with my son, he is not going to cooperate and it's not going to turn out good if I do that. I can't do it, you know? (Constance, caregiver)

Participants discussed this struggle over parenting methods, especially in family units where their child was the first in the family to have an autism diagnosis. Participants were often tasked with balancing what they believed was best for their child, all while also trying to fulfill familial or cultural expectations of appropriate child behavior.

> My husband is not Hispanic; my husband is just White and I mean at first when we wanted him to do something when he was like little – I was always used to like you know you spank them on the bottom or whatever. He didn't care but it was like he would still do it even if he got hit. he just hits himself more or if somebody pushes him he's pushing himself into the wall or whatever so we don't spank. (Elizabeth, caregiver)
>
> I have very little to do with the biological dad. He's in Houston and we haven't seen him in 4 years. We have very little to do with him because he's even made the comment "If you leave me alone with your son, I'll straighten him out." And I'm like "Yeah, you're not touching my kid." Because you can't beat this [autism] out of him. (Amanda, caregiver)

4.7 Effects on the Family

Flexibility was often required from the entire family, and participants balanced the needs of their other children around the needs of their child with an ASD diagnosis. At times, this also meant siblings were not able to enroll in extracurricular activities due to conflicting schedules as their sibling's therapy needs took priority:

> He can't do sports or after school activities because we have to get his brother to therapy. (Elizabeth, caregiver)
>
> People sometimes they don't understand what it is having a child with autism when she's screaming and yelling or something like that. We go to the parties, don't get me wrong, those other people know that she has a little problem, but when I'm talking they don't know how to react. So, we go to a party and there's loud music we stay for 5-10 minutes because she can't tolerate the things even though her sister likes to be there of course we can't stay. We try… (Robert, caregiver)

Participants talked about ensuring their other children did not feel undervalued or ignored while they worked to help their child with ASD:

> You try to make her understand how she should react to her baby sister. How to get her involved so that she can ask questions about why she's [baby sister] different. Like why doesn't she play with me like other kids. You have to teach and explain her the reasons and explain how you have to get her into your play. She won't come by herself. And then divide: how to share and give out. This is for her, that is for you. Nothing hard but bigger ones learn how to go with it. (Aayna, caregiver)
>
> It helps – we just try to understand older sister about the needs that she has because we try not to make them see a difference. Why? Because sometimes she feels like we pay more attention to her sister because the problem that she has. As I'm talking to her we try to keep her all the attention to her [older sister]. We see sometimes a little bit of anger or hurt, not because she doesn't love her sister it's because she feels like “why she can get away with things” and “you don't let me get away with things.” So, even though the response try to be the same, of course the punishment is different because we know older sister can understand it a little bit better than her sister. But it changes our approach, but we always – but then I came from a very loving family so we've always been about kisses and hugs and stuff like that so it has hasn't really changed in a way. We love both of them the same way. Always will. (Robert, caregiver)

Long distance travel oftentimes meant that participants would need to stay on site or nearby while their child was in clinic. Participants talked of having to adjust the schedule of the entire family to ensure that their child was on-time to receive therapy. Participants highlighted how the need for flexibility in their schedules also prevented them from being able to hold down a traditional full-time job, with participants often having to either work part-time or stay home with the child. 50% of participants classified themselves as stay at home parents, while the other 50% discussed working part-time or unconventional schedules that allowed them to take their child to therapy, doctors’ appointments, or deal with issues at school on short notice:

> I feel like I can't work or I can't work full time. I worked part-time because I need to work to help support the family but I have to be available to go to the school anytime. If I get called 10 times a year that he’s having an allergic reaction and we don't know what it is because he can't tell us or we don't know what he did because we didn't see and he can't tell you what happened or he got hurt and he can't talk or he can't talk enough now that he actually started… and before we

> came to The Client we would go to the Hope Center twice a week and I had to be able to get him out of school early to bring him to therapy and then we would be going to Speech, we'd have to go to OT, doctor's appointments – when he goes to the dentist and needs a filling it's a hospital visit to put him in outpatient surgery, to do his eyes it’s outpatient surgery so they can put him to sleep and check his eyes, and he's just been to the hospital for different things. I can't imagine what a babysitter would cost because nobody watches him but me. (Elizabeth, caregiver)

4.8 Experiences with Providers

Experiences with providers was another significant theme and point of stress for participants. This theme was ever changing and growing for participants as it was not an event or something concrete such as receiving a diagnosis. Participants discussed the issues they faced when seeking out initial diagnostic and screening services and treatment once they had an official diagnosis. The experiences with providers theme broadly includes situations that describe how families seek out and use care; within this theme there are two relevant sub-themes which include delays to diagnosis and delays to treatment.

4.8.1 Delays to Diagnosis

A major complaint from participants was the amount of time it took just for them to be seen once they spoke to their pediatrician about their concerns. The start for many participants’ journeys to receive screening services began in their child’s pediatrician office, and then branched off to either specialized medical offices or organizations that were geared towards autism screening. This first step was similar for several participants as their pediatrician was their first stop in seeking out help for their child. Participants discussed what happened after this first step, and experiences varied among participants; some did not receive received a comprehensive list of screening service providers, and others were tasked with researching and securing screening alone.

> It could have been a little bit earlier, it should be earlier. Even though the doctors – they saw her before every six months, you know going to check up on her. So, we are not experts but we could have done a little bit more at the beginning and the doctor should be able to identify whatever it was before we went in for the time – when that time when we went to the child study center and we started doing all the paperwork and stuff like that to get a response it takes a little while because you don't know what time you don't have any information to see what you're looking for. (Robert, caregiver)

At times participants felt as though they were not taken seriously in their concerns, given false hope or misled in their experiences seeking out screening for their children. Several participants discussed how they brought their concerns to the pediatrician, or other healthcare providers, only to have them brushed off:

> He was speech delayed and we sought out ECI and wanted the speech and OT therapy. And I think the thing that… I was concerned about speech delays but there's a lot of things that can cause speech delay, but I was more concerned that he wasn't waving. I was more concerned that he wasn't clapping. He wasn't pointing. Those are more of the worrisome early autism symptoms and people would just tell me "Oh he's going to speak any day soon." And it's like okay, but what about the waving, the clapping, and everything else? (Reese, caregiver)

Seeking out screening services was challenging for participants and some encountered roadblocks along the way. One participant described how she encountered paywalls at each step while working with a highly-recommended diagnostic pediatrician. The office had a tiered system where clients had to spend more and more money as they moved through the diagnostic process. The participant described a situation that arose when the pediatrician’s office wanted her family to pay a large fee to receive their child’s diagnostic results:

> Well, there were delays because a lot of the doctors said “Well, we can’t see anybody for six months or three months” and then the one doctor that we could get into, even though we had recommendations, he had a weird system and you had to go through 3 appointments, pay this up front and finally on the 3rd appointment you get to speak with a doctor. And it just seemed like – this isn’t real, this is a racket! The negative experience we had, you know – at first, we were trying to get the report: “Can you just give us the report? No, you have to agree to come back in again and pay this other office fee for $400." And my husband showed up and was like “look, just give me the report or I’m going to be making some calls to the people I know at Children’s. And I’m going to be telling some people what happened. Our story and this is going to come to light.” And then they were like “No we won’t, I’m going to call the police on you!” It’s so crazy! All we wanted to do was get my child’s diagnosis sheet and then finally we got it all worked out but it was really kind of discouraging and most people don’t have that experience but we did. (Irma, caregiver)

Participants largely described their initial experiences while trying to access care for their child as negative and stressful. Reasons for stress included being unaware of how to seek out services, being unsure of where to go to first or what questions to ask, or feeling alone during the process. Prior to receiving an autism diagnosis, participants discussed receiving treatment to address some their child’s delays; these therapy options as including occupational or speech therapy. In hindsight, participants did not believe these pre-diagnosis therapies were as effective they could have been and for some participants, they described them as lost or wasted time:

> We followed whatever the child study center told us; one of the doctors was really good about giving us guidance about where to go, what is the next step – like I said we did the check, we went to do the brain MRI – in school they tell us – we waste a little time doing the OT and the speech therapy because it was just 30 minutes so by the time she went from the floor to learn anything that's already been 15 minutes. So, she was doing it for 5 minutes and then after that she's got to go home. So, the time was so limited that she didn't learn nothing and we did it for about a year-and-a-half. Those two things, we thought were only things that

> would help her. Once again, we tried to reach ABA but we never qualified for it so we didn't know what else to do we thought we were doing enough. It wasn't it, wasn't enough to me to be honest. One of the things that I kicked myself about is we shouldn't have push them about it, but at the thing is they didn't tell us any different. Nobody explained to us “You can do this, or you can go and try this one.” Nobody told us that so we’re doing whatever we were doing thinking it was enough, but it wasn't enough.

They acknowledged that the therapies were important, but believed that the therapies would have been more effective when combined with an autism-centered treatment such as ABA therapy. One participant described how her child received what she believed to be ineffective services and providers who were unsure or unwilling to work with her child:

> we were doing ECI and they tried OT but the OT was like “He won't cooperate, he won't do anything we ask of him." You know, as a two-year-old he wouldn't participate at all. He would just kind of sit and stare and twist his fingers and twist his toes. And so, OT stopped coming because if he didn't cooperate with them, they couldn't do anything. And so, he didn't have OT. And nobody told me autism. (Elizabeth, caregiver)

4.8.2 Delays to Treatment

Once an official diagnosis was secured, participants were then tasked with finding treatment options that were not only affordable, but also worked for their child and their needs. The experiences of participants varied depending on which center or area they were located. Participants talked about traveling long distances from their home city to access services. One mother mentioned that while there were providers who offered speech and occupational therapy in her home city, ABA providers were in short supply. Additionally, she originally received services through of the Client’s South Dallas center, but its closure required her to travel an even further distance to the North Dallas site so her child would not experience a lapse in services. However, while she could prevent a lapse, she believed she would eventually have to stop bring her child since the traveling from her home to the center was difficult:

> It will be it will most likely be like the last year with him being with The Client because the South Dallas location is closed and we live all the way in Mesquite. And Mesquite and Carrollton it's like far away, you know? (Constance, caregiver)

Participants talked about time delays, and participants from the Fort Worth location mentioned issues with finding organizations that provided treatment services, specifically ones that specialized in ABA or accepted their health insurance. Participants spoke about placing their names on several waitlists for different organizations and then waiting for a spot to open. The time spent waiting for a spot to open varied among the organizations participants reached out to, but this wait time was anywhere from 6 months to a year for spots. Troublesome issues that participants also encountered with organizations included unclear instructions on how to apply for admission or funding or no follow up on their applications once their application was submitted.

> I also tried another organization but they just blew me off completely. Like I filled out all the paperwork and I tried to call to check-up what’s going on, but I just never really heard a callback or anything. (Constance, caregiver)

Another largely cited issue that affected access to care dealt with finding organizations that accepted participants’ health insurance.

Participants stayed proactive during these wait times and either continued with the therapies that their children were already receiving or created their own activities to bridge the gap. One participant explained how she filled the time between when her child was first diagnosed and finally received services through The Client:

> Because of the health profession [she is a nurse], I knew what I had to do and how long I have to wait for something. It kept me balanced and the family balanced. We knew what was going to happen, you know? It's something you can treat and then something – and while we were waiting for a spot for therapy I would play with her using educational toys, educational-type games and talk to her and make her do things and all that. (Aayna, caregiver)

Experiences with providers at all stages of autism care was a significant theme across participants. For participants, these experiences could be classified as either positive or negative, and often served as lessons learned. A common complaint among participants was the lack of help or reassurance in their early interactions with pediatricians or autism diagnosticians. Some participants felt as though not enough was done during regular check-ups to screen for "red flags" or that their concerns were not taken seriously.

> I remember I went to his pediatrician one day at that time and I was like, "I noticed that – something's not right with my son's development. Something's not right. I was wondering if you could evaluate him." And then he's like, "What does he do?" and I'm like 1. He doesn't want to talk anymore really, and his vocabulary is not advancing like it should. 2. His behavior is kind of like different than other kids around his age. And he was like, "Well he just" – the doctor just brushed it off. He was like, "Well he is a boy; sometimes boys take longer to talk." And then he was like "How about we give until he turns 3-years-old." And at the time he was like 18-months. I think he was about to turn 2. And he was like how about we give it about another year until he turns 3. I know that he mentioned when he was 3 years old. I felt like unsatisfied. I was still like stubborn. No, I am not going to wait until he is 3. What is something is not right and I'm waiting all this time? And you know it's like time wasting. And I felt that rush. I don't know why, I just felt like that. So, desperate. (Constance, caregiver)

Participants expressed urgency in their need to find out what issues their child faced and secure appropriate treatment. While participants felt a sense of urgency, this feeling was not shared by every health provider they encountered. For participants, the experience of dealing with their child’s needs and issues was new and unknown territory that they were not sure how they needed to approach the dilemma.

