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An Examination of Types of Health Insurance and the Reported Prevalence of Autism in the United States

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AN EXAMINATIN OF TYPES OF HEALTH INSURANCE AND THE
REPORTED PREVALENCE OF AUTISM IN THE UNITED STATES

by

Jennifer L. Thompson

A dissertation submitted to the Graduate College
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
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AN EXAMINATION OF TYPES OF HEALTH INSURANCE AND THE REPORTED PREVALENCE OF AUTISM IN THE UNITED STATES

Jennifer L. Thompson, Ph.D.

Western Michigan University, 2021

The prevalence of Autism Spectrum Disorders continues to rise despite barriers of changes to diagnostic criteria and lack of insurance coverage. Increases in prevalence affect costs associated with a disorder since cost of health care services are often estimated based on utilization of services. This can also affect an individual's ability to access to health care services. To equitably distribute autism services to individuals an accurate estimation of the true prevalence of autism is needed.

Access to health care can be influenced by the type of insurance coverage a person holds. Other factors, such as socio-economic status, ethnicity, location of diagnosis and geographic residence of the patient may influence the ability of individuals ability to access health care services. This is potentially also true for autism.

To examine the national prevalence of autism in relation to the type of insurance a person holds, the region of the country, recent provider visit and SES using a publicly available, data from the National Health Interview Survey was examined. Statistical methods determined change in variable proportions over time and a logistic regression model was used to determine the relationship between the predictor variables (e.g., insurance type, geography, SES, and provider visit) and a diagnosis of autism.

There were statistically significant differences in the change of the predictor variables over time, yet the change in percent of proportion was small. The regression model revealed Medicaid (as compared to Military insurance, private pay and employer-based insurances) was significantly related to a diagnosis of autism.

Medicaid enrollment appears to provide increased access to a wider variety of autism services compared to private insurances, which could affect the ability of an individual receiving an autism diagnosis. However, further exploration of other potential factors were inconclusive, and future studies should consider more the role of specific provider types as well as site of diagnosis (educational vs clinical).

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CHAPTER I

INTRODUCTION

Overview

“Autism Spectrum Disorder” has become a familiar term due to the continued increase in the prevalence of autism disorders over the last 20 years (CDC, 2020) in both the medical and educational realms. As any disorder, an increase in prevalence results in the increase in utilization of health care providers and services which are associated with the diagnosis. Specialized services such as the ones typically recommended to treat autism, are often limited in availability due to a lack of trained or licensed providers (CMS, 2011). A lack of providers is a problem as specialized autism services are highly sought after due to the recommendations for a high level of frequency and intensity of services such as behavioral interventions. This is due to the intertwined relationship of health care with insurance coverage, access, and utilization of services.

The ability to access autism services has been limited by the factors of ethnicity, socio-economic status, geography, and insurance coverage. To access diagnostic and therapy services, an individual requires an autism specific diagnosing provider and insurance coverage for the treatment of autism (or the ability to pay out-of-pocket). Yet available autism providers and insurance coverage/ability to pay does not guarantee access to services also requires an ICD-10 (International Classification of Diseases, 10th Edition) diagnosis code of Autism Spectrum Disorder (F84.0). The lack of available providers and a lack of health care insurance coverage is significant for children with autism as they are more likely to require multiple, specialized care due to co-occurring morbidities such as other developmental disorders, mental health/behavioral components and intellectual impairments (Cheak-Zamora, N. C. et al., 2017; Prokup, J.A. et al.,

2018; Kogan, M D. et al., 2009; Boyle, C. A., 2011;) Due to the presence of multiple disorders access to services is necessary; without which many symptoms would worsen or intensify (Boyle, C. A., 2011; Zablotsky, B. et al., 2019; Thomas, K., et al., 2012; Yingling, M., et al., 2018; Douglas, M.D. et al., 2017). Although it is well documented children with autism experience an increased frequency of co-occurring disorders, some have not and some still do not, have access to specialized services. The reason for a lack of access to specialized care maybe due to a relationship between the diagnosis given and the policy holder's specific insurance coverage.

People diagnosed with autism often require multiple specialty therapies (e.g., behavioral/mental health, ST, OT), 1:1 assistance with activities of daily living (e.g., requiring home health aide), respite care (e.g., requiring home health aide) and pharmaceutical intervention. Many of these services are inaccessible without a diagnosis of an autism spectrum disorder, which for some individuals is difficult to obtain due to geographic area, insurance coverage, and socio-economic status. As autism resources are both limited in availability and high in demand, estimating an accurate prevalence of autism diagnoses is important to ensure treatment availability for the people who need that treatment as inaccurate estimations of prevalence can reduce access/availability of resources and services. This allocation of monies for reimbursement of services is connected to the estimated prevalence of a disorder which is bound to an ICD-10 diagnosis code; therefore, it is vital to understand the factors which are influencing the diagnosed prevalence.

A Brief History of Autism

Since the introduction of "infantile autism" as a diagnosis in the 1940s, the stigma and perception of autism disorders has dramatically shifted. Autism was first characterized by Leo

Kanner (a child psychiatrist at Johns Hopkins University) after he studied the behaviors of 11 children institutionalized in a psychological ward. The children exhibited limited communication abilities and impairments in social interaction (Silverman, C. 2011). This study led to Kanner's original theory that autism was an emotional disturbance but that a person's cognition was not affected (Zeldovich, L., 2018). Within a few years of Kanner's study, Hans Asperger completed a similar study with a small group of children with varying levels of autism symptoms. He described the behaviors and characteristics of the patients like how Kanner had captured his group, yet Asperger's group demonstrated higher level verbal and cognition abilities (Johnson, C. et al., 2007). Asperger suggested these behaviors were a type of "autistic psychopathy" as they presented differently than Kanner's study group. These differences in presentation and interpretation of symptoms eventually lead to Asperger's syndrome becoming a stand-alone diagnosis in the mid-1990s (Johnson, C. et al., 2007). The creation of Asperger's syndrome as a separate diagnosis would grow into a community of individuals with strong views of how different Asperger's was from Kanner's Autistic Disorder (Cooper, R., 2014 2012)

As a new diagnosis autism did not garner much attention from the medical community. At the time, autism was viewed as a form of childhood psychosis from cold or absent parental interaction (Silverman, C., 2011). As such, there were few assessments a practitioner could use for diagnosing autism; most diagnoses were made based on clinical judgment and often related to the level of experience of the practitioner (Silverman, C., 2011). The first formal autism diagnosis criteria were not established until 1956 when autism appeared as a form of childhood schizophrenia with an occurrence of a detachment from reality (Zeldovich, L., 2018). "Autism" symptoms were characterized as "extremely aloof behavior, repetitive and circumscribed

activities and near typical intelligence” (Silverman, C., 2011). It wasn’t until the 1980s the diagnosis was expanded from schizophrenia and added to the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition (DSM-III) as a stand-alone diagnosis (Zeldovich, L., 2018). This was the first time an operationalize definition of autism appeared in the DSM. The DSM-III defined Autistic Disorder (AD) in broad terms and included pervasive developmental disorders-not otherwise specified (PDD-NOS) as alternative diagnosis for children who didn’t meet the autism criteria characteristics (Zeldovich, L., 2018; Silverman, C., 2011, Johnson, C. et al, 2007; Lai, M.C).

As autism gained prevalence in middle 1980’s two significant discoveries were made in the fields of neurology and social psychology which changed the way autism was perceived (Silverman, C., 2011). Neurologists found significant differences between the neurological patterns of individuals with autism compared to those without when reviewing the MRIs of patients with and without a diagnosis of autism. It was proposed these differences were due to a lack of development in the cerebellum which could influence the presentation of autistic behaviors (Silverman, C., 2011). Social psychologists, on the other hand, proposed a new theory that individuals with autism lacked the ability to engage in “theory of mind” (TOM) or the ability to infer the metal state of other (Silverman, C., 2011). Unlike typically developing children or children born with other developmental disabilities such as Down syndrome, it was suggested children born with autism lacked the ability to relate with the perspective of others (Silverman, C., 2011). These discoveries led practitioners to arrive at the conclusion autism was both a biologically based neurodevelopmental disorder and a social-communication disorder (Silverman, C., 2011). This view of the presentations of autism allowed for the signs and

symptoms of autism to be grouped into developmental patterns and compared while also considering the accompanying biomedical deficits to determine a diagnosis (Silverman, C., 2011).

The difficulty in finding a specific biological explanation for the underlying cause of autism has added to the difficulty of identifying autism accurately. The lack of a clear etiology has required practitioners to rely heavily on clinical judgment to accurately recognize the signs and symptoms of autism while differentially diagnosing autism from similar developmental disorders (Silverman, C., 2011). Advancements in autism research, increases in prevalence and increases public awareness contributed to the addition of Asperger's syndrome (AS), childhood disintegrative disorder (CDD) and Rett syndrome to 1994's DSM-IV (Zeldovich, L., 2018; Johnson, C. et al, 2007). The additional diagnoses of PDD-NOS, AS, Rhett's and CDD were meant to help providers accurately capture autism from other similar disorders. Yet the increase in the number of similar subcategories of disorders created difficulties for providers when attempting to differentially diagnosis the symptoms of autism from the other PDDs (Johnson C. et al. 2007).

Through the 2000s the prevalence of autism increased again causing critics of the DSM-IV to argue the additional diagnostic criteria was not sensitive to accurately capture the differences between the presentation of the PDDs (Lai, M.C., et al., 2014). Critics also claimed the lack specificity was leading to a lack of consistency among clinicians in varying states creating an overabundance of autism diagnoses (Lai, M.C., et al., 2014). Epidemiologists believed the rise in prevalence could be due to several factors: the broadening of the diagnostic criteria from the DSM-III-R to the DSM-IV, a more thorough identification of autism cases

found through epidemiological research and better detection of the presence of autism due to increased public/professional awareness (Silverman, C., 2011).

Following deep criticism, the autism criteria underwent another revision in the 2013 update to the DSM-5 (Bennett, M. & Goodall, E., 2016; Foley-Nicpon, M. et al., 2017; Huerta, M., Bishop, S. L., Duncan, A., Hus, V., & Lord, C., 2012; Kupfer, D, Frist, M., & Regier, D., 2002). In this version Autistic Disorder (AD) and the subsequent PDD diagnoses were reduced to an umbrella term of autism spectrum disorders (ASD), thereby removing the previous diagnostic categories of (PDD), AS and (NOS) previously added in the DSM-IV revision. Additionally, the general criteria for meeting an autism diagnosis were reduced from triad into a dyad (Lai, M.C. et al., 2014). Prior to this change, patients needed to meet the criteria of deficits in the areas of communication/language, repetitive interests and presenting with atypical language development (Lai, M.C., et al., 2014; Cooper, R., 2014). Under the DSM-5 patients only need to meet the criteria for difficulties in social communication/interactions and restricted repetitive behavior/interests/activities as the condition of atypical language development was removed (Lai, M.C., et al., 2014, Cooper, R., 2014; Silverman, Cl., 2011). These changes were meant to reflect individual characteristics, patterns of unique strengths and weakness, and to remove the ambiguity surrounding the differences between AS, PDD, and PDD-NOS thereby increasing accuracy of diagnosis (Lai, M.C., et al., 2014; Cooper, R., 2014, Silverman, C. 2011).

Autism Disorders and Health Care

Insurances have not traditionally covered or have only partially covered health care services for autism due to the high cost resulting from higher rates of utilization of specialized services (Fry-Bowers, E.K., 2015; Caldwell, J., 2010; Parish, S.L., et al., 2015; Chatterji, P., et

al, 2015). Individuals with autism have also experienced denials of treatment from providers due to low reimbursement rates and the constraints from insurance companies such as denial of payment for costly services (Magana, S. et al, 2012; Wang, L., et al., 2013; Saloner, B. and Barry, C. 2019; CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). This same trend can be seen by reviewing the history of Attention Deficit and Hyperactive Disorder (ADHD). After ADHD gained more notoriety as a diagnoses and people became familiar with the signs and symptoms the rate continued to increase (Olfson, M., et al, 2003) Between 1987 and 1997, the rate of ADHD increased from .9/100 to 3.4/100 across all SES levels and all ethnicities (Olfson, M. et al., 2003). ADHD saw an increase in prevalence following increases in insurance coverage of mental health treatments, increased public awareness, and its inclusion into the IDEA as an educational eligibility for Special Education services (Olfson, M. et al., 2003). As with autism spectrum disorders, minorities diagnosed with ADHD had greater disparities in the type of treatment they received compared to Caucasian people (Olfson, M. et al, 2003). The same trends are outlined in the research on the historical and current prevalence of autism (Silverman, C. 2011, Cooper, R., 2014).

Denial or non-coverage of treatment places children with ASD at risk for poorer health outcomes and significant disparities in health care (Cheak-Zamora, N. et al., 2017).

