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PARENTAL CAREGIVER GUIDE FOR AN ADOLESCENT WITH DOWN SYNDROME: TRANSITIONING OUT OF HIGH SCHOOL

Kalindi Rachey

Hailey Johnson

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by

Kalindi J. Rachey, MOTS

Hailey N. Johnson, MOTS

Advisor: Gail Bass, PhD OTR/L

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This Scholarly Project Paper, submitted by Kalindi J. Rachey and Hailey N. Johnson in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Gail S Bass Ph.D., OTR/L

Faculty Advisor

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Date

PERMISSION

Title: Parental Caregiver Guide for an Adolescent With Down Syndrome: Transitioning Out of High School

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ABSTRACT

Title: Parental Caregiver Guide for an Adolescent With Down Syndrome: Transitioning Out of High School

Kalindi J. Rachey, MOTS, Hailey N. Johnson, MOTS, and Gail Bass, PhD, OTR/L. Department of Occupational Therapy, University of North Dakota School of Medicine and Health Sciences, 1301 N Columbia Rd. Grand Forks, ND 58203-2898.

Purpose: The current literature revealed a need to address the establishment, organization, and application of primary health care as well as support programs for parental caregivers of adolescents with Down syndrome, especially during the transition period out of high school (Barros, Barros, Barros, & Santos, 2017). Providing information, resources, and support to parental caregivers of adolescents with Down syndrome and health care professionals, such as occupational therapists, can help alleviate caregiver burden and promote the parents' quality of life. Occupational therapists can play an important role during the post-secondary transition period for adolescents with Down syndrome by assisting them in developing adaptive behaviors, increasing self-advocacy and self-determination, gaining employment skills, and life skills (Berg, Jirikowic, Haerling, & MacDonald, 2017); however, they can also address the needs of the parental caregivers, especially self-care needs, to assist them through this process and ease caregiver burden.

Methodology: During our extensive review of literature and resources, it was found that there was a gap in information, support, and resources for parental caregivers relating to issues that are faced during the transition process out of high school for their adolescent with Down syndrome. This in-depth literature review also revealed that parental caregivers would benefit from a manual to guide and support them and their adolescent with Down syndrome during this transition period out of high school.

Results: *Parental Caregiver's Guide for an Adolescent With Down Syndrome: Transitioning out of High School* is a manual designed to provide information, resources, and support to parental caregivers of adolescents with Down syndrome and health care professionals. While the need for resources and information for parental caregivers to help ease stress and burn out while their adolescent transitions out of high school is evident, it is anticipated that the following findings and educational manual will assist parental caregivers through this transition process by providing resources, guidance, tools, strategies, and support. The topics addressed in this manual include post-secondary preparation, promoting health and wellness, advocacy, post-secondary education, employment, community involvement, healthcare, housing, finances, legalities and guardianship options, and taking care of you. The hope is that this educational manual will help parental caregivers prepare, make informed decisions, and take care of themselves, and their adolescent with Down syndrome during the transitional period out of high school.

Conclusion: The purpose of this scholarly project was to fill a gap in the literature and resources by providing information, support, and resources to parental caregiver's of adolescents with Down syndrome transitioning out of high school to help alleviate some of the stress and burdens the caregivers may face. The result was a manual titled, *Parental Caregiver's Guide for an Adolescent with Down syndrome: Transitioning out of High School,* developed with the intention to help guide and provide support to parental caregivers through this transition process to fill this gap.

CHAPTER I

Introduction

The purpose of the product, *Parental Caregiver Guide for an Adolescent with Down Syndrome: Transitioning Out of High School*, is to provide resources and information for parental caregivers of adolescents with Down syndrome to utilize during the adolescent's transition out of high school. The overarching goal is to promote the parental caregivers' quality of life, with a focus on promoting self-care, while decreasing caregiver burden. The product was created in a workbook format for the parental caregivers to work through with and occupational therapist, on their own, or with other parental caregivers. There are 12 chapters in the manual, that focus on education and information that can be incorporated into the parental caregiver's daily habits, routines, and planning process. Each section includes information and resources that can benefit the parental caregivers during this transition period. In addition, most chapters include at least one worksheet to assist the parental caregivers to identify and meet their personal needs and to stay organized and initiate tasks during the planning process.

The development of this manual was designed and guided by the utilization of the Ecology of Human Performance (EHP) model, which is described mere in-depth in Chapter IV, and the Adult Learning Theory. According to Dunn (2017), the framework for EHP emphasizes the connections between the person, context, task, and performance. The primary focus of EHP is to supply a structure that accentuates the role context plays in participation and the profound essence of the connections between the person, their context, and the task in order to comprehend and appreciate their performance (Dunn, Crown, & McGuigan, 1994).

Chapter II presents the results of a comprehensive literature review in addition to an overview of the product. Chapter III presents the methodology and the activities used to develop the product. The product is overviewed in Chapter IV and can be found in its entirety in the Appendix of this document. Finally, Chapter V is a summary of the project and includes recommendations and limitations of the product.

CHAPTER II

Review of Literature

According to a quantitative study by Barros, Barros, Barros, and Santos (2017), parental caregivers of adolescents with Down syndrome were found to experience notably more caregiver burden than parents of adolescents without a disability. The literature provides evidence of the essential need to address the establishment, organization, and application of primary health care as well as support programs for parental caregivers of adolescents with Down syndrome, especially during the transition period out of high school (Barros, Barros, Barros, & Santos, 2017). By providing information, resources, and support to parental caregivers of adolescents with Down syndrome, health care professionals can help alleviate caregiver burden and promote the parents' quality of life. As there is limited literature available on this population and the role of occupational therapy during this transition, literature from other health care disciplines was utilized for this scholarly project.

The purpose of this project was to construct a parental caregivers guide to support this population through their child's transition out of high school. In order for the content of this guide to have validity, it must have a foundational basis in the current research and literature. The following chapter is divided into 12 sections. The first two sections provide an overview of the populations addressed with this guide and their health care needs. The next two sections describe the role of the school during the transition and post-secondary opportunities for the adolescent. The following four sections outline information related to the legal guardianship, housing, financial, and community involvement of the adolescent during their transition out of high school. The next three sections address elements to consider in relation to the caregiver of the adolescent with Down syndrome. The final two sections describe both the role and intervention options for occupational therapy with parental caregivers of adolescents with Down syndrome. The literature that is reviewed in this chapter provides an analysis and description of the needs of parental caregivers of adolescents with Down syndrome during the transition out of high school and the need for occupational therapy to address these needs through interventions.

Population

Adolescents with Down syndrome.

The life expectancy of people with Down syndrome is known to be shorter than the general population; however, it has increased significantly from 25 in 1983 (Yang, Rasmussen, & Friedman, 2002) to approximately 60 with 25% living over 63 years (Glasson et al., 2002). According to (Mai et al., 2019), Down syndrome occurs in approximately 1 in every 700 babies born in the United States making it the most commonly diagnosed chromosomal condition in the United States (CDC, 2019). Adolescents with Down syndrome often present with delayed performance in motor, functional, and cognitive areas (Moriyama et al., 2019). Adolescence is typically the developmental stage that occurs between the ages of 12 and 18 with late adolescence occurring between ages 17 and 21 (Vroman, 2015; Arnett, 2000; Radzik, Sherer, & Neinstein, 2002).

A study completed by Moriyama et al. (2019) found that children with Down syndrome display a lower level of performance in obtaining the functional abilities to complete self-care, mobility, and social tasks; therefore, they require more assistance from their caregivers. In addition, adolescents with Down syndrome are less likely to move out of the family home than those without a disability (Dyke, Bourke, Llewellyn, & Leonard, 2013).

According to Taylor, Cobigo, and Quellette (2019) people with Down Syndrome transitioning to adulthood experience more frequent and more distressing worries than do their typically developing peers. Adolescents with Down syndrome have described feeling anxious, social isolation, unprepared for adult responsibilities, and uncertain for their future (Taylor, Cobigo, & Quellette, 2019).

Parental caregivers.

Parental caregivers of adolescents with Down syndrome are often informal caregivers. Informal caregivers provide unpaid care services of varying degrees with activities of daily living and instrumental activities of daily living for individuals who have a chronic condition or disability, often a family member, without receiving formal training or education related to caregiving (Roth, Fredman, & Haley, 2015). Historically, research has shown that the mother has taken on the role as the primary caregiver for their adolescent with Down syndrome within the family (Prudent, Barbosa, & Porto, 2010). Taking on the role of being the primary caregiver for a child with Down syndrome can be demanding as the child is dependent on their caregiver. This can lead to emotional, physical, and financial burden along with decreased involvement in social and leisure activities (Bourke-Taylor, Howie, & Law, 2011). Taking on a role as a primary caregiver can also have a positive impact along with life satisfaction. However, these two impacts can co-exist with an increased likelihood of depression, poor quality of life, and caregiver burden (Dyke et al., 2013). According to Dyke et al. (2013) parents of adolescents with Down syndrome have been found to experience lower levels of physical and mental health when compared to the general population.

Health Care Needs

For many parental caregivers of adolescents with Down syndrome, the transition from adolescence to adulthood is a stressful period of time filled with the unknown. Small, Raghavan, and Pawson (2013) found that it is difficult for parents to identify potential in their child and how they can help them after age eleven. This uncertainty often causes feelings of anxiety in the parental caregivers as they worry about not finding a school, professional, or health services to support their child through a successful transition to adulthood (Raghavan, Pawson, & Small, 2013). In a quantitative study examining health care planning transitions in adolescents with Down syndrome compared to adolescents with other special health care needs, Nugent, Gorman, and Erdie-Lalena (2018) found that only 11% of adolescents with Down syndrome met the outcome of the transition outcome compared to 40% of adolescents with other special health care needs. The adolescents with Down syndrome were found to be four times more likely to not be encouraged to take responsibility for their own care despite research demonstrating a link between independent self-management and quality of life with this population (Nugent, Gorman, & Erdie-Lalena, 2018). Therefore, professional support and guidance from health care professionals is essential to assist the parental caregivers in successfully transitioning their adolescent with Down syndrome to adulthood.

Families are often met with many challenges with making a health care transition from pediatric to adult-based health care services. The Department of Health (2006, p. 14) defines a health care transition as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems." Parental caregivers of children with Down syndrome making this health care transition reported challenges related to the transition from pediatric to adult-based health care. They reported feeling a loss of emotional support, loss of support for their individual needs and contribution to home care, lack of coordination with their child's health care services, and confused about accessing adult health care services for their child (Brown, Higgins, & MacArthur, 2020;

Moriyama et al., 2019). Based on the findings of a qualitative study by Brown et al. (2020), parents of adolescents with intellectual disabilities often viewed their children as becoming more vulnerable following the transfer to adult services. The authors noted that parents felt information about new services lacked details related to the legal dimensions that would allow them the ability to remain involved in decisions about their child's health care (Brown et al., 2020). The authors also noted the parents worried about availability and access as well as feeling excluded while their adolescent is receiving care. Furthermore, parents view adult health services as ill-prepared to meet the multifaceted needs of people with Down syndrome (Brown, et al., 2020).

Down syndrome used to be considered a "pediatric" condition as the life expectancy was remarkably shorter than the general population; however, the life expectancy for an individual with Down syndrome has increased exponentially over the last few decades and is expected to be similar to the general population in the next few decades (Bittles & Glasson, 2004). As Down syndrome was considered a "pediatric" condition until recently, many health care providers are not prepared and confident to provide appropriate, quality care to adults with Down syndrome. In a study conducted by Okumura et al. (2010), 50% of internal medical providers perceived themselves as being unprepared to provide health care to an individual with special health care needs, and 62% of pediatricians perceived that it would be challenging for these individuals to find an adult-based health care provider to meet all of their health care needs. This gap in care is often due to a lack of knowledge, experience, and educational foundation necessary for adult-based health care professionals to provide quality and appropriate care for the adult population with Down syndrome (Carling-Jenkins, Torr, Iacono, & Bigby, 2012; Lauria & Waldrop, 2020).

Providing health care for adults with Down syndrome requires a comprehensive approach due to the complex nature of functional limitations and a high rate of associated comorbidities (Carfi et al., 2019). This complexity often builds heavily upon the workload for primary care health professionals as they need to coordinate care between many primary care providers such as medical specialists, therapists, and special education services (Schieve, Boulet, Boyle, Rasmussen, & Schendel, 2009). Comprehensive assessment and management is an option that would provide adults with Down syndrome with optimized medical intervention and enhance prognosis along with restoring, maintaining, and maximizing functional autonomy while providing the necessary support and improving quality of life (Carfi et al., 2019). This approach has the opportunity to provide quality and appropriate health care services that would greatly benefit adults with Down syndrome.

With the concerns regarding unmet health needs and access to health care, further developments are needed to stop the population with Down syndrome and their families from being at a disadvantage. Specifically, at the point of transition from child to adult health care and beyond (Brown et al., 2020). The issue of decreased accessibility to health care on the impact it has on the transition to adult services can negatively affect the health and quality of life of the family members. The negative experiences of the transition as well as the decrease in services following the transition can greatly affect the parents physical and mental health and, consequently, their ability to care for their children (Brown et al., 2020). Therefore, both the needs and the roles of the family members need to be acknowledged at the point of transition to ensure that the families health and well-being are not affected (Brown et al., 2020).

