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Challenges and Tennessee Support Systems for those Affected by Developmental Disabilities  
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In 2022, it was estimated that around 17% of children within the US have one or more developmental disabilities (CDC). Developmental disabilities can be defined as disabilities that lead to cognitive and/or physical disabilities (“Developmental Disabilities”). Among the many developmental disabilities that exist, the most common are autism spectrum disorder, cerebral palsy, down syndrome, and intellectual disability (“Developmental Disabilities” and “The Five Major Developmental Disabilities”). With a prominence among children, the importance of understanding both the challenges and available resources for children and family members affected by developmental disabilities has never been more important.

In an effort to have a greater understanding of the many challenges those with developmental disabilities face, basic facts and challenges surrounding each of the four most common developmental disabilities will be explored, starting off with autism spectrum disorder (ASD). Around 1.9% of US children are diagnosed with ASD, with numbers rising with each subsequent year (“The Challenges of Autism”). It is important to understand that most ASD symptoms are not physical and there is a wide range of abilities for those with ASD. The disability develops before three years old and continues throughout a person’s life. As those with ASD grow, many are more likely to develop conditions such as depression and attention-deficit disorder, leading to multiple diagnoses. Those with ASD tend to have more trouble in social scenes and have trouble with behavior. Additionally, those with ASD may also tend to repeat certain behaviors or interests. With the lack of a definitive test for those with ASD, many individuals may not be diagnosed until much later in life, making life while undiagnosed very difficult (“What is Autism Spectrum Disorder?”). Many challenges for children with ASD include communication, behavioral, and learning differences which can in turn affect abilities to socialize. With these difficulties, more problems can arise such as stress and potential bullying. Additionally, parents of children with ASD can also face challenges such as their children having seizures and frustration meltdowns. However, the earlier the disability is detected, the more likely those affected by ASD can develop social and learning skills (“The Challenges of Autism”).

One of the other most common developmental disabilities is cerebral palsy (CP), affecting approximately one million people within the US (“Cerebral Palsy Statistics”). CP is caused by damage to the parts of the brain responsible for movement. CP can be developed before or during birth, as well as in the first couple of years of a child’s life; however, most are born with the disability (“What Causes Cerebral Palsy?”). CP can be caused by a lack of oxygen, events throughout pregnancy, and delivery events. Additionally, there are multiple factors that can lead to an increased chance of having a child with CP. Mothers who are under twenty and over thirty-four, women of lower income, and women giving birth to a male child have an increased risk. Cerebral palsy causes many parts of the body to be weaker causing differences in movement and posture (“Cerebral Palsy Statistics”). Just like ASD, the severity of CP varies greatly among individuals, leading to some needing only part-time assistance while others requiring full-time assistance. The most common challenges for those with CP are troubles with moving, communicating (due to inability to coordinate mouth and tongue movement), eating and

drinking, hearing, and bladder control. Additionally, those with CP can have learning disabilities such as trouble with language and concentration, an increased risk of having epilepsy, and trouble sitting due to hip displacement and pain causing many of those with CP to use a wheelchair (Cerebral Palsy Alliance Research Foundation).

One of the other most common developmental disabilities is down syndrome. Affecting 1 in 700 kids, down syndrome is the “most common genetic cause of intellectual disability” (Boston Children’s Hospital). Down syndrome occurs when chromosome 21 divides incorrectly, resulting in either a partial copy or a full copy of the chromosome. Those with down syndrome suffer from intellectual disabilities that cause learning disabilities, developmental delays, and possible medical complications. With down syndrome, there are many levels to the different symptoms individuals can experience. Starting with physical differences, those with down syndrome can suffer from features such as a flattened face, upwards slanting eye lids, small ears, and being shorter than the average person. As far as intellectual disabilities, those with down syndrome tend to have language delays, problems with memory, and some degree of cognitive impairment (Mayo Clinic Staff). Finally, medical problems for those with down syndrome can include congenital heart defects, lung damage, and hearing loss (Boston Children’s Hospital). Among the obvious health and intellectual challenges that those with down syndrome face, social and developmental challenges are also present. Extra help with speech development is often required, as well as special help with fine motor skills. Additionally, those with down syndrome can face social challenges as well through both stigma and discrimination. This can affect those with down syndrome by damaging their self-esteem and delaying their social development (“Diagnosis and Beyond: Understanding the Challenges and Joys of Raising a Child with Down Syndrome”).