Non and/or limited coverage of therapies have created challenges for individuals and families in gaining access to a variety of necessary health care services such as Applied Behavior Analysis (ABA) and Speech Therapy (ST). The lack of access to services is potentially harmful because 30% of children born with autism experience complex, chronic conditions requiring multiple, specialized interventions (Cheak-Zamora, N.C., et al., 2017; Lello, F.T. et al., 2019)

The increased number of co-occurring disorders means an individual will have greater health care needs as compared to children with fewer co-occurring disorders (Lello, F.T. et al., 2019; Magana, S. et al., 2012; Prokup, J. et al., 2018; Yingling, M., et al., 2018). The level of severity of a primary disorder (e.g., autism) is directly related to the number and type of co-occurring or secondary conditions (e.g., language delays, gross motor impairment, etc.). The greater the severity, the greater the number of additional therapies which will be required to make functional gains toward communication and behavioral outcomes (Calvo, R. & Hawkins, S.S. 2015; Park, C. et al., 2014; Ngyen, C.T. et al., 2016). Not only does the presence of multiple disorders influence the number and type of providers needed; access to treatments is influenced by a patient's primary diagnosis/condition, level of cognitive functioning, insurance coverage, annual income, and region of residence (Cheak-Zamora, N.C. et al., citing Lollar et al., 2012; Nageswaran et al., 2008 and Strickland et al., 2014). These factors have created hardships for some families locating providers qualified to treat children with multiple, severe medical conditions (Prokup, J. et al., 2018 citing Russell and Simon, 2014). Even if families can find a provider who is willing and qualified to treat severe developmental disorders, children born with autism are more likely to experience unmet health care needs as compare to children with other disabilities (Lello, A., 2019; Prokup, J., et al., 2018; Cheak-Zamora, N. et al, 2017, Magana, S. et al., 2012). And even though children with autism need consistent, specialized care, they are also four times more likely than other children to experience delays in receiving care and six times more likely to have problems gaining referrals to specialists (Prokup, J., et al., 2018; Magana, S. et al., 2015).

Meeting health outcomes is particularly important in children with autism as they are not acquiring skills and behaviors at predetermined developmental benchmarks (Caldwell, J., 2010). The keys to acquiring absent developmental skills are through *habilitative* (e.g., any service which helps a person attain or maintain skills) services versus rehabilitative (e.g., the retraining of prior skills) services. Children with autism are typically recommended to attend a high frequency of habilitative services such as speech-language pathology (ST), occupational therapy (OT) and behavioral services. However, these services have not always been covered by insurance as such therapies have been viewed as “not medically necessary” or these therapies are expected to be provided by educational services, who by nature do not submit for insurance reimbursement (Berlin Baller, J et al., 2016; Karpur, A., et al, 2018; Foxhall, K., 2015; Razi, R. R. 2017). Habilitative therapists are most important during the early toddler and pre-school years which are crucial years in a child’s development (Cheak-Zamora, N.C. et al., 2017; Lello, A., et al., 2016; Travers, J. & Krezmien, M., 2018; Adelman, C.R. & Kubiszyn T., 2017; Daniels, A.M. and Mandell, D.S., 2014). It is during this developmental stage that the frequency and intensity of habilitative services can work to reduce the need for intensive interventions later in life. More importantly these services can be the difference between talking or not talking (Fry-Bowers, E. K., 2015; Zamora, N. et al., 2017).

Individuals with autism continuously face difficulties in gaining access to health care. In addition to requiring highly specialized care, there are often other preexisting factors influencing the ability to access levels of health care. The most common factors are race/ethnicity, the need for additional behavioral/health services, geographic location of the patient (part of the country), and socio-economic status. These four factors have been consistently found to be associated with

the difficulty in accessing health care, compounded by also having a developmental disability, such as autism (Rosen-Reynoso, M. et al., 2016; Magana, S. et al., 2012; Calvo, R. and Hawkins, S., 2015; Kuang, X. et al., 2017; Glassgow, A.E. and Van Voorhees, B., 2017; Christensen, D. et al., 2016).

Race/Ethnicity

Minorities have faced persistent disparities in the access, utilization, and quality of health care due to a complexity of factors such as socio-economic status, lack of health insurance and unequal access to health care (Jones, D., Crump A., and Lloyd J., 2012, Magana, S. et al., 2012; Calvo, R. & Hawking, S.S. 2015; Fulkerson, N., et al., 2013; Lello, A., et al., 2019; Magana, S et al., 2012). These disparities are so deeply engrained in the health care system, that even if all other factors were equal, such as access to care and adequate health insurance coverage, health care disparities would still exist between ethnic groups across all health outcomes (Langellier, B, et al, 2016; Son, E. et al., 2017). Minorities have also consistently experienced difficulties in accessing health care services compared to other families. Minorities are less likely to have a family doctor or insurance and are more likely live in under-served geographic areas as compared to Caucasians (Adelman, C. & Kubiszyn, T., 2017; Langellier, B, et al, 2016; Rose, R. et al., 2010, Magana, S. et al., 2012; Jones, D., Crump A., and Lloyd J., 1971). A lack of providers and access to services increases the chances a child will not receive a well-child visit with a pediatrician (Daniels, A.M., & Mandell, D.S., 2014; Marcin, J.P. et al., 2016; Langellier, B.A., et al., 2016). Well-child screenings are vital to the early identification of autism as consistent check-ups with the same provider yields a greater chance of diagnosing the signs and

symptoms of autism early (McGrath, K, Bonuck, K. & Mann M., 2020; (Daniels, A.M., & Mandell, D.S., 2014; Marcin, J.P. et al., 2016; Langellier, B.A., et al., 2016).

Yet simply having health care insurance is not a guarantor of access to health care services as minorities still must navigate complex health systems to find providers (Langellier, B.A., et al., 2016; Son, E. Parish, S., & Igdalsky, L., 2017; Magana, S., Parish, S.L. & Son, E. 2015; Dougherty, D. et al., 2013). Due to this complexity many Black and Asian families are less likely to have a Primary Care Provider and Latino families are less likely to have coordinated care between providers, less preventative care, and are more likely to experience a delay in care (Langellier, B., et al., 2016; Calvo, R. & Hawkins, S. S, 2015; Magana S. et al., 2012; Park, C et al., 2014; Fulkerson, N. et al., 2013).

A lack of a consistent provider or lack of coordination of care between providers can lead to delays in diagnosis (Langellier, B., et al., 2016; Calvo, R. & Hawkins, S. S, 2015; Magana S. et al., 2012; Park, C et al., 2014; Fulkerson, N. et al., 2013). As stated above this is particularly problematic for those diagnosed with autism. Navigation of health care systems becomes more complex for parents of children born with special health care needs (SHCN) such as autism, physical and cognitive impairments since they often require specialized services and programs not only to treat disorders but also to manage the chronic symptoms (Glassgow, A.E., & Van Voorhees, B., 2017; Rosen-Reynoso, M et al., 2016; Karpur, A., et al., 2018). In the case of minority children with SHCN, the health care disparities are felt on a deeper level as compared to minority children without SHCN due to lack of adequate insurance coverage needed to access highly specialized services (Yu, S. et al., 2015). Minority families have an estimated 2-4 year wait between the onset of the signs and symptoms and a diagnosis of specialized disorder such as

autism (Glassgow, A.E. and Van Voorhees, B., 2017; Kuang, X. et al., 2017; Adelman, D. R. & Kubiszyn T. 2017).

The navigation of health care systems is not the only barrier minorities face as many also experience limited insurance coverage and/or high policy deductible costs (Shea, L. L., et al., 2018; Foxhall, K. 2015; Zhang, W. & Baranek, G., 2016; Candon, M.K. et al., 2019). For many people a lack of coverage or ability to cover the cost services influences where or if they receive health care. The variation in the lack of coverage increases the chance of inconsistent provider visits and discoordination of care (Zhang, W. et al., 2017; Daniels, A.M., & Mandell, D.S. 2014). An interruption and discoordination of services is harmful in that it can result in delays in diagnosis and referrals to specialty providers and can create an inconsistency in access to necessary treatments needed to produce functional outcomes such as verbal communication and a reduction of non-compliant behaviors such as physical aggression, verbal aggression, and property destruction (Daniels, A & Mandell, D. 2014; Coombes, J. et al., 2018; Boyle, C.A. et al., 2011; Travers, J., & Krezmien, M., 2018; Adelman, C.R, & Kubiszyn, T., 2017). Immigrant and/or English Language Learning (ELL) status further increases the odds of experiencing greater difficulties of being seen by a provider due to language barriers as only 20% of Spanish speakers have access to care (Calvo, R. and Hawkins, S., 2015; Kuang, X. et al., 2017; Fulkerson, N. et al., 2013; Rosen-Reynoso M. et al., 2016). The lack of access to care can be partially attributed to the fact many immigrant families are ineligible for public insurance due to the illegality of their citizenship and therefore are less likely to have health insurance (Adelman, C.R, & Kubiszyn, T., 2017; Langellier, B.A, et al., 2016; Rose, R.A. et al., 2010; Yu, S. Lin, S. & Strickland, B., 2015; Fulkerson, N. et al., 2013; Rosen-Reynoso, M et al., 2016). A second

problem facing immigrant families is that many are living well below the Federal Poverty Level (more than any other minority group) and due to immigrant status do not qualify for Medicaid, yet they cannot afford to purchase private health insurance (Langellier, B. et al., 2016). This leads to immigrant children being less likely to have well-child visiting results in delays in care (Langellier, B. et al., 2012; Zhang, W. et al., 2017). All these challenges are compounded when an immigrant parent has a child born with a SCHN. The added challenges of obtaining highly specialized services for their children, reading evaluation reports, finding recommended therapies, and following up with referrals in an unfamiliar language leads some parents to not seek medical intervention (Yu, S. Lin, S., & Strickland, B., 2015; Rose, R et al., 2010).

When immigrant parents do seek a provider, providers have been found to be dismissive of cultural practices and beliefs (Langellier, B. et al., 2012, Jones; D., Crump A., and Lloyd, J., 1971; Rose, R., et al., 2010). Furthermore, providers are less likely to complete a well-child or autism screening on a child of an immigrant status person (Son, E. et al., 2017; Langellier, B., et al., 2016; McGrath, K. et al., 2020). This is concerning since 25% of all children in the United States belonged to an immigrant or ethnic minority family in 2015 (Calvo, R. and Hawkins, S., 2015). A lack of child well-visit screenings in the immigrant population increases the possibility of a child not being identified with a developmental disability, such as autism, until a child reaches school age and is identified through educational modalities (Christensen, D. L, et al., 2016; Johnson, C.P & Myers, S.M., 2007;). This creates a large gap between the onset of symptoms and initiation of treatment which directly impacts therapy outcomes (McGrath, K et al., 2020; Travers, J. & Krezmien, M., 2018; Adelman, C. R. & Kubiszyn T).

Access to preventive services is important for any child to develop and grow. Without access or with reduced access children are at higher risk for reduced overall health status, increased hospitalizations, and increased medical needs (King, C. 2016; Son, E. et al., 2017; Langellier, B., et al., 2016). Minorities and immigrants face deeper health care disparities in access as compared to other ethnic groups. These disparities in access to needed services are exacerbated when the individual is born with SHCN and does not have insurance coverage.

Geographic Region

Ethnicity is not the only factor in the disparities of the health care systems as regional differences also contribute to a significant portion of an individual's overall health disparity level (Xiaoxin, K. et al., 2017p; Fry-Bowers, E.K. 2015; Zablotsky, B. et al., 2019; Christensen, D. et al., 2012; Coombes, J. et al., 2018). When comparing overall health care access across regions, children residing in northern states have increased access to health care services as compared to children residing in southern states (Fulkerson, N. et al., 2013; Coombes, J. et al., 2018). In addition, children living in Southern states are also more likely to have unmet medical needs and children diagnosed with ASD living in the south are less likely to be able to see a specialist when needed as compared to children living in the North (Fulkerson, N. et al., 2013; Coombes, J. et al., 2018 Zablotsky, B., Maenner, M.J, & Blumberg, S. J., 2019).

One of the reasons suggested for the significant differences between the North and South specifically is that the South has historically engaged in racial segregation, discrimination, and conservatism (Kuang, X., 2017). These ideologies and policies have a direct impact on the health of people in the form of abject poverty and lack of access to health care services. As a result of these policies, the Southern states have had the highest population of children living in poverty

(Kuang, X., 2017; Thomas K., Parish, S., Rose, R., and Kilany, M., 2012). These variations suggests that the regional differences are more likely due to individual child and family characteristics (Zablotksky, B. et al., 2019; Adelman, C and Kubiszyn, T. 2017; Daniels, A.M. & Mandell, D. S. 2014). Other regional differences exist between the northern and western states when ethnicity is a factor. In the northeast was the highest prevalence of autism was among Caucasian children. Whereas, in the West the highest prevalence was among Spanish speaking people (Zablotksky, B. et al., 2019; Christensen, D. et al., 2016 and Xiaoxin, K. et al, 2017).

Not only is a macro level of geography influential on health care access, but local and community level characteristics also heavily influence a person's physical health and access to care (Xiaoxin, K. et al., 2017). Children in rural areas have less access to health care services and providers and have increased odds of unmet medical needs as compared to children in urban areas (Fulkerson, N., et al., 2013; Zhang, W. et al., 2017). The odds that a child living in a rural area has a routine visit with a pediatrician at least once a year since birth decreases significantly when compared to children in urban area (Xiaoxin, K. et al., 2017; Coombes, J. et al., 2018). Another factor is that rural areas have long struggled to recruit providers as these areas do not provide the same opportunities for compensation and lifestyle as cities. In addition, many states require specialty therapies such as Applied Behavioral Analysis (ABA) and Speech Therapy (ST) to be licensed in that state to provide services; yet some states have not adopted regulations establishing licensing for those disciplines (CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). This limits the number of qualified and/or specialized providers attracted to an area among an already small pool of available providers able to deliver quality services for children with multiple disorders (Zhang, W. et al., 2017; Marcin, J., et al., 2016;

CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). In 2016, the number of sub-specialist providers in rural areas was 40/100,000; in urban areas the ratio was 134 /100,00 (Marcin, J., et al., 2016). Without available providers, rural families are forced to travel long distances to access care. However, many rural families also face transportation difficulties (Marcin, J. et al, 2016).

