TRANSITION TO ADULTHOOD FOR YOUNG ADULTS WITH DOWN SYNDROME:
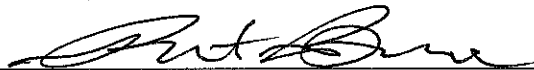BEST PRACTICE

by

Hannah Cary

Honors Thesis

Appalachian State University

Submitted to the Department of Social Work
in partial fulfillment of the requirements for the degree of
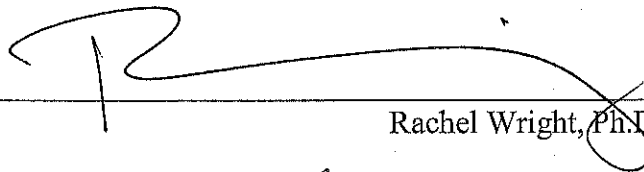
Bachelor of Social Work

May, 2020

Approved by:

_____

Robert Broce, Ph.D., Thesis Director

_____

Peter Fawson, Ph.D., Second Reader

_____

Rachel Wright, Ph.D., Third Reader

_____

Mary Strong, MSW, Outside Reader

_____

Emily Dakin, Ph.D., Departmental Honors Director

Table of Contents

Acknowledgements

This process was a very challenging yet rewarding experience. I learned a great deal about the research process and more about a practice area that I am extremely passionate about. However, this achievement would not have been possible without the sage guidance of Dr. Robert Broce, my thesis advisor. Your thoughtful critiques and constant encouragement allowed me to produce a piece that I am very proud of, as well as become a stronger researcher.

I would also love to express my sincere gratitude to my readers, Dr. Rachel Wright, Dr. Peter Fawson, and Mary Strong. Your expertise and guidance enhanced the quality of my thesis immensely. Thank you to the Social Work Department, Dr. Lauren Renkert, and Dr. Emily Dakin for this wonderful educational opportunity. Thank you, Janice Koppenhaver, for your constant encouragement and thoughtful advising throughout my time here at Appalachian.

Lastly, I would like to thank my friends and family who have supported me with insight and empathy along this journey. It was not always easy but you have all shown me compassion and advice when I needed it most, and for that I am forever grateful.

Abstract

Individuals with Down Syndrome, or other conditions that affect both physical and cognitive functioning, can have a difficult time navigating the transition to adulthood. Transition to adulthood can be challenging for all individuals, but especially for those that are developmentally delayed and may need additional support moving toward independence. Transition to adulthood is also one of the most life changing and impactful stages in one's life and can have far-reaching effects into an individual's future. This thesis explores what can be done during the process of transitioning to adulthood to support individuals with Down Syndrome in developing quality, meaningful adult lives. Transitional factors include social life, employment, living arrangements, and overall health and well-being. This literature review explores the challenges to successful adult transition and seeks to identify potential best-practice solutions through a multi-systemic lens. Many of the studies in this area focus on the lived experiences of individuals with Down Syndrome, and suggest that inclusive policies and organizations, person-centered planning, and long-term goal oriented programs are the most helpful. While there have been strides in making employment and other services more inclusive and comprehensive for this population, accessibility and funding are still significant challenges.

Definitions

Down syndrome (DS) is a genetic disorder where chromosome 21 has three, full or partial, copies instead of just two ("Down Syndrome," 2018; "Learning About Down Syndrome," 2017). There are three different types of DS including Trisomy 21, Mosaicism, and Translocation. Trisomy 21 occurs when there is an extra copy of chromosome 21 that is replicated in all of the cells of the body and is the cause for 95% of DS cases ("Down Syndrome," 2018). Mosaicism, the least common type of DS, occurs when there is a mixture of some cells that have the usual 46 chromosomes and other type of cells that have 47 chromosomes, with the extra chromosome being chromosome 21 ("Down Syndrome," 2018). Translocation, which causes 4% of all DS cases, occurs when there is an extra, full or partial, part of chromosome 21 that attaches itself to another chromosome ("Down Syndrome," 2018). Individuals who have DS have learning difficulties, different physical characteristics, and other health related problems such as heart defects, celiac disease, and hearing loss ("Learning About Down Syndrome," 2017). DS is classified as an Unspecified Neurodevelopmental Disorder in the DSM-5 under the category of intellectual disability (American Psychiatric Association, 2013). The DSM-5 states that an intellectual developmental disorder is characterized by inability to succeed in general mental abilities at the typical age of mastery. These abilities include reasoning, overcoming obstacles, planning, hypothetical thinking, judgment, scholastic learning, and experiential learning (American Psychiatric Association, 2013). This condition affects 1 in 800 to 1 in 1000 live born infants ("Learning About Down Syndrome," 2017). Not all parents know their children have DS before they are born, despite prenatal screens becoming more accessible. As a result approximately 87.5% of DS diagnoses are postnatal (Marshall et al.,

