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Occupational Therapy's Needs Assessment for Service Navigation for Children with Autism

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Occupational Therapy's Needs Assessment for Service Navigation for Children with Autism

Capstone Project

Nova Southeastern University

Dr. Pallavi Patel College of Health Care Sciences

Department of Occupational Therapy

Post-Professional Doctor of Occupational Therapy (Dr.OT) Program

Submitted August 03, 2020 by

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to

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For the Doctor of Occupational Therapy (Dr. OT) degree

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Abstract

Background. This capstone project brings to our attention the importance of occupational therapy's role in meeting the continued needs of children with autism. As the prevalence of autism spectrum disorders (ASD) continues to increase, so does the disparity in the accessibility of services for children and their families. Therefore, it is imperative to facilitate a diagnostic process and identify the child's specific needs, to implement early intervention strategies. The medical model of disability, an internationally recognized approach in diagnosing children with autism, views autism as a problem that individually belongs to the child. Although the current medical model is preferred by medical professionals during the diagnostic process, children are diagnosed later in life compared to when early signs of autism are noticed.

Purpose. The purpose of this needs assessment was to explore the barriers associated with identifying children with autism, which could potentially impact children's ability to access early interventions; and to utilize the knowledge gained to examine the potential for occupational therapy's role in diagnosing autism, specifically towards advocating for early diagnosis.

Method. An Family-Centered Care system and Occupation-Centered Assessment with Children framework were used to explore the gaps in identifying autism, which impacts occupational engagement. A survey flyer was posted on open-group autism-specific Facebook forums. Using a mixed-methods design, surveys from caregivers of children with autism in Miami-Dade County were analyzed using Survey Monkey.

Results. The results of these analyzes indicated there is a delay from noticeable red flags of autism to when the child is diagnosed, caregiver dissatisfaction, and health care provider and caregiver lack of autism knowledge.

Discussion. This capstone project proposes program development to improve autism education, awareness, advocacy, and self-empowerment. Details of the problem, solutions, proposed program, and implications for the future will be presented.

Key Words: Autism Spectrum Disorder, occupational engagement, family-centered care, early intervention, early identification, occupational therapy

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Occupational Therapy's Needs Assessment for Service Navigation for Children with Autism

Chapter 1: Introduction

Based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) the American Psychiatric Association ([APA] 2013) classifies autism spectrum disorder (ASD) as a developmental disorder characterized by deficits in social communication and interaction and restricted and repetitive behavior. While there is no known single cause for autism, symptoms present in early childhood and vary in severity of impact on an individual's function. ASD affects an individual's ability to participate in meaningful daily activities. Autism is diagnosed by physicians based on symptoms, signs, and testing according to the parameters of the DSM-5 (APA, 2015).

Early diagnosis of ASD can lead to the accessibility of early intervention (EI). Children that receive access to interventional services at an earlier age have a more favorable prognosis compared to children diagnosed later in life (Centers for Disease Control and Prevention [CDC], 2018a). EI services are focused on helping children gain basic developmental skills to increase participation in meaningful daily activities. Until recently, ASD was considered a lifelong disorder, however, with EI, the removal of the autism diagnosis in some children later in life is possible (Fein et al., 2013). While an early diagnosis of autism is associated with a positive prognosis, children continue to be misdiagnosed or ensure delays in receiving a diagnosis. Despite extreme worldwide efforts, the current focus is on the etiology, interventions, and curative approached to address autism, not in facilitating an improvement in the diagnostic process. The knowledge gained by understanding the barriers associated with the current ASD diagnostic system will allow us to examine occupational therapy's role for improving the diagnostic process in our community.

The role of occupational therapy expands beyond the treatment realm; with foundational principles in advocacy and an emerging role in primary care. Occupational therapy's primary role in advocacy is to speak out on reforming healthcare policies and aid individuals in overcoming obstacles, to receive needed services. The American Occupational Therapy Association ([AOTA], 2014) defines advocacy as "efforts directed towards promoting occupational justice and empowering clients to seek and obtain resources to fully participate in daily occupations. The outcomes of advocacy and self-advocacy support health, well-being, and occupational participation at the individual or systems-level" (p. 30). These aims can be accomplished through direct advocacy efforts, or indirectly by training clients in self-advocacy or through supporting and training involved health care providers (HCP). Occupational therapy's role in primary care is an emerging one. Developing standards for best practice in primary care involves a coordinated team-based approach that promotes collaborative care. Occupational therapy's top-down and holistic perspective of the individual leads to a unique perspective and client-centered approach to the diagnostic process of autism. Occupational therapy must seize the opportunity on this emerging role of primary care to improve outcomes for children with autism.

Background and Significance

Autism affects 1 in 59 children (Autism Speaks, 2019a), with approximately 31,133 children between the ages of 3 to 21 diagnosed with ASD in Florida (U.S. Department of Education, 2018). ASD is often associated with delayed language development, persistent repetition of words, repetitive behaviors, difficulty with change in routine, and unusual and intense reactions to sensory stimuli (Autism Speaks, 2019b). Research shows that parents notice signs associated with autism as early as six months of age (Planche, Lazartigues, & Lemonnier, 2004), and children can be reliably diagnosed as early as 12 months (Osterling, Dawson, & Munson, 2002). With early detection of ASD, children have an earlier opportunity to access EI,

which is considered essential for achieving optimal outcomes (Pierce, Courchesne, & Bacon, 2016).

EI is defined as the support and services a child from birth to the age of three years old, can receive to overcome developmental challenges. Advocates of EI argue that starting services at an earlier age provides the best opportunity of altering neural connectivity during the time of optimal brain plasticity (Pierce et al., 2016). EI offers the best chance to support the development of cognitive, communication, and social skills in children (Clark, Vinen, Barbaro, & Dissanayake, 2018); as well as reduce long-term intellectual, behavioral, and functional impairments (Dawson et al., 2012). The outcomes of EI should be sustained, even after services cease. Researchers found that infants considered high risk, two years post EI, continued to demonstrate reduced severity of ASD at three years of age (Green et al., 2017). Estes et al., 2015 found that two years post-EI children continued to demonstrate reduced autism symptoms and improved adaptive behaviors. A similar study by Pickles et al. (2016), found reduced autism symptoms during follow-up of middle school-aged children. These findings show a sustained higher level of function in children that received EI, in comparison to children who sustained a lapse in EI services due to delayed diagnosis.

Physicians currently have the role of diagnosing children with ASD. Physicians have adapted a traditional medical model, which focuses on symptom reduction and management. Occupational therapists have discovered that the medical lens is a single lens through which to view autism. To maximize a holistic approach to improve outcomes, multiple lenses must be utilized during the diagnostic approach, rather than a single lens medical model approach. A holistic model encompasses a multifaceted approach in focusing on all the components of an individual, not just the disorder (Muir, 2012). Occupational therapists have embraced a holistic,

top-down, family-centered approach to deliver comprehensive assessments in addressing functional deficits, performance skills, and contextual factors, which impact function and engagement of meaningful occupations. Occupational therapists are experts in the transactional relationship between occupations, functional performance, and health. Occupational therapists have a distinctive understanding of the impact familial roles and routines have on the health and wellbeing of the child. This quality makes a unique contribution of occupational therapy to primary care.

Problem Statement

The number of children diagnosed with ASD later in life and its impact on accessing EI services promoted the pursuit of this capstone project. Although findings support that parents are noticing signs of ASD as early as six months of age and the benefits of EI, the median age of children diagnosed with ASD is three years and six months in Florida (CDC, 2018a). As a result, children in Florida diagnosed with ASD later in age are missing these critical opportunities for EI. This research will focus specifically on Miami-Dade County, which is the highest populated county in Florida. Providing a comprehensive needs assessment offers the potential to limit or reduce potential barriers and promote the accuracy and reliability of diagnosing children with autism in Miami-Dade. The core focus of this project is to explore the gaps in the current practice of diagnosing children with autism and define occupational therapy's role in minimizing those barriers. This needs assessment will increase the probability of positive client outcomes for children with autism and their families in Miami-Dade County.

While there is a variety of ASD screening and diagnostic assessments that can be completed by several HCP's, pediatricians are typically the diagnostician for the child before the age of three. This is primarily due to pediatricians being in regular contact with children before

they reach school age, in comparison to other professionals (CDC, 2018a). Children are typically evaluated by pediatricians multiple times per year during the child's well-child visits or other health concerns. A child's well-child visit is a routine screening to track the child's health and overall development. These visits usually contain the presence of the child, caregivers, and pediatrician. Although the CDC (2018a) recommends routinely screening for autism during well-child visits, these ASD screenings do not occur or are of poor quality. Current hypotheses that led to children's delay of autism diagnosis include

- Caregivers report that even if they note their concerns, there is a lag in time before their child is diagnosed with ASD by a doctor (Oswald, Haworth, Mackenzie, & Willis, 2017).
- Sociodemographic differences, such as maternal education (Hidalgo, McIntyre, & McWhirter, 2015), and socioeconomic status, such as family income levels (Mazurek et al., 2014), affect the age a child is diagnosed with ASD.
- Medical providers lack training in diagnosing children with ASD (Rhoades, Scarpa, & Salley, 2007).
- The caregivers' failure to respond to the initial diagnosis, such as avoiding available services, results in a delay of early intervention (Rhoades et al., 2014).

While initiatives are focused on determining the etiology and cause for ASD, there is limited research associated with improving the current process for identifying children with ASD and accessing EI services. The health care system has not taken advantage of occupational therapy's unique holistic perspective and foundational advocacy principles, that can produce effective positive results in the diagnosis process of ASD. This needs assessment will focus on the barriers which impact the diagnosis of ASD and illustrate the role of occupational therapy in supporting

and advocating for children and their families while demonstrating meaningful occupational engagement.

Purpose and Objectives

Decreased knowledge of the gaps and barriers to the current diagnostic process of ASD prompted the quest for this research. The goals of this project are to use a grounded theory approach to collect data from the caregiver's perspective and to identify gaps in the system and to develop solutions for improving the identification of ASD. Occupational therapy's foundational principle of occupational engagement utilizing a family-centered care (FCC) approach, will guide the research proposal. The capstone objectives include

- Identify system barriers that impact the accuracy and reliability of diagnosing children with ASD.
- Identify health disparities that contribute to inequality for accessing diagnoses and services.
- Identify occupational therapy's role in advocating for health equality.
- Highlight occupational therapy's role in primary care for improving system solutions in identifying children with ASD.

Definition of Terms

There are several terms used throughout this capstone project. The definition of these terms is as follows:

ASD – a developmental disorder, which generally manifests in the first two years of life.

Individuals with autism have difficulty with communication and social interactions, demonstrate restricted interests and repetitive behaviors, and present with impairment to participate in daily functional activities (New Autism Definition Could Reduce Number Diagnosed. 2012).

.EI- the services and supports available to children under the age of three years old with developmental delays. Services are focused on learning new skills and overcoming challenges (Conroy et al., 2018).

Grounded theory- a research method that will enable the development of a theory to explain the primary concern of a problem and how it can be resolved (Glaser, 1992).

Occupational therapy- services which support a child and family's meaningful participation in occupations. Such occupations include a child's engagement in self-care, rest and sleep, play, social participation, and education (Frolek Clark & Kingsley, 2013).

Health disparities- comparable health differences that are linked to economic, social, or environmental disadvantages (Healthy People, 2020).

Occupational performance- the act of accomplishing a specific performance skill or activity, as a result of the dynamic relationship between the client, context, and occupation (AOTA, 2014).

Occupational engagement- the “doing” or engaging or performing in a role or activity (Fidler & Fidler, 1963; Landau & Bogus, 1977).

Chapter 2: Literature Review

This literature review will explore evidence-based research to define prospective barriers to identifying children with ASD in Miami-Dade County. This review includes an in-depth analysis of the barriers to early identification and accessing services, as well as reviewing occupational therapy's prospective innovative role. Literature from 2014 to 2020 was reviewed. Search terms include autism, ASD, barriers, diagnosis, occupational therapy, early identification, and children. The research was limited to the English language. The literature review focused on the potential barriers that can and often do arise during the diagnostic process of autism, which significantly impacts a child's accessibility to EI and occupational engagement.

Impact of Early Intervention

The benefits of EI contribute to the urgency in identifying children with autism at an earlier age. EI occurs at or below three years of age, while brain plasticity is still relevant during the child's development (Dawson et al., 2010). EI often includes occupational therapy, speech and language therapy, family training, educational programs, family coaching, and nutrition services. The goal of EI is to assist children in gaining the skills they typically learn in the first few years of life, (i.e, physical, cognitive, communication, social, and emotional skills), while reducing signs or symptoms of ASD. Research supports the benefit of EI on developmental and behavioral outcomes in young children and has the potential for major long-term positive effects on ASD symptoms (Wallace & Rogers, 2010). With EI, some children with autism progress to the extent that they are no longer considered autistic when they are older and the ASD diagnosis is removed (Fein et al., 2013; Helt et al., 2008).

