

**Low-Income Single Mother Caring for 3 year old child with Down Syndrome in Jackson
County, GA: A Needs Assessment**

Kyla Gaddis, Amber Bullard, Lily Hill, Jacqueline Hodges, Logan Leggett

The University of Georgia

HPRB3200

Professor Katie Hein

April 28, 2020

TABLE OF CONTENTS

Health.....3-7

Treatment.....7-9

Culture of Jackson County.....9-12

Down Syndrome and the School System.....12-13

Needs Assessment.....13-19

Resources.....19-26

References.....27

Health

The typical child is born with a total of 46 chromosomes. These chromosomes hold the genetic material that lay the blueprint for growth and development that initiate as early on as conception and throughout the lifetime (CDC, 2020). Each year, approximately 6,000 babies in the United States are born with Trisomy 21 (CDC, 2020). Trisomy 21, most commonly known as Down Syndrome (DS), is a condition in which a child has a third chromosome, an extra copy, on the 21st pair. This extra chromosome results in several dysmorphic physical features, delayed psychomotor development, and increases the child's risk for developing a variety of other health conditions (Weijerman & de Winter, 2010). The cause of DS is unknown, but maternal age of 35 and older has been linked to increase the risk of DS (CDC, 2020). Other than maternal age, there are no other known risk factors for DS, but it is assumed that there is a myriad of factors and conditions that increase the likelihood of this genetic misstep (CDC, 2020).

The prevalence of DS has not been linked with specific factors such as race, nationality, religion or socioeconomic status (Agarwal Gupta & Kabra, 2014). However, families of lower socioeconomic status tend bear a larger burden in caring for children with DS due to financial conditions and the access to and quality of care (Agarwal Gupta & Kabra, 2014). When speaking to the prevalence of DS, it is important to note that in countries where abortion is illegal, such as Ireland and the United Arab Emirates, the prevalence of DS is higher compared to countries where abortion is more common, like France (Weijerman & de Winter, 2010). With recent advancements in technology and a growing understanding of DS, the quality of care of individuals with DS has greatly improves resulting in increased overall life expectancy (Agarwal Gupta & Kabra, 2014).

Symptoms

Individuals with DS have defining physical characteristics that make postpartum diagnosis

effortless (Agarwal Gupta & Kabra, 2014). Most children born with DS have a short necks and skulls, flat facial profiles with flat nasal bridges, protruding tongues with a small mouths, small and low set ears, upward slanted eyes, short and broad neck with excess skin, short and broad hands, hyper-flexibility, and low muscle tone (Agarwal Gupta & Kabra, 2014). Due to neurodevelopmental delays, individuals with DS have IQs that fall into lower ranges and are slower to speak than other children (CDC, 2020). In children with DS, the development of fine and gross motor skills requires extensively more time and work than those of neurotypical children. As a result of this these children have more difficulty with communication and language skills, poor articulation due to the smaller mouth, and are slower at comprehending speech (Agarwal Gupta & Kabra, 2014). Other common health conditions associated with DS are congenital heart disease, recurrent otitis media, obstructive sleep apnea, hearing loss, visual impairment, thyroid disease, hematologic disorders, atlantoaxial instability, among others (Bull, 2011). These comorbid conditions require additional care and focused medical attention. Due to the complexity of this disorder and the severity of associated health risks and conditions, a full roster of medical providers are needed to achieve the best most successful health outcomes (Agarwal Gupta & Kabra, 2014). Many children born with DS are seen by pediatricians, developmental specialist, psychologists, neurologists, cardiologists, ophthalmologists, ENT specialists, speech, physical, and occupational therapists are essential for the best health outcomes (Agarwal Gupta & Kabra, 2014). With such an extensive list of medical services required, families of children with DS bear a large financial burden and are more likely to experience job insecurity as a result of the attention needed to care for a child with DS (Agarwal Gupta & Kabra, 2014). As mentioned before, families of low socioeconomic status often bear a heavier financial burden and sometimes cannot afford the care their child needs (McGrath, Stransky, Cooley, & Moeschler, 2011).

Different Types of Down Syndrome

When DS was discovered by John Langdon Down in 1866, he published a book identifying the symptoms and the methods of diagnosis (NDSS, 2020). Contrary to his peers, Down saw the inherent value in children with DS and created services and adaptive education programs for them (NDSS, 2020). It was not until 1959, that French doctor, Jerome Lejeune, discovered that DS was a genetic condition resulting from chromosomal differences. Lejeune determined that people with down syndrome had an extra copy of the 21st chromosome (NDSS, 2020).

Though an extra copy of the 21st chromosome is found in all cases of DS, there are three distinct subtypes of down syndrome: Trisomy 21, Translocation, and Mosaicism (CDC, 2020). Trisomy 21 is a result of nondisjunction, an error that occurs in the cell division process (CDC, 2020). Nondisjunction can occur at any location along the genetic sequence, but nondisjunction that takes place at the 21st chromosome specifically causes it to divide into 3 copies instead of the typical 2 (NDSS, 2020). Trisomy 21 accounts for 95% of all cases of down syndrome (NDSS, 2020). The DS subtype Translocation is more rare and accounts for approximately 3% of DS cases (CDC, 2020). With this subtype of DS, the correct number of 46 chromosomes are present, but the extra copy of chromosome 21 (or a partial piece of it) is “translocated” and attached to another chromosome, the 14th chromosome more often than not (NDSS, 2020). This translocated 21st chromosome expresses itself the same as Trisomy 21 (NDSS, 2020). The most rare subtype of DS is Mosaicism accounting for approximately 2% of all cases (CDC, 2020). With this subtype of DS, some of the body’s cells contain the typical 46 chromosomes while others contain 47. The cells containing 47 chromosomes have an extra copy of chromosome 21 (CDC, 2020). Some research suggests that individuals with Mosaicism exhibit fewer characteristics of DS because of this “mosaic” of typical and atypical chromosome counts

within the cells of the individual (National Down Syndrome Society, 2020).