2014). Life expectancy for individuals with DS has also increased from about 35 years of age, in the early 1980s, to now about 55 years and older (Marshall et al., 2014).

Development

Children with DS experience developmental milestones at different rates than children with typical development (TD). On the explicit physical side, the gross motor skills of children with DS can be 1 month to 3 years behind those of children with TD ("Early Intervention", 2018). Children with DS may not walk alone until the age of 4 years, whereas children with TD can do so within the ages of 9 to 18 months ("Early Intervention", 2018). The language gap is even more pronounced because children with TD could be forming two-word phrases from ages 15 to 32 months compared to children with DS who can only do so around 2, to possibly 7.5, years of age ("Early Intervention", 2018). There are some differences among the social and self-help milestones, however the most pronounced ones are bowel control and getting dressed unassisted. Children with DS may not master bowel control until the age of 7 years while children with TD can do so between the ages of 16 and 42 months. Similarly, children with DS could be 8 years old by the time they master independently dressing themselves, whereas children with TD have reached this stage between the ages of 3.25 and 5 years ("Early Intervention", 2018). Although these differences are primarily physical, they may have larger implications later in life. These differences in developmental abilities can distinguish individuals with DS from their peers at a young age, which may impact how they are able to integrate socially.

Abbeduto, Finestack, and Palmer, (2012) examined the macrostructural language comprehension of young adults with DS compared with young adults with TD and those with Fragile X syndrome (FXS). Macrostructural language is the overall organization of the narrative

of speech. Microstructural language refers to the coherence of smaller units of speech such as words, phrases, or sentences. Almost all of the individuals with DS and FXS had challenges with their language development, specifically in areas of microstructural conversation and narrative language. Young adults with DS, however, performed at a significantly higher level in macrostructural narrative language than those of the same mental age with TD (Abbeduto et al., 2012). Understanding specific deficits and strengths in language development may have implications for intervention and work to reduce stigma about the abilities of individuals with DS.

Barisnikov and Lejeune (2018) explain that students with DS have proven to be less prosocial in the classroom than their peers with TD and that they need more assistance getting play started. Cebula, Moore, and Wishart (2009) also explain the common misconception that children with DS are highly social compared to their TD peers. They may be more outgoing than their classmates with TD, however their social cognition is usually more underdeveloped. Social cognition is "the ability to make sense of other people and includes the ability to plan and execute appropriate ways of responding in everyday social contexts" (Cebula et al., 2009, para. 5). Most studies have been designed in a way that assumes that children with DS are cognitively delayed but socially they are at the same level as their peers with TD. However Cebula and colleagues (2009) found evidence that social cognition in children with DS is still delayed compared to children with TD and autism. One example of this is that children with DS were less likely to engage when participating in activities designed to encourage feedback, such as requesting or commenting, but more likely to engage in a simpler type of conversational interaction.

Children with DS also have difficulty comprehending emotion and then choosing an appropriate corresponding response. It is important to recognize, however, that these data are highly dependent on the family and social environment of both children with TD and DS. Other studies have found that there have been many reported cases of children with DS having socio-emotional disorders and social functioning difficulties (Barisnikov & Lejeune, 2018). Another pattern of development that is different from children with TD of the same age, is that children with DS mostly have the same test results whether the category of rules are moral or conventional (Barisnikov & Lejeune, 2018). This suggests that their awareness of morality develops at a different rate than children with TD.

Transition

Stage-development theories can help explain why individuals with IDD may struggle more with transition to adulthood than their TD peers. Erik Erikson developed a theory for human development across the entire lifespan based on societal values. His theory suggests that there is a basic psychosocial conflict at each stage of development and how each conflict is resolved determines if the outcomes will promote success in the next stage. In adolescence, for example, the key psychosocial conflict involves role confusion and the development of identity, or finding a place in the broader social context. Establishing identity is seen as a necessary precursor to the development of capacity for intimacy and long-term relationships in early adulthood (Berk, 2013; Erikson, 1963).

