EXAMINING SOCIODEMOGRAPHIC DISPARITIES IN AMOUNT AND TYPE OF INTERVENTION USE

by

HANNAH S. DURHAM

(Under the Direction of Ashley Harrison)

ABSTRACT

Research suggests early intervention services lead to better outcomes for children with a range of disabilities (e.g., Dawson, 2010; Perry et al., 2011; Zwaigenbaum et al., 2015). Children with disabilities, such as autism spectrum disorder (ASD), benefit most when intervention services are provided as early as possible but unfortunately, children from sociodemographic minority groups do not equitably receive services at the same age (i.e., Latino, African American). Although prior research has addresses broad disparities in assessing or not accessing certain intervention services, limited studies have documented the extent of the disparity by examining differences in the total number of hours of services families are utilizing across a broad range of services for children with ASD ages 2 to 12-years-old. Using a nationally representative data set (Simons Simplex Collection (SFARI)), the current study investigates variability across sociodemographic groups (i.e., race, ethnicity, household income, occupation, and education) on total number of hours of intervention types, including intensive therapy, occupational therapy, speech therapy, and psychotropic medications. Results revealed the underutilization of services in racial minority and socioeconomically disadvantaged populations across two different age ranges (i.e., 2 to 5 years and 6 to 12 years). In addition, psychotropic medication use was observed at higher rates by Whites than Asian, African American, or Other racial groups. Implications for practice and future directions are discussed.

Keywords: autism, autism spectrum disorder, disparities, intervention, early intervention, therapy, Simons Simplex Collection

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DEDICATION

I would like to dedicate this thesis first and foremost to my family. I am forever and endlessly grateful. You all have shown me steady support and love in both the ups and the downs, and I would not have been able to do it without you ALL.

To mom and daddy for always wiping my tears and sharing in the excitements and challenges I have faced these past few years. You both have given me the roots and the wings to fly. To my brothers, Matt and Zach, for always believing in their little sister. To my better half Wes, thanks for moving with me to UGA and believing in my dream, thank you for knowing how to talk me through situations and teaching me how to better handle the emotional roller coaster that is grad school, and for making each day full of laughs. To my grandparents, Nan, Pop, and Nana for all of the financial support and words of wisdom along the way. To my Papa who did not make it to witness the completion of this project, I know you have been looking down from heaven rooting for me along the way and I know I have made you proud. Lastly, to my nieces and nephews, Madyson, Kai, and Cullen, this is for you to know you can do it! You have everything it takes to chase any dreams you may ever have and always know aunt Bean will be there to fully support and love you along the way.

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CHAPTER 1

INTRODUCTION

A mounting body of research evidence supports the existence of disparities across racial/ethnic minorities groups and groups of varying income/education levels who have been diagnosed with autism spectrum disorder (ASD) and access to diagnostic services (Burkett et al., 2015, Daniels & Mandell, 2013; Liptak et al., 2008; Little et al., 2015; Magaña et al., 2012; Mandell et al., 2006; McIntyre & Zemantic 2018; Nguyen et al., 2016; Pearson & Meadan, 2018; Williams et al., 2014; Zuckerman et al., 2014). With regard to diagnoses, disparities are found for diagnostic timing, accuracy, and quality. Studies have been designed to begin to investigate causes for these diagnostic disparities. One potential contributor to these disparities are biases found in screening measures and tools used specifically for the diagnosis of ASD (Mandell et al., 2002; Murray et al., 2016). We also see variability in familial satisfaction of provider care and its quality (Mandell & Novak 2005).

Emerging evidence for disparities is also found for ASD treatment with many potential explanations for treatment disparities. Children with ASD present differently across a spectrum of symptoms. For example, those who present with ASD and comorbid intellectual disability (ID) are more likely to be treated with psychotropic medications (Aman, Lam, & Collier-Crespin, 2003; Witwer & Lecavalier, 2005), whereas children who present as higher functioning with ASD might be more likely to attend social skills groups (Reichow, Steiner, & Volkmar, 2012). In addition, Akins, et al., (2014), found that parents with higher education levels might have a higher likelihood of using complementary or alternative medicine-type treatments.

Disparities in Diagnostic Timing

Although there are many interventions available to treat symptoms of ASD (Green et al., 2006), unfortunately, many children with ASD do not receive intervention as early as they should. It is essential that children acquire an accurate diagnosis as soon as possible to determine their eligibility for school and community-based services. It is known that late diagnosis of children might lead to untimely intervention services during the most critical time period of a child’s development. This early time in a child’s life is a particularly sensitive period in the process of their development and if interventions are initiated during this time frame, a greater potential for change has been observed (Warren, et al., 2011). Unfortunately, diagnostic services are not occurring equitably across all groups. For example, minority groups in the U.S. might be at a particular disadvantage for receiving timely diagnostic services (e.g., Nguyen et al., 2016). Other work by Liptak et al. (2008) identified children from minority groups with ASD as having generally less access to diagnostic services compared to their White peers.

There are a variety of factors that could be related to these disparities including a wide range of sociodemographic factors. For example, racial and ethnic health service disparities are associated with socioeconomic (SES) differences, although some research indicates that even after controlling for SES, racial and ethnic disparities remain (Agency for Healthcare Research and Quality, 2019). More specifically, a diagnosis of ASD is often delayed until school age among African American children (Mandell et al., 2002). This delay is particularly important as research suggests that intervention during the preschool years plays a particularly vital role in beneficial outcomes for children with ASD (Zwaigenbaum et al., 2015). Other research found that Latino children are more likely to be diagnosed one year later than White children and at the point of more severe symptoms (Magana et al., 2013; Zuckerman et al., 2014). Delays in diagnosis, which might be related to inadequate screening practices, impede early intervention services that are vital for children's improvement in many areas of development (Sices, 2007).

An additional factor contributing to these untimely diagnoses might be a lack of awareness of ASD symptoms that manifest early on in life (Heidgerken et al., 2005). This limited awareness is a specific factor contributing to gender differences in identifying ASD symptoms. Research suggests that female symptoms may present differently, which might lead to a more difficult time diagnosing or a later accurate diagnosis compared to males when using gold standard measures (Matheis et al., 2018; Reinhardt et al., 2014; Rivet & Matson, 2011; Ros-Demarize et al., 2019; Werling & Geschwind 2013).

Additionally, required financial resources and geographic location might play a role in untimely assessment and diagnosis, which has proportionately affected minority populations (Mire et al., 2018). While research indicates the negative impact of delays in diagnosis on minority populations with ASD, we can assume that these diagnostic delays could lead to treatment barriers; however, less is known about the specific sociodemographic patterns that might affect the access and utilization of such intervention services.

Disparities in Diagnostic Accuracy

In addition to importance of having a timely diagnosis of ASD, the accuracy of the diagnosis is equally essential. An incorrect diagnosis can be harmful for the individual (i.e., receiving incorrect or no services, stigma, etc.). Research suggests these diagnostic errors occur more readily for minority populations. For example, African American children are less likely than White children to receive an initial ASD diagnosis, instead receiving diagnoses of adjustment and conduct disorder (CD; Mandell et al., 2007). Goldstein & Schwebach, (2004) reported symptoms frequently observed in children with ASD, such as hyperactivity and behavioral difficulties, can lead clinicians to incorrectly diagnose attention deficit/hyperactivity disorder (ADHD) instead of an appropriate diagnosis of ASD. This misdiagnosis can include other symptoms such as repetitive and restrictive behaviors, often seen in children with ASD, and which might lead to diagnoses of obsessive-compulsive disorder (OCD), or a noncompliance disorder, such as oppositional-defiant disorder (ODD) or CD. The main goal of an accurate diagnosis is to provide appropriate interventions for these children. Issues can arise if children receive interventions that are paired with an incorrect diagnosis.