Additionally, participants voiced concerns about how they were perceived by health providers depending on their timing of seeking out screening or care, or depending on how delayed their child was.

> when I first took him to ECI (Early Childhood Intervention) to be assessed, the diagnosticians at ECI saw what I saw. The speech therapist… I think they thought I was the worst mother ever because he wouldn’t speak. But the diagnosticians saw what I saw… but when we tried to explain what we were and weren’t seeing she was trying to explain away… Like eating food weird because that’s how he saw the dog eat and stuff like that. She just took such personal offense that he wasn’t where he should be developmentally. (Reese, caregiver)

Participants discussed how negative experiences with providers affected their access to resources. Participants were less likely to return to a provider that they had negative experiences with and cited several reasons. Participants did not feel comfortable complaining or raising concerns with the care providers their child out of fear that they would receive backlash or substandard care. Situations like this limit the pool of providers that a family can rely on, reducing their access.

> I feel like if I was ever to complain, I feel like afraid I won’t get treated the same. It won’t be taken too serious because like I feel like - what about his emotions interfering? So, like that’s why I try to avoid it and just switch instead of arguing about it. I don’t know, that’s just the way I usually react to things that I notice. (Constance, Caregiver)

Instead, participants decided that it would be best to seek out a new provider and start over. Doing such things also empowered participants to advocate on behalf of their children. One participant spoke on how she had no problem sacking providers if they did not mesh well with her child:

> We fired the pediatrician after multiple, multiple negative experiences. We were done. It wasn’t working and it was one of those “Wow this is just not working and I’m not going to torment my kid or myself to do this every time. It’s not worth it." (Amanda, Caregiver)

Tough and uncomfortable decisions such as the one above were commonplace and always done with the best interests of their child in mind. Participants rationalized that it would be better to recognize that a provider was not working out early on and then continue the relationship out of fear of offending the provider. Participants acknowledged that time were of extreme importance when it came to their child receiving treatment and prioritized that.

> I saw my mom fight and fight and fight for me with the school growing up and it just seemed to earn her a lot of frustration; and she ended having to do a lot of it on her own. My whole thing is I’m not gonna spend a lot of time trying to convince someone who has a different worldview that this is what’s going on and that this is what he needs. What I’m going to do is take him away from that person and find someone who sees what I do and is going to work with me and find someone who’s on the same page. (Reese, caregiver)

As stated previously, participants experienced both positive and negative interactions while dealing with providers and noted that both were instrumental in the current care options they selected for their child. Through these interactions, participants could identify people, organizations or treatment methods that worked in addressing their child’s needs. Participants found what worked for them, but acknowledged that just because they did not find an organization or treatment method helpful, did not mean it was not a resource for other families. One participant talked about how the needs of every child were different, and while one organization was not able to help his daughter, it still was useful to others. The participant provided a critical look at the motivations behind organizations and concluded that at the end, the priority should be the children:

> Even with the therapist, ABA sometimes, we have to work for the kids! It's not a competition “Oh I'm this organization” or “I'm...” – well we know some other places but anyways it shouldn't be a competition. It should be “Okay let's work together to get our kids the best that they can get.” Sometimes it's more business. (Robert, caregiver)

4.8.3 Insurance

Participants often spoke about funding their child’s therapy and the issues they encountered. Several participants talked about the issues they encountered while trying to find coverage for ABA therapy. Insurance was a tricky issue, and participants found that while an insurance provider would provide coverage for one type of therapy, it did not mean that it would cover another. Additionally, participants often ran into issue where their insurance provider supported difference kinds of therapy (i.e. occupational, speech and ABA), but did not always authorize payment for therapies from the same organization. So, for example, an organization could offer occupational, speech and ABA therapy, but only authorize payments for one or two therapy options. This forced parents to either travel between different therapy organizations, or prioritize their child’s therapy needs and pick what they believed was pertinent or waiting until they qualified for the services at an organization that was convenient:

> We’ve got the ABA, but the occupational and physical and speech therapy that she would need – they don’t approve it for here so we would have to take her all the way to Parkland. So, now we’re going to try find if we can get it through the school district. (Irma, caregiver)

> I'm trying to get insurance to pay for the therapy – outside therapy – which my husband works for Aetna, which did not cover it at the time or they said it was on

> a case-by-case basis. But basically, they wouldn't pay for it. They would just case-by-case tell you "No." But they did pay for speech therapy so we were doing that at Cook Children's. (Elizabeth, caregiver)

Dealing with insurance companies to find out what was covered and where was a very large part of participants' search process and was an ever-present issue as family and job situations changed. Help navigating insurance policies was cited as an important tool that participants wish they had or had taught themselves. One participant stated that once she received a diagnosis for her child, her first step was calling her insurance company to see where they could go and what would be covered. The Client was an organization covered by her insurance, but she still sat on a waitlist for 9 months until a spot opened.

> Insurance would have been issue. Otherwise, we could have done it before that to get insurance things and wait for your turn to come and appointment all took three months for each. And even though she got her diagnosis at 2 we could not start therapy until 2 years and 9 months. It took nine months for insurance to make out and then get to go to appointment or to get a position at The Client to start therapy. (Aayna, caregiver)

A few participants stated that they received funding through the DARS grant to receive services from The Client, however this option had stipulations that limited the amount of time a child could receive services under the grant. Participants stated that while using the DARS grant, they were limited to six months "in" program and then six months "out" of program. During these "out" periods, participants searched for other organizations to fill the gap or they waited until they could re-enroll their children. Ideally, participants wished to have their children in services all-year round but were not able to afford the out-of-pocket expense.

> Because she's taking a scholarship, something like that. Like insurance and something help me pay for the therapy and now she needs to take that break for

> six months so she does the therapy 6 months and the break is 6 months. (Nora, caregiver)

4.9 Experiences with the School System

The experiences participants had with school systems was an important thing to consider within the context of accessing care. For some participants, screening through a school district's special education program was their child's first opportunity to be screened for autism or receive an autism diagnosis.

> He's 9, he's about to be 10. He was 2 [when this was going on] because ECI stops at 3. He did ECI for a maybe a year-and-a-half, maybe a year and they were like "okay he's aging out and you have to go to the school for him to give speech". They tried OT again and he wouldn't participate, they gave it a break and they tried OT later. He still wouldn't participate. They wanted him to take things out of rice, he wouldn't touch anything at all. He wouldn't touch anything. He wasn't going to put his hands in some rice and so everybody just kept telling me he's delayed, but that was it. And when we went to get him evaluated to get him speech therapy at the school, that's when they said he definitely needs he has autism, you know, we were doing the autism assessment as well.

