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Disparities in Autism Diagnoses: The Role of Physicians, Schools, and Families

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Abstract: Early intervention is crucial for improved outcomes for individuals with autism spectrum disorder (ASD). Clear disparities exist, however, within rates and patterns of diagnosis such that underserved communities do not receive the same support as those with better access to healthcare. These disparities fall significantly along racial and socioeconomic lines, and diagnostic disparities lead directly into disparate treatment and outcomes for individuals with ASD. This project investigates the role of healthcare providers, schools, early childhood educators, and families in the identification and diagnosis of ASD. This research includes conversations with pediatricians, psychiatrists, early childhood educators, and experts in the field of autism in order to gather background information and determine potential directions of research, explored through a review of the literature. Effective strategies for partnerships will be explored and described, along with typical challenges to meaningful collaboration. Generally, the purpose of this capstone is to identify ways to create productive partnerships and systems to reduce disparities in early ASD diagnoses.

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Author's Note

My interest in autism was sparked by a volunteer experience beginning during my first year at Yale. I had the privilege to join the Yale Volunteers in Public Schools program, through which I spent a few hours a week working with the special education teachers and their students at a local public elementary school. I spent much of my time with one student in particular, who I will call James. James and I met every Friday afternoon, one-on-one, and spent our hour and a half together catching up about the week and working our way through some schoolwork from his regular classroom or the special education teacher. Working with James provided me with some insight into the experience of a student with autism in the New Haven public schools, as well as a first experience working with individuals on the autism spectrum in general.

I was interested in learning more, and so spent my summer working for the Virginia Institute of Autism (VIA), an organization dedicated to providing a full range of services for individuals with ASD. I spent my mornings in the early intervention outpatient clinic, observing and working with children ages two to five who were receiving behavioral and educational services to prepare them for integration into regular schooling. For children requiring more services than could be provided in other schools, VIA has a school specifically for individuals with autism, where I spent my afternoons in a classroom of middle and high school students. I was impressed daily by the commitment of the teachers, and also the structure of the programming at VIA, which left me thinking a lot about the differences in what I observed there versus in the New Haven elementary school. James spent all but a few hours a week in a classroom with 25 other students and just one teacher, resulting in little individual support, especially when compared to the nearly constant one-on-one care received at VIA. Though treatment for every individual with autism is different, and there are certainly a variety of

appropriate settings based on individual needs, I felt as though the support James was receiving in New Haven was inadequate, especially in contrast to the high-quality, data-driven, individualized care received by the students at VIA.

In my sophomore year, I continued to work with James and found myself researching more and more about autism and writing about the condition whenever I had the opportunity in my classes. In developing ideas for my capstone, I knew I wanted to continue this research. I was also interested in investigating the relationship between medicine and education, a driver in my interest in the Education Studies program at Yale, as well as my aspirations of medical school. In trying to tie these interests together, I landed on studying the diagnosis of autism. As I hope my paper explains, an early and accurate diagnosis is a crucial step towards obtaining treatment and support for individuals with ASD. Disparities in diagnosis lead to disparities in treatment which, crucially, contribute to disparities in lived experiences and outcomes at the individual level. A diagnosis of autism can, and often does, fall at the intersection of medicine and education, with a team of individuals working together to support children and their families. I remain excited about the possibilities for partnerships between physicians and educators to better support individuals with ASD and their families to access and navigate the diagnostic and treatment process, and believe successful collaboration can be a crucial step towards mitigating current disparities.

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Background – Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a category of developmental disorder, characterized primarily by deficits in social communication and social interaction, as well as repetitive and rigid behavior (American Psychiatric Association, 2013). The present paper begins with an overview of autism spectrum disorder itself, before focusing on the identification and diagnostic process. As will be discussed, an early diagnosis is a crucial step towards improving outcomes for individuals with ASD, making this a critical area on which to focus.

Diagnostic Criteria

Autism spectrum disorder is diagnosed based on behavioral and developmental patterns, such that the diagnostic criteria describe the typical behavioral features of the disorder. The *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5)* criteria for ASD diagnosis begin with the presence of persistent deficits in social communication and social interaction, demonstrated through deficits in social-emotional reciprocity, nonverbal communicative behaviors used for social interaction, and the ability to develop, maintain, and understand relationships (American Psychiatric Association, 2013). Social and communication deficits associated with ASD commonly result in difficulties with initiating and/or responding to social interactions, abnormalities in eye contact and body language, and/or difficulties adapting behavior in different social contexts. The second primary criteria in the *DSM-5* are restricted, repetitive patterns of behavior, interests, or activities, demonstrated by: repetitive motor movements, use of objects, or speech; insistence on sameness, inflexible adherence to routines or ritualized patterns; abnormally intensely focused, highly restricted, fixated interests; and hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

(American Psychiatric Association, 2013). At least two out of four of these features must be present to warrant a diagnosis.

Autism spectrum disorder is expressed along a spectrum, as indicated by the name. Individuals may present very differently in their condition, while still falling under this category of diagnosis (American Psychiatric Association, 2013). The *DSM-5* illustrates the spectrum using different levels to describe varying support requirements. Categorical distinctions should not be applied at the individual level, as there is stigma surrounding these labels, but they can be useful in understanding the range of conditions along the spectrum. Level 3, “requiring serious support,” indicates an individual with serious deficits in verbal and nonverbal social communication skills that cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. On the other end, Level 1, “requiring support,” indicates individuals who, without supports in place, have deficits in social communication that cause notable impairments, including difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others (American Psychiatric Association, 2013). When thinking about intervention strategies, it is critical to understand the nature of the disorder, and specifically the way it falls along a spectrum in order to implement appropriately individualized treatment.

Behavioral, psychological, and educational therapy are the primary components of ASD treatment, as described by the National Institute of Mental Health (NIMH). Quality programs are generally individualized, highly structured, and intensive, and designed to help develop life-skills necessary for independent living, reduce challenging behaviors, increase natural strengths, and improve social, communication, and language skills (National Institute of Mental Health, 2018). Though success depends on several factors, including age, language ability, autism severity, and

environmental factors, early intervention, occurring in the first few years of life, is generally crucial and can drastically improve outcomes for individuals with ASD (Corsello, 2005; Itzchak & Zachor, 2011; Vivanti et al., 2018).

Outcomes

Autism is a lifelong condition, and, though treatment can effectively reduce symptoms in some individuals, for many, they continue to require support throughout their lives. Over the next decade, an estimated 707,000 out of 1,116,000 teens with autism will enter adulthood, aging out of their school-based autism services (Maenner, 2020). Services designed to facilitate this transition into adulthood are crucial, though often difficult to receive. Many young adults with ASD do not receive any healthcare for years after aging out of their pediatrician's care. Notably, medical expenditures for individuals with ASD have also been found to be 4.1 to 6.2 times greater than for those without ASD (Shimabukuro et al., 2008; Rogge & Janssen, 2019). In addition to its healthcare requirements and challenges, ASD also impacts ability to live independently. More than half of young adults with autism remain unemployed and unenrolled in higher education during the two years after high school, and nearly half of 25-year-olds with autism, furthermore, have never held a paying job (Maenner, 2020). Effective treatment has been shown to help reduce autism symptoms and increase daily living skills, indicating the importance of expanding access to evidence-based early intervention strategies like those described above (Maenner, 2020).

Prevalence

In 2020, the CDC reported that approximately one in 54 children in the United States is diagnosed with ASD. Most children are diagnosed after the age of four, though diagnoses can be reliably given as early as two years of age (Maenner, 2020). Autism affects individuals of all

racess, genders, ethnicities, and socioeconomic groups; however, as will be discussed in depth below, diagnostic disparities exist along gender, race, and class lines. Typically, children of color are diagnosed later in life, and for more severe conditions than White children. Additionally, 2016 data indicated that one in 34 boys in the U.S. is diagnosed with ASD, compared to only one in 144 girls (Maenner, 2020)¹. Researchers do not yet have a complete understanding of the causes of gender disparities in diagnostic rates, or differences in the presentation of ASD itself, and more work is needed to inform strategies to mitigate these disparities, as well as those occurring along racial and ethnic lines.

ASD is also commonly accompanied by intellectual disability, with 31% of children with ASD falling into this category, 25% falling in the borderline range, and 44% having average to above average IQ scores (Maenner, 2020). Intellectual disability is a categorization used to describe individuals with certain limitations in cognitive skills and functioning, including communication, social, and self-care skills.