Brown et al. (2020) found that this population is living longer with a range of complex physical, psychological, and behavioral support needs which will include more transitions from child to adult health services. Furthermore, the transition process for some is complex and poorly coordinated, leading to stress and anxiety with the potential for poor health outcomes. There is no doubt that families want to be involved in the transition process; however, they also do not want to feel like they are responsible for ensuring that all the needs of their adolescent are met (Brown et al., 2020). With that being said, health professionals who work with adolescents with Down syndrome should be acknowledging the need to care for the caregivers.

Role of School in the Transition Process

The transition from school to post-school activities can be challenging for an adolescent with Down syndrome and their parental caregivers. If the student with Down syndrome is receiving special education services as documented on an individualized education program, the public school has certain responsibilities as defined in the Individuals with Disabilities Education Act (IDEA). With that being said, according to the U.S. Department of Education (n.d.):

> IDEA and its implementing regulations addresses transition services for children with disabilities.
>
> The term “transition services” means a coordinated set of activities for a child with a disability that:
>
> - is designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation
> - is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests
> - includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation

> Transition services may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education (Secondary Transition).

To make the transition process easier the Individuals with Disabilities Education Act (IDEA) was put into place. Part B of IDEA defines school programs for eligible students between 3 and 21 years of age (Myers, Case-Smith, & Cason, 2015). Part B of IDEA specifies that an individualized education program (IEP) must be designed to include special education and related services to all students from 3 to 21 years of age if it determined by the educational team that the student require services to benefit their public education (Bazyk & Cahill, 2015). An IEP, legally documents the adolescent's educational needs, the individualized set of supports and services determined to be appropriate by the special education team to allow the student to benefit from their education and participate at school (Bazyk & Cahill, 2015). The IEP is developed based on the contributions of the special education team including the occupational therapist, and is informed by a comprehensive multidisciplinary assessment (Bazyk & Cahill, 2015). According to the Office of Special Education and Rehabilitative Services (2011):

> The IEP for each child with a disability, must, beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually thereafter, include (1) appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and (2) the transition services (including courses of study) needed to assist the child in reaching those goals (p.5)

In addition, occupational therapists collaborate with other team members such as the special education teacher, the general teacher, the parents, one of the school district representatives and occasionally other disciplines including a speech language pathologist (Bazyk & Cahill, 2015). Occupational therapists contribute to the referral, evaluation, intervention, and outcome processes. Therefore, with those outcomes in mind, a key question guiding the special education process could include "What does the adolescent need or want to do to be successful as a student now and to prepare for future roles" (Bazyk & Cahill, 2015, p. 670)?

There is a need for coordinated planning, collaboration, and decision-making among the school staff, families, and community agencies involved in this transition period (Leonard et al., 2016). Leonard et al. (2016) found that parents felt there was a lack of available opportunities such as support and services for after their adolescent had left school. Also, the parents felt that attempting to navigate the school system was very time consuming and stressful. Therefore, the parents felt overwhelmed and confused with the transition process, wanting better communication and information provided about services available to them, and that there was a lack of awareness about available services (Leonard et al., 2016). The way information was communicated to the parents impacted the role, the expectations, and the responsibilities of adolescents going through the transition process. In a study by Mullan, Prendeville, and Kinsella (2019), the role of the support teacher, secondary school head teacher, learning support teacher, and the parents were involved throughout the transition process. Since the school system was actively engaged and involved, they took the responsibility for managing the process which allowed the parents to focus on other relevant aspects of the transition process (Mullan, Prendeville, & Kinsella, 2019). For instance, the parents focused on preparing their adolescent emotionally and framing the process in a positive manner. Therefore, when the roles and responsibilities were not clearly discussed, the parents often took on the schools' role for preparing their adolescent for the transition (Mullan et al., 2019). A clear delineation of roles is an essential element of a successful transition and reinforces the importance of clear communication between parents and schools to support adolescents with Down syndrome through this transition process (Mullan et al., 2019).

Post-Secondary School Opportunities

Employment.

Adolescents with Down syndrome have a couple different opportunities for post-secondary school endeavors. One of these options is searching for and obtaining employment. Pursuing this post-secondary school option of employment could allow the adolescent with Down syndrome an opportunity to gain financial autonomy as well as playing a vital role in the adolescent's well-being and quality of life (Jahoda, Kemp, Riddell, & Banks, 2008). In addition, work can influence and give one a sense of identity, self-worth, health, socioeconomic status, and quality of life which have all been strongly correlated with one's ability to work and make a living (Corcoran, 2004; Pedretti, Pedretti, & Early, 2001). Work is relevant to individuals with all levels of skills and abilities (Clearly, Persch, & Spencer, 2015), but it can be fairly challenging for people with disabilities, especially developmental disabilities. Zwicker, Zaresani, and Emery (2017) completed a secondary analysis of a survey completed in 2012 by around 45,500 people between the ages of 15 and 64 with a self-reported developmental disability, cerebral palsy, or on the autism spectrum. The authors found that finding and participating in employment is a significant challenge, especially for people with developmental disabilities. According to Lin et al. (2015), young adults with Down syndrome that perform at a higher level of functioning in activities of daily living (ADLs) are more inclined to attend open employment or training sessions in place of sheltered employment or recreational day programs. In order to improve the likelihood of full time employment these individuals need to work on skills that are required at most places of employment, such as time management and organization, participation in work-study programs, vocational education courses, internships, and mentorships in order to improve the likelihood of obtaining full-time employment (Clearly, Persch, & Spencer, 2015). Adolescents with Down syndrome may not have all of the skills required to maintain a job; however, there are alternative options such as supported employment and customized employment. Supported employment provides on-the-job training with ongoing support in the workplace in order to acquire and maintain employment within the community (Clearly, Persch, & Spencer, 2015). This option is supported by evidence such in the information that was found in the following studies. Morgan and Alexander (2005) investigated employers' perceptions on hiring individuals with developmental disabilities through a survey. The authors found that most employers that had hired an individual with a developmental disability in the past shared that it typically worked out and they would hire someone with a developmental disability again. Employers that did not have experience hiring someone with a developmental disability indicated that they were open to hire an individual with a developmental disability. The advantages of hiring an individual with a developmental disability that were found are the following: consistent attendance, diversity within the workplace, long term employment, and coworker cooperation. The main concern that was found was safety. Bush and Tasse (2017) analyzed data from the National Core Indicators Adult Consumer Surveys from 2011-2012 and 2012-2013. They concluded that adults with Down syndrome had around a 16% rate of paid community employment which was at a higher rate than adults with autism or an intellectual disability. Moore and Schelling (2015) completed a qualitative study through interviews with 26 students and found that people with intellectual disabilities who take part in postsecondary programs have more significant positive outcomes related to employment than those that do not.

Customized employment is described as a process that individualizes the relation between the employee and the employer in order to meet the needs of both parties (Gusfield, 1984). There are many benefits for adolescents with Down syndrome to obtain employment; however, these individuals still face a variety of barriers in obtaining and keeping a job. Khayatzadeh-Mahani, Wittevrongel, Nicholas, and Zwicker (2020) utilized two participatory qualitative research methods and a focus group with 31 participants in order to improve their understanding of the experiences and barriers that people with developmental disabilities face related to employment. The authors concluded that out of the 140, the most three most prevalent barriers found in obtaining employment for people with developmental disabilities are the following: the employers' knowledge, capacity, attitude, and management of the workplace (Kocman, Fischer, & Weber, 2017); the "concept of work" and culture of the workplace as well as education earlier (Su, Lin, Wu, & Chen, 2008); and competition as well as inadequate alignment and standards between providers and professionals (Swanson & Woitke, 1997). Other common barriers were discrimination (Erickson, von Schrader, Bruyére, & VanLooy, 2014), stigma (Hulbutt & Chalmers, 2004), and the employer's limited understanding and misperception of employees with disabilities (Hagner & Cooney, 2005). Possible solutions for addressing these barriers include, but are not limited to, promoting and advocating for employer education and competency, advanced education within high school to assist with the transition, altering financial assistance to decrease barriers, improving available employment opportunities, and providing education to others on inclusion, acceptance, and differences early on in both school and in the workplace (Khayatzadeh-Mahani, Wittevrongel, Nicholas, & Zwicker, 2020).

Post-Secondary Education.

A second opportunity option for adolescents with Down syndrome to pursue after high school is a post-secondary education (PSE). PSE is often associated with the following three options: a two year or community college; a vocational, business, or technical school; and four-year colleges (Cleary, Persch, & Spencer, 2015). Until recently, within the last 40 years, there was no expectation that students with intellectual disabilities would attend PSE or learn right along with their peers without disabilities (Heward, 2013). The new focus on transitioning out of high school along with the emphasis on the importance of work has converted into a range of possibilities for after high school. In addition, there were amendments made to the IDEA in 1990 that mandated every single secondary student who receives special education services to have school-to-post-school transition plans incorporated into their IEP (Sheppard-Jones, Kleinert, Druckemiller, & Ray, 2015). This mandate specifically includes addressing post-school employment and independent living options as well as PSE as appropriate to meet with the individual's career goals (Certo et al., 2008). Furthermore, Congress continues to recognize the essential necessity of transition planning as well as the vital role adult service providers play in making the transition out of high school successful in subsequent reauthorizations of the IDEA in 1997 as well as in 2007 (Sheppard-Jones et al., 2015).

Pursuing PSE may provide adolescents with Down syndrome with various opportunities including, but not limited to, the following: social participation opportunities, additional role of being a college student, and a raise in possible employment options available to them. There are many benefits for adolescents with Down syndrome to pursue PSE; however, there are also some barriers that these adolescents may face. Although there is legislation to help support adolescents with Down syndrome in pursuing PSE, there is still a large gap between their enrollment in PSE and their peers. In a longitudinal study conducted by Newman et al. (2011) on a sample of more than 11,000 high school students who had received special education services in high school, the rate of adolescents with disabilities who decide to pursue PSE is lower than those without disabilities. Grigal, Hart, and Migliore (2011) also found that adolescents with intellectual disabilities are less likely to participate in PSE than their peers. The study by Newman et al. (2011) also found that many adolescents with disabilities are more likely to pursue education from a two-year or community college, may take more time to enter PSE, might not consider themselves disabled at the time they enter PSE, and may need assistance in order to request the proper accommodations.

Legal Guardianship

According to the U.S. National Council on Disability (2019), guardianship is a state legal process where a court can eliminate a few or many rights relating to legal, financial, and personal decision-making from the individual. These rights are then transferred, either some or all, to another person who is called the guardian or conservator. As the adolescent with Down syndrome nears graduation from high school, the matter of who will be their legal guardian arises. When the adolescent reaches the age of 18, they are legally their own guardian unless their parents request, through a court hearing, to be the legal guardian of the adolescent. The process of guardianship is typically initiated by a family member, government agency, or service provider, by filing a petition to the court with jurisdiction. Based on information from the U.S. National Council on Disability, once a petition has been filed, the following steps are taken: a notice that the petition has been filed is commonly sent to the parties involved, an attorney is appointed to represent the allegedly incapable person, a capacity evaluation is performed, a court hearing takes place, and if guardianship is appointed, letters of guardianship are drafted. In a majority of cases this guardianship lasts until the individual under guardianship either passes away or has their legal rights restored. The responsibilities of the guardian under state law may involve presenting a guardianship plan as well as initial and annual reports submitted to the court (U.S. National Council on Disability, 2019). It is up to the parental caregiver if they would think taking these steps is appropriate and if they would like to pursue this option; however, there are other alternative options if they do not want to take these actions.

Alternatives to guardianship are often less restrictive meaning that supports for decision-making should be tested and found to be inadequate prior to considering guardianship according to The Arc of the United States and the American Association on Intellectual and Developmental Disabilities (2019). Examples of alternatives to legal guardianship consist of health care surrogates by the operation of state law, representative payees, trusts, as well as joint ownership (U.S. National Council on Disability, 2019). When looking at alternatives, the options may consist of services or supports that allow needs of the individual to be met without a legal guardian. These options may consist of voluntary participation in services for money management, in-home care and case management services, delivery of food and prescriptions, and person-centered planning among other options (U.S. National Council on Disability, 2019). These less restrictive alternatives and decision-making supports may be an adequate option to consider before taking steps to pursue legal guardianship as it can promote self-reliance and self-sufficiency in the adolescent with Down syndrome.