Once they had an ASD diagnosis in hand, participants were then able to access treatment options in-school or receive recommendations for outside resources. However, a common criticism from participants dealt with the ineffectiveness of teachers and paraprofessionals when dealing with their child or the extremely limited time available for therapy in-school when factored into the other daily activities the child was expected to participate in. Participants cited teachers' and paraprofessionals' limited understanding of autism or a broad-brush approach to interventions as causes for concern and strife.

Once participant mentioned the issues she was encountering while trying to come to a mutual understanding about the homework load her child was receiving.

> Yup! And he does, and that is why we struggle with homework. His teacher claims he can do the work there in class in 5 minutes but we'll end up here for an hour with him crying and screaming. And I've noticed this with people too. If he sees his old aide that he had, amazing woman – he had her for 2 years, every day at school. If he sees her outside of school, he doesn't know who she is. if he sees her on the campus of school, he doesn't know who she is. She has to go into the teacher's classroom, and then he's excited and peeing himself. We ran into a Speech therapist that he had, she took him from nonverbal to verbal. 4 years. He had no clue who she was. So, he very much compartmentalizes. These people go here; these things go here. (Amanda, caregiver)

Participants with school-aged children also faced the decision of keeping their children in a traditional school setting full time, or pulling them out on either a full-time or part-time basis to receive ABA therapy. One participant explained his reasoning behind pulling his child from school to receive ABA therapy. While his daughter did receive services through the school, they were often truncated and broken up by other classroom tasks.

> We try to do the best for her. That's the main thing, that's the main goal. I mean does she go to school? It's like I said she's 6. So, she'll go to school full time – they tell us "You've got to choose." We can give the ABA treatment that she needs or go to the school. If she's in school she's going to learn a little bit and she's going to be here for an hour, it's up to you. We work with the system, we work with the school… She had to go to the school from 8 to 9, we get out at 9:15, we come over here from 10 to 3 and then we combine everything. And it's working better than what it was; it's not exactly all that we want. We want for her to be able to talk already but it hasn't happened yet. We're working on it. (Robert, caregiver)

For another participant, a fear of her child being labeled as a "problem child" pushed her to search for services geared towards working with children on the spectrum. The interactions that families have with school systems while having children with ASD are important. For some families, the school district is one of the only or the closest diagnostic providers that can be accessed. School districts are also tasked with

> At the time, he had the diagnosis he was in PPCD at the school district… and just so much of that time is a blur. He was getting OT and speech therapy and he really wasn't getting ABA there… and it's just kind of… the situation went from deficient in some areas to bad when they tried to put him in a blended Pre-K classroom and the teacher was supposed to be knowledgeable about special needs but she didn't know anything about autism. And she started… he had difficulties with transitioning and he would sit on the floor when he had difficulties transitioning. And she would label it as defiant behavior… well she didn't label it as defiant behavior. She called him straight up defiant. No, he's being autistic and that's something that people with autism do when they're overwhelmed and stuff. It just got so bad there that I started looking for other places and that's when I found The Client. (Reese, caregiver)

4.10 Experiences with The Client

Participants largely described their experiences with The Client as positive. At the time of the interview each participant had a child who was enrolled and receiving services through The Client's autism treatment program. Participants discovered The Client through different methods including online searches, drive-by and walk-up visits, and through their social networks. For a few participants, The Client was not the first autism treatment program they utilized, so they often drew comparisons between the different organizations. Participants commented on the ease they felt when interacting with The Client, and noted several instances where The Client stepped in and helped them with issues that other organizations could not or refused to assist with.

> He's home! This isn't school and this is what I'm starting to notice a pattern of. He's compartmentalizing things. He's struggling at ABA to get the homework done. She's saying "I don't understand how he's getting this done in 5 minutes like the teacher's claiming because he's struggling." So, two people are saying

> the same thing, and one is saying something else. I’m wondering what’s going on so we’re going to find out on the 19th and case manager is coming. Thank you for the back up because there is no way he’s doing this in 5 minutes. (Amanda, caregiver)

Moments of collaboration between participants and The Client were another thing that participants highlighted as a positive interaction. Parent trainings were cited frequently as an opportunity for the participant and The Client to come together and regroup, reflect and plan for the future. Parent trainings took place either in-clinic or at the home of the caregiver. During these trainings, the case manager checked in with caregivers to see how interventions were going and if the caregiver had any concerns or skills that they would like to work on. Case managers were also able to observe caregiver-child interactions and model appropriate responses to behaviors. Participants stated that parent training allowed them to state concerns that they had in a targeted and intentional environment, and they expressed how it made them feel more confident in their parenting abilities and noted that the trainings helped them when dealing with their other children’s behaviors.

> She is 18 months. They’ve been helpful with her actually. The behaviors have started to be bad so I’ve been using them with her. They’ve been teaching me. They help us when she’s trying to tantrum or anything. Because she is very sassy (laughs)! So, like when she is crying for something that she wants or things like that I try to use those strategies with her like that. And you know, just like speech or whatever. You learn how to take care of them better and showing them things more properly I guess. (Constance, caregiver)

Participants discussed the process of becoming more patient and how this process changed the ways they interacted with their other children. One participant mentioned how caring for a child with autism had made her more understanding and empathetic towards her other children:

> I guess – the whole thing has been tempered with patience and kindness and some of the struggles that she has, I might not understand them so I have to try and get down to where I understand what's going on. It's changed how I talk with the other kids, too. So, I might be more attentive to "So, what's your environment like at school?"What's going on that you're not telling me?" Particularly with my son because he doesn't open up about it. He can have anxiety over a test coming up and not be sleeping, you know? (Constance, caregiver)

Participants discussed ways in which they connected with their child after they received a diagnosis. A common theme involved working with where the child was at and doing activities that the child found to be fun and engaging. A few participants cited different forms of electronic media such as tablets, YouTube videos and games as ways they spent time with their children. Even when participants did not understand the significance of the child's preferred activity, they still made sure to be present and engaged with their child in that moment. A few participants cited outdoor activities, such as hiking or swimming as one of their child's favorite activities and a way they connected. An interesting point was brought up by one participant as she discussed that while her child enjoyed playing in water, she was nervous since she had read new stories about children with autism being attracted to water and drowning. This discussion also highlighted the lack and need of accessible, safe and affordable recreational activities for children with disabilities.