Causes and Risk Factors

ASD is a relatively complex disorder, and researchers have yet to identify any exact set of causes or contributing factors. It is widely suggested, however, to result from a combination of genetic and environmental factors (Muhle et al., 2004; Hallmayer et al., 2011; Chaste & Leboyer, 2012;). The genetic component of autism is well-supported by research studies with twins (Bonora et al., 2006; Lichtenstein et al., 2010; Chaste & Leboyer, 2012). Lichtenstein et al.

¹ Though these gender differences are alarming and certainly worthy of investigation, they fall outside the scope of this project, as they do not necessarily occur because of the same factors causing disparities along racial and socioeconomic lines. Researchers continue to study gender differences in presentation of autism, and have yet to agree upon any single explanation. One popular theory is that females with autism are better able to “camouflage” their symptoms, making them less likely to receive a diagnosis (Schuck et al., 2019). Because theories around gender disparities deal with differences in presentation, rather than access and other structural factors alone, this is a more complicated, and, for the purposes of this capstone, separate field in need of further research. For more research, see Halladay et al. (2015), Lai et al. (2015), and Schuck et al. (2019). Full citations listed in *Appendix*.

(2010) states that ASD is among the most heritable mental disorders, pointing to the strong genetic effects on variation found in studies of ASD presentation in twins. Monozygotic twins have been shown to have significantly higher concordance rates compared to dizygotic twins, indicating the importance of genetic effects (Muhle et al., 2004; Lichenstein et al., 2010; Hallmayer et al., 2011). However, ASD also seems to be influenced by environmental factors, and there is also a significant relationship between environmental and genetic factors. Among the most discussed environmental contributors are children born to older parents, and children born to parents with a previous child with ASD (Chaste & Leboyer, 2012).

Introduction

Early intervention using evidence-based treatment strategies is the most effective way to drastically improve the quality of life of individuals with autism spectrum disorder (ASD). There are multiple approaches, like ABA, that have gained support and been shown to improve verbal and social-emotional abilities and generally reduce the severity of autism symptoms (Corsello, 2005; Itzhak et al., 2011). In order for young children to access early intervention services, however, they need an early, accurate diagnosis (Ennis-Cole et al., 2013). Disparities, significantly present along racial and socioeconomic lines, are persistent in rates and timelines of diagnosis. Typically underserved communities suffer the most, often experiencing missed or late diagnoses when compared to better served communities (Daniels & Mandell, 2014; Fountain et al., 2011; Jarquin et al., 2011; Jones et al., 2020; Mandell et al., 2007). Perhaps obviously, access to a diagnosis facilitates access to services and treatment for autism. And, so, disparities in diagnosis, resulting from the inaccessibility of healthcare, connect directly to life outcomes, which are influenced by medical, educational, and other services that cannot be accessed without a diagnosis.

This is a clear example of the relationship between medicine and education, and specifically the ways in which access to healthcare can define educational (and life) outcomes. This paper will examine the role of **healthcare providers** (primarily pediatricians and psychiatrists) and **educators** (primarily early childhood educators) to investigate strategies for effective partnerships allowing for a more comprehensive approach to identification and diagnosis of ASD in young children.² It specifically concentrates on how to reduce present disparities and better support individuals with ASD and their families in underserved populations.

There are a number of factors that can contribute to late or missed diagnoses, including inadequate screening practices, slow response to parental concerns, a lack of awareness of symptoms that occur early in life, and systemic issues contributing to the general inaccessibility of healthcare for certain populations (Jarquin et al., 2011). These factors affect the outcomes of certain groups more than others. Young Black children, for example, are consistently less likely to receive an early diagnosis of autism than young White children (Jarquin et al., 2011; Mandell et al., 2007). These disparities are also present for other children of color and ethnic minorities, and extend beyond race (Mandell et al., 2009). Socioeconomic status has also been linked with differential rates of ASD diagnosis (Durkin et al., 2010; Durkin et al., 2017). Taken in the context of the healthcare system, in which race and socioeconomic status have been found to significantly impact access to care, these disparities happen in predictable ways. Individuals who struggle to access healthcare, and particularly quality healthcare, are more likely to suffer missed

² Throughout this capstone, various terms will be used to describe individuals responsible for providing medical care. Much of the research is around pediatricians (and physicians) specifically, so these terms are often used. However, it can and should be assumed that there are a variety of healthcare providers/clinicians (psychiatrists, nurse practitioners, clinical psychologists) that could fulfill similar roles to pediatricians in the partnerships described. The important piece is the connection between medicine and education.

and late diagnoses. The autism diagnostic process and criteria are relatively complex, and thus require quality care and careful evaluation. As a result, disparities in access to quality care, and specifically access to providers who are skilled at making these assessments, are reflected in disparities in diagnostic rates and timelines such that poorer people and people of color are underserved (Jarquin et al., 2011).

In order to begin addressing these disparities, it is necessary to understand the processes and players involved in the identification and diagnosis of ASD in young children. Pediatricians and other healthcare providers, in theory, have an opportunity to be an invaluable resource for children and their families in the early stages of autism intervention (Sandler et al., 2001). If adequately prepared to recognize the early signs of autism, pediatricians and other primary care providers are well positioned to be a first point of contact for families. The American Academy of Pediatrics Council on Early Childhood has stated that pediatricians should play an active role in determining school readiness, specifically monitoring physical, language, social and emotional development (AAP Council..., 2016). If pediatricians are understood to be capable of monitoring these aspects of development, it is reasonable to include autism screening and diagnosis, as the early signs of autism are often abnormalities within these areas. However, with limited access to healthcare, relationships with pediatricians and other primary care providers are likely to be different for underserved communities (Branson et al., 2008). As a result, this paper will expand beyond healthcare and also examine the role of schools, and specifically early childhood educators.

Early childhood educators are well positioned to identify potential developmental delays in children — they spend significant time with children and have ample opportunities to compare a specific child's physical, behavioral, and social development to that of other children (Janvier

et al., 2016). Pediatricians, though often the first point of contact for families with concerns about their child's development, are not always the most effective component of the identification and diagnostic process. Pediatricians experience difficulties with completing the available screenings because of a lack of time, staff, and inadequate reimbursement for developmental screenings. Early childhood educators, alternatively, have the experience and capacity to identify children with potential developmental delays, and spend significantly more time with the children than pediatricians and other physicians. Even in settings in which educators may not spend an abundance of time with each child individually, much can be learned from observing children within the context of a group of students, as these situations are likely to elicit differences in social patterns resulting from autism.

This capstone is an exploration of opportunities for a more collaborative relationship between healthcare providers and educators. Specifically, my research is focused on developing a more comprehensive approach to autism diagnosis and intervention that is more likely to reach underserved communities in an effective way.

Research Questions

1. What factors drive racial and socioeconomic disparities in rates and timelines of autism diagnoses, such that typically underserved populations more commonly experience missed or late diagnoses?
2. How can clinicians and schools collaborate to mitigate these disparities?
 - a. What is the role of the family in the diagnostic process, and how can providers of care best incorporate them into partnerships?³

³ The role of the family is intentionally separated from the assessment of the relationship between physicians and schools. While intimately linked and all groups should work together, I am particularly interested in how physicians

Scope of Research

This project will focus primarily on two groups that provide care, healthcare providers (particularly pediatricians and psychiatrists) and educators (particularly early childhood educators). The two groups are well positioned to be the first point of contact, as well as powerful resources for identification and diagnosis for families with developmental concerns about their children. Disparities in ASD diagnosis are made clear when examined through racial and socioeconomic lenses, and indicate the need for improvement. Though there are a wide variety of areas that could be addressed with regards to ASD diagnosis and treatment, I am choosing to focus specifically on pathways to diagnosis, thinking specifically about the role of these two groups, pediatricians and early childhood educators, because of the presence, importance, and skill set of early childhood educators and the typical role of pediatricians.

Methodology

This project brings together the understandings of development of early childhood educators and pediatricians (and other primary care clinicians) in order to assess partnerships for improving the identification and diagnostic process for young children with ASD and their families. Though some research has been done about potential partnerships, there is significant room for this specific investigation, and, in particular, a focus on identification and diagnostic practices and the relationship between (early childhood) educators and healthcare providers. The bulk of this project is a literature review investigating the current landscape of diagnostic processes and other factors associated with potential strategies for collaboration and a more comprehensive approach. The following is a brief outline of the literature review.

and educators could collaborate (along with other providers of care) to present a more united front of care to families, with less of a requirement for parent facilitation of services.