While the primary goal of EI is focused on improving the child's outcomes, EI also positively impacts caregivers. Caregivers benefit from learning early in the child's life, how to assist the child to improve mentally, emotionally, and physically throughout the developmental stages. Research supports a transactional relationship between child intervention outcomes and caregiver well-being (Karst & Van Hecke, 2012). As children benefit from EI, caregivers express better well-being; and vice versa, caregivers that express positive EI outcomes from provided resources and supports, report greater child outcomes. This early caregiver EI support can reduce the family's stress and strain and lead to positive family experiences. As a result, EI is considered an essential component for improving the perceived quality of life for children with ASD and their families.

Gaps in Accessing Services Related to Health Disparities

It is essential to learn what the current barriers are to design a needs assessment for the diagnostic process of ASD in young children in Miami-Dade County. The presentation of autism can range significantly for each child, resulting in the variability of symptoms expressed. This inconsistency makes it challenging to reliably diagnosis children with ASD. Since there is no single algorithm for diagnosing autism, diagnostic decision-making is a complex process. In addition to the vague diagnostic process, contextual features such as sociodemographic factors, parental lack of education, lack of agreement between families and health care professionals, and structural factors result in delaying the diagnostic process.

Sociodemographic Influences

Given the influence of early identification and treatment of ASD symptoms on a child's prognosis, it is essential to examine how sociodemographic factors, like race, socioeconomic status (SES), and parental education affect the diagnosis process. The below findings support that minority children, children of low SES, and reduced parental education negatively impact the rate of diagnosis. There is a correlation between these factors and the statistical findings of Miami-Dade County. This association may contribute to the difference between the average age of diagnosis of autism in Florida, compared to the United States.

Race.

Williams, Matson, Beighley, and Konst (2015) found that providers are not promptly or adequately addressing the concerns of caregivers of children of minority racial backgrounds compared to Caucasian children during the diagnostic process. Minority children are more likely to be misdiagnosed and less likely to receive EI services (Dababnah, Shaia, Campion, & Nichols, 2018). Caregivers of minority children report providers ignored initial concerns regarding their

child's developmental delays and experienced racial bias during caregiver-HCP interactions (Dababnah et al., 2018). This lack of proactive responses to the concerns of minority families results in delayed diagnosis for children. Miami-Dade County is composed of 87% of ethnic individuals, in comparison to 46.5% in the United States (United States QuickFacts, 2019). These significant differences, between children of ethnic backgrounds, could negatively affect the rate of ASD diagnosis in Miami-Dade County.

Socioeconomic status.

In Miami-Dade County the average household income is \$48,982 compared to the United States average of \$60,293; also, more individuals are considered below poverty at 16% in comparison to the United States average of 11.8% (United States QuickFacts, 2019). SES is not determined by a single factor of an individual's income but rather also encompasses educational attainment and occupation (American Psychological Association, 2020). SES is a measure of a family's social and economic position in relation to others. Households are typically deemed low, medium, or high SES based on those factors. To be considered low SES, a household's SES factors are unable to protect against the negative impact of adverse health events (American Psychological Association, 2020). As a result, individuals of low SES, on average, are more likely to experience poor health and reduced health opportunities than those with more favorable SES.

Children of low SES are less likely to be diagnosed with ASD, and their parents are more likely to experience dissatisfaction with care. Durkin et al. (2017) found racial and ethnic disparities in low-SES children in comparison to children of high-SES; the proportion of children of low SES receiving ASD therapeutic services is significantly lower than expected. Parents with higher SES report increased satisfaction with their child's care and faced fewer barriers to

accessing these services (Hidalgo et al., 2015). The above findings support that families of low income in Miami-Dade may face greater significant obstacles in obtaining the ASD diagnosis and more likely to experience dissatisfaction with care.

Parental education.

Similar SES differences were discovered in education levels as 81.5% of Miami-Dade County residents graduated high school, compared to 88% in the United States (United States QuickFacts, 2019). The level of paternal education can impact the caregiver's ability to understand typical childhood development; therefore, are less likely to raise concerns on their child's development to providers. Due to inaccuracies of caregiver report, Khowaja, Hazzard, and Robins (2015) found that children of parents with low maternal education are more likely to be screened positive than children of parents with higher maternal education; however, on the follow-up, the majority of children are screened negative for autism. This is a result of caregivers providing inaccuracies on the child's development, resulting in an initial positive screening, but on follow-up providers determine this to be a false positive. In other cases, Zuckerman, Lindly, & Sinche (2015) discovered that due to the challenges of making sense of the red flags their child exhibits, parents may remain silent and not share their concerns with providers. In both cases, caregivers of children with lower education may have difficulty articulating and communicating their concerns to professionals. As a result, children are either misdiagnosed or inaccurately diagnosed with ASD. If the parent recognizes the early signs of autism, as described by the DSM-5 (APA 2013) like reduced eye contact, hyperactivity, and decreased social engagement, the caregiver can seek the appropriate medical services needed.

Structural Barriers

The National Autism Association (2019) advocates for autism-specific screenings at the child's 9-, 18-, and 24- month well-child visit. Figure 1 illustrates the CDC's (2018b) suggestion for integrating routine developmental screening into the primary care setting. Developmental screening tools are designed to assist in the identification of developmental delays in children. A positive screening result of developmental delays should be followed by a thorough assessment. There are various autism screening tools including Ages and Stages Questionnaires, Modified Checklist for Autism in Toddlers, and Screening Tool for Autism in Toddlers and Young Children.

Pediatric Developmental Screening Flowchart

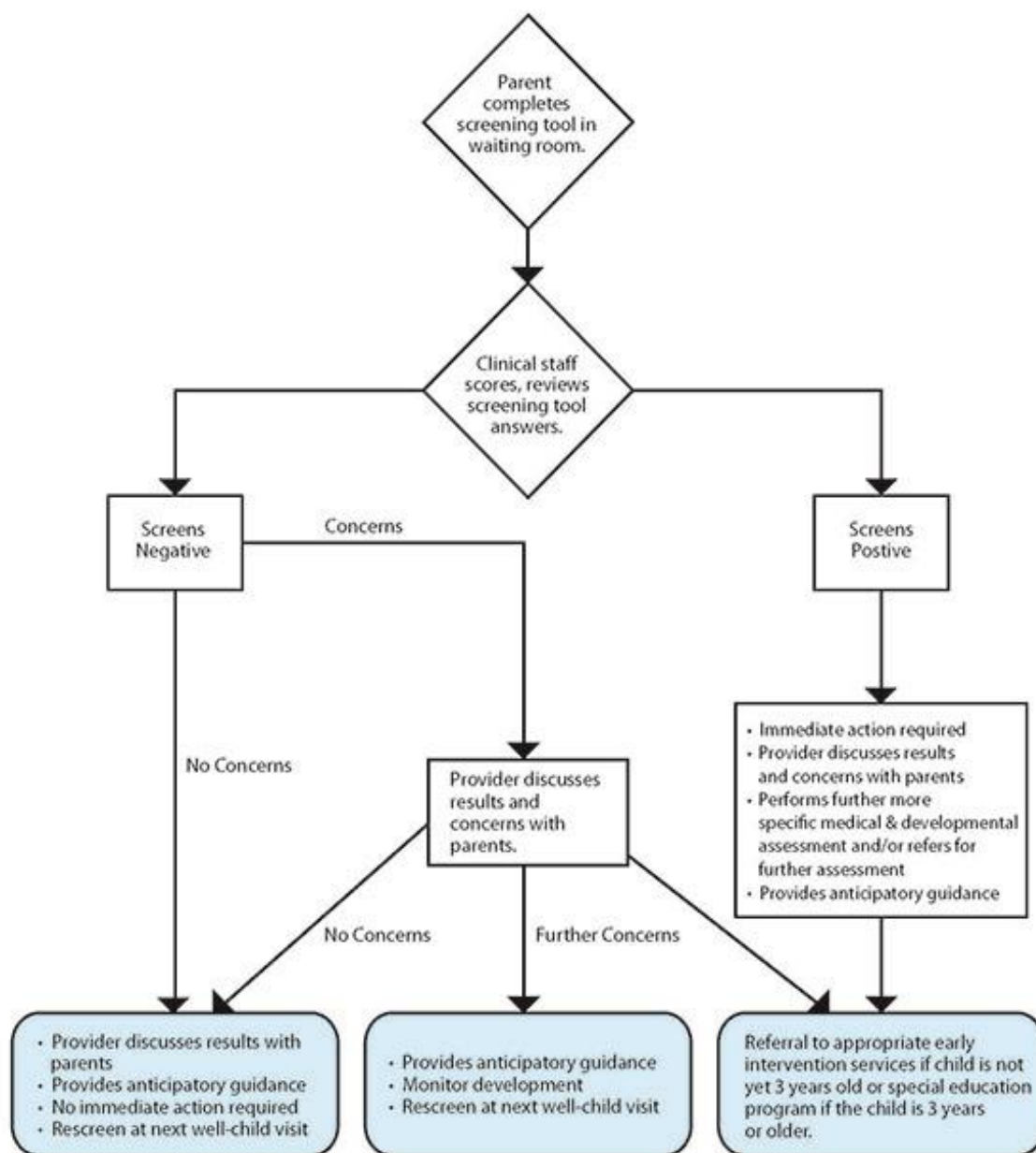


Figure 1.1: CDC's Primary Care Flow Chart for Developmental Screening. (CDC, 2018b).

Note. First, the parents complete the screening tool. The clinician reviews the assessments for red flags of developmental delays. If the child screens positive, immediate action is required and the child is referred to services. If the child screens negative, and there are concerns noted, the provider gives anticipatory guidance and the child is rescreened at the next well-child visit. If

there are no concerns, the provider discusses the results with the parents, and the child is rescreened next well-child visit.

Operational barriers to screening ASD.

Structural factors, such as time constraints and long waiting periods, can significantly impact the efficiency of the developmental screening process. Due to the numerous objectives which must be realistically completed during the time allotted and lack of reimbursement, HCPs do not find screening for autism as efficient use of their time. In the representation of Figure 1, during a well-child visit, HCPs are expected to score and review the screening assessments, followed by a discussion of concerns and findings with the caregivers. In addition to developmental screenings, the HCP is expected to perform a physical examination, complete measurements, and give the appropriate immunizations. Due to the high expectations and limited time, HCPs report difficulty addressing caregiver's concerns while simultaneously addressing the recommended health objectives in the practice guidelines (Fenikilé, Ellerbeck, Filippi, & Daley, 2015). Concurrently, HCPs' fault lack of reimbursement for their reluctance in screening children for ASD during well-child visits. Fenikilé et al. (2015) found that HCPs do not typically screen for autism since the additional amount of time spent during the screening is not reimbursed as it is bundled with the well-check visit.

In addition to HCPs' concerns of financial reimbursement, HCPs fear diagnosing children with ASD leads to financial strain for families. Autism specific services may include behavioral and educational interventions or complementary and alternative medicine, dietary consultant, or medications to manage the symptoms of ASD. These treatments can be costly. According to the CDC (2018b), it costs an estimated \$17,000 more per year to care for a child with ASD compared to a child without autism. For a child with more severe ASD, costs rise to over \$21,000 more per year (CDC, 2018b). Due to the lack of insurance reimbursement, HCPs are

hesitant to refer families to services families will be required to pay-out-of-pocket for (Fenikilé et al. (2015). This reluctance is more common in mild cases of ASD, where the child may not qualify for reimbursement. HCPs fear that diagnosing a child with ASD that would not be eligible for services or a child whose parents cannot afford services would add increased stress on the family (Elder, Brasher, & Alexander, 2016). Miami-Dade County has adapted a managed care systems approach in an attempt to lower the costs for insurances in covering those with disabilities (Marcu et al., 2014). As a managed care system restrains HCPs from recommending services to reduce insurance costs; this significantly reduces the likelihood of HCPs recommending services to families. By families not receiving a referral for recommended services, the services are less likely to be reimbursed by insurance companies. This managed care system limits the family's accessibility to health care services and increases financial strain which can impact the child's autism prognosis and perceived well-being.

HCPs screening knowledge and response to caregiver concerns.

There is a high chance of misdiagnosis or delay in diagnosis if there is a lack of awareness about the signs of autism. In agreement, caregivers and HCPs expressed that HCPs lack the knowledge and adequate training in identifying early signs of ASD. Fenikilé et al. (2015) found that most HCPs are not aware of the recommended routine screening for autism during well-child visits, and those that were aware to screen lacked knowledge about specific autism screening tools. Families that are not guided in the screening process and must independently seek the proper specialist to diagnoses their child with autism had to wait nearly twice as long for a diagnosis (Martinez et al., 2018). A study by Self, Parham, and Rajagopalan (2015) revealed that only 30% of HCPs routinely screen for ASD using the recommended screening tools during a well-child visit. The lack of HCP awareness or education on available

assessments may contribute to HCP's lack of routinely or accurately screening for ASD (Fenikilé et al., 2015). HCP education and awareness of routinely screening autism and available autism-screening tools contribute to families having to self-seek specialists to receive assistance; therefore, resulting in a delay of accessing services.