Cultural differences in the presentation of ASD and interpretation and description of symptoms of ASD (i.e., parents and providers) might also play a role in accurate diagnostic disparities (Mandell & Novak, 2005). One study found that non-Hispanic Black and Hispanic children were less likely than non-Hispanic White children to even have a diagnosis of ASD. (Wiggins et al. 2019). Overall, one-fourth of the children from this same study who met criteria for an ASD diagnosis, did not have one, and of that one-fourth, 55.3% did not receive ASD related services in the public-school setting. Wiggins et al. (2019) also suggested a parent-doctor interaction to be another possible reason for these disparities. Blacher, Cohen, and Azad (2014) found that Latina mothers described more general developmental delays in their children, while White mothers reported more

ASD specific concerns, even though the Latino children had more severe ASD symptoms than the White children. This study suggested three possible explanations for the discrepancies between parents and professionals in perceptions and reporting of ASD symptoms (e.g., parents might not be aware of the symptoms, certain mothers are more concerned with social communication deficits over other deficits, and cultural beliefs and practices might mask the ASD symptoms exhibited by children). African American and Latino families of children with special health care needs were less likely than White families to feel they received the necessary information and were less satisfied with the interactions from their provider (Coker et al., 2010). Even more specifically, African American, and Hispanic parents described a poorer quality of care, including a lack of cultural competence and understanding of their values and beliefs compared to White parents.

In addition, variability in diagnostic timing has been observed between genders. This finding might be in part because ASD symptomatology or presentation can differ between males and females (Ros-Demarize et al., 2019). For example, one study suggests differences in phenotypic presentation (Werling & Geschwind, 2013), reporting findings that females have fewer restricted and repetitive behaviors and eternalizing behaviors compared to boys, which might contribute to a male diagnostic bias or a tendency to under diagnose females. The research examining sex differences yields conflicting findings. More specifically, Matheis et al., (2018) found that among children 17 to 37 months old, females had greater motor deficits and less communication impairments compared to males. In contrast, Ros-Demarize et al., (2019) suggested social communication deficits to vary by age, and found that young girls diagnosed with ASD, ages 17-72 months of age were found to have greater social communication deficits than young boys. Other research found females to have fewer restrictive and repetitive behaviors (Nicholas et al. 2008) and fewer social communication symptoms (Zwaigenbaum et al., 2012). Because of these gender differences, disparities are found in female diagnostics. In addition, it will be important to think about these differences in gender also being associated with screening measures (e.g., parent report, teacher report, etc.) and the diagnostic assessments employed which might play a role in children's diagnostic presentation and overall scores. As such, it is important to also examine if similar disparities exist in intervention service utilization between genders.

Issues surrounding disparities overlap and play a vital role in receipt of services when most vital to the child's development. Parents' perceptions of their experience with providers and the quality in which children receive healthcare services might play a role in parental choices to utilize intervention services. Overall, a wide body of documented evidence supporting disparities associated with diagnostic services and why they may exist is present in the scholarly literature. There is substantially less data examining whether these same disparities patterns exist for treatment, to what extent, and why disparities might be occurring.

Disparities in ASD Intervention Dosage

Under the Individuals with Disabilities Education Improvement Act (IDEIA), early intervention services are federally mandated in the United States for all children with disabilities ages birth to 21 years old. The National Research Council, (NCR) (2001) recommends intervention across 5 days per week, for a minimum of 25 hours per week for children with ASD. Similarly, according to Myers and Johnson (2007), the American

Academy of Pediatrics recommends that children with ASD be involved in intensive therapy, which includes active engagement of the child at least 25 hours a week, 12 months a year, in systematically planned, appropriate educational settings. Despite these recommendations, as families of children with ASD access services, the intensity of the services tends to be below recommendations (Downs & Downs, 2010; Wise et al., 2010). Children with higher severity scores, using the Autism Diagnostic Observation Scale (ADOS; Lord et al., 1989) demonstrate more developmental gains with higher numbers of intervention service hours (Venker et al., 2014). Other studies have revealed positive outcomes in both social communication and language with 25 hours of intervention services per week (Dawson et al., 2010; Kasari et al., 2010).

Only 12% of early intervention programs approximate the recommended 25 hours of services per week (Downs & Downs, 2010). More specifically, Wise et al., (2010) found that almost half of early intervention programs across the United States provided fewer than 5 hours per week to young children with ASD. Thus, findings suggest that not only do children with ASD not receive intervention as early as they should, but they also are not utilizing these interventions to their fullest potential, nor do service providers provide the necessary number of hours. As not all children with ASD have the same severity of disorder, some children present with more severity than others. Unfortunately, symptom severity is not the only factor that contributes to variability in amount of ASD service access. Evidence is mounting that suggests that similar to disparities in ASD assessment, disparities in ASD service use also exist.

Evans et al., (2015) explored attitudes and perceptions of African American parents on child disability and early intervention services by taking a deeper look into the underrepresentation of African American children who are enrolled and utilizing early intervention services. Smith et al., (2020) found some of the same patterns of underrepresentation in the early intervention literature, specifically in special education services for Hispanic and Asian children as well. Their study found that treatment services, such as Individualized Education Plans (IEP), ASD specific therapies, occupational, and speech language therapy (SLT) were under-utilized among Hispanic and Asian children. Other research conducted by Irvin and colleagues (2012) indicated Hispanic children with ASD receive a smaller amount of occupational and speech therapy in comparison to their White peers. In addition, Asian children were found to be less likely to receive occupational therapy and speech therapy compared to White children, and Hispanic children were less likely to receive IEPs, have access to ASD specific therapies, receive occupational therapy, and speech therapy, in comparison to non-Hispanics.

Acquiring culturally competent services for minority populations, identification, and recruitment of African American families into early intervention services might be correlated to parent’s overall attitudes and perceptions of disability and treatment. This resembles the previously mentioned diagnostic disparity related to the quality-of-care African American families might be receiving and their level of comfort with their providers. Reviews of early intervention service delivery research detail that interventions suggested for minority families are often culturally inappropriate and insensitive to their needs. What is challenging in such studies is the use of a total number of hours of intervention making it difficult to describe the relationship between intervention and parental attitudes and perceptions.

Other examples of inequities also span across other treatment types. Education and occupation have been an additional barrier in treatment service usage across minority populations. Families with higher SES were more likely to utilize applied behavior analysis (ABA) services and private outside services, such as Occupational Therapy (OT), than those with lower SES (Irvin et al., 2012). Magana et al. (2013) noted that service utilization was associated with higher levels of parental education, thus, we hypothesize that education and occupation do in fact matter regarding service utilization specific to children with ASD.

The studies summarized above demonstrate preliminary evidence of disparities in treatment, but many limitations are found, specifically needing a more in-depth examination of the disparity itself and why it may be surfacing across these different sociodemographic populations. Although clear documentation of the existence of disparities in service use is emerging, the nuances about these disparities can help inform approaches to improve equitable access.