1. *Current Diagnostic Approaches:* An overview of current diagnostic approaches, specifically addressing the roles of clinicians and (early childhood) educators, the distinction between medical and educational diagnoses, and an overview of legislation and provision of services through the public education system.
2. *Early Diagnosis and Effective Treatment:* An introduction to literature supporting the importance of early diagnosis and intervention, as well as research-backed intervention strategies.
3. *Diagnostic Disparities:* An introduction to rates and timelines of diagnosis by race and socioeconomic status, and an investigation of the factors contributing to missed and late ASD diagnoses.
4. *Family Involvement:* An investigation of the role of families in the identification and diagnostic processes.
5. *Current Collaboration:* An overview of models for collaboration, as well as relevant barriers.
6. *Trust and Other Barriers to Care:* An overview of minority family experiences with mistrust in, and other difficulties with, the healthcare system as a barrier to care.

In order to narrow the literature review and produce a set of key considerations for improving diagnostic approaches, I also had a number of conversations with experts in the field and individuals involved in the identification and diagnostic processes, including autism researchers, pediatricians, child psychiatrists, early childhood educators, and individuals in leadership roles in clinics. These conversations were relatively casual and loosely structured. Our discussions generally began with an overview of the work of the individual, their specific role in

the diagnostic process, and a discussion of barriers to diagnosis and interventions for underserved populations. We then discussed the relationship between educators and healthcare providers, as well as the role of the family in the diagnostic process, and strategies for collaboration between these three groups. These conversations were conducted in order to narrow my research to focus on best potential practices, based on the experiences of professionals in the field.

Literature Review

Current Diagnostic Approaches

This section provides an overview of the medical and educational diagnostic processes, as well as commentary on the limitations of each. These two processes are distinct, as will be described, though share some common features. The diagnostic process for autism is oftentimes long, complicated, and intensive, while typically including a series of evaluations by different professionals including, but not limited to, pediatricians, psychologists, psychiatrists, educators, and speech and language pathologists. These evaluations, though screening tools and questionnaires may be used, are based primarily around observation, as there is no clear medical detection tool for autism (NIMH, 2018).

In considering potential partnerships between educators and clinicians, it is necessary to begin by investigating current strategies, tools, and skills employed by both groups. The typical medical diagnostic process through pediatricians falls within the context of general developmental screenings (Branson et al., 2008; Lipkin et al., 2020). It is recommended that developmental surveillance occur at health visits at 9-, 18-, and 30-month visits, under the direction of the pediatric healthcare professional, and performed by other clinic or office staff (Lipkin et al., 2020). More specifically, the American Academy of Pediatrics recommends that

all children be screened for autism at 18 and 24 months, along with regular developmental surveillance (Hyman et al., 2020).

Developmental surveillance refers to, “a flexible, longitudinal, continuous and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems” (Branson et al., 2008). Any developmental concerns discovered through these screenings should be followed by standardized developmental screening testing or direct referral to intervention and special medical care. Children who are identified through these screening programs or other methods (e.g., identified by parents and introduced into the diagnostic process) move on to a second stage of more detailed evaluations in pursuit of a medical diagnosis (NIMH, 2018). The second evaluation is typically conducted by a team of doctors and other health professionals who are experienced in diagnosing ASD. This team may include a combination of developmental pediatricians, child psychologists or psychiatrists, neuropsychologists, and/or speech-language pathologists. These follow up evaluations focus on assessing cognitive level and thinking skills, language abilities, and the age-appropriate skills required to complete daily activities independently, like eating, dressing, and using the restroom. Reviews highlight the importance of paying special attention to developmental surveillance at the 4- to 5-year well-child visit, which typically occurs prior to entry into elementary education, making this a crucial time for identification in order for children to receive support as they begin formal education (Lipkin et al., 2020).

These best practices can be difficult to implement, however, even for families with access to quality healthcare (Branson et al., 2008). Moreover, even when pediatricians screen for developmental delays, they often do not screen specifically for ASD, as autism screening instruments are neither widely nor systematically used (Janvier et al., 2016). There are also

questions regarding the effectiveness of screening tools, and particularly their relevance for diagnosing minority children.

Among the most commonly used screening tools is the Modified Checklist for Autism in Toddlers (MCHAT), which is an approximately 20-item questionnaire intended for parents to fill out evaluating the behavior of their children between 16 and 30 months of age (Autism Research Institute, n.d.). There are mixed results from studies evaluating the MCHAT's effectiveness. It has been demonstrated to have high specificity (ability to correctly identify individuals without disorder) and sensitivity (ability to correctly identify individuals with disorder) in some populations, but not others (Murray et al., 2021; Robins et al., 2001). Specifically, it has been shown to be less effective in identifying females and minority, urban, and low-income children. This may result from cultural differences not reflected in the questionnaire, physician bias, and/or parental education status and understanding of autism, among other factors. Disparities also exist due to a lack of, for example, developmental and ASD screening in Spanish (Janvier et al., 2016). This ineffectiveness highlights the importance of developing culturally sensitive screening tools, and increasing rates of professional follow-up to confirm results when delays are suspected. In one study of the MCHAT's effectiveness for 18-month-old children, it was found that the test only flagged about a third of children who eventually received an ASD diagnosis (Stenberg et al., 2014). Similarly, a study evaluating the effectiveness of a comparable screening tool used on children at 36 months of age found that it only identified one in five children with autism (Pål Surén et al., 2019). The Social Communication Questionnaire (SCQ), another commonly used screening tool, also struggles with similar issues (Eaves et al., 2006).

In general, screening tools primarily identify children with more significant developmental delays, and tend to miss children with less severe conditions. The heterogeneity

of autism contributes significantly to difficulties with developing a single, simple method for identifying the disorder, as it can present in a wide variety of ways. So, while these tools have some evidence in their support, they do not yet seem to be an effective way to mitigate current racial and socioeconomic disparities because of their lack of relevance for minority children as well as children on the more neurotypical side of the autism spectrum.

Beyond the use of screening tools with the potential for bias, identification delays are generally more common in low-income, minority communities. This is the result of disparities in access to healthcare generally, which “have been well documented and may result from factors such as limited availability of services in the community, financial hardship, diverse cultural beliefs, and social prejudice” (Janvier et al., 2016).

Barriers to healthcare access along racial and socioeconomic lines indicate the need for other pathways for identification and diagnosis of ASD. One potential solution for mitigating these diagnostic disparities is broadening the points of entry into the diagnostic process. One such point of entry is early childhood educators, who can play an effective role in identifying children with potential developmental delays. They spend significant amounts of time with the children and have ample opportunity to compare a specific child’s physical, behavioral, and social development to that of other children (Janvier et al., 2016). Despite being typically ignored as resources for early identification, daycares and preschools have been suggested as an especially useful aspect for minority children in the US (Janvier et al., 2016). In a study in which developmental and ASD screening was performed in early childhood education settings in an attempt to identify children in medically underserved communities, researchers emphasized the importance of including professionals, like early childhood educators, who interact with young children on a regular basis in the early identification process. They can be useful in addition to

healthcare providers, who may be difficult to reach and limited in their capacity to identify ASD in particular. The researchers explain the need to, “increase attention and resources on developing community-based screening programs that include community childcare providers as partners in the identification and referral of children at-risk for autism spectrum disorders” (Branson et al., 2008).

Along these lines, diagnoses are not limited to those from medical professionals. With autism and other similar diagnoses, there is a divide between a medical and educational diagnosis (Center for Autism Research, n.d.). As described above, medical diagnoses typically emerge from a progression of evaluations according to the DSM-5 performed by doctors and other specially trained clinicians. However, there is also significant legislation surrounding public education and autism and other disorders that creates a separate process for diagnosis. The central legislation for education for children with disabilities, autism included, is the Individuals with Disabilities Education Act (IDEA). IDEA requires that all states provide all eligible children with a free and appropriate public education that meets their individual needs. Children may also be entitled to early intervention services and special education. There are a few central terms included in this legislation about the provision of services. A free and appropriate public education (FAPE) means that children receive an “appropriate” education individualized to fit their needs, and one that will allow for educational progress. While required to offer *appropriate* or *sufficient* care, the school district is not required to provide the *best* or *optimal* care – families, therapists, and teachers may have ideas for optimal care and often need to advocate and push to get these services (Autism Speaks, n.d.).

The timeline for provision of services in the public education system is broken up into early intervention services and special education services. Early intervention services are

available to any child younger than three who is determined to have a developmental delay or other condition, and must be provided free of charge through federal grant funded programs. Services can include, but are not limited to, speech and language pathology, occupational therapy, physical therapy, applied behavior analysis, and psychological evaluations. These services are outlined in the Individual Family Service Plan (IFSP), a document for each child requiring services detailing their condition, plan, and goals for progress (Autism Speaks, n.d.). After age three, the IFSP changes to an individualized education plan (IEP), and children begin to receive services through the special education department of their local school district. The shift from IFSP to IEP leads to a change in the scope of services, with IEPs having a narrower focus on school, rather than the comprehensive approach taken with the IFSP and early intervention services. For autism, there are marked benefits to the kind of comprehensive care provided through early intervention, and so, once again, an early diagnosis is incredibly important. However, receiving an educational diagnosis can be a lengthy and complicated process.