> There's one thing that I would love to send my son for. Swimming classes because I'm just traumatized on so many stories that – I don't know what the percentage is about kids wandering off – kids with autism wandering off. They're attracted to water and most of them have passed away because they find them, you know, drowned. And it's just scary. So, that's one thing that I would like and

> maybe it would help him because he loves water too. He loves water.
> (Constance, caregiver)

4.11 Employee Groups

I conducted one focus group and one group interview with employees from The Client's two autism treatment centers. The goal of the employee focus groups was to learn more about the strategies used when interacting with families from different backgrounds and how these strategies are used to recruit and retain clients. My original plan was to conduct a focus group at each center, but low attendance at a scheduled focus group prevented that. Instead, I have classified that interaction as a group interview since there were only two participants. In total, nine employees participated in the employee-centered activities; all employees that participated were female. Seven employees participated in a focus group, while two employees participated in a group interview. For the focus group, the employees were a mix of five junior employees and administrative staff including one case manager and the director of the autism treatment program. The focus group was made up of a diverse group, and participants self-reported and identified as African American (n= 1), Asian (n= 2), Hispanic (n= 1) and/or white (n= 3). For the group interview, both participants were case managers. The case managers both self-reported and identified as being of South Asian descent.

The role each employee played and their level of interaction with families varied. The director oversaw operations for both centers and was familiar with all the families who had children receiving care from The Client. Case managers were familiar with all families receiving care at their center, and more specifically with the families who were a part of their caseload. Junior staff members worked directly with the children, carrying out treatment plans developed by the case manager. Their interactions with parents were more limited than the other two roles.

The purpose of the focus group and group interview was to learn more about the strategies employees used while interacting with families from diverse backgrounds. The question guide consisted of four questions with several probes that asked participants about how they interacted with families from backgrounds similar or different from their own, their experiences integrating families' culturally relevant practices into care, and the barriers they believed families receiving services from them encountered. The focus group lasted for 36 minutes, while the group interview lasted for 56 minutes.

From the coding and analysis of the focus group and group interview transcripts, several major themes emerged. These themes included: cultural responsiveness, moments of collaboration, and identifying barriers to care. For both the focus group and the group interview, administrative staff talked extensively about the use of "cultural responsiveness" while interacting with clients and developing treatment plans. Cultural responsiveness is based in education, and used in other disciplines, including behavioral health-focused professions. It is defined as a "the ability to learn from and relate respectively with people from your own culture and those from another culture" (Hardman, Drew, and Egan, 2016, p.97). Administrative staff take a family-centered approach when creating treatment plans, and the input from families was considered very important and was encouraged at every step.

4.11.1 Cultural Responsiveness

Administrative staff described working with families from backgrounds different from their own as challenging at times, but rewarding. Oftentimes they were tasked with figuring out ways to include programming that may not be in line with a family's cultural practices or the dynamic of the home. Administrative staff discussed having to navigate everything from play, gender dynamics and the expectations and hopes that the caregivers had for their children. In instances where the caregiver did not agree with the programming or focus of clinical sessions, the case manager worked to find out what the caregiver's wants for their child were, and how they could be integrated into care. Administrative staff highlighted that their interventions were family-centered and planned with the entire family in mind.

> And think with our intake process – and the director and I are the ones who do it. We have an initial interview and talk to them to find out what's important and what matters and what their priorities are. But I think from there that's when I gain the most understanding of what are the priorities and whether or not those are culturally related or not. my tendency is to respect them and say "That's what will do and that's how we will program." Because ideally the family is where the child is going to be for their lives, you know? That's their natural support and so everything that we do in my opinion should be geared to maintaining those skills within a natural support setting. In another context like school or the community settings they have to learn new skills, but that's my usually my initial reaction. (case manager, location one)

> I was recommended to our HRC which is the human rights committee where we bring in cases that we may be struggling with and I was struggling with a family that wasn't really sure how to navigate it cuz there was a lot of history and a lot of other things going on and what was recommended was to kind of have a polite conversation in a positive light of what is helpful on my side that I've done what wasn't and what's helping between the parents and really just focusing on positive aspects and to make it more about the child so that way they can build unity. And it was the most beautiful experience I've ever had and literally right after crying because Mom and Dad saying the sweetest things to each other about how much they love each other, how much they admire how they take care

> of each other's kids. They had never heard that from each other before and suddenly wanted to be more part of the family and mom was more positive about everything and they started going out on more outings and just to see that shift in the family dynamic develop in that kind of relationship that mom was talking about, so that they do feel comfortable talking to you, having those conversations that are child-centered but also family-centered because the child like Mo said isn't alone. They come with their squad. (Case manager, Location 2)

As stated, junior staff had limited interactions with families in comparison to administrative staff who spent more extensive one-on-one time with caregivers during intake, program planning and parent trainings. However junior staff member worked to also include cultural responsiveness into care and paid close attention to the cultural behaviors exhibited by the children they worked with, as well as their families. Employees also worked together to better serve the families they worked with. If an employee was from the same cultural background or familiar with certain cultural habits, they could identify them and serve as a liaison between employees and clients. Employees also stated that families from similar cultural backgrounds felt more comfortable around them and were open to sharing concerns.

> And since I do speak Spanish any parent that knows I speak Spanish they definitely are more relaxed around me. They're like “Oh, how are you” in a very relaxed type of Spanish and they always speak to me in Spanish. Even though they're fluent in English they will talk to me in Spanish. I feel like they're definitely more relaxed once they know that I speak Spanish. (Junior coach, Location 1)

4.11.2 Moments of Collaboration

Additionally, employees viewed their role as one that was not just limited to the facility they worked in. They found that they were also capable of teaching others within the community about autism and connecting them to resources. Employee participants were also from diverse backgrounds, allowing them to empathize with families who were struggling to not only fit into and adapt to a culture different from their own, but also address the needs of their child while balancing duties and expectations from their culture. One employee participant discussed perceptions of autism within her own racial community, and how she could use her professional work as a bridge to build understanding:

> A lot of communication goes through the case manager, I but I would say outside of work I'm learning that a lot of people, my family, a lot of my friends, they comment on some of their own kids, my nieces and nephews it's very confusing. I don't know if it's lack of education and also on a very cultural level. One person that was having issues and concerns about their child and I was able to help. I was like ”Go to this website, look at this literature and we can talk about it. I can tell you some of the things that I encounter.” Being able to educate somebody else so that they can have a network – because it's very hard to come here – the parents here don't talk to each other. It's important to have a little network where they can go back home and can talk to their aunts and uncles and family member. They don't know and people love to tell “You there's nothing wrong with them, they'll just grow out of it.” So, just a whole overhaul about how people learn about it, and should be a big thing for people to know because there are a lot of people that I know that don't know what autism is. So, I talk to family about my other job they're like “Oh so you work with a lot of special kids” and I'm like “No it's not like that.” I have to sit down and let them know this is what I do; they need to find out this I can't just force it down their throat. But it's just easier to learn more about it when it's more known cuz a lot of people don't understand it; what is, what it looks like, or what it doesn't look like and how you can look perfectly normal like everyone else but your brain just works a little differently. (Junior staff, Location 1)