Those with DS develop at a more delayed rate than their peers ("Development and learning," 2018), and therefore may still be navigating their identity vs. role confusion conflict while their age-matched peers have moved on to the intimacy vs. isolation stage. These emotional strains can contribute to stress about the whole process of figuring out the next steps.

Parents also carry the burden of this emotional strain because they too have to adjust to a different lifestyle. Most youth with disabilities will stay emotionally dependent on their parents and have to navigate complex emotions with their support staff and families during this stage of life (Pandey & Agarwa, 2013).

Force, Hogan, Janicki, and Jokinen (2012) explain that all life stage transitions usually cause insecurity and fear. As people grow older these transitions become more complex once the prospect of leaving the house or starting a career becomes more evident. There are reports of transitions causing intense emotional distress for individuals with IDD. The authors also note that transitions will always affect entire families and not just individuals. The transition to adulthood and can affect the trajectory of their lives (Pandey & Agarwa, 2013). During this transition, young people will most likely leave home and start adapting to life without the friends and family they have relied on for support (Force et al., 2012). They may also go through significant emotional, psychological, and physical changes and be expected to develop their social and professional identities (Pandey & Agarwa, 2013). There are also changes in the roles these individuals play in their families, social circles, and communities.

Many young individuals lose contact with long-term relationships they had during high school, yet this can be harder on individuals with IDD. It is already more difficult for individuals with disabilities to form these meaningful relationships, and much harder to make them later in life, so losing a friend from childhood often poses a bigger loss than it would for those with TD. It is also more challenging for individuals with a disability to get involved in the community through work, volunteerism, or education systems (Pandey & Agarwa, 2013). In fact, these individuals are 30% less likely to be employed and 50% less likely to be enrolled in higher education than their age-matched counterparts with TD (Pandey & Agarwa, 2013).

There are many resources, implemented by both education and government systems, that aid young adults in their complex navigation into adulthood. Typical high school curriculum allows students to prepare their college applications, start making their resumes, apply for jobs, and practice financial planning. However, for individuals with developmental disabilities, there are few resources worked into high school curriculum that are designed for their specific psychological, social, educational, and economic needs (Pandey & Agarwa, 2013). The main transition resource that is provided to individuals with IDD is the formalized transition plan that is incorporated into the Individualized Education Plan (IEP) ("Post-High School," 2018). It is required by federal law, Individuals with Disabilities Education Act (IDEA), that by age 16 individuals with IDD must have a statement of transition services outlined in their IEP. This can be a lengthy and very involved process as the drafting of this document includes individuals with IDD, parents, teachers, school counselors, school administrators, and affiliated agency representatives ("Post-High School," 2018). It is essential to have a thorough and well-prepared transition plan because at the age of 21 the families can no longer access the school and government resources that were provided by the IDEA law.

One of the most important goals for individuals with IDD is the freedom to have emotional autonomy (Pandey & Agarwa, 2013). After relying on others for continuous support, they are suddenly in a position to have more independence yet this is hard for their support system to comprehend. Their families and care providers are so invested in their lives that it is often difficult for them let a little of that control go to allow their child to have the freedom they deserve. The family itself is usually going through changes that affect everyone such as siblings moving out, grandparents getting older, and parents planning for retirement (Force et al., 2012;

Leonard et al., 2016). When funding, programs, or policies for this population are not available, the absolute most important support in the process is the parent (Pandey & Agarwa, 2013).

Many parents of children with IDD take on the responsibility of planning for their children's future so that they are taken care of when the parents eventually die. However, many such parents have been found to be unaware of the housing and other transition services available to them (Force et al., 2012). Even though most evidence supports the notion that the family and child should both be deeply involved in the transition planning process, the child's requests and desires are often overlooked and sometimes left out of the process entirely (Force et al., 2012; Leonard et. al., 2016; Pandey & Agarwa, 2013). A study in 2016 about the transition to adulthood for individuals with DS reports that 87% of parents were involved with the decision making process whereas only 59.5% of young people with DS were actually involved (Leonard et. al., 2016). Individuals with developmental disabilities usually want to be as involved in the process to decide their educational and employment future as their peers with TD, however they are too often left out of the planning (Pandey & Agarwa, 2013).

Having a long-term condition, such as DS, is a significant barrier to future education and therefore employment in adulthood (Pandey & Agarwa, 2013). The most common and key barriers to successful adult transition for individuals with DS and their families are the lack of accurate knowledge, lack of availability and funding of services, lack of supportive policies, and lack of experience and confidence in the individual with the disability (Pandey & Agarwa, 2013). The lack of opportunity and education for youth and parents to prepare for this transition during their childhood also makes for a more difficult process when the time actually comes. Externally, stigma from society and individual attitudes from the public about people with DS often interfere with individuals seeing and acting on their own potential (Pandey & Agarwa, 2013).

Researchers have found that one of the most essential, yet often overlooked, domains of transition is social and community life (Pandey & Agarwa, 2013). More and more people with DS are choosing to live in supported living settings, residential care, and shared lives placements ("Where to Live," 2018). However, many people also choose to stay living with their family in their original home. It is possible to arrange for the individual to stay living in the family home with support when the family is gone ("Where to Live," 2018).

Contextual Risk

Bronfenbrenner's Ecological Systems Theory recognizes that children's surrounding systems influence how they grow and develop ("Ecological Systems Theory," 2013). There are five concentric levels of external influences that individuals are enmeshed in. The microsystem includes the interplay between the individual (with unique temperament, genetic, and biological factors) and their most immediate influences such as family, school, and close peer relationships. Next is the mesosystem, which includes connections between microsystems, such as family and friends or school and family. The exosystem consists of extended entities such as workplaces of parents or extended family that indirectly affect individuals. The macro system is the largest reaching system and includes cultural values and beliefs of children. Finally, the chronosystem accounts for the influence of time, changes in family structure, and impactful societal changes.

Within the microsystem individuals with DS may have other comorbidities. Although it is rare, about 1-11% of those with DS are also diagnosed with Autism Spectrum Disorder (ASD) and 10-20% of those with DS who have behavioral problems are at an increased of developing ASD (Bacanli, 2016). Individuals with both ASD and DS may experience irritability that can lead to excessive anger and behaviors that could cause harm to themselves or others (Bacanli, 2016). Therefore, individuals with this dual diagnosis will most likely require additional, and

even more specialized, treatment and education than would be needed with just the diagnosis of

DS (Bacanli, 2016). Individuals with DS can also live with a variety of other comorbid

diagnoses.

Individuals with DS usually have added stress within the mesosystem that contributes to

the challenges they face. It has been reported that some of these individuals can become involved

with substance abuse and criminal behaviors which can lead to school failure and unemployment

(Pandey & Agarwal, 2013). With a criminal record or an addiction the transition process, for

these individuals, will be even harder to navigate. Their parents may experience added stress

because certain programs may not be available to young adults who have a criminal record.

Additionally, social inclusion and acceptance is a vital factor in the success of individuals with

DS (Pace, Shin, & Rasmussen, 2010). If their peers are allowed to bully them by their teachers,

they will not seek out and gain success.

Unfortunately economic macro systems encroach on the families of individuals with DS

as well. Many individuals face complicated transitions because they experience poverty, racial or

ethnic discrimination, or immigration barriers (Pandey & Agarwal, 2013). Many of the programs

and resources available to families and individuals with DS are very expensive and not always

accessible to those in a lower financial bracket. Unfortunately, there is also still discrimination

based on race and ethnicity in this country, as well as systematic trends for non-white

communities to receive less funding or opportunity ("Unequal Education," 2012). Additionally,

accessing government aid is extremely complicated, risky, and sometimes just not allowed for

individuals who are not American citizens (Blazer, Broder, & Moussavian, 2015).

Within the chronosystem it is usually societal norms and expectations that inhibit

individuals with DS who are trying to push past the limitations that are put on them. Research

shows that the general public still holds negative attitudes towards people with DS (Pace, et al., 2010). In school other students are encouraged by teachers to be inclusive of their peers with DS. However, overtime, once children grow up, there is no longer consistent encouragement to include individuals with DS. Since this diagnosis presents itself both internally and externally, many people have stereotyped attitudes toward these individuals before they even get to know them. However, studies show that those with higher education levels receive more public approval than those who may have only graduated high school (Pace, et al., 2010). Therefore, as individuals with DS grow and begin to gain success society is more inclined to acknowledge and include them.

Best Practice

It has been reported that including individuals with DS in a work environment can improve work-satisfaction rates for all employees ("Self-Advocate Employment Initiative Grants," 2018). However, there is still a 70% unemployment rate for individuals with IDD ("Our Story," 2018) and the majority of individuals with DS are employed in positions that largely under-utilize and under-appreciate their skills (Neal, 2018). The research shows that preparing individuals with IDD while they are young for life after school produces the most effective and sustainable results (Pandey & Agarwa, 2013). This is done best when the individual is at the center of the planning process, the goals are career oriented instead of just focused on getting any job available, and the individual has received a post-secondary education (Pandey & Agarwa, 2013). Therefore, programs and policies that support inclusive, integrative, and meaningful employment before graduation from college or high school will give more individuals with DS chances for successful, quality adult lives.

Productive Policies

An example of recent legislation supporting individuals with disabilities is the Achieving a Better Life Experience (ABLE) Act of 2014. This federal bill was the most bipartisan piece of legislation in the 113th Congress. The act is aimed to increase financial independence and allows individuals with IDD to receive tax breaks as well as disability benefits ("Federal Legislation," 2018). This act increased financial independence and allows individuals with IDD to receive tax breaks as well as disability benefits. The ABLE Act is currently helping individuals with disabilities protect and make the most out of their money and benefits by allowing individuals to hold up to $100,000 into ABLE accounts so they can still qualify for Medicaid and SSI benefits ("Federal Legislation," 2018).

The recently passed ABLE to Work Act of 2017 extends the 2014 law and allows individuals with disabilities and their families to exceed the annual savings cap of $14,000, and save up to the federal poverty level in their ABLE accounts if the beneficiary on the account is earning an income by working. This important extension further incentivizes employment programs for individuals with disabilities who receive federal aid ("Federal Legislation," 2018).

The following bills are pieces of federal legislation that have been proposed in the past year or two but have not yet been passed. The passage of these bills would represent a significant step forward in support for individuals with disabilities. Additional advocacy will be needed from social workers and others to move these measures forward. The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act of 2018 (HEADs Up Act) is a federal bill that aims to amend the Public Health Service Act to promote more access to and improve care at health care centers for individuals with IDD (H.R. 6611, 2018). This proposed bill would allow the government to fund more grants to provide additional

primary, dental, and specialty care for these individuals (H.R. 6611, 2018). Funded specialized

treatment would also be required for individuals with IDD in addition to primary care services

(H.R. 6611, 2018). This bill could greatly increase the quality of care for individuals with IDD

and help coordinate care services to improve efficiency for the patient and the service provider.

Another important federal bill that was proposed in 2017 is the Disability Integration Act.

This bill prohibits institutionalization for individuals with disabilities that require long term or

daily assistance (H.R. 2472, 2017). It also prohibits health care providers from funding the long

term care facilities that exclude community based services that would allow individuals with

IDD to live independently in the community (H.R. 2472, 2017). Such legislation would

encourage the funding of and access to local community based housing and services for

individuals with IDD.

Another progressive piece of federal legislation that supports those with IDD's transition

to adulthood is the Transition to Independence Act of 2018. This act incentivize Medicaid Buy-

In States to expand employment opportunities for those with disabilities. These states could

receive bonus payments if they expand integrated employment options, reduce low-paying

placements that can take advantage of individuals with disabilities who receive Medicaid funded

services, and make other strides to promote quality employment for individuals with disabilities

(H.R. 4931, 2018).

Productive Organizations

There are many movements and programs working diligently to advocate for the best

possible future for individuals with DS and IDD in general. One example is the Be Thoughtful

movement that is based in West Hartford, Connecticut. The collaborators are raising awareness

about the lack of employment opportunities for people with IDD who have aged out of some of

the federal support systems at age 21 ("Our Story," 2018). They strive to lower the 70%

unemployment rate for individuals with IDD in the United States. An important component of

this movement is finding meaningful job opportunities for individuals with IDD that align with

their goals and dreams about their future. The Be Thoughtful Movement is also prepared to

educate people on these services, policies, and programs that are available to them so this

process does not have to be a barrier between an individual and quality employment. One of their

main tactics is encouraging local businesses to hire a more diversely-abled workforce. This

movement is specifically partnering with the New England Pasta Company and their new café

called BeanZ & Co. ("BeanZ & Co.," 2018). This new inclusive coffee shop's mission is to

employ people with and without IDD and foster an inclusive environment. Their hope is that this

company will inspire its workers, patrons, and surrounding businesses to see that just because

their abilities are different, individuals with IDD are capable, hard workers. The goal is also to

encourage more business owners to start hiring at least one or two individuals with IDD and have

this trend grow from there.

The National Down Syndrome Congress (NDSC) and the National Down Syndrome

Society (NDSS) both provide resources for families on development, healthcare, and

employment concerns as well as advocate for progressive policy change and general inclusion

(NDSC; NDSS, 2018). Families can utilize these organizations to locate day to day or long-term

services as well as helpful education on how to navigate confusing systems and government

programs. Individuals can support these groups in their fight to make the United States a more

inclusive place to work and live.

The Global Down Syndrome Foundation promotes programs, resources, education and

advocacy for individuals with DS and their families around the world. This organization also

awards Self Advocate Employment Initiative Grants to DS organizations to help hire employees with DS for meaningful employment ("Self-Advocate Employment Initiative Grants," 2018). Their goal is to allow more individuals with DS the opportunity to thrive in purposeful careers with employers who do not take advantage of them.

Productive Programs

State funded programs can provide day services and employment opportunities for individuals with IDD. One of these providers, serving North Carolina, is Turning Point Services. Through this organization there are a range of options from employment, personal care, and residential living services. They offer transportation services to and from their jobs or just around town if they need it. There are also respite care services available that allow the rest of the family and the individual time away from each other if needed.

DSWORKS is a federal employment program, from the National Down Syndrome Society, that encourages corporations to hire individuals with DS and expand the arena of competitive employment for this population ("Employment Program," 2018). Corporations and companies have partnered with DSWORKS in order to create sustainable employment for more qualified individuals with DS. Their advocacy campaign also works to promote productive policies and lobby to change policies that create barriers for this population.

The ABLE Alliance for Financial Empowerment promotes ABLE programs across the nation and fights to improve ABLE legislation, such as the ABLE to work Act of 2014 (Federal Legislation, 2018). ABLE legislation includes additional bills and laws that enforce employment and financial freedom for individuals with disabilities. 49 states, and the District of Columbia, have passed legislation to start implementing ABLE programs and 35 states have officially established ABLE Programs.

Implications

Implications for Research

Although some studies provide insight into the challenges for individuals with various

diagnoses within the IDD population, several key questions remain unanswered. For example, it

was noted that there is not an actual statistic on the percentage of how many people with DS are

unemployed (Neal, 2018). With more than two thirds of the general IDD population

experiencing unemployment, it is probable to believe that the DS unemployment percentage

would also be high. Accurate statistics are needed to demonstrate to program designers and

potential employers just how important opportunities are for this population. Such findings could

also persuade policy makers to write or revise policies that would lower the unemployment rate

for a population that is in desperate need.

A review of literature identified several policies, organizations, and programs that are

helpful to individuals with IDD, however few focused critically on issues of access or other

barriers. While multiple sources alluded to the fact that certain policies were written in a way

that can exclude particular benefits from this vulnerable population, few research studies

addressed these concerns. Interaction with local service providers also show that many programs

seem almost impossible to access, due to time, money, and location, and may not provide quality

care (See Appendix A). Additional research is needed to explore issues of program quality and

barriers to access.

The next step for research in this area would be further studies about the lived

experiences of those with DS during this transition process, specifically in regards to meaningful

employment. Existing literature suggests that meaningful or quality employment should be

supported, but researchers have not yet determined what that means for individuals with DS. A

qualitative study of the employment experiences of individuals with DS could explore the concepts of meaningfulness and quality.

Implications for Advocates, Social Workers, and Policy Makers

Social workers and other advocates need to support progressive policies that increase meaningful employment opportunities, financial independence, and stable living environments for young adults with DS. This includes participating in and support movements that promote inclusion of individuals with DS in local and large businesses, as well as their communities in general. There needs to be more activism to change policies that lessen access to competitive employment opportunities, long term care facilities, and complete healthcare coverage for individuals with DS. Furthermore, social workers must advocate to increase funding for effective work and living programs.

Policy makers should understand the importance of properly employing, insuring, and housing individuals with DS as they transition to and live through adulthood. Without the general feeling of inclusion these individuals cannot work and live in healthy, safe environments. Legislators, activists, business owners, and educators must lead the way in fostering an environment that not only allows but encourages these individuals to live their lives to the fullest.

Earlier this year, the NDSS just hired the first ever registered Capitol Hill lobbyist with DS (Perkes, 2018). Her name is Kayla McKeon and she has already aided in the passage of the ABLE to Work Act on behalf of all individuals with IDD. The next step for advocacy will be empowering individuals with DS to hold leadership positions and placing well deserving individuals in positions of power to advocate for themselves. These individuals know what they want and need better than anyone and therefore they are the most qualified activists for their rights.

References

American Psychiatric Association. (2013). Neurodevelopmental disorders. *Diagnostic and*

    statistical manual of mental disorders, *5*. Doi:10.1176/appi.books

    .9780890425596.744053

Bacanli, A. (2016). Aripiprazole use in children diagnosed with Down Syndrome and comorbid

    Autism Spectrum Disorders. *Journal of Child and Adolescent Psychopharmacology,*

    26, 3. doi.org/10.1089/cap.2015.0193

Barisnikov, K., & Lejeune, F. (2018). Social knowledge and social reasoning abilities in a

    neurotypical population and in children with Down Syndrome. *PLOS*.

    https://doi.org/10.1371/journal.pone.0200932

BeanZ & Co. (2018) Retrieved from https://www.bethoughtfulmovement.org/beanz-co-2/

Berk, L. E. (2013). *Child development*. Normal, Illinois: Pearson Education.

Blazer, J., Broder, T., & Moussavian, A. (2015). Overview of Immigrant Eligibility for Federal

    Programs. *National Immigration Law Center*. Retrieved from

    https://www.nilc.org/issues/economic-support/overview-immeligfedprograms/

Cebula, K. R., Moore, D. G., & Wishart, J. G. (2009). Social cognition in children with Down's

    Syndrome: Challenges to research and theory building. *Journal of Intellectual Disability*

    Research, 54(2):113-34. doi: 10.1111/j.1365-2788.2009.01215.x

Development and learning. (2018). Retrieved from

    https://www.down-syndrome.org/en-us/about-down-syndrome/development/

Disability Integration Act of 2017, H.R. 2472, 115th Cong. (2017)

Down syndrome. (2018). Retrieved from

    https://www.ndss.org/about-down-syndrome/down-syndrome/

DSWORKS employment program. (2018). Retrieved from https://www.ndss.org/work/dsworks/

Early intervention. (2018). Retrieved from

      https://www.ndss.org/about-down-syndrome/down-syndrome/

End Law Syndrome. (2018). The bill. *NDSS.* Retrieved from https://www.lawsyndrome.org/

Erikson, E. H. (Ed.). (1963). *Youth: Change and challenge*. New York: Basic Books.

Federal legislation. (2018). Retrieved from https://www.ablealliance.org/advocacy

Finestack, L. H., Palmer, M., & Abbeduto, L. (2012). Macrostructural narrative language of

      adolescents and young adults with Down Syndrome or Fragile X Syndrome. *American*

      Journal of Speech-Language Pathology, 21, 29–46. Doi: 10.1044/1058-0360(2011/10-

      0095)

Force, L. T., Hogan, M., Janicki, M. P., and Jokinen, N. S. (2012). The middle years and beyond:

      Transitions and families of adults with down syndrome. *Journal on Developmental*

      Disabilities. 18(2), 59-69. Retrieved from https://oadd.org/wp-content/uploads/2012/

      01/41012_JoDD_18-2_59-69_Jokinen_et_al.pdf

Global Down Syndrome Foundation. (2018). Retrieved from

      https://www.globaldownsyndrome.org/

HEADs Up Act, H.R. 6611, 115th Cong. (2018).

Learning about Down Syndrome. (2017). Retrieved from

      https://www.genome.gov/19517824/learning-about-down-syndrome/

Leonard, H., Foley, K. R., Pikora, T., Bourke, J., Wong, K., McPherson, L., … Downs, J. (2016).

      Transition to adulthood for young people with intellectual disability: The experiences of

      their families. *European Child & Adolescent Psychiatry*, *25*(12), 1369–1381. Doi:

      10.1007/s00787-016-0853-2

Marshall, J., Tanner, J. P., Kozyr, Y. A., & Kirby, R. S. (2014). Services and supports for

    young children with Down Syndrome: Parent and provider perspective. *Child:*

    Care, Health and Development, 41, 365–37. Doi:10.1111/cch.12162

National Down Syndrome Society. (2018). Retrieved from https://www.ndss.org/

Neal, W. (2018). Employment in adults with down syndrome. NCHPAD. Retrieved from

    https://www.nchpad.org/1415/6299/Employment~in~Adults~with~Down~Syndrome

Our story. (2018) Retrieved from https://www.bethoughtfulmovement.org/our-story/

Pace, J. E., Shin, M., & Rasmussen, S. A. (2010). Understanding attitudes toward people with

    Down syndrome. *American Journal of Medical Genetics, Part A 152A,* 2185–2192.

    Retrieved from http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1264&

    context=publichealthresources

Pandey, S., & Agarwal, S. (2013). Transition to adulthood for youth with disability: Issues for

    the disabled child and family. *IOSR Journal Of Humanities And Social Science*, *17*(3),

    41-45.

Perkes, C. (2018). New York woman is nation's first lobbyist with Down Syndrome. Retrieved

    from https://www.disabilityscoop.com/2018/06/26/new-first-lobbyist-down-

    syndrome/25237/

Post-high school. (2018). Retrieved from https://www.ndss.org/resources/post-high-school/

Self-advocate employment initiative grants. (2018). Retrieved from

    https://www.globaldownsyndrome.org/employment-grants/

Students of color still receiving unequal education. (2012). Retrieved from

    https://www.americanprogress.org/issues/education-k-12/news/2012/08/22/32862/studen

    s-of-color-still-receiving-unequal-education/

Transition to Independence Act of 2018, H.R. 4931, 115th Cong. (2018).

What is Bronfenbrenner's Ecological Systems Theory? (2013). Retrieved from

https://www.psychologynoteshq.com/bronfenbrenner-ecological-theory/

Where to live. (2018). Retrieved from

https://www.downs-syndrome.org.uk/for-families-and-carers/supported-living-2/

Appendix A

Personal Interviews

Dawn Maddox shed light on the realities of the services her son with DS receives. The employment opportunities offered to him are in mostly factory-like settings and people are not placed in a job that directly correlates to what they are passionate about. Additionally, it can take up to nine years of waiting to receive the funding they apply for because the service is so underfunded and understaffed. It is also sometimes difficult to find quality caretakers once they receive funding. Most of the staff and care providers are young, untrained people just looking for a job because there is limited training that is required. Even so, her son is very happy in his position because he is providing a service and feels fulfilled after every day of work. He has also made very meaningful relationships that bring him joy in everyday life (D. Maddox, personal communication, August 28, 2018).

The couple who created the Be Thoughtful Movement started researching and getting educated about possible programs for their own son, Harold, well before he aged out. They had so much fear about him having nothing to provide him with purpose. Harold has always expressed a passion for travel even though travel is much more difficult for individuals with disabilities. They eventually found a self-directed government program that provides him with funding so that he can work in a travel vocation and help those with disabilities feel more comfortable with travel. Harold is now in a position that he goes to regularly, gets paid, is doing what is meaningful to him, and inspiring others to live their dreams and be accepting. Even so, getting Harold on this path was very time consuming, difficult to understand at times, and expensive (S. Johnson, personal communication, July 22, 2018).

   Joseph Cary was a college career counselor for individuals with disabilities and he explained that the coursework is sometimes too difficult for individuals, with learning disabilities, to complete. Unfortunately, most of the time the student knows the material but the teacher is either unwilling or not creative enough to find ways to adapt tests and assignments to allow the student to prove what they know and be successful. For individuals with disabilities challenges such as physical, sensory, cognitive and communicative limitations, and environmental barriers pose the most difficulty for their transition to adulthood (J. Cary, personal communication, September 19, 2018).