In order to qualify for educational and other services through public education, children must be identified as having one of fourteen specified disabilities (including autism) *and* determined to be in need of special services. Thus, it is possible for a child to have a medical diagnosis but not be granted educational services. It is generally recommended that families pursue both a medical and educational diagnosis in order to improve likelihood of receiving services quickly (Center for Autism Research, n.d.). However, as will be discussed in depth below, this is a rather involved process, and one that requires significant, and perhaps overwhelming, commitment and knowledge from parents in order to advocate for their children and push the process along.

For children under three, parents contact their local early intervention agency to begin the diagnostic process; children over three enter the process through their local school district. Once in the diagnostic process, there are typically a series of evaluations and steps required before services are provided. Evaluations can include, but are not limited to, an unstructured diagnostic play session, developmental evaluation, speech-language assessment, parent interview, evaluation of current behavior, and an evaluation of adaptive or real-life skills (Autism Speaks, n.d.).

For children receiving a diagnosis through the public school system, there is a team made up of various school professionals and the student's parents that is responsible for determining educational eligibility and developing a plan for services. This group is the planning and placement team (PPT). Notably, this team includes teachers, a representative from the local educational agency who is knowledgeable about curriculum and resources, and parents. The IDEA does not require the team to include a medical professional, separating this process from that of medical diagnoses (Goodwin Proctor LLP, 2010). A medical professional and/or medical diagnosis may be informative in this process, but is not required. Broadly, the process can be broken down into four steps: 1) the child is evaluated by the school; 2) the school convenes a PPT; 3) the PPT reviews evaluations and determines special education availability, and, if eligible; 4) the PPT develops an IEP including goals and objectives based on the specific needs of the child (Center for Children's Advocacy, n.d.). This process can be quite drawn out, as collecting the evaluations alone is often quite time consuming, even before the results are reviewed by the PPT and eligibility is determined. Specifically, the state educational agency has 60 days after parent request and consent to determine if the child has a disability, and this

evaluation occurs before any special education services or provisions may be implemented (Goodwin Proctor LLP, 2010).

Families play an important role throughout this process, and are often expected to be a primary advocate for their children. Family involvement will be discussed in depth below, but this can be a significant limiting factor in accessing a diagnosis and services. The Connecticut Parent Advocacy Center (2009), for example, has a resource guide for parents highlighting a list of 16 steps recommended for preparing for a child's PPT meeting, ranging from talking with their child's teachers, therapists, and other families who have experienced the process, to collecting various documents and other sources of information indicating the condition and needs of their child. Centrally, parents are expected to have a thorough understanding of their child's condition, current status, and goals moving forward, along with services that may be necessary to achieve these goals. Put simply, the requirements of this process can be overwhelming even for families with the appropriate education and resources, let alone for families who, for example, are not native English speakers, or do not have the time, money, or work flexibility to take on this role.

Early Diagnosis and Effective Treatment

Psychology, medicine, and education literature consistently back the importance of early identification, diagnosis, and intervention for children with autism spectrum disorder. From a developmental neuroscience point of view, this can be justified in the context of a dramatic period of synaptogenesis⁴ and brain development during the first months and years of life (Klin et al., 2020). Put simply, the first few years of life are critical for children's development. A

⁴ Synaptogenesis refers to the formation of synapses, the points of contact where information is transmitted between neurons. This is integral for creating brain networks, and for the overall architecture of brain connectivity. (Estrin & Bhavnani 2020)

reliable diagnosis of ASD can be made as early as 24 months, yet the average age of diagnosis in the US is over four years of age. An early diagnosis allows for the implementation of early intervention services, which have been demonstrated to improve outcomes by better taking advantage of early periods of brain development (Daniels et al., 2014; Klin & Jones, 2018; Klin et al., 2020). Improved outcomes resulting from early intervention, while obviously beneficial for individuals with ASD, are also significantly more cost effective (Klin & Jones, 2018). And still, despite our knowledge of the necessity of an early diagnosis and the importance of early intervention, diagnoses are commonly delayed (Klin et al., 2020).

There are a variety of approaches to early intervention. Applied behavioral analysis (ABA), for example, is among the most recommended approaches for treating ASD. ABA is an evidence-based treatment strategy which uses positive reinforcement to adjust behavior. ABA is data-driven, allowing for the evaluation of effectiveness over time, and is typically conducted in one-on-one sessions with a child and therapist. These sessions are highly individualized and should occur regularly. ABA is the most widely endorsed strategy for treatment of ASD (“ABA: The Most Effective Treatment”, 2019; Dawson, 2008).

Though there is a need for more conclusive empirical evidence backing ASD early intervention strategies, research has generally demonstrated the efficacy of early intensive behavioral intervention. Intensive, structured intervention like ABA has been shown to improve cognitive performance, language skills, adaptive behavior skills, and generally reduce autism severity (Reichow et al., 2018; Warren et al., 2011; Wetherby et al., 2014). Though precise strategies may vary, and certainly not every program uses ABA principles, there are common themes across methods of care. Dawson et al. (2010) completed a particularly notable study showing the efficacy of the Early Start Denver Model (ESDM), a comprehensive developmental

behavioral intervention. In a randomized, controlled trial, the researchers found that the ESDM has the potential to improve IQ, adaptive behavior, and autism diagnosis over a two-year period in which the intervention was applied. This model is based on the principles of ABA (“ABA: The Most Effective Treatment”, 2019; Dawson, 2008). Outside resources, such as occupational and speech therapists, are also commonly integrated into intervention within typical ASD programs (Hébert et al., 2014).

Diagnostic Disparities

Research indicates the importance of early intervention, yet early diagnoses are often difficult to attain, especially for individuals in certain populations (Broder-Fingert et al., 2020). Research has identified a number of factors contributing to missed and late ASD diagnoses, specifically race and socioeconomic status, which should be examined when considering potential interventions. In general, disparities exist along racial lines such that children of color experience higher rates of late and missed diagnoses compared to White children. Specifically, young Black children are consistently less likely to receive an early diagnosis of autism than young White children. Minority children also face more obstacles to access services and disproportionately have intellectual disabilities, according to the US Center for Disease Control and Prevention (Constantino et al., 2020; Jarquin et al., 2011; Jones et al., 2020; Mandell et al., 2007). Broder-Fingert et al. (2020) examined potential causes of delayed diagnoses, and, though more empirical data is required to understand the more precise mechanisms behind inequities, it is likely that traditional contributors, including structural racism, prejudice, education, and income are at play.

Late diagnoses are further put into context by the fact that Black and Hispanic children are also more likely to experience significant delays between initial parent concern and a final

ASD diagnosis (Broder-Fingert et al., 2020). Specifically, there is, on average, a 3-year lag between parental recognition of potential developmental delays and an autism diagnosis for Black children. These delays have been suggested to result from a number of factors, including racial bias and discrimination, lack of diversity in health professionals (which impacts patient-provider relationships), and concentration of specialists in wealthier, predominantly White areas (Broder-Fingert et al., 2020; Constantino et al., 2020). These factors, and others, are discussed in more depth in the section entitled “*Family Experiences*” below.

When Black children are diagnosed with ASD, furthermore, they tend to have more severe conditions, in addition to being older at the age of diagnosis. White children, alternatively, are more likely to be diagnosed for subtler, less severe, ASD, which is critical to taking advantage of early intervention services (Jarquin et al., 2011). This is an important aspect of the disparities to identify. White children are more likely to receive a carefully given, appropriate diagnosis at a young age, whereas Black and other children of color are less likely to receive a diagnosis, unless their condition is on the more severe end of the spectrum. In general, children from other minority racial and ethnic backgrounds generally experience similarly inadequate diagnostic practices (Angell et al., 2008).

Diagnostic disparities are made increasingly alarming when examining rates of intellectual disability (ID) in individuals with ASD. There is a persistent, unexplained excess of intellectual disability comorbidity in the Black ASD population in comparison to that of the White population. ASD prevalence data from the Centers for Disease Control and Prevention (CDC) highlights the increased burden⁵ – the burden of intellectual disability among Black children with ASD is 47%, almost double that of White children at 27%. Hispanic children fall

⁵ The term “burden” is used here in the context of public health, in which it is defined as the impact of a health problem as measured by financial cost, mortality, morbidity, or other indicators.

between these two groups, with a burden of ID of 36% (Klin et al., 2020). It has been suggested that this increased burden of ID comorbidity is a result of delays in diagnosis combined with poorer access to quality intervention services (Constantino et al., 2020). This data presents relatively straightforward evidence for the importance of early diagnoses, as well as the consequences of a delayed process.