4.11.3 Identifying Barriers to Care

Employees were aware of the barriers that families faced in seeking out care. Common barriers that they observed both in the literature and in practice included: lack of understanding of autism, lack of support, disparities in the availability of services in different areas, how different socioeconomic issues can compound and reduce access to resources. Administrative staff also discussed the differences in available resources between the two centers and their surrounding areas:

> I think and we serve really diverse population across all of our sites but one of the things for me as a director and being able to go between South Dallas in North Dallas and Fort Worth it's really eye-opening to see the differences in the discrepancies and services. So, when I go to the North Dallas Center and a client that comes in my door I can recommend 20 other locations within a 5-mile radius and it's just so dense in terms of resources and access to services for families in that area because it tends to be more affluent area. But if I go to South Dallas other than our Center that was there was Metrocare and that was it. There was only two locations really for them to get a ABA services and not really a whole lot of resources to even educate them on “Oh well go here to get funding for transportation or you can talk to this person or do this.” And then for here, there's a little bit more than there was in South Dallas but really between us and child study center those are kind of locations in downtown. I think that it's just difficult that we’re in this Metroplex and we're all in the same type of network but looking at the discrepancies and where the money is and how many resources are available versus families who in the research are shown to be at high risk to have a child with disabilities there is no resources. (Director, both locations)

Employee participants stressed the need for families to be as prepared as they can be for the future. The idea of future planning was discussed extensively during the North Dallas group interview, and the case managers emphasized that this was a topic they tried to have families think about on a regular basis. If families had questions or concerns, the case managers would then try their best to connect them with relevant resources. My investigation into recruitment and retention practices were limited due to a couple of factors. Firstly, the original intent was to work with an auxiliary program at The Client that was focused on outreach and recruitment to underserved groups. However, by the time I was ready to start my thesis research the program had been put on hold. Secondly, while The Client tries its best to retain clients oftentimes there are factors, usually financial, that prevent some families from continuing services on a regular basis or schedule. In other instances, a child may have needs that are outside the scope of what The Client can provide. In both cases, The Client looks to their links in the community and partner organizations to connect families with resources to avoid lapses in care.

CHAPTER 5

DISCUSSION

5.1 Theoretical Implications

Participants' narratives were a focal point of my research. Through the development of my research questions, I hoped to provide a space were participants could reflect on their journey so far. For many participants, this was their first time having an opportunity to talk about the struggles they faced while caring for a child with autism. Their narratives provided a complex and nuanced view into the experiences of families in the North Texas area. Through these interviews, I hoped to provide The Client with a current view into the lives of their clients. Cultural and personal understandings of autism are an important thing for providers to consider when interacting with clients and developing interventions. Through interviews with participants I learned about the different journeys families took to secure care for their children.

In this section I discuss how my results are supported by the theoretical frameworks and literature discussed in my third chapter, and the recommendations. The theoretical frameworks most relevant during my research included phenomenology, the socioecological model of health, critical medical anthropology and social networking theory. A discussion of the listed theoretical frameworks and how they intersected with my research is provided.

5.1.1 Phenomenology

Svenaeus' (2001) study of phenomenology and health can be used to understand the cultural and personal understandings of autism held by participants. Svenaeus (2001) proposes that health can be explored and conceptualized using phenomenology, as the theory lends credence to the idea that illness and disease is something that is lived through (p. 90). This was present in participants' thinking as they hoped that therapeutic interventions focused on building life skills could help move their children towards management or reduction of symptoms. This is aptly discussed by Svenaeus in the following quote:

> phenomenology provides us with such a language in its focus on lived experience – that is the feelings, thoughts and actions of the individual person living in the world. Such a theory of health will of course be normative, since it will fundamentally rely on the individual's interpretation and evaluation of his situation and not only on a biological investigation of his body. (Svenaeus, 2001, p. 87)

While the focus of my research was on caregivers, their perspectives on their child's diagnosis and subsequent management can still be interpreted using phenomenology. Participants were wholly responsible for their children's care and the ways participants described the health of their child, which was oftentimes within the context of their child's diagnosis, varied. It was oftentimes based on combination of factors including their definition of health, cultural and family norms and what their personal goals for their child involved. Health could be defined as learning skills such as independent toileting, feeding oneself, appropriate social interactions or a reduction in self-injurious or harmful behaviors. For other participants, health may be building the basics of these listed skills and then adapting them again to fit within their cultural context. Participants' discovery of autism through their own child’s diagnosis was a common theme and an important lived experience that influenced the entire family. The experiences of participants before and after their child’s diagnosis are points of learning and discovery, building upon each other and affecting their present health decisions.

A point of my research study was to learn more about the experiences of caregivers as told in their own words and based on their lived experiences. While my study was not purely phenomenological, I did use methods that allowed for open-endedness in both question and answer.

5.1.2 Critical Medical Anthropology

Critical medial anthropology (CMA) is also another useful tool and shed a light on the inherently sociopolitical environment in participants existed and the effects on how they understood autism and sought care for their child. CMA can be used to examine the environment in which participants and their families live. The literature chronicles that disparities in autism screening and treatment and how communities of color, low-income families in low-resource areas are often the hardest hit. Montanez (2016) states that autism can be studied from a CMA perspective as it allows for the examination of health and medicine “as it functions in concordance with political and economic influences” (p. 316). CMA also aids in the identification of culturally relevant explanations of health and illness; this information can be used to better serve families from different backgrounds. CMA aided me as I made connections between the experiences of caregiver-participants to macro-level socioeconomic and sociopolitical issues currently going on in the Dallas-Fort Worth metroplex and the nation. Caregivers identified structural issues that they believed affected their children’s health and their day-to-day lives.

5.1.3 Socioecological Model and Social Networking Theory

Participants exist and navigate an inherently political structural environment where access to care can be limited by a myriad of issues. The consideration of the different levels of the socioecological model of health was present in both my research design and analysis of the results. The socioecological model of health includes five dimensions: intrapersonal, interpersonal, institutional, community, environmental and public policy (Obrusnikova and Miccinello, p. 64, 2012). I discuss four of the five dimensions and how they relate to my research findings. Intrapersonal factors describe both the modifiable and unmodifiable factors that individuals hold that can explain the lack or presence of barriers to health. Intrapersonal modifiable factors include knowledge, beliefs or attitudes that individuals hold, and nonmodifiable factors include things people cannot change such as their race/ethnicity or their age (Obrusnikova and Miccinello, p. 64, 2012).