Finally, another very common developmental disability is intellectual disability. People who suffer from intellectual disability can be described as having limits on their ability to learn and function daily (“Facts About Intellectual Disability”). Around 1.65% of Americans are diagnosed with intellectual disability in 2021 (“Diagnosed Developmental Disabilities in Children Aged 3-17 Years: United States, 2019-2021”). This disability is caused by either infections or genetic disorders that are identified at birth (“Australian Disability Clearinghouse on Education and Training”). Some common examples of causes of intellectual disability are fetal alcohol syndrome, fragile X syndrome, and birth defects (“Facts About Intellectual Disability”). As with the three previous disabilities, the severity of those with intellectual disability varies greatly among individuals. The most common challenges for affected individuals include having trouble with new information, problems with communication, and having a slow cognitive processing time (“Australian Disability Clearinghouse on Education and Training”). Since it’s hard to physically identify if an individual suffers from intellectual disability, there are some behavioral signs that can lead to a diagnosis. For example, individuals with intellectual disability can have a delay in learning to walk and talk, difficulty with memory, and difficulty with social etiquette (“Facts About Intellectual Disability”).

As seen with these four examples of developmental disabilities, there is a wide variety of ways individuals develop their disabilities, show the signs of disabilities, and most importantly, understand the effects these disabilities have on individuals as well as those around them. These disabilities have many challenges that come with them, so it is important to understand the organizations that exist to help individuals affected by these developmental disabilities, specifically those located in Tennessee. The rest of this paper will mainly focus on the resources and organizations within Tennessee available to those with the four developmental disabilities

stated above: autism spectrum disorder, cerebral palsy, down syndrome, and intellectual disability.

Starting with resources available to those affected by autism spectrum disorder, one main Tennessee organization stands out: Autism TN. Autism TN focuses on specific programs such as outreach, self advocacy, and employment. Starting out with outreach programs, Autism TN provides connections through community and college ambassadors programs where these ambassadors raise awareness about ASD, help with community events, and fundraising. A program called Spectrum Dad is also available where fathers and father figures are able to connect with families and share experiences and advice surrounding individuals with ASD. A similar program called Spectrum Families is also available where families can connect and share tips, experiences, and advice for any individual affected by ASD. Additionally, Autism TN has self advocacy programs for individuals with ASD. For example, CONNECT is an adult social networking program for adults with ASD where experiences can be shared and individuals feel welcomed and safe. Autism TN also works hard to find resources for individuals interested in employment. For example, the website has many resources dedicated to job training for individuals with ASD, college programs that help with social development, and information about rights people with ASD have. Additionally, the website provides a vast amount of information regarding life coaches, housing options, financial planning, and a list of local employers that actively hire people with ASD. Autism TN also works to educate others about ASD through monthly presentations available to anyone interested. Finally, the Building Bridges Program works to educate childcare and preschool teachers about tools to help provide a good and safe environment for kids with ASD (“Autism TN”).