Diagnostic disparities also extend beyond racial lines, however. Socioeconomic status (SES) has also been shown to relate to rates and timing of ASD diagnoses. In a sample of over 17,000 children with autism in California, it was found that children with highly educated parents were diagnosed earlier, and there exists a gap in the age of diagnosis between high and low SES children that has decreased, but not disappeared (Fountain et al., 2011). In multiple cross-sectional studies on US children, diagnostic disparities have been found to exist along socioeconomic lines (Daniels & Mandell, 2014; Fountain et al., 2011). Specifically, “socioeconomic variation in prevalence suggest[s] potential underascertainment of ASD in economically disadvantaged groups” (Durkin et al., 2017). The researchers went on to suggest racial and ethnic disparities in ASD prevalence are confounded by SES, addressing the nature of the association between race, ethnicity, and socioeconomic status in the United States. This is influential in access to healthcare across the country, and certainly not only in ASD diagnostic rates. The SES gradient found in these studies of ascertainment bias has been related to significant disparities in terms of access to diagnostic and other services for children with ASD in typically underserved populations across the US (Durkin et al., 2010). Race, ethnicity, and socioeconomic status are intimately linked, and the importance of this relationship can be observed in the rates of missed and late diagnoses in ASD.

Family Experiences

As described above, it is critical to consider the role of the family in the identification and diagnosis process, and specifically how family members can, and are expected to, work with educators and healthcare providers. In considering the role of the family, it is important to address the relationship between culture and communities' differing ASD-related resources, which significantly impact treatment strategies and outcomes for individuals with ASD (Mandell et al., 2005). For example, Latino children are typically diagnosed with autism spectrum disorders at older ages and as a result of more severe symptoms (Zukerman et al., 2014). A number of factors were identified by parents to have influenced the diagnostic process, including low levels of ASD information and high levels of mental health and disability stigma in the Latino community, poor access to healthcare as a result of poverty, limited English proficiency, and lack of empowerment to take advantage of services. Parents have also reported experiencing providers who dismiss their concerns, and described the ASD diagnostic process itself as slow, inconvenient, confusing, and uncomfortable for the child. This variety of limiting factors led many parents to, "normalize their child's early behaviors, deny that a problem existed, and lose trust in the medical system" (Zuckerman et al., 2014).

Denial is an especially significant problem, and one that must be overcome through the development of a trusting relationship between parents and providers of care, including healthcare providers and educators. Stigma, as well as the nature of ASD and its lifelong impact, make this an exceedingly difficult diagnosis to hear as a parent, independent of negative experiences with healthcare providers. As a result, parents can avoid identification and/or deny that there is a problem. With parents often responsible for navigating the diagnostic and treatment processes for their children, denial is likely to result in children with ASD not having access to the resources critical to their development. Parents are often instrumental throughout

the process, but not if they fail to develop acceptance and trust in the diagnosis and those involved.

Family involvement in the ASD diagnostic process is also often a crucial component of early identification. Parents often recognize problems in the development of their children before health professionals can, resulting in recommendations for increased involvement of parents in this process (Carlsson et al., 2016). Parents are likely to have spent more time with their child than any other individual and so typically have incredibly valuable information about their children for the diagnostic process, but require health care providers who recognize its importance. In a study investigating family experiences in the diagnostic process, significant delays between when a parent first noticed the delays in their children's behavior and when they received a diagnosis were reported. Additionally, delays were significantly longer for non-White children (Sansosti et al., 2012). Families with children diagnosed at a later age also generally expressed lower satisfaction with the diagnostic process, only adding to parents feeling overwhelmed after a diagnosis is made (Carlsson et al., 2016; Sansosti et al., 2012).

The diagnostic process for ASD tends to be long, complicated, and involved even for relatively well-prepared families. In a study interviewing parents of children with ASD, who reported being from a high socioeconomic background, parents consistently reported the drawn-out timeline of the diagnostic process, as well as numerous obstacles and complications along the way (Lappé et al., 2018). Parents constantly commented on long waiting periods between their child's initial referral to a specialist and the actual meeting to receive a formal ASD diagnosis, and how that lead to feelings of uncertainty and frustration with the process. As one parent stated "the process took almost a year. So, the system is kind of bad, it's very bad... If you do the process soon, you can get more therapy and more help for my kid, right? But this doesn't

happen” (Lappé et al., 2018). Looking broadly at diagnostic trends, a year is a relatively short timeline, especially in contrast to delayed diagnoses experienced by minority and poorer children, and, yet, parents undergo significant stress. Wide knowledge of the benefits of early intervention are in stark contrast to a drawn-out diagnostic process.

Perhaps obviously, difficulties for families extend far beyond the diagnostic process. Nearly all of the parents in the Lappé et al. (2018) study expressed emotional, financial, or social challenges in navigating the ASD service system, leading many to feel as though they had to personally advocate for their child to receive adequate services. This advocacy requires an extensive commitment of time and energy, leading to major shifts in employment and living situations. Once again, this study interviewed families reportedly from high socioeconomic backgrounds, and even they report extensive difficulties navigating the process.

Current Collaboration

Though research is limited in terms of literature around collaboration between physicians and educators for autism specifically, models can be taken from partnerships designed to address other health needs in schools. For example, Shahidullah et al. (2020) examined the relationship between school psychologists and clinicians, which provided insight into barriers to partnerships, as well as recommendations for future work. Mismatch in eligibility criteria for educational classifications versus medical diagnoses, lack of delineated roles and responsibilities of other providers, and limited infrastructure around information were among the barriers for collaboration identified (Shahidullah et al., 2020). In general, there seems to be a disconnect between schools and medical professionals in their understandings and approaches to identifying and treating conditions like ASD. Medical diagnoses can often be somewhat isolated from the actual educational classifications important for the development of educational interventions.

And, differences in understanding and approaches to treatment can lead to difficulties with collaboration and the determination of the specific roles and responsibilities of schools and clinicians when working together.

A study of the perspectives of community-based providers indicated similar barriers to collaboration — school personnel training and expertise in ASD, sharing of information, and delineating between special education classifications and medical diagnoses (Azad et al., 2021). Despite these barriers, however, coordination of care remains a highly recommended practice, and one that should be implemented in educational settings (Shahidullah et al., 2020). With regards to ASD specifically, this recommendation, combined with the notion that (early childhood) educators could be valuable in reducing diagnostic disparities, suggests the potential for collaboration between educators and clinicians (Janvier et al., 2016). It is specifically suggested that early childhood educators could improve access to early diagnosis and thus reduce potential healthcare disparities among underserved populations (Janvier et al., 2016).

Collaboration is generally recommended as a best practice in literature discussing the assessment and treatment of children with autism spectrum disorder. Volkmar et al. (2014) include a detailed list of recommendations in this area, a number of which directly address collaboration between clinicians, schools, and families. First, they state that, “clinicians should coordinate an appropriate multidisciplinary assessment of children with ASD” (Volkmar et al., 2014). In expanding upon this point, the researchers suggest the importance of combining medically and psychologically-based tools. Early childhood educators have the potential to contribute a psychologically-based understanding of identification and development that complements the medical approach taken by healthcare providers. While obviously not all early childhood educators have formal training in psychology, they do have an abundance of

experience observing child development from a relatively holistic perspective. The experience educators have with observation of children's development is distinct from that of healthcare providers, as they spend significantly more time with children and have consistent opportunities to see them interacting with peers. These observations present a somewhat more complete picture of child development, resembling that considered in the psychology of child development.

The researchers go on to suggest that, "the clinician should help the family obtain appropriate, evidence-based, and structural educational and behavioral interventions for children with ASD" (Volkmar et al., 2014). This recommendation highlights the importance of involving clinicians in decisions about interventions for children. This could be a first step towards greater collaboration between healthcare professionals and other providers of care, including early childhood educators. Collaboration is further emphasized in a subsequent recommendation that, "the clinician should maintain an active role in planning and family support and the support of the individual" (Volkmar et al., 2014). This once again points to the importance of a relationship with the clinician, and their involvement in decisions about treatment, while also highlighting a problem with this model. In many cases, clinicians are unlikely to have the capacity to be involved in detailed long-term planning, and there is a significant population without consistent access to one single clinician. Access to long-term, quality relationships with clinicians is only one of many potential barriers to early identification, and, in contrast, is a strength of early childhood educators as identifiers. Early childhood educators are often more likely to have a long-term, consistent relationship with the children they serve.