Financial Implications

Research continues to suggest that many individuals with DS do not receive the full extent of care that they need (Pless, Satterwhite, & Vechten, 1976). Direct costs associated with DS include but are not limited to hospital services, caregiving (for children with working parents and/or eldercare), psychosocial services, adaptive education and technologies, unpaid work leave, out-of-pocket expenses, etc. (Dawson et al., 2014). A 2004 study reported that approximately 25% of parents with children with severe healthcare needs either stopped working or reduced time at work in order to care for their child (Kuhlthau, Hill, Yucel, & Perrin, 2005). Forty percent of these families identified financial conditions as a barrier to accessing care (Kuhlthau, Hill, Yucel, & Perrin, 2005). A study analyzing hospital costs of children from 1998- 2007 reported that children with down syndrome have a median hospital cost of approximately \$8,000 per year (Dawson et al., 2014), and after adjusting for inflation, that value has risen to \$10,187.27. On average, children with DS are admitted into the hospital on average 9.7 times before the age of 16, resulting in approximately \$98,816.519 in hospital costs alone (Fitzgerald, Leonard, Pikora, Bourke, & Hammond, 2013). This does not include the cost of day-to-day care of a child with DS; these estimated costs would be significantly higher if so. As a reminder, children with DS in low income and low socioeconomic status homes typically do not receive the proper health care due to these financial hurdles.

Disabilities in Healthcare

Health insurance is vital to the affordability of healthcare. This is especially true for families that have a child with disabilities. Families of children with disabilities under the age of 18 who also meet the Social Security Administration's definition of low-income/resource may qualify for Supplemental Security Income (SSI), a monthly stipend intended to offset the costs

of caring for a child with disabilities. although it rarely fully covers it (SSA, 2020). While SSI is provided by the federal government, each state is responsible for administering it (SSA, 2020). Because of this, the monthly allotment varies depending on state residency (SSA, 2020). Regardless of state residency, once an individual with disabilities turns 18 and is considered a legal adult, they are eligible to apply for Medicaid and Social Security Disability Income irrespective of parental of parental/household income (Children's Hospital of Philadelphia, 2014). In 2017, Medicaid covered 47% of the 13.3 million children with special health care needs (Kaiser Family Foundation, 2020). Children with disabilities average Medicaid expenditure is estimated to be on average \$17,831, seven times higher than those who qualify for Medicaid through other pathways at \$2,484 as of 2013 (Kaiser Family Foundation, 2020). Just under half of families receiving Medicaid assistance because of childhood disability meet the federal poverty guidelines (Kaiser Family Foundation, 2020). As of January 2019, all states have opted in to expand financial eligibility for children above 138% the poverty line (Kaiser Family Foundation, 2020). Medicaid is an important source of revenue for families supporting children with disabilities so that they can receive the care they need.

Treatment

Since DS is such a complex disorder that expresses itself differently in each and every individual, there is not a one size fits all treatment that is generalizable to all children with DS (NICHD, 2020). In fact, the most effective treatment for patients with DS is considered to be patient-centered, strengths-based, and goal-oriented (NICHD, 2020). Treatment for such a complex disorder as DS requires a complex team of professionals, and treatment often times starts as early as birth (NDSS, 2020). Due to increased risk for certain conditions like heart defects and ear canal structural deformities, some patients with DS

undergo surgery immediately following birth or in the year that follows (NICHD, 2020). After any initial, potentially fatal health concerns are addressed, the treatment that follows typically is in collaboration with a team of therapists for the development of skills and practitioners when medication is needed (NDSS, 2020)

The NIH reports that early intervention programs (EIPs) are the most effective in patients with DS (NICHD, 2020). EIP addresses the symptoms of DS that tend to be most noticeable, the ones that have the most long term effects, and the ones that are of highest priority to the child and/or the child's family. Such treatment typically addresses speech/adaptive communication, muscle tone (for self-support, rolling over/crawling/walking, sensory integration, among others (NDSS, 2020). EIP is typically conducted by a team of Physical Therapists (PTs), Occupational Therapists (OTs), and Speech Therapists (STs) (NICHD, 2020). PTs work with children with DS to improve their muscle tone and learn how to perform gross motor functions such as rolling over, crawling, self-supporting, etc (NICHD, 2020). OTs focus more on fine motor skills needed for activities of daily living such as feeding, dressing, writing (NICHD, 2020). OTs often times work on sensory integration by teaching children with DS how to receive and respond to external stimuli (touch, balance, hearing, etc.) (NICHD, 2020). STs work with patients with DS on communication skills (both verbal and nonverbal) and swallowing (NCHID, 2020). As patients with DS grow older their treatment adapts to the progress they are making and the new challenges that begin to face (NCHID, 2020). Occasionally, patients with DS will be treated by mental/behavioral health counselors/therapists for a number of co-occurring conditions such as anxiety, depression, ADHD, OCD, aggression, social withdrawal, among others since individuals with DS are at an increased risk for comorbid mental health conditions (NCHID, 2020). Some assistive devices are used in conjunction with therapy to help patients with DS to better adapt to their challenges and their environment (NCHID, 2020). Examples of these

assistive devices include hearing amplification, bands to help with movement, adaptive writing and eating utensils, and technology that includes touch screens and larger buttons/keyboard (NCHID, 2020).