Similarly, one of the best Tennessee resources found for individuals affected by cerebral palsy is United Cerebral Palsy of Middle Tennessee. This organization works to allow disabled individuals to work towards full citizenship and independence. The organization works with volunteers and fundraising to help provide the most help for affected individuals. For example, through golf tournaments, direct donations, and a Holiday and Specialty Cards Program, UCP is able to gain the means to help many individuals. UCP provides many programs and services for a wide range of individuals to help work towards comfort and independence for those with CP. For example, the Tennessee Disability Assistance Program works with donations and partners to help low-income disabled individuals get housing. Additionally, UCP orchestrates an equipment exchange that takes donated medical equipment, such as wheelchairs, scooters, car seats, and bed rails, and gives them to families and individuals with little to no insurance who need these items to help live independently. UCP also works to help families with home access by constructing ramps within homes to help those with wheelchairs become more mobile. Sports Night is another UCP initiative that helps those with CP develop both physical abilities and social skills through board games, movie nights, bowling, and basketball. Finally, the organization helps provide resources to help with long term planning as well as provides links to Tennessee and Federal Government services that might provide assistance for disabled individuals (“United Cerebral Palsy of Middle Tennessee”).

One outstanding program available to those affected by down syndrome is Down Syndrome Association of Middle Tennessee. DSAMT works hard with parents, grandparents, siblings, educators, and many more of forty counties within middle Tennessee to support those with down syndrome as well as their families. DSAMT has many programs to help those affected by down syndrome and ensure both support and awareness for the down syndrome community. Starting off with the First Call program that supports families that have recently

found out their child will have down syndrome. This program works to provide these families with resources, connect them with other families to contact, host baby showers for them, and find other ways to learn more information. Additionally, DSAMT has many educational programs such as workshops, educational advocacy support for parents with children in school with down syndrome, conferences, and training on how down syndrome affects students as well as provide strategies to help these individuals. The organization provides many inclusive programs such as Music at Belmont meetings, a book club, and arts camps for anyone wanting to participate to help everyone within the community connect and learn. DSAMT works to advocate for those with down syndrome through parent mentors that help parents navigate the educational system. Additionally, DSAMT works to inform both parents and the general population about down syndrome through education about the rights of children, advocating at the local, state, and national level, and contacting local legislators to help bring more change. The organization partners with many schools to help train teachers and staff as well as work with employers to help promote the hiring of individuals with down syndrome and create a welcoming work environment. Finally, DSAMT provides the Middle Tennessee community with many opportunities to get involved like an Extra Mile fundraising event, license plates, and providing a list of businesses to support that are run by or support individuals with down syndrome (“Down Syndrome Association of Middle Tennessee”).

Lastly, one great resource for Tennessee individuals affected by both intellectual and developmental disabilities is The Arc: Davidson County and Greater Nashville. Their mission is to support, protect, and advocate for individuals with intellectual and developmental disabilities as well as their families. Their programs offer a wide range of services and support for anyone in need. For example, their advocacy and education programs help make the community more informed, refer individuals in need of more information, as well as provide families with updates on laws that affect those with disabilities. The Arc also provides training resources, webinars, and workshops to better equip individuals wanting to help disabled individuals. The organization works with families to help them understand both their responsibilities as well as the rights of disabled individuals, while also working with Metro Schools to teach staff more skills to better equip disabled students for success after school. The Arc also provides support to families through both financial aid as well as providing many resources to help families with greater financial needs. The organization also works to set individuals up for success through future planning aid to make disabled individuals' lives as independent as possible. The Arc makes sure to provide an extensive list of links that are divided by topics such as rights, education, and healthcare to provide both reliable and up-to-date information to those who are interested. Finally, The Arc makes sure to provide many opportunities for the greater Middle Tennessee community to get involved as well. Through the Pick Up Service that picks up old clothes and items to be sold for profits for the organization, taking vehicles as donations, giving out memberships, and large corporation partnerships with companies such as Amazon and Kroger, The Arc works hard to gain as much support as possible for disabled individuals (“The Arc Davidson County and Greater Nashville”).

Living with developmental disabilities like the ones previously discussed obviously comes with many challenges. From trouble socializing and learning, to requiring constant care, disabilities affect many people within the Tennessee community. However, there are many organizations and individuals working hard to make the lives of disabled individuals and their families just a little bit easier through hard work and the participation of the whole Tennessee community.

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