In addition to considering models and strategies for collaboration, it is important to investigate barriers to collaboration between early childhood educators (and schools generally)

and clinicians. In addition to the barriers mentioned above, educators working primarily with low-income children described a lack of awareness about the possibility of speaking with pediatricians. They also identified concerns about parental trust and privacy as two primary reasons for unsuccessful collaboration with pediatricians (Lemkin et al., 2019). Privacy is an important and significant barrier to collaboration, as there is strict guidance around privacy limitations for clinicians. None of this communication, perhaps obviously, can occur without parental consent, and working within the regulations for medical and educational privacy. This seems to connect with a lack of commonly practiced collaboration, as schools were wary of parental concerns about privacy and a perceived need to isolate information within school and medical settings. Educators did not want to break trust with parents by communicating with clinicians. This seems, however, to be a potentially resolvable issue by establishing consent practices for collaboration, and making this type of communication more standardized.

A lack of delineated roles and responsibilities of providers is also commonly cited as a barrier to collaboration, as well as difficulty determining with whom to collaborate, and accessing appropriate partners (Lemkin et al., 2019; Shahidullah et al., 2020). Perceived lack of interest in or disregard for physician recommendations and gaps in pediatricians' knowledge of special education practices have also been identified (Lemkin et al., 2019; Sheppard et al., 2016). In response to these concerns and others, the American Academy of Pediatrics, in collaboration with the Council for Children with Disabilities and the Council on School Health, recommends that physicians learn special education law and practices in order to increase their ability to work with schools to support children with disabilities and their families (Sheppard et al., 2016).

Trust and Other Barriers to Care

Trust and other aspects of physician-patient relationships are well-documented as barriers to adequate care. It is quite clear that, “a legacy of racial discrimination in medical research and the healthcare system has been linked to a low level of trust in medical research and medical care among African Americans” (Boulware et al., 2003). Difficulties with trust extend beyond the Black community, with other minorities and poorer individuals also experiencing mistrust in the healthcare system. For example, Parish et al. (2012) found that healthcare quality mediates the relationship between ethnicity and healthcare utilization disparities, with three indicators of patient-physician relationship quality as significant contributing factors. Specifically, patients reported feeling as though their providers did not spend enough time with their children, were not culturally sensitive, and did not make parents feel like a partner (Blanche et al., 2015; Parish et al., 2012). Mistrust in the healthcare system occurs within the context of other common barriers to care for these communities, including non-English speaking status, financial constraints, health insurance issues, lack of transportation, lack of childcare, and inability to take time off of work (Blanche et al., 2015, Zuckerman et al., 2014). The diagnostic process for autism, in light of these barriers, is commonly described as confusing, time-consuming, inconvenient, and unpleasant for both the child and caregivers (Zuckerman et al., 2014). Quality of relationships and other factors influencing care have a tangible impact on access, with minority groups and low-income populations experiencing less access to acute care, specialized services, educational services, and community services compared to higher-income and White families (Smith et al., 2020).

There is also research indicating contributing factors on the side of providers. Mandell et al. (2002) found that clinicians may have different expectations about treatment and service needs by race – occurring within the context of findings indicating less frequent use of screening

tools for Black families, and more frequent discounting of parental concerns for Black parents in comparison to White parents. These trends are proposed to result from clinician knowledge and attitudes in both mental and primary healthcare settings, as well as the nature and quality of the relationships and interactions between families and clinicians. The trends are also influenced by clinicians differing behaviors with families of different races, and differential family experiences within, and views of, the medical system (Mandell et al., 2002). Cultural divergence is considered a significant barrier to diagnoses for Black children, which highlights, in part, the notion that healthcare provider perceptions and expectations for Black and other parents of color interferes with access to services (Pearson & Meadan, 2018).

Similarly, Latino-White disparities in ASD diagnosis are thought to result, at least in part, from clinicians' viewing Latino parents as less knowledgeable about ASDs and other factors contributing to lower quality patient-clinician relationships (Zuckerman et al., 2013). With some Latino (and other) families in particular, there is the added difficulty of a language barrier, which can complicate clinician relationships as well as the use of screening tools, which are not widely available in non-English languages (Blanche et al., 2015; Zuckerman et al., 2013). These difficulties, however, extend beyond a language barrier, with findings indicating that healthcare providers generally face greater difficulty recognizing the characteristics of ASD in Latino and Black children, as opposed to White children (Pearson & Meadan, 2018; Zuckerman et al., 2013). In an interview-based study with Black parents about their experiences with the diagnostic process, parents consistently stressed the need for providers to be more receptive to parent voices, citing the delay in diagnosis in comparison to parents first suggesting a potential developmental delay (Pearson & Meadan, 2018).

Discussion and Recommendations

The discussion and recommendation section of this capstone will pull from the literature review above, as well as my conversations with individuals who work in the diagnostic and treatment processes of autism. Foundationally, this capstone has made clear that coordination of care represents best practice in autism treatment, and should be applied at the diagnostic level as well. Autism is a complex and heterogeneous disorder, and one that requires a variety of tools for both diagnosis and treatment. As a result, families are faced with a disjointed, complicated, and lengthy process just to receive a diagnosis, and that is only a first step in the long road of treatment and access to services. To better serve families and children, clinicians and educators, as well as other providers of care involved, should better work together to present a unified front of care.

Through this project, I have identified three primary areas on which to focus for developing these relationships and coordination of care. This discussion section will walk through each of the three components to facilitate higher quality care and collaboration between clinicians, educators, and families. First, coordination of care requires logistical support, which will be discussed in the context of two primary example systems for connecting families with various resources appropriate for care. Second, relationships between educators and clinicians must be built on mutual trust and respect for the roles that each group plays in the diagnostic and treatment process. Finally, and essentially, this process simply does not work without the development of family trust.

(1) Logistical Coordination of Care

Logistical barriers to collaboration and access to care represent a significant contributor to ineffective partnerships between clinicians, educators, and families. The autism diagnostic

process is complex and involves a variety of individuals including, but not limited to, pediatricians, psychiatrists, psychologists, teachers, and parents. With parents, even those with exceptional access to resources, regularly reporting overwhelming and negative experiences, it is clear that the process should be streamlined (Carlsson et al., 2016; Lappé et al., 2018; Sansosti et al., 2012). Currently, “systems of care exist in silos, with different eligibility requirements and treatment plans that are not integrated between systems” (Carbone et al., 2010). Working to bring together these different systems of care is crucial for diagnosing and treating autism. The nature of the disorder warrants a comprehensive approach, necessitating collaboration and coordination of care. Coordination of care is a relatively accepted component of medical practice. Specifically, for example, the medical home model is a commonly recommended practice, which aims to provide comprehensive, patient-centered, coordinated care for individuals with complicated health needs to increase access to continuous and coordinated services (Shahidullah et al., 2018). Care coordination and integration are key aspects of the medical home model commonly lacking for children with autism, and areas in need of improvement (Todorow et al., 2018). The medical home model is a concept designed to help patients navigate the complexities of the medical system. Though research in this area primarily focuses on the medical home model for the *treatment* of autism, it can and should be expanded and better applied to the autism *diagnostic process* as well.

The logistical portion of the diagnostic process is a challenge that can potentially be mitigated by added tools or people focused on streamlining the connection between families and the variety of services they require. The present section discusses two models for the coordination of care and facilitation of an early diagnosis for families with autism.

The care coordinator model addresses challenges relating to time, motivation for collaboration, and knowledge of pathways by having a team dedicated to guiding families through the care process. Care coordination is a relatively common practice in certain areas (e.g., rural areas) and for certain conditions (e.g., cancer) in which individuals require additional support to receive appropriate care from a variety of providers. The Clifford Beers clinic in New Haven, a clinic serving primarily Medicaid patients, with a variety of tools and strategies targeted towards easing access to care for this population, provides one example of a care coordinator model. They describe their care coordination model as, “a family-focused program that uses the wraparound team model,” which means their Care Coordinators work with children, “in every facet of their life including family, teachers, doctors, and other significant people or providers to deliver care that is consistent and reliable” (*Programs & Services*, n.d.). These coordinators aim to assist families in identifying issues, coming up with solutions, and guiding families through community resources to better establish a network of care. Families can work with Care Coordinators free of charge, making this especially useful in considering disparities in access to care along socioeconomic lines.