Culture of Jackson County

It is fairly easy for anyone to imagine the culture of a small town. Large areas of open land inhabited by small amounts of people characterize the image of a rural town. The realities of living in rural communities include limited job opportunities, limited resources, close community interactions, various demographics, and cheaper expenses. The economy is driven by revenue made from the agricultural industry. Farming and growing crops for sale is what some people use their large areas of land for. However, in recent years, agriculture has been affected by the incorporation of technology. The technology used in the agriculture industry has replaced the jobs of some people in these areas.

Community resources may be scarce in some rural areas. Some resources meant to service those in the community may be jeopardized because of funding. Programs that are funded by grants or other government funds are not sustainable for the health of the community. Another issue regarding resources is that some low-income residents cannot access those resources due to transportation. In many cases, those who reside in rural areas live far away from facilities and buildings, so they must use a vehicle for transportation. An alternative to this is to have the services to come to the person, but this still requires money for gas and time spent by that person (Weirich & Benson 2019). Traveling to patients has been done before in which providers traveled to “remote areas” even during “dangerous, unpredictable weather” (Doolittle, Nelson, Spaulding, Lomenick, Krebill, Adams, ... Barnes, n.d.) Another option is to use telemedicine. Telemedicine has been used to provide care for hospice patients in rural areas. It could be a great option for other medical specialties to use in rural areas when budgets are cut

or facilities close down (Doolittle, Nelson, Spaulding, Lomenick, Krebill, Adams, ... Barnes, n.d.) Many differences separate rural from urban areas. Rural areas are more industrialized with large buildings and companies. Rural areas do not have many large buildings but more open land. For that reason, people who do not find work in their rural community often travel to urban cities to work (rural area). This commute allows people to travel to a city and make a higher salary. The cost of living is higher in urban areas than it is in rural areas. Those who commute can benefit from living in an area where expenses are lower.

Jackson County, Georgia is a small community that resides in north Georgia. This rural town, while small and quiet, is home for many people. Nearly sixty thousand people live their lives in this small town of Jefferson right outside of Athens. Like other small towns, Jefferson prides itself in small businesses and natural attractions. These small businesses make the town unique but it does not allow many individuals to find jobs like they could if more franchises were there. It is safe to say, the town lacks many job opportunities. According to the Jackson county chamber of commerce website, no local jobs are available at this time (Jackson County Area Chamber of Commerce). The website does list websites that serve as resources for anyone who is interested in starting their own business in Jackson County. I imagine this causes many people to search for jobs in other areas or in minimum wage jobs like the food industry. Jefferson has an elementary, middle, and high school that has a phenomenal quality of education. According to the school system's website, this school system has SAT and ACT scores that were beyond the average for the state and the nation (Jefferson City Schools). The website gave astounding facts about each school in its system. With the University of Georgia one county over it is quite clear that education is important in this area.

According to the latest U.S. census, the population of Jackson county is roughly more than 70,000 people. Of these 70,000 individuals, Caucasians make up roughly eighty-eight

percent while Hispanics make up eight percent, African Americans make up 7.3% and American Indians and Native Hawaiians make up less than one percent. This town lacks the diversity that is found in other cities like Athens. Only twenty-one percent of people in Jackson County have at least a bachelor's degree (U.S. Census Bureau QuickFacts: Jackson County, Georgia). While the median income is roughly 60,000 annually, almost nine percent of people live in poverty (U.S. Census Bureau QuickFacts: Jackson County, Georgia). With all of these facts, Jackson county is a rural town with much potential. While its school system values education, not many adults are getting their bachelor's degree. Similarly, many people are living off of comfortable salaries but almost nine percent of people are impoverished. These demographics show that this community has the capability to provide the services it needs to those in need if it is willing to diversify its community and welcome.

The community resources in and around Jackson county helps out with most family and individual needs. For example, the Jackson County Family connection is a non-profit organization that helps families and children in need. It collaborates with local businesses, leaders, and faith based organizations to provide its support for what is needed for most families to succeed. They support events such as "Warm hands, Warm hearts" which provides people in need with coats, socks, and gloves, during the winter season (Jackson County Family Connection). Their holiday connection program allows sponsors to select a family or child to donate Christmas items. The Jackson county Family Connection website lists many other events that they do to help those in this community.

The Boys and Girls Club of Jackson county provides opportunities for disadvantaged youth to excel in various areas of development. It has been in this community for nine years in which that time has allowed it to grow tremendously. This club focuses on five major areas of development: "character and leadership development, education and career development, health

and life skills, the arts, and sports, fitness, and recreation” (Boys and Girls Club of Jackson County). These areas of development are taught by volunteers and staff through various programs. Tutoring to alcohol and drug awareness is taught to the young children who attend this club.

