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AUTISM ACROSS THE GLOBE  
A MASTER'S THESIS

SUBMITTED TO THE FACULTY  
OF BETHEL UNIVERSITY

BY

MEGAN NICKEL HAACK

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AUTISM ACROSS THE GLOBE

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August 2023

APPROVED

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### Abstract

The purpose of this study was to investigate what autism is like across the globe. Autism is a developmental disorder that is associated with social difficulties, restricted and repetitive behaviors. The prevalence of autism diagnoses had increased significantly in the United States. Since autism impacts every aspect of an individual's life, it is important to understand the implications an autism diagnosis has on the individual and the family. Additionally, culture is a strong force in life. Culture shapes social expectations and the way behavior is perceived. Therefore, the study reviewed previous research that investigated autism in a variety of cultures. The core symptoms of autism remained consistent across the globe, however, stigma experienced, healthcare, education, and financial support looked different around the world.

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## Chapter I: Introduction

### History of Autism Diagnostic Process

Since Leo Kanner's original description of autism in 1943, perceptions and definitions of autism have evolved (Rosen et al., 2021). Kanner originally classified autism through observance of two features: severe problems in social interaction and connectedness as well as resistance to change. One year after Kanner's findings, Hans Asperger reported observations like Kanner's description of autism. However, they differed because Kanner labeled autism as a developmental condition, whereas Asperger classified his findings as a personality disorder. While Kanner described features that continue to be recognized today, such as echolalia, he also documented features that we now know to be false. For example, Kanner suggested that autism was an early form of schizophrenia. Additionally, he believed that autism could not coexist with additional medical conditions. Forty years after Kanner's original recognition, early misperceptions were cleared, and diagnostic concepts validated. In the 1970s, autism was included as a psychiatric diagnosis category. The first autism symptom evaluation checklist was created, however the definition of autism continued to evolve. Delayed and deviant language, as well as restricted interests and repetitive behaviors were added to the definition and included in Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III). In 1980, autism was first included as its own class of conditions, however, the term "infantile autism" was used. It was not until a 1987 revision of the DSM that the terminology changed to "autistic disorder". The DSM-III revision also organized the diagnostic criteria into three domains: "qualitative impairments in reciprocal social interaction", "impairments in communication", and "restricted interests/resistance to change and repetitive movements". In

2013, continued research impacted changes made in the DSM-5. For example, autism changed from a multi-categorical diagnostic system to a single diagnosis. As illustrated above, perceptions and definitions autism continue to change (Rosen et al., 2021).

### **Personal Interest**

Throughout my time attending graduate school, I learned about the history of autism. I was surprised to learn that autism was a relatively new discovery. Not only was it a newer discovery, but there had also been countless revisions to both the definition of autism, as well as the beliefs surrounding the disorder. With autism prevalence continuing to rise, I could not believe that opinions were still developing. The lack of an agreed upon cause of autism appeared to create misconceptions surrounding the disorder. For example, the theory of refrigerator mothers was believed in recent history. This theory blamed a child's autism diagnosis on the lack of affection or warmth a mother gave to her child. Childhood vaccines, specifically for measles, has been another source of confusion and controversy surrounding the cause of autism. Not only were opinions developed in recent history, but so too were autism diagnostic tools. The newness of autism and the way that beliefs continued to evolve with added information raised my interest in the way autism was diagnosed.

As I continued through graduate school, I learned more about autism diagnostic tools. I found the qualifying criteria in an educational setting intriguing. As my field experiences allowed me to participate in evaluations, I enjoyed reviewing parent feedback and comparing it to what the educators witnessed in school. I remember having the realization that behaviors can be perceived differently based on individuals and the context. The realization led to my curiosity about the way the subjectivity impacted an autism diagnosis. My curiosity urged me to

discuss the topic with my dad. My dad had been an elementary teacher for over 30 years. The school where he taught was more diverse compared to the school I worked. As I explained to him, my interest in the way autism is being evaluated in schools, I was surprised when he mentioned that the obstacle to autism diagnoses that he perceived was that parents either did not understand what autism was or did not believe that autism was a real disorder. While I was aware of documented confusion and changing opinions surrounding autism, I had not previously heard about denial of the disorder. My dad continued to explain that he currently had a student who received an initial autism diagnosis in second grade. The family of the student recently moved to Minnesota from Somalia. This was the first they had heard about the term "autism". The family appeared surprised and upset. The student had high needs and easily qualified under the educational autism criteria. Regardless, the family was convinced their son did not have the same needs in their home country. Therefore, the family decided to move back to Somalia. The mother explained to the school that her son "just needs to play in the dirt and he'll be okay". As I first heard this story, I was shocked. But as my experience in education has grown, so too has my experience hearing similar stories.

The story from my dad opened my eyes to the way people in different cultures perceive disability. I began to learn more about the importance of understanding cultural contexts in education through my graduate classes. Additionally, my first teaching job was at a school having a predominantly Somali population. As part of training, I was required to participate in culturally responsive teaching (CRT) modules. During the CRT modules, I learned more about why it is important to understand the culture of my students. The instructor stressed that understanding cultural background is important to build relationships, not only with the



student, but also with their family. To demonstrate this point, the instructor explained that in the Somali language, there is no word for “autism”. In fact, the instructor reported that many Somali immigrants in North America call autism “The Western Disease”. Hearing this not only reminded me of the story my dad told me, but also sparked my memory of a previous study I read about the rising number of autism diagnoses in the Somalian immigrant population. Knowing that there was research surrounding autism and specific cultures continued to pique my interest in the topic.

Halfway through my first teaching job, I had an experience that turned my curiosity about the topic into discovering the topic I wanted to research for my thesis. One student on my caseload came from a Somali background. He was an extremely bright and high functioning student who arrived with an autism diagnosis. I spoke with his mother a few times early in the school year, but she did not attend our open house or parent-teacher conferences so I had never met her in person. In early December, the student slipped when playing at recess and chipped his front tooth. The school nurse called his mom. When the mom arrived to school, she was furious about the situation. She met with the principal and me and said that her son should not be able to go to recess and that we needed to put him in a padded room instead. The mother repeated that “he is not right in the head” and “that I am so sick of having a disabled child”. I left the meeting shocked. Not only were the words spoken sad, they were also untrue. I wondered if the mother understood how intelligent and independent her son was. The school social worker met with me and as I shared the experience with her, she explained that she had seen similar reactions from a lot of parents who have different cultural backgrounds. The social worker noted that often families are told their child has autism without further explanation

about what it means. Not only is autism often a foreign or misunderstood term, but the families are also not given support or guidance once the diagnosis is received. The explanation provided by the social worker helped my experience make more sense. It helped me consider how confusing the diagnostic process can be for a family from a different culture or a family who speaks English as a second language. I became curious about whether immigrant families, and even American families, truly understood what an autism diagnosis means for the child. Since then, I wanted to learn about the way autism is diagnosed and perceived in diverse cultures. The fact that a lot of the autism diagnostic criteria is based on social expectations of Western culture also made me wonder about the impact on the diagnostic process in other cultures. For example, in some cultures eye contact is a sign of disrespect, whereas in the United States, eye contact is an expected social behavior. Since the autism diagnostic criteria includes evaluation of social behaviors, is the diagnostic evaluation tools accurate when used outside of the culture of origin? This question contributed to my growing interest in the topic of autism diagnosis and perceptions across cultures.

Additionally, I wondered about the way the education systems in other countries served students with autism. With knowledge about autism and the autism diagnostic process evolving, I wondered if the education systems also evolved with new knowledge. Education systems are different nation to nation and I wanted to know how those differences impacted the supports provided for individuals with autism. These curiosities led me to this literature review to answer my questions about what does autism look like across the globe?

## **Chapter II: Literature Review**

### **Literature Search Procedures**

To find the literature and information for this thesis, searches of EBSCOhost were conducted for studies published from 2010-2023. The key words that were used in these searches included "autism in Europe", "autism in Greece", "autism in Australia", "autism in Asia", "ASD prevalence in Europe" "autism in Spain" "autism characteristics", "autism in Africa" "autism in Mexico", "cultural differences in autism", "autism education system", "autism in Russia", "autism in immigrant populations", "autism causes", "autism diagnostic process", "autism across the globe", "autism stigma", "autism in Latin America", "autism in the Middle East", and "autism prevalence in Serbia". This chapter will review the literature on the differences in autism across the globe in six sections in the following order: Autism in North America; Autism in South America; Autism in Africa; Autism in Europe; Autism in Europe: and Autism in Australia.

#### **Autism in North America**

Esler et al. (2017) reported that with increased autism awareness in the United States, the needs of diverse families with autism have also increased. The researchers noted that the increased prevalence of autism in the United States is well documented. However, despite rising numbers of immigrants and refugees, the rates of autism among non-white children are lower than that of white children. In 2015, research reported that 13.2% of the United States population was foreign-born resulting in increased diversity. The researchers reported that 46% of immigrants were of Hispanic origins, 26% Asian, 9% black, and 15% other. In addition to immigration diversity, refugees represented a subset of immigrants in the United States. Over

the course of 10 years, the United States admitted about 85,000 refugees per year with 37% of from Africa. The researchers used these statistics to stress the needs of immigrant and refugee families who have children with autism.

Autism has heterogeneity in characteristics across individuals. It impacts all developmental areas and can co-occur with other disorders. The autism diagnosis relies partially on behavioral characteristics such as social interaction and communication. Esler et al. (2017) noted how this opens the door for culture to impact the diagnosis. However, there have been few studies conducted on this topic. The researchers referenced previous studies that found in the United States, white children had higher autism prevalence than Hispanic, black, and Asian children. Also, there was a relationship between socioeconomic status and autism prevalence. When comparing these results to the immigrant population, researchers found different results. A previous study reported that autism prevalence in Somali, Black African, and Black Caribbean was twice that of other ethnic groups. Another study found higher autism risk in children from immigrant mothers from the Caribbean and Africa. The researchers noted several other studies that found high rates of co-occurring intellectual disabilities in immigrant families. The same studies noted that the risk of autism and intellectual disability were highest when families migrated from a region with low human development index. The results beg the question of whether immigrant groups from low human resource index countries experienced more functional impairment with autism compared to other groups. To answer the question, the researcher analyzed a subset of findings from a previous study, the Minneapolis Somali Autism Spectrum Disorder Prevalence Project (MSASDPP).

The MSASDPP study focused on the prevalence of autism in children from the Somali diaspora, specifically in Minneapolis, Minnesota. The overall findings of this study showed that autism prevalence did not differ statistically from white to Somali children. Esler et al. (2017) reviewed this study and examined the differences in autism symptomatology and associated features reported. The researcher reviewed cases of 234 children with autism. Out of these participants, 51.2% were white, 22.6% were non-Somali black, 13.2% were Somali and 12.8% were Hispanic. When analyzing the patterns in individual symptoms, Somali children met the Social Interaction criterion. The researchers noted that Somali children had symptoms such as lack of spontaneous seeking for shared enjoyment, interests or achievements documented in their diagnoses compared to white and Hispanic children. The lack of varied, spontaneous play or social imitative play was also documented more for Somali children than white, Hispanic, and non-Somali black. White children were more frequently noted for restricted/repetitive behaviors compared to Hispanic children. Preoccupation with parts of objects was documented most frequently in Somali children.

Esler et al. (2017) reported the most significant difference found in the analysis was that 100% of Somali children with cognitive data in their files had IQ scores in the intellectual disability range, compared to just 32.6% of the remaining sample. The researchers noted that this result called for further investigation into causal mechanisms and risk factors for autistic, Somali children. While this study did not seek to answer that question, the researchers did offer some hypotheses to why Somali children had a higher frequency of autism with intellectual disability. Cultural bias in assessments, language barriers, and lack of cultural knowledge could have impacted the results. The researchers also referenced the fact that cultural beliefs may

have affected the referral patterns. They went on to explain how cultural beliefs impacted the level and type of behaviors that families reported as concerning.

Overall, the results of Esler et al. (2017) study proved that children of immigrants and refugees from low human resource index countries, such as Somali children, were diagnosed with autism and co-occurring disabilities more than any other group. While this study did not aim to explain why this was the case, it demonstrated the importance of better understanding the Somali diaspora and how to implement interventions that target the needs of autism and intellectual disability.

Shepherd & Waddell (2015) reported that discussion of autism policy was a hot topic in Canada. Since the 1990s, parents of children with autism and provincial policymakers continue to debate autism policy, including funding for early autism interventions. In Alberta, the courts set a precedent that services for those with developmental disabilities also included those with autism. The researchers discussed an important case known as the Auton case. In this court case, the Auton family sought early intensive behavioral intervention (EIBI) funding for preschool children in British Columbia. The case made its way to the Supreme Court of Canada where the family stated the lack of funding for EIBI violated the *Canada Health Act* and the *Canadian Charter of Rights and Freedoms*. However, the Supreme Court dismissed the case. When the Supreme Court dismissed the case, they stated that children with autism had equal access to healthcare services, which then gave provincial governments the power over health funding.

Despite the Supreme court ruling, Shepherd & Waddell (2015) noted that most provinces increased autism services funding. However, due to Canada being a federalist nation,

each province used their own approach. This meant that early intervention services varied across the country. The researchers explained that in Nova Scotia and Ontario public intervention services were available for preschool children with autism. But in British Columbia and Alberta, individualized funding was provided to families to use for private interventions. Despite the variety of services, most Canadian children with autism receive some sort of early intervention. However, parents of children with autism continue to advocate for national autism policy.

The researcher noted that rising autism prevalence rates are well documented (Shepherd & Waddell, 2015). With rising cases of autism comes an increased number of families expected to bear the burden of care costs. The researchers explained that this combination created high expectations for public services for autistic children. Therefore, the goal of this study was to understand what is causing the conflict between families and government and to determine the basis for improving services for children with autism.

The Shepherd & Waddell (2015) results delineated five overarching categories. The first category explained the implications of litigation. When they asked participants to reflect upon court cases, such as the Auton case, none of the parents responded that they were fully satisfied with the outcomes. They noted that access to services, while better, needed improvement. Long waitlists were the main complaint in provinces with public-provided services and parent burden was the main complaint in provinces with individualized funding in private services. The researchers also noted how the lack of guaranteed government funding raised concern among families.

The second category found by the Shepherd & Waddell (2015) analysis was Parents in The Lurch. Many parents in the study noted their first encounter with autism arrived with panic. They reported hearing about the importance of early intervention, but with no guidance about where to start the process. This led to parent disagreement about whether autism was curable with early intervention. The researchers noted the impact autism had on these families. Between finances, relationships, and stress, families reported feeling the impact of the autism diagnosis. Because of this, parents felt strongly about advocating for their child and other children who had needs due to autism.

Shepherd & Waddell (2015) defined the third category as Policymakers in The Crucible. Policymakers reported feeling surprised by the intensity of the public debate on autism policy. However, they also noted the admirable efforts of parent advocates. The Policymakers also explained that they felt their treatment programs were fair and an accomplishment. The fourth category was researchers in The Mix. Researchers reported feeling empathy for children with autism and their families. Through their clinical studies, they found several families that the system failed. They also noted how this has led to their collaboration with policymakers to develop appropriate intervention programs.

The fifth category was Children in The Balance. While conflict between policymakers and parents was intense, both sides wanted increased collaboration. They noted how it was the children who suffered from the conflict. Supporting children with autism is the goal of both sides. This support includes addressing geographic and socioeconomic inequities, comprehensive services, and transition services.



Overall, the findings in this study showed that parents of children with autism influenced policymaking in Canada. Despite the burdens the families carry, Shepherd & Waddell (2015) noted their desire to impact policy. While the researchers reflected upon parental influence, they also noted the importance of future research surrounding autism policy.

Saroukhani et al. (2020) reported that parents could recognize autism symptoms during early infancy and throughout childhood. While the symptoms have lifelong implications, the impact varies from individual to individual. Some individuals with autism can live independently, while others need long-term care. Despite a large body of research on autism prevalence across the globe, in countries such as Jamaica, the etiology of autism is not well understood or researched. Researchers believe genetic and environmental factors are connected to autism. Therefore, Saroukhani et al. (2022) explained that exposures during the perinatal period may relate to neurodevelopmental disorders such as autism.

The researchers noted previous studies that explored how cesarean delivery and perinatal factors were related to autism diagnoses. From these studies, it was found that perinatal complications increased the risk of fetal and neonatal hypoxia and over-activation of dopamine, both suspected for negatively impacting brain development and autistic behaviors. Furthermore, previous research suggested children with autism were more likely to be born through cesarean section compared to typically developing children. However, researchers noted this was only found in emergency cesarean deliveries (Saroukhani et al., 2020).

Developed countries are responsible for most of the research surrounding the association of perinatal factors and autism. Therefore, a gap of research exists in low- and middle-income countries. Saroukhani et al. (2020) described Jamaica as having an upper middle

income, with a vulnerable and slow growing economy. Researchers reported a limited number of specialty care options for individuals with autism in Jamaica. Lack of infrastructure and documentation necessary for epidemiological studies hindered researchers' ability to conduct autism prevalence studies. According to Saroukhani et al. (2020), the Child and Family Clinic at the University of Hospital of the West Indies (UWI) developed the only database to keep record of autism in Jamaica. Through use of the UWI database, previous studies documented increased maternal and paternal age, as well as exposures to fever, infection, physical trauma, and oil-based paints as connections to autism in Jamaica. However, research regarding the relationship between perinatal factors and autism in Jamaica is lacking. Therefore, Saroukhani et al. (2020) sought to evaluate a potential connection between cesarean delivery and suboptimal characteristics at birth with autism in Jamaican children.

Saroukhani et al. (2020) described Jamaica's health system as government-based. National health insurance coverage does not exist; however, the public health system is free of cost. Access to child care services, as well as the immunization rate for young children is high. Researchers reported that most children accessed public clinics or private family doctors. If developmental concerns are raised during child visits, the family is sent to the public hospital, which provides general pediatric services. The researchers reported that facilities capable of providing appropriate assessment and support for autistic children are limited and only located in Kingston, Jamaica's capital city. Saroukhani et al. (2020) also stated there were two developmental pediatricians in Jamaica who evaluated children using standard diagnostic tools.

Researchers compared the sociodemographic characteristics of children with autism and typically developing children. Saroukhani et al. (2020) reported that 94% of participants and

their parents were Afro-Caribbean. A higher number of autism respondents had a parent over the age of 35 compared to typically developing peers. Additionally, researchers found that children with autism had 79% higher odds of being born via cesarean section than typically developing children. The Kingston Parish, which serves mainly urban residents, reported a cesarean delivery of an autistic child was 2.30 times more likely than for a typically developing child. However, other parishes with more rural residents reported no connection between autism and cesarean delivery. Saroukhani et al. (2020) found no association between low birth weight or preterm birth and autism.

Overall, Saroukhani et al. (2020) found that a child's parish impacted the association between autism and cesarean delivery in Jamaica. The researchers reported that while the study resulted in significant findings, further research was necessary to understand the implications of perinatal characteristics related to autism.

González-Cortés et al. (2019) reported that the prevalence of autism has received increased attention over the last decade as rates have drastically increased. Individual countries have conducted studies to discover autism rates. The researchers noted a study in Mexico that estimated the prevalence of autism to be 1 in 115. However, they also reported difficulty finding this data due to the variety of autism symptoms, the lack of biological markers to aid in diagnoses, and changes in diagnostic criteria. In addition, autism impacts all areas of development such as language deficiencies, behavioral and psychological conditions including aggression, attention deficit, hyperactivity, and anxiety. The researchers also reported atypical sensory performance as an autism characteristic. The wide variety of symptoms requires substantial time and clinical judgement for diagnosis.

Not only are the symptoms of autism wide-ranging, but so too are the severity of the symptoms. González-Cortés et al. (2019) noted that an individual with autism can experience mild to profound deficiencies in everyday life. Therefore, the severity classification of autism is based on levels of support needed. The researchers explained the DSM-V classified autism severity into three levels. Individuals who need support in some areas are in Level 1. In Level 2, the individual requires substantial support and in Level 3 the individual requires a significant increment of substantial support. The researchers also stressed that symptom severity can regress, advance, or remain stagnant depending on the level of intervention provided. Due to the dynamic nature of autism, it is vital for early identification. The researchers noted there was little research exploring differences in behavioral characteristics of autism for different populations. Furthermore, in Mexico, there was no data that described the status of autism in accordance to the DSM-V. Therefore, the purpose of this study was to report the main characteristics of autism in Mexico.

González-Cortés et al. (2019) completed a descriptive study which investigated 203 children diagnosed with autism in Mexico. The first stage of diagnosis included a rigorous interview with the child's guardians. This interview provided reliable information about the child's characteristics and behaviors. It also included an observation of the child's behavior during the interview. The Department of Neuropsychology conducted the second stage of the evaluation. They evaluated cognitive, linguistic, and executive and behavioral functions characteristic of autism. The researchers then integrated the medical record with the clinical evaluation.

The results of the study showed the average age of participant to be 5.52 years, which aligned with previous research that found 55.5% of children in Mexico received a diagnosis from ages three to five. In regards to symptom severity, Level 2 classification included 47.78% of the participants, while 35.96% were in Level 1 and 16.26% in Level 3. The researchers also noted that one in four of the participants were medicated. Children in Level 2 and 3 were medicated in greater proportion than Level 1 participants (González-Cortés et al., 2019).

González-Cortés et al. (2019) found a correlation between age of diagnosis and symptom severity. They reported finding that the more severe the autism symptoms presented, the earlier they received a diagnosis. The average age of diagnosis in the Level 1 category was 6.44 years. In Level 2, the average age of diagnosis was 5.05 years and in Level 3 was 4.85 years. Regardless of which level of severity the participants fell into, all presented core signs of autism. The researchers found that social communication impairments were more common in Level 3 compared to Level 1 and 2. Level 3 participants also had a harder time recognizing the emotions of others. Additionally, the participants in Level 3 avoided physical contact more than those in the other two Levels. Lastly, the population studied by the researchers showed an inverse relationship between IQ and the level of autism severity. The highest proportion of children with a normal IQ were in the Level 1 group, whereas Level 3 showed 77.77% of children had some sort of intellectual disability. Therefore, the researchers concluded that the severity of autism symptoms was related to the individual IQ.

Overall, the findings in this study discussed the severity of symptoms seen in autistic individuals in Mexico. González-Cortés et al. (2019) explained the importance of documenting the prevalence and severity of autism for public systems to prepare for their responsibilities. As

the researchers noted, little research regarding autism symptoms in Mexico existed. Therefore, they suggested further investigation surrounding autism and diagnostic processes.

Obeid et al. (2015) reported that while autism prevalence rates have been rising, the topic remains largely absent in low-income countries. Therefore, the services needed to support individuals with autism and to inform the public are not implemented the same across the globe. The researchers emphasized the need for culturally relevant autism services. To develop these services, the researchers suggested more cross-cultural research, including the low-income countries.

This current study investigates the perceptions of autism in Lebanon and the United States. Obeid et al. (2015) noted that Lebanon has limited supports for individuals with autism, whereas the United States has more supports for individuals with autism, even though the services do not reach individuals equally. To investigate these perceptions, the researchers studied knowledge of autism and the stigma that surrounds an autism diagnosis in each country.

Obeid et al. (2015) noted that previous studies have shown there are misconceptions and stigma about autism across the globe. The previous studies reported lack of knowledge of core autism symptoms, lack of knowledge on how to support individuals with autism, and misconceptions about etiology. The lack of accurate knowledge about autism contributed to stigma of people with autism. The researchers defined stigma as attributes that do not fit into society norms, which results in a spoiled social identity for those possessing the attributes. The individuals who experienced stigma often also experienced poor self-esteem. Previous studies reported those with autism often experienced social exclusion and bullying due to perceived

and experienced stigma. Stigma towards individuals with autism was reported by people in the United States, as well as across the globe. The researchers noted that accurate knowledge of autism often corresponds with lower stigma. Another goal of this study was to investigate if online training improved understanding of autism in countries with varying levels of support.

The amount of research on autism varied greatly among countries. For example, in Arab countries only 75 total articles regarding autism were published between the years of 1992 and 2012. Whereas the United States published 1040 autism research articles in just one year. Obeid et al. (2015) noted that the autism prevalence in Arab countries is lower than the global average. They explained this could be due to the fact than many autism cases in Arab countries are unidentified because of the lack of trained professionals and public knowledge about autism. To prove this point, the researchers referenced a previous study conducted in the United Arab Emirates. In this study, none of the preschoolers that the researchers identified as autistic had previously received an autism diagnosis. This could have been because Arab countries infrequently provided high quality, government-based, autism-specific education services. Adults with autism have an especially difficult time finding appropriate services. The researchers explained that the lack of formal support not only caused individuals with autism to experience heightened exclusion in education, but also forced families to rely on informal supports. The lack of autism knowledge and support in some countries, calls for a need to examine stigma of autism in Arab countries.

In this study, Obeid et al. (2015) examined the knowledge of autism in Lebanon. Lebanon is a small country in the Middle East and is multilingual and multicultural. The researchers noted that Lebanon has a collectivistic culture, which means they value group

norms more than personal goals or interdependence. Additionally, the researchers found that it was rare for middle or low-income countries to have government-supported services for those with autism. This aligns with reports that autism-specific schools in Lebanon do not have training on evidence-based practices. The lack of services for individuals with autism in Lebanon may impact the stigma associated with autism in the country. The researchers reported high levels of stress a financial burden experienced by families of an individual with autism. This could be due to the negative attitudes towards disabilities in Lebanon that lead to stigma.

Obeid et al. (2015) also evaluated the conceptions of autism in the United States. The researchers noted the drastic difference in autism research and well-funded organizations in the United States compared to Lebanon. The Individuals with Disabilities Education Act (IDEA), mandates the government to provide services to all children with disabilities, including autism. However, the researchers pointed out that the United States had a disparity in access to support for those of lower socioeconomic status and for adults with autism. Organizations often emphasize awareness of autism among young children, not adults. This leads to a misconception that autism is primarily a childhood disorder.

Compared to Lebanon, the United States has an abundance of autism resources. However, Obeid et al. (2015) noted that misconceptions and stigma still exist. They referenced previous research that found school-age children demonstrated more negative attitudes and behaviors towards children with autism than towards typically developing children. A survey of adults also showed misconceptions about autism diagnosis and treatment. Healthcare providers also showed inaccurate knowledge of autism symptoms.



In this study, Obeid et al. (2015) found that overall, knowledge of autism was higher and stigma was lower in the United States compared to Lebanon. However, researchers also found that some aspects of autism were better understood in Lebanon. Women in both Lebanon and the United States reported endorsing lower stigma towards those with autism compared to males from either country. The researchers documented that knowledge of autism was lower in countries with reduced autism services. Interestingly, this study showed that misconceptions about autism were more common in the United States compared to in Lebanon. The findings of this study showed that autism information was unequally distributed internationally. The researchers noted that this study also showed that different cultures have unique perspectives of autism. They suggested further investigation into online training for autism services to help reduce misconceptions and increase support.

### **Autism in South America**

Paula et al. (2020) reported about six million individuals with autism live in Latin America. Brazil, Argentina, Chile, Uruguay, Venezuela, and the Dominican Republic committed to working together to gain a better understanding of autism in the region. In the current study, researchers from these countries collaborated to explore the challenges, barriers to care, and stigma experienced by families of individuals with autism. Researchers surveyed 2,942 caregivers to explore the topic.

Previous research revealed that individuals with autism living in high income countries had the most unmet needs in regards to treatment and support compared to individuals with other disabilities. Stigma and lack of infrastructure represented barriers for autistic individuals from high income countries. However, Paula et al. (2020) noted that in low- and middle-income

countries public policies for individuals with autism was a significant barrier. Research investigating the cost of services, as well as the experienced stigma in low- and middle-income countries does not exist. However, the researchers noted the importance of learning the priorities and challenges from individuals with autism across the globe.

Paula et al. (2020) explained that Latin America was lacking in public policy for autism, however, many Latin American countries sought to provide universal health coverage. In turn, access to care has improved in Latin America. Researchers reported that although the region still lacked in support for individuals with autism, progress was visible. For example, questionnaires and screening tools for autism were recently translated into appropriate languages and validated in some of the Latin American countries. The rights of individuals with autism have also improved in recent years. In 2012, the Ministry of Health and Social Development in Brazil recognized autism as a disability. Similarly, the same decision was made in Chile just two years prior. Lastly, autism research in the region was strengthened when the Red Espectro Autista Latinoamerica (REAL) was formed. REAL included researchers from six of the 37 Latin American countries. The current study was the first collaborative work completed by REAL. The goal was to detect the primary challenges and priorities for individuals with autism in the region; identify barriers to accessing care; and to describe the stigma and financial burdens of families with an autistic individual in Latin America (Paula et al., 2020).

The findings of the study showed most families accessed private health systems. The Brazilian respondents had the oldest average age, while the Venezuelan respondents were youngest. Individuals with autism from Brazil and the Dominican Republic were less verbal compared to individuals from other studied countries. Individuals from the Dominican Republic

accessed the private sector more than other countries. The researchers reported communication difficulties, social interaction deficits, and adequate education as the caregivers' main concerns. Caregivers also listed greater community awareness and improvements in the education system as their priorities (Paula et al., 2020).

Paula et al. (2020) reported 80.7% of participants received some sort of service in their lifetime. Speech and Language Therapy was the most used service, followed by occupational and behavior therapy. However, families reported higher levels of satisfaction with behavior and occupational therapy compared to speech therapy. The researchers also reported about barriers to receiving treatment. Long waiting lists were the most frequently reported barrier. High costs and lack of available services followed as additional barriers to care. Respondents from Brazil reported the highest levels of dissatisfaction with autism information provided to them. When analyzing responses regarding stigma, researchers found feelings of helplessness for having a child with autism and feeling discriminated against were highest in Brazil and lowest in Venezuela. The financial impact of autism was significant across the six countries. Half of respondents reported experiencing financial problems, with the highest percentages coming from the Dominican Republic.

Overall, the results of the current study aligned with results from other cultures and countries. However, Paula et al. (2020) noted the challenges described in the study were different than challenges found in high income countries. The researchers stated that despite the differences, all the challenges were related to adaptability, acceptability, and the demands of everyday life for individuals with autism. Additionally, frustration over the education system appeared to be a global frustration. Researchers explained the importance of awareness for

policymakers from Latin America. Community awareness of autism was listed as the main priority in Latin America, which was different than the priority in high income countries, this suggests less autism awareness in Latin American countries compared to high income countries. Regardless, the findings from this study expanded the knowledge regarding autism in Latin America.

Nunes & Walter (2020) reported that the prevalence of autism in developed countries, such as the United States, is 1.42% of the population. Whereas, in developing countries, such as Brazil, the prevalence of autism is closer to .3% of the population. Regardless of the epidemiological data, professionals agreed that the prevalence of autism increased globally. Additionally, researchers failed to find evidence supporting the claim that autism characteristics varied depending on cultural, ethnic, or racial groups. Core autism characteristics, such as lack of functional speech or communication skills are universal, as are the interventions used to improve these skills. Augmentative and Alternative Communication (AAC) is an internationally respected and proven intervention. The researchers noted several global studies that included descriptive reviews and meta-analytic investigations, however, they mentioned that such studies were lacking in Brazil. Therefore, the goal of this article was for the researchers to create a descriptive summary of the studies targeting AAC for individuals with autism in Brazil.

The researchers conducted a literature review on AAC use in Brazil. Nunes & Walter (2020) explained the results of their study will help guide future research for AAC and autism in Brazil. The researchers reviewed 19 studies. Of the 19 studies, eight focused on the use of Picture Exchange Communication Systems (PECS) or the Brazilian adaptation of PECS. The researchers discovered that there was a mix of results regarding the generalizability of PECS

across settings and social partners. However, social skills gains and reduction in behaviors also existed in the literature.

One of the literature findings proved that an Adapted-PECS can be generalized when the instructors or partners are professionally trained. Nunes & Walter (2020) highlighted a study conducted in a Brazilian school. The educators in the study reported feeling unequipped and unaware of how to communicate with their students with autism. They also reported not knowing what interventions to implement. In this study, the educators attended a course about how to use AAC and later deemed this intervention viable. The study outcomes highlighted the level of training Brazilian teachers received. As the researchers noted, the educators lacked skills needed to sustain interactions with autistic individuals.

Nunes & Walter (2020) discussed the lack of appropriate teacher and paraprofessional training in Brazil. Many educators had limited knowledge about working with autistic students despite the adopted Inclusive Paradigm. The researchers noted that Brazil has only two public universities with special education undergraduate programs. This creates an education field full of educators unequipped to teach students with autism and other disabilities. The researchers reviewed a survey completed by general and special education teachers. The results of the survey showed the teachers had little training and could not meet the needs of students with autism, specifically the communication demands. Alarming, the researchers found only one educator was knowledgeable in the field of AAC. According to the researchers, the results aligned with studies in the United States.

Most of the studies reviewed by Nunes & Walter (2020) discussed the use of low-tech communication systems. There were, however, a few studies that investigated the use of high-

tech devices. Three studies included SCALA, which is a Brazilian AAC software that stands for System of Alternative Communication for Literacy Learning for Individuals with Autism. The studies including this technology also used other low-tech in addition to the SCALA. They found that the ACC systems increased the development of gestures, peer interaction and participation for the students with autism. The researchers reported that parents of students with autism favored the low-tech systems, as they cited, because they were easier to implement in the home.

Nunes & Walter (2020) noted that investigations of Brazilian AAC usage found adults who assisted students with autism used less experimental rigor compared to similar studies from developed countries. North American and European studies used more reversal designs and robust approaches. The researchers reported that in the studies they reviewed, only a few mentioned the severity of the autism symptoms. They explained how this lack of a clear diagnoses could be due to the lack of qualified evaluation tools and professionals to complete evaluations. In Brazil, the average child with autism does not receive a diagnosis until after the age of four. The researchers emphasized the importance of developing assessment protocols for autism, as well as training for health professionals and teachers.

Lopez-Espejo et al. (2021) defined autism as a neurological developmental disorder, which persists throughout life. Affected children typically show symptoms before the age of two. However, researchers noted less than 50% received a diagnosis before the age of four. Previous studies showed the importance that early intervention has on quality of life. Health-related quality of life (HRQOL) is a concept that measures ones physical, mental, emotional, and social functioning. When an individual is unable, or too young to self-report their HRQOL,

researchers use the Pediatric Quality of Life Inventory (PedsQL). Caregivers or parents complete the PedsQL to report the autistic child's quality of life. Understanding quality of life also illuminates the impact autism has on the family. The researchers noted HRQOL had not been investigated in South America. Lopez-Espejo et al. (2021) sought to learn the HRQOL of autistic, preschool-aged children in Chile, South America.

To achieve the purpose of the study, Lopez-Espejo et al. (2021) used results from the PedsQL. Researchers selected autistic children who attended a treatment program at the Unit of Neurology, Division of Pediatrics School of Medicine, Pontifical Catholic University of Chile for assessment. All participants had an autism diagnosis according to DSM-5 criteria and were five years or younger. Of the participants, 72 were boys and 21 were girls. The researchers noted 13 participants resided in rural areas. Two domains of HRQOL, physical and psychosocial health, were assessed through the Spanish version of PedsQL. The psychosocial domain score was the mean score of emotional, social, and school functioning items.

Lopez-Espejo et al. (2021) reported 38.7% of participants were diagnosed before the age of four. Most parents reported noticing autism symptoms between 12 and 18 months, with only five parents noticing symptoms before 12 months. The researchers found language regression in 20 of the participants ages 12 to 30 months. Results showed low scores in HRQOL, suggesting how parents perceived their child's well-being. The researchers explained the scores aligned with self-reports of other children with autism. This result promoted the use of PedsQL during early childhood years to best support children with autism.

The physical health subscale for autistic children were like scores of children with chronic illness. Lopez-Espejo et al. (2021) explained that while autism alone did not impact

physical health, comorbidities, and lack of independence in activities contributed to the low score. Another finding showed the age of diagnosis correlated with lower PedsQL scores, meaning the earlier autism was diagnosed, the lower the HRQOL scores. Researchers also explained that experiencing intense autistic traits during early developmental years harmed adaptive behaviors, which led to caregiver low HRQOL perception.

Results from this study aligned with previous research on the quality of life for autistic adults. With Hispanic pediatric participants, Lopez-Espejo et al. (2021) was able to validate the PedsQL. Additionally, the findings contributed to knowledge about the well-being of autistic children in developing countries. Overall, researchers found that toddlers with autism had demonstrated impaired HRQOL.

### ***Autism in Africa***

Eze (2018) noted that while autism awareness is high in the United States and other first-class countries, this awareness has yet to spread to developing countries, especially Africa. The continent of Africa has a population of one billion people, 40% of which are children under the age of 14. As of late, communicable conditions have been the health-care focus in African countries over neurodevelopmental disorders. As the prevalence of autism has grown across the globe, Eze (2018) stated that African public health care systems should be prepared to better handle this burden. An increased understanding of the prevalence of autism in Africa needs to occur to help prepare the health care system.

In 1970, the psychiatrist, Lotter, published a study that rebuked a previous belief that autism was a culturally-bound disorder and therefore not present in some areas such as Africa. In this study, nine children in African hospitals had autism. These children were from nine



different African countries, highlighting that autism was indeed in Africa. While this study proved autism existed in Africa, current immigration studies showed the prevalence of autism in Africa may be higher than originally believed. Eze (2018) referenced a study conducted on Somalian women who migrated to Sweden. The study found that the frequency of autism in the Somalian children was three to four times higher than the children of Swedish mothers. Knowing this, the researcher acknowledged the growing need for Africa to better understand autism.

Currently, Eze (2018) reported a strong, negative stigma associated with autism in Africa. Abuse, isolation, and lack of support are a daily occurrence for individuals with autism. High levels of poverty and the lack of proper diagnosis further complicates the life of an autistic individual. The researcher also cites the lack of proper services as another example of the minimal autism awareness in Africa. Not having easy access to receiving a diagnosis and then not having proper supports if one receives a diagnosis, speaks to the lack of autism education and awareness in Africa.

In addition to there being a lack of accessible services, the stigma attached to autism in Africa serves as an even greater hindrance to the success of the autistic individual. A child receiving an autism diagnosis brings great fear and shame to the family of the individual. Eze (2018) tells the story of an African immigrant living in Canada. When in Canada, the immigrant's child received an autism diagnosis. The father showed great fear and anxiety when it came to sharing the news with other family members. The researcher notes that one needs understanding of the negative impact autism has on an African family for the father's reaction to make sense.

Eze (2018) noted how the media made it difficult for the African family to accept and live with an autism diagnosis. According to the researcher, the media only shows stories of when white, middle-class individuals receive an autism diagnosis. This led to Africans associating autism with Caucasians, Asians, and some Caribbeans. It was difficult to accept a diagnosis when they believed it was a condition that could not affect them. These beliefs continue to haunt African families that moved to Western countries. The researcher reported that while many Africans who lived in the West tried to assimilate to the new culture, many of their values and beliefs remained sympathetic to their African culture. Therefore, their native culture impacted their views on disabilities, specifically autism.

Africa has 54 countries and about 3,000 languages. Eze (2018) reported that despite this diverse continent, little was known about autism. Doctors, health care providers, and even special education teachers know little about autism and best practices for autism. The researcher pointed to themes in African culture as reason for the lack of autism knowledge. For example, traditionally, Africans believe in supernatural causes. This includes punishment from God, witchcraft, evil spirits, and curses. The researcher noted that this cultural belief impacted African understanding of autism. Families viewed an autism diagnosis as a supernatural cause. In Africa, autism is associated with bad omens that impact not only the direct family, but also the community. The cultural beliefs lead to isolation and secrecy when an individual receives an autism diagnosis. An African family admitting to having an autistic child runs the risk of being outcast and isolated from the community so the “curse” does not spread. This is what led to the negative stigma of autism and proves that about the cause and characteristics of autism is lacking in Africa.

Eze (2018) used the country of Nigeria as an example of the lack of autism awareness in Africa. Concern about rising autism cases was growing in Nigeria, however, even doctor knowledge remained low. According to the researcher, medical community members were only familiar with infantile autism symptoms. Some of the medical professionals reported they, falsely, did not believe autism was treatable, while 70% of medical professionals said they did not know where to refer cases when they were sure of an autism diagnosis. Due to this lack of awareness and support, many children in Nigeria ended up misdiagnosed or not diagnosed. Many autistic children were hidden in their home or grouped in with the deaf and mentally ill children. The researcher explained how many rural areas did not have psychiatric hospitals, therefore, much of their autistic population ended up on the street and treated as insane.

The researcher, Eze (2018) used these examples from Nigeria to highlight the differences in autism awareness from African to Western countries. The researcher pointed out that most Western education systems were based on inclusion. However, in African countries, specifically Nigeria, many schools included students with disabilities. In most Western countries, a student with autism would have a whole team of specialists working together to create a plan that best supported the student and their family. In Nigeria, there was no recognition of autism as a disability, therefore, there was no team of specialists or even schools that could support the individual. The researcher also pointed to the lack of welfare programming in Nigeria as a reason that no education services were available to autistic children. The financial burden of having specialized services belongs solely to the families, making it rare for the services to occur.

To increase the awareness of autism in Africa, Eze (2018) believed more adequate research needed to happen. There is a lack of academic research surrounding autism in Africa, which has led to misunderstandings. One barrier to increasing autism awareness is the lack of standardized tools that are culturally appropriate. Translations and adaptations of diagnostic tools, created in the west, are not culturally appropriate in Africa. Not having appropriate and relevant diagnostic tools prevents families from receiving accurate information about autism. The researcher reported an urgent need to change the provided education and the stigma about autism in Africa. An increased number of trainings, financial support, and education are needed to address this problem.

Mithimunye et al. (2018) noted that autism affects 1 in 88 children globally, with boys affected five times more than girls. As the number of autism cases grow, the prevalence of autism in South Africa is still unknown due to lack of research. The researchers referred to the organization, Autism South Africa, which predicted they would diagnosis 933 cases of autism each month. The focus of this study takes place in Western Cape Province, South Africa. In this area, researchers estimate there to be 1,684 children with an autism diagnosis. These numbers suggest the parents of individuals with autism will inevitably face challenges related to their child's educational development.

South Africa has a history of apartheid policy, which impacted the accessibility of special education. In the past, low-income children, specifically those who were black, were excluded from special needs education. White learners with disabilities had access to proper schools, while black learners with special needs went to schools that were systematically under resourced. In the post-apartheid era, South Africans acknowledged the need for change in their

education system. The researchers reported the introduction of the White Paper 6 policy. This policy places emphasis on special education and inclusion. Introduced in 2001, the White Paper 6 policy promotes education in the least restrictive manner and strives to provide proper instruction within a public setting. Despite the policy, inclusion is still lacking in some South African areas. The researchers found that in the Western Cape Province not all schools would accommodate learners with autism (Mithimunye et al., 2018).

To gain a better perspective of the state of inclusion education in South Africa, Mithimunye et al. (2018) conducted a study to discover the perceptions of parents of autistic children focused on factors that enhanced or hindered the educational needs of their children. The participants of the study came from low and middle socio-economic conditions and resided in Cape Town. Focus discussion groups provided insight for the researchers. Four themes came from the study. The first theme was about the developmental and educational awareness and support. According to the researchers, all parents agreed the development of their child was important, as was their education. However, lack of community autism awareness acted as a hindrance to those values. Developing parents, family members and community awareness of autism was a step towards supporting the development and education of an autistic child. It also prevented the labelling and stigmatizing often associated with autism. While lack of awareness was a hinderance, the parents described support groups as an enhancement.

The education system was the second theme found in the study results. The results showed that parents were unsatisfied with the education system and found it to be inadequate for serving their child's needs. Lack of school access was a major factor contributing to the inadequate schooling system. Schooling options are limited, and waitlists are long. The

researchers reported that 744 of 1,684 children in the Western Cape Province with autism are on a waiting list. This leaves many children with autism at home with nowhere to go. Of the children able to get into a school, 90% are in a special needs school, while only 10% are in a mainstream school. The researchers pointed out the lack of inclusion in the mainstream schools, as many are not sufficient for students with autism. This often forces parents to choose between private schooling or home facilitation (Mithimunye et al.,2018).

The third theme was specialized training for teachers. Mithimunye et al. (2018) reported parent concerns that teachers were underprepared to instruct students with autism. Inadequately trained teachers affect the ability to learn for children with autism. The parents noted that inadequate training not only impacted the instruction but also their beliefs and intentions surrounding working with special needs students. The researchers reported negative approaches from teachers, including aggressive behaviors, due to their lack of proper training (Mithimunye et al.,2018).

Financial needs were the final theme reported in this study. Mithimunye et al. (2018) reported private schooling, private interventions, and health care as some of the costs that impacted parents of autistic individuals. Private schooling is costly and parents often must make sacrifices to meet their child's educational and developmental needs. The researchers reported that children with autism experienced higher costs than neurotypical children due to costs associated with behavioral and communication difficulties.

Overall, this study revealed the barriers experiences by children with autism in South Africa. The researchers, Mithimunye et al., (2018) believed the insights gained in this study will help develop new intervention strategies that will contribute to inclusive education.

Baker et al. (2020) stated that while autism crosses racial and ethnic lines, previous research showed discrepancy regarding diagnoses and access to services across those lines. Since 1991, the Somali Civil War created a diaspora of Somalians. Many Somalians sought refuge in the Horn of Africa, as well as Europe and the United States. The researchers referred to previous research that suggested children born in the Somali diaspora had a greater chance of receiving an autism diagnosis, would receive the diagnosis later than other groups, and develop co-occurring disabilities. It is rare in Somalia to receive a diagnosis of autism. Because of this, many of the families who have children with this diagnosis struggle to understand the disability and the related service arena that can be difficult to navigate. Participating in their child's educational decision-making is another challenge for many Somali-American families.

Due to the rise in Somali American students with autism, special educators and Somali-American parents collaborate now more than ever. Baker et al. (2020) reported that legislation such as the Individuals with Disabilities in Education Act (IDEA) requires special educators to include family members of students in educational decision-making. However, the researchers noted how this requirement assumed that "all parents regardless of cultural background perceive disability and education-related issues similarly" (Baker et al., 2020). Due to children from diverse cultural backgrounds, the researchers stated that previous research noted that culturally and linguistically diverse families demonstrated challenges participating in Individualized Education Program (IEP) meetings due to logistical barriers. Technical terminology often fills IEP meetings, which is difficult for non-native English speakers to understand. While the law requires that interpreters are present if needed, the researchers pointed out that the conversations require a nuanced interpretation compared to a linguistic

translation. Because of the barriers experienced by many Somali-American families, the researchers sought to discover how capital influenced interactions between Somali-American mothers of an autistic student and the educational process across phases of the special education planning process.

To determine how capital impacted the understanding of special education by Somali-American families, Baker et al. (2020) used Bourdieu's capital theory as the lens for analyzing the results. Bourdieu's capital theory reveals the way families with greater economic, cultural, and social capital are at an advantage participating in the public education system. Since capital is not equally distributed, the researchers argued that immigrant families were at a disadvantage due to their limited knowledge of American educational norms. The researchers stated that this created a scenario where educational inequity was reproduced instead of interrupted.

Baker et al. (2020) conducted a qualitative case study project in a large metropolitan area in Northeastern United States. At the time of the study, about 10,000 Somali Americans lived in the area. Three families participated in the study and all lived in the same metropolitan area. One of the families lived in an affluent suburb the other two lived in different working-class communities. All the families came to America after the Somali Civil War began in 1991. To find these participants, the researchers connected with a community-based organization called the Center for Somali Advocacy.

The researchers divided the study into three time periods. The first phase was "Before the Meeting" (Baker et al., 2020). This phase studied the interactions the mothers had with the school before the IEP meeting. The first mother explained her son's school hosted events such



as dances and performances. The school encouraged family participation and even had a parent-teacher organization. Since this was not in her local school district, the mother noted that she spent about \$200 for gas every few weeks to travel to attend school events. While she noted this was a huge economic sacrifice, she explained the school valued family participation and that she wanted to build her social capital with her son's educators. The second mother reported that while her son typically rode the bus to school, she would still spend time volunteering in his classroom. This mother was highly educated and professionally connected, which provided her currency in the school setting. The researchers also reported witnessing a close relationship between this second mother and her son's teacher. They argued that this mother leveraged cultural capital to develop relationships with the educators. This in turn, provided her with more social capital during formal IEP processes. The third mother differed from the first two mothers in that she did not have much contact with her son's educators. This mother did not have a car, meaning her visits to the school were infrequent. The researchers noted that this mother even had limited interaction with the in-home service providers due to the language barrier, which was considered cultural capital. This led the researchers to conclude that families who possess and can leverage capital, have more opportunities to build relationships with educators and develop social capital.

The second phase reported in this study was the IEP meeting. The IEP meeting with the mother from the affluent suburb illustrated many best practices. First, the meeting leader provided an outline of the meeting agenda to all members. Second, name tents were positioned at each seat so that participants could use names instead of titles. Lastly, the meeting leader told personal stories about the student, which made the meeting more

intimate. The researchers argued that these best practices provided the mother an opportunity to leverage her capital to participate in the decision made during the meeting. On the other hand, during the third mother's IEP meeting, the best practices were absent. Topics such as funding for residential placement were on the agenda for this meeting, that educators scheduled for just one hour. The researchers reported this lack of time led to a quick-paced meeting, which left the mother excluded from the conversation and had limited time to make decisions. Observations noted that team members turned to the mother and explained that these were "just business discussions", which again excluded her from participating. The researchers concluded that this mother lost some of the authority she had due to her lack of knowledge and the language barrier in this certain situation (Baker et al., 2020).

The last phase studied by Baker et al. (2020) was the post-meeting decision. IDEA created guidelines for the process of how the IEP gets signed, however, there was some room allotted for schools to create their own practices. The first school discussed, reported that the educators suggested that the mother take the draft home to review on her own before signing it. Whereas, the third mother's school encouraged her to sign the IEP during the meeting. The researchers attributed the difference in the finalization process to the families in the district. They reported that affluent districts, such as the first mother's school, had highly educated families who understood the legal aspects of the IEP process, which the researchers labeled as cultural capital. In addition, the families had resources (economic capital) and networks (social capital) that helped them advocate for their child. In conclusion, the researchers noted that the mothers' experiences highlighted the effect capital had on a child's educational placement and the family's ability to participate in the educational decision-making process.

**Autism in Europe.** Kossyvaki (2021) noted that in the 21<sup>st</sup> century in Greece, the perception of autism has changed. The data on the exact number of people with autism in this country is unknown. In the early 2000s, autism was widely unknown in Greece. Special classes formed in mainstream schools in 1985. However, it was not until 2000 that the first public school for autistic children opened. Currently, five school options are available for autistic individuals. Students can attend mainstream schools, inclusion classes within a mainstream school, generic special schools, autism specific special schools, or home schooling. Despite these choices, Kossyvaki (2021) reported that many children with autism did not access an appropriate education. An economic crisis beginning in 2009 also impacted the educational system, including the field of Special Education Needs and Disabilities (SEND). The economic crisis not only impacted the field of SEND, but also teaching methods for autistic individuals (Kossyvaki, 2021).

Kossyvaki (2021) reviewed the state of autism education in Greece and divided the findings into four themes. The first theme described was the autistic individual. This theme referenced the voice of autistic individuals along with intervention strategies. While it is common for autistic people to participate in research, this was not happening in Greece. Greek scholars have noted the importance of including the opinions of individuals with SEND in research, but few had done so. One reason suggested for this lack of involvement reflected the stigma surrounding individuals with autism. Researchers have found that parents of children with autism were hesitant to allow their children to participate in research, as participating in research may cause the children to become aware of their autism diagnosis. Adult individuals with autism have also reported reluctance to participate in research due to the lack of

understanding and acceptance of autism in Greece. This lack of understanding and acceptance contradicts what happens in other European countries.

The second theme to emerge in Kossyvaki's (2021) literature review was the family around the autistic individual. In Greece, not much research includes the parents of children with autism. The Greek culture places value on the role of the extended family in raising a child, which created the need for more family training in autism. The entire family surrounding the autistic individual is impacted by the stigma that the Greek culture places on autism. In Greece, autism is viewed as a tragedy or misfortune. Parents may feel judged and helpless. It is common for parents of autistic individuals to keep the diagnosis a secret in their work environment. This stigmatization of autism in Greece is also seen in the field of education. Teachers reported their belief that classroom peers should not be told about the presence of an autistic peer so that stigmatization can be avoided. Parents would withhold their child's autism diagnosis from the school or purposefully delay seeking a diagnosis to protect the child from the stigmatization that exists in Greek education and society.

The role of teachers was the third theme found in the Kossyvaki (2021) research. A need for more specialized training in SEND was evident in a study that showed how Greek teachers viewed autism and that their knowledge of core ASD characteristics was incorrect and outdated. The gaps in knowledge were visible for special education teachers as well. Greek special education teachers reported moderate levels of stress. However, those with more training in autism reported less stress than those without. Researchers also believed that the economic crisis of 2009 impacted teacher stress levels in Greece. The number of teachers and

teacher salaries significantly decreased. Greek teacher salaries are lower than teachers in other European countries, which could be a contributing factor to teacher stress levels.

The final theme of the Kossyvaki (2021) research was the impact of autism on the wider society. Part of this theme included parent-teacher collaboration. Greek parents reported a lack of satisfaction based on research supporting the importance of this collaboration for educating autistic children. The medical/deficit model of disability also contributed to beliefs in the wider society. Research shows that the medical model guides teaching and treatment of autistic individuals in the school setting. This means that rather than accommodating individual needs or placing value on the individual or family opinion, society valued medical professional opinions above others. Kossyvaki (2021) investigated inclusion in regards to the wider society. Greek schools did not apply the concept of inclusion. Rather, spatial integration more accurately described Greek schools. Greek teachers reported a positive attitude towards the idea of inclusion; however, they felt ill-prepared to include children with autism in their classroom. Greek general education teachers also reported that children with autism were the most challenging to manage and that special schools would be a more appropriate setting. In this setting, they could learn social skills, rather than academic curriculum. Parents of neuro-typical children also showed some resistance related to inclusion. The parents expressed concern that their own child may mimic the inappropriate behaviors demonstrated by children with autism. While researchers reported positive attitudes about inclusion in Greece, the implementation was lacking and contributed to the stigma surrounding autism in the country.

Overall, autism is still a developing construct in Greece. Factors other than the needs of the child impact education and participation in Greek society for individuals with autism. The social stigma in Greece significantly impacts the daily lives of autistic individuals.

Researchers Loukisas and Papoudi (2016) acknowledged autism has an impact on more than just the individual receiving the diagnosis. Autism also affects the family of the diagnosed individual. The autistic family is impacted by several factors that dictate their well-being. Loukisas and Papoudi (2016) used a qualitative approach to review public blogs from five mothers of autistic children. All five mothers were from and live in Greece. As Loukisas and Papoudi (2016) pointed out, to better understand autism, it is important to listen to worldwide voices. The mothers' blogs discussed similar topics and broke the topics into three themes; the child's diagnosis, the education system, and the social stigma that they have experienced.

The mothers' perspective of receiving the autism diagnosis was the first theme discussed. The blogs viewed the disorder primarily from a developmental perspective, which shifted the focus from the challenges the disability to the development of functional skills that could benefit the child in the future. To achieve this perspective, the blogs discussed the process of receiving the autism diagnosis and the emotional roller-coaster that accompanied that process. Mothers described the beginning of the diagnostic process as painful. They grieved the loss of a "normal" life. From there, they moved to a phase of sadness and shock. However, Loukisas and Papoudi (2016) insisted this was not the phase that the mothers reported as permanent.

The research also described the diagnostic process as expensive, time-consuming, and demanding. The blogs indicated that frustration and a loss of time resulted in a harmful cost to

the individual. The grueling diagnostic process prevented early interventions and provision of education that was crucial for the development of functional skills. The delay in diagnosis also created more financial stress on the families. The mothers from the blogs blamed the late diagnosis on the organized institutional framework for autism in Greece. The blogs called for early autism screening for all children in Greece, something that has yet to be established. Due to the lack of screening and early intervention services in Greece, Loukisas and Papoudi (2016) explained that mothers of those with autism were required to serve not only as the parent, but also the therapists. To play this role successfully, mothers understood they needed to be well-informed about autism and problem-solving skills. One mother summarized the situation best by saying, "I need to learn the rules of his autism world" (Loukisas and Papoudi, 2016).

The second theme discussed in this study was the mothers' experience with the education system. The blogs reported a great concern in the operation of the schooling system, the political impact on education, and the attitudes and culture of the educational systems (Loukisas and Papoudi, 2016). All the mothers commonly expressed the lack of appropriate educational settings for individuals with autism in Greece. Due to a lack of staffing and the structure of public Greek schools, many individuals with autism either did not receive an education or required costly private services. The Greek National Insurance Service only covered a small portion of the private services; once again placing a large financial burden on families with autistic children. The rejection of autistic students from public education has become the norm in Greek schools. The rejection underlies the entire educational system and is seen through the lack of implementing special education laws. Knowing this, the mothers were concerned for their child's future.

Due to the lack of educational options for children with autism in Greece, the blogs reported high levels of concern about children's ability to learn skills that would help them with future employment, health care and independence. Minimal provisions for autistic adult services in Greece, which speaks to the social stigma and lack of educational opportunities. One of the mothers visited an institution and referred to them as "dumping grounds for forgotten people" (Loukisas and Papoudi, 2016). In Greece, the lack of educational opportunities and the cultural stigma that autism carries are main the main stressor for autistic families.

The third and final theme refers to the social environment and struggle against discrimination for autistic individuals and their families. Not only does the individual experience discrimination, but so does their family. This research discussed the mothers' experiences with social rejection and loss of friends due to the child having autism. Not only does this social stigma impact home life, but it also carries weight outside the home. The mothers all reported experiencing negative comments in public due to the child's behavior. The social interactions demonstrated the way people viewed autism in society. They reported that society thought of autism as a "lack" or "social deficit", rather as a diverse way of being. Naturally, this belief isolated and neglected those with autism and their families. The media continues to reinforce the stigmas, despite the families call for inclusion. The experiences shape the way of being for individuals with autism and their families (Loukisas and Papoudi, 2016).

Researchers analyzed the mothers' experiences highlighting the way in which people viewed and reacted to autism in Greece. The research concluded that the struggle to educate autistic children is prominent. The lack of inclusion was seen throughout societal systems beyond education. The blogs and research called for advocating for better treatment and



inclusion of individuals with autism. To do this, Greek society needs to understand autism through the experience of individuals (Loukisas and Papoudi, 2016).

In 1943, Leo Kanner was the first to label autism spectrum disorders as a neurodevelopmental disorder. Autism symptoms include poor social interaction and communication skills, along with restrictive and repetitive behaviors. These characteristics can be identified in early childhood, typically before an individual is 36 months old. In 1966, the prevalence of ASD in England was four per 10,000 children. In 1990, the autism prevalence in the United States was four or five/10,000. Since 2000, autism prevalence has increased globally. The estimate of the worldwide autism prevalence is about 76/10,000. As the numbers have increased, so too has the cost of care for an individual with autism. In the United States, the average cost of care for a person with autism is about 3.2 million dollars. Due to this significant cost, Skonieczna-Zydecka et al. (2017), noted that it is important to know the number of children diagnosed with autism to enable public health care planning. The researchers wanted to discover the prevalence of autism in Pomeranian regions of Germany and Poland (Skonieczna-Zydecka et al., 2017).

The researchers used 921 participants from West Pomerania and 1593 from Pomerania. Male participants outnumbered female participants. All participants had an autism diagnosis and the researchers received their data from the government and private institutions. Participants were 16 years old or younger. According to Skonieczna-Zydecka et al. (2017), the autism diagnostic process in Poland includes a team of doctors, psychologists, educators, speech therapists, and therapists. Once one receives an autism diagnosis in Poland, it is

classified as a Pervasive Developmental Disorder (PDD) and the certificate of disability is recorded by the Provincial Disability Services Commission.

Skonieczna-Zydecka et al. (2017) found the prevalence of autism in the West Pomeranian Region to be 32/10,000 children. The highest prevalence in this region occurred in children between ages 4-7, as the prevalence was 53/10,000. The researchers found that autism prevalence increased in males compared to females. The capital city of the region was home to the most autism diagnoses. In the Pomeranian Region, the researchers discovered an autism prevalence of 38/10,000. In this region's capital city, the autism prevalence rose to 58/10,000. Like in the West Pomeranian Region, the highest prevalence rates occurred in 4- to 7- year-old children and in males. Overall, the results of this study showed an average autism prevalence in these two regions of 35/10,000 with the male-to-female ratio of 4.3:1. In both region's capitals, the prevalence rates significantly increased. The researchers attributed this to the easier access to diagnoses in larger cities. The results found by Skonieczna-Zydecka et al. (2017) aligned with other epidemiological autism studies performed across Europe, however, direct comparisons were difficult to make due to the varied procedures and methods used in the studies. The researchers highlighted that the average autism prevalence in these regions was significantly lower than the autism prevalence in Sweden.

To better understand the cost of autism care in this region, the researchers goal was to discover the prevalence of autism in the Polish population. While they achieved this goal, the researchers noted the number of autism cases may have been an underestimate due to the passive administrative method utilized in identifying children with autism. Another reason to consider that the results may underestimate the actual autism population, was because not all

patients used government health systems, which meant there may have been cases of autism not included in this specific research. Poland requires no obligatory reporting of autism diagnosis. Screening children for autism can be completed by a government agency or by private practice. It takes less time to complete the assessment process in a private practice. Regardless, cases were not required to be reported.

The researchers also noted a trend of autism underdiagnosis in Poland. Lack of autism awareness and the country's conservative culture may have contributed to the underdiagnoses. There remains a stigma associated with autism, specifically in the rural areas of the country. The regions studied in this research rest on the border with Germany. Skonieczna-Zydecka et al. (2017) noted the possibility that people left these regions to seek health services in Germany due to logistical or financial benefits. All the above-mentioned possibilities contributed to an underestimate of the autism prevalence rate.

Overall, the researchers found the prevalence of autism in Polish children between the ages of 0-16 was 35/10,000. They believed their research helped fill some gaps related to knowledge of autism prevalence in Poland. However, a call for more epidemiological studies in more regions was made.

Özerk (2018) noted the importance of autism prevalence studies. Healthcare and educational authorities depend on these studies to inform their planning and funding. Previous worldwide autism prevalence studies documented the rise of autism diagnoses over the past decade. With the rates of autism rapidly increasing, so too has the concern over the lack of qualified educators and special education decision makers. The researcher emphasized the necessity of implementing evidence-based educational programs for children with autism. To

support this need, the researcher conducted a study that investigated the prevalence of autism in preschool-age children and school-age children. This study also explored the gender differences in autism prevalence. Oslo, Norway was the location of the study.

It is important to note that Oslo has separate school administration, kindergarten administration, and healthcare administration. In Oslo, kindergarten is not required for children ages 1-5. If parents choose for their child to attend kindergarten, they pay a tuition fee. Therefore, this study considers children ages 6-16 “school-age children” as they are part of the 10-year basic school system. The researcher noted that the study reported on the prevalence of autism among 1 to 16-year-old children. To gather data for this study, the researcher used the national patient registry. Since Norway provides free health care services under their universal health care, the well-established patient registry provided accurate data for the researcher (Özerk, 2018).

One of the goals of this research was to determine the prevalence of autism in preschool-age children (ages 1-5) and in school-aged children (ages 6-16). Özerk (2018) found that the overall prevalence rates of autism in Oslo doubled between the years of 2012 to 2016. When looking at the prevalence rates in preschool-age males, the researcher reported an increase of 90% from 2012 to 2016. Similarly, the prevalence rate in preschool-age females increased by 196% from 2012 to 2016. The researcher concluded that the data not only showed an overall increase in autism in preschool-age children, but also showed the gender gap in preschool-age children is narrowing.

The other subgroup of this study was 6–16-year-old children with autism. These school-age children also showed an increase in prevalence. From 2012 to 2016, the rate of school-age

males with autism increased by 85%. The prevalence of autism in school-age females increased 73% from 2012 to 2016. Unlike the gender gap in preschool-age children, the gender gap of autism prevalence did not narrow among school-age children (Özerk, 2018).

Through this study, Özerk (2018) found evidence pointing towards the “school-age effect”. The school-age effect means that the school-age children are more likely to receive an autism diagnosis compared to preschool-age children. The researcher found that this remains true for both males and females. This study proved there to be a likelihood between 220% and 290% for males to receive an autism diagnosis at the school-age compared to the preschool-age. Likewise, the prevalence of autism in school-age females was 275% to 543% more likely compared to preschool-age children.

Özerk (2018) compared the results of this study to previous research conducted in Norway. The researcher found that Oslo had lower rates of children with autism compared to the average prevalence rate in Norway. However, the school-age effect was consistent throughout the country, as the number of six to 16-year-old children continued to show higher prevalence rate across the nation compared to preschool-age children.

The findings of this study emphasized the need for increased educational and healthcare planning to meet the needs of the growing number of autistic children in Oslo. The researcher also expressed a great need for developing competency among more school staff. As the number of school-age children increases in Oslo, the researcher provided this information so that children with autism could be best served (Özerk, 2018).

Colic et al. (2022) noted that the symptoms associated with autism increase the stress levels of parents raising a child with autism. The researchers reported that previous research

found families who had a child with autism experienced higher levels of stress compared to families of children with other intellectual and developmental disabilities. Even though previous research studied the relationship between quality of family life and having a child with autism, the researchers pointed out that all research resided in either North America or Western Europe. This left a gap in research about family experiences with autistic children in Eastern Europe. The prevalence of autism in Eastern Europe is also largely unknown. The researchers reported that autism remains largely unheard of in countries such as Serbia and Croatia. Lack of access to diagnostic tools and trained therapists, contribute to the lag of knowledge in these regions. The researchers noted that most clinics were in bigger cities, leaving families from rural areas unable to access the necessary interventions. Therefore, the researchers conducted this study to learn more about the experiences of parents of children with autism in Eastern Europe.

To conduct this study, Colic et al. (2022) used the Double ABCX Model as the framework for reviewing the literature. Researchers used the ABCX Model to predict levels of marital adjustment, depression, and parenting in mothers of children with autism. The authors divided this model into four areas. The first area (aA factor) referred to the child's characteristics. The severity of the child's autism symptoms was identified as severe cognitive, communication, and social impairments associated with higher levels of stress. The second area (bB factor) considered the internal and external resources available to families. The mindsets of families referred to the internal resources that families could rely on during stressful situations, whereas sources of support were external resources for families with a child with autism. The Cc factor referred to the appraisal of stressors. This factor reflected the way the family reframed situations and the child's needs. The final factor (BC) focused on coping strategies.

The way a family coped with the stress and used resources predicted the outcome of their mental health. This Model was the primary tool used in this study.

Colic et al. (2022) selected 15 studies for review and to conduct the ABCX Model. All studies came from Eastern Europe. The researchers pointed out how the current political state has resulted in no unanimous agreement on what countries comprise Eastern Europe. Therefore, for the purposes of this study, the researchers noted they focused on former communist countries in Eastern and Southeastern Europe. Countries discussed in this research included Poland, Serbia, Croatia, North Macedonia, Romania, Slovenia, Albania, Bulgaria, and Turkey. When the researchers analyzed the results from the first factor of the Model (aA), they found that challenges related to child characteristics were more prevalent in families of children with autism compared to families of typically developing children. This finding aligned with previous research conducted in the Western world. Parents with children who have autism also reported more severe personal and family problems compared to families with typically developing children. Financial problems were another common challenge found by the researchers.

Adaptive resources (bB factor) in Eastern Europe were the second factor reported by Colic et al. (2022). The researchers found many of the participants reported financial challenges, as well as challenges in finding external support. Some parents reported using government support, however, they also reported challenges in financial resources. The researchers concluded this meant that government funds given to the families of autistic children were not enough to cover service fees. Families also reported challenges in

educational support and healthcare. The researchers noted that further research was needed to better understand the external resources available in Eastern Europe.

When Colic et al. (2022) analyzed the perception of stressors, they found that negative perceptions of the autism diagnosis correlated with greater stress levels. The researcher also found that families of children with autism had higher stress levels than families with typically developing children. Coping (BC factor) strategies results differed from findings in previous research in Western Europe. The researchers reported that fathers of children with autism used more support-seeking strategies compared to fathers of children with other disabilities. There were also mixed results about the use of escape-avoidance strategies. The researchers found that families of children with autism engaged in fewer avoidance strategies than families of typically developing children. These findings did not align with previous research. Therefore, the researchers noted that differences in Eastern European culture and parenting styles should be further researched. Furthermore, the researchers noted that parental experiences raising children with autism was underexplored in Eastern Europe and would be beneficial to expand.

Colic & Milacic-Vidojevic (2021) reported that in Latin, stigma translates to “a mark made on skin by burning with a hot iron”. This definition hints towards the lasting impact of perceiving stigma, as the researchers pointed out how the condition of stigma has long-term effects. Previous research conducted in relation to the impact of stigma for mental health, and how individuals with autism dealt with stigmatization, however, the researchers reported there were no previous studies that explored how parents of children with autism experienced stigma. The researchers mentioned that people experienced stigma differently depending on the culture in which it occurs. Because of this, any results of studies conducted in the West,



would not generalize to Eastern Europe. Researchers proved that perceived stigma could predict depression. They also found that when a parent's perceived stigma increased, so did the child's engagement with peers. Therefore, the researchers highlighted the importance of understanding the stigma surrounding disabilities, specifically autism, so that governments and agencies can create support plans.

To complete the link in research from the United States to Eastern Europe, Colic & Milacic-Vidojevic (2021) conducted research in Serbia. The researchers explored the differences in perceived stigma between parents of children with autism and those who had children with physical disabilities in Serbia. Since this was the first study of its kind, there was no known tool available to measure the researcher's goal. Some scales on perceived stigma previously existed, however, the researchers noted that it was developed for use in the United States, so it was not a culturally sensitive instrument. Therefore, the researchers developed a new instrument, Parental Perceptions of Public Attitudes Scale (PPPAS), for Eastern European parents.

The study included 82 parents who were citizens in Serbia. Forty participants had a child with autism and 42 participants had a child with a physical disability. The researchers identified three goals for the study. First, they sought to validate the PPPAS. The second goal was to measure the perceived stigmas for parents whose children had autism or physical disabilities. Lastly, the researchers examined the relationship between perceived stigma and sociodemographic characteristics (Colic & Milacic-Vidojevic, 2021).

Colic & Milacic-Vidojevic (2021) found that the PPPAS had good convergent validity. Like previous research from the United States, the researchers found that parents who reported higher levels of perceived stigma also reported lower levels of life quality. The researchers

concluded that the relationship between perceived stigma and quality of life was similar regardless of the culture. The researchers also found that most participants indicated low-to-moderate degrees of perceived stigma with 46.3% of participants who reported low degrees of stigma, 36.6% of participants reported moderate degrees of stigma, and 16% reported high levels of stigma. Parents of children with autism in Serbia reported an overall higher degree of perceived stigma, compared to parents of children with a physical disability. The researchers explained these results by referencing a previous study which reported that the public in Serbia blamed the families of children with autism and believed family members were contaminated by autism.

The researchers found no relationship between perceived stigma and gender or parental level of education. They also noted a negative correlation between perceived stigma and child age, but a positive correlation between the number of children in a family and perceived stigma. Lastly, the researchers found that perceived stigma decreased as the child received more treatment (Colic & Milacic-Vidojevic, 2021).

According to Colic & Milacic-Vidojevic (2021), the response rate of this study spoke to the overall attitude of autism in Serbia. The researchers reported having a difficult time getting parents to participate as they reached out to 114 parental support associations, but only received participation from nine associations. They found that 70% of Serbian parents of autistic children reported financial problems. This could be because the Serbian government only provided funds for support programs, which also speaks to the view of autism in Serbia. The researchers also reported that 36% of Serbian parents reported frustration with finding

services for their child with autism. The lack of services contributes to the culture surrounding the parents and their perceived stigma.

Overall, Colic & Milacic-Vidojevic (2021) reported that the PPPAS was a reliable instrument and there was a wide-range of perceived stigma surrounding autism in Serbia. The researchers suggested using this research to further examine how public attitudes in Eastern Europe impact child and parental beliefs. This research could also be used to support programs that empower families of children with autism to improve their quality of life.

Roig-Vila et al. (2020) noted that the significant increase of autism prevalence, as well as the limiting effect of autism has been well-researched. Due to the limiting effect of autism, the diagnostic process is vital. Previous research emphasized the importance of early identification and intervention, as this is related to the child's prognosis and parent well-being. The researchers reported a growing trend towards family-centered strategies. The model of family-centered strategies places the intervention focus on the context in which the diagnosed individual lives, rather than focus on the child with autism. The goal of this model is for the child with autism to learn how to function in their natural environment. Therefore, positive results would not only help the child with autism, but also their family unit.

Despite international research supporting the family-centered model, Roig-Vila et al. (2020) reported that the autism diagnostic and intervention process in Spain has yet to implement this model. Because of this, the researchers stressed the need for more research about the diagnostic experience of families in Spain. Previous research reported that pain of the diagnosis, concern for the future, difficulty in accessing educational services, and price of the interventions contributed to parental stress during the diagnostic process. Families listed

professionals' attitudes, excessive waiting time, and support provided after the diagnosis as their main problems with the diagnostic process. According to the researchers, Valencia, Spain recently implemented changes in the diagnostic process, which has not yet been reviewed.

In 2014, Valencia, Spain created a new protocol to standardize comprehensive care for children with autism. Before 2014, the diagnostic process did not use standardized criteria throughout the whole region. This led to discrepancies in interventions and communication between professionals. Since the new protocol began, detection mechanisms were set into motion, which reduced waiting time for families. It also provided clear path to diagnosis, which improved professional communication and collaboration. Since the region of Valencia, Spain has not been well-researched in regards to the diagnostic process, the researchers sought to investigate the family opinions about the quality of their experience with the diagnostic process (Roig-Vila et al., 2020).

Roig-Vila et al. (2020) uncovered a wide-range of situations, which highlighted the lack of a homogeneous diagnostic process in Valencia. According to the research data, 47.1% of the participants noticed initial autism symptoms at 12-24 months with 26.5% of participants not identifying symptoms until after 24-month mark. In regards to who first noticed the symptoms, 70.6% of participants reported the parents as the first, with only 2.9% reporting the pediatrician as the first to identify symptoms. Once they reported symptoms, 41.2% of participants received a referral to a different consultant. After the initial referral, participants reported seeing several specialists before receiving the diagnosis. Of the participants, 29.4% saw three different specialists, while 23.5% saw five or more specialists. This led to the average diagnostic process

taking anywhere between one month to one year. For some families, the process lasted longer than two years.

The findings of the Roig-Vila et al. (2020) study showed the lack of a unified diagnostic process in the region, which the researchers stressed was necessary to insure the standards of coverage and quality in diagnosis for all families. The results of this study also noted that some participants documented an acceptable level of satisfaction with care, while a few rated it as low quality. The researchers explained these mixed results as a sign of the recent improvements made in the diagnostic process.

The researchers were surprised by the results that indicated most parents reported they identified symptoms during the 12–24-month age range. Roig-Vila et al. (2020) noted that this finding conflicted with previous research. They explained that greater awareness of autism and increased social visibility of autism could have helped parents identify symptoms in their children earlier. Overall, the results of this study showed some improvement to the diagnostic process in Valencia, Spain, however, the researchers stressed the importance of universalizing protocols so that every child with autism and their family can benefit from a high-quality process.

The increasing rates of childhood obesity is a public health issue (Healy et al., 2017). Research reported limited physical activity and excessive screen time as factors for increased obesity prevalence. Healy et al. (2017) referenced previous studies that proved physical activity not only helps control weight, but also prevents the development of other health-related issues. On the other hand, behaviors such as extended screen time contributed to health-related issues such as type 2 diabetes and cardiovascular disease. To follow this public health

issue, Ireland conducted a survey to evaluate the level of youth physical activity. The researchers reported that consistently higher activity rates have been reported in Ireland than other nations. According to a survey, 31% of girls and 43% of boys met the guidelines of recommended physical activity in Ireland.

While physical activity is important for all youth, for children with autism, there are additional health benefits. Healy et al. (2017) listed social skills improvement and better sleep quality as additional benefits for children with autism. Unfortunately, previous research showed that children with autism were less likely to engage in physical activity compared to typically developing children. This could be caused by lack of motor domain skills, social exclusion from activities and lack of social-communication skills. Additionally, children with autism spend more screen time than typically developing peers. The researchers attributed this finding to the fact that the parents may need something to occupy the children with during the day. The lack of physical activity combined with more screen time resulted in children with autism having higher rates of obesity and lower fitness levels compared to their typically developing peers. Research on this topic is limited to specific geographic regions. There is a lack of research on obesity of youth with autism in Ireland. Therefore, the researchers conducted this study to compare physical activity participation, screen-habits, and obesity and reported reasons for lack for participation in sport between Irish children with and without autism.

This study consisted of 141 children with 67 having an autism diagnosis and 74 typically developing. Researchers used self-reported measures in the form of a questionnaire. The questionnaire measured the participants vigorous activity, moderate activity, and light exercise. Participants also answered questions regarding participation in sport. To measure the screen

time variables, the researchers asked questions about how much time they spent watching television and on the computer during an average week. Questions asking why the participant did not participate in an activity or sport helped determine their reasons for activity levels. Next, the researchers collected participants body mass index to measure the degree of body fat.

The results of the this studied showed the most common number of days children with autism reported 20 minutes of exercise over the past 14 days was 1-2 days (Healy et al., 2017). Whereas, the most common number of days that typically developing children reported 20 minutes of exercise was 9 or more days. In terms of participating in a sport with a coach, the researchers reported that 25 typically developing children reported playing a sport with a coach in the past week compared to just three children with autism.

Healy et al. (2017) found that children with autism spent an average of 121 to 150 minutes per day watching television. Typically developing children reported spending an average of 91-120 minutes per day watching television. When calculating the body mass index, the researchers found that the average for children with autism was 21.21, while the average for typically developing children was 20.42. The researchers also found it was more likely for children with autism to fall into the overweight/obese category compared to typically developing peers.

Healy et al. (2017) reported findings that reflected the inactivity of children with autism. Parents of children with autism reported their children participated in limited types of activities. This supports the finding that stated children with autism participated in sports involving a coach less frequently than typically developing children. The researchers noted that in Ireland,

the options for sports that required a coach were typically soccer or Gaelic games. These sports have a social nature to them that makes it challenging for children with autism to participate. They also pointed out that often sports that involve a coach are typically competitive, which could deter children with autism. Parents of the participants with autism reported time and financial constraints and lack of opportunities as additional barriers to sports. The researchers found that preference for screen-based activities was the most reported barrier to physical activity or sport.

Overall, Healy et al. (2017) found a difference in activity levels and obesity rates in children with autism compared to typically developing children. The researchers noted that as this was the first study of its kind in Ireland, future research should to continue to explore perspectives on this topic targeting children with autism.

Saemundsen et al. (2010) defined intellectual disability as having cognitive limitations due to organic brain dysfunction. Standardized intelligence tests measure cognitive ability. An individual who has an IQ score below two standard deviations from the mean has an intellectual disability. Besides the standardized intelligence tests, a developmental history, measures of adaptive behavior and clinical appraisal of the data contribute to an official intellectual disability diagnosis. The researchers also noted that there is a high prevalence of coexisting disorders exist with intellectual disabilities. Autism is one disorder that often coexists with an intellectual disability. While previous research has documented the growing prevalence of autism, little research has explored the prevalence of autism and severe intellectual disability in adults. The researchers reported clinical diagnosis as a prerequisite for adequate services and treatment. Therefore, they stressed the importance of recognizing autism symptoms in



individuals with an intellectual disability. Also, to properly plan and organize services, the prevalence of autism in individuals with intellectual disability must be known.

The researchers conducted this study to determine if autism was underdiagnosed in adults with intellectual disabilities in Iceland (Saemundsen et al., 2010). To do this, they used a three-stage methodology. They reported their main source of information as the Regional Office for the Affairs of the Handicapped (ROAH), which is in Reykjavik, Iceland. The ROAH is a government agency that falls under the Ministry of Social Affairs and Social Security. This agency is responsible for managing special services for disabled people in the area, specifically residential services for those with developmental disabilities. Therefore, all individuals with intellectual disabilities are eligible to ROAH services and listed in their registers. This study included participants with severe intellectual disabilities. To qualify in the severe category, individuals must have an IQ below 50. In Reykjavik, 256 individuals between the ages of 18 to 67 fell in the severe intellectual disability category with 139 males and 117 females. Of these participants, 11 also had an autism diagnosis.

To complete this study, Saemundsen et al. (2010) divided the process into three stages. In the first stage, they used the Bryson scale. The Bryson scale is a questionnaire that researchers developed for the epidemiological study of autism. It consists of 19 items that the researchers translated it into Icelandic. In the second stage, the researchers used the Childhood Autism Rating Scale (CARS). The CARS is a 15-item behavioral rating scale and uses a 7-point scale for scoring. The third stage was diagnostic, based on the Icelandic translation of ADI-R. THE ADI-R is an investigator-based interview that examines the symptoms of autism.

Saemundsen et al. (2010) diagnosed 14 additional autism cases through this study. The additional diagnoses bring the total number of cases to 25, meaning the prevalence of autism coexisting with severe intellectual disabilities was 21%. The researchers reported the average age of autism cases was 32.56 years. Twenty-two of the individuals with autism lived in group homes, while three reported living with a parent. Ten of the autism cases included individuals who were verbal. The researchers also found that 15 of the cases had an epilepsy diagnosis as well. This aligns with previous studies of the prevalence of epilepsy in individuals with autism.

According to Saemundsen et al. (2010), the lack of ROAH records hindered their study. They explained that the lack of IQ measures in Iceland contributed to the lack of records and especially excluded older age groups. Additionally, the researchers cited a reluctance to diagnose an individual who already used handicap services due to an intellectual disability. While medical declarations provide access to services for the handicapped, the researchers explained the lack of existing protocol for specific declarations undermines the ability for ROAH to ability to contribute to epidemiological research.

In conclusion, this study found that 21% of individuals with severe intellectual disabilities were also autistic. While Saemundsen et al. (2010) suggested their findings may be underestimating the cases of autism, the findings did support their hypothesis that there are many undiagnosed autism cases in Icelandic adults with intellectual disabilities. The researchers noted that it is important for stakeholders to understand how a correct autism diagnosis would benefit adults with intellectual disability. Therefore, they suggested that future research targeting undiagnosed autism should be further studied in varying categories of intellectual disability.

Höfer et al. (2022) defined autism as profound deficits in the areas of social interaction and communication, and restricted, repetitive, and inflexible patterns of behavior or interests. Previous research showed that half of individuals with autism also experienced an intellectual disability. High rates of co-occurring disorders have been documented in individuals with autism. Because of the wide range of symptoms and severity, individuals with autism require a wide range of services. A wide range of services creates a high societal cost. Researchers documented previous studies that estimated the cost of supporting an individual with autism as 1.4 million United States dollars. The high cost of care demonstrated the need for appropriate planning.

Research regarding autism-related costs mainly stems from the United States. The few studies regarding autism cost of care in Europe come from the UK, Sweden, and the Netherlands. Höfer et al. (2022) noted that while those studies existed, the research methods used theoretical cost-of-illness models. Researchers explained that using this approach potentially impacted the accuracy of the findings. The lack of real-life user data from European countries on related costs for individuals with autism led to the current study. Höfer et al. (2022) sought to estimate health service use and associated costs through a sample of German children, adolescents, and adults with autism.

Höfer et al. (2022) reported that within the German health insurance system, most services are free for patients. Additionally, most services used by individuals with autism, such as diagnostic procedures, follow-up examinations, medication, and interventions for co-occurring disorders, were reimbursed through health insurance funds. Regardless, researchers noted interventions and support targeting the core symptoms of autism were covered through

integration support aid, which is funded by social services. Of the participants, 50.9% were 18 years or older. Regarding inpatient services, psychiatric/psychosomatic care was most frequently reported, while occupational therapy was the most used non-physician practitioner service.

The annual cost for health services per individual with autism averaged at 3287 EUR. Höfer et al. (2022) noted female respondents incurred a higher cost than the male respondents. Additionally, costs for children with autism was higher than cost for adults or adolescents with autism. When the researchers compared the results to studies, they noted how differences in countries health care systems drastically impacted predicted costs. For example, psychological therapies in the UK are less accessible when compared to Germany. In Germany, psychotherapy is reimbursed through health insurance funds and is offered to adults and children. Researchers also documented the mental health system in the UK placed an emphasis on outpatient care, while Germany had the most inpatient beds in Europe.

The researchers were surprised that the costs of pharmacotherapy and occupational therapy were similar, as occupational therapy is not commonly recommended for treatment of autism symptoms in the age group. Höfer et al. (2022) explained the common use of occupational therapy in Germany, as well as its accessibility, led to the peculiarity in cost.

When Höfer et al. (2022) examined cost predictors, they found lower IQ, female sex and Asperger syndrome were all related to higher health care costs in individuals with autism. Age and symptom severity were not correlated with health care costs in the current study. Researchers noted the findings contrasted with previous studies, however, being that the current study was the first of its kind, they did note any concern.

Autism-related health costs are important to understand for societal planning. Höfer et al. (2022) expressed it will be important for future research to focus on educational costs for autistic individuals, as that cost could also be significant. Overall, the health costs documented in the study fell into the medium range of costs and are worth further exploration.

***Autism in Asia.*** The South Asian region consists of eight nations, sometimes referred to as the SAARC countries (Sharma & Rangarajan, 2019). These countries include, Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. While this region homes more than 20% of the globe's population, there is not much research evaluating the prevalence of autism, compared to the growing research in the West focused on the rising autism rates. Sharma & Rangarajan (2019) reported Bangladesh, India, and Sri Lanka as the only South Asian countries to commit to significant research regarding the prevalence of autism in the region.

While there has been some increase in South Asian countries regarding autism awareness, there remains significant work to be done. The researchers reported there was significant variability in autism and intervention screenings in the region. Low- and middle-income countries in the region also showed an inability to use evidence-based practices when teaching students with autism. The researchers reported an absence of systematic reviews on interventions or teaching strategies used to support students with autism in Southern Asia. However, they identified a review of interventions used in India. While the review provided some information about autism, the results could not be generalized. The results also did not provide information about specific strategies used in schools to teach students with autism (Sharma & Rangarajan, 2019).

The researchers conducted a scoping review to fill the gaps of research on autism in South Asia. The goal of the research was to understand which current teaching practices supported students with autism in the region (Sharma & Rangarajan, 2019). This region, specifically Bangladesh, India, and Sri Lanka historically lack a focus on schooling, leading to large numbers of out-of-school children. High rates of poverty and malnutrition contribute to the challenges of educational progress. The researchers found evidence that poverty and disability were mutually reinforcing. Additionally, children in poverty who experienced malnutrition were at a greater risk to develop impairments. The information also highlighted the lack of resources available to low- and middle-class families who had a child with autism. In India, there were only 22 autism-specific organizations in ten states. There are 61 specialized schools in 13 states and one diploma course with an autism emphasis offered. Research showed that most of the autism assessment or intervention centers found in this region, specifically in India, were in urban settings.

Sharma & Rangarajan (2019) reported how the concentration of resources in urban areas left a gap for those outside of the cities. Often, parent-led interventions for children with autism was the result of not having access or being able to afford the urban-based programs. In addition to lack of accessibility, socio-cultural implications impacted families with autistic individuals in South Asia. Disability, including autism, can be perceived negatively regarding social, gender, and religious expectations. For example, families may choose not to provide services to a girl with autism because the stigma surrounding her disability could make a future arranged marriage difficult.

Due to challenges in providing support for autism across the region, many countries-initiated policies and legislation to increase provision of appropriate education to all students with disabilities. While these policies exist to improve the quality of education for students with autism, school teachers feel unprepared to teach in an inclusive classroom. Because of this, Sharma & Rangarajan (2019) purpose to systematically review the primary teaching practices used to support autistic students in the South Asian region.

The researchers discovered nine main teaching strategies frequently used in the region to teach autistic students. The first strategy was to provide an early assessment. Early identification of students with autism considering their background, interests, and needs provides information to best support the students in a classroom setting. The second teaching strategy identified was lesson planning related to the environment. This strategy implied the teachers was developing predictable routine, adapting tasks, and had a clear purpose for each area of the classroom. Next was to incorporate students' strengths and interests. Considering the students interests when developing lesson plans increases engagement levels and improves learning. The fourth teaching strategy focused on creating learning relationships. Building a strong teacher-student relationship promoted inclusive practice within the classroom and deepened the learning experiences. The fifth teaching strategy included the use of alternative and augmentative communication (AAC). AAC increased the autistic student's ability to communicate with others and engage in learning.

Parent implemented instruction and programs was the sixth strategy named by Sharma & Rangarajan (2019). Research proved that including parents in their child's education led to positive outcomes. Social skills and social stories were noted as the seventh teaching strategy.

Autistic students benefited from this intervention as it supported them in social situations. The eighth teaching strategy focused on information and communication technology (ICT). The strategy included use of video modeling and software designed to facilitate learning and communication. Lastly, ongoing evaluation was the ninth teaching strategy. Evaluation implied that student progress was continuously monitored, and achievements were highlighted more than deficits. The nine teaching strategies were found most often in South Asia for students with autism.

Most of the research reviewed by Sharma & Rangarajan (2019) originated in India, Pakistan, and Sri Lanka. Because of this, the researchers reported the need for more robust research on autism and teaching practices in all South Asian countries. Most of the reported practices were developed based on Western standards, which led to question the effectiveness or relevance in more diverse contexts. Since one-fourth of the world's population lives in the South Asian region, researchers emphasized the need for more localized research to find effective interventions for students with autism in this region.

Liu et al. (2021) explained that autism is a disorder that include deficits in social skills, communication, and behaviors. Early detection of autism is important in generating the best possible outcome for the individual diagnosed. The earlier an individual receives a diagnosis; the sooner interventions are implemented that improve emotional and behavioral outcomes. The researchers noted that it is important to have reliable tools and instruments to measure autistic traits and screen high-risk children. Access to reliable instruments aids in early detection.



Since evaluation instruments are crucial to early autism detection, Liu et al. (2021) noted that Western Europe and North America developed most of the autism screening tools. The researchers suggested that the creation of instruments by high-income countries may mean the knowledge of autism is culturally and contextually based. To model this suggestion, the researchers shared an example about identifying children with autism in Japan. Disinterest towards other children is an indicator of autism in the United States and is included in most screening tools. However, previous research referenced by the researchers indicated that Japanese caregivers did not report this as an autism symptom. This could be because Japanese culture is more introverted than western cultures. Liu et al. (2021) used this example to show how assessment tools standardized in the West may not be applicable to non-Western cultures.

Culture is not the only role that Liu et al. (2021) analyzed in this study. The researchers investigated the role socioeconomic status and demographic information played in reporting autism traits. Previous studies represented that parent's with lower incomes and less education generally over-reported autism traits on assessment tools. It is unknown if socioeconomic status or demographics impacted the reporting of autistic symptoms cross-cultures.

The Autism-Spectrum Quotient questionnaire (AQ) is the most frequently used autism screening tool worldwide (Liu et al., 2021). The questionnaire includes 50 items and is completed by the autistic individual or parents to quantify autistic traits in the individual. Children ages 4-11 answer questions across five domains. The domains include social skills, attention to detail, attention switching, communication, and imagination. The researchers noted that the differences interpreting and understanding autism in different countries may have limited the generalizability of Western screening tools in Eastern cultures. Based on this

assumption, the researchers determined three goals for the study. First, they examined the structure of the parent-reported version of the AQ for children in China and Netherlands. Second, they compared the autistic traits of children in China and the Netherlands. Lastly, the researchers explored the impact of parental socioeconomic status and children's age and gender when parents reported the autistic traits for children in China and the Netherlands.

Liu et al. (2021) concluded that the relations between factors in the Chinese and Dutch exploratory factor analysis ranged from very weak to moderate. The researchers were surprised to discover that increased attention to numbers and patterns was related to better social skills in China. This study also showed that unemployed Chinese parents reported fewer autistic traits in their children than those of employed Chinese parents. The researchers also found that low-income Chinese parents reported better mind-reading skills in their autistic children than parents at middle- and high-income levels. However, in the Netherlands, the researchers found that Dutch parents who were unemployed reported worse mind-reading skills in their autistic children compared to employed Dutch parents. No cross-cultural gender differences were found by the researchers.

The results of this study identified that social skills, attention switching, and imagination were more prevalent for children with autism in China than children in the Netherlands (Liu et al., 2021). The researchers found that the way parents understood the questionnaire items and reported their child's symptoms varied across cultures. For example, the item "S/He finds it easy to go back and forth between different activities" was seen as attention switching in the Netherlands, whereas in China the same item was scored on the social skills factor. The researchers suggested this could have been due to Chinese cultural values of preserving group

harmony by switching between activities and contexts. Another example was the item that read “s/he finds it difficult to work out other’s thinking and feeling by looking at their face”. In China, this item was considered a social skill, while in the Netherlands it is a mind-reading factor. The researchers noted how previous studies indicated that Americans focused on the face when reading social contexts, while Asians focused on the social context.

In conclusion, Liu et al. (2021) explained that the results proved a difference in the factor structure of the parent-reported AQ scores, which inferred that the reporting and interpretation of autism symptoms was likely dependent on culture. Variation found in item-factor loading created difficulty during cross-cultural comparisons. Therefore, it was found the Chinese version of AQ measured autism traits differently than the Western version. The researchers concluded that the results showed a need to create more diverse autism assessment tools.

Varlamov et al. (2020) described autism as a developmental disorder, which includes social and communication impairments. However, they noted what now falls under the term autism spectrum, used to be separate diagnoses of infantile autism, atypical autism, Asperger’s syndrome, and pervasive development disorder. “High-functioning autism” and “low-functioning autism” indicate whether an intellectual disability co-exists with the autism diagnosis. The researchers reported that low-functioning autism was more commonly diagnosed compared to high-functioning autism. Autism is one of the most common developmental disorders with a global prevalence rate of 1%. This prevalence rate implies social significance.

Previous research documented the negative impact of autism for individuals and their families. According to the researchers, Varlamov et al., 2020, low-functioning autism is difficult to treat. Without proper, early intervention, the individual with autism remains completely dependent on their family or caregivers. The researchers noted that high levels of support are important. This support, however, comes at a great cost to the individual family and the state support system. The researchers pointed out that while the interventions and treatments are costly, the benefit exceeds the cost, as the goal of the intervention is to improve the autistic individual's ability to contribute socially and economically to society.

Varlamov et al. (2020) described Russian society as struggling in terms of improving the quality of support for individuals with autism. The lack of support referred to included inclusive education, comprehensive support systems, and increased public awareness. Researchers noted that while many of these issues are being addressed improvement is needed to yield positive results. The researchers noted that some of the problems are universal, such as inequity of access to therapy and education, family burden, and social stigma. Other issues are unique to Russia. According to the researchers, the Ministry of Health officially uses the term "childhood autism" when diagnosing individuals with autism. Varlamov et al. (2020) reported that the official use of this term makes it harder for Russian adults or adolescents with autism to get support, because autism is only diagnosed under the age of 18. It is typical for individuals with autism to have their diagnosis changed to a psychiatric diagnosis once they turn 18. This practice not only impacts the individual, but also hurts the data on autism prevalence in Russia. A lack of accurate data hinders society's ability to understand autism, in turn damaging support systems and delaying improvement for inclusion in Russian society.

Not only does the diagnostic practice of autism in Russia hinder support for the individual, but the regional inequity in Russia does also (Varlamov et al., 2020). The researchers reported that both the quality and variety of services in rural areas are lower for children with autism. Quality services are also less accessible in rural areas due to the lower economic status of the residents. The researchers noted the socioeconomic status in Moscow and surrounding areas is significantly higher than the remainder of the country. Russia's unique geography creates an even more curious inequity. The researchers reported that 25% of Russian population lives in rural areas and 25% live in small towns, which have the social infrastructure of a village. Low density territories make up 66% of the country. This geography makes accessibility to support increasing difficult.

Varlamov et al. (2020) conducted a multidimensional survey measuring stakeholder opinions about special education, inclusion, general education, and e-learning in relation to individuals with autism in Russia. For the study, 134 participants completed the survey. Of the 134 participants, 61 respondents were parents of individuals with autism, 70 participants were autism education or therapy specialists, eight participants fell into both groups and 11 were charity activists. Special education and general education were the first areas of support evaluated. Private organizations received higher score ratings than state supported facilities. The participants also gave poor ratings for the efficiency of interaction between organizations. The researchers reported that state-employed professionals rated private and non-governmental facilities higher than state-owned facilities. Accessibility to education was also rated low. All stakeholders rated the implementation of inclusive education poorly, even though the concept of inclusive education was rated positively. The researchers pointed out

that several barriers still existed related to the implementation of inclusive education. The participants named the lack of unprepared teachers, supportive equipment, environments, adapted teaching materials, and negative attitude of typically developing children as some of the barriers that exist.

Varlamov et al. (2020) also measured levels of family support and parental education. They noted that financial support received was rated lower than psychological or family support for parents. Participants in Moscow rated autism awareness initiatives as significantly higher than those outside the capital region. Regarding the quality and accessibility of support for autistic individuals, the researchers reported lower ratings in autism-specific services compared to general services. Due to the geography of Russia, the researchers decided to investigate the quality of distance education opportunities. They found participants from Moscow reported more positive experiences than those outside of Moscow.

Overall, this study reported different stakeholder experiences and opinions about autism in Russia. Varlamov et al. (2020) noted that while satisfaction scores were low, Russia has significantly increased support for individuals with autism in the past decade. While some improvement occurred, the researchers noted that disparity between the experiences of people in Moscow and outside the capital remains a problem. Knowing this, the researchers emphasized the importance of private and public collaboration to raise awareness of autism across all social service areas in Russia.

Simashkova et al. (2019) reported that over the last several years, professionals in Russia improved their awareness regarding to early autism diagnoses. In Russia, federal programs emphasized the importance that early autism diagnosis has on improving the quality

of individual life and health. Early diagnosis also impacts medical-social-educational rehabilitation. As the prevalence of autism increased globally, so too has the practice of early intervention. Professionals have not thoroughly studied the prevalence of autism in Russia. The researchers reviewed a previous epidemiological study completed in Russia that showed the prevalence of child psychiatric disorders was 70% higher than similar studies in Britain. While the study shed light on the overall prevalence of disorders in Russia, it did not specify the prevalence of autism. Regardless, the researchers stressed that early intervention for autism was important. The Ministry of Health of the Russian Federation began screening children at 18-24 months. This screening developmental risks for mental illness, specifically early detection of children at risk for developing autism.

To execute the screening process, the Ministry of Health used a two-stage screening process (Simashkova et al., 2019). The first screening stage included a survey at a health care facility followed by a psychiatric assessment. While the screening is ongoing, initial data indicated the prevalence of autism was 5:10,000. The researchers noted that use of terms like “childhood autism” and “atypical autism”, may have impacted the data, as the diagnoses had only been used in the Russian register of adult mental health diagnoses since 2014 (Simashkova et al., 2019).

The priority of the Russian National Policy for Mental Health in Children and Adolescents was to prevent the development of mental and behavioral disorders. To do this, primary health care clinics frequently tested Russian children. The process exists to detect autism early and begin treatment immediately. The researchers also noted how the process could provide guidelines for preventive measures. By this, the researchers inferred the use of genetic

predispositions and neurobiological anomalies as preventive measures (Simashkova et al., 2019).

Researchers have commonly studied the autoimmune systems of children with autism. Simashkova et al. (2019) mentioned how the measures of inflammatory and autoimmune markers found in the blood of individuals with autism could be key in supporting the diagnosis. In addition, EEG, and non-invasive brain biopotential monitoring showed potential use as neurophysiological biomarkers to support clinical autism diagnoses. This research has changed Russian autism diagnosis. In 2015, Russia made the switch to clinical-biological autism diagnosis. This meant that neurophysiological investigations supported clinical assessments. The researchers reported that 20% of Russian children who completed autism assessments also received neuroimaging. The use of neuroimaging prevented other abnormalities such as tumors, epilepsy, or brain malformations from presenting as autism.

In addition to neuroimaging, the new protocol for autism diagnosis in Russia also includes biomarkers and blood tests (Simashkova et al., 2019). The clinical side of the diagnostic protocol uses assessments with psychometric scales. The Childhood Autism Rating Scale is an example of clinical assessments. On the Biological side of the diagnostic process, EEGs and blood tests measure significant risk factors in the children. The researchers explained how blood tests measured leukocyte elastase, proteinase inhibitor activities and autoantibody levels against myelin basic protein. Previous studies found correlation between psychosis and blood levels of the mentioned markers. The researchers reported that since the neuroimmune markers were nonspecific to autism, but instead psychosis, the technology was somewhat limited. The Russian diagnostic protocol will continue to adapt, specifically with publication of



an updated International Classification of Diseases-11. However, the researchers acknowledged that the use of routine screening of autism blood biomarkers, not only supported an autistic clinical diagnosis, but also pharmacological treatment. Therefore, the goal of the Russian diagnostic protocol is to improve the long-term outcomes of individuals with autism and their families.

Porter & Loveland (2019) reported that the increasing autism prevalence impacted the globe. In the United States 1 in 68 children have autism. However, research conducted in Asia show higher autism prevalence. For example, researchers found that the autism prevalence in South Korea to be 1 in 38 children which is 2.65% of the population. Whereas in Japan, autism affects 1.47 to 3.74% of the population. When looking further into Japan's autism prevalence, researchers found that 6.5% of elementary and middle school children had diagnoses of either autism, ADHD, or learning disabilities. While autism prevalence is well studied, the researchers noted that not much is known about the impact that autism has on families across the globe. Because of this, they sought to discover factors that impacted parenting stress in mothers of children with autism in Japan.

Parenting a child with a disability impacts the whole family. Previous research from industrialized countries found that parents of children with autism experienced significant more stress compared to parents of typically developing children. These high levels of stress can lead to psychological distress such as depression and anxiety. Porter & Loveland (2019) noted that early childhood development can be negatively impacted when a parent experiences a psychological problem. Studies showed that parental stress can lead to children who experience anxiety and to a reduced quality of their relationship. Additionally, a study in Tokyo

found that parents of children with intellectual disabilities were more likely to physically punish their children compared to parents of typically developing children. Therefore, it is important to understand parenting-related stress, as it impacts the child's well-being.

To better understand parenting stress, Porter & Loveland (2019) referenced a developmental psychologist who created the Parenting Stress Index (PSI) to identify parents who are at risk for dysfunctional parenting behaviors. The PSI examined stressors related to the child domain and the parent domain. The child domain evaluated traits and temperament of the child that could lead to stress. The parent domain evaluated parental characteristics and perception of social support. Researchers often use the PSI model when researching families of a child with autism.

Porter & Loveland (2019) noted that cultural norms and parenting beliefs impact the family. For example, Arab-Israeli mothers of children with autism, who accepted their child's disability, demonstrated more sensitivity. The researchers explained this was because the Arabic culture viewed disability as punishment for parental transgressions. Religious beliefs of the Hispanic culture buffered parent stress of mothers of children with autism. Despite these examples, research investigating the way the Asian culture impacts parental stress is lacking. In the current study, the researchers reviewed existing research about parenting stress in mothers of children with autism in Japan.

The findings of this study showed higher rates of stress in mothers of children with autism compared to mothers of typically developing children and children of other disabilities. Porter & Loveland (2019) also noted that a child's characteristics related to levels of stress. For example, the child's attachment, behavior problems, poor maternal mental health, guilt, and

lack of social support were all the most prominent characteristics in mothers of children with autism. A child's heightened behavior problems such as tantrums, hurting of self or others and repetitive and focused interests positively correlated with higher parent stress. They also found that maternal characteristics impacted levels of stress. For example, the researchers explained that lack of social support had the largest impact on the mother's psychological well-being. Within the category of social support, the researchers included lack of support from family and community as well as inadequate organizational support systems.

While these results aligned with previous research, Porter & Loveland (2019) explained that their study yielded new results related to Japanese cultural influences on parenting stress. For example, children with autism often did not show age-expected behaviors, which led to greater stigma towards the child and parent. The researchers explained that Japanese culture places a high value on conformity and not inconveniencing others. Therefore, the parent of a child with autism experiences high levels of stress within the context of their culture. Maternal parenting efficacy was low in this study. Researchers reported that Japanese mothers were less confident and less satisfied with their role than mothers in industrial nations. This put Japanese mothers at higher risk of stress.

Porter & Loveland (2019) noted that the findings showed correlation between attachment and parenting stress. They explained that Japanese parenting style places value on mother and child closeness. Therefore, if they are unable to build a close relationship with their autistic child, they may feel stress due to cultural conditioning. Japan also holds a strong societal gender expectation that mothers are responsible for housekeeping and raising the children. This means the mothers are the ones blamed for the child's behaviors. Because of this,

the researchers suggested the gender ideology contributed to the mother's stress. Additionally, in Japan, the father is not expected to spend much time with the child. The lack of involvement leads to lack of spousal support, which was associated with higher stress levels. Overall, Porter & Loveland (2019) noted how this research should reinforce the importance of understanding the cultural environment of children and their families. The researchers also reiterated the importance of supporting families of children with autism.

Zhou et al. (2022) noted that financial well-being impacts overall quality of life. The US Consumer Financial Protection Bureau (CFPB) defined financial well-being as having the financial freedom to make choices, absorb shocks, and stay on track for long-term goals. Additionally, a family financial well-being impacts the development of children with autism. Low financial well-being impacts community participation for children with autism, which leads to increased social exclusion. The researchers reported that China has the world's largest autism population. Therefore, it is important to understand the financial status of families with autistic children in China.

Researchers reported increased public support for children with autism. However, finding affordable services in China remains a problem. Previous research showed that autism was associated with significant costs across the lifetime of a family. Researchers explained that autism and family financial well-being may be connected, especially in China. Zhou et al. (2022) noted a significant gap in research regarding the way autism impacted family financial and general well-being. Because of the gap in knowledge, researchers investigated the financial well-being of families raising autistic children in China.

A Chinese nonprofit organization, YiBao Plan, helped distribute an online survey to families of children with autism. Zhou et al. (2022) selected responses from families with an autistic child aged 0-18 years. A standardized financial well-being scale, developed by the US CFPB, was translated to Mandarin for participants. Statements such as “I am just getting by financially” and “My finances control my life” were asked and included five-level Likert responses. The out-of-pocket expenses per month for autism services was also included in the study. Researchers noted that one Chinese Yuan was equal to 0.15 US dollar.

Participants represented all 34 Chinese provincial administrative regions. Zhou et al. (2022) reported half of the participants resided in urban areas. Half of the respondents had an education past high school and 60% were employed. The average annual family income ranged between 50,000 to 99,999 Yuan. Within three months prior to responding, families experienced three out of five types of hardship. Researchers listed food, utility, housing, medicine, and education as types of hardship. Over half of the children were the only child in the house. Of the respondents, 47% reported being covered by public medical insurance, while 57% received social welfare benefits, and 43% received medical assistance.

Zhou et al. (2022) defined an average financial well-being score as 40.85, which is 13 points lower than the average score in America. Researchers found one quarter of respondents reported no health expenditures, while another quarter reported monthly expenditure of 5,000 to 10,000 Yuan. Included in this cost average was the child’s health care, medical, social, and rehabilitation services. Additionally, researchers noted more than 40% of participants reported spending less than 5000 Yuan per month, and 5% spent 10,000 or more Yuan.

The findings of this study showed that the higher the health expenditure, the lower the family financial well-being score. Zhou et al. (2022) noted that the median range of monthly health expenditures was 3.5 times the per capita wage in China. Additionally, the child's age, self-care ability, parental employment status, annual income, and material hardships proved to be predictors of financial well-being. Researchers also discovered that health expenditures from the study were higher than reported by US respondents. While there were claims that the whole Chinese population had access to public medical insurance program, many of the children were not covered by the program. This lack of coverage from public supports placed financial burden on the families, which then impacted their financial well-being. Overall, the findings from Zhou et al. (2022) study demonstrated the impact that raising a child with autism had on financial well-being. To support family well-being, the researchers suggested that public policy should increase and understanding the impact of autism on families should be further studied.

Sulaimani & Mursi (2022) referenced previous research concluding that parents with autistic children experienced higher levels of stress and depression compared to parents of children without a disability. Researchers believed that the challenges associated with understanding autistic behaviors and communication methods lead to the heightened stress levels. Increased financial stress and marital problems were additional stressors associated with a child who receives an autism diagnosis. While the stresses experienced by families with an autistic child are known in the United States and other Western countries, there is a knowledge gap of how the same diagnosis impacts families within alternative cultural contexts. To help fill

this gap, the researchers studied the experiences of mothers with autistic children in Saudi Arabia.

In Saudi Arabia people with autism experience stigmatization (Sulaimani & Mursi, 2022). Saudi Arabian culture views autism as unacceptable and an abnormality. The researchers reported that the stigmatization associated with autism impacted all family members. However, in patriarchal societies, such as Saudi Arabia, the stigmatization impacts the mother the most. This is due to the gender roles of the culture. Women are expected to maintain a traditional role at home, even when they have employment outside of their home. The woman's responsibilities include caring for the children and meeting her husband's needs. The husband provides for the family and has no expectations to care for the needs of the children, including those of an autistic child. The Saudi culture creates a context where the mother feels guilty for the child's autism diagnosis. Knowing this, the researchers believed that research would shed light on the way cultural contexts and institutions should support mothers who experience stigmatization due to a child's autism diagnosis (Sulaimani & Mursi, 2022).

Sulaimani & Mursi (2022) reported that Saudi Arabian government and the Department of Special Education are responsible for providing special education services. Because of this, the researchers emphasized the importance of spreading information about this disorder so that more students with autism could receive appropriate services. The researchers referenced previous studies that showed that most people in Saudi Arabia have heard of autism, however, they were confused and unaware of the causes. Parents often attributed their child's autism to either medical, psychological, or cultural factors. Vitamin deficiencies, vaccinations, or pregnancy complications were some of the medical factors that Saudi Arabian parents

expressed as causes of autism. Childhood trauma was an example of psychological factors they believed could cause autism. Black magic or the evil eye were cultural factors that some parents believe caused their child to develop autism.

While there is a six percent chance that a child will receive an autism diagnosis in Saudi Arabia, the Saudi community believes autism is a psychiatric problem. The confusion surrounding the cause of autism has led to guilty feelings for the mothers, who feared they contributed to their child's autism diagnosis. In addition to mothers feeling guilty, the confusion of what caused autism led to a variety of interventions. The researchers reported that in Saudi Arabia, the most common autism intervention parents used was to read Quran verses or seek healing from religious healers. Therapies focused on behavioral, educational, or developmental interventions were not reported by parents as options. Some mothers were reluctant to seek support for their child with autism due to the fear of stigma surrounding the disorder in their country (Sulaimani & Mursi, 2022).

To further close the gap of knowledge about autism in Saudi Arabia, Sulaimani & Mursi (2022), completed a study exploring the experiences of mothers who had children diagnosed with autism. The research focused on how living in a patriarchal society affected the mother's experience raising a child with autism. Fifteen mothers from Jeddah, Saudi Arabia participated in the study. They fell within the age range of 22-42 years and had autistic five to 12 years old. The researchers addressed the mothers' concerns, and responses, partner challenges, difficulties accessing resources, and response of others hearing of the diagnosis in the study.

Mothers in the study reported concerns with their child's lack of focus and awareness, as well as lack of communication, physical behaviors, and bad temper. Feelings of surprise,



shock, sadness, and denial were common for the mothers when receiving the initial autism diagnosis. These feelings, as well as the increased stress, was consistent with previous findings. In addition to the mothers wrestling with these feelings, the researchers reported the impact that partner challenges had on the mothers. When the fathers had negative responses, the mother's stigma experiences increased. Ignored responsibility for caring for the child was another father response, which led to greater feelings of isolation and stigma for that mother (Sulaimani & Mursi, 2022).

The mothers in this study attributed their experiences based on their level of autism awareness of those around them. The mothers experienced others who called the individual with autism weird or retarded. Some people accused the autistic individual and their mother of disrespecting the social norms. To help learn and cope with their child's autism diagnosis, mothers used the internet. They reported that they conducted their own research on Google and YouTube to better learn about the disorder. The researchers also found that the mothers relied on their faith to help them manage their new reality, as well as a means of healing. Reliance that Allah would provide a miracle and staying connected with Him was one-way mothers responded to their child's diagnosis. This behavior was consistent with previous studies that found that informal interventions, such as reading the Quran, were the most common ways parents tried to treat autism (Sulaimani & Mursi, 2022).

The lack of specialized institutions could explain the use of informal interventions in Saudi Arabia. Sulaimani & Mursi (2022) reported the mothers had negative experiences with specialized institutions. Some received inaccurate or contradictory diagnoses. The researchers cited the lack of standard regulations and guidelines as a reason for the number of

misdiagnoses. Mothers also reported issues with accessing services for their children. The lack of public institutions qualified to serve a child with a disability has led to the rejection of many children. The researchers reported the mothers who found good support groups or resources from an autism educated medical professional felt better equipped to fight the feelings of stigma and to better understand their child.

The findings of this research showed that many mothers depended on receiving a diagnosis from a doctor to acknowledge their child has autism. However, the number of mothers who seek a doctor's opinion is decreasing, as many people in Saudi Arabia consider autism to be a curse, not a medical condition. To help limit the stigma and isolation faced by mothers in Saudi Arabia, awareness of autism needs to spread. Increased autism awareness would also work to help parents seek appropriate interventions for their child, without fear of stigmatization. The researchers reported the need for policymakers in Saudi Arabia to establish guidelines for proper diagnosis. Prioritizing the accommodations for all people with disabilities, including the long-term care of individuals with autism has been recommended by the researchers. Lastly, the researchers mentioned that autism is a public and societal health burden that must be addressed by all stakeholders to minimize the stigma that exists for mothers and their children with autism (Sulaimani & Mursi, 2022).

### **Autism in Australia**

Jones et al. (2021) recognized the growing prevalence and change of definition of autism in Australia. Historically, the definition of autism focused on the deficits experienced by the individual. The researchers acknowledged the term "neurodiversity" as an up-and-coming term that emphasized differences as opposed to deficits. This change in view emphasized the

strengths that are associated with autism, such as attention to detail and pattern detection. Besides the change in definition, Jones et al. (2021) referenced the 2015 Australian Survey of Disability, which reported a 42% increase in autism diagnosis over the course of three years. This increase in autism prevalence has worked to increase public awareness and concern. Some reported explanations for this so called “autism epidemic” include higher rates of seeking diagnoses, increase of diagnoses of individuals with less need for support and change in diagnostic criteria. The increase in public awareness also led to increased misconceptions about autism. Due to this epidemic and change in perception, the researchers investigated public awareness and knowledge about autism in Australia. To do this, they conducted two studies.

The first study conducted focused on Australian adults 18 years or older. Researchers conducted online and telephone surveys through the Life in Australia panel. The researchers invited 3,204 individuals to participate in the study of which 75.7% of individuals accepted the invitation. To develop the surveys, the researchers developed questions specifically for this study, drawn from previous academic literature. To ensure the questions were relevant and measured the aim of the study, autistic individuals and families of autistic individuals collaborated with the researchers to develop the survey. The goal of the survey was to measure how the Australian public understood autism. To do this, the survey addressed five areas of knowledge: awareness, prevalence, causation, outcomes, and impact (Jones et al., 2021).

The researchers divided the participants into two groups. One group did not identify as autistic or have a close relative who was autistic (non-autistic responders). The other group identified as autistic or had a close relative who is autistic (autistic responders). The results of the study showed that 97.6% of the participants reported they had heard of autism, 1.1% had

not heard of autism and 1.2% were not sure. The results indicated the awareness of autism in Australia is high.

The prevalence results were mixed. Over half of non-autistic responders correctly believed the number of autism diagnoses was increasing. Non-autistic responders were less confident in their responses regarding if the number of autistic girls was increasing, as 54% reported they were unsure. The autistic responders were more likely to agree that the number of autistic people and number of autistic girls was increasing (Jones et al., 2021).

Compared to non-autistic responders, autistic people and those with close autistic relatives were more likely to correctly agree the cause of autism was unknown. However, the respondents who had close autistic relatives were more likely than autistic and non-autistic responders to incorrectly believe vaccines caused autism (Jones et al., 2021).

Considering respondent beliefs, the researchers found 22.2% of non-autistic responders incorrectly believed one could outgrow or cure autism. This meant that only a little over half of the studied population knew there was no cure for autism (Jones et al., 2021).

Non-autistic individuals reported awareness that autism affects people differently with 88.4% indicating they knew some characteristics of autism, such as light and noise sensitivity, difficulty making friends and struggle to find employment. A concerning result of this study was that 19.2% of non-autistic responders incorrectly believed people with autism were violent and schools could refuse to include students with autism. The results of this first study showed that most Australians know about autism, but had gaps in their knowledge and impact of the disorder. The results indicate the need for increased awareness, as well as a clarity around myths (Jones et al., 2021).

In the second study conducted by Jones et al. (2021), 1353 participants from Victoria, Australia aged 18 or older completed a survey. The participants were either autistic or a family member or caregiver of an autistic individual. The researchers collaborated with three autistic researchers who were not involved in the study to review the survey questions and review the results. The purpose of this study was two-fold. First, to promote autistic views and life experiences and secondly, to learn what those individuals wanted the public to know about autism. To achieve this purpose, the survey included questions about diagnosis, support/services, perceived community awareness, and what the subjects would like communities to know about autism.

Most respondents (92.8%) reported they received a formal diagnosis of autism, while 3.8% had not received a formal diagnosis and 1.3% were unsure. The researchers found it was more likely for those under the age of 24 to have a formal diagnosis. External services such as therapy, counseling, or a disability support person was reported by 88% of subjects. Of respondents who did not report external services, over half said they felt they need external support. Of those who received external services, 42.8% reported their level of support was inadequate. The report of inadequate support increased with the subject's age (Jones et al., 2021).

While most respondents agreed most of the community knew about autism, few reported believing that community members understood the affect autism had on their behavior or how to best provide support. Participants reported that difficulties autistic individuals experienced social situations was something they wished other people would understand. Anxiety about unexpected changes, needing extra time, and sensory sensitivity

were other challenges the autistic respondents wished community members knew (Jones et al., 2021).

The results of these two studies revealed several negative consequences when autism is not fully understood. The researchers were concerned about the lack of external or adequate support for individuals with autism. They discussed ways the government is fails to recognize the needs of autistic individuals, specifically autistic adults. The discrepancy in external services based on age was noted in secondary school. The researchers referenced lack of services in secondary school for autistic individuals and the impact that had on their post-secondary success. According to Jones et al. (2021), only 32.5% of autistic people in Australia received post-school qualification, compared to 66.2% of those with non-autistic disability and 70.1% of non-disabled students. Overall, Jones et al. (2021) exposed gaps between public awareness and the lived experiences of autistic individuals. These gaps suggested a superficial type of autism awareness in the Australian society.

Autism is most easily recognized by failure to meet milestones in early childhood. While a diagnosis often occurs during childhood, Evans et al. (2021), pointed out the increase in diagnoses during adulthood. Due to more accurately understanding the core features of autism, adult autism diagnoses have increased in the last decade. Evans et al. (2021) pointed out that there are two groups of adults who typically seek an autism diagnosis. One group may have missed an early diagnosis due to a lack of cultural awareness or restrictive criteria. The second group may have symptoms that presented subtly, which caused a failed early diagnosis. Little research has explored the adult diagnostic experience and levels of patient satisfaction (Evans et al., 2021).

The few studies in the United Kingdom explored the topic of adults who received a late autism diagnosis. Evans et al. (2021) illustrated how diagnostic experiences were likely to differ depending on the health care system and cultural determinates of each country. The researchers sought to explore the experience of autistic adults in New Zealand. The objectives of the study were to understand the individual experience of the diagnostic process, satisfaction with the process and post-diagnostic support stages, and to identify what impacted the satisfaction levels.

The researchers surveyed autistic adults 18 years or older, who received a formal autism diagnosis in New Zealand in the past 10 years and lived in New Zealand. The study included 70 autistic adults who completed a 65-question survey that took about 20 minutes. Questions on the survey explored how the subjects discovered the pathway to diagnosis, how straightforward the process was, the amount of time it took to get an assessment appointment, if participants sought a second opinion, the cost of the assessment process, the levels of stress experienced, and the level of coordination of post-diagnostic supports (Evans et al.,2021).

The aggregated results showed the average age the participants received an autism diagnosis was 33.5 years. Two-thirds of the participants reported satisfaction with the early query stage of the diagnosis process, yet, over half of the participants expressed confusion with the diagnostic pathway as they cited an unclear process. The average wait time for an initial diagnostic assessment experienced by the participants was less than six months (Evans et al., 2021).

When processing the results of the diagnostic assessment stage, researchers found that only 25% of participants received their autism diagnosis from the public health system of New

Zealand, the remaining participants used private health services. Travel time for participants to receive their diagnostic assessment averaged less than two hours. Considering who evaluated the participants, the researchers found the majority saw a psychologist, while a psychiatrist saw one-third of participants and 36.5% of participants saw other health professionals such as an autism specialist, general practitioner, or occupational therapists. Six participants sought a second opinion after receiving their initial autism diagnosis. On average, the entirety of the diagnostic assessment process took less than four weeks and cost \$600, the equivalent of \$400 American dollars. Participants reported the process was quite stressful, but overall reported satisfaction (Evans et al., 2021).

The results of the study showed dissatisfaction with the post-diagnostic support stage. This dissatisfaction came from a poorly coordinated system of supports. Participants reported a lack of support with post-diagnostic information regarding cognition, sensory, and gut health. Written information about autism was the only post-diagnostic support where participants noted satisfaction.

Overall, Evans et al. (2021) discovered levels of satisfaction in the early query and diagnostic assessment stages and low levels of satisfaction with the post-diagnostic assessment stages for adults with autism. The researchers credited the high levels of satisfaction in the early stages to the fact that most participants received an autism diagnosis when they initially sought assistance. They also discussed the possibility that New Zealand's comprehensive clinical guidance, which was available upon early query, may have impacted their findings.

The researchers found that a timely autism diagnosis strongly influenced the levels of participant satisfaction. The lack of multidisciplinary input during the diagnostic process does



not support international best practice. The researchers also discussed the heavy use of private health services as proof of lack of public health responsiveness. Researchers expressed a desire to increase the involvement of autistic adults in improving the quality of services and supports in New Zealand (Evans et al., 2021).

## Chapter III: Discussion and Conclusion

### Summary of Literature

The research from this literature review demonstrated the growing prevalence of autism, as well as differences in perceived stigma, healthcare, and education options for individuals with autism across the globe. One common theme found throughout the literature was the rising prevalence of autism. The phenomena of rising autism diagnoses were present in several studies and did not differ between cultures. The cost of care for individuals with autism is significant, as is the impact autism has on health care and educational systems. Because of the significance of autism, many researchers have conducted studies to discover the prevalence of autism in their respective nations to assist with making decisions about public funding and health care planning.

In all the reviewed literature, researchers found rising autism prevalence rates. Skonieczna-Zydecka et al. (2017), reported the global autism prevalence as 76 in 10,000. By 2018, global autism prevalence was reported to affect 1 in 88 children (Mithimunye et al., 2018). To extend existing research, Skonieczna-Zydecka et al. (2017), focused on the Pomeranian regions of Germany and Poland. Through the study, the autism prevalence in the Pomerania area was found to be 35 in 10,000. Özerk (2018) also found rising autism rates in Norway. Between the years of 2012 to 2016, the autism prevalence in Oslo, Norway doubled. In Australia, Jones et al. (2021) reported a 42% increase of autism diagnoses over the course of three years. Additionally, Mithimunye et al. (2018) reported that about 933 cases of autism were diagnosed each month in South Africa. While the growing prevalence of autism was a theme throughout the reviewed literature, several researchers also referred to a gap of autism

prevalence research outside of the Western world. Eze (2018) reported that there was an abundance of autism awareness and research in first-class countries, however, in developing countries, there was a lack of autism knowledge and autism prevalence studies. Similarly, Colic et al. (2022) reported that Eastern Europe has little research surrounding the topic of autism, including the prevalence of autism in the area.

Due to the lack of research on autism in non-Western cultures, the researchers conducted studies to gain greater understanding of autism across the globe. The stigma surrounding autism was another theme that arose throughout the literature review. For example, Sulaimani & Mursi (2022) reported that the Saudi Arabian culture projects stigma on individuals with autism, as well as their families. According to researchers, autism is considered unacceptable and a curse in Saudi Arabian culture. In Serbia, Colic & Milacic-Vidojevic (2021) conducted a study to learn about the quality of life and perceived stigma of individuals with autism. According to Colic & Milacic-Vidojevic (2021) families of children with autism in Serbia are blamed and believed to be contaminated by the autistic individual. In the Japanese cultural, high value was placed on conformity, which led to individuals with autism experiencing elevated levels of stigma (Porter & Loveland, 2019). In Brazil, Paula et al. (2020) reported that parents of individuals with autism expressed feelings of helplessness and discrimination.

Researchers reported that stigma towards individuals with autism was correlated with lack of autism awareness or education. Throughout the literature review, it became clear that education surrounding autism varied across the globe. In Greece, Kossyvaki (2021) reported that until 2000, there were no public-school options for autistic individuals. As of 2021, education options for autistic individuals had expanded, however, Kossyvaki (2021) noted that

many autistic children did not have access to appropriate special education. Likewise, Mithimunye et al. (2018) reported that in South Africa, specifically the Western Cape Province, not all schools accommodated learners with autism. In the same study, the researchers noted that parents of children with autism felt the education system was inadequate for serving their child's needs. Long waitlists, lack of inclusion, and teacher training were the main factors that contributed to the dissatisfaction of the education system (Mithimunye et al., 2018). Nunes & Walter (2020) reported similar findings in a study conducted in Brazil. Educators were surveyed to discover how AAC was used to support individuals with autism. The results showed that, educators reported feeling unequipped and unaware of how to communicate with or support students with autism (Nunes & Walter, 2020). In Russia, implementation of inclusion and education accessibility were rated low by stakeholders (Varlamov et al., 2020). The lack of inclusion and appropriate access to education, and appropriate teacher training, were common themes that emerged in the literature review.

Healthcare access and systems was another general theme that emerged in the literature. The autism diagnosis process is impacted by the quality of the healthcare system in a country along with intervention implementation and financial affordability. Because autism requires a variety of specific services, societal costs were high. Researchers estimated that it cost 1.4 million United States dollars to support an individual with autism (Höfer et al., 2022). The high societal cost of autism has caused piqued interest into how healthcare systems support individuals with autism. In Russia, early autism detection became a priority. Simashkova et al. (2019) reported that the Ministry of Health of the Russian Federation choose to begin the autism screening process at 18-24 months. In the federalist nation of Canada, each

province provides different levels of healthcare funding. According to Shepherd & Waddell (2015) provinces such as Nova Scotia and Ontario provide public intervention services for preschool children with autism, while in other provinces, such as British Columbia and Alberta, families receive funding towards private interventions. On the other side of the globe, Höfer et al. (2022) reported that most services are free to patients within the German health insurance system. Furthermore, services used by individuals with autism are reimbursed through health insurance funds. Additionally, psychotherapy in Germany was also reimbursed through health insurance funds (Höfer et al., 2022). The above examples demonstrate that access and cost of services for individuals with autism varies across the globe.

### **Professional Application**

The findings of the literature review have further implications for special education in the United States and in Minnesota. Each of the previously mentioned themes provide examples and lessons for individuals who work in education. As many researchers explained, understanding the prevalence of autism is vital to public funding and autism awareness. It is important to know the prevalence of autism in the United States. Knowing how many individuals are impacted by autism and how many individuals will need support services and interventions helps determine cost of care, which in turn, helps with government budget planning. It also helps schools plan for an accurate number of students with autism. It is reasonable to assume that accurate planning for autism services within a school would predict the number of staff needed and improve the appropriateness of support for students with autism. Therefore, it is important for autism prevalence studies to continue and be documented for public record.

There is also professional application from this literature review in regards to education children with autism. Several studies discussed stakeholder frustrations with the education system, specifically for individuals with autism. Lack of teacher training, inclusion, and accessibility were all themes important to ascertain from the research. Knowing that these areas are proven to have room for improvement, it is important to place greater value on training teachers with best practices for teaching and supporting individuals with autism. Additionally, it is important for teachers in Minnesota to be educated about cultures representing their students and to learn how best to serve a diverse group of students with autism.

#### **Limitations of the Research**

One limitation of the research was the lack of current research in large or prominent countries. I was surprised by how little research there was on autism in countries in South America, Europe, and in China. It was difficult to find current studies about autism prevalence, education, or perceptions in those areas of the world. With autism rates rising, I expected it to be easier to find research on the topic in most countries. I excluded some studies that were based in the West, as the goal of my research was to discover what autism looked like across the globe, not just in the well-researched Western world. I attempted to focus on research conducted in under-reported countries, specifically countries where the culture is different than the culture in Western countries. Due to this focus, I expected to find more research describing differences in autistic characteristics across the globe. While I found differences in diagnostic procedures and stigma surrounding autistic characteristics were found, I did not find any research that described differences in the core features of autism.

### **Implications for Future Research**

While the research I reviewed answered several questions, it also opened the door for future research. It is important that autism prevalence studies continue to occur across the globe, specifically in developing countries. Many of the prevalence studies I found through my research led to further investigation into funding, autism awareness, and stigma. The study of autism awareness across the globe should also continue to be explored, as increased autism awareness correlated with decreased stigma. Lastly, future research should continue to focus on the etiology of autism. Many of the studies I reviewed, reported confusion, and misunderstanding related to the cause of autism. Therefore, it is important that research continues to explore the topic.

### **Conclusion**

In conclusion, the goal of my research was to discover what autism was like across the globe. I found that while the core characteristics of autism remained the same across cultures, differences in diagnostic procedures, education, stigma, and services existed across the globe. Lastly, the way a culture perceived an individual with autism, often impacted other areas such as education, quality of life, and financial well-being. Overall, while autism exists across the globe, improvement is needed to understand autism characteristics and social stigma more completely to better support autistic individuals across the globe.

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