Within my research, participants cited intrapersonal factors such as a lack of understanding of autism prior to their child’s diagnosis, their perceptions of the disorder and being unsure of the screening and treatment process. Interpersonal factors include “formal and informal social networks and groups” that can influence access to healthcare resources (Obrusnikova and Miccinello, p. 64, 2012). Participants cited social networks and the support they received from family and friends as being instrumental in their journey in seeking out care. Having an established social network provided participants with support in babysitting, dropping children off for therapy sessions and finding resources within the community. Inversely participants who shared that they did not have solid social networks cited issues with securing childcare or support in daily life tasks. Participants were also tasked with taking on the responsibility to find therapy services by themselves.

Community factors include the availability and number of resources in a community that are both accessible and affordable. Several participants discussed having to travel long distances from their hometown, and struggled with finding support groups within their communities that offered childcare that would allow them to attend. Additionally, a few participants discussed the need for sibling support groups that would allow their children to connect with other children who also had siblings with ASD.

Institutional factors can reduce access to care in the form of health providers who are not up-to-date or aware of autism symptoms or screening measures. The CDC and the American Academy of Pediatrics (AAP) recommend that pediatricians screen for autism and other developmental disabilities during wellness check-ups (Facts about ASDs, 2017). However, this is not always the case, leading to families to have to search and seek out specialists on their own. Participants mentioned wishing that their pediatricians had noticed delays or taken their concerns seriously when they expressed them. Institutional barriers also existed within school systems, where teachers and paraprofessionals often must manage classrooms with many other children making it difficult to effectively administer interventions. If children do receive services in school, they are oftentimes curtailed for other school activities.

Political barriers for accessible autism services have steadily increased in the last few years in Texas. As mentioned, legislative changes in 2016 cut Medicaid coverage for ABA therapy, forcing families who relied on the social program to seek out alternative funding measures and providers (Harrington 2016). These cuts led to a reduction in service providers and some non-profit organizations that served low-income families have been forced to seek out other funding measures or close their doors. Several participants shared that they relied on a DARS grant that allowed their child to receive services through The Client six months out of the year. During the six months that they were out of service, participants had little choice but to wait it out until they could re-enroll their child.

Participants need financial support and stable access to autism-related services. Access to care in the Dallas-Fort Worth area varies depending on where a family is located. For families located in low-resources areas accessing care can be difficult. Attending therapy services requires access to stable transportation and hefty time and financial commitments. If the caregiver has other children or must work to support the family, those obligations must be worked around the needs of the child with ASD. When a child is diagnosed with autism, the effects are felt by the entire family. Families need varying kinds of support across the life span. Generally, there is a need for increased awareness of what autism is and the care that is required. This increase in awareness and knowledge is not just for the medical community, but for everyone.

CHAPTER 6

RECOMMENDATIONS AND REFLECTION

6.1 Recommendations

This section details the recommendations that I have developed based on my review of the literature and interviews with both caregivers and employees. Recommendations focus on actions that can be done both at an institutional level and at the state level.

Lack of support was a common issue for participants, and several participants mentioned an interest in having a support group that was exclusive to caregivers whose children received services from The Client. Some participants were aware of, or participated in support groups already, but they expressed a desire to connect further with their peers and wanted the development of sibling services that allowed for their children to connect with children who were going through similar experiences of having a sibling on the spectrum.

One of the most common concerns and causes of worry for caregiver-participants was the issue of finances and funding their child’s therapy needs. If a family does not have health insurance that allows them to access certain kinds of therapies, or are only permitted to access therapy services on a limited schedule, their child does not get the help they need. The answer to this would be to provide more comprehensive services to families with children that have disabilities. Comprehensive services go beyond ABA providers and would require buy-in from primary care physicians, social service-oriented organizations, school districts, the community and society. Comprehensive services could include transportation to and from appointments, readily available respite and daycare providers, health navigators who assist with choosing health providers who accept the family’s insurance or financial support to supplement lost income. Reestablishing Medicaid coverage for ABA treatment in Texas is another important recommendation and would allow existing organizations to better support to vulnerable families and reduce lapses in treatment. The reestablishment of Medicaid coverage and providing additional funding support to family is out of the scope of The Client’s abilities and would need to take place at the local, state and federal Level. There is a high need for financial support of families with children that have ASD and other disabilities and that need should be prioritized at every level of government.

Future planning was identified as an important action for caregivers to do, but it is also something that needs to be considered by policy makers. Future planning can include everything from drafting a living will, researching assisted living facilities to having conversations with family members about what will need to be done when parents pass away and arrangements still need to be made for the child with ASD. Children with ASD will eventually be adults and will require more special behavioral and health interventions. If they are not provided with care in their youth, the issues they face in adulthood will be more complex and require costly interventions. Adults with developmental disabilities are more likely to report having poorer health, little to no social and emotional support and live in poverty (Havercamp, Scandlin and Roth, 2004, p. 421).

There is also need for an increase in knowledge among the general public about what autism is, how it presents itself and how it can be treated. Increasing the understanding of autism will allow for intentional responses in different sectors, including healthcare and the education system. There needs to be standardization in ASD screening among pediatricians and primary care providers who work primarily with children. The American Academy of Pediatrics (AAP) recommends that pediatricians screen for ASD during care visits, but this is not always feasible (CDC). Fenikile et al. (2015) examined physician-identified barriers to autism screening and the most commonly cited issues included a “lack of time, lack of knowledge (training), and lack of funding” (p. 360). Addressing of these issues will not be easy, but governing bodies of pediatric medicine, such as the AAP, can be helpful in the dissemination of screening recommendations and guidelines.

Increased knowledge among parents, caregivers and those who are interested in becoming parents is also important. If these groups are provided with the tools to identify potential red flags, this may lead to a decrease in the average age of screening and diagnosis. Collaboration between caregivers and healthcare providers is important so the facilitation of positive and open dialogue is important.