Extra Special People is another organization that aids the youth and young people who have developmental disabilities. They serve four hundred and fifty counties and up to two thousand individuals (Extra Special People, Inc.). A big event they host is their summer camp. The camp is an eight week long event where the participants are allowed to dress up, take field trips, and go horseback riding. The camp’s activities vary in cost, but Extra Special People hosts fundraisers and scholarships for families who may need extra help.e more workplaces. Another great resource for parents is the local down syndrome support group. These groups create a community for parents to talk about feelings, care giving, resources, and share experiences. These groups, which are organized through the National Down Syndrome Society, are more focused on providing resources for the family members rather than the child with down syndrome. Aside from support group meetings, parents can find resources such as siblings workshops, early intervention programs, social activities and events to raise public awareness.

Down Syndrome and the School System:

Many people have misconstrued myths regarding down syndrome. Some of these myths include children with down syndrome being unable to learn or that they are always happy. These myths are untrue, children with down syndrome are just as capable of learning as children without disabilities, and people with down syndrome have an extensive range of emotions. Another common belief is that children with down syndrome would learn better in a “special” school, segregated from children without down syndrome. Again, this is a myth that

needs to be dispelled. Children with down syndrome should be included in regular classrooms. Though, they may need additional supports that are offered through the school system. In the state of Georgia, The Georgia Department of Education has a division for special education. The Division for Special Education Services and Supports is responsible for providing any and all services that a child with a disability would need in the school system. This division has material available for teachers to better know how to teach and help a student with down syndrome. Also, they set regulations and standards for schools so that they meet the needs of their students with disabilities (Down Syndrome Association of Greater St. Louis).

Most public schools have school based occupational and speech therapists. Therapy services in schools serve multiple purposes. First, they help children accomplish basic needs such as, gripping a pencil, handwriting skills, using scissors, or improving effective communication. Therapy services also act as a bridge between the child, the school, their parents, and any other extracurriculars the child is involved in. They do this by helping to create and maintain intervention plans for the student to aid them in their everyday life as a student and a developing child (Georgia Department of Education).

Needs Assessment:

Financial Assistance

Lucas's mother (we will call her Jane for the purposes of this paper) is a single mother working full time at a minimum wage job. Unfortunately, a minimum wage job in Jackson County is not a livable wage, especially for a family with a child with Down Syndrome. Minimum wage is \$7.25, and assuming Jane works the full 2,080 hours in a work year, she only makes \$15,080 per year before taxes. After taxes, Jane takes home about \$13,660 annually. According to the U.S. Census Bureau poverty threshold for 2019, a household with a single

mother and one child is considered below the poverty line if their annual income is less than \$17,622. (United States Census Bureau, 2019). This puts Jane and Lucas at 86% of their poverty threshold, making it very difficult for Jane to afford basic life needs like shelter and food, and almost impossible to afford the necessary therapy and medical treatments for Lucas. Jane would have to make at least \$8.48 per hour or work an additional 351 hours per year to reach the poverty threshold. For a mother raising a child with Down Syndrome, working an additional 351 hours per year is extremely impractical. Jane most likely has to take sick days frequently to provide extra care to Lucas making it impossible for her to add the additional work hours to meet the poverty threshold. Unless a Federal Law is imposed to raise the minimum wage to a living wage or Jane finds another job with better pay, Jane and Lucas will continue to live beneath the poverty threshold.

According to the Department of Urban Studies and Planning at the Massachusetts Institute of Technology, in Jackson County, the living wage for a household with 1 adult and 1 child is \$23.34 per hour. This model defines a living wage as a geographically specific expenditure data related to a family's likely minimum food, childcare, health insurance, housing, transportation, and other basic necessities like clothing, personal care items, etc. (Massachusetts Institute of Technology Department of Urban Studies and Planning, 2018). Using the estimated living wage for Jackson County, a single parent should make \$48,547.20 per year to provide the basic needs for their family. This is more than three times what Jane's current annual salary is, indicating that she can only provide for 1/3 of the basic items needed to support a family. These numbers are calculated for the average American family and do not account for families caring for a child with Down Syndrome. Jane's current earnings are clearly not sufficient to support herself and Lucas, so financial assistance is crucial for the well-being of their family unit.

Food

Because of Jane's limited income, she will need assistance in providing adequate food for herself and Lucas. The Supplemental Nutrition Assistance Program (SNAP), also known as the Food Stamp Program is a federally funded program that provides benefits to low-income households to help pay for the cost of food. Jane needs to apply for SNAP through the Department of Family and Children Services office in Jackson County or online via Georgia Gateway website (<http://gateway.ga.gov/access/>) and complete an interview following the application submission. Jane will qualify for SNAP given her current financial situation and begin receiving benefits within 7 days. Jane will receive a maximum of \$192 per month to spend on food for herself and Lucas, averaging to about \$6.40 per day designated for food (The Division of Family and Children Services, 2018). Even with assistance, it would be difficult to provide food for two people for only \$6.40 per day, so it is important for Jane to find ways to get the most amount of food for the lowest cost. Luckily, Jackson county has a number of grocery stores that accept food stamps, so Jane has access to cheap, nutritious foods like canned or frozen vegetables that are typically unavailable at gas stations.