The lack of available providers can create a serious problem for children with behavioral problems because when behavioral needs are not supported, the behaviors worsen over time (Cheak-Zamora, N.C. et al., 2017; Lello, A., et al., 2016; Travers, J. & Krezmien, M., 2018; Adelman, C.R. & Kubiszyn T., 2017; Daniels, A.M. and Mandell, D.S., 2014). The worsening of the behaviors often will result in the need for immediate psychological/medical intervention. The fastest way for people living in rural communities to gain access to psychiatry and medical care is through the Emergency Department (ED) (Zhang, W. et al., 2017). The ED has become a primary source of care for many rural, immigrant and minority families due to a lack of providers in the area who are qualified to treat their children's specialized needs. Because of the lack of providers in rural areas, children with autism are nine times more likely than children with other DDs to utilize the ED for these reasons (Zhang, W. et al., 2017; Daniels, A.M & Mandell, D. 2014). Frequent trips to the ED to treat issues which should be managed by a PCP can equate to the patient seeing too many different providers and lead to a lack of coordination or incorrect care and for children who much later diagnosis of autism (Daniels, A.M. & Mandell, D., 2014). However, living in an urban area doesn't necessarily guarantee a child will have access to health care. Children in urban areas who lack a supportive neighborhood, or a positive home or community environment have also been found to have lower rates of preventive medical

visits (Monz, B. U., Houghton, R., Law, K., & Loss, G.,2019). A supportive environment is necessary for continued reinforcement of therapeutic goals in different situations. Environments which are supportive ensures the generalization of skills which are necessary in gaining independence (Monz, B. U., Houghton, R., Law, K., & Loss, G., 2019).

Behavioral Health

When children experience unmet health care needs, they are at greater risk for developing chronic health care issues such as developmental delays and behavioral/emotional difficulties (Glassgow, A. E. & Van Voorhees, B. 2017). Behavioral health services are vital for children on the autism spectrum as they are more likely than children with other types of DDs to require these types of interventions. The reason for the increase in need for behavioral health services is often due to the co-occurring disorders which cause significant delays in communication and cognitive growth. Lower cognitive and communicative abilities have been associated with higher incidents of self-injurious behaviors (SIB) (Soke, G.N. et al., 2018). As SIB are unlikely to fade without intervention, access to behavioral health services is imperative for children to develop the skills necessary to participate in academic, social and community environments (Boyle, C.A. et al., 2011; Soke, G.N. et al., 2018). Beyond the presence of SIBs, children with Autism Spectrum Disorders also exhibit restricted and repetitive behaviors (often bordering on obsession/compulsion) (e.g., only wanting to eat round foods or only watch “Thomas the Train”) as well as exhibiting sensory processing challenges (e.g., sensitivities to sound, touch, light) and food sensitivities (e.g., aversions to textures and temperatures) (DSM-5, 2013). Due to these difficulties, children with ASDs have been consistently found to have a higher rate of need of mental and behavioral health services as compared to normally developing children or children

with other types of disabilities (Glassgow, A. & Van Voorhees, B. 2017; Kogan, M.D. et al., 2009). Yet, many parents of children with ASD have reported they did not or could not receive the mental health services they needed (Kogan, M.D. et al., 2009). The need for access to behavioral health services is imperative for the 10% of children in the United States that have been diagnosed with a mental illness. Of this group, only 25% of the children who need mental health services received treatment (Park, C., et al., 2014). To compound matters, children with autism have a 4% higher prevalence in exhibiting more severe types of behavioral difficulties such as physical aggression and/or Self Injurious Behaviors (SIB) as compared to typically developing children. Given that children with ASD are at a higher risk for engaging in self-harm, who also have sensory and compulsive behaviors, they require very specific, skilled intervention to reduce, fade or replace these behaviors (Soke, G.N., et al., 2018; Glassgow, A. & Van Voorhees, B. 2017; Kogan, M.D. et al., 2009). As with other developmental difficulties mental health needs are best addressed earlier in life when it is easier to change or replace a behavior (Soke, G. N. et al., 2018). If the behavior persists into the school age years, the behaviors become harder to manage requiring more specialized intervention (Soke, G.N. et al., 2018). Furthermore, hard to manage behaviors then interfere with academic and social learning furthering the social and academic gap between children with ASD and their peers (Cheak-Zamora, N.C. et al., 2017; Lello, A., et al., 2016; Travers, J. & Krezmien, M., 2018; Adelman, C.R. & Kubiszynm T., 2017; Daniels, A.M. and Mandell, D.S., 2014).

Socioeconomic Status

Poverty has long been a risk factor in determining access to health care and/or having insurance coverage (Fulkerson, N. Haff, D.R. & Chino, M, 2013). Children and families who

live below the Federal Poverty Levels (FPL) are far more likely to experience unmet health care needs and not have insurance coverage as many are not eligible for public insurance but do not earn enough to privately purchase insurance. (Zhang, W. et al., 2017; Zablotsky, B., et al., 2019). Without insurance, health care becomes a substantial financial burden for many families who must pay out-of-pocket for supportive therapies, mental health intervention, and medical services (Berlin Baller, J., et al., 2016; Karpur, A., et al., 2019; Foxhall, K., 2015; Havens, L., 2019; Candon, M.K., 2019). With the passage of the Affordable Care Act in 2010 access to habilitative services, mental health services, wellness services and pediatric services was expanded for children with autism and needed behavioral and therapeutic interventions, people living at or below the poverty line and people with pre-existing conditions (Caldwell, J., 2010). The additional Medicaid expansion under the ACA was significant as it provided individuals at 133% of the FPL to have access to Medicaid insurance (Caldwell, J., 2010) and provided cost sharing assistance for individuals at 400% of the FPL to purchase insurance provided through the federal health insurance exchanges (Caldwell, J., 2010; Zablotsky, B., et al., 2019) providing relief for LSES families and many children with disabilities as a high proportion live below the poverty level and depend on Medicaid coverage (Caldwell, J., 2010).

As previously mentioned, health care disparities associated with socio-economic level are compounded for children of minority status as LES areas are more likely to include minorities, people with public insurance and children with special needs (Rosen-Reynoso, M. et al., 2016; Fulkerson, N. Haff, D.R. & Chino, M, 2013; Christensen, D. et al., 2016; King, C. 2016). Lower socio-economic (LSES) areas are also more likely to have limited providers/services which results in a lower rate of preventative medical care (Kuang, X. et al., 2017), poorer health care

outcomes and increased utilization of ED services (Prokup J.A. et al., citing Boulet et al, 2009; Krahn et al., 2006; Scior 2011; Staniland 2009; Wilson and Scior 2015; Park C. et al., 2014).

A lack of access to health care services is evident based on disability, ethnicity, SES and geographic region. As one of those factors alone is has been found to impede an individual from receiving the care they require; it is logical to conclude the aggregate of these factors could dramatically decreases the number and type of services to which an individual has access. For children diagnosed with ASD, access to accurate, early detection and intervention is paramount as many individuals with ASD require a long-term team approach to treatment including habilitative, medical, educational, and mental health professionals.

Statement of the Problem

Children with autism have long faced disparities in equality of access to needed medical services since historically these services have not been covered or minimally covered by insurance. The disparities in access are exacerbated by poverty, ethnicity, and geography. Growth in prevalence influences the level of demand for health care providers and services. Increases in the demand for health care contributes to the increase of the overall cost of care for that diagnosis incurred as well as creating long waitlists to access specialized services and providers (Stuart, M., 2011; Lavelle, T., et al.,2014; Fifield, J. 2016; Cooper, R, 2014; CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). Increases in demand for autism services, a lack of available providers and/or available licensed providers and the rising costs of health care advanced insurance reform and a revision of the DSM to the foreground of the 2010-2020 decade. During this period the federal government mandated states pass autism insurance reform measures (Cooper, R., 2014 2014; Stuart, M. 2011). The autism mandates

required public and private insurance companies (excluding ERISA policies) to provide some level of coverage for treatment of ASD (Stuart, M., 2011). These federal mandates were important to increase access to specialized autism treatments as recommended by health care providers but not typically covered by insurance due to cost (Stuart, M., 2011). While the mandates required insurance providers to cover some autism services, the law allowed private insurance companies to underwrite restrictive access to services using monetary caps, age limits or visit limits on therapies such as ABA, which are traditionally expensive (Lavelle, T., et al. 2014; Newschaffter, J. and Curran, L., 2003; Vohra, R. et al, Havens, L.A., 2015; Kaiser Foundation, 2016). These allowances resulted in furthering the existing variations in the type and number of services covered by the various insurance types (e.g., public, private, government) acting to further the difficulties individuals of minority, LSES and rural geographic status in accessing a diagnosing provider (Parish, S.L. et al., 2015; Havens, L.A., 2015; Kaiser Foundation, 2016).

Concurrent with the mandates, the DSM-IV was criticized as contributing to the overall prevalence of autism as the expansion of the DSM-III diagnosis criteria was thought to be too general for providers to make an accurate diagnosis between PDDs (Mazurek, M.O. et al., 2017, Young, R.L., & Rodi, M.L., 2014, Kulage et al., 2014, Yaylaci, F. & Miral S., 2017, Bennet, M., & Goodall, E., 2016, Maenner, M.J. et al., 2014). Under the revised DSM-5, a new diagnosis of Autism Spectrum Disorders (ASD) was created. The implemented changes were designed to delineate the presentation of autism signs and symptoms for providers to increase accuracy in diagnosing (Copper, R., 2012). Yet this reasoning for revising the autism criteria was provided for revision of the DSM-5 to intent was to increase the accuracy of autism diagnoses and reduce

over-identification slowing the diagnosis rate (Cooper, R., 2014 2012; Bent, C. A., Barbaro, J., & Dissanayake, C., 2017; Peters, W., & Matson, J., 2019; Maenner, M. J., et al., 2014). A reduction of prevalence, however, was not found even as barriers associated with SES, ethnicity, and the consistent revising of the ASD diagnosis criteria as the prevalence of autism continued to effect provision of services.

When the prevalence of any diagnoses (such as ASD) increases, utilization and the cost of care associated with services also increase. Given that health care costs are estimated by number of diagnosis codes (e.g., autism) utilizing specific services (Cooper, R., 2014 2014), it can be reasonable concluded the cost of health care services associated with autism will continue to rise as the prevalence rises. As the estimated prevalence of a disorder influences the availability of services and providers accessible to individuals it is therapeutically important to answer the question of why the diagnosed prevalence of autism continues to rise given the barriers of a strict diagnosis criteria, limited insurance coverage and preexisting conditions.

Purpose of the Study

A diagnosis of ASD is lifelong and affects all aspects of an individuals' existence from academics to social activities, and future career opportunities. The treatment of autism frequently requires multiple, and often intense, therapies yet access to autism treatment has been limited by ethnicity, geography, socio-economic status and lack of insurance coverage. The autism insurance mandates increased access to providers and health care services for some but not all (Douglas, M.D., Benevides, T. W., & Carretta H., 2017, Chatterji, P., Decker, S. L., & Markowitz, S., 2015, Saloner, B. and Barry, C. 2019, Barry, C. 2019). Accessible health care services are specifically necessary for individuals diagnosed with ASD as there is an increased likelihood of co-morbidities (e.g., mood disorder, bi-polar disorder, obsessive/compulsive

disorder) typically requiring multiple, specialized therapies to meet functional daily living goals (Barry, C., 2019). However, coverage of autism diagnoses services is not guaranteed based on the individual's insurance policy and a diagnosis of autism does not automatically grant access to therapeutic services due to the variability of insurance coverage, level of socio-economic status, ethnicity, and geography (Stuart E., et al., 2017, Berlin Baller, J., et al, Wang, L., et al., 2013; Ngyen, C. T., et al., 2016, Gibson, J et al., 2013). Diagnoses provides access to specific services hence any changes to diagnostic criteria will have a direct impact on utilization, cost, type, and amount of services an individual receives (Lavelle, T., et al., 2014, Cooper, R., 2014, 2014). This is because the inclusionary/exclusionary language of diagnosing criteria and type of insurance coverage act as a gatekeeper for accessing specialty services. These hurdles lead to questions of what factors are influencing autism prevalence as the prevalence continues to rise despite the barriers. This will further the body of research have aimed at examining health disparities for children with autism. Additionally, examining variable associated with diagnosed prevalence of autism and type of insurance coverage along with examine the influence of other variables such as ethnicity, SES, geography and recent visits with a provider study will provide insight into the probability of a specific type of insurance is significantly related to a diagnosis of autism while considering the other influencing factors. The information derived from this study has important implications for policy level when determining to add therapy licensing regulation or reimbursement rates for providers. Policy changes can then be made at the local, state, and federal levels regarding coverage/access to services which can influence therapy outcomes for people with autism (Newschaffter, J. and Curran, L., 2003; Lavelle, T., et al.; 2014 Fifield, J. 2016; Copper, R. 2014). Beyond policy change, analyzing the variables associated with

insurance related to the prevalence of autism will assist providers in accurately identifying individuals with autism as insurance coverage is key to accessing diagnosing providers. If specific insurance types are found to be associated with a diagnosis of autism, this could suggest individuals do not have access to the diagnosing providers and thereby skewing the actual prevalence of autism and influencing the level of utilization and overall cost of care.

Research Questions

An initial study's (Thompson, J. 2018, The Prevalence of Autism on a National Scale following the changes to the DSM-5. Unpublished Manuscript. Western Michigan University), findings did not support previous research studies which predicted a 30% decrease in the prevalence of autism as a result of the stringent DSM-5 diagnosis criteria (Anderson, C., 2012; Peters, W., & Matson, J., 2019; McPartland, J., 2012; Bent, C. A., Barbaro, J., & Dissanayake, C., 2017; Mazurek, M.O. et al, 2017; Yaylaci, F., & Miral, S., 2017; Bennett, M., & Goodall, E., 2016; Maenner, M.J. et al., 2014; Young, R.L. & Rodi, M.L., 2014; and Lobar, S.L., 2016). When national data was examined, a significant change in the domestic prevalence of autism was not found. This study continued the previous investigation and extended the questions that surfaced after not finding a significant change in the prevalence of autism diagnoses. This study was designed to answer two questions 1) "Is there a change in proportions of insurance coverage, visits to a provider, geographic region, ethnicity, and socioeconomic status over time and is it significant?" and 2) "Are specific insurance types such as Medicaid, Tricare, and Private, associated with the diagnosed prevalence of autism following the changes to the DSM-5 and the implementation of the autism insurance mandates for the years 2010 and 2018?".