6.2 Limitations

There were several limitations that occurred during the study that I detail below. My original research design included a caregiver focus group. However, after discussion with my client site and completing a few caregiver interviews I realized that this would not be feasible. The time that caregivers had to spare to sit down for interviews was limited, but could be arranged around the time their child was at The Client and receiving services. A focus group would have been very hard to schedule as

I would have needed to factor in the needs and time constraints of 5 or more people who each had their own priorities and responsibilities. Since it was already quite difficult to schedule individual interviews, I thought it would be best to scrap it. The original goal of the caregiver focus group was to provide a more formal space for caregivers to share their thoughts on autism, learn from one another and possibly brainstorm ways to effectively utilize the resources in the DFW area. However, discussions with my site sponsor and the case managers provided context on why this may not be feasible. Many families that receive services from The Client do not live within the city where the centers are located and may not be able to attend a focus group before, during or after their child's session hours due to work, family or personal obligations.

Another limitation was the recruitment of families from different backgrounds. I hoped to have a sample that was representative of the client pool at the organization. I wish that I had been a bit more strategic in my recruitment process and had started earlier. I lost a lot of time during the observation stage, observing but not really connecting myself with the program so that I could develop rapport with caregivers. Once I started to interact with caregivers and explain my project, recruitment was a little easier. Additionally, I had issues with caregivers agreeing to participate, but not following through with the interview or pulling out at the last minute. During the data collection phase I had a total of four cancellations. Two of these cancellations were from Black caregivers, with one who seemed a bit apprehensive with participating as she was unsure how the information would be used, and if I would expose the personal information of her and her family. This situation was a cause of much reflection and reminded me of articles I had read about disparities in research, fears of exploitation and if my recruitment methods were unclear or appeared forceful.

6.3 Reflection

During my thesis, I experienced numerous personal and professional milestones that limited the amount of time I could dedicate to my project or delayed it all together. Luckily, the support provided by my advisor and client site helped me stay on track to complete the project. This journey has been an emotional one, and I am thankful for every participant that took time from their busy lives to share their stories. This project has ingrained the importance of thinking critically about the sociopolitical environment we live in and how it may affect those who have different experiences from our own. This project has shown me the importance of inclusiveness and advocating for those who may not be able to advocate for themselves. A major motivation and push to finish this project was drawn from the interviews that I had with both caregiver and employees. Participants mentioned that they were excited to read and learn from my research, and even mused that it may be of help to other parents on a larger scale. While I do not know how my research will impact others in the future, the chance to add to the literature on autism, especially from a public health and anthropological background has been exciting. I hope to contribute to not only the literature but also the community in a way that is intentional but impactful. This project has allowed me to not only grow as a social scientist, but as a person.

APPENDIX A

CAREGIVER INTERVIEW GUIDE

Cultural Perceptions of Autism and their Effects on Behavior and Health Interventions: A Qualitative Study

Interview Questions

Demographic Information

1. Age
2. Gender
3. What ethnicity/race do you identify with?
4. What is your country of origin?
5. Marital Status
6. Employment Status
7. Number of children in home
8. Is child with ASD firstborn, lastborn, etc.?
9. Relationship to child receiving services at The Client
10. Are you the primary caregiver for the children in home?
11. How is childcare distributed among the adults in the home?
    a. Probe: who takes care of health-related issues?

Cultural Experiences with Autism

12. Tell me about your experiences and understanding of autism. Take as long as you need to tell your story.
    a. Probe: do you remember anything from your background that has helped you better understand what was going on with your child?
    b. Are there any parenting methods that you use that you would describe as culturally-unique or specific?
13. How does having a child with autism effect your daily life?
14. If you have other children, has autism influenced the strategies you use when caring for them?

Experiences with Initial Diagnosis

15. You may have covered this a bit in the previous question, but I want to cover some more specific questions. Let’s talk a bit about your child’s initial diagnosis and the experiences that occurred before it was received. Is there any story that you’d like to share that could explain how you started to notice that there was something special about your child? Could you tell me about some of the initial experiences that led you to seek out screening for autism?
    a. For example, tell me about the first time you realized there was something unusual that happened that made you start thinking that your child was special.
    b. Probe: were you referred by an outside source? (Pediatrician/School official)
16. At what age was your child diagnosed?
    a. Probe: did you feel that this happened in a timely manner?
17. Were there any delays to seeking out screening?

    a. Probe: Can you talk a little about what caused the delay? (Financial/insurance issues, unsure of screening process, cultural barriers, physical/transportation barriers)
18. Did you encounter any delays caused by a lack of accessible screening services?
    a. Probe: how did you work around this?
19. What went through your mind when you first learned that your child had autism?
20. Were there any concerns then that you still have now?
21. Once you received an official diagnosis, what worked for you regarding connecting with your child/getting to know them better?
22. What are some of the things that you like to do with your child?
    a. How do you connect?
    b. What makes you or your child happy?
    c. Are there any specific games that you like to play with your child?

Experiences with Seeking Care

23. And this next set of questions builds off the last, but has more to deal with your experiences with seeking out care for your child. Once you received an official diagnosis, how did you first seek out care? Where was the first place you went for help? Who did you lean on for support?
    a. Referrals?
    b. Word of mouth/based on experiences from someone you know?
24. Prior experience with seeking out autism-specific care?
25. Did you experience any barriers to accessing the care you <u>needed</u>?
    a. Transportation issues
    b. Financial issues
    c. Limited services in area
    d. Ineffective services
26. Did you experience any barriers to accessing the care you <u>wanted</u>?
27. How would you describe your experiences with health and clinical professionals once you were able to receive care for your child?
    a. Probe: if you had a negative experience, how did you work around this?
    b. Seek out different providers?
28. How have prior experiences and gained knowledge influenced your current treatment decisions?

Experiences with The Client

29. How did you learn about The Client?
    a. Social networks?
    b. Medical Referrals?
30. Have you ever shared with staff ways that you address your child's behavior that may be culturally specific? Anecdotes, strategies, little things that work for you?

    a. Probe: If yes, how was that experience?
    b. Probe: If no, what were the reasons?

31. Are there any ways in which you have incorporated learned experiences from The Client into caring for your child?
    a. Probe: In what ways?

APPENDIX B

EMPLOYEE FOCUS GROUP QUESTIONS

Focus Groups (Staff)

Goals:

- **Learn about the communication strategies used by staff when working with families from different backgrounds**

1. Describe unique ways that parents from different backgrounds interact with their children
    a. Probe: Have you ever integrated this into care?

2. How do you identify behaviors that may be culturally specific?

3. What strategies do you employ to connect with families from backgrounds that are different from your own?
    a. Probe: Have you encountered any issues?
    b. Probe: What are additional ways that you can connect with families?

4. What are some potential barriers that families may face when seeking out care?
    a. Probe: what are the issues?
    b. Probe: can you think of ways that you (as a therapist/analyst) can approach the issue?

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