The lack of awareness or education on screening tools may contribute to HCP's passive response to the concerns of families. Families report encountering passive responses from professionals regarding their concerns about ASD symptoms. Approximately 44% of children and their families report a delay in the responses of HCPs to the initial parental report of ASD symptoms; on average, having to consult with 3.3 professionals (Barnard-Brak, Richman, Ellerbeck, & Moreno, 2017, Wong, Yu, Keyes, & McGrew, 2017). As a result of HCPs dismissing the initial concerns of caregivers, families are forced to seek multiple professionals; increasing the average wait time from the caregiver's initial concern and the diagnosis to 29 months (Wong et al., 2017).

Lack of HCPs' proactive response contributes to the delay in diagnosis. A child's delay in diagnosis can increase to two times greater if the child is initially misdiagnosed as not having autism (Martinez et al., 2018). While parents are often the first to recognize ASD-like behaviors; caregivers report professionals do not respond adequately to their concerns regarding early signs (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014). Daniels and Mandell (2014) found that HCPs will mistakenly inform the caregiver, that as the child matures, the ASD behaviors will reduce. Whereas, when HCPs actively respond to caregiver's concerns, the amount of time between the caregiver's concerns and diagnosis is reduced (Zukerman et al., 2015). Caregivers perceive the HCPs' lack of response as uncaring, although it could be related to the lack of knowledge of autism screening and diagnosis (Lappé, 2018). Since services generally require a

confirmed diagnosis, this long lapse in the screening process can potentially translate into children missing valuable EI opportunities and available family resources.

Supporting Theories and Frameworks

Autism is a lifelong condition, characterized by various symptoms that can impact a child's occupational engagement and the severity can differ for each child. While there is no cure for autism, it is a treatable condition; using interventions from a variety of disciplines that can help mitigate symptoms, allowing children to engage in daily occupations. Occupational therapy practitioners currently support meaningful participation which enhances the quality of life for children with autism and their families. The guiding philosophies of occupational therapy align with theories that support a strong client and family-professional partnership. Occupational therapy is one of the most frequently provided services for children with autism to address the impact on childhood occupations, however, the referral for services relies on pediatricians, physicians, EI specialists, and parents (Interactive Autism Network, 2008). The role of occupational therapy practitioners is not limited to providing direct services but encompasses consulting and collaborating with others, and advocating for clients and coaching families. Occupational therapists demonstrate our foundational theories through practice; therefore, theories should cement the purpose of this research.

Occupational Engagement

Occupational therapists are grounded in the understanding and significance of occupational engagement for the health and well-being of individuals regardless of disability and have an opportunity to influence positive outcomes of individuals with autism (AOTA, 2014). Occupational engagement is defined as “doing” or engaging or performing in a role or activity (Fidler & Fidler, 1963; Landau & Bogus, 1977). The World Health Organization (2001)

considers occupational engagement as the ultimate indication of health and functioning; therefore, occupational therapy practitioners are increasingly required to evaluate and treat occupational performance issues associated with ASD (AOTA, 2014; Tanner, Hand, O'Toole, & Lane, 2015). Social participation and play are critical occupations throughout childhood and into adolescence, and children with ASD commonly experience barriers in engagement (AOTA, 2014). There is a great disparity between children with ASD and children without disabilities in regards to their levels of engagement, as children with ASD typically demonstrate decreased participation (Law, Petrenchik, King, & Hurley, 2007). Reduced social and play engagement contributes to social isolation, decreased friendships, and negative psychological outcomes (Law et al., 2007). As participation in social and play is within the occupational therapy's scope of practice; nonparticipation in these areas is of great concern to occupational therapists. The role of occupational therapy is to improve everyday skills which allow for increased occupational engagement and participation in these areas.

Family-Centered System

The aim of Family-Centered Care (FCC) is to optimize the client and family experience through a health care delivery approach that is grounded in a mutually beneficial relationship between clients, their families and health care providers (Coker, Rodriguez, & Flores, 2003; O'Malley, Brown, & Krug, 2008). The core concept of FCC is to work "with" the family, as opposed to just "doing it" for the family. The core concepts of FCC reflect dignity and respect, participation, collaboration, and sharing of information (Johnson & Abraham, 2012; O'Malley et al., 2008).

1. Dignity and respect. HCPs listen to and honor the family's perspectives and choices.

2. Participation. Families are encouraged to and are supported in participating in the care of and decision-making process.
3. Collaboration. Families and HCPs collaborate in the delivery of care and policy change and program development.
4. Information sharing. HCPs communicate and share complete, unbiased, and accurate information with families.

The proposal of FCC represents a cultural shift in healthcare delivery; rather than HCP driven, families are the primary decision-makers. With the use of FCC, HCPs form a supportive environment as they establish services to fit the specific needs and values of the family (Rogers & Vismara, 2014). Christon and Myers (2015) found that HCPs with a high level of reported self-efficacy are more likely to implement FCC in practice despite not having adequate training in using this model. Benefits of FCC in practice include increased family adherence to recommended interventions (Woodside, Rosenbaum, King, & King, 2001), increased caregiver well-being (King, King, Rosenbaum, & Goffin, 1999), reduced family emotional distress, increased coping and adjustment, and increased family satisfaction with the child's care (Carbone et al., 2013; Gabovitch & Curtin, 2009). While FCC has been indicated as an important component in pediatric practice, there is limited research on its effect on families of children with autism. The involvement of family members of children with ASD is essential to increase teaching opportunities, as well as skill generalization across the child's naturalistic environment (White, 2012). The use of the FCC model will be the core premise for the development and outline of this research. Consistent with the AOTA Centennial Vision (2017a) and AOTA Vision 2025 (2017b) effectiveness is correlated with a commitment to developing client-centered,

occupation, and evidence-based interventions in collaboration with children with autism and their families to impact positive outcomes.

Occupation-Centered Assessment with Children (OCAC) Framework

The Occupation-Centered Assessment with Children (OCAC; Brown & Chien, 2010) provides the theoretical foundation that shaped this needs assessment. The OCAC framework supports a top-down, family-centered, and ecological assessment approach to occupational therapy (Brown & Chien, 2010). This top-down approach encourages a holistic lens to gather information on the client's occupations and the context in which these occupations occur (Brown & Chien, 2010). The term top-down focuses on the analysis of the occupations the child values, rather than performance components of individual abilities and disabilities. The top-down approach complements the holistic approach, which refers to addressing the whole person and not just a part of the person. This top-down, holistic perspective begins with identifying a problem in occupational engagement and then taking steps to analyze and assess to determine performance components or contextual factors that impact participation. A benefit of an FFC approach is that it allows a clinician to focus on occupational performance issues most important to the child and family. The OCAC encourages communication by the family and child, thereby giving a voice to the individual, promoting active participation in identifying the needs and supports required for occupational engagement. The framework supports occupational therapists in addressing the barriers associated with a child's reduced valued occupations in a naturalistic environment.

To implement the OCAC in practice, the occupational therapists first needs to understand that the child and family have unique values, interests, habits, routines, and roles that are specific to their occupational identity (Brown & Chien, 2010). Secondly, barriers to occupational

engagement should be directly identified in their relation to the function of the occupations (Brown & Chien, 2010). Lastly, the role of occupational therapy is to address these barriers which impact the child's occupational engagement. Occupational therapists typically implement OCAC during the establishment of an occupational profile. This is to form the child's occupational identity and those meaningful occupations which are impacted by performance components.

The Biopsychosocial Model

While the traditional medical model favors a reductive approach to address disease and dysfunction, this model lacks a holistic, client-focused approach integrating biological factors with psychological and social influences (Gentry, Synder, Bastow, & Hamson-Utley, 2018). The biopsychosocial model proposes an explanation for how biological, psychological, and social factors are impacted by disease and disorders. While the traditional medical model solely focuses on the genetic makeup of the disorder, the biopsychosocial model includes the psychological factors which influence personality and developmental experiences and the social factors which address how the influences of others and cultural and situational differences impact an individual (Gentry et al., 2018). There is a need to embrace a holistic approach to bridge the divide between the current narrow methodology to offer a more inclusive and client-centered approach to identifying children with autism. The biopsychosocial model and its application toward ASD can be described through four principles.

1. Biological markers influence a child's psychological and social factors. Biological factors of children with ASD include genetic makeup, brain chemistry, and hormonal levels (Silva et al., 2013). These factors can influence the course of a child's development, including the child's linguistic, cognitive, and motor development (Stromswold, 2006).

Current treatment and services tend to focus efforts on the physical aspects of the child; however, if the focus is on this single area, there is the potential to miss other important psychological and social factors that impact the child's occupational engagement.

2. The subjective experience for each child varies. The biological, psychological, and social factors affect each child differently. Therefore, the approach to care needs to be altered to fit the individualized needs of the child and their family.
3. All three systems have a dynamic relationship; changes in one system will influence other factors of the model and the child's health (Moseley, 2002). The term dynamics is used to emphasize that these systems are not fixed, but rather interact with one another. Each component of the model includes systems that reciprocally influence the other factors.
4. The dynamic interaction between the biological, psychological, and social systems influence the child's health over the life span (Lehman, David, & Gruber, 2017). This theoretical principle is shown in Figure 2. This health-centered model is an expansion of the originally proposed biopsychosocial model. The model integrates the existing conceptualizations of the biological, psychological, and social systems, but further elaborates on the influence these dynamic systems have on health.

The biopsychosocial model provides a framework for a holistic approach to care, which addresses the psychological and social factors in addition to the biological nature of the disorder. Given the inclusive, client-centered nature of this model, the integration of specific interventions and approaches to care is used to develop an individualized biopsychosocial method to fit the child and family's needs.

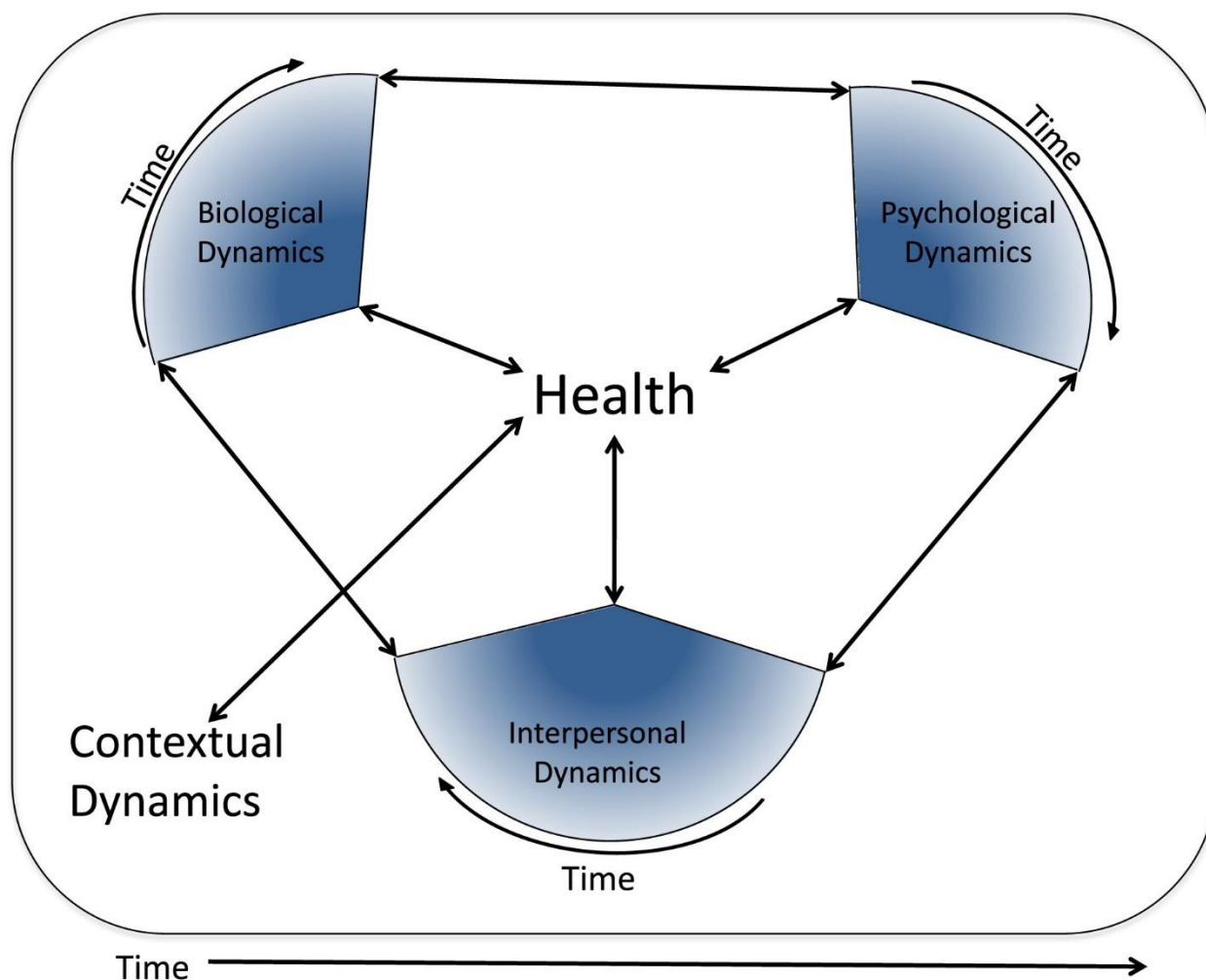


Figure 2.1: Biopsychosocial Model of Health. (Lehman et al., 2017).

Note. The dynamic Biopsychological Model. The model expands on the previously proposed biopsychological model by incorporating a dynamic systems perspective and further clarifying the system's effects on the individual's health over a lifespan.

Advocacy

The Occupational Therapy Code of Ethics (Occupational Therapy Code of Ethics, 2015) requires occupational therapists to become skillful advocates for their clients and families.

According to the Occupational Therapy Practice Framework, advocacy is defined as the efforts given to promote occupational justice and empower clients to acquire the resources to participate in meaningful occupations (AOTA, 2014). Self-advocacy supports health, well-being, and

occupational engagement (AOTA, 2014). Advocacy is composed of beneficence, justice, and veracity.

Benefice.

Occupational therapists establish beneficence through the demonstration of concern for the client's well-being and safety (Occupational Therapy Code of Ethics, 2015). The core of beneficence is based on assisting clients in the pursuit of meaningful causes and accessibility to care. The responsibilities of an effective advocate engaging in beneficence, expand beyond the traditional responsibilities of an occupational therapist, and are typically nonbillable opportunities. Examples of these services include writing letters to access services, attending meetings or conferences and research of law and regulations.

Justice.

The principles of justice, fair public policy, and social justice are inherent throughout the Occupational Therapy Code of Ethics. Advocacy allows the opportunity for occupational therapists to implement social justice for the community. Justice is demonstrated through advocating to legislate for language and regulations, elimination of service limits, and increase funding for service programs specifically for individuals with disabilities (Stover, 2016). Occupational therapists exemplify justice through advocating for a client's abilities and after an insurance or service denial.

Veracity.

The concepts of veracity refer to providing clients with comprehensive, accurate, and objective information (Occupational Therapy Code of Ethics, 2015). Veracity requires occupational therapists to be truthful in presenting the client's abilities and disabilities and the likelihood of success in the client meeting their goals. To establish a therapeutic relationship

with a client and family, the complete transmission of information is owed. Veracity establishes trust and strengthens the therapeutic relationship between an occupational therapist and a client.

Summary

As the literature has indicated, family of children with autism experience many barriers getting their children diagnosed early, delaying early access to services in Miami-Dade County. These barriers are even more challenging for children and families of minority groups, low SES, or low education levels. Other health disparities are a result of operational or structural barriers, such as lack of HCP autism-specific education or time constraints. Occupational therapists acquire the knowledge to make community change to effect positive outcomes for children with autism and their families. This transformation will increase the number of children able to access services at an earlier age, to promote occupational engagement. The AOTA Vision 2025, Code of Ethics, and Occupational Therapy Practice Framework support occupational engagement through an FCC, holistic approach.

Chapter III: Methods

The literature findings provide research into nationally identified barriers, however, lacks the specific insight to support the difference in age between when parents identify signs of autism and the diagnosis age for children in Miami-Dade County. Therefore, these findings indicate a need to further investigate the reasons children in Miami-Dade are diagnosed at three years and four months of age, although parents begin noticing signs of ASD at six months of age.

To identify the issues associated with the current diagnostic process for ASD, a needs assessment will incorporate a concurrent embedded mixed-methods design approach. Data will be collected from caregivers of children with ASD, via online surveys. The collection of data will focus on identifying possible barriers in the identification of ASD from the caregiver's

perspective. The gaps and barriers recognized from this research can then be used to further develop community-based solutions to improve diagnostic outcomes.

Needs Assessment

A need is defined as the gap between the present state of affairs and the desired future state of affairs for a certain population with an identified issue (Witkin & Altschuld, 1995). A needs assessment contributes to program planning, monitoring, and evaluation; the concepts of a program life cycle. As represented in Figure 3.1, program development is an endless cycle of phases beginning with preplanning (exploratory), needs assessment, program plan development, program implementation, process evaluation, program evaluation and sharing of results, and returning to needs assessment for constant program growth and development.

Prior to developing a program, the first steps are, to begin with, an exploration stage and conduct a thorough needs assessment of the community to evaluate the necessity of the program for the intended target population (Brownson, 2001). The identification of an issue to address with the autism diagnostic process became relevant during the exploratory phase of the literature review. The exploratory phase answered that children with autism and their families and HCPs have an invested interest in the early identification of autism; all individuals have a shared interest to improve the process, and multiple factors and barriers prompted these concerns. Findings from the exploratory phases defined key questions for the needs assessment. Occupational therapists conduct needs assessments to assist in the decision making for programs and services that affect groups of populations. A thorough needs assessment includes collecting and analyzing data, determining priorities, identifying solutions, and creating a plan of action (Brownson, 2001). Needs assessments assist occupational therapists in prioritizing issues and facilitating strategies of change to address population concerns. In addition to detecting specific

needs, this process identifies the available resources for a specific population, establishes priorities, and forms the criteria for interventions to meet in order to address the needs of the population (Witkin & Altschuld, 1995). In return, the needs assessment will result in a clear set of program objectives and goals.

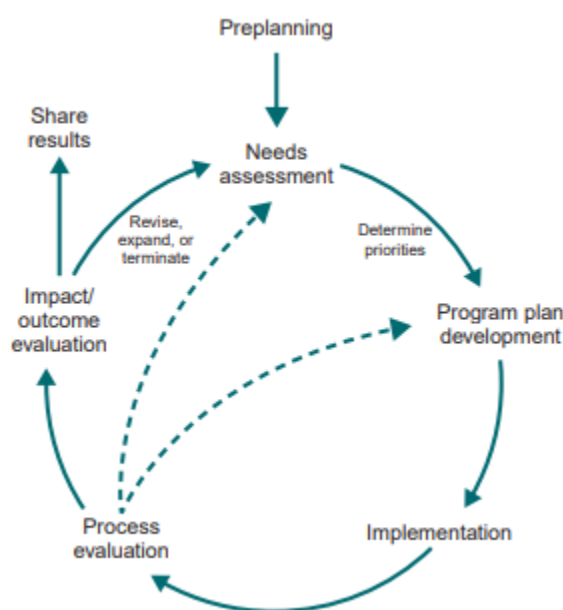


Figure 3.1: The Cycle of Program Development (Simons-Morton, Greene, & Gottlieb. 1995).

Needs Assessment Process

1. Complete exploratory/preplanning phase through a literature review.
2. The exploratory phase will lead to identified population, need, and issues that inhibit need.
3. The exploratory phase will determine if further investigation is needed.
4. Conduction of comprehensive needs assessment through a qualitative and quantitative survey completed by the key informants, the parents of children with autism.
5. Data will be analyzed and synthesized to determine priorities of the gaps and barriers which inhibit meeting the identified needs

6. Formulate an action plan

As a result of the exploratory literature review, it was relevant further investigation was necessary to conduct a needs assessment to determine the gaps and barriers in identifying children with autism in Miami-Dade County, from the caregiver's perspective. Findings from the needs assessment will later lead to program planning, implementations, evaluation, and sustainability of the program.

Mixed-Methods Design

A concurrent embedded mix-methods design was selected to collect data. Both qualitative and quantitative data was collected simultaneously (Guest, 2013). The survey emphasized quantitative data, with qualitative embedded within. The collection of both types of data simultaneously was used to enrich the description of the sample participants. A mixed-methods approach offered the researcher a better understanding of the problem and yielding complete evidence, gaining both depth and breadth into the topic. A mixed-methods approach incorporates the advantages of both qualitative and quantitative methodologies into one cohesive framework. Qualitative analyses produce expressive data in descriptive details, while quantitative analyses employ descriptive and statistics to examine the study's research objectives. The purpose of both qualitative and quantitative data allows for a more complete and credible evaluation to support research findings. The data methodology was selected based on the characteristics of the target group and survey respondents and the amount of interaction desired by the audience (Witkin & Altschuld, 1995). The family system theory will guide the development of the survey design, as it will focus on identifying system gaps that impact the family's timely diagnosis of ASD. This approach will emphasize the importance of the caregiver's, perception to identify key priorities, drive system improvement, and flag the factors

which impact the identification of autism. Findings will lead to the development of a proposed action plan for future program development, to meet the needs of the population.

Outcome Instruments

Online surveys can be easily distributed to a vast number of people in a short amount of time and at minimal costs. Surveys can take the form of written questionnaires and can be administered to collect nonexistent information. Inferences from the survey will lead to prioritizing the needs of the population. The most effective type of survey, informant perception, will be utilized to collect information on the experience, background, and knowledge from parents of children with autism (Witkin & Altschuld, 1995). Survey flyers were posted online, via Facebook open group forum pages. Online surveys have the greatest potential to increase response rates since the informants can complete the surveys at their own chosen pace. The results of the surveys were automatically inputted and stored into the survey database, Survey Monkey, decreasing the possibility of data errors. Data analysis will determine gaps in services and population needs, to meet the demands of the community in the identification and accessibility to autism-specific services.

Survey

The survey consisted of quantitative (closed-ended) and qualitative (open-ended) questions. One important characteristic of a needs assessment involves forming a community profile in which the program will be located. The community profile involves collecting population and social demographics. The survey collected population demographic information to gain data about the family and child with ASD such as age, race, ethnicity, education, and income. In addition, social-demographic information of social and health data regarding the informant's experience on the diagnostic process was collected. The development of survey

questions was based on the general findings found during the exploratory phase. See Appendix A for a list of caregiver survey questions.

Survey Participants

Survey informants included those individual's representative of the target population and stakeholders. The criteria for informants included (a) the primary caregiver during the time of initial diagnosis; (b) the current caregiver to a child with ASD; (c) child is between the ages of 0-18 years old and diagnosed with ASD within the last 2 years; (d) child was diagnosed in the Miami-Dade County area; (d) family and child must currently reside in Miami-Dade County. The exclusion criteria for caregivers excluded non-English speaking participants. Caregivers are typically considered the child's parent; however, for the purpose of this research, caregivers will be regarded as the person responsible for the direct care and supervision of the child. The participant criteria were chosen to embody an accurate representation of caregivers of recently diagnosed children with ASD in Miami-Dade County. The ideal representative number of survey participants is five informants.

Caregivers were recruited via survey flyers from Facebook open group forum pages specific for caregivers of children with autism in Miami-Dade County. Survey flyers contained a hyperlink text to the survey URL. See Appendix B for the survey flyer. The surveys were posted on the following Miami-Dade County, autism-specific Facebook group pages; Special Needs Parents Florida, Autism Families of South Florida, ASD Informal Support group, and Special Needs Families Miami. Caregivers signed a consent form to participate in the study. See Appendix C for the consent form. All participants were entered to participate in a lottery raffle. One participant was randomly drawn from a lottery and entitled to a 50-dollar Amazon gift card winning within two weeks of the survey closing.

Data Collection

Data was automatically entered into a data collection program, Survey Monkey. Data-collecting methods yielded raw data. Data was stored on an encrypted password-protected computer. Locked in a drawer in a locked office. Only the researcher has access to this computer. No personal or identification was collected for this research. Data will be stored for 36-months post-study, after that, it will be destroyed through degaussing. Data analysis was used to decipher the data for practical use for program development. Although the needs assessment is a form of survey research, the data analysis resulted in a planning tool for program development rather than as a statistical collection of information. As a result, the needs assessment relies on the identification of the need, significance of the problem, and accessibility to services (Timmreck, 1995). Survey Monkey projected data through charts, tables, and graphs, and once analyzed was presented in an easily understandable manner to stakeholders. The last step of the needs assessment was the interpretation of the data needed for program planning purposes. The purpose of data analysis is to strategize in setting priorities, suggest interventions to address the needs of the population, and propose a program plan to implement solutions.

Chapter IV: Results and Findings

The needs assessment was approved by the Institutional Review Board at Nova South Eastern University: Dr. Pallavi Patel College of Health Care Sciences. The needs assessment was conducted, using an online survey, to assess the perspective of caregivers on the identification and accessibility to autism-specific services in the Miami-Dade County area. Mixed quantitative and qualitative data were collected. The quantitative and qualitative results will be analyzed and interpreted simultaneously, as they are complementary to one another. Along with caregiver perception of the diagnostic process and accessibility to services, population and social

demographic information were collected. The survey questionnaire was managed using an online survey manager, Survey Monkey. All participants were provided with written informed consent. Quantitative data were extracted from the survey questionnaire using Microsoft Excel. Demographic data were analyzed using descriptive statistics to provide profiles for respondents and children with ASD. Qualitative data were extracted verbatim from open-ended questions and analyzed thematically. Data from the survey were collected, analyzed, and interpreted. Data analysis will then lead to determining population-specific community-based priorities, identify possible solutions, and create a plan of action.

Quantitative Data

Miami-Dade County population consists of 20.2% (approximately 504, 279) children under the age of 18 years old (United States QuickFacts, 2019). Given that CDC (2018a) reports the national statistic of ASD to be approximately 1 in 54 children, we can estimate that 9, 338 children in Miami-Dade County are affected by autism.

Profile of Parents

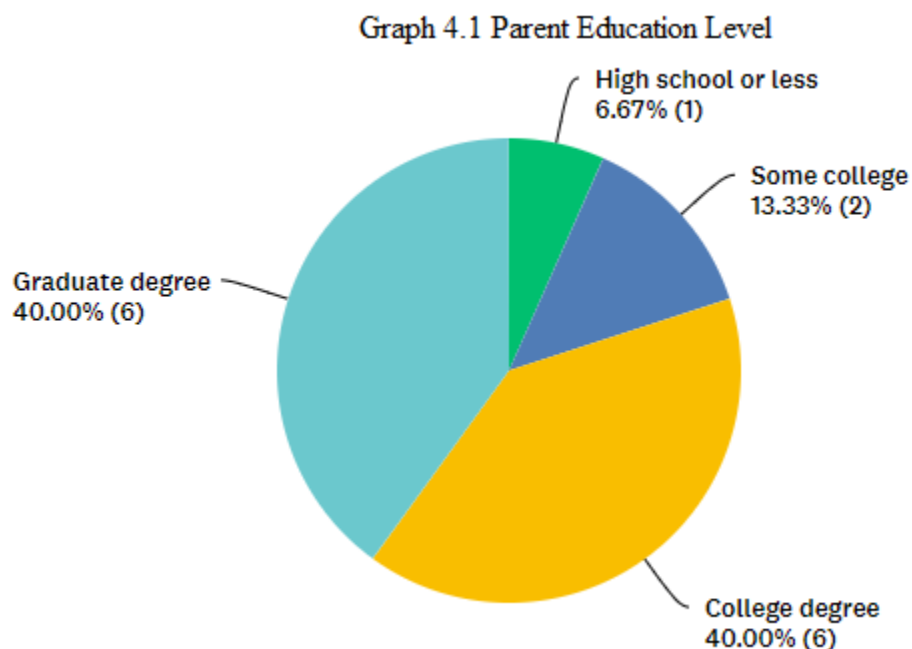
Informants were recruited from, via survey flyers posted on Facebook open group forums specific to families of children with autism, residing in Miami-Dade County. Caregivers of children with ASD diagnosed within the last two years and living in Miami-Dade were invited to participate. The survey questionnaire was open for a period of 13 days. The sample size was $n=24$, which $n=15$ met the inclusion criteria; being the primary caregiver of the child currently and at time of diagnosis, live in Miami-Dade County currently and at the time of diagnosis, and the child was diagnosed with autism within the last two years. Parent and caregiver demographics are presented in table 1. All informants are parents to a child with autism and are married to or living with their partners. The majority of the participant's ($n=14$) primary

language spoken at home is English, while n=1 speaks Spanish. Two participants indicated they have two children diagnosed with autism at home, however, only completed the survey for one of their children.

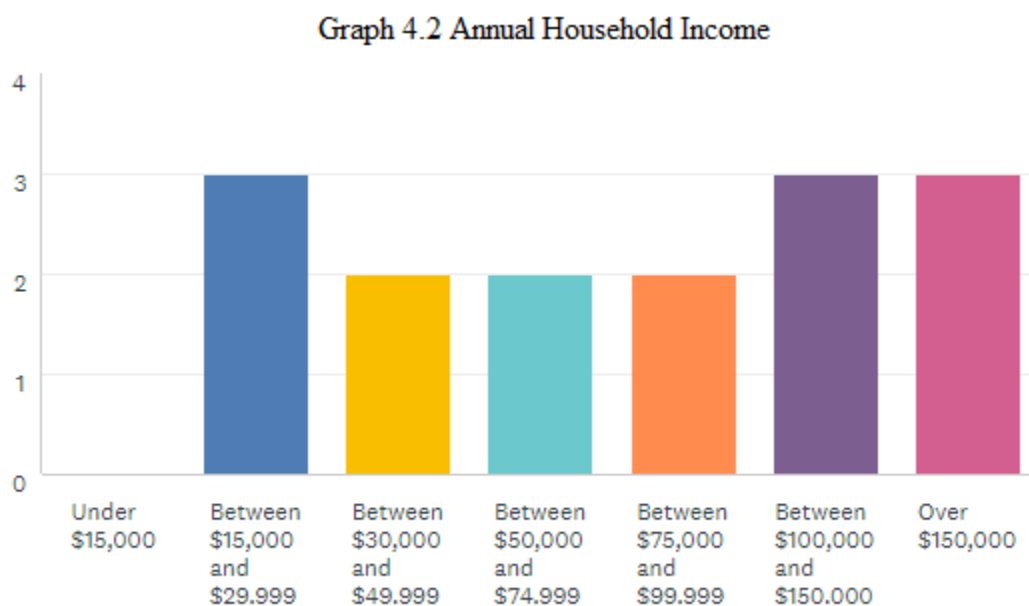
Table 4.1. Demographic Description of Caregivers (n=15)

Informant	Relationship to child	Gender	Age range	Language spoken at home	Children at home	Children with autism in home	Marital status
1	Parent	Female	25-34	English	1	1	Married/ living with partner
2	Parent	Female	25-34	English	2	1	Married/ living with partner
3	Parent	Female	35-44	English	3	2	Married/ living with partner
4	Parent	Female	25-34	English	2	1	Married/ living with partner
5	Parent	Female	45-54	English	1	1	Married/ living with partner
6	Parent	Female	18-24	English	1	1	Married/ living with partner
7	Parent	Female	25-34	English	1	1	Married/ living with partner
8	Parent	Male	25-34	English	1	1	Married/ living with partner
9	Parent	Female	35-44	English	2	1	Married/ living with partner
10	Parent	Female	35-44	Spanish	3	1	Married/ living with partner
11	Parent	Female	18-24	English	2	1	Married/ living with partner
12	Parent	Female	35-44	English	3	1	Married/ living with partner
13	Parent	Female	25-34	English	1	1	Married/ living with partner
14	Parent	Female	45-54	English	2	2	Married/ living with partner
15	Parent	Female	25-34	English	1	1	Married/ living with partner

As shown in Graph 4.1 a high proportion, 80%, of the participants had at least a college degree (n=6 college degree, n=6 graduate degree).



Graph 4.2 represents the annual household income, with n=10 informants making above Miami-Dade County's average household income of \$50,000.



Profile of Children with ASD

Table 2 is representative of the demographic description, as completed by the informants on their child with autism. The male to female ratio is 12:3. The majority of children are of Hispanic or Latino (n=11) ethnicity, while the remaining is of White or Caucasian ethnicity (n=4). The average current age of the children is 3 years and 11 months.

Table 4.2: Demographic Description of Children (n=15)

Informant	Gender	Age (years. months)	Race/ethnicity
1	Male	3.6	Hispanic or Latino
2	Male	2.5	White or Caucasian
3	Male	3	Hispanic or Latino
4	Male	4.2	Hispanic or Latino
5	Female	3.9	Hispanic or Latino
6	Male	3.4	Hispanic or Latino
7	Male	6.4	Hispanic or Latino
8	Male	2	White or Caucasian
9	Male	6	White or Caucasian
10	Female	2.9	Hispanic or Latino
11	Male	3.6	Hispanic or Latino
12	Male	5.11	Hispanic or Latino
13	Male	3.3	Hispanic or Latino
14	Female	5.4	White or Caucasian
15	Male	4	Hispanic or Latino

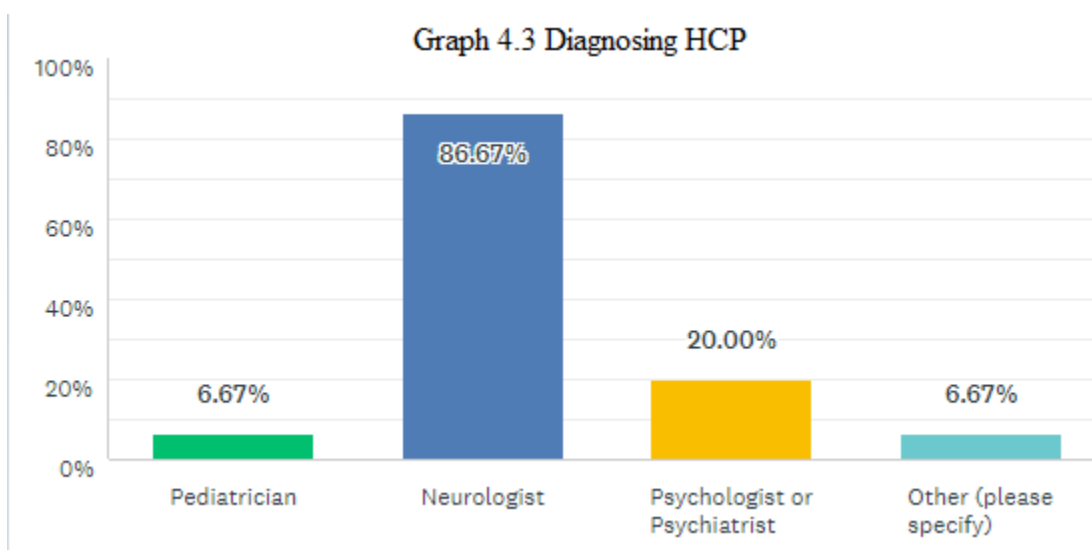
Perception of ASD Diagnostic Process

Table 3 represents the children's age as they progressed through the autism identification phases; from parents recognizing early signs of autisms, parents mentioning concerns to HCP, and finally to the child receiving the diagnosis of ASD. The average age of when the parent reports first noticing signs of autism and when concerns are initially mentioned to HCP are both 1 year and 6 months of age. Based on survey findings, children were diagnosed with autism at 2 years and 9 months on average (Table 3).

Table 4.3: Timespan of Children Ages through Diagnostic Process

Informant	Age of the child when a parent first recognized signs of ASD (years.months)	Age of child when concerns were mentioned to a health professional (years.months)	Age of child when diagnosed with ASD (years.months)
1	1.2	1.2	1.6
2	1.3	1.3	1.9
3	1	1	1.6
4	2	2.6	3.1
5	1.6	2	1.7
6	1.2	1	2.1
7	1.1	2	4
8	3.8	4.1	5.1
9	0.3	1	4.8
10	1	1	2
11	2.3	2	2.6
12	0.6	0.3	4
13	1.6	1.5	2.3
14	2	n/a	3.5
15	2	1.6	2

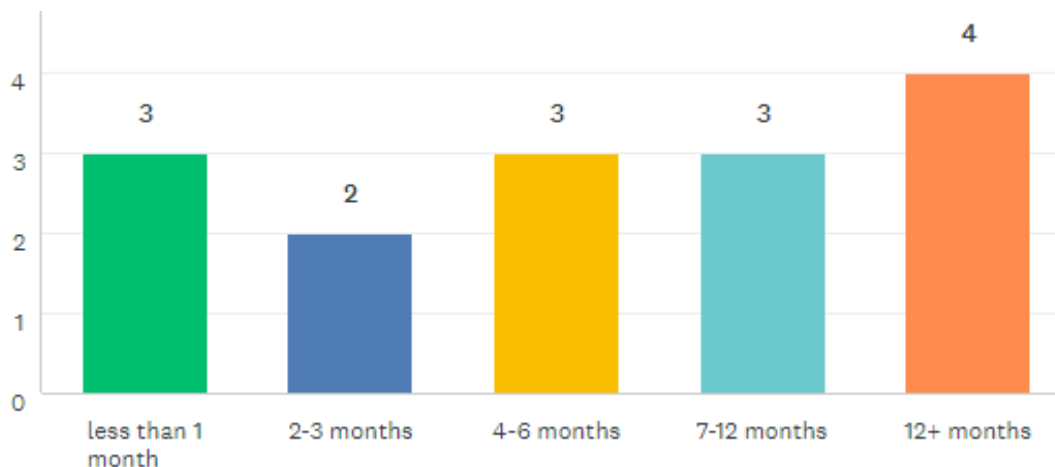
A high proportion of children were diagnosed by the neurologist (n=13), sequentially followed by psychologist or psychiatrist (n=3), pediatrician (n=1), or a multidisciplinary team of a neurologist and expert medical review (n=1).



Parents reported waiting over six months ($n=7$) from the time they initially mentioned autism-specific concerns to their HCP to when their child received the autism diagnosis (Graph 4.4).

Only $n=3$ parents report attaining an ASD diagnosis for their child within three months of mentioning their initial concerns to an HCP.

Graph 4.4: Timespan from Initial Concerns to Diagnosis

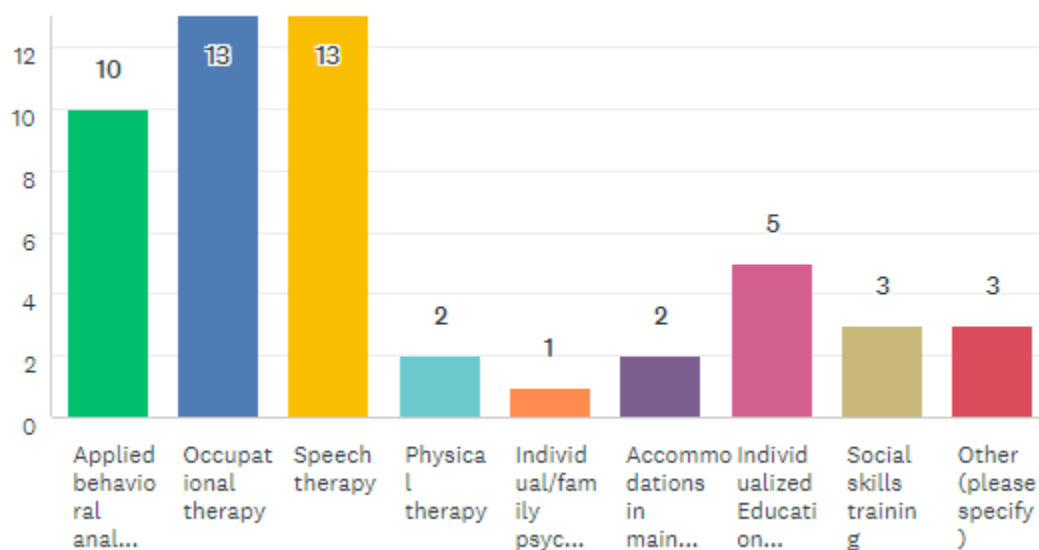


Overall, the majority of parents report feeling somewhat satisfied ($n=7$) with the diagnosis process; while $n=2$ felt mostly satisfied and $n=2$ felt completely satisfied; $n=1$ felt slight satisfied and $n=2$ felt not at all satisfied.

Perception of Autism-Specific Services

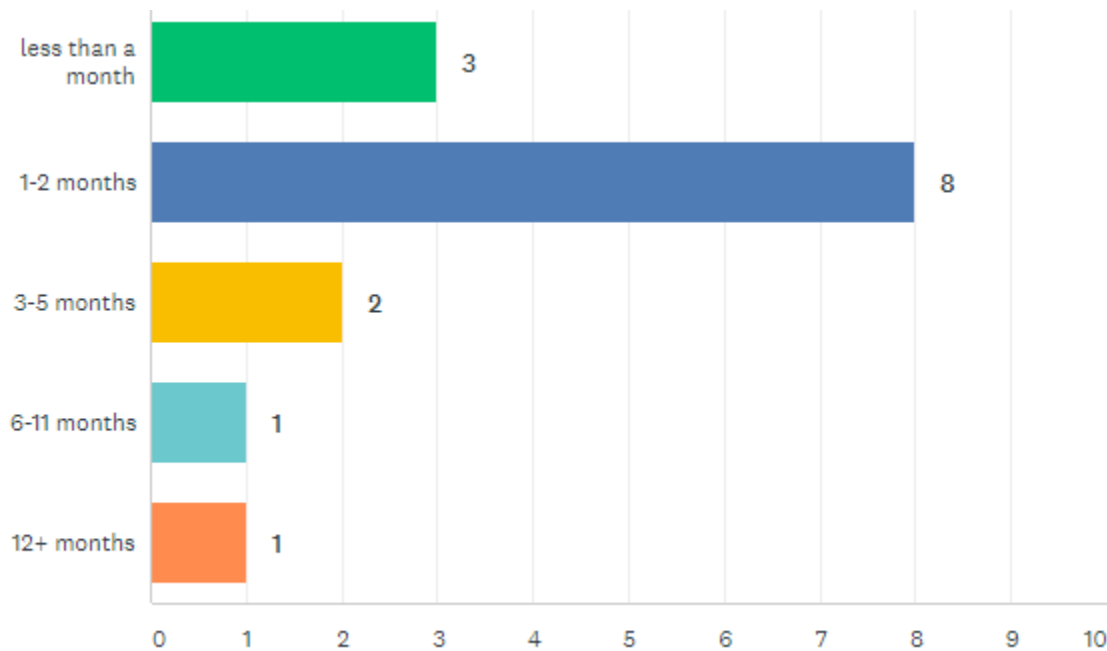
Graph 4.5 represents the services the child with autism is currently receiving. The majority of children are receiving occupational therapy ($n=13$), speech therapy ($n=13$), and applied behavior analysis ($n=10$). A reduced number of children are receiving individual or family psychology ($n=1$), school accommodations in a mainstream classroom ($n=2$), social skills training ($n=3$), and an individualized education program ($n=5$).

Graph 4.5: Services Child Receives



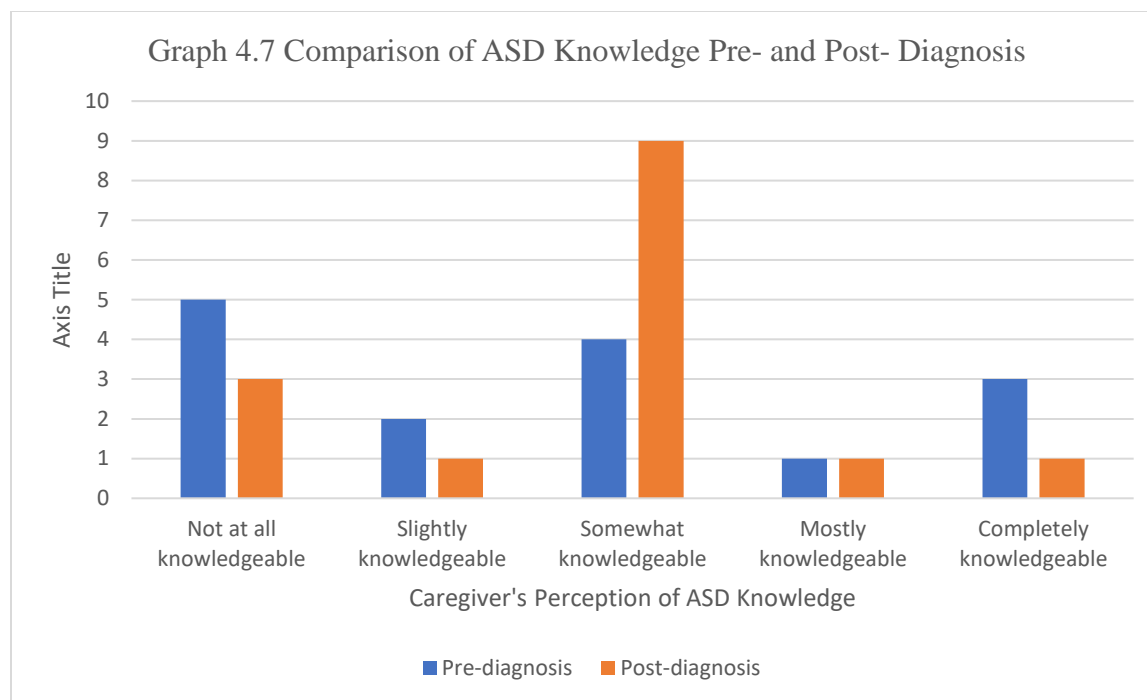
Graph 4.6 represents the length in time from the child's autism diagnosis to when the child was able to access autism-specific services. A high proportion of children were able to access services within less than two months of receiving the autism diagnosis (n=11). 60% of children were able to access EI services prior to receiving the autism diagnosis. The majority of parent's report being completely satisfied (n=5), while only n=2 reported somewhat satisfied and n=2 not at all satisfied with the autism-specific support services their child receives.

Graph 4.6: Timespan to Access Services



Perception of Caregiver Knowledge of Autism

As shown in Graph 4.7, parents report an increase in perceived knowledge of autism from not at all and slightly to somewhat from pre-diagnosis (n=5, n=2, n=4) compared to post-diagnosis (n=3, n=1, n=9). Simultaneously, parents report feeling less knowledgeable post-diagnosis of autism; while the parents that reported feeling completely knowledgeable decreased from pre-diagnosis (n=3), as compared to post-diagnosis (n=1).



Qualitative Themes

The survey consisted of five open-ended questions for qualitative collection of information. The purpose of the open-ended questions was to further elaborate on the perceived feelings and attitudes, which would otherwise not be accomplished through closed-ended questions. For each open-ended question, themes were developed to characterize particular perceptions. The themes that emerged regarding HCP's response to parents' initial concerns include response error, passive response, and active response (Table 4).

Table 4.4 Qualitative Themes and Examples of HCP's Response to Concerns

Theme	Example
Response error	"He is a boy and they develop slower"
Passive response	"He may just grow out of the quirks and intensity"
Active response	"prescription for therapy"

Other qualitative themes that emerged concerning the overall process include a disconnection, lack of autism knowledge, accusation, and frustration. Parents felt disconnection

with their HCP while communicating their concerns and attempting to access needed referrals for specialists. Other times, parents reported HCPs not being knowledgeable in autism or in lacking the ability to inform and explain autism to parents. A few indicated the interaction with the HCP made them feel they were to blame or were responsible for the child displaying red flags of autism. Lastly, parents expressed frustration with the diagnostic process of autism and the accessibility to services.

Data Interpretation

An integrative approach was used, by combining the findings from both the quantitative and qualitative research, to provide more insightful understandings. The use of qualitative research is useful to identify issues that would not otherwise be obtained through quantitative research. The combination of both data types further enriched the research findings.

Finding 1: Delay from Noticeable Red Flags to ASD Diagnosis

Osterling et al. (2002) support that children can be reliably diagnosed at 12 months of age. Consistent with research by the CDC (2018a), this study supports that children with ASD receive a delayed diagnosis, despite the fact that they are substantially younger when parents were first concerned with their development. While the survey findings support that there are delays in diagnosing children with autism, the length of time varied throughout the process compared to research (Table 5). The literature review revealed that parents begin to notice early red flags of autism at six months of age; in comparison, the survey found the median age to be later, at one year and six months of age. According to the CDC (2018a) and Planche et al. (2004), the median age of children diagnosed with ASD is three years and six months; while the survey findings reported the median age to be two years and nine months. The survey revealed

the average length in time from when parents first notice signs to the ASD diagnosis was shorter, at one year and three months, in comparison to the CDC (2018a) findings of three years.

Table 4.5: Research Comparison of Timespane from Concerns to Diagnosis

	CDC (2018a)	This study
Median Age of Noticeable ASD Signs	6 months	1 year, 6 months
Median Age of ASD Diagnosis	3 years, 6 months	2 years, 9 months
Average Length of Time in Delay	3 years	1 year, 3 months

These findings support that there are barriers that interfere with the diagnosis process from the time parents first notice red flags to when the child is diagnosed with ASD. This discovery supports the need for providing education to HCPs, in addition to caregiver educational resources, to improve the timeliness, rate and reliability of the diagnostic process; therefore, improve the child's opportunity for accessing EI services associated with positive outcomes.

Finding 2: Caregiver Dissatisfaction

As a result of feeling disconnected throughout the process, qualitative findings exposed parent's dissatisfaction with the current diagnostic process. These findings parallel the literature regarding parents perceiving the response from HCP's as passive or inaccurate (Barnard-Bral et al.; 2017; Daniels & Mandell, 2014; Wong et al., 2017). Parents report that HCP's responded passively, by dismissing their concerns and insisting that as the child ages he or she will mature out of these red flag concerns. In other instances, the HCP inaccurately informed the parents that these concerns are related to his gender, as males develop more slowly than females. Similar to findings from Wong et al. (2017), the lack of proactive response and disconnect from HCPs contributed to the child's delay accessing a diagnosis and referral for services. The caregiver's

level of satisfaction is correlated to the HCP's response; therefore, education is imperative for proactive responses for improved family satisfaction.

Findings 3: Lack of ASD Knowledge

There were inconsistencies in Likert scale responses regarding perceived knowledge of ASD, pre- and post-diagnosis. The comparison of both perceptions revealed mixed reactions regarding confidence in the knowledge of autism. Ironically, as parents were informed of the child's diagnosis, autism perception increased from not at all to somewhat knowledgeable. However, on the other end of the spectrum, as parents were informed of the child's autism diagnosis, their perception reduced from being completely knowledgeable to somewhat, indicating decreased understanding of autism with the diagnosis. These findings expand off of the literature regarding caregiver's confusion of parents making sense of autism (Zuckerman et al., 2015). Parents report relying on HCPs as their primary source of education but are unsatisfied with the outcomes. This sentiment is reflected by parents indicating a desire for HCPs needing more education on autism, and instructing families on the process and availability of resources. There is a need for easily accessible, evidence-based caregiver education on autism. Additionally, caregivers would benefit from HCPs providing proactive education and resources to support both themselves and the child throughout the diagnosis and treatment process.

Several findings emerged from the caregiver survey questionnaire. The current traditional medical model is not meeting the needs of children and their families. Current findings support the current approach is a pillar in delaying the child's autism diagnosis, caregiver dissatisfaction, and reduced ASD knowledge. All 15 survey informants revealed a level of dissatisfaction with the current diagnosis process and accessibility to services, indicating a need for transformation.

Chapter V: Discussion

This needs assessment sought to understand the barriers associated with identifying children with autism, which can delay accessibility to EI services. This delay directly impacts their participation in occupational engagement. This research was inspired by a desire to understand the barriers associated with delayed identification of children with autism, in order to develop a community-based program model to meet the needs of this population. The process of prioritizing needs will help guide the development of solutions and create a plan of action.

Determining Priorities

A systems theory could be used to identify gaps and barriers as defined by the literature review. Based on previous research, the system factors include; (a) inputs of formal developmental screening tools, time constraints, sociodemographic factors, and structural and operational barriers; (b) outputs of the rate and accuracy of diagnosing children with ASD and commencement of ASD interventions; and (c) feedback loops of lack of resources, accessibility to services, and caregiver education which return as inputs into the system.

The quantitative and qualitative survey data completed by parents of children with autism in Miami-Dade County were consistent with the literature regarding the rate and accuracy of autism identification and lack of autism education. This study identified a new concern of decreased level of parent satisfaction with the process. It is necessary to identify the needs that are of the highest priority of the community.

Priority 1. Parents indicate a lack of HCPs and self-education on early signs of autism awareness. As the number of children with autism rises, it is imperative to educate families and HCPs on the importance of identifying red flags of autism for accessibility to EI services.

Priority 2. The data also supports a need for HCPs to proactively respond to the concerns of caregivers. An immediate response from HCPs would decrease the length of time from the parent's initial concern to the diagnosis. This proactive response would contribute to the child accessing EI services at an earlier age, which is directly correlated to positive outcomes, and an increase of parent satisfaction.

Priority 3. Data from the Likert scales indicate inconsistencies regarding parents perceived knowledge of ASD pre- and post-diagnosis. This variation may be a result of parents perceiving to be knowledgeable of ASD signs prior to their child being diagnosed; however, post-diagnosis, parents may experience a lesser perceived knowledge of how to care for their child with autism. This difference also reflects the parents understanding of the diagnostic process and the accessibility to resources and services.

Solutions

Focusing on a family-centered, occupational engagement approach will transform the current traditional model into a holistic community model. The findings offer evidence to support a family-centered system using an OCAC framework that highlights the need for occupational engagement for children with autism. Advocacy for social justice is needed throughout the process to empower children, families and HCPs. Children with autism are at a greater risk for the disparity in occupational engagement, as compared to their peers. As mentioned, the fundamental premise of occupation and measure of health is dependent upon an individual's ability to engage in meaningful occupations, regardless of disability. Therefore, it is essential to identify solutions that promote meaningful engagement of occupations for the autism community in Miami-Dade County.

Promotion of a Family-Centered System

An FCC approach supports families as equal contributors in diagnosing children with ASD through a family-provider partnership. The purpose of this partnership is to improve communication between the family and HCP, contribute to educating the family on their child's diagnosis of autism and services available, and improve the HCP's knowledge of the family's specific needs and preferences. Promotion of all three factors will lead to research supporting an FCC model for a greater positive experience for the child and family, as well as promote positive outcomes for the child (Carbone et al., 2013; Gabovitch & Curtin, 2009). The core concepts of FCC reflect dignity and respect, participation, collaboration, and sharing of information

To resolve the issues found in this study, the concepts of FCC, dignity, and respect, participation, collaboration, and sharing of information need to be the foundation on which future programs are built on. Johnson (2000) found that organizational support is a barrier to implementing FCC for children with autism in practice. To promote an FCC approach in practice, there needs to be an organizational change which makes the diagnostic process family-centered and facilitates collaboration between the HCPs and parents. Research supports a need for HCPs to treat families with dignity and respect by actively listening and responding promptly to caregiver concerns. Active listening promotes the ethical principles of beneficence, as the HCP is acting in a way to promote the welfare of the family and the child with autism (Occupational Therapy Code of Ethics, 2015). Families with increased self-advocacy will experience better health, well-being, and occupational engagement (AOTA, 2014). Therefore, it is essential to teach families to self-advocate, enabling them to be key contributors to their child's diagnostic process.

The research revealed that both HCPs and caregivers lack ASD knowledge. Caregivers' perception of HCP's unresponsiveness to concerns could be contributed to HCP's lack of ASD education. HCPs are unable to engage in information sharing if they are not knowledgeable themselves. In addition, caregivers indicated a need for ASD knowledge, pre- and post-diagnosis. Prior to their child being diagnosed with ASD, families need to be educated on red flag signs of autism and the expected typical development of children. This knowledge-base will facilitate greater awareness of nontypical development, which can prompt them to address their concerns with the HCP. Secondly, families need additional education on the post-diagnosis process, which includes knowledge of available resources and accessibility to services. Encouraging ASD knowledge from both partners, the HCP and family will allow for efficient information sharing and collaboration, which facilitates a mutually beneficiary relationship. It is imperative that solutions are focused on promoting HCP and family ASD education, along with encouraging an active listening skill set by HCPs.

Integration of OCAC Framework

Likewise, to FCC, the OCAC also supports a top-down, holistic approach for care. The OCAC supports gathering information on the child's daily occupational engagement, in the context in which these occupations occur (Brown & Chien, 2010). This encourages evaluating the child in their natural environment, either by observation or by parent interview. As mentioned, social participation and play are key occupations for children, and children with ASD have difficulties in these occupations. Therefore, it is beneficial to observe the child engaging in these occupations, in their natural context, to more accurately identify noticeable red flags of autism. The process begins by recognizing that the child has difficulty participating in these occupations; then performing an analysis to identify the contributing factors for nonengagement.

This framework promotes self-empowerment through the family's role of communication and active participation in identifying the needs and support required for occupational engagement. Families will act as key informants in providing information to HCPs, regarding the supports and barriers which impact the child's ability to participate in meaningful occupations.

Merger of Biopsychosocial Model

The Biopsychosocial model will be used to replace the pre-existing traditional medical model. This model will further support a holistic approach, while primarily focusing on how influential factors impact health. Since occupational engagement is the ultimate indication of health and function, it should be the primary focus during a child's evaluation (World Health Organization, 2001). Literature does not support HCP's assessing the child's occupational engagement during ASD screenings or well-child visits. This may be a result of it solely being the expertise of occupational therapists. Occupational therapy practitioners are sufficiently skilled to evaluate and treat occupational performance issues associated with ASD (AOTA, 2014; Tanner et al., 2015). Using this client-centered, holistic approach, occupational therapists can analyze the biological, psychological, and social influences which impact a child's occupational engagement to health.

Proposed Plan of Action

Early and accurate diagnosis plays a crucial role in outcomes and improvement of occupational engagement in the child. Despite not being diagnosticians, occupational therapists play an essential role in identifying children with autism through the lens of occupational engagement. In addition to our unique perspective, occupational therapists provide direct care and support to families that have concerns regarding their child's atypical behaviors (Gibbs, 2017). Occupational therapy originated in mental health, using engagement in meaningful

occupations to address an individuals' physical, cognitive, psychological, and social factors (AOTA, 2017c). The comprehensive holistic approach utilized by occupational therapists compliments the use of an FCC to develop a comprehensive autism process conceptualized from the foundational principles of occupational therapy.

Although the role of occupational therapy is to focus on the client's subjective experience from a holistic perspective, occupational therapists are rarely consulted during the child's developmental screenings. Typically, the role of an occupational therapist comes after the ASD diagnosis, during the rehabilitation phase. Although occupational therapy expanded into a clinical rehabilitation setting, its professional holistic philosophy remains the same, occupational engagement as a measure of health and well-being (AOTA, 2011). Occupational therapy considers all the Biopsychosocial model factors (biological, psychological, and social) when developing individualized treatment plans. A similar comprehensive lens can be utilized to conduct a holistic inclusive assessment of the child during the identification process. Occupational therapy's holistic approach focuses on the child's and family's personal experience, the child's ability to function daily, and how the disorder impacts the child and family (Donnelly, Brenchley, Crawford, & Letts, 2014). This diversified approach allows occupational therapy to move beyond a narrowly defined medical model, focused on biological factors, to consider a broader range of factors that significantly impact a clinical diagnosis. Early recognition and identification of ASD will help families in devising well-constructed, streamlined, family-center plans for their child. Potential roles for occupational therapists in improving the efficiency of identifying autism and accessibility to services include:

Community-Based Screenings

Community-based screenings could address the issues of delays often found from passive or lack of responsiveness from HCPs, regarding caregiver concerns. To address the challenge of early identification of autism, occupational therapists can provide community-based screenings to facilitate early access to referrals. The benefit of a community-based screening is that it allows for the opportunity to observe the child in his or her natural ecological setting. The OCAC framework supports gathering information in a naturalistic environment for an accurate representation of a child's occupational engagement. The child's natural environment includes assessing the child at home, daycare, or community programs. Occupational therapists can observe the child during their occupations of social participation and play, to recognize any deficits or red flags, which may require referral to a diagnosis professional, for an autism specific assessment.

Occupational Therapy in Primary Care

Since the occupational therapy practitioners are broadly trained in conceptualizing a holistic lens to observe a child's development, health promotion, and occupational engagement, occupational therapists could be fundamental to reducing fragmentation in the health care process. Occupational therapists can work collaboratively with HCPs to endorse early identification of autism. Occupational therapy's role in primary care can include providing holistic services; focused on how autism symptoms are affecting occupational engagement and participation, improve patient satisfaction by addressing a broader array of caregiver concerns, other than just on symptom reduction, and provide community group education sessions to address prevalent issues among the population being served. To effectively facilitate or promote change, a prompt response to the parents' initial concern is needed. This key opportunity is

during the child's visit to the HCP since the concern prompted the visit. Therefore, to be fully effective, the full-time presence of an occupational therapy practitioner, in a HCP's office, is necessary to gather a holistic and comprehensive understanding of the child and family.

Occupational therapists can work as a coordinated team with HCPs, to assess the child, identify issues interfering with occupational engagement, and collaborate to determine the appropriate referrals and recommendations. This unified approach encourages the inclusion of a team, as a whole, to meet the needs of the child and family to promote occupational engagement.

Advocacy

Through advocacy, occupational therapists can promote autism awareness and health justice. Organizational and structural barriers that negatively impact the diagnosis of autism has been identified as gaps in the process. From an ecological system perspective, changes at an organization level can influence individual professions and subsequently the family and child with autism (Bronfenbrenner, 2005). Occupational therapists can speak out to reform organizational and healthcare policies to promote a better quality of care and HCP response. This can be achieved by occupational therapists sponsoring opportunities for in-services and professional development for HCPs, which focus on early identification of autism, autism-specific assessment tools, and educational and referral resources; but more importantly, promoting families at being the center of care, through the development of active listening skills and proactive response to caregiver concerns. These structural changes will reduce organizational barriers identified in research and prompt accurate and reliable autism diagnoses.

By embracing the nation's public health agenda, occupational therapists can also take an active role in eliminating health disparities identified in the literature. This elimination of inequalities can be achieved by occupational therapists providing support to families in

communities that experience greater disparity. Support includes community-funded screenings and caregiver education on red flags of autism and accessibility to community programs and resources. This advocacy offers the opportunity to promote the importance of occupational engagement on a child's health and early identification of autism for families that experience greater barriers. Occupational therapy's advocacy involvement in organizational policy reform and within communities that experience health inequalities can better ensure equitable access to early identification of ASD and accessibility to EI.

Caregiver Education

While autism-specific education tools are made readily available to the community, research shows parents are not aware of these learning opportunities. Occupational therapists can collaborate with these autism-specific movements to bring awareness to these campaigns. An example is CDC's (2012) "Learn the Signs. Act Early" public awareness campaign aimed to educate families about child development, including early signs of ASD and encourages developmental screening and EI. Another resource, AOTA (2020), educates the community and advances the occupational therapy profession by providing autism-specific resources and serving as an autism advocate. Occupational therapists can further progress this ongoing relationship with the CDC and AOTA to enhance public education in ASD. Occupational therapists can provide strategies to community members in accessing and sharing the CDC's "Learn the Signs. Act Early" and AOTA's autism educational resources. Increased education will positively correlate to self-advocacy, and as a result, families will experience greater health, well-being, and occupational engagement (AOTA, 2014). Through collaboration with pre-existing educational resources, occupational therapists can bring awareness to the community on autism education.

Limitations

There are several limitations to this capstone project. During the time of data collection, there was a worldwide pandemic. This altered the initial methods plan to collect data information from HCPs and occupational therapists, in addition to caregivers, for a more comprehensive assessment. There was a small size sample of 15-qualifying caregivers limited to Miami-Dade County, so the results of this project must be applied to a larger population cautiously.

An additional limitation of this study was the lack of diversity amongst demographics. Initially, survey flyers were to be placed in various pediatric settings across Miami-Dade County, such as pediatrician offices, daycares, pediatric, rehabilitation settings, and autism community organizations. Instead, surveys were distributed to Facebook open group forums, which limited participants to those that had access to a computer and were part of this social online group. The majority of participants were educated parents, of the upper or middle class. The results of this study could be significantly altered based upon demographics.

Implications for the Future Research

This comprehensive needs assessment offers a transformational approach to identifying children with autism, for improved engagement in meaningful occupations. The plan of action is grounded in self-advocacy, family-centered principles, which allow children and families with the opportunity to eliminate health disparities observed in the autism community. Literature indicates that parents of children with autism are dissatisfied with the autism process and accessibility to services. These features reduce the likelihood of children and families receiving the tools needed for optimal occupational engagement. The plan of action will promote self-advocacy and education to support families and HCPs in making reliable, proactive decisions to become better advocates for children with autism. This needs assessment also features

occupational therapy's role in identifying children with autism through the lens of occupational engagement. In addition, the study demonstrates a need for advocacy and knowledge within the community regarding autism awareness and the tools available.

Future research should further explore the perspectives of HCPs, in-depth perspectives on the satisfaction of caregivers, broader demographics, and investigate the efficacy of legislative factors for a more comprehensive assessment. More research on occupational therapy's role in identifying children with autism and implications for autism education is necessary to develop a successful community program to meet the needs of the autism population.

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Appendix A

Survey Questions

Parent and Caregiver Interest and Informed Consent Letter**Participant Letter for Anonymous Surveys****NSU Consent to be in a Research Study Entitled*****Accessing Services: Occupational Therapy's Role in Advocating for Autism Diagnosis*****Who is doing this research study?**

This person doing this study is Kristina Paula with Dr. Pallavi Patel College of Health Care Science. This will be helped by Dr. Debra Misrahi.

Why are you asking me to be in this research study?

You are being asked to take part in this research study because you are (a) must be a current caregiver to a child with ASD between the ages of 5-18 years old who was diagnosed after the age of 3 within the last 2 years or a caregiver of a child with ASD under the age of 4 who was diagnosed before the age of 3; (b) must have been the primary caregiver during the time of initial diagnosis; (c) must have been diagnosed in South Florida; and (d) must currently live in the South Florida region.

Why is this research being done?

The purpose of this study is to investigate the barriers which result in the delay of detection of autism and to define occupational therapy's role in advocating for families for early diagnosis.

What will I be doing if I agree to be in this research study?

You will be taking a one-time, anonymous survey. The survey will take approximately 10 minutes to complete.

Are there possible risks and discomforts to me?

This research study involves minimal risk to you. To the best of our knowledge, the things you will be doing have no more risk of harm than you would have in everyday life.

What happens if I do not want to be in this research study?

You can decide not to participate in this research and it will not be held against you. You can exit the survey at any time.

Will it cost me anything? Will I get paid for being in the study?

There is no cost for participation in this study. Participation is voluntary and no payment will be provided.

How will you keep my information private?

Your responses are anonymous. Information we learn about you in this research study will be handled in a confidential manner, within the limits of the law. No personal or identification will be collected for this research. This data will be available to the researcher, the Institutional Review Board and other representatives of this institution, and any granting agencies (if applicable). All confidential data will be kept securely on an encrypted password protected computer, locked in a drawer in a locked office. All data will be kept for 36 months from the end of the study and destroyed after that time through degaussing.

Who can I talk to about the study?

If you have questions, you can contact Kristina Paula at 305-609-3534 or Dr. Debra Misrahi at 305-632-1795.

If you have questions about the study but want to talk to someone else who is not a part of the study, you can call the Nova Southeastern University Institutional Review Board (IRB) at (954) 262-5369 or toll free at 1-866-499-0790 or email at IRB@nova.edu.

1. Do you understand and do you want to be in the study?

If you have read the above information and voluntarily wish to participate in this research study please select agree to continue.

- ☐ Agree
- ☐ Disagree

The Perspectives of Caregivers of Children with Autism

*** 2. Your relationship to the child**

- ☐ Parent
- ☐ Other relative
- ☐ Primary guardian/caregiver

*** 3. Your gender**

- ☐ Male
- ☐ Female

*** 4. Your age**

- ☐ Under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65+

*** 5. Do you and your child live in South Florida?**

- ☐ Yes
- ☐ No

* 6. What language is spoken at home?

- ☐ English
- ☐ Spanish
- ☐ other

* 7. Number of children in your home?

* 8. Number of children with autism in your home?

* 9. What is your highest level of education?

- ☐ High school or less
- ☐ Some college
- ☐ College degree
- ☐ Graduate degree

* 10. Marital status

- ☐ Married/living with partner
- ☐ Single
- ☐ Separated/divorced
- ☐ Widowed

*** 11. Annual household income**

- ☐ Under \$15,000
- ☐ Between \$15,000 and \$29,999
- ☐ Between \$30,000 and \$49,999
- ☐ Between \$50,000 and \$74,999
- ☐ Between \$75,000 and \$99,999
- ☐ Between \$100,000 and \$150,000
- ☐ Over \$150,000

*** 12. The gender of your child with autism**

- ☐ Male
- ☐ Female

*** 13. What is the current age of your child diagnosed with autism spectrum disorder (ASD)?**

Years

Months

* 14. What race/ethnicity is your child with ASD?

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Asian or Asian American
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Another race

* 15. How old was your child when you recognized he or she might have a problem?

Years

Months

* 16. How old was your child when he/she was diagnosed with autism?

Years

Months

* 17. How old was your child when you first brought up concerns to your child's pediatrician or other health professional?

Years

Months

I did not bring up
concerns to my
healthcare
provider

18. When you mentioned your concerns, what was the initial response from your healthcare provider?

* 19. Who diagnosed your child with ASD?

- ☐ Pediatrician
- ☐ Neurologist
- ☐ Psychologist or Psychiatrist
- ☐ Other (please specify)

* 20. How long from the time you initially discussed your concerns with the pediatrician to when your child was formally diagnosed with ASD?

- ☐ less than 1 month
- ☐ 2-3 months
- ☐ 4-6 months
- ☐ 7-12 months
- ☐ 12+ months

* 21. How many years/months has it been since your child's diagnosis?

Years	<input type="text"/>
Months	<input type="text"/>

22. How satisfied were you with the diagnosis process?

Not at all satisfied	Slightly satisfied	Somewhat satisfied	Mostly satisfied	Completely satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 23. Which services is your child currently receiving or previously sought?

- ☐ Applied behavioral analysis (ABA)
- ☐ Occupational therapy
- ☐ Speech therapy
- ☐ Feeding and Swallowing therapy
- ☐ Physical therapy
- ☐ Individual/family psychology
- ☐ Nutritionist
- ☐ Family support group
- ☐ Accommodations in mainstream classroom
- ☐ Individualized Education Program/504 meetings
- ☐ Social skills training
- ☐ Picture Exchange Communication System
- ☐ Other (please specify)

24. After your child's diagnosis, how long did it take to access services?

- ☐ less than a month
- ☐ 1-2 months
- ☐ 3-5 months
- ☐ 6-11 months
- ☐ 12+ months

25. Did your child receive early intervention services prior to being diagnosed with ASD?

☐ Yes

☐ No

* 26. How satisfied are you with the support services your child receives?

Not at all satisfied	Slightly satisfied	Somewhat satisfied	Mostly satisfied	Completely satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 27. Have you had any training related to parenting your child with autism?

☐ Yes

☐ No

☐ If so, name or briefly describe the training

* 28. Prior to your child being diagnosed, how much knowledge of autism did you know?

Not at all knowledgeable	Slightly knowledgeable	Somewhat knowledgeable	Mostly knowledgeable	Completely knowledgeable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 29. After being given the diagnosis, how informed were you of your child's diagnosis and services available?

Not at all knowledgeable	Slightly knowledgeable	Somewhat knowledgeable	Mostly knowledgeable	Completely knowledgeable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 30. If there is anything else you would like to tell us about your experience during the diagnosis process as a parent of a child with autism, you may enter your comments in the box below.

Appendix B

Survey Flyer



Participants Needed for Research Study on Autism Diagnosis.

This research seeks to discover parent's perspectives on the diagnosis process of Autism.

You May Qualify if You

- Are a parent or caregiver of a child diagnosed with autism within the last 2 years
- Live in South Florida
- Speak English

Participation Involves

- A short 10-15-minute survey
- Survey will consist of collecting demographic information and perception of your child's diagnosis process of autism.

Survey Monkey URL:

<https://www.surveymonkey.com/r/A50Spectrum>

FOR MORE INFORMATION

Please contact Kristina Paula at 305-609-3334, email KP22T@nova.edu.

Potential Benefits

- Participating in this study may impact awareness and advocacy for the autism population.
- Participants will be eligible for drawing of **\$50 amazon gift card**. An email address is required to participate in the gift card raffle.



The raffle will be conducted with compliance to the Florida Gambling laws (Florida Statute 818.0000) after completion of the survey and data. NO PURCHASE NECESSARY TO ENTER OR WIN A PRIZE. Purchase or research participation will not increase your chances of winning. The raffle entry period begins at 8:00 a.m. Eastern Time (ET) on 8/18/20 and ends at 11:00 p.m. ET on 8/28/20. You may enter the raffle drawing one time. The drawing will be held on 8/28/20 at 8:00 p.m. ET and the winner will be selected randomly via <https://www.randomizer.com/randomizer.php>. The prize is one individual Amazon gift card, valued at \$50. Funding for prize provided by researcher, Kristina Paula.

- Raffle winners will not be predetermined; they will be selected by random selection.
- Participation in research activities will not be required as a condition of entry for the raffle.
- The raffle drawing will not be conducted based on a minimum number of participants engaged in research activities.
- The date, time, or location of the raffle drawing will not be rescheduled or changed for any reason.
- Raffle entrants who have not participated in research activities will be allowed to participate in the raffle exactly as if they entered solely and their entry forms cannot be arbitrarily removed, disqualified, disallowed, or rejected. Discrimination in any manner between raffle entrants who participated in research activities and those who did not is strictly prohibited.
- The raffle winner will be promptly notified at the location of the raffle drawing or via email if not present that he or she has won the raffle.
- The raffle prize will be awarded as stated or advertised.

Appendix C

Consent Form

**OCCUPATIONAL THERAPY
DR.O.T. AND PH.D. POST PROFESSIONAL PROGRAMS**

3200 South University Drive
Fort Lauderdale, Florida 33328-2018
PHONE: (954) 262-1242
800-356-0026, ext. 1242
WEB: nova.edu/ot

Participant Letter for Anonymous Surveys**NSU Consent to be in a Research Study Entitled**

Accessing Services: Occupational Therapy's Role in Advocating for Autism Diagnosis

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You can decide not to participate in this research and it will not be held against you. You can exit the survey at any time.

Will it cost me anything? Will I get paid for being in the study?

There is no cost for participation in this study. Participates have the option to enroll in lottery win \$50 Amazon gift card.

How will you keep my information private?

Your responses are anonymous. Information we learn about you in this research study will be handled in a confidential manner, within the limits of the law. No personal or identification will be collected for this research. This data will be available to the researcher, the Institutional Review Board and other representatives of this institution, and any granting agencies (if applicable). All confidential data will be kept securely on an encrypted password protected computer, locked in a drawer in a locked office. All data will be kept for 36 months from the end of the study and destroyed after that time through degaussing.

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