Despite being designed for a wide variety of conditions, this coordination model appears to be easily applicable to families and their children with autism specifically. Care coordinators can help bridge the gap between clinicians and educators, as well as these two groups and the other variety of psychological and other services commonly involved in the treatment of autism. This can also prove useful in the diagnostic process, in which care coordinators can help guide families through the complexities of gaining evaluations and an eventual diagnosis. The use of social workers and other individuals to coordinate autism care has been discussed in the literature with, for example, Casey & Elswick (2011) arguing for the benefits of guiding families through

the diagnostic process and facilitating access to a variety of services in order to reduce the burden on the professionals and families. Parents often take on the task of navigating this difficult and complex process, and this is likely a significant contributor to diagnostic disparities (Lappé et al., 2018).

This model, however, is not without its drawbacks. Perhaps most significantly, it requires funding. In order for care coordinators to work free of charge, it must be subsidized or in some way funded by the responsible organization, as this is not typically a billable service. Along these same lines, in order for this model of coordination to be effective, the individuals responsible for working with families need to be knowledgeable about the complete process, requiring time and money dedicated to training. Even if there are no specific degree requirements, which there are not for care coordinators at Clifford Beers, training is significant as a barrier. Ideally for autism, care coordinators would be comfortable and knowledgeable in guiding families through the process of receiving a medical and educational diagnosis, and bridging the gap between these two. This would require thorough training regarding the diagnostic process of autism from a medical standpoint, special education law and the educational diagnostic process, as well as knowledge about the various other resources available for families with a child with ASD. In this way, care coordinators for autism would combine aspects of medical care coordinators and educational advocates. Despite this relatively intensive training requirement, this does remain an appealing option for better care coordination and guidance for families through this process.

A relatively cost-free alternative to care coordinators is online tools for care coordination and education for parents. Autism Navigator (autismnavigator.com), for example, is, “a unique collection of web-based tools and courses” designed to educate parents, and guide them through

the diagnostic process. Autism Navigator is a tool created with Baby Navigator, an online program designed to provide resources and tools for families to support their children's early development. Autism Navigator includes a course for parents to help them better understand the early signs of autism, allowing them to be more informed entering the diagnostic process. The site also includes professional courses, a virtual community for families, and a how-to-guide for families entering the diagnostic process. It seeks to present a digestible, easily accessible, and relatively complete guide to help parents through the autism identification and diagnostic process. There is also an option to connect with providers through the site, though this does not seem to be fully developed, as providers are only located in certain areas of the country. This seems to be a crucial element to further develop in order for this tool to be broadly applicable to families and relevant for care coordination.

This tool was described to me in a conversation I had with a researcher in the field as a promising potential resource, and though this may not necessarily be exactly the right tool for all families, as it still requires the parents to take on a significant role in the process, it does indicate the potential for similar tools to aid in the coordination of care. An essential aspect of a resource like this would be taking a step further than parent education and really expanding on the coordination aspect. A more ideal and complete tool, for example, could include a telehealth option for initial early identification, followed by connection with local providers of care in instances where ASD or other developmental delays are thought to be present. Online tools and platforms designed to help families connect with doctors and other providers of care in their area could greatly streamline the collaboration process. This would be a significant undertaking to set up, as it would require buy-in from enough providers to be effective, but remains an interesting possibility.

Whether an online tool or an individual responsible for guiding families through the diagnostic process, it seems clear as though some intermediary is needed in order to facilitate the coordination of care for young children seeking an autism diagnosis. There are too many individuals involved in the process to expect all families to be capable of navigating the process on their own, at least not on the timeline at which this should occur. A tool designed to guide families through the process and facilitate access to various aspects of care and evaluative practices could drastically reduce the burden on parents to advocate for their children and navigate the diagnostic process on their own. Furthermore, this tool would also help providers of care, as they could benefit from the work and knowledge of each other that they contribute throughout the development of care.

(2) Mutual Respect – Professionals

Throughout my literature review, and especially in the conversations I've had in developing this project, the value of educators to the diagnostic process has been made clear. The experience that teachers, and early childhood educators in particular, have with observation and behavior management of children allows them to bring a unique perspective to the diagnostic process. Autism diagnoses are typically based around observation, making educators particularly apt at making these assessments. While educators cannot actually provide a diagnosis, they can be an invaluable resource to families in helping identify potential developmental delays. However, far too often, early childhood educators are met with skepticism from pediatricians and other healthcare professionals. Difficulties come from both sides of this relationship, with pediatricians identifying difficulty accessing school personnel and a perceived lack of interest or disregard of physician recommendations as obstacles to collaboration, along with limited time, reimbursement, and training (Lemkin et al., 2019). So, while educators and medical

professionals are both thoroughly involved in the diagnostic process, they are often operating separately.

From a holistic perspective, both early childhood educators and clinicians bring valuable knowledge and information to the diagnostic process. Educators typically have time and experience with children that is distinct from that of clinicians, and they bring a different developmental perspective and understanding. If met with respect, and willingness to collaborate, early childhood educators could be a great aid to physicians and other providers of care involved in the diagnostic process of autism in identifying children and providing insight on their behaviors and developmental trajectory.

It is clear that respect and willingness are required from all individuals in this process. A collaborative, team approach would best serve children and their families, providing them with coordinated care across medical and educational aspects of the diagnosis, but is not possible without willingness from those involved. A common model for this type of collaboration seems to be clinicians partnering with schools in an advisory capacity, allowing teachers to communicate readily with medical professionals. However, it seems as though a shift on a larger scale, to facilitate greater communication between early childhood educators and pediatricians, would increase the benefits of these relationships.

A model for the facilitation of communication between educators and healthcare providers can be taken from research around using early childhood mental health consultation (ECMHC) to mitigate disciplinary disparities. In this model, a mental health professional partners with an early childhood care and education provider to serve as a problem-solving and capacity-building resource (Albritton et al., 2018; Perry et al., 2010). Currently, mental health consultation is a requirement in certain states, at least at the preschool level. These mental health

providers can help in the identification of early mental health problems, and simplify the referral process for evaluation, diagnosis, and treatment. This model is used by many of the individuals, including teachers and clinicians, with whom I spoke through this project. This model, if implemented thoughtfully and pushed to be the norm across schools, could significantly enhance the relationship between educators and healthcare providers. Having a platform for consistent communication allows for the development of a truly collaborative relationship. It is essential, however, that there is respect from both sides in order to build up trust and take full advantage of the opportunities this model provides.

(3) Developing Trust

Finally, and perhaps most importantly, none of these recommendations will be effective without improving familial trust in relationships with healthcare professionals and educators. If parents do not have trust in the medical and educational systems and providers with whom they are working, they are unlikely to follow their guidance and take advantage of the resources they offer. Parent and child experiences in the diagnostic process directly impact their future use of services and treatment for autism (Carbone et al., 2010). So, with families regularly experiencing stressful and dissatisfying surveillance, screening, and diagnostic practices, they are increasingly likely to lose trust in the medical system for the later provision of services. This is especially true for typically underserved populations, who may come into the diagnostic process with mistrust in the healthcare system (Mandell et al., 2002). Without addressing widespread mistrust in the healthcare system in particular, it will be exceedingly difficult to improve the diagnostic outcomes for these populations.

Mistrust is a complex and deeply rooted problem in the healthcare system. Though this obviously makes it a difficult problem to mitigate, it also means there are a variety of potential

entry points to eliminating particular barriers for families. For example, much of the literature around Spanish-speaking Latino family experiences in the autism diagnostic process cite language as a barrier to services and diagnosis (Blanche et al., 2015; Parish et al., 2012; Zuckerman et al., 2013). This problem alone warrants a varied approach to mitigating its negative effects. On one hand, screening tools should be developed that specifically target Spanish and other non-English language individuals for diagnosis. On the other hand, we could be thinking about diversifying the healthcare profession to better match the patient populations. Language barriers need not be a significant problem in the diagnosis of autism, though this change will obviously take time.

Changing the demographics of the healthcare profession more broadly is a commonly cited potential solution to mistrust. Black patients visiting physicians of the same race generally rate their medical visits as more satisfactory and participatory than do those who see physicians of other races (Cooper et al., 2003). This obviously requires systemic level change, whether it be increasing equity in medical school admissions or reducing the cost of medical school for aspiring physicians, and especially those preparing to work with underserved communities (which are commonly individuals of color according to Marrast et al. (2014)). This, however, will certainly be a slow process. In the meantime, models like incorporating care coordinators can help to bridge the gap. Clifford Beers, for example, specifically seeks out individuals for these roles that are representative of the demographics of the populations they serve. So, even if healthcare professionals are not representative of the target populations, these individuals can help to bridge the gap between families and services, and perhaps improve trust.