Significance of the Study

Children diagnosed with autism face a multitude of health care challenges. One of which is finding health care providers who are licensed in the individual's state and understand the complexity and course of autism disorders (CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). These challenges are exacerbated when ethnicity, socio economic status and geography are considered (Lello, A., Frazier, T., Dixon, P. J., Shih, A. J., & Karpur, A., 2019; Dougherty, D. et al., 2013; Magaña, S. et al., 2012; Park, C. et al., 2014). The additional challenge of limited access to care due to incorrect estimations of the prevalence of autism will only continue to further health disparities. Health care policy, insurance coverage, allocation and distribution of services are tied to diagnosis codes. Diagnosis codes provide access to specific interventions linked to those codes (e.g., ASD codes provide respite and monetary assistance to families). Yet access to autism services have been historically limited by a lack of insurance coverage, geographic area, ethnicity, and SES. Inaccurate estimations of autism prevalence influence the utilization of resources increasing the possibility some individuals will not be able to access a diagnosing provider (Ngyen, C. T., et al., 2016; Parish, S. L., Thomas, K. C. , Williams, C. S. , & Crossman, M. K., 2015; CMS, 2011; Havens, L.A., 2015; DHHS, 2014; Kaiser Foundation, 2016). Without access to providers the possibility to meet positive, functional outcomes becomes reduced; manifesting in decreases in educational performance and poorer social relationships (Coombes, J. et al., 2018; Glasgow, A.E., & Van Voorhees, B, 2017; Christensen, D. L, et al., 2016). Determining reasons for the continued rise in the prevalence of autism, when barriers such as insurance coverage and diagnosis criteria restrict access will assist

health care providers, policy makers and insurance providers to better understand how to impart individuals with the most effective autism services needed to experience increased quality of life.

CHAPTER II

LITERATURE REVIEW

The Relationship between Autism and Insurance

Autism is life-long and most often accompanied by other co-occurring morbidities such as: bipolar disorder, mood disorders, gastrointestinal problems, and sensory disorders (Karpur, A., et al, 2018, Cooper, R., 2014 2014). Individuals diagnosed with ASD frequently require multiple, specialized care. The cost of specialized care over a lifetime is around \$2.4 million per person (Saloner, B., and Barry, C., 2019; Stuart, M. J.D., 2011). The continued increase in the diagnosed prevalence of autism has influenced the demand and utilization of autism related health care services. The lack of or limit of insurance coverage for autism related services has created challenges for individuals and their families not just in accessing therapies but in being able to access a provider who can diagnose an Autism Spectrum Disorder (Saloner, B., and Barry, C., 2019, Wang, L., et al., 2013, Barry, C., 2019).

Prior to the implementation of the ACA many insurances were less likely to cover therapy services for a child with autism. In response to public push for increased access to autism services and rising costs of health care, the federal government mandated states write legislation instructing insurance companies to cover evaluation and treatment for autism. The autism mandates included coverage for behavioral therapies (e.g., ABA), functional therapies (e.g., ST, OT) and other mental health services. The intention was to lessen health care disparities between individuals with autism and individuals with other disabilities. A result of expanded coverage was access to early intervention services for some but not for all (Douglas, M.D. et al., 2017; Ngyen, C. T. et al., 2016; Zeleke, W., Hughes, T., and Drozda, N. 2019; Yingling, M., Hock,

R.M., and Bell B., 2018; Thomas, K. et al., 2012; Stuart, E., et al., 2017; Berlin Baller, J., et al, 2016, Karpur, A., et al, 2018). Within a few years of the mandates, multiple studies found the mandates had a greater positive overall effect of increasing access to therapies under public insurance options (e.g. Medicaid) compared to private insurance options (e.g., Aetna) (Parish S.L. et al., 2015; Barry, C. 2019; Thomas, KC., Williams, CD., and DeJong, N., 2016). The mandates also were found to reduce out-of-pocket costs for individuals with public insurance which contrasted with the high out-of-pocket costs experienced by individuals with private insurance (Parish, S.L., 2015, Saloner, B., and Barry, C., 2019; Wang, L. et al., 2013).

While the mandates did have positive effects on public insurance coverage, the mandated legislation was limited to public and private insurances, employer-based policies and privately purchased policies through open markets. This excluded ERSIA policies (e.g., companies who ensure their own workers and some small businesses). The language in the legislation gave insurance companies the freedom to create restrictive monetary and age caps whilst it granted states the right to set its own mandate laws in accordance with the Federal law.

The allowance for some insurance policies to be excluded from the mandates along with flexibility of what services are covered under an insurance policy created a potential for further disparities because of the differences in coverage which directly impacted access to services (Stuart, E., et al., 2017, Berlin, J. et al., 2016, Douglas, M.D. et al., 2017). When examining private insurances, Aetna, for example, requires a preauthorization (e.g., a request from a provider to an insurance company for permission to provide services) before the insured can schedule an autism evaluation. The ASD evaluations are only approved as “medically necessary” if those with signs/symptoms exhibited have persistent difficulties in the areas of language,

social skills and the like across multiple contexts as noted in the DSM-5 autism diagnosis criteria (Aetna, 2019).

For individuals covered under United Healthcare®, autism coverage specifies that an individual diagnosed with autism can only receive speech therapy if it has been deemed as medically necessary by a physician or psychologist. United also implements limitations on the number of therapeutic visits an individual can receive from each therapy discipline (e.g., ST, OT, and SW). United, like Aetna, also has the provision of allowing employers and direct policy purchases the ability to choose their level of coverage some of which significantly limit autism services (United Healthcare®, 2020). Blue Cross Blue Shield of Michigan covers autism services until the age of 18, through customizable employer offered policies. The customization allows for limitation on coverage and can limit coverage or require high co-pays/deductibles (BCBS Michigan, 2019). Unlike United and Aetna, Blue Cross Blue Shield requires an autism evaluation be conducted at an authorized Autism Evaluation Center (ACE) by a comprehensive evaluation team (e.g., psychology, OT, MD, ST, etc.) where many other insurances require an evaluation from a psychologist/psychiatrist or MD (BCBS Michigan, 2019). The requirement of families having to schedule an autism evaluation at an accredited center creates barriers in wait time and a possible lack of providers (depending on the geographic area) (Marcin, J.P., Shaikh, U., Steinhorn, R.H., 2016).

In comparison, Medicaid coverage guidelines state that Medicaid should “address the specific service needs of any individual but it must be medically necessary” (Havens, L.A. 2015). Under these guidelines states may cover autism services under different categories such as “section 1905 (a)(6) other licensed practitioners; 1905(a)(13)(c) preventive services and

1905(a)(10) therapy services” (DHHS, CMS, 2014). These guidelines allow for states to choose how they will allocate monies to reimburse providers for Medicaid autism services. The flexibility in how to cover autism treatment creates challenges for both providers and families/individuals as Medicaid requires therapists to be licensed in a state to provide services (DHHS, CMS 2014). A problem arises when there is a demand for autism services in a state, but that state has not adopted regulations for Medicaid licensed providers. This significantly reduces the availability of providers able to address the autism needs in that state (DHHS, CMS, 2014). For example, Texas previously refused to cover ABA services as the state did not implement regulations to establish ABA licensing under Medicaid. The Texas state government responded to criticism for its lack of Medicaid autism coverage that Applied Behavioral Analysis (ABA) treatments were not specifically mandated as having to be covered, therefore they (Texas) did not to have establish regulations for ABA providers to practice in the state (Kaiser Family Foundation, 2016). States refusing to establish therapy licensing/regulations creates significant obstacles for individual to access diagnosing providers.

An additional problem with state’s rights in implementing the Medicaid autism expansion are some state’s low Medicaid reimbursement rates. A Pew research study from 2013 found physician’s acceptance of new patients with Medicaid was lower than Medicare or private insurance, especially in states with lower Medicaid payment rates (Ollove, M., 2018). As of 2018, Medicaid only reimbursed providers 72% of what Medicare pays for the same services (Ollove, M., 2018). When reimbursement rates are low, it can cause providers to not accept Medicaid patients as well inhibit the attraction of qualified providers to that geographic area. A lack of available, licensed and/or qualified providers creates longer wait times or requires

traveling long distances for care (Ollove, M., 2018). These variations with Medicaid coverage and licensing of providers in different states create significant barriers for families to access diagnosing providers, even when Medicaid insurance is present.

Variations between insurance coverage occur on a large scale, but variations in insurance coverage also exist at the micro level with the frequency with which an individual receives services (Monz, B.U., 2019; Thomas, K et al., 2012; Nuyen, C. T., 2016; Zeleke, N., et al., 2019; Karpur, A. et al., 2018). People with public insurance coverage receive 15 hours (or less) of direct therapy services per week but reported access to a wider variety of therapies as compared to individuals with private insurance. Whereas private insurances holders reported restrictions to accessing services but experienced a higher frequency of direct services once services were initiated (Nuyen, C. T., 2016, Wang, L., et al., 2013; Saloner, B, and Barry, C. 2019; Douglas, M.D., et al., 2017). The variation in the frequency of services directly impacts the ability of an individual to make the best gains and achieve the most optimal outcomes (Bennett, M., & Goodall, E.; 2016; Zwaigenbaum, L., et al., 2015; Newschaffter, J. and Curran, L., 2003).

These highly variable differences in insurance coverage have been also found to occur at the state level as each state can create laws for coverage equitable to the minimum coverage provided by the federal government. While this practice isn't unique to autism disorders, the historical restrictions in coverage and access to care are lessened by these practices. For example, in Alabama, ASD therapies are limited to what is prescribed by the PCP, and not necessarily the treating therapist. Alabama also established a limit on insurance coverage of \$36,000.00 maximum benefits per year (Alabama Legislature, 2012). In Michigan, however, coverage for treatment is no longer available after the age 18. To add to this, the law also stipulates that the

monetary coverage for therapies will decrease every 6 years beginning at age 6 (Michigan Legislature, 2012). In Colorado, autism treatment plans must be approved and/or developed by a “licensed physician or a licensed psychologist” and the treatment plan must be developed within the patient’s medical home and any recommended follow up treatment must be prescribed by an M.D. or a licensed psychologist (Colorado, C.R.S. 10-16-104, 2012). These allowances can become barriers for the financially struggling to gaining access to autism services.

Analyses comparing insurances have found the type of insurance coverage directly influences how much care and what type of care an individual is entitled to receive as people with public insurance received less therapy per week compared to private insurances (cite). The problem with insurance restrictions/limitations is that most individuals don’t choose their insurance provider or policy as it is usually chosen by an employer or through what they receive from Medicaid. In other words, most individuals do not get to choose what their insurance policy covers only the level of coverage from employer chosen options. When families must purchase insurance privately it places children living in and around the poverty line at a significant disadvantage with lower socio-economic families being more likely not to have insurance coverage and/or have pay for services out-of-pocket (Coombes, J. et al., 2018; Rosen-Reynosos, M. et al., 2016; Nuyen, C. T., 2016, Wang, L., et al., 2013).

Variations in health care coverage create barriers for some and easier access for others; creating confusion and difficulty for families/patients trying to navigate health care systems. Due to these barriers it’s not unusual to find clinicians in other areas of mental health services engaging in “workaround” practices. Workarounds occur when a service provider assigns a more severe or different diagnosis to allow the patient to gain access to service(s) they would not

normally receive (Wynia, M. K. et al., 2000; Whooley, O., 2010; Kirk, S.A., & Kutchins, H. 1988; Rushton, J.L. et al., 2002; Rappo P.D. 2002; Braun, S.A. & Cox, J.A. 2005; Johnson, C., et al., 2007; Kogan, M.D. et al. 2012) Provider trend analyses have shown providers favor a few diagnoses they view as “helpful” for their patients. Anecdotal evidence from a 2012 study (Lord et al., 2017) supported as the authors suggested a diagnosis of Asperger’s was dependent upon the clinic and/or provider the patient visited. Assigning a diagnosis to be “helpful” situation is problematic because if a diagnosis is based on the context versus presentation of symptoms, then the reliability and stability of a diagnosis are affected yielding no standard; thus: providers can’t be sure they are accurately prescribing the necessary course of action (Cooper, R., 2014, 2012).

Autism and the DSM

At roughly the same time the federal mandates were passed, the DSM underwent a 5th revision. Since autism’s introduction to the DSM the diagnostic criteria have been revised/refined with every updated release of the DSM. The trend was continued with the 5th edition/revision as the of the DSM criteria for diagnosing Autistic Disorder (AD) was again revised. The proposed changes were so significant they drew both positive and negative attention. Proponents of the changes argued the DSM-IV diagnostic criteria was too broad and the broadness might be contributing to some of the increase in the prevalence of Autism and therefore a change was needed (Copper, R., 2014). Those lobbying for changing the autism criteria made the case that the DSM-IV was not specific enough in its ability to accurately draw distinctive conclusions among Pervasive Developmental Disorder (PPD) /PDD-Not Otherwise Specified (NOS), Asperger’s (AS) and AD (Williams et. al., 2008). It was speculated the lack of ability to differentiate between PDDs could also be contributing to the rise in prevalence as

children with true PDDs and AS were being over identified as having autism (Williams et. al., 2008). Advocates concerned with the rising costs of health care argued that changing the criteria could help to slow the prevalence which could decrease utilization and thereby influence cost (Cooper, R., 2014, 2014; Harmon, A., 2012, Kupfer, D., First, M., & Egier, D., 2002; Kupfer D., 2012; Verhoeff, B., 2010). As a result of public persuasion, political climate and the increasing costs of health care, the decision was made to modify the autism diagnosis criteria again as a means of increasing accuracy in the diagnosis of autism (Peters, W., & Matson, J., 2019; McPartland, J. 2012; Worley and Matson 2012; Cooper, R., 2014, 2014).