Children with DS are more likely to struggle with obesity and have multiple food allergies, the most common being gluten, dairy, chocolate, and bananas (Center for Disease Control and Prevention, 2020), so Jane must pay special attention to the foods she is feeding Lucas, even with her low budget for food. Although diet requirements differ widely based on the specific needs of each child with DS, there are some basic dietary recommendations for children with DS that Jane should keep in mind. She should shop for fiber-rich foods like fruits, vegetables, pulses, wholegrain cereals and whole meal bread, foods high in water content like fruit, yogurt, and smoothie drinks, and foods low in sugar, preservatives like MSG, and trans fats (Marshall, Tanner, Kozyr, & Kirby, 2015). With Jane's financial status, it may be difficult

to provide the essential nutrients Lucas needs for proper development, but not impossible. Jane can purchase frozen or canned produce, use coupons or purchase in bulk, and avoid buying any unnecessary snacks like chips, soda, or candy to save money and help Lucas remain at a healthy weight.

Housing

With Jane's limited income, affording housing in Jackson County would be extremely difficult. The average monthly rent for a one bedroom apartment in Jackson county is \$616 per month and \$814 for a two-bedroom apartment (National Council of Housing Market Analysts, 2020). Because Lucas is still a toddler, they could likely live comfortably in a one bedroom apartment, but when Lucas gets older, they will have to upsize to a two-bedroom apartment for nearly \$200 more per month. If Jane got an apartment without assistance and paid \$616 per month, she would only have \$640 left to pay for all other expenses. This would clearly be an overwhelming financial burden on Jane, so she would probably resort to governmental housing assistance. The Department of Housing and Urban Development offers a program called Section 8 that subsidizes anything above 30% of your adjusted monthly income to an established limit (Georgia Department of Community Affairs, 2020). Jane needs to find affordable housing in Jackson County that accepts Section 8 vouchers or subsidizes the rent in some way.

Insurance Coverage

Jane's minimum wage job likely does not provide good benefits like health insurance, resulting in her using her own funds to provide insurance for herself and Lucas. Luckily, Lucas's Down Syndrome qualifies as a disability to receive Supplemental Security Income

(SSI), which also qualifies him for receiving Medicaid (Social Security Administration, 2020). The SSI payment varies depending on each child's needs, but the federal base rate for 2019 is \$771 per month. This money can be used to pay for Lucas's basic need or cover medical expenses that Medicaid does not cover, although Medicaid for children with disabilities is likely to cover most of his medical services. Services including occupational, speech, and physical therapy, and specialty care like visits to endocrinologists, ophthalmologists, audiologists, feeding specialists, and other medical visits are covered under Medicaid. Home medical equipment like nebulizers are often included in coverage as well. Medicaid in Georgia only covers adults that are below the 34% poverty level, making Jane ineligible for Medicaid for herself (Center for Medicare and Medicaid Services, 2020). Jane needs to apply for SSI and Medicaid on Lucas's behalf, but she will need to find a separate affordable insurance plan to cover her own healthcare expenses.

Educational/Daycare Support:

As Lucas gets older, he will need the daycare and school system to have the resources to support him. Since Lucas' mother is a single mother who works full time, Lucas will most likely need to attend a daycare center until he is old enough to go to school. Infants and toddlers with down syndrome do not differ much from infants and toddlers without down syndrome. Therefore, Lucas should be able to adjust well to a daycare facility. Though, young children with down syndrome do develop at a slower rate than children without down syndrome, and may have trouble expressing their feelings using words. When this happens, they often exhibit aversive or disruptive behaviors, so it is important that daycare or child care providers are aware of this and able to recognize and help a child with down syndrome (Better Health, 2020). When Lucas is old enough to attend school, it is important that the school system has adequate resources to support him. These accommodations include having school therapists available,

visual or auditory accommodations in the classroom, and extra time to learn and complete assignments (Gavin, 2018).

Therapy:

Most children with down syndrome receive physical, occupational, and speech therapy. All three of these therapies are able to help children with down syndrome better function and develop. Physical therapy focuses on building muscle strength and improving posture and balance. Occupational therapy focuses on fine motor skills such as writing and grasping and self care skills such as getting dressed, eating, or using a computer. Speech therapy helps children with down syndrome develop communication skills and increases their language skills. It is crucial that children with down syndrome receive these therapies early in their life because it will help them develop crucial life skills at a quicker rate (National Institute of Health, 2017).

Social Support

Raising a child as a single parent is not an easy task, and when your child has a medical condition, such as down syndrome, it is that much harder. It is important that Jane has adequate social support to assist her in raising her son, and to provide companionship and comfort. Jane will need to build a support system for herself and her son, such as a group for mothers of children with disabilities. These social support will help Jane not to feel overwhelmed and to provide answers and support when she has questions about Lucas' down syndrome, different therapies, or different schooling options for Lucas. Having a support system will protect Jane's mental health and help to better provide for her son.