Establishing trust also comes down to the individual level — clinicians need to be trained and prepared to interact with a diverse patient population. This requires culturally responsive

practices and careful thought by clinicians about how they are seeking to build relationships with their patients and their families. For example, it has been demonstrated that interventions targeted at improving providers' cultural sensitivity and behavior during clinical encounters can reduce disparities in the healthcare utilization of Latino children with autism and other developmental disabilities (Parish et al., 2012). Other studies identify the need for greater clinician cultural sensitivity for interacting with Black patients and families, and more effort on the part of practitioners to include families in decision-making processes (Pearson & Meadan, 2018). The diagnostic process for autism is long, complex, and commonly overwhelming for parents. This could be improved drastically with greater trust established between healthcare providers and families such that parents do not feel they have to be advocating for their children and guiding the process themselves, and instead feel as though they are a member of a broader team in the development of care for their children.

Trust at the systemic level is likely slow to change. With a complicated historical relationship between underserved populations and the healthcare system, it will take significant efforts to build broader trust. There is, however, opportunity at the individual level to make progress, and even effort at this level can have a significant impact on the diagnostic process for children with ASD and their families. This could begin, for example, with expanding provider education to include specific training regarding working with a diverse patient population. The individuals with whom I spoke had a number of recommendations and strategies for building trust with individual patients and their families. Above all else, it is important to make clear to parents and families that they are valued members of the process, and coming in as equals to conversations about their children is essential to opening up these relationships. Beyond that, healthcare providers can continue moving methodically through the diagnostic process and

communicating openly with families throughout, and allow for continued input and discussion in order to ensure families are understanding and in agreement with the steps taken.

Relationship building is also centrally important between families and educators, especially if they are to increase their presence in their process. Though perhaps less so than medicine, there is a level of mistrust in the school system among minority families (Walker, 2017). Relationship building for educators can often emerge through parent involvement and inclusion in their children's education. Creating a connection between not only teachers and students but also the family is central to expanding the role of educators in the identification of autism.

Limitations

Fundamentally, this capstone and its scope are limited by the nature of the project itself. This is a one-year project, completed during undergraduate school along with regular classwork, and this certainly influenced decisions surrounding its scope. As a result, this project has had to put aside certain significant, but distinct, areas of the field in order to attempt to find progress in answering the primary research questions of interest.

First, this project was centered around improving diagnostic disparities, focusing specifically on those occurring along racial and socioeconomic lines. As was mentioned early on, there are also alarming and perplexing sex/gender differences in rates of autism. This is an incredibly complex, and not particularly well understood area, not considered here because it differs in nature from disparities occurring along racial and socioeconomic lines. There is also further depth and nuance to the relationships between race, socioeconomic status, and access to care that could not be fully investigated in this project.

Additionally, the nature of the research conducted was chosen to maximize the relevant ground to be covered, but, with more time and resources, a more complete study would likely take a different approach. Though I had conversations with individuals involved in the diagnostic process along the way, it would be truly indispensable to hear from parents who have gone through this process themselves to better understand their experiences. Along similar lines, a lot of the research contributing to this project has come from the study of somewhat ideal models. The individuals with whom I spoke were largely located in the New Haven area, typically working at the intersection of Yale and its surrounding, but interrelated network. A great challenge of this project has been taking what I have learned from studying this somewhat ideal model, and thinking about how to apply its principles at a more widespread level, and in a more accessible manner.

While the conversations I conducted were primarily with individuals working within resource-rich settings, it is also worth noting that much of the research conducted around autism in general has been in these types of settings. Disparities in treatment and access extend out to who is included in research studies, and who receives this type of attention. In addition to expanding autism research around gender/sex disparities, it is essential to expand to better understand the diagnostic and treatment process as it relates to race, ethnicity, and socioeconomic status to ensure that best practices are widely applicable, and not appropriate only for those with the resources available.

Future Research Directions

The limitations of this capstone, fortunately, translate rather directly into potential future directions of research.

First, the intricacies of the relationship between sex/gender in autism presentation, diagnosis, and treatment represent a significant field in which future research could be incredibly influential. This research, once more fully developed, would contribute significantly to this project as another group on which to focus to ensure a more complete and comprehensive diagnostic process to reduce disparities.

As was described above, a much deeper dive into family and child experiences through this process would be valuable to get a better understanding of the inside workings of the diagnostic process. Along these lines, an in-depth interview study of teacher experiences would prove valuable as well to better understand their potential role in these relationships, and the diagnostic process generally. Of particular importance is conducting these studies in a way that amplifies the experiences of typically underserved populations such that it connects to logical and thoughtful changes in the process to reduce disparities.

The process of receiving an educational diagnosis is incredibly complicated, and often drawn out and difficult. There are a lot of players involved in reaching special education status, and a lot of work and negotiation that goes into gaining a diagnosis, even before finalizing a treatment plan. This process includes far more than just the complexities of an autism diagnosis. An investigation of the legislative, political, and financial drivers influencing experiences and progress within the special education system would also be illuminating for this research.

Finally, issues of access and trust in the healthcare and education systems warrant significant future research and reform. Autism is only a small piece in a much broader environment of difficulty and alarming disparity within healthcare and education, and there are a nearly endless number of areas in which to focus within these systems to attempt to mitigate these problems.

Conclusion

At the heart of this capstone is an investigation into the division between medicine and education when it comes to autism spectrum disorder. For a condition necessitating such a widespread approach, this divide is largely illogical, at all levels from diagnosis to treatment. Early intervention is at the forefront of recommendations for maximizing outcomes for individuals with autism. Time is valuable, and yet the diagnostic process is long, complicated, confusing, and disjointed. Children can go through the medical diagnosis process, and still not receive services from their school. Diagnosis and treatment for autism should go hand-in-hand, yet there is too often a disconnect in time between the two. A more unified approach is a large task, but one that can start with small changes to the nature of relationships between healthcare providers and educators.

Healthcare providers, from pediatricians to psychiatrists, are classically understood to be instrumental in the diagnostic process for autism. They bring, at least in theory, a specific understanding of the nature of the disorder, as well as the process for diagnosis. This can, and should, be complemented by the perhaps more complete, holistic view and understanding of development brought by educators, and specifically those involved in early childhood education. These teachers have such a powerful opportunity and level of experience with observing children not just individually, but in a classroom setting. With the nature of autism, and its hallmark social challenges, these teachers are likely to have valuable observational experience to contribute to the diagnostic process, as they see children in action in a wide variety of settings and circumstances.

Not only does the diagnostic process necessitate the facilitation of partnerships between those in education and medicine, but also the nature of treatment. High quality autism care

typically brings together a broad team of individuals, from pediatricians to psychologists, speech and language pathologists to occupational therapists. This approach is inherently a combination of medical care and educational support. So much happens within the classroom, and yet so much needs to occur behind the scenes in order to facilitate student learning and success. Without the right balance of educational resources and experiences, and medical support behind the scenes, students are far less likely to progress and develop in the optimal manner.

At the core of this project, and these partnerships, is the understanding that this needs to be an approach based in compassion and care. The diagnosis of autism is a difficult experience, and one made far more difficult by the demands placed on families throughout the process just to reach a conclusive diagnosis, let alone access care. None of this works without the development of relationships built on trust and respect. Negative experiences through the diagnostic process not only delay access to services, but also spiral into mistrust of the systems responsible, resulting in further isolation of families in the most need. This isolation can go on to limit the use of services and supports potentially available to their children, those that are so crucial for the management of ASD.

With this in mind, interventions aimed at improving family experiences through the diagnostic process should be targeted at those most in need. Minority families, and families of lower socioeconomic status, groups that are widely underserved in the healthcare system and suffer from worse educational outcomes, should be elevated by changes to the identification and diagnostic process. Small changes in the nature of relationships, paired with logistical support to begin tackling systemic barriers could have an immense impact for these children and their families.

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Appendix:

1. Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., Messinger, D., Pelphrey, K., Sanders, S. J., Singer, A. T., Taylor, J. L., & Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism*, 6(1), 36.
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 - a. *A summary of the main points of discussion and suggestions for future research on gender disparities from a 2014 meeting of almost 60 clinicians, researchers, parents, and self-identified autistic individuals, organized by Autism Speaks and the Autism Science Foundation.*

2. Lai, M.-C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11–24.
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 - a. *A detailed review summarizing relevant literature on sex/gender differences in autism, as well as an outline of topics and directions for future research.*

3. Schuck, R. K., Flores, R. E., & Fung, L. K. (2019). Brief Report: Sex/Gender Differences in Symptomology and Camouflaging in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 49(6), 2597–2604. <https://doi.org/10.1007/s10803-019-03998-y>
 - a. *An investigation of camouflaging in females with autism compared to males with autism.*