The changes made to the autism diagnosis in the DSM-5 revision were controversial as the criteria for diagnosing autism no longer distinguished among the previous diagnostic subcategories of PDD, PDD-NOS, Asperger's Disorder (AS), and Autistic Disorder (AD), as stand-alone diagnoses in the DSM-IV. Instead, AD, AS and the PDDs were replaced with a new diagnosis of "Autism Spectrum Disorders" (ASD) in which observed/reported symptoms are rated along a continuum and assigned a level of severity (1= Mild, 2= Moderate, 3 = Severe) (DSM-5, 2012).

The resistance to the removal of Asperger's as a diagnosis was relatively fervent as Asperger's had developed a strong cultural and community identification around the diagnosis and its uniqueness from Kanner's "Classic Autism" (Cooper, R., 2014). Those against its removal argued that Asperger's was still a "new" diagnosis (only established in 1994); therefore, it was still too new to appropriately make claims confirming or discounting its existence as a separate diagnosis (Cooper, R., 2014). Other practitioners expressed fear the reduction of the separate disorders into a single category would downplay the biological heterogeneity of the

syndrome (Silverman, C., 2011). Further concern was voiced by patients and advocates that the removal of Asperger's as a diagnosis would result in a loss of a diagnosis and access to therapies (Stuart, E., et al., 2017, Berlin, J. et al., 2016, Douglas, M.D. et al., 2017). The potential for loss of a diagnosis was a valid concern since the diagnostic methods traditionally used to diagnose Asperger's were inconsistent making an arrival at an accurate diagnosis difficult. These inconsistencies and differences in the characteristics of AS led clinicians to employ a greater amount of clinical judgement when attempting to differentially diagnose PDDs (Silverman, C., 2011; Lai, M.C. et al., 2014; Cooper, R., 2014). Arguments for and against the removal of Asperger's as a separate diagnosis were most often based on the individual's clinical view of the nature of Asperger's. People who viewed Asperger's as a distinct syndrome separate from autism requiring unique and specific interventions were mostly against the change (Silverman, C., 2011; Lai, M.C. et al., 2014; Cooper, R., 2014)). Others, who believed Asperger's was a "higher functioning" form of autism, were in support of its removal (Silverman, C., 2011).

Given the amount of push back over the significant changes prior to its release, several studies comparing the AD (DSM-IV) and ASD (DSM-5) diagnostic criteria were conducted during the DSM-5 field trials. When the DSM-5 criteria were applied to cases of autism diagnosed under the DSM-IV, researchers found an average of a 30% reduction in ASD diagnoses (Anderson, C., 2012; Peters, W., & Matson, J., 2019; Maenner, M. J., et al., 2014; Halfon N. and Kuo AA., 2013). The studies speculated that due to the strict criteria of the DSM-5, individuals previously diagnosed with PDD/NOS and Asperger's were less likely to meet the criteria for mild levels of ASD under the DSM-5 (Anderson, C., 2012; Worley and Matson 2012; Maenner, M. J., et al., 2014; Kulage et al. 2014).

Not all previous comparison studies between the DSM-IV and DSM-5 reported there would be a reduction in prevalence. Several studies found the DSM-5 to be equitable while more specific than the DSM-IV. These studies suggested that due to the provisions written in the DSM-5 criteria, individuals with a historical diagnosis of AD would maintain a diagnosis of ASD after the change (Silverman, C., 2011). It was also speculated if a diagnosis of ASD wasn't maintained the new diagnosis of Social Communication Disorder (SCD) would be sensitive enough to capture individuals previously diagnosed with Asperger's and PDD's allowing for therapy to continue under a different diagnosis (Cooper, R., 2014).

However, the SCD diagnosis is not without its' criticism. One of the main arguments against the diagnosis is that it is difficult to capture mild forms of pragmatic deficits and the SCD criteria focuses on specific pragmatic language abilities versus all language abilities which autism specific instruments evaluate (Cooper, R., 2014). Another factor working against SCD as an alternative diagnosis is that social communication deficits are often accompanied by comorbidities causing difficulties in differential diagnoses (Brukner-Weirtman, Y., et al. 2016; Huerta et al. 2012). Like the AS diagnosis criteria, there are not a large array of standardized tests to accurately assess SCD meaning clinicians must rely on clinical judgement to reach a diagnosis (Rushton, J.L. et. al, 2002).

Several other criticisms of the addition of the SCD diagnosis were noted prior to its release in the DSM-5. First, the language used in the criteria for diagnosing social communication disorders is problematic as the definition uses vernacular not equal to the wording used in the previous diagnosis definition of PDD/NOS (Brukner-Weirtman, Y., et al. 2016). Second, is the use of the long-standing "gold standards" of protocols used to diagnosis

autism; the Autism Diagnostic Observation Schedule (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R). These assessments have been found unable to differentially diagnose SCD from ASD when used alone. It has been reported that clinicians in the field often administer only one of the two assessments (Brukner-Weirtman, Y., et al. 2016; Gibson, J. et al. 2013; Foley-Nicpon, M. et al. 2017). Finally, the pragmatic communication skills needed to meet the criteria for SCD are based on higher level language skills which do not manifest in children until ages 4-5 (Foley-Nicpon, M. et al. 2017) two years after ASD can be reliably diagnosed (Bennett, M., & Goodall, E.; 2016; Zwaigenbaum, L., et al., 2015; Newschaffter, J. and Curran, L.,2003).

A true SCD diagnosis is difficult to reach due to the lack of sufficient diagnostic instruments as well as the ambiguity surrounding the language of an SCD diagnosis. This means that there is a reliance on clinical judgement which is subjective and open to bias (Brukner-Weirtman, Y., et al. 2016 and Foley-Nicpon, M. et al. 2017) and could lead to SCD becoming a diagnosis of convenience for people who don't "fit" into an ASD diagnosis (Skuse, D.H. 2012).

The Statistical Problems with the DSM

The removal and addition of diagnoses to the DSM raised questions regarding the comparability between versions (Cooper, R., 2014). Anecdotal evidence from epidemiology studies have suggested that with each change to the diagnostic criteria could be attributed to some of the rise in autism since the 1990s (Cooper, R., 2014). A comparison study applying the DSM-IV autism diagnosis criteria to an original autism data set circa 1970 found when the DSM-IV was applied to this data set, the prevalence of autism was three times higher than the original rate from 1970 (Silverman, C., 2011). These results suggest each time the criterion for

autism is modified, more children are found to have autism. Due to the significant changes between DSM versions researchers claimed the estimation of ASD prevalence could not accurately be calculated for the DSM-5 using the DSM-IV criteria because the characteristics of autism were given greater prominence in the DSM-5 as compared to the DSM-IV (Silverman, C., 2011; Cooper, R., 2014); ergo an accurate comparison could not be made between the two versions because of the differences in analysis, construction and changes to diagnostic criteria (Cooper, R., 2014). Not to compare versions of DSM was the conclusion reached by the revision committee who determined a 1:1 comparison between the DSM-IV and DSM-5 would be “too cumbersome” to complete because of the magnitude of those types of comparison studies (Cooper, R., 2014). While a 1:1 direct comparison may be difficult due to changes in criteria, the reliability information would be useful to providers who are expected to make accurate diagnosis on a regular basis (Cooper, R., 2014).

Comparing versions of the DSM is also made problematic due to the inconsistent interpretation of inter-rater reliability (Cooper, R., 2014). The DSM has long utilized Cohen’s kappa values as a standard statistical analysis of the inter-rater reliability of each version of the DSM (Cooper, R., 2014). Kappa values refer to the chance two clinicians will agree on a diagnosis when implementing the same criteria; a value of 0 indicates a chance agreement and a value of 1 indicates perfect agreement. When standardizing criteria, the greater the kappa value the more confident providers can be in giving an accurate diagnosis which influences the demand, utilization and cost of services Cooper, R., 2014 2012; Bent, C. A., Barbaro, J., & Dissanayake, C., 2017; Peters, W., & Matson, J., 2019; Maenner, M. J., et al., 2014). The variability in the interpretation of kappa values can make direct comparisons between versions of

the DSM difficult. What has been considered a “good” kappa value has significantly changed since the addition of Autistic Disorder in the DSM-III. The DSM-III had a kappa value of .7 which, at the time, was considered the threshold for “good agreement” (Cooper, R., 2014). This interpretation was in alignment with the kappa values for most other mental health disorders such as schizophrenia and affective disorders which had kappa values of .8 (Silverman, C. 2011).

The 5th revision saw a change in the way the kappa values have historically been interpreted. Interpretations of kappa value ranges were adjusted for the change to the DSM-5. Instead of .7-.8 being the threshold for what was “good”, values of .8 were considered “miraculous”, values of .6-.8 were “cause for celebration”, values of .4-.6 were “realistic” and values of .2-.4 were “acceptable” (Cooper, R., 2014). A kappa analysis of the entire DSM-5 was conducted, and it was found to have an average kappa value of .4. This was a significant decrease from the DSM-III and IV which had values of .7 (Cooper, R, 2014). Moreover, when specific disorders from each version the DSM were compared head-to-head, all the major affective disorders with kappa values of .8 in the DSM-III were found to have kappa values of .28 in the DSM-5 (Cooper, R., 2014 2012). Additionally, of the 20 new diagnoses added to the DSM-5, only 3 were found to have kappa values of greater than .6 (Cooper, R., 2014, 2012).

The change and varied interpretation of kappa values points to a larger problem with the reliability of DSM. As there is not a universally agreed upon standard of what is considered an acceptable kappa value among researchers. For example, at the time of the DSMs III and IV, Robert Spitzers’ standards or Landis and Koch’s standards (1977) were mainly utilized. These standards ranked kappa values of .2-.4 as “fair”, .41-.6 “moderate”, .61-.8 “substantial” and .81 as nearly “perfect” (Cooper, R., 2014). Later in the 90’s, kappa values below .2 were interpreted

as “poor” and anything above .61 was interpreted as “good” (Cooper, R., 2014). Then in the early 2000’s, Fleiss, Levin and Cho Paik theorized kappa values below .4 were “poor”, .4-.75 was “fair” and anything above .75 was “excellent” (Cooper, R., 2014). This lack of consistent interpretation leaves too much variation which has direct implications on prevalence as it does not allow for a true comparison between diagnosis criteria. This again creates difficulties for providers arriving at an accurate diagnosis upon which access to services are dependent.

Differential Diagnosis in Early Years

The task of attempting to differentially diagnosing autism from other developmental conditions is difficult for even seasoned professionals because conditions, such as genetic disorders (e.g., Down syndrome, stunted growth, and developmental abnormalities), present with characteristics like ASD yet the causes are not related to autism (Johnson, C., et al., 2007). There is a thin line when attempting to differentially diagnose autism from similar developmental disorders (DDs) such as a cognitive impairment (CI) as compared to attempting to differentially autism as a co-occurring disorder when other developmental disorders are present (e.g., autism and cognitive impairment). The presence of similarly appearing disorders, such as CI, can also manifest with global developmental delays and non-compliant behaviors (e.g., kicking, screaming, hitting as a means of protesting) causing providers to assign a diagnosis of autism as the primary condition when it in fact, is not (Johnson, C., et al., 2007). The difficulty in accurately differentially diagnosing autism from other developmental disorders can lead to inaccurate estimations of prevalence which influences the availability and utilization of services and providers.

Shifts in Provider Perception

Another factor which could be influencing the diagnosis prevalence rate could be a shift from provider centered patient care where the provider directs medical decisions for the patient to care which is centered on the patient. In the patient centered model of health care, patients'/families' wants, feelings and beliefs are taken into consideration by providers when making a diagnosis (ASHA, 2020). Considering patients' wants can embolden parents/patients to request providers to assign a diagnosis of autism to access specific services (Cooper, R., 2014). The change from clinician centered to patient centered care also reflected the changes in parental and societal attitudes regarding autism. Through the 1940s, 50s and 60s, a diagnosis of autism (as most mental health disorders) was viewed as something of which to be ashamed and the result of "cold parenting" methods (Silverman, C. 2011). Families were less likely to seek out a diagnosis of autism because of the stigma associated with the disorder. Increases in research, education of the signs and symptoms of autism, sensitive early identification assessments, and advocacy for autism have changed the overall public perception of autism to one which is more accepting of the disorder (Cooper, R., 2014). As autism has become accepted and the mandate for autism insurance coverage has been implemented there are increased numbers of parents /individuals who will advocate physicians for an autism diagnosis to access habilitative and mental health services (e.g., ABA services) which might not be covered under other developmental delay diagnoses (e.g., speech and language delay) (Rose, Roderick A, et al., 2010; Silverman, C., 2011; King, C., 2016; Zeleke, W., Hughes, T., and Drozda, N., 2019). If providers only consider individuals wants without considering the presentation of symptoms this will

contribute to an overabundance of people incorrectly diagnosed with autism taking away services from people who truly do have an autism spectrum disorder.

Increases in Awareness in Education

Public understanding of autism has increased through awareness, advocates and research has changed the way autism is viewed in education. Prior to 1990, AD/ASD was not included in the Individuals with Disabilities Education Act (IDEA). Before inclusion in special education eligibility, children exhibiting severe forms of developmental impairment were typically given the eligibility label of cognitive (CI) or emotionally impaired (EI) to access behavioral and communication services (Johnson, C.P. et al, 2007). The action of adding ASD to Special Education Eligibility increased the importance of the role of schools in identifying children with autism as school ASD eligibilities account for 75% of all the ASD cases in the U.S (McGrath, K. & Mann, M. 2020).

While an eligibility of ASD for special education differs from a medical diagnosis it still accounts for increases in prevalence. This is due to shifting the burden of autism identification to educational entities as children who do not have access to medical care and/or insurance coverage are often diagnosed with autism once they reach school age and are identified by an Interdisciplinary Education Plan (IEP) team (Johnson, C. et al., 2007; Kogan, M.D. et al., 2007). This is also partially due to the refusal of insurances to cover habilitative therapy services as insurances have denied claims on the terms habilitative services could be provided by the school district (Johnson, C. et al., 2007). As the burden of identification is placed on educational systems any increases in autism will directly impact special education funding (e.g. the need for 1:1 paraprofessional, behavior assistants, staff training, modifications to the environment, etc.)

(Kogan, M.D. et al., 2007) as Special Education funding is based on the number of students who are enrolled and required additional assistance.

Culture

Cultural/racial factors may also have an influence on the prevalence of autism as minorities have experienced significant racial disparities across all health outcomes (Magana, S. et al., 2012, Dougherty, D., et al., 2013). On average, children from minority families use far less health care and mental/behavioral health services as compared to children from Caucasian families who are also far more likely to have access to preventative care and screening services (Coombes, J. et al., 2018; Fulkerson, N. et al., 2017, Dougherty, D., et al., 2013). In general, the differences between ethnic groups are significant as children from Black and Latino families have been found to have poorer mental health outcomes, live in lower socio-economic (LSES) households, and are enrolled in public insurance even when insurance coverage, income, age, and severity are held constant (Magana, S. et al., 2015; Calvo, R et al., 2015). Among all minorities, immigrant families are less likely to be aware of the health care services in their communities and more likely to not hold insurance (Calvo, R. & Hawkins, S., 2015). Immigrant families also face the difficulty of language barriers when interacting with providers (Fulkerson, N. et al., 2013). Only 20% of Spanish speaking individuals have access to health care leaving around 80% of the Spanish speaking population without resources to well-child visits which are required to gain referral for specialty providers (Fulkerson, N. et al., 2013).

When comparing the utilization of health care services among racial groups, black families were less likely to have a PCP and Latino families were less likely to have coordinated care (Park, C. et al., 2014; Magana, S. et al., 2012; Xiaoxin, K. et al., 2017, Dougherty, D., et al.,

2013). The lack of a PCP and coordinated care causes difficulties for minority families as it hinders the ability to gain referrals required for a special evaluation for disorders such as autism and subsequent therapeutic intervention(s). The health disparities are further compounded in minority children diagnosed with ASD as they have less access and greater difficulties accessing specialty care compared to any other developmental disabilities (Magana, S. et al., 2012; Christensen D., et al., 2012).

Cultural perceptions which individuals and their families hold regarding health care in general have also been found to influence health care outcomes in minorities. Traditionally minorities have reported negative views of mental health disorders and consider them to carry a stigma. Cultures which view mental health (and illness in general) as a punishment from a higher power are less likely to seek a diagnosis/treatment because of stigma and beliefs (McLaughlin, L. & Braun, K., 1998, Wong, E. C. et. al, 2017, Razi, R.R. 2017; Quazi, S. et. al, 2008, Koenig, BA & Gates-Williams, J. 1995, Eylem, O., et. al, 2020, SAMSA, 2015, Wong, E.C., et. al, 2017). Negative perceptions of mental health disorder exist at higher levels among Latino (84%), Black (61%) and Asian (86%) populations which have reported prejudice associated with mental health disorders (Wong, E. C. et. al, 2017). In addition, an increased percentage of Latino (42%) and Black (35%) people specifically reported they would put off seeking treatment for mental health difficulties due to the perceived stigma (Wong, E.C., et al, 2017; Langellier, B. A. et al., 2016). These negative views of health care act as additional barriers causing delays in care or delay in management of the disorder.

Misconceptions regarding ethnic culture by providers have consistently reported by minorities stating their PCP was not sensitive to, understanding of, or respectful of their cultural

considerations (Calvo, R. & Hawkins, S., 2015). These perceptions were not unfounded as studies examining health care provider behaviors demonstrated providers had lower expectations of Latino and Black families compared to Caucasian families. It was found that providers made fewer referrals for their minority patients and have lower quality interactions with minority children diagnosed with DDs (Magana, S. et al., 2015; Calvo, R. & Hawkins, S., 2015).

Lack of access to health care services, historical racism, stigma of mental health disorders and a lack of coordination of care for services have long been obstacles minority children have faced when attempting to access health care providers and services. These systemic issues are worsened when the child also is born with a DD and requires access to specialty care. The delay in or lack of seeking care has resulted in minority children being more delayed in the age of their first autism diagnosis as compared to Caucasian children (Christensen, D. et al., 2012). Access to providers is important as the age of a first diagnosis influences, when and if, comprehensive evaluations are completed. Completed evaluations result in referrals to special therapies, which without a formal diagnosis cannot be accessed (Christensen, D. et al., 2012). Again, many minorities are underrepresented in health care due to a lack of insurance/access and the stigma of mental health disorders the actual prevalence of autism could be significantly larger. To appropriately maximize autism service utilization all people with autism need to be accurately identified through access to well-child visits.

Socioeconomic Status and Health Care

Children born into poverty have long been at risk for being born with developmental delays (Simon A. et al., 2013, Becker, G. & Newsom, E. 2003, Adler, N. & Newman, K., 2002, Volberding, J., 2018, Razi, R.R., 2017). A person's socio-economic status (SES) is directly

related to insurance status as lower SES families are more likely to be uninsured and/or more likely to have Medicaid insurance (Kuang, X. et al., 2017; Becker, G. and Newsom, E 2003, Razi, R. R., 2017, Kuang, X., et al., 2017). LSES families have experienced less access to medical care/therapies compared to families of middle and upper socio-economic statuses (Alder, N. and Newman, K. 2002). Less access to health care means that LSES households are also less likely to engage in routine check-ups with a PCP (Fulkerson, N., et al., 2013; Glassgow, A.E. and Van Voorhees, B., 2017). In comparison, children from higher SES families are more likely to have insurance, be able to afford care, be enrolled in private insurances through employment, and have an established medical home. Access to a medical home is important as it provides a child with comprehensive primary care and acts as a coordinator for gaining access to other therapeutic interventions (Magaña, S., Parish, S.L., & Son, E. 2015; Park, C., et al., 2014; Fulkerson, N., et al., 2013; King, C., 2016; Langellier, Brent A, et al., 2016). Families living at or below poverty are less likely to have a medical home which has been shown to have a significant influence on access to health care services (Kuang, X. et al., 2017; Park, C., et al., 2014, Dougherty, D., et al., 2013, Xiaoxin, K., et al., 2017).

When attempting to navigating the landscape of health care, lower SES families have reported more difficulties and are less likely to seek out a provider for care. Whereas middle to high SES families are more likely to seek out providers for a diagnosis (Razi, R. R., 2017; Lello, A., et al., 2016). As noted earlier, the shift to patient centered care helped promote patient advocacy for access to preferred, required and/or unattainable services. Levels of patient engagement in advocacy are determined by socio-economic factors where those with the ability

to afford/access specialty services are the ones who are more likely to advocate for and receive services.

SES levels can also influence where an individual can receive care. Lower SES families typically must receive care in under-funded areas with less access to specialty providers as compared to middle to high SES families (Becker, G. and Newsom, E., 2003). This situation is troublesome as increased levels of poverty are associated with higher odds of having a probable developmental delay with accompanying emotional and attention disorders (Simon, A.E. et al., 2013). Yet 60% of all children under 6 years old, living less than 100% below the FPL are unable to see a health care provider regardless of having a higher prevalence of mental health disorders (Volberding, J. 2018).

The ACA implemented mandates for preexisting conditions, such as autism, but it also expanded Medicaid. The expansion of Medicaid was very important for LSES families as the prevalence of people who are under insured has been greater than the prevalence of people who do not have insurance (King, C., 2016). The Medicaid expansion extended coverage to LSES families/individuals who hadn't qualified for Medicaid services in previous years due to income limits. Families at this socio-economic level were often left without insurance because it was not provided through their employment, or it was too expensive to independently purchase (King, C., 2016). The Medicaid expansion was positive for many LSES children with developmental disabilities who are more likely to utilize Medicaid services (Prokup, J., et al., 2018). The Medicaid expansions were not expansive enough to include all LSES families leaving many to continue to experience poorer health outcomes, utilize more specialty services and have increased barriers to accessing care (Prokup, J., et al., 2018). As with cultural barriers, families

living at or below the FPL may be underrepresented in the national prevalence due to the lack of access to diagnosing providers. Again, a lack of representation affects the estimation of the use and cost of limited and expensive autism services.

Health insurance is a strong predictor of whether an individual will have access to health care services as the under and non-insured continue to face significant barriers in obtaining health care (King, C., 2016). Yet, having insurance coverage does not ensure access to services, it may also come in the form of high deductibles, limited benefits, or coverage of services (King, C. 2016; Parish, S.L. et al., 2015; Douglas, M.D., et al, 2017; Chatterji, P., et al., 2015; Wang, L. et al., 2013; Barry, C., 2019). The variability in coverage leads individuals to experience very different health care outcomes; again, contributing to the overall national health disparities.

The ability to afford care, have access to care, and advocate for care are tied to ethnicity, insurance, geography, and SES status. If the greatest number of people diagnosed are limited to individuals with insurance/coverage or who can afford care and can navigate the system then the diagnosed prevalence of autism will be skewed toward specific populations, socio-economic statuses, and coverage levels. Such factors will cause misrepresentation of the true prevalence of autism. To meet the health care service demands a true estimate of prevalence needs to be found. As with cultural barriers families living at or below the FPL may be underrepresented in the national prevalence due to the lack of access to providers; a lack of representation affects the estimations of use and cost of limited and expensive autism services.

A reduction of prevalence of a disorder results in the reduction in the utilization of services and costs. Predictive research models estimated a decrease in prevalence following the changes to the DSM due to strict criteria of the DSM (Mazurek, M.O. et al, 2017; Yaylaci, F.,

& Miral, S., 2017; Bennett, M., & Goodall). This was not found as the prevalence continues to rise despite limitations set by insurance companies, racial disparities, and economic/financial hardships. Previous inquiries have examined the relationship between the cost of health care and a diagnosis of autism, the effects of autism mandates on access/utilization/cost, as well as the evaluation of the relationship between insurance type (e.g., government, public, private) and access to services. To date, a study examining the relationship of a diagnosis of autism and specific insurance types on a national level when other factors are controlled, has not been investigated.

Theoretical Framework

The purpose of this study is to examine other possible factors contributing to the increase in the prevalence of autism while controlling predisposing factors which influence access to care (e.g., race, SES, geographic area). To do this, the study follows the theoretical model of the Anderson and Newman Framework of Health Services Utilization (1995). The Anderson model provides a method to measure access to health care services as a function of three population characteristics: Predisposing Factors, Enabling Factors, and Need Factors. Predisposing Factors are preexisting conditions an individual already experiences before a diagnosis. These are individual level factors which influence health care habits such as ethnicity, cultural considerations, and personal values and beliefs toward health care providers in general. (Lix, L. et al., 2005). Enabling Factors are those which influence the logistics of how a person receives care such as the ability to navigate different health care systems, the ability to utilize regular source of transportation to access services, how to find available health professionals/facilities within their area and individual psychological factors such as motivation and drive to seek out

treatment (Lix, L. et al., 2005). Need Factors are elements which generate from problems that require immediate health care attention such as SIBs. Need factors also consider patients' perceptions of the quality of care provided as well as a patient's evaluation of how the care was provided (Lix, L. et al., 2005).

This research is intended to consider the effects of environment (e.g., region, county, home) on population characteristics, how population characteristics (e.g., socio-economic, race, geography) influence health behaviors, and finally how health behaviors and access to health (e.g., seeking care, navigation of insurance and insurance coverage) influence health outcomes (e.g., prevalence levels and autism diagnosis). The factors in Anderson's model directly align with the questions of the study regarding the effect of changes in the study populations of SES, ethnicity, geography, and insurance type overtime as well as the question of a whether a relationship exists between an autism diagnosis and specific type of insurance.

Summary

Access to health care services has long been difficult for children born with developmental disabilities. Problems accessing care are furthered when a child with autism are of minority status, lives in a non-metro geographic area or from a lower-socioeconomic income bracket. The introduction of the autism mandates and expansion of Medicaid were meant to increase access and they did, for some. For others not covered by the mandate legislation or those who didn't qualify for Medicaid it did not. As a result, many children with autism still have a barrier to accessing diagnosing providers due to of a lack of insurance coverage.

The refinement of the autism criteria in the DSM-5 was meant to increase the accuracy of an autism spectrum diagnosis while helping control the increased level of prevalence. Previous research suggested the removal of the PDD sub-category diagnoses would result in a reduction of

people identified with autism spectrum disorders, positing that the DSM-5 was not sensitive enough to accurately capture the subtle differences between mild forms of autism. This change would leave people with former diagnoses of PDD and AS without a diagnosis and therefore potentially face a loss of access to services. Other research posited that a measurable reduction of prevalence would not occur since the changes now included the SCD diagnosis and also allowed the historical diagnoses of autism to continue under the new criteria.

Yet, even with the addition of the SCD diagnosis, evaluating the strict ASD diagnosis criteria, considering issues of barriers to insurance coverage, factors associated with socioeconomic status, potential effect of geographic region, and consideration of the disparities between racial groups and possible under representation of minorities, the national prevalence has continued to increase. In fact, with every refinement of the DSM criteria, the prevalence of autism has continued to increase. Other factors, such as increased public awareness/acceptance of autism, expanded insurance coverage and improved diagnoses and screening practices have been considered as variables associated with the increase in prevalence; however, these three factors cannot account for all increases in prevalence. Determining if other factors that might be reflected in evaluating insurance type used by the family might contribute to the prevalence of autism is important since the relationship between diagnoses codes and insurance coverage for therapeutic services for other conditions has already been established. Diagnoses rates influence the rates of utilization of services as well as the overall cost of care. In addition, prevalence of a conditions such as autism influences policy and legislation at local, state, and federal levels since decisions regarding insurance coverage, cost and access are often decided based on the reported prevalence of a health condition (Monz, B.U., 2019; Thomas, K et al., 2012; Nuyen, C. T., 2016;

Zelege, N., et al., 2019; Karpur, A. et al., 2018). Understanding the factors which influence the diagnosis of autism will provide decision makers with data that is valuable for making changes to coverage, staffing, service provision, and reimbursement. These changes in turn enhance the ability to access capable providers, which is key for accessing necessary therapies.

CHAPTER III

METHODS

To answer the questions regarding the relationship between the types of insurance coverage and a diagnosis of ASD, this study examines variables over two distinctive years. To mark the years pre-mandate/pre-DSM revision the year 2010 was chosen and to mark the post-mandate/post-DSM revision the year 2018 was chosen. The best way to retroactively analyze the relationship between insurance and autism diagnoses is through the analysis of secondary data. The data set chosen for this task is accessible through the web-based databank at the University of Minnesota. The data was derived from the National Health Interview Survey (NHIS) which is an annual survey used to analyze health trends and outcomes in the United States. The focus on the specific relationship between the type of insurance and rates of autism diagnosis while holding SES, race and region constant is to determine other possible factors influencing the continued increase in the prevalence of autism over the years. Consent to use the data from the survey was provided by the participants prior to participation in the surveys. HSIRB approval was given by Western Michigan University's IRB committee for exempt studies examining secondary data.

Research Questions/ Hypotheses

This study was designed to answer two questions 1) "Is there a change in proportions of insurance type or predisposing characteristics over time and is it significant?" and 2) "Are specific insurance types such as Medicaid, Tricare, and Private, associated with the diagnosed prevalence of autism following the changes to the DSM?". The research literature has suggested that individuals with Medicaid have an increase in coverage for a wider variety of services under

the ACA. Previous research also suggests that the implementation of the autism insurance mandates have been found to have increased access to health care services for some individuals with private insurances (Foxhall, K., 2015; Barry, C., 2019; Stuart, E., McGinty, E., Kalb, L., Huskamp, H., Busch, S., Gibson, T., Barry, C., 2017; Berlin Baller, J., et al., 2016; Shea, L. L., et al., 2018).

National Health Interview Survey

Population and Sample

For this study, children from 0-18 years of age residing in the United States whose parents completed the National Health of Interview Survey (NHIS) for the years 2010 and 2018, and whose parents reported their child was given the diagnosis of autism are included in the extracted data set. The NHIS is an annual face to face survey of households in the United States. The NHIS dataset has a yearly sample size of $n = 87,500$. Using the exclusion criteria presented above, the final sample size for this study was $n = 162,807$.

The NHIS relies on a stratification and clustering sampling strategies to survey individuals residing in households and “non-institutionalized, multiple people living units” (e.g., apartments) (IPUMS, 2019). Geographic regions are divided into primary sampling units (PSU) such as local counties. Cluster samples are nested with a PSU from which addresses within are chosen to participate in the survey. Finally, the survey is distributed to the selected addresses in the selected PSUs.

Instrumentation

The outcome and predictor variables chosen for this study are taken from an NHIS data available through the University of Minnesota’s Institute for Social Research and Data

Innovation. The Institute provides researchers access to an extensive bank of secondary data from over 750 health and census data archives (Lynn, A.B. et al., 2019). The Integrated Public Use Microdata Series (IPUMS) data bank at the University of Minnesota synchronizes and records the variable codes from the survey (Lynn, A.B. et al., 2019). The survey variables are assigned specific codes which are documented in a manner which allows researchers to make comparisons across various years of NHI survey data. As described, the survey questions were previously administered by NHIS volunteers in person. All the survey responses were recorded in real time using close-ended, multiple choice answers. The responses were aggregated, organized, and recoded by category and stored in the IPLUMS databank at the University of Minnesota. To access the databank, a request was made to extract variables for the requested years (e.g., 2010 and 2018). Once the data request was approved, a key was provided to access a downloadable SPSS data file. All data analyzed was previously deidentified prior to extraction and stored on a secure, finger-print protected laptop.

Operation of Variables

The variables of interest in this study are derived from questions on the National Health Interview Survey (NHIS) for the years 2010 and 2018. The outcome variable of interest is a diagnosis of an autism spectrum disorder. The survey question best representing this variable is: “Have you ever been told your child has autism?” The principal predictor variable to be examined in this study are type of insurance and preexisting characteristics. Questions from the survey best representing the types of insurance coverage are: “Do you have any Medicaid/other public assistance” (e.g., all public health plans), “Are you covered by military health insurance?” (e.g., CHAMPUS, TRICARE, VA), “Do you have private insurance that you’ve purchase

directly?” (e.g., purchased through health care exchange or other open market health insurance exchanges), “Do you have private insurance paid in part or full by your employer?” (e.g., all insurances which employer contributes to the premium costs). It is hypothesized there will be a relationship between one or more of the insurance types and a diagnosis of autism given the expansions in coverage over time. Additional predisposing variables of interest were selected based on region of the U.S. (e.g., Northeast, North Central/Midwest, South, West), race/ethnicity (e.g., White, Black, Native/Alaskan, Asian/Pacific Islander, Hispanic), socio-economic status (e.g., at or above poverty level and below poverty level) and how recently an individual visited a provider (e.g., within the last 12 month or more than 12 months).

The variable of timing of last provider visit was considered since diagnoses of autism are contingent upon visiting a provider. Therefore, visiting a provider within the last 12 months before completing the NHIS survey along with having a diagnosis of autism could be an indication that in this dataset, the timing of provider visits may be correlated with a diagnosis of autism, as well as with the response to the survey question which asked, “Have you been told your child has autism”. This very general, self-reported item on the survey does not specify if the person with autism has a medical diagnosis of autism or if it was diagnosis within the system, but only that at some point the respondent has been told “your child has autism”, regardless of the source. It is estimated that 75% of all the ASD cases in the U.S (McGrath, K. & Mann, M. 2020) are first diagnosed in the educational setting. Since access to medical treatments are dependent up on a medical diagnosis of autism and not special education eligibility, it is important in this study to investigate whether a reported diagnosis of autism was related to a recent provider visit, given that insurance coverage becomes an issue only if a medical provider is the source of the

diagnosis. Evaluating the change in diagnosing practices for autism (e.g., DMS-5) and insurance coverage over time is potentially influenced by how frequently an individual visited a provider, since insurance only becomes important with a medical diagnosis of autism. This variable is an attempt to validate a medical diagnosis of autism.

The years 2010 and 2018 were secondary predictor variables representing the period prior to and following the autism insurance mandates (effective 2010-12) and the full implementation of the DSM-5 (effective after 2013). The large interval provided time for the effect of implementation to take effect. This also allowed for accounting for the impact of late implementation of some states in adopting the mandates, and for allowed health care entities to fully change to following the criteria of the DSM-5.

Analysis

For purposes of analysis, all the multiple-choice questions from the survey associated with the dependent and independent variables were recoded from multiple categories into binary categorical variables of “yes” or “no” To increase the chances of analyzing only “true” yes or no responses, the “Not in Universe” (NIU), “Refused to Answer”, and “I Don’t Know” (see Operational Definition of the Variables) removed from consideration.

Descriptive analysis and frequency counts were performed on all variables to determine if patterns exist within and among the variables. A z-test of proportions (two tailed test, $p = .05$ alpha level) was performed following the descriptive analysis to answer the question if there were changes in the proportions of the predictor variables between the years of 2010 and 2018. To evaluate and answer the question regarding if a relationship between the type of insurance an individual uses and a diagnosis of an Autism Spectrum Disorder exists a binomial logistic regression was conducted.

Other variables considered in the analysis were socio-economic status (e.g., above or below FPL), geographic region (e.g., north, Midwest, south, west), ethnicity (e.g., White, Black, Native, Asian), and how recently an individual had visited the doctor (e.g., with in 12 months or more than 12 months). Additionally, interaction terms associated with visiting a provider and geographic region and visiting a provider and type of insurance were considered to determine if these variables influenced the likelihood of being diagnosed with autism above and beyond the primary variable of interest (insurance type). The predictor variables were analyzed through a simultaneous entry method SINCE there was no theoretical basis for one insurance type or covariate having a presumed relationship more than any of the other variables. All statistical analysis was completed using SPSS version 27.

CHAPTER IV

RESULTS

Descriptive statistics were calculated for each variable to examine distribution comparability across variables. Prior to the analysis all the survey variables were recoded into dichotomous “yes” and “no” categories to ensure only “true” “yes” and “no” answers were included in the analysis. The dependent variable related to the presence or absence of Autism (e.g., ASD Yes or ASD No) and independent variables related to the years pre and post DSM/Insurance mandates (e.g., 2010 and 2018), type of insurance (e.g., Medicaid, Military, Private Self-Pay and Private Employer Pay), ethnicity, SES, geographic region and last visit with a providers (e.g., Within the last 12 months or more than 12 months since last visit) were included in the z-test and regression model to answer the questions of a change in proportion over time and if a relation between a diagnosis of autism and insurance type exists. The demographic characteristics of the survey participants and crosstabulation proportion percentages are expressed below in Table 1.

Table 1: Demographic information for variables related to predisposing conditions of recipients of autism diagnoses using the DSM IV and DSM -5 from the NHIS survey (N= 162, 807)

Demographic Variables	Frequency for 2010	Frequency for 2018
Ethnicity:		
<i>White</i>	66741	57267
<i>Black</i>	14854	8953
<i>Native</i>	994	1171
<i>Asian</i>	6721	4648
Region		
<i>North</i>	14095	12089
<i>South</i>	32804	26431
<i>Midwest</i>	18238	16092
<i>West</i>	24839	18219
Income		
<i>At or above poverty level</i>	64190	60405
<i>Below poverty level</i>	14830	7515

The z-test was performed to determine if the proportion changed between the year prior to the DSM changes and the implementation of the insurance mandates, the results of which are contained in Tables 2 and 3.

Table 2: Insurance coverage changes over time in those who received autism diagnoses under the DSM IV and DSM-5 from NHIS data (N= 162, 807)

Significant Variables: Type of Insurance	z score	p value	Proportion % for 2010 (DSM IV)	Proportion % for 2018 (DSM 5)
<i>Medicaid (n=161,312)</i>	6.65	p<.00001	19%	18%
<i>Military Based (n= 161,318)</i>	-21.94	p<.00001	3%	5%
<i>Employer Provided (n=47804)</i>	29.02	p<.00001	77%	69%
<i>*private insurance did not have a value for 2018 therefore a proportion was not found</i>				

Table 3: Change in theoretically influential variables over time for those who received a diagnosis of autism under the DSM IV and 5 from NHIS data (N = 162, 807)

Significant Variables: Demographic	z score	p value	Proportion % for 2010 (DSM IV)	Proportion % for 2018 (DSM 5)
Ethnicity:				
<i>White (n =124,008)</i>	-23.45	p<.00001	74%	79%
<i>Black (n =23,807)</i>	22.87	p<.00001	16%	12%
<i>Native (n = 2,165)</i>	6.49	p<.00001	11%	1%
<i>Asian (n=11,369)</i>	42.01	p<.00001	7%	6%
Region				
<i>North (n=26,184)</i>	-5.55	p<.00001	15%	16%
<i>South (n =59,235)</i>	158.2	p<.00001	36%	36%
<i>Midwest (n=34,330)</i>	-9.86	p<.00001	20%	22%
<i>West (n=43,058)</i>	9.13	p<.00001	27%	25%
Income (n= 146,840)	37.69	p<.00001	18%	11%
Provider Visit				
<i>(n = 19, 408)</i>	-14.4	p<.00001	78%	86%

All variables included in the analysis that were found to have a significant change in proportion between the years pre and post changes to the DSM and implementation of the insurance mandates were included in the logistic regression. While the difference in proportion over time was found to be significant, the percent of change was minimal and determined to be not noteworthy. The geographic variable and last visit with a provider variable were included in the regression model even though the change in proportion between the years was minimal

(Table 3) since some research suggests that geographic region of residence and timing of visits with providers could be influencing factors in the ability to access autism health care services.

The results of the regression model are shown in Table 4. The logistic regression model was statistically significant, $X^2 = 62.335$, $p < .000$. The model explained 5.4% (Nagelkerke R^2) of the variance in autism and correctly classified 98.7% of the diagnosed cases of autism (e.g., autism yes). Of the predictor variables included in the model, the variables which were statistically significant were the year (OR 1.12, $p = .000$), living in the south (OR .054, $p = .013$), living in the west (OR 0.116, $p = .021$), and Medicaid insurance (OR 4.99, $p = \leq .001$) as well as the interaction variables of visiting a provider within the last 12 months *residing in the south (OR 12.79, $p = .036$) and visiting a provider within the last 12 months * residing in the west (OR 8.42, $p = .029$) (see Table 4)

Table 4: Logistic regression results of variables associated with diagnosis of autism under the DSM-IV and DSM-5 from NHIS for the years 2010 and 2018 (N= 162,807)

Predictor Variables Included in the Regression Model + = variables found to significantly related to an ASD Diagnosis	Wald	OR	%95 CI	sig. p <.05
<i>Insurance Type</i>				
<i>Medicaid</i> ⁺	24.18	4.99	2.63-9.48	<.001
<i>Military Based</i>	.073	.943	.613-1.44	.0788
<i>Employer Based</i>	1.71	.458	.143-1.47	.190
<i>Year</i> ⁺	2.93	1.12	.983-1.28	.087
<i>Region</i>				
<i>North Region (referent)</i>	9.26	-	-	.026
<i>South Region</i> ⁺	4.41	.054	.005-.547	.013
<i>West Region</i> ⁺	5.30	.116	.019-.725	.021
<i>Midwest Region</i>	1.178	.457	.111-1.88	.278
<i>Income</i>				
<i>SES</i>	.000	.000	.000	.997
<i>Ethnicity</i>				
<i>White (referent)</i>	18.59	-	-	.501
<i>Black</i>	1.001	.710	.363-1.38	.317
<i>Native</i>	.002	1.04	.140-7.88	.963
<i>Asian</i>	1.5	.594	.258-1.36	.220
<i>Provider Visit</i>	3.44	.218	.044-1.08	.063

Table 4 – Continued				
<i>Interaction Terms</i>				
<i>Provider Visit *North (referent)</i>	8.99	-	-	.029
<i>Provider Visit *South+</i>	4.41	12.79	1.18-137.78	.036
<i>Provider Visit *West+</i>	4.78	8.42	1.24-56.66	.029
<i>Provider Visit *Midwest</i>	.141	1.34	.288-6.25	.707
<i>Provider Visit *Medicaid</i>	.469	.539	.092 – 3.1	.494
<i>Provider Visit *Military</i>	.000	.218	.000	1.000
<i>Provider Visit *Employer</i>	1.74	2.34	.662- 8.33	.186
<i>Provider Visit *SES</i>	.000	39220182.4	.000	.997

CHAPTER V

DISCUSSION

Prior to the release of the DSM-5, previous research predicted an average reduction of 30% in the number of individuals receiving an ASD diagnosis since the DSM-5 has been found to under identify individuals with mild severities of Autism (e.g., Asperger's or PDD-NOS) (Peters, W., & Matson, J., 2019; McPartland, J. 2012; Worley and Matson 2012; Cooper, R., 2014). A previous study examining the proportion of individuals concluded that the total proportion of individuals not receiving an Autism diagnosis did not significantly change at the .05 level between the DSM-IV and the DSM-5 even though the overall proportion increased by 1.3 percent (Thompson, J. 2018,). Since the results of this study did not support the previous claims of a 30% reduction in prevalence on a national level other questions arose concerning the influence insurance coverage and access to providers were raised. As a result, this research was designed to investigate other associations related to diagnosis of autism, and to answer the questions, "Is there a significant change in proportions of insurance type or predisposing characteristics?" and "Are specific insurance types such as Medicaid, Tricare, and Private, associated with the diagnosed prevalence of autism following the changes to the DSM?". The change in the proportions of all the predictor variables were statistically significant over 8 years. While the change in the proportions were found to be significant, the percent of change over time was minimal (e.g., Medicaid change was 1.2%, Employer provided insurance change was 11%, etc.). This may be due to continuously changing federal guidelines for what is considered "living below the federal poverty level", since the FPL standards for Medicaid eligibility fluctuate as the economy and/or political administrations change. These types of ongoing and unpredictable

changes can affect the qualifying threshold levels of socioeconomic status for Medicaid eligibility. In addition, individual employers can choose whether to provide their employees with insurance coverage and to set the terms of the coverage, potentially resulting in employed individuals not having employer-based insurance for certain conditions or at all, and thereby influencing the proportions with reported insurance coverage.

Logistic regression analysis determined that there was an association between the diagnosis of autism and Medicaid insurance. This analysis also considered other variables such as geographic region, ethnicity, SES and reported last visit with a provider as potentially influencing an autism diagnosis. Other main effects variables were not significant, suggesting the influence geography, SES and ethnicity is minimal. Additionally, the interaction between reporting the time frame for visiting a provider (within the last 12 months) and region of the country were examined since previous literature has suggested regional variations may be important. In fact, certain regions of the country, such as southern states, do have less available providers than others (e.g., due to a high number of rural and LSES areas). The results of the logistic regression analysis found a significant relationship between Medicaid, geography and the interaction term of geography and visiting a provider within the last 12 months (for two geographic regions). The relationship between Medicaid and a diagnosis of autism was not surprising since previous studies suggested Medicaid is reported to cover a wider variety of autism services such as compared to private insurances. While private insurances have been found to reimburse providers for autism services at a higher rate compared to Medicaid the differences, lack of coverage and/or limitations on reimbursement for services between the

various private insurance types (e.g., BCBS, Aetna, etc.) can result in a lack of access to diagnosing providers for some individuals.

A possible reason for the relationship between geographic region, the interaction between region and last provider visits and a diagnosis of autism could be attributed to a few things. For example, from a geographic standpoint, some regions have a higher concentration of large urban areas. It is also possible that larger urban areas provide not only an increase in access opportunities for clinical and diagnosing services (since there are likely an increased number of providers living in urban areas), but could also have larger, more well-established school-based services. It is important to note that while significant, and with large odds ratios reported for the two significant interactions (OR provider visit * South = 12.79, OR provider visit * West = 8.42), the confidence intervals for these interaction terms were very wide (e.g., visit with a provider * southern region CI = 1.2 – 137.8). The wide range of confidence intervals may be due to the wide range of services both clinically and educationally in the metro versus non-metro geography of the south and west, which often has a larger concentration of people in one metropolitan area (such as Atlanta, GA compared to areas such as rural Mississippi). In short, the predictor variables of geographic region and timing of last visit may be reflective of wide variations in the regional capacities.

Finally, from an insurance perspective, since individual state insurance regulations often affect autism diagnosis, variations among and between states in regions makes it impossible to view geographic regions as monoliths. Additionally, states did not adopt the federal autism mandates within the same time frame as some states were quick to adopt the mandates and other didn't full adopt the mandates until several years after they were required. Despite the significant

relationship, absent a national insurance policy, there is no way to impose insurance standards across state lines, as such the relationship between geographic region is difficult to interpret as federal guidelines for insurance coverage are not regionally adapted or applied in the same manner. What can be concluded however is that the regions are different regarding the regional influence on provider visit since the influence of North or Midwest was not significant. Further research considering state by state variations in access to providers, insurance coverage and diagnosis rates should be conducted to determine if these findings are real or artifacts of variations within a geographic region.

Since only reported Medicaid coverage was significantly related to a diagnosis of autism, the results from this study prompt further questions about the influence of insurance coverage and reimbursement for services and access to care. If Medicaid is the only insurance which is covering services at a higher rate this could influence the willingness of providers to accept patients with other types of insurance. This could lead to a large portion of the population with insurance coverage other than Medicaid with limited access to a diagnosing provider, thereby influencing the overall reported diagnosed of autism.

The overarching results of this study suggest that the type of insurance does factor into how and when someone will see a diagnosing provider. Since age at which someone is diagnosed impacts outcomes in therapy, and a later diagnosis of autism often results in increased symptoms it is clinically important that individuals are seen as early as possible (Cheak-Zamora, N.C. et al., 2017; Lello, A., et al., 2016; Travers, J. & Krezmien, M., 2018; Adelman, C.R. & Kubiszynm T., 2017; Daniels, A.M. and Mandell, D.S., 2014). Results of analysis of types of insurance coverage suggest that individuals with private insurances or without insurance

coverage are at a significant disadvantage when attempting to access a diagnosing provider in any region of the United States.

The strengths of this study are in the large sample size of national data and the conservative analysis approach. The national level data allowed for a large sample to be analyzed. In removing all the “extra” survey response choices (e.g., NIU, I don’t know and No Response) only the “true” yes and no responses for a diagnosis of autism and type of insurance held was included in the analysis allowing for increased accuracy in responses analysis of “yes” and “no” responses.

One of the main limitations of the study was the decision to remove all the “other” responses when recoding variables for analysis. In reducing the data set a large portion of the sample was excluded which may have inflated the “yes” percentages as “unknown” responses could have been either true “yes” or “no” responses. A second limitation is, to evaluate change over time, the best method is survey data. When implementing nation-wide surveys there can be complications with administration (e.g., user error), misinterpretation of the questions (e.g., by the respondent) or misinterpretation of the responses (e.g., administrator). In addition, as the data was de-identified and recoded prior to its’ addition to the database it is unknown if the same participants completed the survey in both years, limiting the data on the number of individuals who maintained, lost, or received Autism diagnoses. Finally, the survey is completed by any adult dwelling at the residence who chooses to participate in the survey. This can lead to family members completing the survey without accurate knowledge of the health conditions and status of other individuals in their household.

The implications for this study are wide as access to care is dependent upon insurance coverage and/or the ability to pay for health care services. If diagnoses are tied to specific insurances, this points a larger problem with inequalities in health care coverage in as outlined in the introduction of this paper since individuals who are more likely to have Medicaid coverage are White individuals living at or slightly above poverty level. This excludes all other populations continuing to increase the disparities in health care. The results of this study add to the body of evidence of health care disparities and equities in coverage. This information will be helpful in advocating for the increased access to care and expanded insurance coverage for people on the autism spectrum. Advocating for legislation reform at the state level to add or change licensing legislation to allow practitioners to be licensed with the state to provide autism services will be a start. In addition, state governments can be encouraged to write consistent laws for private insurances with the goal of reducing coverage variations among private insurance providers. State governments can also rewrite laws to codify autism services as a “standard” for care as with other disorders, such as ADHD, thereby requiring employers to include autism coverage in their benefits package. On a larger scale, the implementation of a national health insurance one-payer system could significantly reduce the disparities in access for people with autism spectrum disorders as everyone, regardless of region of the country, income level or employment status would have the same access to coverage and health care.

Future research should examine difference between specific geographic areas such as metro versus non-metro, access to autism specific providers such as comprehensive diagnoses teams and autism diagnosis as specific way of measuring the differences in geographic region and visits with providers.

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Appendix A:

Definition of Key Terms

The following terms are used specifically in Speech-Language Pathology and/or the health care community as they relate to the diagnosis and treatment of autism.

Term 1: ASD: Autism Spectrum Disorder: “any of a group of developmental disorders marked by impairments in the ability to communicate and interact socially and by the presence of repetitive behaviors or restricted interests Autism spectrum disorder.”

The Merriam-Webster.com Dictionary. Retrieved December 28, 2019, from <https://www.merriam-webster.com/dictionary/autism%20spectrum%20disorder>

Term 2: ABA: Applied Behavioral Analysis: “psychological therapy that uses techniques developed from the objective analysis of observable behavior to make changes to socially significant behaviors that are abnormal or harmful”

The Merriam-Webster.com Medical Dictionary. Retrieved December 28, 2019, from <https://www.merriam-webster.com/medical/applied%20behavior%20analysis>.

Term 3: EIBI: Early Intensive Behavioral Intervention: “Consists of 20-40 hours per week of individualized instruction for children with autism beginning at the age of 4 years or younger and continues for 2-3 years.:

Association for Science in Autism Treatment. Retrieved December 28, 2019, from <https://asatonline.org/for-parents/learn-more-about-specific-treatments/early-intensive-behavioral-interventiontreatment-2/>.

Term 5: SLP/ST: Speech-Language Pathologist/Speech Therapist/Therapy: A professional working in the medical or education field who “prevents, assesses, diagnosis and treats speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults”.

American Speech-Language and Hearing Association. Retrieved December 28, 2019, from <https://www.asha.org/Students/Speech-Language-Pathologists/>

Term 6: Autism Mandates: Legislature passed in the late 2000’s requiring private, commercial insurance plans to cover the treatment for autism. The mandates do not include self-funded plans.

American Speech-Language and Hearing Association. Retrieved January 2, 2020, from <https://leader.pubs.asha.org/doi/10.1044/leader.BML.24042019.30>

Term 7: Self-funded Health Insurance: A type of plan in which an employer takes on most or all the costs of the benefit claims and is the one to pay the claims.

Aetna. Retrieved January 2, 2020, from <https://www.aetna.com/employers-organizations/self-insurance-plans.html>

Term 8: Public health Insurance: A program run by federal, state, or local government. The main public health insurance for children with disabilities is Medicaid. *National Cancer Institute*. Retrieved January 2, 2020, from <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/public-health-insurance>

Term 9: Private Health Insurance: Any health insurance plan that is not run by the federal or state government. Private Insurance is provided through employers, state/federal marketplaces, or private marketplaces.

Term 10: DSM-IV/5: The Diagnostic and Statistical Manual is the rule book for making psychiatric diagnosis used by most mental health professionals. Periodically, the American Psychiatric Association updates the manual to reflect changes in research. *American Psychiatric Association*. Retrieved on January 2, 2020, from <https://www.psychiatry.org/psychiatrists/practice/dsm/feedback-and-questions/frequently-asked-questions>

Term 11: AD: Autistic Disorder: stand-alone diagnosis for individuals who demonstrated difficulty with social language, behavior, and social skills in the DSM-IV, now included in the DSM-5 Autism Spectrum. *University Of Michigan Medicine*. Retrieved on January 2, 2020, from <http://www.med.umich.edu/yourchild/topics/autism.htm>

Term 12: PDD/PDD-NOS: Pervasive Developmental Disorders (Not Otherwise Specified): stand-alone diagnosis for individuals who demonstrated difficulty with social language, behavior, and social skills but not to the same extent as an individual with autism and did not meet criterion for an autism spectrum disorder DSM-IV, now included in the DSM-5 Autism Spectrum. *University Of Michigan Medicine*. Retrieved on January 2, 2020, from <http://www.med.umich.edu/yourchild/topics/autism.htm>

Term 13: Asperger's Disorder: stand-alone diagnosis for individuals with normal intelligence and language development but also some autistic-like traits such as rigidity and restricted interests but do not meet criterion for an autism spectrum disorder, now included in the DSM-5 Autism Spectrum Disorder. *University Of Michigan Medicine*. Retrieved on January 2, 2020, from <http://www.med.umich.edu/yourchild/topics/asperger.htm>

Appendix B:

Anderson's Model for Health Care Utilization of Services