Resources

In this case, resources are needed for both the mother and her son. An examination of

each of their needs is performed to bring to light the resources that are available for families that have disabilities in their lives. Both Jane and Lucas would benefit from social service programs in Georgia. SNAP is a food assistance program that would help Lucas and Jane get the proper food they need. This program provides benefits for low-income households to use to pay for certain foods (Department of Human Services Division of Family and Children Services). To receive the benefits a person must satisfy the eligibility requirements and go through an interview. The amount of funds provided through SNAP depends upon the circumstances of that household. The funds are provided on an EBT card that is used to purchase food.

The state of Georgia has a Housing Choice Voucher Program (Section 8) that allows low income families to find affordable housing to rent. Federal funds provide subsidy payment to the landlord of the home on behalf of the tenants (Georgia Department of Community Affairs, 2020). Families are chosen from the waitlist to receive the benefits. It is up to the family to find a living space that is compliant with the program to allow the subsidy payment. Jane and Lucas can receive help paying for housing through this program if they would like to stay in Jackson County. This is a good option for them to live in a safe place with little worry about paying rent there. If at all possible Jane should look into this voucher program, so she can have help with paying her rent.

Supplemental security income provides aid to children with disabilities of low-income (Social Security Administration). Lucas qualifies for SSI aid because of his developmental disability. The aid he receives depends upon the amount of income that his mom brings in. Whatever the aid may be, it can help with getting Lucas the resources he needs from school to daycare. While the application for SSI is not currently online, Jane should look into where she must go to apply for SSI for her son.

The SCHIP program in Georgia is called PeachCare for kids. This program allows children of low-income families to receive insurance even if their family does not qualify for Medicaid. Under PeachCare, Lucas can receive dental, preventative, specialist, and vision care (Georgia Department of Community Health). Hospitalizations and emergency room visits are also covered under this SCHIP program. Lucas can receive the medical care he needs because of PeachCare for Kids. Money will not keep him from getting the care he needs to stay healthy.

For Jane, an affordable health care insurance plan can be Peach State Health Plan. This plan is meant to help people depending on their age, income, size of family, and what special needs must be considered (PeachState Health Plan, 2020). Jane should go online to see what this plan is willing to offer her in regards to primary care and prevention efforts. If this plan is as affordable as she needs, it would be a great plan for her to invest in.

Advantage Behavioral Health Systems

For the son, specifically, he is in need of resources that will help him navigate life with his disability. Advantage Behavioral Health Systems have helped those in surrounding areas for over forty years. Now with ten locations, it reaches even more children and adults. The mission of this organization is to provide treatment for individuals or families affected by disabilities, mental illness, or addictions through various services (Advantage Behavioral Health Systems, 2020c). With four prestigious accreditations, specifically one from the U.S. Department of Homeland Security, Advantage values the improvement of its clients.

Jackson Creative Community Resource Center and Advantage Behavioral Health Systems serves Jackson County along with other counties with their Developmental Disability Services (Advantage Behavioral Health Systems, 2020a). What is most unique about this service is that it helps with physical, mental, and social issues a person faces due to the

disability. The services of Advantage Intellectual & Development Disabilities are based on the individual needs of the client (Advantage Behavioral Health Systems, 2020b). Specific services include helping the client learn personal care, how to live independently, and how to search for resources within the community (Advantage Behavioral Health Systems, 2020b). Behavioral support consultation services provide help through interventions. This program will help the son with activities of daily living such as brushing his teeth and getting dressed. Additional help with activities of daily living would help with allowing the son to learn how to do the things a three-year-old is expected to do. He would be able to keep up developmentally with his peers and be able to attend preschool with his peers. It also takes some of the pressure off of the mother who may be worrying about her son being behind developmentally.

Extra Special People

Another resource for the son is to attend Wellspring Camp in Jackson County. This camp is available for adults and children who have special needs or developmental disabilities. The camp is now a part of the Extra Special People organization, however its goal of helping others remains the same (Extra Special People, 2017). Extra Special People was created in 1986 by Martha Wyllie, a young woman passionate about helping others with special needs. Since then this organization has grown to offer programs after-school and during weekends in addition to the camps that take place during the summers. Located in Watkinsville, ESP serves thirty counties including Jackson County. Both the programs and summer camps are great activities for Lucas. The after-school programs are known as enrichment programs during the fall and spring. Monday through Thursday, 4pm to 6pm is filled with the kids learning topics from cultures to yoga. There are fees for the after-school program that range for the amount of days your child plans to attend. Luckily, for parents like Lucas's mom, there are scholarship options that will help with the cost of the program. The camp takes place during the summer

and provides these individuals with an eight week overnight stay (Camp Hooray). While at camp, Luca will have the opportunity to learn to swim and bowl. On Thursdays, he can participate in field trips to places like Six Flags. The overnight camp is done through a partnership with Camp Twin Lakes. The purpose of the overnight camp is to give campers the ultimate experience of being at camp where parents are not around for an extended amount of time. Transportation is offered to and from camp. The cost of the camp is subsidized through fundraising and other activities for those who may be able to afford the full cost (Extra Special People) Through his time at the camp he will learn new things through mentors and his peers. He will stay active through swimming and other fun activities. He will also develop relationships with the counselors there. This will really allow him to blossom despite his disabilities.