Limitations with Research Documenting Intervention Disparities

Dosage of Intervention

In spite of the knowledge that dosage of intervention clearly matters, most of the current research investigating disparities in intervention service usage focuses on dichotomous outcome variables such as “never used” or “have used” treatments at a single time point (Evans, Feit, & Trent, 2015; Mire, et al., 2018). Because research has indicated the total number of hours dedicated to intervention services makes a difference, using a dichotomous variable might not be painting an accurate picture of the patterns in which families from different groups utilize these services. Additional research is needed that examines numbers of intervention service hours to determine what extent different sociodemographic groups are differently utilizing interventions services.

Heterogeneity in ASD Intervention Types

Given the heterogenous nature of ASD symptoms (Masi et al., 2017) and frequent experienced psychiatric comorbidity (Joshi et al., 2010), the field has cultivated many interventions for individuals with ASD. Most of these treatment options can be broken down into the following categories: Behavior and Communication Approaches, Dietary Approaches, Medication, and Complementary and Alternative Medicine (CDC, 2019). More specific types of treatments exist within each of these categories. For example, Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Early Start Denver Model (ESDM), Pivotal Response Training (PRT), Verbal Behavior Intervention (VBI), Assisted Technology, "Floortime," TEACCH, Occupational Therapy, Social Skills Training, and Speech Therapy are all examples of Behavior and Communication Approaches. Although behavioral intervention such as ABA are among the most implemented, there are a wide range of other interventions with known empirical support (Wong et al., 2014).

Most of the current disparities on which research focuses suggest use of only one or two types of intervention at a time or focuses on either public services or private services. These investigations fail to take into account intervention substitution for a different type of intervention when documenting disparities. By examining a wide range of intervention types at a certain time, one can examine how usage patterns differ between groups. This strategy also prioritizes an examination of a wider type of therapies rather than focusing more narrowly. Further, future research has highly prioritized examining interventions that the child likely receives in the school context, including occupational therapy, speech therapy, and ABA therapy. Smith and colleagues (2020) found that caregivers with a higher SES were found to be more likely to enroll their child in private ABA and OT over those with lower SES. Locke and colleagues (2016) found that Latino children were less likely to utilize in-school services than White children, while Irvin and his team (2012) found that Asian families were also likely to receive a smaller dose of in school services than their White counterparts. However, studies have noted that there are meaningful differences in private and public service use between sociodemographic groups. For example, Irvin et al. (2012) found that African American families are less likely than White families to utilize private interventions outside of the school. Thus, failing to take into consideration the rates of private service utilization in addition to school services may result in a meaningful underestimate of actual disparities.

Research estimates 30% - 60% of children and adolescents with ASD have used psychotropic medications (Mandell et al., 2008; Rosenberg et al., 2010). Most children with ASD are prescribed medications in hopes that the medications will help monitor and decrease problem behaviors (i.e., irritability; Howes et al., 2017; Karst & Van Hecke, 2012). However, much of the ASD service use disparities research has failed to examine sociodemographic differences in this type of intervention. However, Coury et al., (2012) did examine psychotropic medication utilization examining racial and ethnic variables across children ages 2 to 17 years old. Findings indicated that White and non-Hispanic or Latino participants were more likely to receive medications. Similarly, Leslie et al., (2003), Frazier et al., (2011), dosReis et al., (2005), and Chirdkiatgumchai et al., (2013) all found that White children with ASD had a higher number of psychotropic medications usage than other racial and ethnic groups. Although not specific to ASD literature, but still important to note, Zito et al., (2007) found that Whites were more likely than both Hispanic and Blacks to receive medications for behavioral conditions.

Research notes comorbid disorders play an impact on number of psychotropic medications; however, in general, individuals with a diagnosis of ASD demonstrate higher usage of psychotropic medications than those without ASD (Esler et al., 2019). Further, children with comorbid epilepsy and ADHD were found to have increased odds of receiving more medications in comparison to children with schizophrenia, bipolar, sleep disturbances, anxiety disorders, CD, depression, or ID (Houghton et al., 2017).

Additionally, to support a disparity in age, a longitudinal study conducted by Esbensen et al., (2009) found that age was a factor in the number of psychotropic medications that were consumed, reporting that more psychotropic medications were taken by adults than adolescents with ASD.

Intervention Age

One of the biggest gaps in the literature on ASD is research related to later developmental periods in the lifespan trajectory. One study documented parents and practitioners feeling that research focuses too much on children and not enough on adolescents or adults with ASD (Pellicano, Dinsmore, & Charman, 2014). Another study by Camm-Crosbie and colleagues (2019) suggests a lack of knowledge in both understanding and being involved in the treatment and support of adults with autism. This gap in the other developmental periods is clear in the service use disparities literature as well.

After reviewing the ASD service use disparities research, findings mostly focused on the birth to 6-years-old age range, with few studies including children as old as 10-years-old (Burkett et al., 2015; Little et al, 2014; Nguyen et al., 2016). However, research indicates it is not appropriate to make assumptions about the service use patterns of older children based on what is occurring among younger children. For example, Thomas, et al. (2007) found that children under the age of four were more likely to receive speech therapy than children over the age of five, suggesting clear developmental variability. Thus, extending research to the next developmental period (school age children) to examine differences across different age levels regarding service usage also has merit. Current research limitations might inhibit the understanding of intervention utilization throughout the lifespan as it is challenging to relay utilizations of early childhood interventions to later childhood intervention use. According to Carter, Brock, & Trainor (2012), the needs of adolescents with ASD are far more complex, including higher education, jobs, community involvements, and independently living skills. While younger children are receiving more specified and discrete interventions, such interventions are far too restricted for older individuals with ASD. Even more specifically, Odom et al., (2010) reported that intervention packages for children at the secondary level have been absent in the literature.

Sociodemographic Variables

Most of the research on disparities in ASD focuses narrowly on race and ethnicity without examining other sociodemographic variables. However, a range of cultural factors might influence the way family's access ASD resources for many reasons (Ravindran & Myers, 2011). By examining the relation between diverse aspects of culture and service, researchers can understand how other cultural variables might impact treatment seeking or access. For example, patient values and beliefs are understudied factors (Mandell et al., 2007), more specifically values and beliefs may differ by culture and race. Socioeconomic status (SES) remains one of the strongest determinants of variation in health status (Williams & Collins, 1995) and is interconnected to a myriad of other variables that may contribute to health disparities. SES is understudied in individuals with ASD and their treatment access. Durkin, Maenner, and Baio (2017) reported that the correlation between ASD and SES might have a relation to healthcare resources and education services.

Lower SES is a barrier when financial resources inhibit access to services; however, this alone does not account for the under diagnosis, misdiagnosis, and poor quality of services families with children with ASD are experiencing. Families who live in lower SES neighborhoods might also have limited access to doctors and services due to a lack in transportation. Because many factors have not been studied in the context of ASD intervention utilization, research should aim to include other related variables in addition to SES but that are distinct, such as parental education and parental occupation., which have also been related to service utilization for families of children with ASD (Nguyen et al., 2016).

Current Study

While there are many intervention options accessible to individuals with ASD, even with available large sample size datasets and participants in many geographical locations, the existing research only examines a subset of intervention types. Relating to intervention types, most research focuses solely on a dichotomous (i.e., yes/no, “have used" "never used") label categorizing the child as currently being involved in a specific intervention or not, even though it is clear that amount of intervention matters. Further, the existing disparities research narrowly focuses primarily on early childhood. Lastly. most of the research on disparities in ASD focuses narrowly on race and ethnicity without examining other sociodemographic and cultural variables that might play a role in influencing the access and utilization of intervention services.

To address the age gap in the literature, the current study focuses on treatment use patterns among specific age groups (i.e., 2 to 5 years and 6 to 12 years). The number of total weekly hours of intervention services usage was examined separately for each of these age ranges. There are data to support that in school-based services, minorities underutilize early intervention but then are overrepresented in school age services (Hosp & Reschly, 2003). The current study aims to more comprehensively examine a range of sociodemographic factors thought to contribute to disparities. Additionally, many different factors affect parental choices for their child's treatment of ASD, including education level, background and culture, even professional networks of which families might be a part (Patten, et al., 2013; Ravindran & Myers, 2012; Miller, et al., 2012). As such, this study not only includes race/ethnicity and income, but other additional variables that will be used to determine a more in-depth examination of intervention usage and disparities (e.g., maternal occupation, maternal education, race, ethnicity, gender, and income). Not only does the current study more comprehensively examine age groups and sociodemographic groups the dependent variable coverage is much more comprehensive that past research. Given the documented differences in private versus school-based hours, the current study examined sociodemographic patterns and how other areas of disparities might affect the process of accessing and utilizing services outside the school context.

A range of different types of interventions, including speech therapy, intensive therapy, and occupational therapy will be examined to more comprehensively measure whether distinct sociodemographic patterns exist within these specific interventions. Both speech therapy and occupational therapy are interventions that many children receive through either their school or outside service providers, so we examined both within our analysis. Evidence of effectiveness in naturalistic approaches, such as ABA therapy, has been found; however, are overall more expensive. Thus, looking at this specific intervention related to sociodemographic variables will provide insight into disparities in utilization across intensive therapies in comparison to services children might be receiving in their school settings. An additional psychotropic medication component was examined in the current study. All of the medications that were evaluated within this study were used to target behavioral symptoms of ASD (i.e., hyperactivity, aggression, irritability, and insomnia). By examining total number of hours across different types of interventions, a more comprehensive picture is provided of the different patterns’ families might be using, thus, helping to identify a broader range of potential disparities.

The current study examined the relation between sociodemographic differences (e.g., race, ethnicity, income, education, occupation) and the approximate total number of weekly hours across different types of interventions, including speech therapy, occupational therapy, and intensive therapy, with a total number of psychotropic medications. We hypothesized that underrepresented groups (e.g., Asians, African Americans, Hispanics) would utilize fewer approximate total number of weekly hours of interventions across all types of intervention therapies (e.g., speech therapy, intensive therapy, and occupational therapy) while also utilizing a lower number of psychotropic medications. Based on the literature, we additionally believe that a higher annual income, greater maternal education, and according to Nam & Boyd, (2004) maternal occupation ratings falling on the higher end (i.e., lawyers and doctors) will be associated with higher utilization of psychotropic medications as well as increased approximate total number of weekly hours.

CHAPTER 2

METHOD

Participants

Data from the current study were collected from 2,704 participants from the Simons Simplex Collection (SSC; Fischback & Lord, 2010). The SSC is a genetic database including individuals diagnosed with ASD in the United States. The SSC conducted a standard research protocol that was used across 12 data-collection sites in the United States: Baylor College of Medicine, Children's Hospital Boston/ Harvard Medical School, Columbia University, Emory University, McGill University, University of California (Los Angeles), University of Illinois at Chicago, University of Michigan, University of Missouri, University of Washington, Vanderbilt University, and Yale University.

Data were collected as part of a longitudinal study and through various methods including interviews conducted with parents, and cognitive, language, social-emotional, and physical assessments administered to both children and parents. Parents reported sociodemographic factors and a thorough family medical history, including prenatal and perinatal history, developmental milestones, immunizations, medication usage, and common behavioral treatments. Individuals with conditions that might have compromised the validity of diagnostic instruments, such as nonverbal age, neurological deficits, trauma, perinatal complication, Fragile X syndrome, or Down syndrome were excluded from this study. All participants provided consent in the original study and appropriate

Institutional Review Board (IRB). SFARI approval was granted to use the existing dataset for a secondary analysis. Additional information regarding the dataset, including inclusion or exclusion criteria can be found in the SFARI Research Welcome Packet (Simons, 2010) or a write-up of the study methodology in a published study (Fischback & Lord, 2010).

Measures

For the current study, measures of interest from the SSC included sociodemographic information as independent variables, intervention service usage type, and number of hours as dependent variables. These variables are described in greater detail below and can be found in Table 1. Sociodemographic characteristics were obtained from the standard demographic protocol used in the initial research procedures. Intervention usage was obtained from a treatment history form that was provided to the parents and a medical history interview (MHI) conducted with the parents that was created by the SSC.

Sociodemographic Variables

Child gender. The current study includes both male and female participants with a higher percentage of males (86.6%). As ASD is more frequently diagnosed in males (1 in 42; CDC, 2014), this data in the current study aligns with the gender split that is documented in the literature.

Parent race and ethnicity.

Racial and ethnic data were collected in alignment with standard NIH categories (National Institutes of Health, 2015). Ethnicity was labeled as either non-Hispanic (88.2%) or Hispanic (11.8%). The racial labels included the following: White (80.5%), African American (3.9%), and Asian (3.7%). Native-American, Native-Hawaiian, More-than-one-race, and Other were also included in the original dataset but because of the insufficient number of individuals in the Native-American, Native-Hawaiian, More-than-one-race, and Other categories, these were all collapsed together into one category, which is labeled as Other (11.9%). Although a broader problem in the research, it is not uncommon for genetic samples to include mostly White individuals (Hilton et al., 2009; Zamora et al 2016), thus this sample is consistent with most used in the field from a race/ethnicity distribution perspective.

Maternal annual income, occupation, and education. Demographic data were collected on families via the SSC-created Background History Form, including age of the child at the time of data collection, maternal education level, and annual household income. Income was reported categorical by ranges (<$20-50; 14.6%, $51-100k; 38.4%, and $101- >160k; 38.1%). Maternal education is categorized into four separate groups in the current study. Group 1 includes individuals who attended some high school, less than or equal to ninth grade (1%). Group 2 consists of individuals who completed high-school or obtained a GED (7.7%). Group 3 is comprised of those who attended some-college or have an associate degree (28.3%). Lastly, Group 4 includes those individuals who have a graduate degree or baccalaureate degree (59.1%). Maternal occupation was categorized based on the Nam-Powers-Boyd Occupation Status Scores (OSS; see Nam & Boyd, 2004). Occupations were placed into 13 separate categories. Higher ranking careers, such as doctors and lawyers were identified with higher numbers, whereas lower numbers were assigned to individuals such as dishwashers and cafeteria workers. Military positions and those who were unemployed were labeled as missing as Nam-Powers-Boyd Occupation Status Scores do not rank military positions.

Table 1

Participant Information

Sociodemographic Information		*n (% of sample)*
Ethnicity	Non-Hispanic	2,285 (88.2%)
	Hispanic	319 (11.8%)
Race	White	2,178 (80.5%)
	African American	105 (3.9%)
	Asian	99 (3.7%)
	Other	322 (11.9%)
Gender	Male	2,346 (86.6%)
	Female	358 (13.2%)
Income	>20-50K	394 (14.6%)
	51-100K	1,038 (38.45)
	101-160K+	1,029 (38.1%)
Mother Education	some-hs, less-ninth, up-ninth	26 (1.0%)
	high-school, GED	207 (7.7%)
	some-college, associate	764 (28.3%)
	graduate, baccalaureate	1,597 (59.1%)
Severity Covariates;	*Mean (SD)*	
ADOS Total Score	15.39 (5.21)	
Adaptive Scores (Vineland)	72.92 (12.03)	
Cognitive Scores (DAS-II)	90.20 (20.07)	

Dependent Variables: Treatment Categories

Therapy Variables. In the study's dataset, therapy types were separated into three categories: speech therapy, occupational therapy, and intensive therapy. All treatment categories were gathered using the SSC's Treatment History Form.

Intensive therapy was separated into 2 groups: intensive therapy (e.g., ABA, AVB, PRT, DTT) and other intensive therapy (e.g., TEACH autism program, Floortime). For the current study, these two groups were combined to create one intensive therapy category. Occupational therapy was separated into four groups: private one-on-one, private group, school one-on-one, and school group. Speech therapy was categorized the same. All four groups were added together to create one occupational therapy and one speech therapy category that included both private and group intervention usage.

Because much of the literature uses a dichotomizing variable or a frequency count of interventions to represent intervention usage (Bilaver et al 2015; Mire et al., 2018; Patten et al., 2013) each of the finalized intervention categories: speech therapy, occupational therapy, and intensive therapy were created to represent a total number of weekly hours. These total hours were generated by using parent report of a total number of weeks and a total number of weekly hours the child was utilizing each specific service. A total amount of hours over time was generated as the primary outcome variable. Number of weekly hours of each type of therapy was calculated separately for three age categories (e.g., 2-5 years, 6-12 years, and 13-17 years). This allowed for an overall number of weekly hours for each therapy type within each age range. The third age range (i.e., children ages 13-17 years old) was excluded from analyses due to the magnitude of missing data.

Psychotropic Variables. The psychotropic treatment category in the current study was derived from the MHI conducted with participant’s parents. Parents reported on a wide range of medications but for the purposes of this study, we were primarily interested in medications used to treat behavior concerns. Of the medications listed in this study, behavioral medications included ADD/ADHD medication, antidepressants, antiepileptics, mood stabilizers, sedatives, and tranquilizers. For each of these medications, children received a dichotomous score of yes or no to indicate usage. This coding was done for past and present use. A composite was then created by adding past and present medications together to display a total number of psychotropic medication utilization across time (i.e., 1-6).

Control Variables

Control variables were used in the current study as a way to specifically look at the variance in the utilization of intervention service hours as a function of sociodemographic variables and not the actual impairment differences of each child. The literature suggests children who present on standardized autism measures with deficits in acquisition of adaptive skills can inform the need to intensify adaptive skill interventions. Because there is a relationship between cognitive and adaptive skills, this information can also help to individualize adaptive skill instruction based on the individual's cognitive and developmental level. Similarly, the reduction of specific autism symptomatology is also one of the factors that are addressed in most all treatment and educational settings (National Research Council, 2001). According to Harris & Handleman (2000), children who were diagnosed with ASD were more likely to have better expressive language outcomes and more likely to be placed in general education classrooms if they receive more total hours of specific interventions and began these interventions at a younger age. Similarly, children who are enrolled earlier in intensive early interventions have better daily living and cognitive outcomes (Dawson et al., 2010). We controlled for symptom severity using the *Autism Diagnostic Observation Schedule (ADOS-2nd Edition, Modules 1 through 4),* cognitive ability using the *Differential Ability Scales (DAS-II-2nd Edition, Early Years and School Age versions),* and adaptive skills based on the *Vineland Adaptive Behavior Scale (VABS-3rd Edition).*

Autism Diagnostic Schedule (ADOS). The ADOS is a semi-structured standardized observation assessment that looks across domains of social communication and restricted and repetitive behaviors that are associated with ASD (Lord et al., 2000). Depending on the child's language abilities, a corresponding module was administered (Module 1, Module 2, Module 3, or Module 4). An overall total score was generated for each participant to indicate level of overall ASD symptom severity. For ADOS-2 total scores, higher scores are indicative of more symptoms associated with ASD.

Each ADOS module has difference cutoff scores that are significant to a diagnostic label of ASD. Module 1 comparison scores were matched to a corresponding overall total based on the child's age and their language abilities (e.g., few to no words or some words). Once this overall total was found, it was compared to the specific modules cutoff scores. A cutoff score for "autism spectrum" within the few to no words group is 11, while the cutoff for "autism spectrum" for a child with some words is 8. There are also cutoff scores for "autism." For a child with few to no words, the cutoff score for "autism" is 16, while a child with some words the cutoff is 12. Module 2 is similar in that an overall total is generated with the comparison score; however, this overall total is based not on the age and language abilities of the child like module 1, but rather just two groups that correspond to a child's age (e.g., younger than 5 and age 5 and older). The overall total is then compared to the cutoff scores according to the module 2 algorithm. A cutoff score for "autism spectrum" for children younger than 5 is 7, while the cutoff for "autism spectrum" for a child aged 5 and older is 8. There are also cutoff scores for "autism". For a child younger than 5 years of age the cutoff score for "autism" is 10, while a child aged 5 and older is 9. For a module 3 ADOS, the comparison score is converted to an overall total like all previous modules, except it is specific to different grouping of a child's age (e.g., 2-5 years, 6-9 years, 10-16 years). Once a total score is determined, this will be compared to cutoff scores. The cutoff score for "autism spectrum" is 7, while the cutoff for "autism" is 9.

Last, module 4 is a bit different. A total score for communication and reciprocal social interaction was generated, along with a total score for stereotyped behavior and restricted interests. These total scores were compared to cutoff scores across three categories: communication, social interaction, and communication plus social interaction. Within the communication category, the cutoff for "autism spectrum" is 2, the cutoff for social interaction is 4, and the cutoff for the two together is 7. For the "autism" category, the cutoff for communication is 3, social interaction is 6, and the two together is 10. For this study's total sample, the total ADOS score mean was 15.38 with a standard deviation (SD) of 5.21. This is above the cutoff scores mentioned above for all modules, indicating the sample has a high level of ASD symptoms.

Differential Ability Scales - II (DAS-II). The DAS-II measured each participant's cognitive abilities. Depending on the child's age, either a School Age Record Form (e.g., 7:00 – 17:11) or an Early Years Record Form (e.g., 2:6 – 6:11) was used. The overall General Conceptual Ability (GCA) score was used as a reflection of the child's overall cognitive abilities in comparison to their peers. Higher scores on this measure indicate higher thinking skills whereas lower scores are indicative of lower cognitive abilities. The current dataset had cognitive scores with a mean of 72.92 and a SD of 12.03. Average cognitive abilities fall within scores of 85 to 115, indicating this sample had a mean falling below that of average cognitive skills.

Vineland Adaptive Behavior Scale – Second Edition (VABS). The VABS is a parent interview that allows for a measurement of a child's adaptive abilities across the following domains: Social, Communication, Daily Living, and Motor Skills. For each participant, an overall Adaptive Behavior Composite (ABC) score was provided and used in the current study. Higher scores on this measure indicate better equipped adaptive skills compared to lower scores. The current dataset had adaptive scores with a mean of 90.20 and a SD of 20.07. Unlike the DAS-II, average VABS scores fall within the 85 to 115 range, indicating this sample had a mean adaptive ability falling right within the average compared to other children their same age.

Analysis Plan

Before conducting any analyses, normality of the dependent variables was determined by the output of Q-Q plots resulting in normally distributed data. Consistent with other research using large samples such as this one, some variables were missing large amounts of data. Participants in either 2-5 or 6-12 age groups who were missing substantial portions of sociodemographic and/or had no intervention therapy data were excluded. Individuals with a subset of data were retained. All missing data for participants were labeled with zero in the dataset, and no data were replaced.

To determine if any sociodemographic characteristics were associated with our approximate total number of weekly hours of interventions, we ran linear regressions adjusting for ADOS-2 total scores, cognitive scores, and adaptive scores using IBM SPSS Statistics 26. These analyses were performed for all intervention types separately including speech therapy, intensive therapy, occupational therapy, and psychotropic medications across sociodemographic variables to investigate if socioeconomic and ethnic disparities were present. Linear regressions were conducted separately for each intervention type across two age ranges (e.g., 2-5 and 6-12 years) aside from psychotropic medications, which was a total number across all ages.

Sociodemographic independent variables included maternal education, maternal occupation, race, ethnicity, annual income, and gender. Although we know both mothers and fathers are involved in their children's development, differences have been found regarding this involvement (Duhig, Phares, & Birkeland, 2002). Specifically, Behrani & Shah (2016) found that mothers were more likely to play a more active role in their child's lives compared to fathers. In addition, Sharabi & Marom-Golan (2018) found that mothers reported significantly higher levels of involvement in all aspect of their child's care than fathers (i.e., greater attendance to educational programs, more involved in maintaining constant contact between caregivers, etc.), including mothers with higher education were found to be more socially involved. Based on these findings, maternal variables were examined in the current study.

Control variables included in all analyses were ADOS total score, cognitive GCA score from the DAS-II, and total adaptive ABC score from the Vineland. This allowed for a more tightly controlled investigation of the sociodemographic variable relation to service use.

CHAPTER 3

RESULTS

Preliminary Analysis

Table 2 contains descriptive statistics for cumulative intervention therapy choices (e.g., speech, occupational, intensive, and psychotropic medication) employed across two separate age groups (2 to 5 years and 6 to 12 years). As can be seen, across intervention types, specifically across usage for participants under the age of five, the approximate total number of weekly hours ranged from 121 (speech) to 180 (occupational), with occupational therapy utilized the most across this age range. For children who were 6 to 12 years old, the approximate total number of weekly hours ranged from 104 (speech) to 280 (intensive), with intensive therapy being the most highly utilized therapy. These numbers also revealed that speech therapy is the lowest utilized treatment service being accessed across both age groups. The max number in this table refers to all children under the age of 5, not just one participant. For example, one child at age 2, 3, 4 and 5 would be included in the 2-5 age group column together. The assumption of no multicollinearity has also been met, meaning none of the VIF values were below 0.1 and none of the Tolerance values were above 10.

Table 2

Intervention Descriptive Data

Type of Intervention	Min. Hours	Max. Hours	Mean Hours	SD
Speech				
Under 5	.20	121	6.8	9.5
6-12	.25	104	6.5	7.7
Occupational				
Under 5	.00	180	4.5	7.5
6-12	.00	153	4.2	6.2
Intensive				
Under 5	.00	160	29.1	32.6
6-12	.00	280	30	48.3

Table 3 refers to the frequency or total number of psychotropic medications that were utilized by children ages 2 to 12 years old. On average, in this sample most participants were utilizing either no medications or one psychotropic medication with fewer children receiving between two and six psychotropic medications. Fanton & Gleason, (2009) indicated an unknown effect utilizing psychotropic medications might have on children’s bodies specifically for children under the age of three. Based on this finding, we created one age range (i.e., 2-12) for this variable as limited results would likely have been found for this younger age range.

Table 3

Psychotropic Medication Utilization

Number of Medications	Frequency	Percent
0	1599	59.1%
1	582	21.5%
2	312	11.5%
3	154	5.7%
4	44	1.6%
5	12	0.4%
6	1	0.0%

Covariates

Correlations between study dependent variables and covariates are displayed in Table 4. We observed that significance was found across all covariates and different types of therapies across age groups confirming findings from prior research (Nguyen et al., 2016).

Table 4

Correlations between therapy types and covariates

Variable	1	2	3	4	5	6	7	8	9
1. OT <5									
2. OT 6-12	.665**								
3. SP <5	.540**	.258**							
4. SP 6-12	.304**	.489**	.397**						
5. IN <5	.138**	.196**	.124**	.209**					
6. IN 6-12	.130**	.266**	.093*	.224**	.559**				
7. Meds	0.02	.083**	0.04	.127**	.062*	0.07			
8.ADOS	.079**	.089**	.095**	.116**	.210**	.263**	0.00		
9. GCA	-.097**	-.072*	-.069**	-.137**	-.095**	-.250**	-0.03	-.360**	
10. ABC	-.069**	-.181**	-.046*	-.235**	-.161**	-.321**	-.208**	-.405**	.451**

**p < 0.01 (2-tailed); *p < 0.05 (2-tailed)

Gender

The first linear regression examined the relation between treatment usage and gender. Females were compared to the male reference group. Because there are gender differences in diagnostic timing as well as diagnostic accuracy; we examined the relation between gender and sociodemographic factors. Interestingly, in this study no differences were found for gender across the utilizations of any services in either age group. More specifically, in terms of children under age 5, no significant differences were found between genders for speech therapy (β= .008, *p*=.751), occupational therapy (β = .021, *p*=.451), or intensive therapy (β=.053, *p*=.130). Similarly, for participants aged 6 to 12, no gender differences were noted for speech therapy (β=-.029, *p*=.341), occupational therapy (β=-.030, *p*=.358), or intensive therapy (β=-.037, *p*=.446). When examining gender differences across all ages for the utilization of psychotropic medications, there were also no significant gender differences found (β= -.033, *p*=.139).

Race

The second linear regression examined the relation between treatment usage and race. Minority racial groups were compared to the White reference groups. Across those under 5 years, no significant differences were found between White children and Asian children for speech therapy (β=-.008, *p*=.747), occupational therapy (β=.001, *p*=.985), or intensive therapy (β=.006, *p*=.875). Also, no significant differences were found between White children and African American children in speech therapy use for participants under age 5 for (β=-.016, *p*=.542), occupational therapy (β=.001, *p*=.998), or intensive therapy (β=-.003, *p*=.928). Similarly, for the Other racial group, no significant differences were found across speech therapy (β=.043, *p*=.140), occupational therapy (β=.021, *p*=.489), or intensive therapy (β=-.014, *p*=727).

As for children ages 6 to12, African American children were more likely to utilize speech therapy at 6 to 12 years of age (β=.069, *p*=.023). No significant differences were observed between White and African American children in terms of occupational therapy (β=-.034, *p*=.294) or intensive therapy (β=-.034, *p*=.485). The differences found in intensive therapy utilization between White children and Asian children ages 6 to12 was approaching significance (β=-.094, *p*=.055) but no significant differences were found for Asian children in terms of speech therapy use (β=-.01, *p*=.719) or occupational therapy use (β=-.003, p=.935). Results for the Other racial group revealed no significant differences across speech therapy (β=.019, *p*=.572), occupational therapy (β=.002, *p*=.961), or intensive therapy use for children ages 6-12 (β=.046, *p*=.400).

For psychotropic medication utilization, significant differences were found between the White and Asian groups (β=-.107, *p*=.000), and the Other racial minority group (β=-.062, *p*=.013). Specifically, children in the Asian and the Other racial minority groups were less likely than White children to use psychotropic medications. However, no differences were found between White and African American children in terms of their use of psychotropic medicines (β=-.035, p=.123).

In summary, disparities were found between African American, Asian, and Other racial populations for speech therapy amount and medication use, such that racial minorities were less likely to engage with behavioral therapies and less likely to use psychotropic medications, than the White majority reference group.

Ethnicity

The third linear regression examined the relation between treatment usage and ethnicity. No significant differences were found for either therapy within either age group when comparing children who were Hispanic to the non-Hispanic reference group. Specifically, for participants under 5 years, no ethnic differences were found across speech therapy (β=.018, *p*=- .528), occupational therapy (β=.002, *p*=.953), or intensive therapy (β=-.024, *p*=.539). Similarly, among participants within the 6 to 12-year-old age range, no significant differences were found across ethnicity in speech therapy (β= .017, *p*=.624), occupational therapy (β= -.036, *p*=.324), or intensive therapy (β= -.029, *p*=.608).

Results indicated that non-Hispanic children were more likely to use psychotropic medications at all ages compared to Hispanic children (β=-.065, p=.010). Disparities were found across non-Hispanic and Hispanic populations specific to psychotropic medication use, indicating that non-Hispanics were more likely than Hispanic populations to use psychotropic medications. No differences were observed across age group for either therapy type.

Maternal Occupation

A fifth linear regression examined the relation between treatment usage and maternal occupation. Results indicated no significant differences related to maternal occupation and amount of intervention services. Specifically, maternal occupation was not significantly related to speech therapy (β=.001, *p*=.955), occupational therapy (β=.019, *p*=.513, or intensive therapy (β=.006, *p*=.865) across participants under age 5. For children ages 6 to 12, maternal occupation again was not related to speech therapy (β=.007, *p*=.821), occupational therapy (β=-.003, *p*=.938), or intensive therapy (β=.041, *p*=.416). When examining the relation between maternal occupation and psychotropic medication use, no significance was found (β=,.026 *p*=.255). Overall, no significant relations were found.

Annual Income

A sixth linear regression examined the relation between treatment usage and household annual income. As far as annual income across participants under age 5, a significant difference was found for intensive therapy (β=.101, *p*=.008). This indicated that the higher the income level the more intensive therapy hours were reported. No other significant differences were found for income levels in amount of speech therapy (β=-.023, *p*=.404) or occupational therapy (β=-.077, *p*=.813) for children under age 5.

Similar, to the younger age group, children in the 6 to12 year old age group, demonstrated similar results in that higher income was associated with more intensive therapy (β =.135, *p*=.011). Additionally, a significant relation between income and amount of speech therapy as well (β=.074, *p*=.020) was observed for participants in this age group. Specific to the older age group, children with higher annual incomes were more likely to utilize speech therapy services. No significant differences were found for occupational therapy in this age group (β=-.007, *p*=.836) No significant effects were found in the relation between annual income and psychotropic medication utilization across ages in relation to income (β=.033, *p*=1.80).

Maternal Education

A seventh linear regression examined the relation between treatment usage and maternal education. Maternal education noted significant differences across participants in the under 5 age group, specifically for speech (β=.070, *p*= .014) and intensive therapy (β =.085, *p*=.026) services. Higher utilization of both speech and intensive therapy services were observed across mothers with higher education level. No relation was found for participants under 5 years old receiving occupational therapy services (β=.046, *p*=.135). As far as participants 6 to 12 years old, no differences were found related to maternal education and speech therapy (β=-.013, *p*=.693), occupational therapy (β=.003, *p*=.933), or intensive therapy (β=-.003, *p*=.955). Specific to psychotropic medication usage, similar results were found (β=-.005, *p*=.832).

Table 5

Results of regression analyses examining sociodemographic group differences in amount of total service use across different types and different age groups

	ST		**OT**		**IT**		**Meds**
Child Age in Years	**Under 5**	**6-12**	**Under 5**	**6-12**	**Under 5**	**6-12**	**All Ages**
Male vs. Female	.008 (.751)	-.029, (.341)	.021, (.451)	-.030, (.358)	.053, (.130)	-.037, (.446)	-.033, (.139)
Child Race							
White vs. Asian	-.008, (.747)	-.011, (.719)	.001, (.985)	-.003, (.935)	.006, (.874)	-.094, (.055)	-.107, (.000**)
White vs. African American	-.016, (.542)	.069, (.023*)	.001, (.988)	-.034, (.294)	-.003, (.928)	-.034, (.485)	-.035, (.123)
White vs. Other	.043, (.140)	.019, (.572)	.021, (.489)	.002, (.961)	-.014, (.727)	.046, (.400)	-.062, (.013**)
Non-Hispanic vs. Hispanic	.018, (.528)	.017, (.624)	.002, (.953)	-.036, (.324)	-.024, (.539)	-.029, (.608)	-.065, (.010**)
Maternal Occupation	.001, (.955)	.007, (.821)	.019, (.513)	-.003, (.938)	.006, (.865)	.041, (.416)	.026, (.255)
Annual Income	-.023, (.404)	.074, (.020*)	-.077, (.813)	-.007, (.836)	.101, (.008**)	.135, (.011**)	.033, (.180)
Maternal Education	.070, (.014**)	-.013, (.693)	.046, (.135)	.003, (.933)	.085, (.026*)	-.003, (.955)	-.005, (.832)

Beta Standard Coefficients Beta, (Significance Value)

**indicates significant at a level of p=.05
*indicates significance at a level of p=.01

CHAPTER 4

DISCUSSION

Studies documenting the extent of disparities in intervention utilization among children diagnosed with ASD is a significant area of interest, as research is clear about a direct relation between amount of intervention and positive child outcomes (Dawson et al., 2010; Estes et al., 2015; Harris & Handleman, 2000; Kasari et al., 2010; Kasari et al., 2014). Unlike the body of research documenting disparities in ASD assessment, there are a limited number of studies documenting the relation between service usage and racial and socioeconomic factors. These studies are limited in that they 1) primarily examine race/ethnicity but do not include other meaningful sociodemographic variables; 2) use a dichotomous variable to represent intervention utilization rather than a continuous assessment of amount of intervention use; 3) examine only a narrow range of intervention types (i.e., popular therapies like ABA or those in the school context alone), and 4) primarily focus on early childhood or a specific narrow age group. The current study augmented prior research by examining other sociodemographic variables, such as maternal occupation, maternal education, annual household income, and gender, in addition to race/ethnicity, by using an approximate number of weekly hours to represent intervention utilization, and by examining a wide range of therapy types (i.e., speech therapy, occupational therapy, and intensive therapy as well as psychotropic medication use) in both early childhood (2-5 years) and school age groups (6-12 years). The results from this study demonstrate the pervasive nature of sociodemographic disparities across developmental age and intervention type even after taking into account cognitive, adaptive scores, and symptom levels. More specifically this study found, that compared to White children, children from racial minority groups (African American and Other) and children from lower income groups used fewer amounts of behavioral therapies. This aligns with research conducted by Nguyen et al., (2016), McIntyre & Zemantic 2018, and Mire et al., (2018) but documents this finding in more detail by examining an approximate total hour amount across two developmental periods.

Esbensen et al., (2009) reported that medication utilizations across children with ASD is increasingly high. In this study, novel findings were found related to psychotropic medication use among non-Hispanics in comparison to Hispanics, and racial minority populations (i.e., Asian and Other groups) in comparison to White children, such that these minority groups report less psychotropic medication use. This aligns with the research documenting that medication usage is higher by Whites than other racial and ethnic minorities (Leslie et al., 2003). This was consistent with research, in the broader use of psychotropic medication literature not specific to ASD (Leslie et al., 2003) and in the literature specific to individuals with ASD (Quebles et al., 2020). More specifically, according to Leslie et al., (2003) African American and Latino children were less likely to report the past use and lifetime use of medications compared to White children. It will be important to examine this medication component further in future research specifically with children who have ASD, to understand other factors, that may play a role in the increased utilization of psychotropic medications in the White and non-Hispanic populations and why it is occurring.

Interestingly, it was also hypothesized that gender, income, maternal occupation, and maternal education would be related to all types of intervention usage based on results previously found in the literature (Angell et al., 2018; Broder-Fingert et al., 2013; Mire et al., 2018; McIntyre & Zemantic 2018). However, in the current study not as many significant differences were found between groups for these additional sociodemographic variables as we would have thought. It is possible that the education variable was not parsed into sufficiently tiered levels (i.e., more than half of this sample fell in the high education group), including mothers with a graduate or baccalaureate degree. It might have been more beneficial to have separated education out to include more levels to gather more information on how education might have impacted amount of intervention. Similarly, the sample population included a large number of mothers in the higher rated occupation codes, according to the Nam-Powers Boyd scale. This might have also impacted our results in the same way and would have depicted a better, more accurate pattern if these were separated out differently. Specific to gender, with an increased rate of males diagnosed with autism, research notes males are receiving more services; however, this specific sample population did not replicate this finding. This also could have been impacted by the high correlation between income, occupation, and education variables that were being used together in this study. After investigating descriptive data across males and females, there is an underrepresentation of cognitively impaired females within this sample population, thus high functioning girls have been left out of this sample with the low IQ and bimodal tendency of this group. It is possible that our sample did not gather females in both of these groups to be able to differentiate service utilization in the most accurate way.

With varying findings in the research (Irvin et al., 2012; Thomas et al., 2007), another interest aspect of this study that should receive more attention is to investigate more thoroughly the differences between private and public services to understand better trends, if any, associated with sociodemographic variables. A more diverse sample size across sociodemographic variables would have been better to investigate these potential differences. Although intensive therapy did reveal significant results related to annual income across both age ranges, the results were not as expected. This category included many different specific types of therapies, and the results might have better showcased differences if the intensive therapy variable was separated out by type of therapy in a more thoughtful way (i.e., Intense Behavior Interventions (ABA), Naturalistic Developmental Behavioral Interventions (NBDI)). Last, specific to intervention types, no trends were found for occupational therapy. When thinking about deficits children with ASD experience (i.e., speech delays, play skills, social skill difficulties, etc.) most of these deficits are not treated with occupational therapy, or better yet, occupational therapists might be using practices that are both empirically and not empirically supported to treat the core symptoms of autism (McIntyre & Zemantic 2018). Occupational therapy deficits (i.e., motor impairments) are more observable across populations, unlike these other deficits, such as, social skills, play skills, speech, etc. Our study's findings might not have been significant because families are seeking out therapies for symptoms primarily related to the core deficits of ASD, or that there are no culture differences related to gross and fine motor skills as children are growing and developing.

Limitations

Study limitations include the possible biases that were related to data collection with regard to the child's type and total number of both intervention service hours and psychotropic medications. Recall biases are common in self-reported data of this kind and errors may have resulted as years might have passed between the child having entered that service and the parent recalling that information for the purposes of the original study (Lance & Vandenberg 2009; Pannucci & Wilkins 2011). Many issues arise when using self-referred sample sets also, in that they are not especially diverse (i.e., higher income and higher education), not including those individuals in the lower end of sociodemographic variables which was the purpose of this study to investigate. However, most data collected on intervention hours are collected in this same way and are random, therefore, not specific to any outcome within this study. As previously discussed, over 80% of our sample population was White, therefore specific details regarding minority populations (e.g., African American, Asian, Other) were based on small sample sizes. Because of this, our sample is not generalizable to the broader ASD population, across racial/ethnic populations. Again, this is a common issue in the ASD literature (Hilton et al., 2009; Zamora et al., 2015). Future research should intensify efforts to include the entire range of race and ethnic groups to ongoing ASD research which will in return help to generalize findings to the broader population.

This study expanded upon the literature by looking at two distinct developmental periods. Most research, only looks at young children (Burkett et al., 2015; Evans et al., 2016; Irvin et al., 2012; Jiminez et al. 2013; Little et al., 2015; Nguyen et al., 2016; Williams et al., 2014; Yingling et al., 2018; Zweiganbaum et al., 2015;). However, due to insufficient data across children ages 13-17 years old, the study again is not generalizable to the broader ASD population regarding age. Literature supports that adolescent and adults with ASD are frequently understudied and should be an emphasis moving forward (Camm-Crosbie et al., 2019; Elias & White 2017; Miller et al., 2014; Pellicano et al., 2014; Volkmar 2016).

Additionally, the current study does not account for age as a covariate. Like previously mentioned, children included in this dataset were all different ages (2-18 years old), which made it hard to account for “opportunity” that a child may have had in receiving intervention services. It was not fully understood how to account for this opportunity aside from controlling for age. For example, if a child at 6 years old was utilizing 12 hours of intervention weekly and a child at 11 years old was utilizing 20 hours of intervention weekly, we cannot compare these two children adequately, within the same group, as they have not had the same amount of opportunity to receive intervention services.

There are many other variables that would have benefitted this study including 1) age of diagnosis, 2) total number of hours receiving services separately in school and private therapies instead of a total number of hours in both, 3) amount of time between diagnosis and entrance to services, 4) geographic location across the United States, 5) cultural differences such as attitudes and perceptions surrounding ASD that might have impacted specific family’s treatment choices, 6) language spoken in the home, 7) birth country, 8) insurance status, and 9) acculturation. Despite these limitations, our participants were all diagnosed using gold standard instruments and our sample size was large and was sufficiently diverse enough to identify racial and ethnic differences in total hours of weekly intervention usage and number of psychotropic medications consumed.

Research has made great strides toward examining and understanding disparities (Kilbourne et al. 2006); however, more research in still needed to determine why these disparities continue to occur and how to reduce them. Continued disparity research should place an emphasis specifically on racial minority and economically disadvantaged populations to better understand these disparities and help to improve access to services for these specific groups, and for their children with ASD.

Future Directions

Future directions can be broken into two categories: research and clinical application. The study strengths include a broader age range of participants, including children 2-5 years and 6-12 years old, a more thorough look at specific intervention services, both in school and outside of school, and an expansion from previous research examining more sociodemographic variables that might impact the use of intervention services. Instead of examining whether children are utilizing services or not (i.e., yes or no), a more thorough examination of a total number of weekly hours was used to identify patterns of access across different populations. Last, most of the research on intervention disparities does not include a psychotropic medication component. This study did include a medication component to better understand treatment options and their utilization across different populations. Using a statistical approach, such as structural equation modeling (SEM), would better help to understand any stronger relation between the sociodemographic variables and utilization of these treatments.

Efforts should be made to help families understand the benefits of early intervention and to ensure the interventions offered are family-centered and culturally appropriate; more specifically, targeting minority and lower income populations. To ensure that all families of children with ASD have equal access to intervention services, sensitive outreach targeting diverse racial and ethnic families should be prioritized to support more equitable intervention use. Related to the utilization of medications, further research should examine the potential overuse of psychotropic medication use among White families as well as the underuse by racial groups. This could be the impact of less available and cost-effective treatment choices in specific geographic locations. Based on these findings, systematic efforts must be made to increase the availability of accessible information and improve community advocacy which can be developed through a deeper understanding of how individual (parent), interpersonal, and societal factors may all play a role in parents treatment decisions for their children.

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