Housing

As adolescents with Down syndrome near graduation from high school, their parental caregivers may start considering possible alternative living arrangements for their child in the future. Some possible living arrangement options include continuing to live at home, living independently or with assistance outside of the parental caregiver's residence or living in a residential facility, group home, or institution. However, a majority of adolescents with Down syndrome continue to live at home with their families who play a central role in their ongoing care and support. Brown et al. (2020) found that individuals with Down syndrome are living longer with a range of interrelated complex physical, psychological and behavioral support needs, and that they will transition from child to adult health services. According to Chenbhanich, Wu, Phupitakphol, Atsawarunngruangkit, and Treadwell (2019), a majority of young adults with Down syndrome live with and are cared for by their parents with 35% living in residential facilities and 56% being cared for either by their siblings or in an institution after the age of 50. A significant transition for people with Down syndrome is entering adulthood and attaining adult roles in the community, which may involve leaving the educational system and pursuing vocational opportunities and moving out of the parental home into another residential option (Taylor et al., 2019).

Financial

According to Franklin et al. (2019), it is well-known that Down syndrome is a complex diagnosis that requires a multitude of health care services and that the cost of health care can add up quickly. According to Huiracocha et al. (2017), money is often a resource that is often in short supply and beyond the families' means to contribute. In addition, mother parental caregivers often prefer engaging in work that is informal due to the opportunity available with this type of work to work from home coupled with increased flexibility in their work hours (Barros et al., 2017). This results in a low contribution to the household's finances which, in turn, reduces the family's financial resources that are available to participate in social, leisure, and health activities (Parkes, Caravale, Marcelli, Franco, & Colver, 2011). This decreased ability to participate in these desired activities due to financial constraints can lead to the development of frustration and dissatisfaction (Fernandes, Ferreira, Marodin, do Val, & Fréz, 2013). A parent reported that they would put money towards private therapy when they were able to, but there is often not money available for it (Huiracocha et al., 2017). Additionally, parental caregivers identified costs experienced as a result of having an adolescent with Down syndrome that include financial burden, inability to travel, loss of job opportunities because of need to ensure economic stability and insurance, marriage difficulty, having a different life and retirement than they had planned, and effects on siblings (Franklin et al., 2019). Therefore, the biggest concern related to costs is the impact on siblings (Franklin et al., 2019).

Community Involvement

Getting involved within their community can be beneficial to adolescents prior to, during, and after making the transition out of high school. As adolescents with Down syndrome can have difficulty with social participation, the utilization of an interdisciplinary approach by their health care team can support their involvement in the community, including activities that promote living and maintaining a healthy lifestyle (Curtin et al., 2013; Marshall, McConkey, & Moore, 2003) as well as promoting engagement in active leisure activities (Mihaila et al., 2017). However, access to transportation is often limited to adolescents with Down syndrome in a majority of group home and independent living situations (Buttimer and Tierney, 2005). This fact makes it challenging for individuals with Down syndrome to access leisure activity opportunities within their community. In fact, Hall and Hewson (2006) found that a monumental 88% of adults that have an intellectual developmental disability and live in a group home or independently went into the community less than once a day. Through the research that has been done, it is apparent that getting involved in the community is vital for not just adolescents, but for all people with Down syndrome; however, it is undeniable that there are obstacles for these individuals to overcome in order to participate actively in their community.

Caregiver Considerations

Parental Caregiver Role.

The parental caregiver of an adolescent with Down syndrome plays a significant role in the success of the adolescent's transition from high school to post-school activities. In addition to carrying out parental duties, advocacy is a major part of this role. Advocacy can be described as supporting, arguing, or speaking out on a specific concern, concept, or individuals who are typically not able to speak out for themselves (Waterston, 2009). Parents can advocate for their adolescent in many areas and in a variety of ways. Some of these areas may include, but are not limited to, health care, guardianship, work, education, housing, and other services. In regards to health advocacy, the parents may advocate for their adolescent to ensure access to proper health care, acquire assistance to navigate the health care system, assemble resources, address health care inequalities, as well as influencing policy that affects health care to facilitate change within the health care system (Hubinette, Dobson, Scott, & Sherbino, 2017). Advocacy can be approached in a variety of ways along a spectrum ranging from simply actively speaking out on an issue or injustice to taking a more unobtrusive, reformative, and constructive approach by figuring out methods to address the problem and influence change (Dyson, 2005).

According to Waterston (2009), some examples of advocacy include writing letters, volunteering, speaking to legislators, and creating a club to spread awareness. Advocating can be carried out successfully by acquiring competency in knowledge, skills, and attitudes, by using knowledge related to the base of evidence for advocacy, media and political processes, services available, and general understanding of the issue, topic, or group of people being advocated for.

The skills Waterson noted include presentation, communication, and the ability to prioritize and organize as well as being persuasive and persistent. Attitudes that contribute to successful advocating include having a strong commitment to the issue, topic, or group of people as well as believing that change is achievable (Waterston, 2009).

In a qualitative study done by Rehm, Fisher, Fuentes-Afflick, and Chesla (2013) that included 61 parents of special education students, 43 parents were satisfied with the outcomes of their child's IEP while 18 parents were dissatisfied with the outcomes of their child's IEP. The satisfied parents were found to heavily draw upon their skills to acquire information, establish relationships with professionals and other parents, and negotiate complicated legal rights and bureaucratic or governmental systems. The authors contributed the parents' success to the efforts put forth to persistently engage with their child's school, form effective relationships with teachers and staff at school, and develop advocacy skills. The parents that were dissatisfied with their child's IEP outcomes disclosed that they felt overwhelmed, exhausted, and frustrated with the inadequate support they received from school officials and the absence of meaningful programs. Based on the study findings, these parents often lacked information related to pertinent services that are available or the process to appeal denial requests for school services, or their lack of persistence in trying a variety of strategies in order to accomplish their coveted outcomes. The authors concluded that these deficiencies are likely amenable to specialized support efforts from professionals to supply information and teach advocacy strategies to these parents (Rehm et al., 2013).

The advocacy efforts that are put forth can provide the parents and other family members of the adolescent with Down syndrome with different experiences and opportunities. In a qualitative study completed by King, Zwaigenbaum, Bates, Baxter, and Rosenbaum (2011), the parents that participated shared their experiences with situations where they were required to protect and consciously decide to advocate for their children. The authors also found that advocating for their child with Down syndrome provided opportunities for family enrichment through traveling and meeting new people which, in turn, lead to building family relationships. Through adopting the role of advocacy, the parents felt their families were enriched and benefited by becoming less self-centered, more compassionate and aware of others' strengths, and more grateful for what they have (King et al., 2011).

Caregiver Needs.

The mother of the adolescent with Down syndrome often takes on the role of the primary parental caregiver (Prudent, Barbose, & Porto, 2010) and they often need support from health care professionals in order to attend to their own individual needs in addition to their adolescent's needs (Moriyama et al., 2019). These individuals' needs to be addressed may include home and work activities that may be impacting their physical and/or psychological care, social participation, and quality of life (Rafacho & Oliver, 2010). A quantitative study completed by Barros et al. (2017) with caregivers of both children and adolescents with Down syndrome found that a majority, 79.8%, of their primary caregivers did not work out of the home with most preferring working from home or with flexible hours in order to meet their children's needs. This was found to lead to a decrease in budgetary resources available for the family to partake in social and leisure activities as well as a decrease in health leading to increased frustration and dissatisfaction of these parental caregivers (Barros et al., 2017). This indicates a need to address employment as well as finances for these parental caregivers of adolescents with Down syndrome.

Another need indicated by the study completed by Barros et al. (2017) is the need to recognize that these caregivers are more likely to have completed a lower level of education. Therefore, these individuals may have a lower literacy and comprehension rate which indicates a need to ensure understanding of information given to these individuals regarding them and their child, especially complex health care terminology. The authors also found in their study that these parental caregivers commonly have worse health conditions as they often neglect their own health care needs in order to put their child's needs in front of their own. The reasons could be, but are not limited to, a lack of time, not being able to leave their child alone, and exhaustion which all impact their overall health (Barros et al., 2017). This indicates a need to address physical, mental, and emotional health of parental caregivers as well as time management and ability to carry out and perform their daily occupations to the best of their abilities.

In summary, the literature indicates a need to address employment, finances, all aspects of the parental caregiver's health, time management, and their ability to complete their daily occupations. These needs may be addressed through providing educational materials along with worksheets on how to utilize the information provided that the parental caregivers can work through when they have time as they are often fairly busy throughout the day. Keeping the parental caregivers' literacy and comprehension rate in consideration when providing interventions, information, and resources to utilize is also important to ensure they understand the materials and how to utilize them.

Other Caregiver Considerations

In a qualitative study by Cairns, Tolson, Brown, and Darbyshire (2012), parents reported overall satisfaction in the areas relating to their leisure and life enjoyment. These parents also reported positive reflections about their sons and daughters and their experiences of being lifelong caregivers. Additionally, the researchers noted that these parents discussed being particularly concerned about the uncertainty with service levels, concerns for the health of all the family members, long term living arrangements, and the future role of siblings when they, as parents, are no longer able to continue caregiving. Similar findings as cited in Cairns et al. (2012) which indicated that many older family members reported a lack of information being provided to them by their health care professionals when their child was born. The authors noted that parents stated that there was little support and information available to them and what they were told by the health care professionals tended to be negative. There were few incidents where individual professionals had been very supportive, but a majority of the time, the parents had to use their own devices to look up information regarding their child's disability. The authors also found that although most of the parental caregivers in this study received minimal support and advice in the early years of their child being diagnosed, most reported that services and support had improved somewhat over the years (Cairns et al., 2012).

Therefore, most parental caregivers felt they were at some point not informed about services that they were entitled to from the very beginning in the caregiving experience. Which resulted in the parents feeling let down and giving up on the services which were available to them and unfortunately this still remains the case today (Cairns et al., 2012). To make the necessary changes for parental caregivers it is important that they receive information, advice and support as quickly as possible to help them continue in their caregiving role. Health care professionals need to develop strategies to help those parental caregivers who have difficulties continuing to provide care and helping them to plan for the future of their adolescent, along with their own future (Cairns et al., 2012).

Role of Occupational Therapy

The role of an occupational therapist is to work with individuals with Down syndrome to help them master skills for independence through self-care, like feeding and dressing, fine and gross motor skills, school performance, and play and leisure activities (Yamkovenko, n.d.). Also, occupational therapists help guide individuals with Down syndrome and their families to help them reach their potential throughout the life span. Therefore, intervention should begin as soon as a diagnosis of Down syndrome is established and should continue throughout the individual's life (Yamkovenko, n.d.).

A major intervention factor that would be beneficial for parents would be to address their need to have greater support from health professionals. There is a definite need for greater attention on the part of health professionals for those families who are in a situation of vulnerability. Additionally, quality of life is seen by parental caregivers as a need to be closer to their children; this is due to the increase of responsibilities as a parental caregiver since their child requires special attention due to having a chronic diagnosis such as Down syndrome (Missias Moreira et al., 2016). However, with properly trained therapists and adapted physical educators with progressive attitudes, it's possible that significant gains could be made by adolescents with Down syndrome in their overall health and physical performance level for more successful participation (Missias Moreira et al., 2016). In contrast, Vehkakosko (2007) found that a majority of doctors are not able to confront and resolve a situation that they interpret as stressful. This has been found to be the result of not being taught the therapeutic communication skills that are required for sensitively communicating information relating to a Down syndrome diagnosis and providing care that is family-centered to meet their needs (Pickering and Busse, 2010).

The parents of adolescents with Down syndrome are often informal caregivers, meaning they have not received much, if any, education or training on how to properly care for their adolescent (Roth, Fredman, & Haley, 2015). Parents require specialized support and information in order to comprehend how they can stimulate and promote autonomy in their adolescent as well as to establish social participation (Dolva, Lilja, & Hemmingsson, 2007). Therefore, using models of instruction to adapt teaching, the curriculum, training strategies and equipment would be beneficial to optimize participation and enjoyment in occupations. Therapists and teachers have an important role to find, share, and relay information about community programs to parents who express strong needs in acquiring such information (Wuang & Chwen-Yng, 2012).

Occupational Therapy Intervention

An adolescent with Down syndrome would benefit from occupational therapy because therapists can help them in finding and retaining productive work, learning independent living skills, and participating in active recreation for health maintenance (Yamkovenko, n.d.). Occupational therapists may assist the adolescent with Down syndrome in developing adaptive behaviors, increasing self-advocacy and self-determination, gaining employment skills, and life skills (Berg, Jirikowic, Haerling, & MacDonald, 2017); therefore, access to occupational therapy services is essential throughout this transition period in the adolescent's life (Moriyama et al., 2019). The profession of occupational therapy can assist by minimizing obstacles for adolescents with Down syndrome by further developing their communication skills as well as by creating interventions and plans that take the families' needs into consideration while also meeting the adolescent's needs (Gillette, 1992; Dolva, Lilja, & Hemmingsson, 2007). The profession of occupational therapy may also assist the adolescent in navigating new roles they may acquire along with demands of pursuing PSE or employment by providing guidance to help the adolescent develop occupational performance skills that are essential for making a successful transition (Jirikowic, Campbell, DiAmico, Frauwith, & Mahoney, 2013). Occupational therapists must advocate for and promote their role in closing the service gap for adolescents with Down syndrome transitioning out of high school (Berg, Jirikowic, Haerling, & MacDonald, 2017).

Caregiver Self-Care

Self-care is a vital, yet commonly overlooked area to address with parental caregivers. Moriyama et al. (2019) specifically designated the profession of occupational therapy, from all of the rehabilitation health care professions, to address self-care. Self-care for parental caregivers of adolescents with Down syndrome requires first identifying the factors that influence the quality of life of these adolescents, which is based on different conceptions among people with different economic, cultural and social conditions. Therefore, any health professional who is working with adolescents with Down syndrome should be attentive to caring for the parental caregivers, looking for ways to mitigate the physical and emotional distress caused by the performance of daily activities and promoting the quality of life of parental caregivers (Missias Moreira et al., 2016). Life is quite often filled with plenty of ups and downs. For parents of adolescents with Down syndrome who are constantly busy working, taking care of their adolescent, and performing home management and maintenance tasks, there is often a deficiency in time for relaxation activities or those that elicit enjoyment (Huiracocha et al., 2017). According to Huiracocha et al. (2017), parental caregivers of adolescents with Down syndrome experience significant mood swings, alternating between happiness and sadness and then back again. This often reflects the phases of struggling with obstacles and overcoming these obstacles that often result in a steady decline in self-confidence and social participation (Huiracocha et al., 2017). Adolescents with developmental disabilities are able to establish, develop and learn skills, earn knowledge and establish the goal and meaning in life through active community participation (Wuang & Chwen-Yng, 2012).

Caregiver Support

Furthermore, it is known that having an adolescent with Down syndrome can be stressful for the parental caregivers, especially during transition periods. White and Hastings (2004) noted that one of the important potential resource variables is the availability and/or helpfulness of social support groups. Research has shown that targeting social support by improving the availability of support networks, identifying a key support contact, or targeting the parent's social skills. This can lead to improvements in the parental caregivers' well-being, including but not limited to, a reduction in stress and mental health problems. First, existing research has found that support from a spouse can lead to lower levels of stress when caring for their adolescent with a disability. Second, support from extended family members, such as grandparents, may help the parental caregivers to cope with the demands of caring for their adolescent. Third, other informal sources of support, like friends and religious groups, have been known to help reduce stress among parents. Lastly, taking advantage of respite care services is another important resource for support that is available to families to help reduce their stress. Additionally, it is important to recognize that some parental caregivers may find it difficult to ask for support from others when they know they will be unlikely to reciprocate the support back. This means that the parental caregivers will need help from health care services and professionals in order to locate alternative sources of support. In conclusion, further research needs to be done on exploring the relationships between social support and positive outcome measures, such as life satisfaction or positive perceptions, of the adolescent with a disability and their caregivers (White & Hastings, 2004).

Family Building and Connecting (BAC) Framework

Roll and Bowers (2019) developed a Family Building and Connecting (BAC) framework to help adolescents with Down syndrome for family building and connecting. The main category to this framework is to develop and maintain social support networks. The main tasks involved with this category included calling the friends of the adult children with Down syndrome to arrange meetings, driving them to activities, finding accommodations and jobs for them, acting as job coaches, and preparing the networks for when they would no longer be around to assist their adolescents. Additionally, relatives of the adolescents with Down syndrome began to notice that opportunities that were occurring naturally for people without Down syndrome. In terms of relationships, independent living, education and jobs none of these existed for people with Down syndrome or were difficult for them to access. Therefore, some of the building strategies that the family members used to build support networks included creating peer opportunities, modifying living environments and ensuring family care continuity. The connecting approach of the framework includes strategies that family members use to connect their adolescents with Down syndrome to professional support services. One of the connecting strategies that was implemented was called using bridge builders. Bridge builders are professionals who create connections between persons with Down syndrome and external opportunities and services. A bridge builder could be a teacher who knows about a specific education program that could help with Down syndrome. Adolescents with Down syndrome valued the emotional, practical and informational support provided by professional staff more highly than that of family members. Additionally, national support groups and volunteer groups exist for adolescents with Down syndrome and provide an important network of support (Roll & Bowers, 2019).

Summary

Due to a lack of transition planning services available, there is a need to address informative support for the parents with an adolescent with Down syndrome. This need for information has not been addressed as parents find it difficult to access the information needed regarding the steps to follow to transition into adult-based health care as well as the options that are available for their child after high school (Gauthier-Boudreault, Gallagher, & Couture, 2017). In addition, parents who receive a limited amount of transition planning services are not able to access this information which is essential for them to prepare for their child's adult life (Gauthier-Boudreault et al., 2017). Furthermore, the parents experienced an increase in anxiety as they approached the end of their child's time in high school due to the lack of services available when their child turns 21 years of age. The parents also reported feeling insecure and uncertain due to the lack of information that was offered to them during this time (Gauthier-Boudreault et al., 2017). Along with the lack of services includes a lack of social participation options for adolescents after high school, which is often the cause for parents to completely abandon their work and social lives to look after their child full time. In addition, the transition to adulthood may have a negative effect on the parents' self-esteem. When parents are no longer required to provide full time care for their child, it can be difficult for them to find other meaningful aspects of their lives to focus their time and energy on (Gauthier-Boudreault et al., 2017). This may require the parents to increase the amount of their time spent on supportive care and attention to the time and attention to find other meaningful aspects of their lives to focus on is limited (Gauthier-Boudreault et al., 2017).

Adolescents with Down syndrome are shown to have lower levels of performance in order to complete self-care, mobility, and social tasks which require them to have more assistance from their caregivers. This means they are less likely to move out of their family home and will need to depend on assistance throughout their entire lives. Since they will require varying degrees of care, the parental caregivers’ needs are often put aside. Evidence has shown that parental caregivers are likely to experience an increase in depression, poor quality of life, and caregiver burden in relation to other parents. They will also experience lower levels of physical and mental health compared to the general population. Therefore, it is critical that we address the caregivers' needs as well as the adolescents with Down syndrome by creating a manual that provides information, strategies, tips, and resources to ease the caregivers' stress when it comes to planning and preparing for their adolescents’ transition out of high school. Missias Moreira et al. (2016) noted that it is important to look for ways to reduce the physical and emotional distress caused on caregivers by the performance of daily activities in order to promote the caregivers’ quality of life. The purpose of this project is to provide resources and information that can be used as a guide for parental caregivers of adolescents with Down syndrome during the transition out of high school. The goal is to promote the parental caregivers’ quality of life while decreasing caregiver burden and promoting self-care. The product is overviewed in Chapter IV and presented in its entirety in the appendix of this document. Chapter III presents the methodology and activities used to develop the product and Chapter V includes a summary, conclusion, and recommendations for this manual.

CHAPTER III

Methodology

The purpose of this scholarly project was to develop an educational manual for parental caregivers to utilize as a workbook on their own time to acquire resources and information as well as means of support as their adolescent transitions out of high school. The overarching goal of this manual is to promote the parental caregivers' quality of life with a focus on promoting self-care in order to decrease caregiver burden during this transition process. Initially, we developed an interest in the population with Down syndrome through our individual work experiences with this population. We further discussed the parental caregivers of this population and how occupational therapy rarely addresses their needs to promote their quality of life. After meeting with our faculty advisor, we discovered a gap in information for parental caregivers relating to health care during transition out of high school for their adolescents with Down syndrome. This heightened our interest and led us to seek out supplementary information on the parental caregivers of adolescents with Down syndrome during the transition out of high school.

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A brief literature review was conducted in order to determine if there was a need for support and resources for this population. After, it was apparent that there was a gap in the literature to meet the needs of parental caregivers of adolescents with Down syndrome; therefore, an extensive literature review was conducted of current and reliable research. The purpose of the extensive literature review was to gain a better understanding of the parental caregivers' needs, the struggles they may experience, the role of the school during the transition process, and the health care needs of the parental caregivers. The literature review was completed utilizing reliable information from textbooks and multiple databases from the School of Medicine and Health Sciences. These databases included CINAHL, PubMed, ClinicalKey, Google Scholar, and AJOT. Search terms that were used to conduct the research included; Down syndrome, transition to adulthood, caregiver needs, occupational therapy, social support groups, quality of life in caregivers, future planning, family strategies, parental advocacy, and families. Literature critiques of the articles were completed in order to ensure the use of only evidence-based, relevant information for the product. In addition to an extensive literature review, websites designed for parental caregivers and adolescents with Down syndrome were reviewed to obtain pertinent, legitimate, and helpful information and resources to include in the manual.

Information from the research was organized into an outline in sections including: 1) introduction, 2) post-secondary preparation, 3) advocacy, 4) post-secondary education, 5) employment, 6) community involvement, 7) health care, 8) promoting health and wellness, 9) housing, 10) finances, 11) legalities and guardianship options, and 12) taking care of you. The manual was then developed for parental caregivers to assist and guide them through the transition process out of high school for their adolescent with Down syndrome.

The Ecology of Human Performance (EHP) model framework was foundational to the research process and development of the manual (Dunn, 2017). According to Cole and Tufano (2008), “Ecology is defined as the transactions between persons and their contexts” (p. 117). The manual was created to improve the quality of life, provide support, and address the needs of parental caregivers of adolescents with Down syndrome transitioning out of high school. By taking into consideration the parental caregivers and their relationships with contexts, tasks, and performance, intervention approaches and strategies were identified to target their areas of need that were identified in the extensive literature review. The utilization of EHP in the development of this manual is mentioned in Chapter I. It’s relationship to the project is described in greater depth in Chapter IV of this document. In addition, the Adult Learning Model was used to develop the materials within this manual. When developing this manual, the following learning needs were considered to make this manual easy to use: common language, user friendly, accessibility, readability level, easy to read text font and size, and a definition section was included in the appendix for a better understanding of terms that the parental caregivers may not be familiar with (Osborne, 2013). This manual was designed in sections to address the common issues that parental caregivers may experience while working through the transition process and to offer possible solutions as well as information to assist in this transition process. The manual is based on information and needs drawn from the literature review to help provide parental caregivers with resources, interventions, strategies, and beneficial information to assist their child with transitioning out of high school to postsecondary options.

CHAPTER IV

Purpose

The purpose of this product, which can be found in the Appendix, is to provide information, resources, and support to parental caregivers as their adolescent with Down syndrome transitions out of high school. As previously noted in Chapters I and III and as described below, the Ecology of Human Performance (EHP) was foundational for this project; thus additionally, the purpose of the manual is to increase the caregiver's performance within the context of their adolescent's transition to adulthood by providing strategies/interventions to address the issues identified in the literature thus establishing a positive "personal-context-task transaction" (Cole & Tufano, 2008, p.118). This manual can be utilized by parental caregivers of adolescents with Down syndrome to help ease their stress and caregiver burden that they can experience during this transition period.

Theoretical Framework

According to Dunn (2017), the EHP framework emphasizes the connections between the person, context, task, and performance. The primary focus of EHP is to supply a structure that accentuates the role context plays in participation and the profound essence of the connections between the person, their context, and the task in order to comprehend and appreciate their performance (Dunn, Crown, & McGuigan, 1994). Thus, EHP the underlying purpose of the manual is to increase the caregiver's performance within the context of their adolescent's transition to adulthood by providing strategies/interventions to address the issues identified in the literature thus establishing a positive "personal-context-task transaction" (Cole & Tufano, 2008, p.118).

EHP is different compared to other models of occupational therapy practice due to the five intervention approaches that were incorporated into it. These intervention approaches are establish/restore, alter, adapt/modify, prevent, and create (Dunn, 2017). The first intervention approach, establish/restore, is to either establish skills/abilities that the client did not previously have or to restore skills/abilities that the client has lost, typically as a result of acquiring a medical condition, an injury, or a disability (Dunn et al., 1994). The second intervention approach, alter, is to change the environment in which the client performs the task for a better match between the two (Dunn et al., 1994). The third intervention approach, adapt/modify, is to enhance or minimize the context or aspects of the task in order to enable the client to participate in the task (Dunn et al., 1994). The fourth intervention approach, prevent, is to prohibit the incidence or growth of maladaptive performance within the client's context (Dunn et al., 1994). The fifth intervention approach, create, is to construct situations that encourage more adaptable performance within the client's context (Dunn et al., 1994). These approaches to intervention support the use of the EHP model in community and consumer-based care as well as to promote health values and practices (Dunn, 2017).

The way the EHP model of practice fits with this scholarly project is due to the emphasis on the connections between the person, context, task, and performance as well as the five intervention approaches. By recognizing the connections present between the person, their context, the task, and their performance are related, we can acknowledge that these relationships are dynamic and vital to understanding performance (Dunn, 2017). This relationship as it applies to this project is shown in the diagram below~~.~~

Application of EHP (Cole & Tufano, 2008)

Environment/Context	Person	Caregiver Tasks
Temporal aspect: time in the caregivers' life in which they are dealing with the issues of their adolescent with Down syndrome making the transition from high school to adult living	Roles in addition to caregiver Personal characteristics and unique traits	Guardian Advocate Caregiver Their own self-care
Environmental aspects: physical, social, and cultural aspects of the transition process that the caregivers are helping their adolescent with Down syndrome navigate		Dealing with transition issues identified in the literature Post-secondary education, employment, community, involvement, health care, housing, finances, and guardianship

Once we understand the dynamic relationships and the aspects that affect performance, we can identify intervention approaches to support the performance needs and meaningful tasks to people (Dunn, 2017). The five intervention approaches of EHP emphasize the complexity of the relationships between the person, the context, and the tasks people engage in to provide a deeper level of understanding (Dunn, 2017). These intervention approaches are diverse and offer a comprehensive perspective to occupational therapists in regard to intervention options (Dunn, 2017). They also encourage appreciation of how the finest interventions can occur when conscientiously considering the relationship between the person and their context (Dunn, 2017).

With guidance from EHP, specifically its emphasis on dynamic relationships and intervention approaches, a manual was created to increase the quality of life of, provide support to, and increase performance needs of parental caregivers of adolescents with Down Syndrome. This was done through conscientious consideration of the parental caregivers and their various contexts; a manual was created with guidance from EHP and its intervention approaches. After taking into consideration the parental caregivers and their relationships with contexts, tasks, and performance, intervention approaches were identified to target their areas of need that were identified in the literature. Next, general interventions based on these approaches were generated to create a manual.

The other theory that guided the development of this manual was Knowles' Adult Learning Theory. The manual was written and designed with how adults learn in mind to keep it user friendly as well as how to help educators be more effective in practice and responsive to the learners' needs, they serve (TEAL Center Staff, 2011). Therefore, the Adult Learning Theory was relevant and beneficial to utilize as a guide during the process of writing the manual. In addition to the theory, Knowles' has a set of assumptions that are associated with guiding adult learning (Corely, 2011). These assumptions include: increasing self-directedness as he/she matures and directs his/her own learning, draws on his/her life experiences to aid learning, ready to learn when he/she assumes new social or life roles, is ready to problem solve and apply new learning, and is internally motivated to learn rather than external, factors (TEAL Center Staff, 2011). Since adults learn best by doing, effective instruction hones in on tasks that adults can perform, rather than on memorization of certain content, worksheets were incorporated into the manual to promote doing and carrying out the information provided in the manual. Adults are also known to be problem-solvers and learn best when the topic is of immediate use; therefore, effective instruction involves the learner in being able to solve real-life problems (TEAL Center Staff, 2011). By utilizing Knowles Adult Learning Theory in the manual, it provides the adult learners the ability to effectively use the information/strategies to solve problems, along with increasing their motivation to learn the information/strategies that are effective in their adolescents' life.

Description of the Product

This product consists of a manual intended for parental caregivers of adolescents with Down syndrome. This manual includes chapters that provide information, resources, and worksheets to address areas of need that were identified by a comprehensive literature review to fill these gaps. The overall purpose of this manual is to provide information and support to parental caregivers of adolescents with Down syndrome transitioning out of high school to assist in the planning and implementation phases of this transition. Chapters I through III include information that is more global and general. Chapters IV through XI look at more specific needs and issues drawn from the in-depth literature review and suggestions on how to deal with them. The last chapter, chapter XII, is about the caregiver and how they can take care of themselves in order to support and care for their adolescent with Down syndrome. The manual begins with an introduction that includes an overview of the manual, the development of the manual, and how to use the manual sections. Following are chapters that address the following areas of need: Post-secondary preparation, promoting health and wellness, advocacy, post-secondary education, employment, community involvement, health care, housing, finances, legalities and guardianship options, and taking care of you. Each of these chapters contains information, strategies, and resources to help support and inform the parental caregivers on each of these topics. A majority of these chapters contain worksheets for the parental caregivers to apply the information and strategies as well as to assist them in staying organized and prepared during the transition process. The resources used to develop this manual are listed after these chapters. Following these resources, there are appendices towards the back of the manual that contain definitions of key terms used in the manual, additional resources available in North Dakota, and a worksheet to help their adolescent identify and improve foundational skills to prepare for pursuing post-secondary education if they so choose. Copyright permission to display any aspect of this manual is not necessary. Contacting the authors with any feedback to improve the efficacy of this manual would be appreciated.

CHAPTER V

Summary

The purpose of this scholarly project was to develop an educational manual for parental caregivers to utilize as a workbook on their own time to acquire resources and information as well as means of support as their adolescent transitions out of high school. The overarching goal of this manual is to promote the parental caregivers' quality of life with a focus on promoting self-care in order to decrease caregiver burden during this transition process. The manual was formatted into sections to address the needs of the parental caregivers that were identified in the extensive literature review with information, resources, and possible solutions to assist them through this transition process.

Implementation

This manual will be implemented through online distribution to professionals, including occupational therapists, and organizations that work with, provide information to, and advocate for adolescents with Down syndrome and their parental caregivers. These professionals and organizations have platforms that can be used to distribute this manual electronically and free of charge to parental caregivers of adolescents with Down syndrome transitioning out of high school. This manual will be available to be sent electronically with no charge to obtain it; therefore, there will be no printing or mailing fees associated with the initial implementation of this manual. At this time there are no barriers identified to the distribution of this manual as there is no cost associated with distributing a digital copy as a "green" distribution option.

The efficacy and usefulness of this manual may be measured through a survey filled out by the parental caregivers of adolescents with Down syndrome who have worked through the manual. The use of Likert-scale questions in this survey will assist in determining the efficacy and usefulness of the manual as well as its implementation. The survey will be sent out with the manual for the parental caregivers to fill out once they finish working through the manual and return to the creators of this manual. Its purpose is to determine its strengths and areas of weakness to address to improve the efficacy and usefulness of this manual. The feedback obtained from this survey is essential to making future improvements on the functionality and utility of this manual for future parental caregivers that utilize it.

Conclusions

Based on the information found in the literature reviewed in Chapter II, the transition out of high school for the parental caregiver of an adolescent with Down syndrome can be a stressful and difficult time for both the parental caregiver and their adolescent, especially without having pertinent and helpful information and resources available. With the development of this manual, the anticipation is that this manual will fill a gap in literature, information, and resources accessible to the parental caregiver and their adolescent with Down syndrome. The use of this manual with parental caregivers by professionals, including occupational therapists, is vital to continue working to fill the gap and fulfill the needs of caregivers so that they are not forgotten during the transition process.

Limitations

A limitation of this manual is that it has not been used by parental caregivers of adolescents with Down syndrome. Once this manual is piloted, feedback on the readability and helpfulness of the information and resources contained in the manual. Another limitation of this manual is that the efficacy and effectiveness of the manual has not been tested. As this manual is designed in a workbook format, feedback from parental caregivers on the efficacy and the effectiveness as well as the functionality of the manual directly from the parental caregivers to improve the manual development. Once feedback has been gathered, changes and adaptations can be made that take the feedback into account and improve the usefulness of the manual.

Recommendations

Recommendations for further development of this manual in the future include research and developing a class based on the contents of the manual. Future research on the manual, particularly the efficacy and the usefulness of the manual and, in turn, making the associated changes to improve the effectiveness of the manual and its contents for its consumers. Keeping the manual up to date with current research as well as ensuring the functionality of the manual for the parental caregivers. In geographical areas with a substantial number of parental caregivers of adolescents with Down syndrome transitioning out of high school, the development of a class based on the material covered in the manual may be beneficial. This class would give the parental caregivers an opportunity to work through the manual as a group in a class format along with opportunities to support each other, ask questions and solve them together, and share resources, experiences, as well as information to help each other out.

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Appendix

Parental Caregiver's Guide for an Adolescent with Down Syndrome: Transitioning Out of High School

By: Kalindi Rachey, MOTS
& Hailey Johnson, MOTS

Reminder:

Having concerns about your adolescent with Down syndrome during this postsecondary transition is NORMAL. Worrying about your adolescent with Down syndrome during this transition is also NORMAL. Your adolescent is about to go through a period of change, and you want the best for them, for them to be happy, and to make a successful transition into life after high school. This manual is intended to help you navigate through this transition period for your adolescent with Down syndrome as well as help you take care of yourself and attend to your needs during this time. You are doing great :)

TABLE OF CONTENTS

Chapter 1:

Introduction

GENERAL INFORMATION ABOUT DOWN SYNDROME:

- Down syndrome occurs in approximately 1 in every 700 babies that are born in the United States which makes it the most commonly diagnosed chromosomal condition in the United States.

- Adolescents with Down syndrome have expressed feelings of anxiousness, social isolation, and unpreparedness for taking on adult responsibilities as well as uncertainty for their future.

- People with Down syndrome contribute to society in many amazing ways through attending school, working, participating in making decisions that affect them, having meaningful relationships, and voting.

- Factors that can support people with Down syndrome to lead fulfilling and productive lives include quality education, stimulating environment at home, quality healthcare, and positive support from family, friends, and the community.

(CDC, 2019; May et al., 2019; National Down Syndrome Society,2017; Taylor, Cobigo, & Quellette, 2019)

Overview

The purpose of the manual *Parental Caregiver's Guide for an Adolescent with Down Syndrome: Transitioning Out of High School* is to provide information and resources for you to utilize during your adolescent's transition out of high school. It was designed to provide guidance, tools, and strategies to help you prepare, make informed decisions, as well as take care of yourself and your adolescent with Down syndrome during this transitional period.

Development of the Manual

The manual was created and designed by Kalindi Rachey, MOTS and Hailey Johnson, MOTS following an in-depth literature review. The authors' experiences volunteering and working with people who have Down syndrome sparked their interest in addressing their primary caregiver/s which led to an in-depth literature review. The literature review demonstrated the need to address the needs of the caregiver during an adolescent's transition out of high school. Some of the needs found include, but are not limited to: emotional, physical, and financial burden as well as decreased quality of life, social and leisure activity involvement, and ability to complete their daily occupations.

How to Use This Manual

This manual is intended to be a user-friendly, occupation-oriented workbook for parental caregivers of an adolescent with Down syndrome to work through either by themselves or with an occupational therapist. Ideally, the parental caregiver will be able to work through this manual at a consistent rate, such as weekly or monthly, throughout their adolescent's transition out of high school; however, it is intended to be beneficial regardless of the time available to work through and implement the material in this manual. Based on current literature and research, this manual is intended to cover issues and concerns that you may face during this transitional period with your adolescent. Each chapter will start with providing information on the topic and then provide resources and worksheets for you to utilize. You may also refer to Appendix A in the manual for terms and definitions you may not be familiar with. The goal of this manual is to provide you with information and resources to help you through your adolescent with Down syndrome's post-secondary transition process.

Sharing This Manual

This manual was developed with the intent to be shared electronically and free of charge. Therefore, there is no cost to obtain or share this manual with others. We just ask that you cite this manual if you use information from it in a presentation or other educational purposes.

Contacting the Authors

Feedback, suggestions, and questions are always welcomed and appreciated to ensure we are providing you with relevant and useful content as we are beginning to pilot this manual. To contact the authors of this manual please use one of the following email addresses:

→ kalindi.rachey@gmail.com
→ hailsnjohnson@gmail.com

You may also complete the survey located at the end of this manual and email it to one of the above email addresses to provide feedback to the authors and continue to improve the usability and utility of this manual.

Thank you for using our manual :)

Chapter 2:
Post-Secondary Preparation

POST-SECONDARY PREPARATION: WHAT CAN HELP?

Preparing for your adolescent's transition out of high school can be a stressful period of time. The goal of this chapter is to provide tips and resources on what can help ease some of your stress and feelings of anxiety as you work through this process.

Organization & Planning

During this transition period with your adolescent, you may find it easy to worry about and stress about their future. Being organized can help ease some of your worry with the planning process and taking steps to create a good, solid transition plan; however, it is important to be open and flexible as plans can change and vary despite how much you have prepared.

Planning your adolescent's transition will more than likely involve a lot of paperwork. Creating a transition binder with tabs to keep them organized in one place for easy access may be greatly beneficial for you as you work on planning your adolescent's transition out of high school. Some of this paperwork may include but is not limited to the following:

- ☐ State ID and Social Security card
- ☐ Applications and paperwork for services your adolescent has received
- ☐ Applications for Supplemental Security Income and Medicaid (if applicable)
- ☐ Papers relating to guardianship/power of attorney
  - ☐ More information regarding legalities and finances will be addressed later in this manual.

(Jacob & Sikora, 2016)

Planning tasks that you may keep in mind when thinking about your adolescent's transition include options that will be discussed later in this manual involving the following:

- ☐ Work and/or Post-Secondary Education
- ☐ Housing and Financial Options
- ☐ Community Involvement
- ☐ Leisure interests

Role of the School and of the Parent

Distinguishing clear roles for both the school and the parent during preparation and throughout the post-secondary transition can help set expectations and establish accountability for both sides. This can help alleviate some potential problems and ease some stress that can occur throughout this process. Collaborating with the school, other family members, and community agencies can assist in coordinated planning and decision making before and during the transition. These individuals and agencies play an important role in establishing and supporting the decisions you and your adolescent make in regard to their life post high school. Active involvement from both you and your adolescent during the preparation phase is crucial to ensure your adolescent has the support and resources they need to make this transition successful.

Individualized Education Program (IEP) Process

Transition planning involves creating a transition plan. This is a document that is required by law as part of your adolescent's IEP starting when they turn 14 up until they are 21. When your adolescent turns 16, the Individuals with Disabilities Education Act (IDEA) requires that your adolescent's IEP includes a statement of

(Jacob & Sikora, 2016; National Down Syndrome Society,2020) transition services or postsecondary agency/services that your adolescent will need to complete the post-secondary transition successfully. An IEP team typically includes the following individuals: your adolescent (student), teachers, parents (or legal guardians), school administrators, and representatives of agencies that may be responsible for providing transition services. These team members need to collaborate and work together to develop long-term goals specific to your adolescent and smaller, measurable goals to help them achieve each goal and contribute to a successful transition. This team should address the following:

- ❑ Assessment/identification of adolescent’s strengths
- ❑ Needs/Preferences in terms of post-secondary education (if applicable)
- ❑ Employment and housing (if applicable)
- ❑ Matching to desired post-secondary educational program (if applicable)
- ❑ Training and preparation for chosen/planned post-secondary option
- ❑ Making sure the appropriate support services are in place

IEP Examples:

- ❖ The following link will lead you to an example of an IEP for an adolescent between the ages of 16 and 20:
    - ➢ https://www.nd.gov/dpi/sites/www/files/documents/SpeEd/Transition/2019%20sample%20IEP.pdf
- ❖ The following link will lead you to example transition goals and activities that are inclusive for post-secondary programs:
    - ➢ https://thinkcollege.net/sites/default/files/files/resources/Transition%20Plan%20Goal%20Areas%20Tables-%20Karla%20Wade.pdf

(National Down Syndrome Society, 2020)

- This link will lead you to a page of example transition activities and strategies for "Instruction," "Community Experiences," "Employment," "Related Services," "Other Post School and Adult Living Objectives," "Acquisition of Daily Living Skills," and "Functional Vocational Assessment:"
  - https://www.nd.gov/dpi/sites/www/files/documents/SpeEd/Transition/ND%20Examples%20of%20Coordinated%20Set%20of%20Activities%20revised.pdf

What Are My Adolescent's Post-Secondary Options?

After high school, there are a variety of options for your adolescent with Down syndrome to pursue that best fits their needs and fulfills their wishes for their life. Chapters four, five, and six will cover three areas that you, along with your adolescent, may choose to pursue: post-secondary education, employment, and community involvement.

Supporting Your Adolescent

What option/s your adolescent wants to pursue and what they want to do after high school is up to them. Having your support and guidance in pursuing what they choose can greatly improve the success of your adolescent's transition. However, it may be difficult to know how to show your support and be there emotionally for your adolescent.

Take time to work together with your adolescent to work through problems and conflicts as they arise. Taking time to talk and work through events as they happen can help your adolescent use their problem-solving skills, gain independence, and prepare them for life after high school.

(National Down Syndrome Society, 2020)

Encourage your adolescent to share their feelings and thoughts with you about the transition, or even how their day is going. This may help your adolescent develop their advocacy skills and to know what they want as well as how they feel. This may also help them to develop their self-determination skills. Self-determination is your adolescent's ability to solve problems, advocate for themselves, make their own decisions, be self-aware, and be independent.

Acknowledging your adolescent's feelings or a situation that they may be going through can help them validate how they are feeling in order to work through a situation. Praise can also go a long way in increasing your adolescent's self-esteem as well as their confidence in their decision making and problem-solving skills.

Please refer to Appendix B in this manual for a table of service providers in North Dakota

(Leonard et al., 2016; U.S. Department of Education, 2020)

Chapter 3: Advocacy

Advocacy

Advocacy can play a substantial role in your adolescent with Down syndrome's future. The goal of this chapter is to provide information about advocacy as well as tips and resources to help you advocate for your adolescent.

What is advocacy?

Advocacy can look like and be about many different issues, but the goal of advocacy is to support and speak up for a person or a group of people who may not be able to speak up for themselves to get their needs met. Advocating for your adolescent with Down syndrome can help support their success as they transition out of high school by ensuring all of their needs are met.

Advocacy can look like a range of actions. A more conservative approach would be speaking out against an issue. A more assertive approach might be coming up with methods to address the issue and take action to help influence change. Some other options are writing letters and speaking to legislators, volunteering, and spreading awareness in your community by word of mouth, educating others, or creating a club or nonprofit to help advocate for your adolescent with Down syndrome.

There is no option of advocacy that is better than the others as anything that you are willing to and have the ability to do can help promote and support your adolescent through this transition period. Finding an issue or topic that you feel strongly about can help motivate you to advocate for and promote change for your adolescent.

(Brown, Higgins, & MacArthur, 2020; Krueger et al., 2019)

Some issues that you may feel the need to advocate for your adolescent may include, but are not limited to, the following possible issues:

- ❑ Health care
- ❑ Guardianship
- ❑ Work
- ❑ Education including IEP meetings
- ❑ Housing
- ❑ Receiving appropriate care and services, especially therapy
- ❑ Community involvement
- ❑ Funding

Outcomes of Advocacy

Through advocacy, you will be provided opportunities to gain, and improve upon, a variety of skills throughout the advocacy process. Some skills that you can acquire and build upon through advocating for your adolescent may include gaining knowledge on a variety of topics such as access to available services, general understanding of the issue you are advocating for, as well as political and legislative processes. A few more skills that you may gain or expand upon include personal and interpersonal skills such as communication, establishing and building relationships, organization, presentation, prioritization, negotiating, being persistent and persuasive, and resilient as you overcome obstacles.

(Brown, Higgins, & MacArthur, 2020; Krueger et al., 2019)

Although you will most likely run into a range of challenges and obstacles while advocating for your adolescent, it is also important to look at the positives of advocacy as well. Some positive aspects that you may notice from advocating for your adolescent may include enrichment for your family through opportunities to travel as well as building connections and relationships with people you meet along your advocacy journey.

Some parents have reported that they feel advocacy has benefited their family as a whole by coming together to support someone they deeply care about as well as becoming less self-centered, more compassionate towards others, aware of their strengths, as well as being more conscious of and grateful for what they have. Some benefits for your adolescent can be an increase in overall happiness and wellbeing, being provided equal opportunities and experiences as their peers as well as more opportunities for inclusion in a range of settings with their peers.

Although advocacy can be trying and challenging at times, it can be significantly rewarding for you and your family as well as provide a variety of experiences and opportunities for your adolescent with Down syndrome to support their transition out of high school and into their next step.

(Brown, Higgins, & MacArthur, 2020; King et al., 2011; Krueger et al., 2019)

Advocating for Your Adolescent

The National Down Syndrome Society National Advocacy and Public Center works with the Congressional Task Force on Down syndrome. This task force is made up of U.S. Representatives and U.S. Senators that seek to educate other members of Congress and their staff about Down syndrome. The NDSS National Advocacy and Public Center also supports the mission of NDSS to be the leading human rights organization for all individuals with Down syndrome by advocating for federal, state, and local policies that positively impact individuals with down syndrome across the country.

Resources

Local

Designer Genes of North Dakota

www.designergenesnd.com

Up With Downs

karaljones@gmail.com/estlouis4@gmail.com

Down Syndrome Association of Minnesota

www.dsamn.org

National/International

National Down Syndrome Congress

www.ndsccenter.org

National Down Syndrome Society

www.ndss.org

Global Down Syndrome Foundation

www.globaldownsyndrome.org

kkk

(National Down Syndrome Society, 2020)

Chapter 4: Post-Secondary Education

Post-Secondary Education

Once your adolescent reaches the end of their high school education career, they may want to continue their education as this is commonly the main goal for a majority of students with disabilities (Cameto, Levine, & Wagner, 2004). Options for your adolescent to continue their education post-secondary include the following:

- 2- and 4-Year College or University
- Trade and Vocational Schools
- Adult Education Programs

If this is an option that you and your adolescent would like to pursue, there are some actions that you can start taking while your adolescent is still in high school to prepare for this transition. One action you can take is having your adolescent take courses that they enjoy and can challenge them in order to prepare for college courses as well as to help figure out what they want to do. Another action is having your adolescent become involved at school and in the community in activities that allow your adolescent to explore different careers and learning opportunities. Another option is to meet with your adolescent's school guidance or academic counselor to discuss your adolescent's goals and how to work towards them including but not limited to: college requirements, admissions process, standardized testing, and available supports. Encouraging and empowering your adolescent to become independent by managing their time/money and making decisions can improve their self-confidence, making the transition easier.

The following link has a wonderful worksheet to help make a plan to work towards college and career foundational skills: https://thinkcollege.net/sites/default/files/files/resources/foundation%20skills%207_6_17mbdt.pdf

(U.S. Department of Education, 2020)

The last action is to actively participate in your adolescent's IEP meetings to make sure your adolescent's needs are being met and the proper supports and services are in place to help your adolescent make a successful transition out of high school. More in-depth information on IEPs is covered in *Chapter 2*.

Something else that can help your adolescent prepare for transitioning to post-secondary education is creating good study habits. They may find it helpful to study at the same time, in the same spot, and to listen to calming music with noise cancelling headphones to complete their homework. Finding what works and creating habits while in high school can greatly contribute to their success as habits can carry over into tpost-secondary education.

High School Diploma Options

When your adolescent is nearing graduation, they may have an opportunity to choose which type of diploma they receive after graduating from high school. The following are the options that they may be presented and what they mean:

- ☐ "Regular High School Diploma"- Standard diploma given to a majority of students who have completed courses that reflect grade-level content and allows them to engage in grade-level achievement standards. This is not the equivalent to a general equivalency diploma, certificate of completion, certificate of attendance, or another similar diploma or certificate.
- ☐ Alternate High School Diploma- Standards-based diploma that is given to students who are unable to complete academic achievement standards due to a significant cognitive disability. It is based on alternate academic achieve standards and students can be eligible for it until their 22nd birthday.

(U.S. Department of Education, 2020)

❑ Alternate High School Diploma- Standards-based diploma that is given to students who are unable to complete academic achievement standards due to a significant cognitive disability. It is based on alternate academic achieve standards and students can be eligible for it until their 22nd birthday.

Your Adolescent's Rights, Responsibilities, and Physical Accessibility in Post-Secondary Education

Being aware of your adolescent's rights and responsibilities going into post-secondary education, along with the responsibilities of the school, is important to help ensure that they have the opportunity to use the benefits available to them to support their educational endeavors.

In post-secondary education, your adolescent will NOT be entitled to the same services and supports that they received in high school under free appropriate public education requirements of *IDEA* or Section 504 if they graduate with a regular high school diploma.

However, in post-secondary education, Section 504 does prohibit discrimination based on disability for recipients of Federal financial assistance. Title II of the Americans with Disabilities Act (ADA) also prohibits discrimination based on disability by public entities. Both Section 504 and Title II require that post-secondary educational institutions supply students with disabilities accommodations which may include appropriate adjustments to academics, auxiliary aids, and services that are essential to provide these students with an equal opportunity to participate in their education.

(U.S. Department of Education, 2020)

However, they are not required to make adjustments or provide services that would fundamentally alter their academic program or inflict an excessive amount of financial or administrative burden.

In order to receive supports, your adolescent must inform the college they choose to attend that they have a disability and need one or more accommodations. The college may require reasonable documentation from your adolescent in order to receive supports. Their IEP or Section 504 plan from high school may help plan the supports, but it most likely will not be enough documentation by itself.

- ☐ More information on your adolescent's rights and responsibilities can be found at: https://www2.ed.gov/about/offices/list/ocr/transition.html

Regarding physical accessibility, both Section 504 and the *ADA* have requirements connected to facility accessibility in post-secondary education. By putting in curb cuts, ramps, convenient parking, modifications to doorways and restrooms, and elevators among other architectural barrier removal or modification, post-secondary education is more inclusive for students with disabilities.

(U.S. Department of Education, 2020)

Common Concerns

When the transition process is imminent, many parents are concerned that their adolescent would find it difficult to emotionally cope with the disruption to their routines and long-time friendships (Leonard et al., 2016). In order to prepare to ease this concern, you may start working on changing your adolescent's routine slowly over time to what their routine may look like after high school. You may also work on setting up a way for your adolescent to remain in contact with some of their long-time friends during and after the transition. They may write letters or emails, make phone or calls, or arrange a meeting every other week or so to stay in contact with some close friends that they have known for a long time. Talking to your adolescent about the transition and how it will affect their routines and friendships may also be helpful. This is a good opportunity for you and your adolescent to talk through how they are feeling as well as problem-solve how to work through these concerns together.

Another concern that will most likely arise during this time is how to pay for college or post-secondary education for your adolescent. Information relating to finances, including financial assistance, will be covered in *Chapter 10: Finances* in this manual.

(U.S. Department of Education, 2020)

Resources

❑ *thinkcollege.net* is a wonderful resource to refer to for additional information and resources about your adolescent with Down syndrome pursuing a post-secondary education. There are resources for you as a parent as well as your family and a tool to assist you in choosing the right college as well. In addition, if you go to the *Resources* tab at the top of the home page and then down to *Innovation Exchange*, there are the following topics: *Academic Access, Campus Housing, College-Based Transition Services, Comprehensive Transition and Post-Secondary (CTP) Programs, Employment, For Families, Paying for College, Peer Mentors, Preparing for College, Program Accreditation, Program Development, Student Credentials, and Vocational Rehabilitation.* Each of these tabs contains relevant information about each topic through "Featured Resources," "Quick Links," "Frequently Asked Questions," and "News & Features" sections.

❑ In North Dakota, Advancing Students Toward Education and Employment Program (ASTEP) is a two to three-year comprehensive transition and postsecondary program for young adults ages 18 to 26. This program focuses on career, academic, social, community and independent living goals. This program also helps to gain employment and learn independent living and social skills (Think College, 2020).

Chapter 5:

Employment

Preparing for Employment

Employment is another option for your adolescent to pursue after high school or even start while they are in high school. There are some things you and your adolescent can do in order to help them decide what kind of career they would like to pursue as well as to prepare them for the transition into working.

According to the U.S. Department of Education (2017), there are four states of career development that your adolescent will go through when deciding on and working towards their chosen career. Knowing where your adolescent is at in these stages can assist in making decisions on what preparation to pursue or the next step in choosing a career.

- ❑ Career Awareness- This stage starts taking place in elementary school when your adolescent starts developing self-awareness as well as exploring and learning about work values and roles.

- ❑ Career Exploration- This stage typically begins in middle or early high school and continues through high school and adulthood as your adolescent works on deciding on a career path. In this stage, your adolescent will start gathering information in order to explore their work interests, skills, abilities, and requirements of career options.

- ❑ Career Preparation- This stage usually takes place throughout high school and post-secondary education when your adolescent begins to understand what their strengths and challenges are in order to make informed decisions on how to prepare for their chosen career.

(U.S. Department of Education, 2020)

- ❑ Career Placement- This stage takes place when your adolescent begins to participate and engage in a job and a career area responsibly and productively.

Being aware of skills that contribute to career, as well as educational, success can help prepare your adolescent for employment as well. Knowing how well your adolescent has learned and is able to demonstrate these skills can be beneficial in preparation for employment. ThinkCollege has a wonderful worksheet titled “Foundational Skills for College and Career Learning Plan” that identifies skills and their characteristics that can be used to structure post-secondary education and employment experiences. This worksheet also guides you and your adolescent to create a plan on how they will learn these skills through developing goals and reviewing them with at least one other person. A copy of this worksheet can be found in Appendix C or at the following link: https://thinkcollege.net/sites/default/files/files/resources/foundation%20skills%207_6_17mbdt.pdf

(U.S. Department of Education, 2020)

Employment Opportunities and Supports

If seeking employment is a post-secondary option that your adolescent is interested in pursuing, there are a variety of opportunities and supports that are available to help your adolescent if this is the path they want to take.

- ❑ Internships/On-the-Job Experience- These options provide your adolescent with an opportunity to learn and develop skills while completing work-related tasks. It also provides your adolescent an opportunity to explore a career that they are interested in. These opportunities can be paid or unpaid depending on the company and work tasks.
  - ❑ One internship that is centered for adolescents with disabilities and their families is called the Crocker Internship. This internship will target these certain areas: legislative advocacy, office work (answering phones, filing, making copies, etc.), community outreach, public speaking, event assistance, and social networking/blogging.

- ❑ Mentorship- This option is where your adolescent will have someone who is either a peer or adult with more experience who will provide feedback and support to them. Mentorships can help your adolescent prepare for independent living as well as working.

(Massachusetts Down Syndrome Congress, n.d.; U.S. Department of Education, 2020)

- ❑ Supported Employment- This would provide your adolescent with support services from a job coach. The job coach would accompany your adolescent in the workplace to help him or her learn the necessary job skills and to prepare to work independently. Over time, this support will decrease as your adolescent becomes more independent (National Down Syndrome Society, 2020).
    - ❑ An employment program called DSWORKS is centered around encouraging corporations and businesses to invest in hiring people with Down syndrome. The focus is to increase the number of opportunities for individuals with Down syndrome to work in meaningful and competitive work settings (National Down Syndrome Society, 2020).

- ❑ Paid Employment- This is where your adolescent would find and apply for a work position with a company and they will be paid for the work that they do, typically at an hourly wage. By pursuing this option, you and your adolescent may have to advocate for their needs to be met, possibly by negotiating with their employer. This could look like making modifications to job tasks such as adding time, simplifying the task, providing written instructions for tasks, and other modifications in order to promote success and independence for your adolescent.

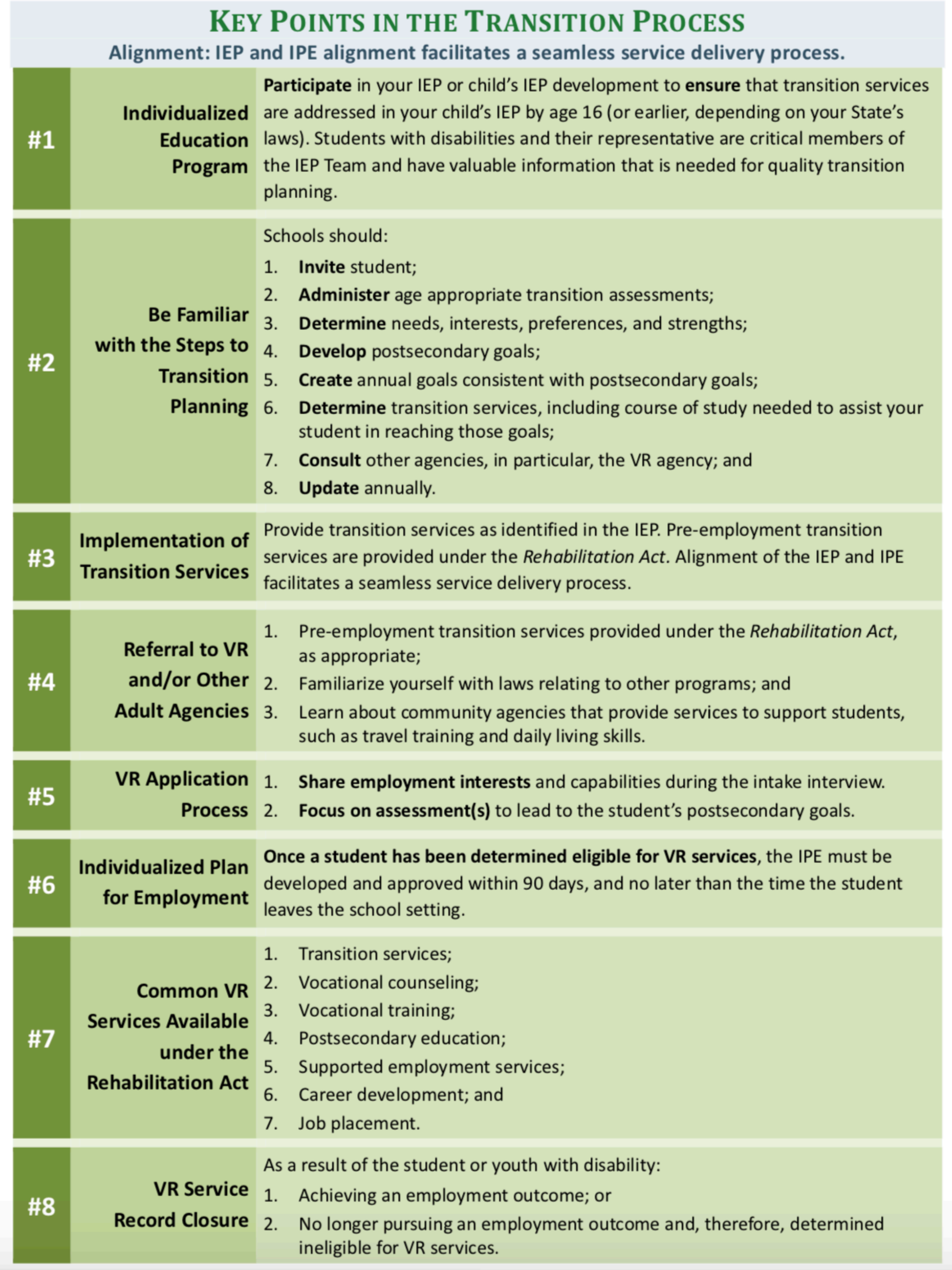
- ❑ Customized Employment- This is when a job position and its associated tasks are designed to meet your adolescent's needs, interests, and capabilities as well as meet the needs of the employer. This could involve developing and tailoring job tasks, work schedule, supervision, and job location to fit the needs of both parties.

(U.S. Department of Education, 2020)

❑ Self-Employment- This involves your adolescent working for themselves for their own income from a trade or business that matches their interests and strengths. This option would provide your adolescent with flexibility of creating their own schedule, place to work, and job tasks that fit their needs as well as the needs of their business. Vocational rehabilitation (VR) agencies provide services and guidance in order to prepare for and start their own business which may include training or start-up costs. The VR counselor will more than likely recommend that your adolescent creates a business plan, including a market analysis, to figure out what the need is for their business, the logistics (such as support services needed, start-up cost, tools/equipment/supplies needed, anticipated income, and their role within their business). This option is great for someone who is passionate about something with a drive and determination to make it into a business.

❑ Work Study Programs- These are inclusive education programs that will prepare your adolescent for success in the workforce and in the community. In this program, your adolescent with Down syndrome will work on taking steps to form a personal relationship with someone, serve on boards, volunteer in their community, and reach their full potential as an adult in the community (National Down Syndrome Society, 2020).

(U.S. Department of Education, 2020)



KEY POINTS IN THE TRANSITION PROCESS

Alignment: IEP and IPE alignment facilitates a seamless service delivery process.

#1	**Individualized Education Program**	**Participate** in your IEP or child's IEP development to **ensure** that transition services are addressed in your child's IEP by age 16 (or earlier, depending on your State's laws). Students with disabilities and their representative are critical members of the IEP Team and have valuable information that is needed for quality transition planning.
#2	**Be Familiar with the Steps to Transition Planning**	Schools should: 1. **Invite** student; 2. **Administer** age appropriate transition assessments; 3. **Determine** needs, interests, preferences, and strengths; 4. **Develop** postsecondary goals; 5. **Create** annual goals consistent with postsecondary goals; 6. **Determine** transition services, including course of study needed to assist your student in reaching those goals; 7. **Consult** other agencies, in particular, the VR agency; and 8. **Update** annually.
#3	**Implementation of Transition Services**	Provide transition services as identified in the IEP. Pre-employment transition services are provided under the *Rehabilitation Act*. Alignment of the IEP and IPE facilitates a seamless service delivery process.
#4	**Referral to VR and/or Other Adult Agencies**	1. Pre-employment transition services provided under the *Rehabilitation Act*, as appropriate; 2. Familiarize yourself with laws relating to other programs; and 3. Learn about community agencies that provide services to support students, such as travel training and daily living skills.
#5	**VR Application Process**	1. **Share employment interests** and capabilities during the intake interview. 2. **Focus on assessment(s)** to lead to the student's postsecondary goals.
#6	**Individualized Plan for Employment**	**Once a student has been determined eligible for VR services**, the IPE must be developed and approved within 90 days, and no later than the time the student leaves the school setting.
#7	**Common VR Services Available under the Rehabilitation Act**	1. Transition services; 2. Vocational counseling; 3. Vocational training; 4. Postsecondary education; 5. Supported employment services; 6. Career development; and 7. Job placement.
#8	**VR Service Record Closure**	As a result of the student or youth with disability: 1. Achieving an employment outcome; or 2. No longer pursuing an employment outcome and, therefore, determined ineligible for VR services.

(U.S. Department of Education (Department), Office of Special Education and Rehabilitative Services, A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, Washington, D.C., 2020, p22).

Chapter 6: Community Involvement

Why is Community Involvement Important?

Community involvement for your adolescent is important because it helps them make connections and participate in activities they enjoy. It also provides opportunities to develop social and life skills such as navigating transportation methods, planning, money and time management, and emotional regulation.

Transportation

Navigating transportation methods within the community is an important skill to have, especially to go places such as the grocery store, bank, school, or work if you or someone else is not able to give them a ride all of the time. Some examples of community transportation available in North Dakota/Western Minnesota include:

- Bismarck/Lincoln/Mandan- BisMan Transit
- East Grand Forks/Grand Forks- Cities Area Transit Dial-A-Ride
- Fargo/West Fargo/Moorhead/Dilworth- MAT Paratransit

You and your adolescent can use the following website to look up community transportation providers that are near the county or city that they live in.

- https://www.dot.nd.gov/divisions/localgov/transit.htm

Community Involvement

Getting involved in the community can provide many benefits for both the individual and their community. To ensure your adolescent can experience these benefits within their community, it is important that the services/activities are chosen to match your adolescent's capacities, support needs, and interests. This is key to make sure these activities support the individual in making a successful transition to adult life post-secondary.

(North Dakota Association for the Disabled, 2016)

Opportunities in the Community

- Having your adolescent get involved in their community may be through volunteering, service learning, working, and participating in various activities. Which option you pursue depends on the amount of time your individual has available, their interests, and what is available for them within your community.

- Volunteering may take place at nursing homes, hospitals, food banks, homeless shelters, animal shelters, community projects, nature centers, and neighborhood block clubs.

- Service-learning opportunities may be an available option for your adolescent as part of their school day for students with disabilities. This option would provide your adolescent with opportunities to develop and advance skills to prepare for employment, post-secondary education, community participation, and other experiences of adulthood.

- Working in the community can help your adolescent meet more people in your community and make connections, work on social skills, problem-solving, and gain work experience. A good free resource that connects private businesses and federal agencies nationwide with job candidates that are qualified with temporary or permanent positions in a variety of career fields is the Workforce Recruitment Program for College Students with Disabilities, also known as WRP.

(Smith, Mavis, & Washenberger, 2020; U.S. Department of Labor, n.d.)

Chapter 7:

Health Care

What is a Health Care Transition?

A health care transition is described by the Department of Health (2006, p. 14) as "a purposeful, planned process that address the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems."

Who is Involved?

The people who may be involved in your adolescent's health care transition plan and process may include, but are not limited to, the following: your adolescent, their guardians, IEP team members, physician and/or general practitioner, nurse, appropriate home health personnel, and possibly any therapists your adolescent is seeing regularly. It is important that you are all communicating and on the same page throughout this health care transition process.

Possible Concerns You May Have:

This health care transition into receiving adult-based health care for your adolescent can become a complex and lengthy process. It is natural that you may develop and have concerns throughout. Some of these concerns you may experience include the following:

One concern that you may be experiencing is feeling a lack of continuity, or sharing, of information between professionals leaving you feeling drained from having to repeat the same information to different health care teams (Brown, Higgins, & MacArthur, 2020).

Another concern you may have is how to choose a primary health care professional to provide adult-based health care for your adolescent with Down syndrome.

POSSIBLE SOLUTIONS TO CONCERNS YOU MAY HAVE:

A few things that may help with possible concern #1 are:

- ☐ Having a general practitioner that takes on a leading role in order to ensure continuity of information to manage general health and acute care.
- ☐ Having a named transition nurse can help with continuity of information between healthcare professionals and serve as an invaluable source of information and support throughout the transition process. This support may include making specialist care and training arrangements, preparing letters and reports to support funding decisions, liaising with consultants, assisting in identifying appropriate adult health care services, advocating for your family as well as providing emotional support and guidance throughout this health care transition process.

In regard to possible concern #2, there are not many health care providers that provide care for adolescents and adults with Down syndrome, however, there are other qualities to look for when choosing. You may also talk to your adolescent's pediatric provider or community program and agency personnel. Some of qualities you may look for may include the following qualities from Chicoine and McGuire (2010) who have extensive experience working with people who have Down syndrome:

☐ Open mind to learn about their patient and get to know them
☐ Belief that your adolescent with Down syndrome deserves the same amount of respect and care as any patient
☐ Ability to listen and learn from your adolescent, family, and other parental figures as these are individuals who know them best
☐ Willingness to consider that your adolescent may be experiencing a medical issue that is not identified with Down syndrome and may require specific treatment
☐ Understanding of human development, particularly childhood development, to utilize when assessing your adolescent
☐ Interest in social aspects of your adolescent's well-being along with the physical

(Chicoine, 2013)

CREATING A HEALTHCARE BINDER WORKSHEET:

What is a healthcare binder and why should I have one for my adolescent?

A healthcare binder contains all relevant and pertinent information relating to your adolescent in one convenient location to help you stay organized and prepared for medical appointments and know what is going on in your adolescent's healthcare. It is up to you if you create a healthcare binder or not depending on your organization system. If you do decide to make one or if you already have one, it may be helpful to keep a digital and an electronic copy in order to have a backup if one gets deleted or misplaced. The rest of the pages in this chapter have some pages that you may find helpful to fill out and place in your binder.

What should be included in a healthcare binder?

- ☐ Information/Contacts
- ☐ Family and emergency contacts
- ☐ Healthcare professionals and contact information
- ☐ Healthcare resources
- ☐ Insurance/Government benefits information relating to healthcare
- ☐ Legal healthcare documents
- ☐ Family/Genetic health history including past and present surgeries/medical conditions, medications, and screening reports

(Create a health care, n.d.)

- ☐ Any questions you may have with space to write the answers when you get them
- ☐ Healthcare goals and progress on them
- ☐ Relating to your adolescent’s diagnosis of Down syndrome:
    - ☐ Treatment/Care plan
    - ☐ Appointment dates, times, location, and contact information
    - ☐ Healthcare and rehabilitation (physical, occupational, and speech therapy) contact information
    - ☐ Any surgery or procedure information
    - ☐ Questions/Primary concerns you want to talk about
    - ☐ Resource recommendations
    - ☐ Testing results
    - ☐ List of medications/supplements, their side effects, and their schedule
    - ☐ Documenting any physical and emotional changes in your adolescent’s health such as their sleep schedule, fatigue, pain, anxiety, depression, social participation, and nutrition

(Create a health care, n.d.)

CONTACTS

Name/Relationship	*Contact Information*

APPOINTMENTS

Date	Where	With Who

MEDICATION LIST

Date Prescribed/Ended	*Medication*	*Side Effects*

HEALTHCARE GOALS

Healthcare Goal #1:

Action Plan:

Progress:

Healthcare Goal #2:

Action Plan:

Progress:

Healthcare Goal #3:

Action Plan:

Progress:

Healthcare Goal #4:

Action Plan:

Progress:

RECOMMENDED RESOURCES

QUESTIONS/ANSWERS

Question:

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Answer:

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Question:

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Answer:

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Question:

Answer:

Question:

Answer:

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Answer:

NOTES

Chapter 8:

Promoting Health & Wellness

How to Help Promote Health and Independence in Your Adolescent with Down Syndrome

During this transition period, promoting health and wellness for your adolescent is important in order to maintain and improve their current level. The goal of this chapter is to provide you with information, tips, and resources to help promote your adolescent's health and wellness as they prepare for their post-secondary transition.

Promoting Occupational Participation, Engagement, and Independence:

- Participating in community activities, such as sporting events, picnics, and camping can be beneficial for the health and the socialization of both your adolescent and your family.
- Opportunities to help address socialization for your adolescent with Down syndrome may include theater programming that incorporates drama to work on speech and language skills as well as various individual and team-based recreational activities, such as sports, music, and crafting groups.
- Post-secondary education options, such as college or working, can be helpful for your adolescent to gain vocational skills.

(Franklin et al., 2019)

Promoting Health and Well-Being:

- Establishing healthy habits and routines for your adolescent with Down syndrome promotes health and can be addressed through nutrition, exercise, and sleep.

NUTRITION

- Eating a well-balanced diet will promote general health and well-being in your adolescent. There is an example, MyPlate, and some tips for healthy eating located on the following two pages. For more information about food and health, you can visit ChooseMyPlate.gov.

- An adolescent with Down syndrome typically burns 200-300 less calories a day than an adolescent without Down syndrome. While this may not seem like much, it can add up to 20 to 30 pounds a year.

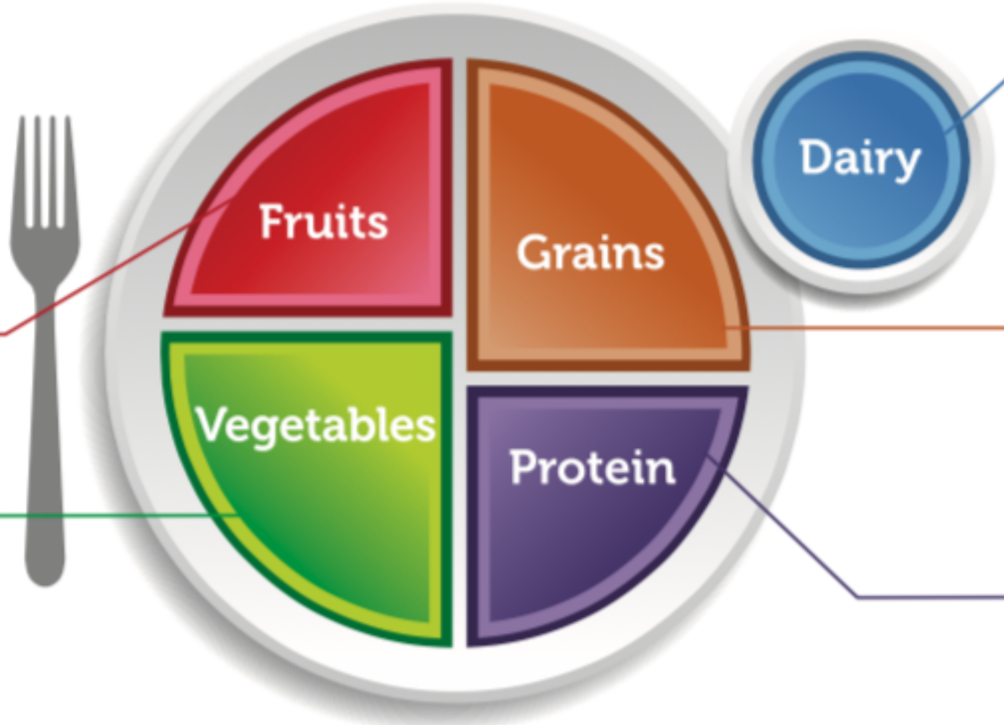
- However, cutting calories, or food, means that your adolescent would miss out on essential nutrients that are contained in this food. Being more active is a healthier alternative in place of cutting calories for your adolescent. There are some examples of ways to be more active in the next section titled "Exercise."

(Chicoine, 2013)

USDA United States Department of Agriculture

MyPlate, MyWins: Make it yours

Find your healthy eating style. Everything you eat and drink over time matters and can help you be healthier now and in the future.



Focus on whole fruits.

Vary your veggies.

Move to low-fat or fat-free milk or yogurt.

Make half your grains whole grains.

Vary your protein routine.

ChooseMyPlate.gov

Limit the extras.
Drink and eat beverages and food with less sodium, saturated fat, and added sugars.

Create 'MyWins' that fit your healthy eating style.
Start with small changes that you can enjoy, like having an extra piece of fruit today.

Fruits	Vegetables	Grains	Dairy	Protein
Focus on whole fruits and select 100% fruit juice when choosing juices. Buy fruits that are dried, frozen, canned, or fresh, so that you can always have a supply on hand.	Eat a variety of vegetables and add them to mixed dishes like casseroles, sandwiches, and wraps. Fresh, frozen, and canned count, too. Look for "reduced sodium" or "no-salt-added" on the label.	Choose whole-grain versions of common foods such as bread, pasta, and tortillas. Not sure if it's whole grain? Check the ingredients list for the words "whole" or "whole grain."	Choose low-fat (1%) or fat-free (skim) dairy. Get the same amount of calcium and other nutrients as whole milk, but with less saturated fat and calories. Lactose intolerant? Try lactose-free milk or a fortified soy beverage.	Eat a variety of protein foods such as beans, soy, seafood, lean meats, poultry, and unsalted nuts and seeds. Select seafood twice a week. Choose lean cuts of meat and ground beef that is at least 93% lean.
Daily Food Group Targets — Based on a 2,000 Calorie Plan *Visit SuperTracker.usda.gov for a personalized plan.*				
2 cups *1 cup counts as:* 1 large banana 1 cup mandarin oranges ½ cup raisins 1 cup 100% grapefruit juice	**2½ cups** *1 cup counts as:* 2 cups raw spinach 1 large bell pepper 1 cup baby carrots 1 cup green peas 1 cup mushrooms	**6 ounces** *1 ounce counts as:* 1 slice of bread ½ cup cooked oatmeal 1 small tortilla ½ cup cooked brown rice ½ cup cooked grits	**3 cups** *1 cup counts as:* 1 cup milk 1 cup yogurt 2 ounces processed cheese	**5½ ounces** *1 ounce counts as:* 1 ounce tuna fish ¼ cup cooked beans 1 Tbsp peanut butter 1 egg

Water

Drink water instead of sugary drinks.

Regular soda, energy or sports drinks, and other sweet drinks usually contain a lot of added sugar, which provides more calories than needed.

Activity

Don't forget physical activity!

Being active can help you prevent disease and manage your weight.

Kids ≥ 60 min/day | Adults ≥ 150 min/week

MyPlate, MyWins
Healthy Eating Solutions for Everyday Life
Choose**MyPlate**.gov/MyWins

Center for Nutrition Policy and Promotion
May 2016
CNPP-29

EXERCISE

- Encouraging regular exercise not only promotes general health and well-being in your adolescent, but also decreases the risk of obesity and Type II diabetes.

- Providing opportunities to participate in both social and recreational activities can make exercising more enjoyable, fun, and an opportunity to be with friends and family.

- