

Case Study 6: Autism Spectrum Disorder

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Community Case Study Scenario

Sam is a 3-year-old boy with a severe developmental disability (Autism). His mom is a single mother who works full time at a minimum wage job. They live in Madison County, Georgia.

Examine what is available and what is needed for them and other who are in this kind of situation.

Health Problem

What is Autism?

Autism spectrum disorder (ASD) is a spectrum of developmental disorders (National Institute of Mental Health, 2016). Individuals with autism are often characterized with deficits in three domains: social skills, communication, and repetitive behaviors or restricted interests (World Health Organization, 1994). Each case of autism varies, some individuals have mild cases on the spectrum and are high functioning while other cases are more severe and fall further on the spectrum. Autism can be treated with various behavioral interventions, behavioral therapies, educational interventions, or medications, although there is no known cure at this time. In the United States, 1 in every 68 children has been identified with autism spectrum disorder and approximately 3.5 million live with a form of autism spectrum disorder (Autism Society, 2014; Centers for Disease Control and Prevention, 2017). ASD is 4.5 times more prevalent in boys (1 in 42) than girls (1 in 189) (Centers for Disease Control and Prevention, 2017). ASD falls into the developmental disability umbrella, which affects 1 in 6 children in the United States. Developmental disabilities range from speech and language impairments to severe developmental disabilities, intellectual disabilities, cerebral palsy, and severe autism (Centers for Disease Control and Prevention, 2017).

Spectrum of Autism

Autism spectrum disorder has various subcategories along the spectrum depending on the severity of symptoms the individual presents. The American Psychiatric Association's Diagnostic and Statistical Manual fifth edition (DSM-5) provides standardized diagnostic criteria to define the three subcategories of Autism (National Institute of Mental Health, 2016).

Autistic disorder, also known as: childhood autism, early infantile autism, Kenner's syndrome or infantile psychosis all previously fell under the autistic disorder category, until the fifth edition of DSM revised it dissolving autistic disorder as a formal diagnosis and changing the diagnosis into autism spectrum disorder (National Institute of Mental Health, 2016). Autistic disorder is characterized by the 3 domains of diagnosis, and encompasses most of the ASD cases (National Institute of Mental Health, 2016).

Asperger's syndrome is a form of autism categorized by normal or above average intelligence levels (Autism Speaks, 2016a). This category of autism had a separate formal definition and the DSM-5 newly revised it to fall under the ASD spectrum (Centers for Disease Control and Prevention, 2016b). Asperger syndrome falls under the high functioning end of the spectrum, which is characterized by difficulty with social interaction, delay in motor development leading to clumsiness, restricted range of hobbies/interests, and no delays in speech development or exceptional speech development (Autism Speaks, 2016a). Individuals with Asperger syndrome may not pick up on social cues, nonverbal communication, or see situations in various perspectives, therefore leading to difficulty in social interactions (Centers for Disease Control and Prevention, 2016b).

Childhood disintegrative disorder (CDD) occurs more rarely and is characterized by the late onset of developmental delays in language, social, and motor skills (Charan, 2012). This sub-type of autism is characterized by normal development until approximately three years followed by a period of loss of previously acquired skills in several areas of development including speech, motor, and social (Charan, 2012). Additionally CDD can be associated with seizures and abnormal EEGs (Charan, 2012). Children with CDD have normal development of speech, motor skills, and social development up to 3-4 old and as old as 10 when they begin to

regress. CDD is the most rare of the subtypes within the spectrum affecting 1.7 per 100,000, which is 60 times less prevalent than Autistic Disorder (Fombone, 2002).

The last subtype within autism is pervasive developmental disorder (not otherwise specified) also known as PDD (NOS). PDD (NOS) is characterized by a pervasive neurodevelopmental disorder that differs from the more prevalent childhood autism. It differs because it fails to meet the three domains necessary for the diagnosis of autism, yet the individual has characteristic abnormalities of autism (Autism Speaks, 2016b). This atypical autism therefore falls within the spectrum, and has been referred to “sub threshold” autism, due to lack of/mild symptoms in one of the three domains (Autism Speaks, 2016b). This category is used when there is a significant impairment in the development of reciprocal interaction.

Signs and Symptoms of Autism

Autism symptoms can vary in severity and onset, therefore it is crucial for a parent to be able to identify symptoms in their child’s early years. Infants with autism spectrum disorder deviate from neuro-typical infants in their social communication and development skills. However, some children with autism spectrum disorder may develop at a normal rate aligning with their peers until they reach 2 years old, where their development will digress and the child will lose skills previously attained. A reliable and valid autism spectrum disorder diagnosis can be attained at the age of 24 months (Autism Spectrum Disorder, 2016). A child can display initial symptoms as early as 6 months old or as late as 3 years old. Initial symptoms at 6 months old include lack of eye contact (limited and nonexistent) and lack of expression (no smiling or laughing). Within neuro-typical 9 months old children, communication is fairly constant and engaging, through expressions or sounds. A neuro-typical 12 months old child, should also

respond when their name is called, engage in babbling, and communicate via hand motions or gestures. By 16 months old, a neuro-typical child should have progressed to the milestone of speaking words and if this milestone has not been reached, this may be indicative of autism. The last milestone for parents to look out for is when the child reaches 24 months, which should be the point in time when a child is able to communicate via phrases of at least two words. While development is different in every child, communication is a skill that should be progressively advanced around 24 months old. However, there are atypical cases in which a child will begin to exhibit positive communication skills up until a certain point and will then begin to digress and. In this scenario, there is a high likelihood that this is a symptom of autism spectrum disorder. Although an autism spectrum diagnosis is most common around 24-36 months, there is not definite age of onset, similar to the ranging spectrum of communication development in children.

While an autism diagnosis is highly reliant on a lack of communicative and interactive skills, there are also a multitude of other possible signs that parents should continue to look for throughout the remainder of their child's development. Some of these symptoms include avoiding eye contact, characteristics of enjoying being alone, inability to fully understand someone else's feelings, delayed language development, non-verbal behaviors, continual repetition of words and phrases, angry or upset behavior when a change in routine or surroundings is experienced, very limited interests, repetitive behaviors including spinning, rocking, and flapping, and uncharacteristic reactions to things such as sounds, smells, colors, tastes, or lights (Autism Spectrum Disorder Fact Sheet).

Autism is classified as a spectrum disorder, which categorizes signs and symptoms that one may express as ranging from very mild to very severe (National Autism Association, 2017). As early as infancy, one can begin to detect possible signs including: not responding to their

name, not pointing or demonstrating interest in any objects, not playing pretend games, avoiding eye contact, wanting to be alone, having difficulty understanding other people's emotions on their own, having no speech or delayed speech, echolalia: repeating phrases or words over and over, giving unrelated answers to questions, getting upset by minor changes or deviations in schedule, having obsessive interests, having under or over-sensitivity to how objects or environments look, smell, taste or feel, having low to no social skills, avoiding or resisting physical contact, demonstrating little danger awareness (Young & Nah, 2016). More severe signs of autism include hyperactivity, impulsivity, meltdowns, causing self-injury, aggressiveness, unusual eating habits, and unusual sleeping habits (Young & Nah, 2016). As important as detecting communicative shortcomings is in young children who may have autism spectrum disorder, being able to detect behavioral flaws is equally as important as autism is a spectrum disorder with ranging severity (Young & Nah, 2016).

Diagnosis of Autism

Diagnosing autism is increasingly complex because there is no medical test; therefore doctors must examine a child's development and behavior over time (Autism Spectrum Disorder, 2016). Older children are often diagnosed when a parent or teacher notices the differences in a child's behavior when playing, socializing and communicating. Diagnosing ASD in older adults is the most difficult due to the overlapping of other conditions such as schizophrenia or ADHD (Centers for Disease Control and Prevention, 2016a). Regardless of age or severity, diagnosis is determined based on the criteria laid out in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), which was updated in 2013 from the DSM-4.

ASD can be accurately diagnosed in children by 2 years old (Lord et al., 2006). Most fine motor, social, and communication developmental delays that occur in ASD are noticeable in a child by 6 months of age (Centers for Disease Control and Prevention, 2017). While ASD can be diagnosed early, most diagnosis does not occur until after the age of 4 (Centers for Disease Control and Prevention, 2017). The milder ASD, such as Asperger syndrome is not diagnosed until 6 years old on average (Centers for Disease Control and Prevention, 2017).

Diagnosis for young children is often a two-step process that consists of developmental screening and comprehensive diagnostic evaluation (Centers for Disease Control and Prevention, 2016b). Developmental screening measures the milestones a child must have, how the child plays, learns, speaks, and moves. Developmental screenings usually occur during well check ups at 9 months, 18 months, and 24 or 30 months (Centers for Disease Control and Prevention, 2016b). If a doctor detects delays during examination, a comprehensive diagnostic evaluation may be ordered.

Comprehensive diagnostic evaluations are more thorough in diagnosing ASD. The evaluation consists of a thorough assessment on a child's behavior and development and a parental interview. The assessment can also include hearing, vision, neurological and genetic testing (Lord et al., 2006). Comprehensive diagnostic evaluations are often conducted by specialists such as: developmental pediatricians, child neurologists, and child psychologists/psychiatrists (Centers for Disease Control and Prevention, 2016b).

Treatment of Autism

While there is no cure for ASD, intervention treatment may help prevent the developmental delays its causes ("Data & Statistics," 2016). From birth until the age of three, a

child undergoes significant development for which treatment for ASD assists. Medicine is not the first line of treatment as is true for other diseases. With ASD, there is no medicinal cure for the core symptoms ("Data & Statistics," 2016). If a child with ASD is on medication, it is often to help with function—such as to focus, to combat depression, or to prevent seizures. One of the most influential forms of treatment is Applied Behavioral Analysis (ABA) ("Data & Statistics," 2016). This treatment can be administered to a patient with ASD by ranging fields from healthcare professionals to schoolteachers. Other treatments may be administered in the form of occupational therapy, physical therapy, speech therapy and sensory integration therapy are all means of treatment that may need to be implemented depending on the severity of the child's ASD (Delobel-Ayoub et al., 2015). These may be administered in an array of settings but are usually expensive to the family and subject to healthcare coverage.

Frequently, children with ASD also have gastrointestinal disorders and require special diet ("Data & Statistics," 2016). In addition to the child's pediatric primary care provider, possible care provider's they may require include a dietician, occupational therapist, physical therapist, child psychiatrist, psychologist, gastroenterologist, speech pathologist and more. Regarding care, it is extremely important that children with ASD have a supportive home. Parents can be some of the most effective administrators of behavioral modification approaches. The care of a child with ASD is extremely labor-intensive and time demanding; this creates an intense need for community and organizational assistance. Different therapeutic options have been discovered that reduce the negative symptoms and improve the skills that many autistic individuals lack. Some other options for improving skills in individuals with autism include setting goals and applying a rewards system, using a multimodal communication system based on the individual such as using sign language and gestures along with spoken language as well as

stressing the importance of family involvement (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015).

Increased Risk

Autism alone rarely causes death, but individuals with autism are at a heightened risk for death due to injuries. Individuals with autism die an average of 35.8 years younger than the general population. Due to the increasing prevalence of autism over the years, deaths of individuals with autism have risen 7 times from 1999 to 2014. Deaths caused by unintentional injury is 3 times more likely for individuals with autism when compared to the general population. The leading injury related deaths for individuals with autism are suffocation, asphyxiation, and drowning (Guan & Guohua, 2017). Due to autism not having a cure, the best way to minimize the increased risk of death would be to increase access to targeted therapy.

There is no early indication of autism but there are circumstances, which increase the likelihood of incidence. Children who are either born to parents of older age or have a sibling that has previously been diagnosed with ASD both have an increased chance of being diagnosed with ASD. This is especially true for identical twins where the likelihood of one twin having ASD is 36-95% if the other twin is also affected (World Health Organization, 2013). It is commonly agreed that genetics play a large role in ASD, as proof with the identical twin ratio. It is also likely that ASD will occur in children with some other specific genetic or chromosomal condition such as Down syndrome, fragile X, or tubercolosis sclerosis (World Health Organization, 2013). Because any population is at risk for ASD, it is most important that they have access to helpful resources after they are experiencing it.

Cultural Impact

Prevalence and Socioeconomic Status

Autism spectrum disorder is a developmental disability with many known and unknown causes, risk factors, and influences, which affects 1 in 68 children in the United States (Centers for Disease Control and Prevention, 2016). Each individual with ASD falls along the spectrum at different points and thus has varying severity of their symptoms (National Institute of Mental Health, 2016). ASD occurs in all racial, ethnic, and socioeconomic groups, yet different demographics and access to healthcare result in deferred age of diagnosis and methods of treatment (Centers for Disease Control and Prevention, 2017). While there is no known cause of ASD, there are many risk factors that may make one more likely to develop certain types of ASD, including biological, genetic, and environmental factors. ASD affects boys at a disproportionate rate when compared to girls, with 1 in 42 boys having ASD in comparison to 1 in 189 girls with ASD; however, the reason for this is unknown (Centers for Disease Control and Prevention, 2017). Over the past 40 years, the prevalence of autism spectrum disorder has increased about 10-fold, yet the cause of this drastic increase remains unknown (King & Bearman, 2011).

Health is somewhat dependent on where a person lives, the resources around them, and socioeconomic status. Neighborhoods have a large impact on health because of the physical environment, social environment, and access to health services/medical care (King & Bearman, 2011). Demographically, ASD occurs in all races, ethnicities and socioeconomic (SES) groups. Only symptoms are more prevalent in poor SES areas because of lack of early treatment (World Health Organization, 2013). Boys have a significantly higher prevalence of ASD at 4.5 times more than girls (World Health Organization, 2013).

Parental Beliefs

Parental beliefs play a huge role in the increased social stigma surrounding children with autism spectrum disorder. Education levels of parents whose children are autistic is a critical factor in the time frame of which the child's developmental disorder will be diagnosed. In addition, parental education is normally correlated with a lower household income. When analyzing household income, a study found that parents who fall in the lowest income category (0-99% FPL) were more likely to believe that their child's condition was a mystery (Zuckerman, Lindly, Sinche, & Nicolaidis, 2016). A parent's likelihood to believe that their child's condition could be prevented or decreased with treatment. Researchers found that parents who fell in the lowest income category (0-99% FPL) were the least likely to believe that their child's condition could be prevented or decreased with treatment (Zuckerman et al., 2016). In addition, when analyzing parental education, those with a higher degree of education were more likely to have prevalent beliefs that the child's condition could be prevented or decreased with treatment on bivariate analysis (Zuckerman et al., 2016).

Parental education and household income levels have been found to play an important role in a child's likelihood to receive treatment and in which treatments the child will receive. One study analyzing treatments used/health services utilized found that if the parents of a child diagnosed with ASD believed that the condition was lifelong rather than temporary, they were more likely to have their child using one or more psychotropic medications (Zuckerman et al., 2016). However, if the parent believes that their child's condition is a mystery (these parents have been found to be in the poorest income category, 0-99% FPL), that they are less likely to treat their child with a behavioral modification (Zuckerman et al., 2016). When analyzing the use of psychotropic medication in relation to one's race, black non-Hispanics and Hispanic children

were found to use less psychotropic medication when compared to white children (Zuckerman et al., 2016). In addition, a lower rate of behavioral intervention or modification is seen in those who identified as non-white race/ethnicity (Zuckerman et al., 2016).

When comparing single mother's beliefs on childhood autism spectrum disorder to a 2-parent biological/adopted family's beliefs, their percentages are very similar. The percentage of single mothers who definitely agree their child's condition is likely to be lifelong rather than temporary is 74.8%, which is higher than 69.8%, which is the percentage of 2-parent families with this same belief (Zuckerman et al., 2016). In addition, the percent of single mothers whose children are currently taking one or more psychotropic medication type(s) on a regular basis is 60.2% compared to 2-parent families with only 47.7% of their children following this same pattern (Zuckerman et al., 2016).

Social Stigma

The stigma surrounding children diagnosed with ASD is strongly associated with the increasing difficulty of treating and raising children with ASD. The social stigma towards ASD includes isolation, exclusion, and stereotyping, which lead to the exclusion of these children from social settings (Kinnear, Link, Ballan, & Fischbach, 2016). Parents and siblings of individuals with ASD often receive associative stigma from being associated with ASD and feel as if they are being blamed for the bad behavior (Kinnear et al., 2016). The lack of understanding and social support adds to the difficulty of raising a child with autism spectrum disorder (Kinnear et al., 2016). In addition, individuals with autism have difficulty detecting social cues, working out conflicts, and asking inappropriate questions, which can make them susceptible to peer conflict and bullying (Tonnsen & Hahn, 2016). Much of the social stigma surrounding

autism occurs due to common misconceptions as a result of people who are unaware of the what autism really is. Their lack of understanding can lead to many problems for the children diagnosed with and the families who have a child diagnosed with ASD.

Treatment Access

Early diagnosis of autism spectrum disorder can lead to earlier treatment and support to help the child progress as far as individually possible. Treatment is most effective if started by age 3 although there are various factors that influence the ability to properly diagnose and treat ASD. The cost of raising a child with autism can cost around \$17,000 per year due to supplemental educational material and ASD related healthcare costs (Lavelle et al., 2014). Children with autism have higher levels of doctors visits and prescription drugs, require more supplemental educational material, and demand more time from their caregivers to take off work in comparison to the general population (Lavelle et al., 2014). For a family that is living beneath the federal poverty level, the cost would altogether prevent access to treatment and possibly proper diagnosis. If a child with ASD's family does not have health care insurance or if their plan does not cover proper treatment/specific specialists needed, a further lack of access to treatment will be experienced; thus, causing more problems altogether for the child and family (Chiri & Warfield, 2012). Even if a family is covered with insurance, the location of these specified services could also become a hindrance to the access and quality of care. The difficulties in accessing transportation, lack of public transportation, and lack of availability of specialists quickly become a barrier to access services for ASD (Chiri & Warfield, 2012).

Needs Assessment

Sam's mother has noticed severe developmental delays while taking care of Sam. Although she may not know fully that it is Autism Spectrum Disorder, his symptoms are consistent with the criteria. To begin the process, Sam would need a formal diagnosis, which would imply that his mother would need access to health care. A formal diagnosis of severe ASD would primarily affect Sam and his mother.

Sam

To achieve a full scope of Sam's needs, it is important to first get a proper accurate diagnosis and track his developmental progress as he continues to age. He will need a variety of supports to get properly diagnosed with ASD and take the Developmental milestone treatment test. After diagnosis he can get referrals to specific doctors, programs, and resources specific to severe Autism Spectrum Disorder from the pediatrician or doctor that diagnosed him.

Due to Sam having severe autism spectrum disorder, Sam will need a variety of supports and therapies. These supports and therapies will require access to healthcare and health insurance. Sam could need pediatricians, speech pathologists, nutritionists, developmental neurologists, geneticists, psychologists, and psychiatrists. He will require an array of different therapies and access to those therapies. Due to his rural location, there may be a low availability of those resources in his area. Finding a way to access affordable healthcare and health insurance will be crucial for Sam's development, as well as accessing the correct doctors and therapists. Health resource persons will be necessary in navigating S-CHIP/PeachCare so that Sam is able to receive the benefits he is eligible for.

Sam's age and diagnosis make him eligible to begin preschool early. It is crucial that Sam is able to receive specialized care and an individualized education plan once he enters into school. The teachers, educators, and psychologists in the education settings would be able to further refine specific skills and assist with any developmental delays.

Sam's Mother

Being a single mother working full time at a minimum wage job, finances will need to be taken into consideration. Sam's mother is going to require housing assistance in order to find more affordable housing so that a segment of her income could go towards additional health costs associated with Autism. The federal poverty level for a family of two is \$16,240. Sam's mother earns a yearly salary of \$15,080, making her eligible for subsidized housing.

Unfortunately, there is no subsidized housing available in Madison County. It is important that the housing be located in a place that could be near her job and/or the health care resources that Sam will need. The housing that Sam's mom is able to receive will determine what type of environment Sam will grow up in. The housing can determine Sam's safety, ability to play outside, and interconnectivity within the neighborhood. Additionally assistance with utility bills may be an additional need.

In addition to potential housing assistance, food subsidies may be necessary to supplement Sam and his mother's diet due to the extremely low income. Sam's mother will have a low proportion of her income available for the nutritious food due to high costs of rent and healthcare services that she will need for Sam. Single mother households have had the highest rates of child food insecurity at 18.7% (Miller, Nepomnyaschy, Ibarra, & Garasky, 2014). If she can qualify for federal or local food aid, it would alleviate some of her costs. Additionally,

children with autism can have sensory difficulties in relation to food, therefore making feeding habits increasingly difficult and oftentimes more expensive (Marci Wheeler, 2004; Washbrook, Waldfogel, Bradbury, Corak, & Ghangro, 2012).

Aside from Sam's mother's financial situation, being a single mother of a child with a disability can cause chronic stress. Literature reflects that parents of children with Autism experience higher levels of stress than parents of neurotypical children (McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017). Sam's mother may not have the necessary time and financial resources to properly handle a child with Autism alone. Besides working a fulltime job, she will have to invest extra time with her son and the treatments he will need. On average, mothers with children who are mentally disabled engage in childcare activities 13.1 hours more per week compared to mothers of children with no disabilities (McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017). Unfortunately, this means that there is a reduction of time available to her for other daily activities. If Sam's mother does not find a proper way to cope, her chronic stress could lead to other health issues that could interfere with her own care as well as Sam's. Single mothers are put under prolonged stress due to single-handed child care and long work hours, which can negatively affect their health as well as their children's health (McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017).

Financial need will be one of the biggest barriers for Sam's mom when navigating all the services Sam will require. Assistance from the father would alleviate some of the costs. This financial support would come in the form of child support. If the father is not willing to cooperate, legal assistance may be necessary to track the father or demand specific performance of his payment. Due to the financial conditions of the Sam and his mother, hiring legal aid may not be a possibility; therefore they may have to use pro-bono attorneys or governmental help.

While Sam's mother is working during the day, he is going to need someone to care for him. A community support network is crucial for Sam's mother to be able to work long hours while knowing her child is getting the proper care he needs. Lack of informational, emotional, appraisal, and tangible support results in daily stressors. These stressors can cause feelings of low self-esteem, isolation, depression, and concern that she is not a good mother (Campbell-Grossman, Hudson, Keating-Lefler, & Fleck, 2005). Having a young child with Autism is already distressing and having a strong relationship with her neighbors and community will help to significantly reduce this stress.

Living in a rural area of Georgia, Sam's mother is going to need access to transportation in order to get to and from necessary locations. One option is public transportation such as bus services. Buses are typically very efficient and affordable. However, the area where Sam and his mother are from is not very populated and public transportation may not be an option. In this case, Sam's mother would need to have access to a car. In her situation it would be best for her to purchase or rent an affordable car with high gas mileage. There also could be resources of nonprofit organizations or health care providers that can help provide transportation or come to her home for Sam's needs. It is crucial for transportation to not be a barrier to accessing the health services Sam will need.

Community Resources

Advantage Behavioral Health Systems

Advantage Behavioral Health System is a governmentally funded provider of behavioral health, developmental disability, and addictive disease services. Governed by a Community Service Board comprised of members from the counties that Advantage Behavioral Health Systems serves, a multitude of services is provided to patients. Advantage offers outpatient clinical services for individuals with mental health and addictive diseases. These outpatient clinics provide needs assessments, education, and crisis services as well as manage medication (Advantage Behavioral Health Systems, 2017c).

Advantage has specific programs for children including assessment of needs (diagnosis), therapy and supports, outreach supports, and medical services. With assessment of needs, a master's level clinician will assess a family's strengths and needs, develop a specific plan to deal with the family's needs and challenges, and connect the family with the services necessary. At advantage, the physician's conduct comprehensive psychological evaluations. After assessment, there are a variety of services and therapies offered including clinic-based individual and family therapy, school-based therapy, individual community support, and group therapy. Additionally, Advantage serves as outreach supports to other community resources including schools, hospitals, private providers, medical professionals, public agencies, and local non-profits to help with a community need or individual cases. This outreach helps coordinate services and resources for individuals (Advantage Behavioral Health Systems, 2017a).

Advantage has programs in place for adults with special needs to learn how to better manage everyday tasks such as taking care of their home, cooking, nutrition education, managing

medications, and organizing their finances. Advantage offers different levels of support based on the need of the adult with a developmental disability. Additionally they have programs for supported employment (Advantage Behavioral Health Systems, 2017b).

Supported Employment Services within Advantage offers help to adults with special needs to learn skills necessary for job searching, interviewing, and computer skills. Supported Employment Services has a network of employers in order to find employment opportunities for adults with special needs. The extended services offered include job coaching, education, and ongoing communication with the future work supervisor (Advantage Behavioral Health Systems, 2017d).

Although Sam may not be eligible for the adult services until he is much older, this would be a good resource once he ages out of the specialized education system and there is no place for him to go. If he is low functioning on the autism spectrum, it would be valuable for him to learn basic skills to be able to do a service or retail job while/if his mother continues to work as well as complete basic tasks around the house. Overall Advantage works with individuals to establish/sustain/extend independent functioning in the community as much as possible. For people living in Madison County, Georgia the closest Advantage Behavioral Health Systems office is located in Athens, Georgia.

Athens Neighborhood Health Center (ANHC)

Athens Neighborhood Health Center provides people with low-income in the Athens-Clarke County and surrounding areas with affordable, high quality primary healthcare. By assigning uninsured or underinsured individuals to a sliding fee scale, the Athens Neighborhood Health Center is about to make healthcare affordable. Medicare, Medicaid, and other insurances

are also accepted. This private, non-profit organization provides evidence-based care, patient/family education, and self-management support. ANHC includes services ranging from primary care for all ages to chronic care, as well as laboratory services, immunizations, and mental health. Additionally, a wide variety of programs are also provided such as the Athens Neighborhood Youth Leadership Academy where youths are taught leadership and everyday life skills. Another important program provided is the Health Care Financial Counseling and Insurance. Included in the staff are certified Health Plan Navigators that can help with enrollment services for the Affordable Care Act, Medicare, Medicaid, and Children's Health Insurance Program (Center, 2017). The Athens Neighborhood Health Center can be physically accessed at their Athens location by personal transportation. While there is public transportation in Athens-Clarke County, someone living in Madison County would have to be able to transport themselves into Athens and to a bus stop that would be able to bring them to the Athens Neighborhood Health Center.

Connections for Special Parents (CSP)

Connections for Special Parents is a group created to establish fellowship and support from other families who also have children with special needs. This group is organized to provide successful parenting tips and information, ways to give their child with special needs an opportunity for greater inclusion in school and community events, provide information on resources that will help each child meet his/her full potential, as well as provide information that will help the parents gain the necessary skills needed to become more effective advocates for their child. This group hosts many camps and events throughout the year to allow the families to get to know each other and the children to learn the necessary life skills. Parent support meetings

are also provided where guest speakers present information on IEPs, Medicaid, financial planning, and advocacy strategies (Connections for Special Parents, 2017). While Connections for Special Parents is a great resource for families with disabled children, the physical location is in Royston, Georgia, which would only be accessible by personal transportation. This resource may not be physically accessible to a family who must rely on public transportation; however, Connections for Special Parents can still provide resources over the phone, online, or through the use of social media for those who cannot physically access the location in Royston, Georgia.

Easter Seals North Georgia

Easter Seals North Georgia is a non-profit organization that provides children with disabilities and their families' equal opportunities to live, learn, work and play in their communities. Health professionals, therapists, and teachers work with each person to help them overcome obstacles and reach goals. Family members are also included and offered support. The provided services include early education and care for children ages six weeks to five years and support services for all ages, including the families with children with special needs.

Easter Seals North Georgia provides support services to all members in a family with a disabled child, regardless of their income or ability, to help them become self-sufficient. Specifically for autism, Easter Seals North Georgia has the Play and Language for Autistic Youngsters (PLAY) Project. The PLAY Project trains parents of children with autism so they can implement therapy at home. Being in a familiar environment allows the children to feel comfortable and be themselves. The project aims to improve language, social, and play skills for the children. Fortunately, this project is highly cost effective, making it a significant resource for families with low-income (Easter Seals North Georgia, 2017). Allowing parents to so easily

incorporate and deliver this type of intervention and therapy into the daily lives of their child diagnosed with ASD progresses their child's development tremendously. Once the PLAY therapists have fully trained the parents, the parents are then able to administer the much-needed 20-30 hours per week of therapy to their children.

The Madison County location of Easter Seals North Georgia is located in Danielsville, Georgia, which would be physically accessed by personal transportation. However, Easter Seals North Georgia has a website that is easily accessible and provides people seeking their services with very useful online resources. The website contains an eNews letter, access to their blog, a Facebook group for support groups/services, and many ways to connect with Easter Seals North Georgia if one cannot access one of the physical sites.

Marcus Autism Center

Marcus Autism Center is a non-profit center formed from a subsidiary of Children's Healthcare of Atlanta. The goals of the center are to provide access and resources to parents and children affected by Autism Spectrum Disorder. Marcus is one of only three National Institutes of Health Autism Center of Excellence (Marcus Autism Center, 2017). Marcus Autism Center provides resources on government, financial, and legal assistance for families with ASD that are available both at the center and easily accessed online. They also provide access to current research studies that are amongst the most innovative in the country. While research can be an effective means of the most current treatment, only five percent of parents with a child with ASD pursue research. The Marcus Autism Center seeks to expand this participant level in the Atlanta and metropolitan Atlanta areas (Marcus Autism Center, 2017). They conduct caregiver workshops and informational sessions both at the center and in the community to expand not

only knowledge about ASD, but the developmental issues that may also occur. While this is a significant resource for Autism Spectrum Disorder in the state of Georgia, it may be difficult to access from far, rural communities or by public transportation. Despite this, there are many resources available online and a few are in-home specific.

Medicaid

Medicaid is a joint state and federally funded program designed to provide health insurance for low-income people. Today, it provides health coverage to 72.5 million Americans including children, pregnant women, parents, and seniors with disabilities. This program was authorized in 1965 by Title XIX of the Social Security Act and was reformed in 2010 by the Affordable Care Act. Every state has different Medicaid provisions and eligibility requirements based on the decision to expand or not. In Georgia, children eligible for Medicaid would be placed under Georgia's State Children's Health Insurance Program: PeachCare for Kids (Medicaid, 2017). As a child with ASD gets older and ages out of PeachCare, Medicaid would aid him or her with healthcare coverage but not any institutional fees or long-term care. Sam's mother would not be eligible for Medicaid in Georgia although she meets the FPL requirements of low income because she is not pregnant, blind, a child or teenager, 65 or older, have a disability, or need nursing home care. If Georgia were to expand Medicaid or Sam's mother was living in a different state that expanded, Sam's mother would have health insurance under Medicaid. Sam would be eligible for Medicaid because he is a child, has a disability, and comes from a household of lower income. Additionally, there have been provisions made to Medicaid such as Katie Beckett that would allow for Sam to receive Medicaid regardless of parental income due to his neurodevelopmental disability.

Medicaid: Katie Beckett Medicaid Program

The Katie Beckett Medicaid Program is a national health insurance program implemented by each state that allows Medicaid services available to certain disabled children, which only takes the child's income and/or resources into consideration ("TEFRA", 2016). The purpose of the program is to provide benefits to certain children under the age of 18 who qualify as disabled individuals and who live at home rather than in an institution and whose parents make too much for them to be covered under Medicaid ("TEFRA," 2016). These income qualifications are solely based off of the child's income, however, a number of different factors are considered for approval. Sam would be a great candidate for the Katie Beckett Medicaid Program due to his amount of assets being low enough to deem him eligible for this program. For Sam, Katie Beckett could provide Sam and his mother with coverage for all medications and treatments. In addition, Katie Beckett can provide a means of transportation for Sam and his mother to and from any medical appointment or resource for his disability (Whitaker, 2017).

Northeast Georgia Health District

Northeast Georgia Health District is a governmentally funded, public service whose goal is to offer free or low-cost services to all people within their area and to promote healthy lifestyles among all members of their community. They offer a range of services and district wide programs that are available to residents of all ages in the ten Northeast Georgia counties. Some of their district wide programs include Babies Can't Wait, Children First, Children's Medical Services, and Women, Infants, and Children (WIC) Supplemental Nutrition Program. Although the Northeast Georgia Health District has its own main office located at the Madison

County Health Department in Danielsville, Georgia, each of the district wide programs have their own regional offices located at various locations throughout Madison County, Georgia.

Northeast Georgia Health District: Babies Can't Wait

Babies Can't Wait is Georgia's statewide service providing a wide range of services for infants and toddlers with developmental delays or disabilities. These services are allowed to start at birth and continue up to the child's third birthday. To be eligible to receive services from Babies Can't Wait, children must meet one of the two following criteria: 1) have a diagnosed physical or mental condition which is known to result in a developmental delay, or 2) have a diagnosed developmental delay confirmed by a qualified team of professionals (Northeast Health District, 2015a). Some of the services that Babies Can't Wait provides to these infants and toddlers includes the care of a highly-skilled team of physical therapists, occupational therapists, speech/language pathologists, special instructors, service coordinators, and others in order to help promote the families' needs to further their child's development to achieve their maximum potential.

In Sam's scenario, Babies Can't Wait would be an incredibly resourceful service to use that is free of charge. Babies Can't Wait provides a service that allows the highly skilled team of professionals to come to the families' houses and formally diagnose the child with their respective developmental disease. This service is free of charge and incredibly convenient in allowing the service to be provided in a comfortable environment for the child (Whitaker, 2017). In addition, through the formal diagnosis conducted by a highly skilled member from Babies Can't Wait, Sam would qualify for an early intervention program that entails an enrollment in Pre-K for children with disabilities. This early intervention Pre-K utilizes speech therapists,

occupational therapists, and physical therapists if needed (Bulmer, Irfan, Barton, Vancour, & Breny, 2010; Whitaker, 2017).

The evaluation and coordination for Babies Can't Wait are provided at no cost and services are provided on a sliding fee scale (Northeast Health District, 2015a). Babies Can't Wait has an office located in Bogart, Georgia that is easily accessible for residents of Madison County, Georgia.

Northeast Georgia Health District: Children First

Children First is Northeast Georgia Health District's district wide program responsible for providing families with resources to help improve health and developmental outcomes for infants and children. This program is free and considered voluntary for families who wish to participate (Northeast Health District, 2015b). In order to be eligible for Children First, the infant or child must be under the age of 5 years and at risk for poorer health or developmental outcomes. Social, economic, or health conditions are all potential factors that put the child's health and development at risk. Normally a referral is made concerning a child who may be experiencing poorer health or developmental outcomes. Once the referral is received, a Coordinator from the program will contact the family and schedule a home visit with a developmental specialist in order to assess the child's behavior. If the specialist identifies a potential developmental delay or medical condition, the family will be connected to a program/agency with which the child and family will receive assistance. Children First also encompasses First Care, a program designed to help families with infants who are at a higher risk for poor health outcomes, with a more intense care plan and support system. First Care schedules regular nurse visits at the family's home in order to allow the parents to ask questions regarding

their baby who was most likely born very small or very early. Similar to Children First, First Care is also both free and voluntary and will help parents contact community resources and services that will be of use to them. Both programs, Children First and First Care, have accessible resources and services for residents of Madison County located at the Children First office in Athens, Georgia.

Northeast Georgia Health District: Children's Medical Services

Children's Medical Services is a statewide public health program created to provide a comprehensive system of quality specialized health care services for eligible children in Georgia. These children must be a Georgia resident, have a chronic medical or handicapping condition(s), be between the ages of birth-21 years, and live in a household with low-income (Northeast Health District, 2015c). Eligible medical conditions include burns, cardiac, and chronic lung; craniofacial anomalies; orthopedic and neuromuscular disorders; and neurological and neurosurgical disorders (Georgia Department of Public Health, 2014). This program is very important in order to enable children to receive quality medical services and alleviate stress of payment for services. Children's Medical Services provide a wide variety of services including physical assessments, medical/diagnostic testing, care coordination, referral to community/appropriate resources, health education, nutrition services, financial assistance, and ongoing healthcare supervision (Northeast Health District, 2015c). All Children's Medical Services distributed within the Northeast Georgia Health District, specifically Madison County, are accessible from the Clarke County Health Department in Athens, Georgia.

Northeast Georgia Health District: Women's, Children's and Infants (WIC) Supplemental Food/Nutrition Program

Northeast Georgia Health District's district wide program to aid in Women's, Children's and Infants (WIC) Supplemental Food/Nutrition Program is in place to provide women and children in families with low-income a healthy start to life. This federally funded health and nutrition program's purpose is to educate pregnant women, new mothers, and young children (ages 1-5 years) about nutritious food supplements and nutrition itself. Eligibility for WIC programs is dependent on one of two criteria: 1) the candidate must be a pregnant, breastfeeding, or postpartum women with low-income, or 2) the candidate must be a parent or guardian with low-income who is the sole provider of children under the age of 5 who are at nutritional risk and who are at or below 185% of the federal poverty line (Northeast Health District, 2015d). Those who are eligible for the WIC Supplemental Nutrition Program will receive information about nutrition to help mothers and their families eat well and make healthy dietary decisions with the aid of special checks only able to be spent on healthy foods from WIC-authorized vendors (foods include milk, eggs, bread, cereal, juice, peanut butter, etc.), support and information about breastfeeding new babies, and help in finding health care and other community services that their family may need (Northeast Health District, 2015d). For Madison County residents, their local WIC Clinic is located at the Madison County Health Department WIC Clinic and Breastfeeding Center in Danielsville, Georgia.

PeachCare for Kids

PeachCare for Kids is a State Children's Health Insurance Program (S-CHIP) for uninsured children living in Georgia. In order to be eligible for PeachCare for Kids, the child

must be a United States citizen or qualified immigrant, a Georgia resident, under 18 years of age, and have a family income level less than or equal to 247% of the federal poverty level as of January 1, 2015 (Georgia Department of Community Health, 2017). This program provides uninsured children with health benefits including primary, preventive (including immunizations and regular check-ups), specialist, dental and vision care (including screenings and eyeglasses). Coverage also includes hospitalization, emergency room services, prescription medications, and mental health care for all children.

Funding for PeachCare for Kids is provided by three main sources: the state of Georgia, the federal government, and premiums collected for children ages 6 through 18. Premiums and co-payments are incredibly decreased for any child receiving health care insurance through PeachCare for Kids. Children under the age of 5 are not required to pay a premium at all. However, children ages 6-18 have a monthly premium based on their household income with monthly premium coverage's ranging from \$11-\$36 for one child and a maximum of \$72 for two or more children living in the same household (Georgia Department of Community Health, 2017). Co-payments will differ depending on the medical services the child is receiving. Emergency services, preventive care services (routine check-ups), immunizations, and routine preventive and diagnostic dental services (oral examinations, prophylaxis and topical fluoride applications, sealants, and X-rays) are all services that do not have a co-payment. Children who are in foster care or who are American Indians or Alaska Natives will never have a required co-payment. To apply for PeachCare for Kids as a resident of Madison County, Georgia, applications are available online; however, they do have an in person office in Atlanta, Georgia. For someone relying on public transportation who lives in Madison County, they may need to focus more on the resources that PeachCare for Kids has online.

Supplemental Nutrition Assistance Program

The Supplemental Nutrition Assistance Program (SNAP), also known as food stamps, is a federally funded program that provides residents of Georgia who have low-income with monthly benefits to help afford the cost of food. Federally, SNAP is funded and administered by the United States Department of Agriculture; although, in Georgia, SNAP is administered through the Department of Family and Child Services. Eligibility is fairly reliant upon household income, considering a household as any amount of individuals, related or unrelated, living and routinely purchasing meals together. To be eligible, a household must have a gross income that falls below 130% of the federal poverty guidelines (Huppertz, 2016). Another factor taken into account when analyzing eligibility is a household's "countable resources" (Huppertz, 2016). A household's "countable resources" cannot be more than \$2,250.00, not counting one's house or land (Huppertz, 2016). United States citizenship is not an eligibility requirement, but legal alien status and a social security number are requirements to receive SNAP benefits.

In Georgia, once the candidate has been deemed eligible to receive Supplemental Nutrition Assistance Program (SNAP), they will receive an Electronic Benefit Transfer card with your monthly benefits. This Electronic Benefit Transfer card can be used at most grocery stores and farmers market like cash. Although this money can be used as if it were cash, there are regulations placed upon the items available for purchase with the card. No paper products, medicine, toiletries, alcohol, cigarettes, tobacco, pet food, or holiday decorations are acceptable to be purchased with the Electronic Transfer Benefit Card. According to Fiscal 2017, \$252.80 was the average national household monthly payout of SNAP benefits (Huppertz, 2016). The Madison County Department for Family and Children Services (DFCS) is the residing in person

location for Madison County residents to apply for Supplemental Nutrition Assistance Program benefits.

Temporary Assistance for Needy Families (TANF)

Temporary Assistance for Needy Families (TANF) is a state program in Georgia created to provide time-limited cash assistance to eligible children in families with very low income. This program was created in 1996 as part of the welfare reform legislation. Eligibility is dependent upon multiple criteria including age, deprivation, income, and citizenship. For age, a child applying to receive TANF benefits must be under 18 years of age. For citizenship, the child must be a citizen of the United States or a lawful resident alien. There are three possible ways in which a child can meet the deprivation requirement, stating that a child must be deprived due to: 1) continued absence from the home of at least one parent, 2) physical or mental incapacity of at least one parent, or 3) death of a parent (Division of Family and Children Services, 2017). When analyzing income, TANF assesses the net income of an assistance unit adjusted for the number of people in the assistance unit. For people living in Madison County, Georgia, they would be able to apply for Temporary Assistance for Needy Families in person at the Madison County Health Department.

Resources Handout

ADVANTAGE BEHAVIORAL HEALTH SYSTEMS

250 North Avenue, Athens, GA 30601

Phone: 1-855-333-9544; Fax: 706-389-6740; Web Address: <https://www.advantagebhs.org/>

Advantage Behavioral Health Systems' office is located in Athens, Georgia for those residing in Northeast Georgia, including Madison County. Advantage Behavioral Health Systems is a tax supported community agency that operates 19 clinics within 10 counties of Northeast Georgia. Advantage offers an array of services for children including needs assessments, therapies and support (clinic-based individual and family therapy, school-based therapy, individual community support, and group therapy), outreach support, and medical services. They offer adult behavioral services that would be applicable to autism such as skill building, employment assistance, and clinical services.

ATHENS NEIGHBORHOOD HEALTH CENTER- EAST

402 McKinley Drive, Athens, GA 30601

Phone: 706-543-1145; Web Address: <http://www.athensneighborhoodhealth.com/>

Athens Neighborhood Health Center provides people with low-income in the Athens-Clarke County and surrounding areas with affordable, high quality primary healthcare. Provided services include comprehensive adult primary care for ages 18 and up, primary care for ages 2 and up, pediatric care from birth to age 18, acute care, chronic care, medication program services, laboratory services, immunizations, and mental health services.

BABIES CAN'T WAIT

202 Ben Burton Circle, Bogart, GA 30622

Phone: 706-369-6101; Web Address: <https://dph.georgia.gov/Babies-Cant-Wait>;

Babies Can't Wait is one of Northeast Georgia Health District's federally funded district wide programs that provides a special needs screening service for eligible children under age 3. If a child is deemed eligible to receive services from Babies Can't Wait, they will be provided with a highly skilled team consisting of physical therapists, occupational therapists, speech/language pathologists, special education instructors, service coordinators, and any other team members needed. Babies Can't Wait provides evaluations for free and the remaining services that are needed are provided based on a sliding fee scale.

CHILDREN FIRST ATHENS

330 Research Drive Suite 130, Athens, GA 30605

Phone: 706-227-7182; E-Mail: rjodonnell@gdph.state.ga.us

Children First is a district wide program implemented by the Northeast Georgia Health District. This program offers children under the age of five to be referred and then analyzed for developmental delays or medical conditions through a behavioral analysis. If a developmental

delay is found, coordinators from Children First will connect the family with the necessary programs and agencies to aid their child in treatment. All services offered by Children First is free of cost and is considered to be voluntary involvement from the parents and children.

CLARKE COUNTY HEALTH DEPARTMENT (Children's Medical Services)

345 N Harris Street, Athens, GA 30601

Phone: 706-389-6921; Fax: 706-389-6897; Web Address:

<http://publichealthathens.com/wp/clinics/health-departments/clarke-county/>

Children's Medical Services is located at the Clarke County Health Department in Athens, Georgia. Children's Medical Services is a statewide public health program created to provide a comprehensive system of quality specialized health care services for eligible children in Georgia. This program offers services including physical assessments, medical/diagnostic testing, care coordination, referral to community/appropriate resources, health education, nutrition services, financial assistance, and ongoing healthcare supervision.

CONNECTIONS FOR SPECIAL PARENTS

56 Franklin Springs Circle, Royston, GA 30662

Phone: 706-498-2104; Web Address: <https://www.autismspeaks.org/resource/connections-special-parents-csp>

Connections for Special Parents' office is located in Royston, Georgia as the nearest accessible location for those residing in Madison County, Georgia. Connections for Special Parents is a group created to establish fellowship and support from other families who also have children with special needs. This group hosts many events such as summer day camps, after school connections, talent and art shows for the children, parent support meetings, community involved day events, holiday parties, and yoga.

EASTER SEALS NORTH GEORGIA

85 Rock Quarry Road, Danielsville, GA 30633

Phone: 706-795-2092; Fax: 706-795-2160; Web Address:

<http://www.easterseals.com/northgeorgia/>

Easter Seals North Georgia has various locations throughout North Georgia; with the closest location to Madison County being in Danielsville, Georgia. Easter Seals is a non-profit organization that provides children with disabilities and their families' equal opportunities to live, learn, work and play in their communities. The provided services include early education and care for children ages six weeks to five years, early intervention in-home therapies for newborn to three years, and support services for all ages. Specifically for autism, there is the Play and Language for Autistic Youngsters (PLAY) Project which trains parents of children with autism so they can implement therapy at home as well as improves language, social, and play skills for the children.

Katie Beckett Medicaid Program

5815 Live Oak Parkway Suite 2-D

Norcross, GA 30093

Phone: 678-248-7449; Fax: 678-248-7459

Katie Beckett Medicaid Program was implemented in order to assist children whose families' low-income doesn't allow them to qualify for Medicaid, with obtaining health care coverage. In order to assist these children, they must have an identified disability and the severity of the disability must allow them to still live at home.

MADISON COUNTY DFCS (Supplemental Nutrition Administration Program)

Courthouse Square, Highway 29, Danielsville, GA 30633

Phone: 1-877-423-4746; Fax: 706-688-0451; Web Address:

Madison County DFCS is the in person location for Madison County residents to apply for the Supplemental Nutrition Assistance Program (SNAP), the food stamp program. This program is administered by the United States Department of Agriculture (USDA) and is distributed by each state office. The Supplemental Nutrition Administration Program is a federally funded program implemented to provide residents of Georgia who receive a low-income with monthly benefits to help afford food. In Georgia, SNAP is administered by the Department of Family and Child Services and requires an application to be filled out and turned in in person. Once an application has been accepted and the applicant has been deemed eligible to receive SNAP, they will receive an Electronic Benefit Transfer card with their monthly benefits. The card is able to be spent at most local grocery stores and farmers market but does regulate what can be purchased with the funds.

MADISON COUNTY HEALTH DEPARTMENT (Northeast Georgia Health District)

1424 Highway 98 West, Danielsville, GA 30633

Phone: 706-795-2131; Fax: 706-795-2632; Web Address:

<http://publichealthathens.com/wp/clinics/health-departments/madison-county/>

Northeast Georgia Health District is located at the Madison County Health Department for those who reside in Madison County, Georgia. Northeast Georgia Health District is a governmentally funded, public service whose goal is to offer free or low-cost services to all people within the northeast Georgia area and to promote healthy lifestyles among all members of the northeast Georgia community. The department itself offers a wide variety of clinical services and district wide programs. The district wide programs that can be useful for children with Autism Spectrum Disorder are Babies Can't Wait, Children's Medical Services, Women, Infants, and Children (WIC) Supplemental Nutrition Program, and Children First.

MADISON COUNTY HEALTH DEPARTMENT (Temporary Assistance for Needy Families)

1424 Highway 98 West, Danielsville, GA 30633

Phone: 706-795-2131; Fax: 706-795-2632; Web Address:

<http://publichealthathens.com/wp/clinics/health-departments/madison-county/>

The Temporary Assistance for Needy Families local Madison County, Georgia office is located at the Madison County Health Department in Danielsville, Georgia. Temporary Assistance for

Needy Families is a state program in Georgia created to provide time-limited cash assistance to eligible children under age 18 in families with a very low-income. Certain requirements will decide if a child is eligible to receive TANF benefits, including the amount of people living in the household.

MADISON COUNTY HEALTH DEPARTMENT WIC CLINIC & BREASTFEEDING CENTER (WIC Supplemental Nutrition Program)

94 Spring Lake Drive, Danielsville GA 30633

Phone: 706-795-3231; Web Address: <http://www.wicprograms.org/li/madison-county-health-department-wic-clinic-breastfeeding-center>

The WIC Supplemental Nutrition Program is located at the Madison County Health Department WIC Clinic and Breastfeeding Center in Danielsville, Georgia. Women, Infants, and Children (WIC) Supplemental Nutrition Program is one of Northeast Georgia Health District's federally funded district wide programs created to assist with the dietary needs for families with low-income. This program was implemented to educate pregnant women, new mothers, and young children between the ages of 1-5 about nutritious food supplements and nutrition itself. If an applicant is deemed eligible, they will receive aid in the form of a specialized check, support and information about breastfeeding newborn babies, and help in finding health care and other community services that the families may need.

MARCUS AUTISM CENTER

1920 Briarcliff Road, Atlanta, GA 30329-4010

Phone: 404-785-9400; Fax: 404-78-9025; Web Address:

<http://www.marcus.org>

Marcus Autism Center is a non-profit center and subsidiary from Children's Healthcare of Atlanta that serves children with autism spectrum disorder. It is one of the largest autism centers in the nation and one of three NIH certified Autism Centers of Excellence. The Center seeks to offer treatment and access to research through grants and some government funding as well as community assistance. The Center offers access to research studies that provide treatment to participants and some may be conducted in-home through internet access.

PEACHCARE FOR KIDS

2 Peachtree Street NW, Atlanta, GA 30303

Phone: 404-656-4507; Web Address: www.dch.georgia.gov

PeachCare for Kids is Georgia's state children's health insurance program (S-CHIP) that covers children up to their nineteenth birthday. There is no premium for any services administered to children under the age of five. Premiums for children aged 6-18 are dependent on their household income with amounts ranging from \$11-\$36 for one child and a maximum of \$72 for two or more children living in the same household. Children covered under PeachCare are provided with a multitude of health benefits include primary, preventive, specialist, dental, and vision care. Co-payments often are not required; although, when they are required they will differ depending on the medical services provided to the child. There will never be a required co-

payment for emergency services, preventive care services, immunizations, and routine preventive and diagnostic dental services.

Sustainable Solutions

Alleviation of Costs

Long-term solutions needed to help alleviate these higher medical costs, aggregate non-health care costs, and educational costs require an increased amount of awareness followed by medical and educational assistance in order to reduce the economic burdens that are accompanied by this unavoidable disease. In addition, an increase in awareness of screening for Autism Spectrum Disorder can be a vital resource to help lower the costs and make these tests more accessible for families. Once diagnosed, children may require intense programs that require professionals to be carried out and can be costly. The most critical long-term solution necessary would be to increase access of insurance to ensure affordable access to care.

When understanding a child's diagnoses of Autism Spectrum Disorder, the family must take into account not only the medical burden of their child, but also the economic burden when considering the cost of educational, medical, and social assistance. Most times the economic burdens associated with this diagnosis are under recognized and can become another very important stressor for families and children experiencing a diagnosis of Autism Spectrum Disorder.

Data collected from the Medical Expenditure Panel Survey concluded that children diagnosed with Autism Spectrum Disorder were linked to more frequent amounts of health care office visits and higher costs of prescription drugs when compared to the amount of visits and cost of prescription drugs used by children not diagnosed with autism (Lavelle et al., 2014). In addition, children diagnosed with Autism Spectrum Disorder were linked to having higher healthcare costs on average of \$3,020.00, higher aggregate non-health care costs on average of \$14,061.00, and higher school costs on average of \$8,610.00 (Lavelle et al., 2014).

In response to families in urban areas having a problem with geographic distance to the closest city with screening tools, a resource that can be readily available and of great use would be the use of telehealth delivery services (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017). Telehealth delivery services can be explained as a method of delivering services for individuals through the use of information and communication technologies to avoid the problem of geographic distance. Through the use of telehealth services, families in rural areas can be provided with ways to pursue diagnosis and interventions in both a costly and time effective way much easier than in person (Antezana et al., 2017). While some forms of telehealth may require computer access, this can be completed through a public library computer or even mobile accessibility. A very common domain of telehealth application is Live Video, which may provide patient/caregiver to provider access with the simplicity of a smart phone. Telehealth delivery systems are highly accessible and very low cost methods for treatment and intervention and highly applicable to this case.

Insurance Policy

Proper health insurance coverage is critical in order for families with children with ASD to have access to the necessary therapies and services. Different health care plans receive different benefits. For example, most health insurance plans have a lack of coverage for autism assessment and treatment services (Baller et al., 2016). Families of children with ASD who have private insurance are less likely to use speech, occupational, or behavioral therapies as well as have health insurance plans that cover needed care (Zhang & Baranek, 2016). Due to the increase in number of autism spectrum disorder diagnoses over the past decade and the high costs for care, 40 states and Washington D.C. have enacted laws requiring autism-specific

behavioral therapies to be covered by health plans in the private insurance market. However, even with these mandates there are still differences between services provided between states. For example, California has reported many small behavioral practices closing due to the strict licensing requirements enforced by the mandates. States with autism mandates do not have significantly better access to care when compared to states without (Baller et al., 2016). To ensure all families with children with ASD are getting proper care, health insurance plans need to alter their policies to fit the required needs.

In addition to access to therapies and services, health insurance plans should reduce the cost of out-of-pocket spending. Children's health care costs can cause financial issues for families. \$9.70 per every \$1,000 of income is spent on a child's health care cost. This cost increases for children with autism spectrum disorder. Annual medical expenditures range from 3 to 10 times more for children with ASD than for children without (Parish, Thomas, Williams, & Crossman, 2015). It is estimated to cost \$35 billion to care for all individuals with autism over their lifetime. This comes from direct costs such as medical and dental costs as well as indirect costs such as parents reducing work hours in order to care for their child. If an individual's autism is not properly treated, the cost over his or her lifetime could be as high as \$3.2 million (Stuart, 2010). These medical expenditures vary by type of insurance. Children enrolled in Medicaid have medical expenditures that are four times greater than a private insurance. The Katie Beckett Medicaid Program in Georgia could help bridge this cost gap as it is available for disabled children, particularly those whose parents make more money than the Medicaid level income. Additionally, children with ASD receive more ASD-specific services such as therapies and behavior modification when enrolled in Medicaid (Parish et al., 2015). Families with private insurance experience significantly greater financial burden for their children's health care (Zhang

& Baranek, 2016). Individuals with autism spectrum disorder may also be charged higher premiums (Stuart, 2010). Insurance policies regarding the cost of care for children with ASD should be adjusted to be the same for all insurance plans.

Overall, changing the policies of all health insurance plans to accommodate the costs and services of autism spectrum disorder is necessary to ensure all needs are met. Families with certain insurance plans such as private insurance can be at a disadvantage when it comes to having access and being able to afford speech, occupational, or behavioral therapy (Zhang & Baranek, 2016). Children with autism spectrum disorder who are not able to receive proper treatment could add additional millions in costs over their lifetime (Stuart, 2010). In comparison to other diseases, ASD carries higher cost than some diseases that receive much more attention. Widespread breast cancer campaigning has had dramatic public health results in prevalence rates and in correlation breast cancer treatment can cost a patient between \$5000 and \$7000 per year (Yabroff et. al, 2011). In comparison, children with ASD may incur costs of over \$17,000 per year and even more in states that do not have an ASD parity policy (Lavelle et. al, 2014). Insurance policy designates how much patients pay out of pocket and should have equity amongst coverage of all diseases. Altering insurance policies will allow all children with ASD to receive equal care and services as well as reduce out-of-pocket costs for their families.

Families without access to health insurance unfortunately do not receive these benefits. The proper solution to health insurance related issues is universal health coverage. Universal health coverage promises equal access to promotive, preventive, curative, rehabilitative, and palliative health services to everyone who needs them, not just those who can afford them (World Health Organization, 2017). Ensuring access to care will alleviate not only the extra costs, but the chronic stress as well.

Improving School Interventions

Currently children diagnosed with Autism Spectrum Disorder (ASD) who are within the public school system do not receive highly specialized, comprehensive care. In Madison County, Georgia, protocol for a child with a learning disability is to have an Individualized Education Program (IEP). These programs are an example of a typical school intervention method where students with disabilities receive plans for adaptation to the standard curriculum and can be carried out by staff with knowledge of the child and curriculum (Georgia Department of Education, 2017). Strategies for Teaching Based on Autism Research (STAR) is a manual-based program created for teachers to implement forms of instruction that optimize possibility for children with ASD. Teaching methodology of the STAR program addresses language, academic, social, and everyday school routine skills. This program requires extensive training for the person who will carry it out and intensive dedication to the program (20-40 hours per week), which studies suggest is not feasible outside of grant-funded research (Mandell et al., 2013). Research into current intervention methods exposes vulnerabilities in the treatment that can cause disparities if not carried out in optimal settings.

With difficulty funding intensive programs and lack of trained personnel to implement programs, many interventions fall short of optimal treatment for children with ASD. Previous research has indicated that children with ASD in un-adapted classrooms experience decreased social activity and performance (Burger-Caplan, Saulnier, Jones, & Klin, 2016). Children with ASD also experiencing social anxiety have been shown to have poorer treatment outcomes due to disengagement. There is a need for specialists highly trained in understanding children with ASD who can identify differences between ASD and social anxiety. Criteria for diagnosis of social anxiety align closely with that of ASD and thus make it difficult to determine if social

anxiety is contributing to slow development (Pellecchia et al., 2016). Furthermore, most programs for developmental disabilities are broad adjustments to curriculum and do not address individual-specific disability needs. There is a need for extensively trained personnel who specialize in children with ASD to create curriculums to which they can adhere rather than an adjustment of a standard curriculum.

While there is a lack of extensive funding and programming in schools, some research of playground behavior shows positive social development without intensive interventions. Results showed that while children with ASD spent significantly more time in solitude than did their non-affected peers, some were not as isolated when paired with another peer. This method of inclusive intervention is practical to implement by non-trained individuals and is cost-efficient (Locke et al., 2016). Because ASD is an increasingly popular diagnosis but little is still known about the disorder, it is especially critical to adhere to the behaviors of children with ASD during development. Under programs that are underfunded and unable to adhere to specific needs like social anxiety in children with ASD, some students may fall farther behind. Policy can help address the gap in knowledge and care as research to understanding ASD continues. Specialists implemented in each district that understand ASD development require training that can be funded with government expansion of special education funding.

Increasing Screening Rates

Screening for ASD is a critical first step in identifying children that may have ASD and will need further assessment, intervention, and services. Currently there is a gap between the age at which children with ASD can be identified and the age they are identified, indicating that detection rates at early ages can be improved. There is approximately a 20-60 month gap

between parental suspicion of ASD and formal diagnosis (Seltzer et al., 2003). Additionally, early detection relies on standardized screening tools and clinical judgment, which may not be accessible or available at all (Young & Nah, 2016). Increasing screening rates promotes earlier diagnosis and possibility for receiving necessary treatments and therapies to improve outcomes of people with ASD. A variety of studies have showed that early intervention at 3 years of age or younger have better outcomes on the core deficits of ASD, IQ, language, and symptom severity (Dawson et al., 2010). Therefore it is crucial that ASD be detected as young as possible.

To achieve long-term solutions, it is important to improve screening rates on the parental side. Assisting parents on recognizing ASD symptoms and signs and bringing their children in for screening is critical for early interventions and maximizing the outcome of children with ASD (Matheis & Matson, 2015). Having parents agree to ASD screening is critical for early detection and intervention. Approximately 23.3% of parents of infants and toddlers refuse ASD screenings, which is higher than the previous 7% in past years (Matheis & Matson, 2015). The mistrust must be improved as well as lowering parental refusal rates by changing language provider's use when discussing screenings, developing protocols for targeting specific excuses for refusal, and explaining the reliability of the screening test for as early as 18 months (Matheis & Matson, 2015).

Relieving Stigma

Because stigma often comes from a lack of understanding or social support, it is important to have methods of intervention that address these barriers. Understanding can be an extremely difficult barrier in parents who are non-English speaking or who may practice a culture different from common American. In Korean culture, the stature of the family is heavily

dependent on the success of the children and, for families with a child with ASD, this can be a barrier to proper treatment. It is not uncommon for parents to deny their child screening for ASD or even dismiss a diagnosis and ASD prevalence rates amongst Korean Americans reflects this at 1/3 of the actual prevalence rate (Kim, 2012). Similarly, some African cultures view children with ASD as “witch children” who may be neglected and ignored by a community (Autism Speaks, 2017). Because of these cultural barriers, it is extremely important to have methods of intervention that are considerate of a community’s beliefs. Health promotion work to remove stigma in these communities may utilize community leaders such as shamans, religious leaders, or community figureheads that know the concerns of a community but can explain the importance of screening and diagnosis.

Language barriers are necessary to overcome when attempting to relieve cultural stigma. Parents who do not understand messages about the development of their child or their comorbid health concerns will not have the urgency for screening and diagnosis. One study showed 1 in 10 primary care providers offered ASD screening and developmental screening in Spanish and not surprisingly that Latino children have lower diagnosed rates of ASD (Zuckerman et. al, 2013). Increasing professionals who are trained to administer these screening methods in Spanish per American Academy of Pediatrics guidelines in areas with high Hispanic populations could help mend the prevalence disparity. Other intervention methods like translational technology at parent-teacher conferences may help a teacher explain any developmental problems she sees in a student and convey the importance of having that child screened for ASD.

Reflections

Natalia

I have always had a passion for physical and developmental disabilities due to my involvement with CURE international, which is an international philanthropic organization that provides free and low cost corrective surgeries to children who have disabilities that could have been prevented at birth. Additionally I have seen the obstacles my 16 year old cousin with Asperger's has had to navigate which has given me a deeper understanding of disability. I have seen how often Asperger's can have comorbidities with depression, and how it can aggravate the symptoms of ASD. I've witnessed the stress of my uncle in navigating and accessing all the therapies necessary for Autism and how it affects the entire family. The background I have with neurodevelopmental disabilities and physical disabilities led me to choose this case study, and I have felt very fulfilled with the knowledge I have gained by this assignment.

Through the process of creating the needs assessment, developing resources, and seeking out sustainable solutions, I was able to see the theory of the classroom be applied. During the site visit, Sue, an LPN who works at the Morgan County Health department whose son has Asperger's was able to tell us many of the struggles and resources she has encountered. It was incredibly helpful for Sue to look at the resources and explain how many of them were more useful in theory than in practice. We realized many of the resources available for ASD had a lot of red tape and were temporary. As a group, we reflected how useful it would have been to have someone like Sue help us while we developed the needs assessment. I see now why it is critical to engage the community as the first step, because without that community, it is truly impossible to develop an accurate needs assessment. Overall, I saw a few the infinite barriers that people of low income face and how sustainable solutions take an entire community to develop.

Sydney

I have always had an extreme interest in medicine and specifically pediatric care. Ever since I was a little girl I've looked up to the professional medical staff at hospitals for their incredible empathy and kindness when treating their patients. This case study allowed me to invest my time in a pediatric developmental disability, which we decided to be Autism Spectrum Disorder, and to analyze the available resources and challenges that a family will go through while raising a child with a developmental disorder. Through the analysis of the wide range of resources we were able to research and from our site visit with Sue Whitaker, an LPN, my knowledge on this topic has grown profoundly.

Understanding how many hardships a family can go through when conducting the needs assessment, analyzing resources available, and assessing sustainable solutions to aid someone diagnosed was an eye opening experience for me. Hearing Sue discuss her own challenges with her 18 year old son who was diagnosed with Autism Spectrum Disorder at age 3 through the resources we were suggesting in our case study allowed me to realize how many policy, stigma/social, and medical changes need to be made. Seeing how many of the resources being suggested for these families were actually only slightly useful and/or were incredibly temporary made our search and whole case study very challenging at times. Throughout community health, the importance of conducting a proper needs assessment has been made incredibly clear to me; however, for the first time, while meeting with Sue, I was able to fully acknowledge that for a family researching a diagnosis for a child who is potentially autistic, that Sue would've been such a necessary component for them. Another hard component for me throughout this case study was realizing how challenging being a low-income family in a rural area really is, especially when seeking medical care and treatment for a developmental disability.

Kathleen

Savannah

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