Butterfly Dreams Farm

Another great resource for the son would be Butterfly Dreams Garden, located in Watkinsville, GA. Butterfly Dreams Farm is a nonprofit organization that works with children with disabilities through therapy. BDF utilizes horses as powerful therapy partners and leverages their gaits and natural empathic abilities to help their riders achieve a variety of treatment outcomes. The two types of therapy offered at BDF are used to target the physical, emotional social, behavioral, and cognitive goals tailored to each individual rider. Being on the farm not only allows children to work with trained therapists, but it also allows them to interact with other individuals from the community. For children with down syndrome, it is important to engage in therapy that is keeping them active and healthy. Horseback riding will offer a unique experience for Luca to be able to exercise in a beneficial way to more than just his physical health. Often times at the farm, there will be more than one child there at a time. This is a great way to get

children to interact with other children from around the same communities and gives them and their families a chance to meet and mingle. BDF also works hard to connect their patients with other resources in the community. For example, if while working with one patient, they learn about resources they are utilizing that are working well for them, they will share this information with other patients to help them have the best support possible. Luca and his mom would both benefit greatly from the therapy, resources, and community support system that BDF provides.

The Arc of Jackson County

As a single mother, Lucas's mom probably has a difficult time balancing work, caring for him, and caring for herself. She is in need of resources that will help her obtain clothing and food for low or no cost for herself and her son, affordable child-care, and services to help her raise her son in the best environment. The Arc of Jackson County is a program ran by a Presbyterian Church in Jefferson, Georgia. This program provides families with paying utilities, rent, prescription costs, and medical needs (Financial Assistance). It even provides transportation to and from medical appointments. His mother can receive help with budgeting and looking for other employment opportunities from the arc as well (The Arc of Jefferson, 2012). Lastly, the Arc is a great place to get moral support. They push for others to take responsibility for their lives and open up their church for those looking for a church home. The mission of the Arc is to help those who are in need of emergency financial assistance because of loss of income (Help Jackson County). Hours of service are Wednesday 9am to 11 am. This program would be great for Lucas's mother since her middle wage paying job may mean that she does not have enough money to cover costs of things besides food and shelter.

Ninth District

Ninth District is another resource that may be of use for Lucas's mother because it ensures that low-income families have proper housing. Through case management and financial aid low-income families are helped with getting stable shelter. The program is available to those who are already homeless or at high risk of becoming homeless (Ninth District Opportunity, 2020b). If she ever was unable to continue paying for her home and lost it, this service would be of great advantage to her. Rent may be one of the hardest things to pay for a single mother working a minimum wage job. With that being said, being unable to pay rent along with other expenses is understandable for someone in her circumstances. The Ninth District also provides heating payment for qualifying homes (Ninth District Opportunity, 2020a). Even though the payment only happens once, it helps when the bitter cold hits in the winter months. It would be a smart idea for Lucas's mother to see if they are eligible and if so, it would be one less bill to pay.

St. Vincent DePaul

The final resource will help her get clothing for herself and Lucas. While located in Atlanta Georgia, St. Vincent DePaul is an organization that helps with obtaining housing, food, clothes, and transportation (Society of St. Vincent DePaul Georgia, 2020). The thrift stores offer worn but nice clothing at an affordable price. With various locations of thrift stores, including one in Commerce, Georgia, Lucas's mom can find affordable clothing for herself and her son as the seasons change. Having to spend less money on clothing would be helpful for her because Lucas's is a growing boy who will continue to need changes in clothes. For her current situation, these resources are ideal for her and her son.

The Aspire Clinic

The Aspire clinic, located on the University of Georgia Athens campus, provides services for those needing help managing various aspects of their lives. The Aspire Clinic strives to help others in the community through teaching, research, and service to live healthy lives (Aspire Clinic, 2020d). Created in 2008, the clinic is a training facility for UGA FACs and law students to help others through counseling, nutrition, education, financial planning, and legal advice. The cost of each service is determined by income and number of dependents (Aspire Clinic, 2020c). Lucas's mom can benefit from the financial planning services and counseling services. Financial planning services includes developing a budget, discussing your credit score, tax planning etc (Aspire Clinic, 2020a). As a minimum-wage worker, she may benefit from someone planning her budget and how she spends her money. A financial planner would help her maximize the money she can save by only spending money on things that are necessary for herself and her son.

It is understandable for someone like Luca's mom to need some emotional support while raising a child with special needs. The counseling services at Aspire deals with stress, anxiety, depression, substance abuse along with many other mental disturbances (Aspire Clinic, 2020b). The clinic does not however prescribe medications. If she is in a position to receive some talk therapy from a professional this clinic is the right place for her.

Since Lucas is only three years old, he is able to attend a daycare program while his mom works. The Childcare and Parent Services Program is a program that offers subsidies for daycare bills to low income parents who qualify for financial assistance. Funding for this service is provided through the federal or state government. With that in mind, funding fluctuates so only a limited amount of people may be selected. In some cases a waitlist can be formed for those needing assistance but others are of greater need. This program requires parents to be working or in a training program in order to qualify, be a legal resident of

Georgia, and choose a daycare provider who is compliant with the program. To apply, you can contact a case manager to walk you through the application process or you can go online and fill out the application yourself.

Childcare and Parent Services (CAPs)

CAPs is a program that supports the importance of learning in early childhood in Georgia. In the program, families are assigned a family consultant to help them find daycare in their area and the scholarship administration unit helps to determine eligibility (CAPS, 2020). Financial assistance for child care would allow the money saved from child care expenses to be allocated to another expense. The money she saves can be put towards utility bills, clothing, rent, or even medical expenses. This mother should waste no time signing up for this program because of the possibility of being put on a waiting list. The soon she can get Lucas in the faster she'll begin saving money. Lucas needs to be in a safe environment while his mom is working and through the CAPs program his mom can be sure that he is safe with staff that are trained and certified to care for him. The CAP program is sure of only working with child care providers who follow the guidelines. Daycare programs compliant with CAP can bring her a sense of relief knowing that her son is being taken care of safely.

References

- Advantage Behavioral Health Systems. (2020a). Developmental Disabilities. Retrieved from <https://www.advantagebhs.org/developmental-disabilities.cms>
- Advantage Behavioral Health Systems. (2020b). Jackson County Services. Retrieved from <https://www.advantagebhs.org/jackson-county.cms>
- Advantage Behavioral Health Systems. (2020c). Home. Retrieved from <https://www.advantagebhs.org/>
- Aspire Clinic. (2020a). Finances. Retrieved from <https://www.aspireclinic.org/services/finances>
- Aspire Clinic. (2020b). Self. Retrieved from <https://www.aspireclinic.org/services/self>
- Aspire Clinic. (2020c). Our Process & Fees. Retrieved from <https://www.aspireclinic.org/about/our-process-and-fees>
- Aspire Clinic. (2020d). About Aspire. Retrieved from <https://www.aspireclinic.org/about/about-aspire>
- Camp Hooray. (n.d.) About ESP. Retrieved from <http://camphooray.com/aboutesp/>
- CAPS. (2020). About CAPS. Retrieved from <https://caps.decal.ga.gov/en/About>
- Center for Disease Control and Prevention. (2020). Down Syndrome. Retrieved from <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>
- Center for Medicare and Medicaid Services. (2020). Medicaid & CHIP in Georgia. Retrieved from <https://www.medicaid.gov/state-overviews/stateprofile.html?state=Georgia>
- Extra Special People. (2017). How We Are Growing. Retrieved from <https://extraspecialpeople.com/how-were-growing/>
- Extra Special People. (n.d.) Year Round Programs. Retrieved from <https://docs.google.com/document/d/13amoLntq9cm6wBwEZpAnaaUZIviRyKetYJic1fFFtQ/edit>
- Extra Special People. (n.d.) Summer Camp. Retrieved from <https://docs.google.com/document/d/1Nb1K1J5vdSEarigm6xfaWJzMEtUBELSzQ2YF6ClaVSU/edit>
- Department of Human Services. (n.d.). How do I apply for SNAP benefits?. Retrieved from <https://dfcs.georgia.gov/food-stamps>
- Financial Assistance. [PDF file] Retrieved from <https://www.nghs.com/resources/crg/jackson/Financial%20Assistance/Financial%20Assistance.pdf>
- Georgia Department of Community Affairs. (2020). Rental Assistance (Housing Choice Voucher). Retrieved from <https://www.dca.ga.gov/>
- Georgia Department of Community Health (n.d.) Background Information. Retrieved from <https://dch.georgia.gov/peachcare-kids>
- Help Jackson County. (n.d.) Developmental Disabilities. Retrieved from <http://helpjacksoncounty.com/>
- Marshall, J., Tanner, J. P., Kozyr, Y. A., & Kirby, R. S. (2015). Services and supports for young children with Down syndrome: parent and provider perspectives. *Child: care, health and development*, 41(3), 365-373. doi:10.1111/cch.12162
- Massachusetts Institute of Technology Department of Urban Studies and Planning. (2018). *Living Wage Calculator: User's Guide*
- National Council of Housing Market Analysts. (2020). Jackson County Fair Market Rent Retrieved from <https://www.rentdata.org/jackson-county-ga/2020>
- Need Help Paying Bills (n.d.) Georgia Free child care assistance Program. Retrieved

from https://www.needhelppayingbills.com/html/georgia_child_care_assistance.html
Ninth District Opportunity. (2013a). Heating Assistance. Retrieved from
<https://www.ndo.org/web/heating.html>
Ninth District Opportunity. (2013b). Housing Assistance. Retrieved
from <https://www.ndo.org/web/housing.html>
PeachState Health Plan. (2020). Get medical insurance in Georgia. Retrieved
from pshpgeorgia.com/get-insured.html
Social Security Administration. (2020). Understanding Supplemental Security Income SSI
for Children-2019 Edition. Retrieved from <https://www.ssa.gov/ssi/text-child-ussi.htm>
Social Security Administration. Supplemental Security Income (SSI) Benefits. Retrieved
from <https://www.ssa.gov/benefits/ssi/>
Society of St. Vincent DePaul Georgia. (2020). Thrift Stores. Retrieved
from [https://www.svdpgorgia.org/what-we-do/clothing-furniture/thrift-
stores/](https://www.svdpgorgia.org/what-we-do/clothing-furniture/thrift-stores/) The Ark of Jefferson. (2012). About the Ark. Retrieved from
<https://arkofjefferson.wordpress.com/about/>
The Division of Family and Children Services. (2018). *Supplemental Nutrition
Assistance Program-SNAP (Food Stamps): In Georgia.*
United States Census Bureau. (2019). *Poverty Thresholds*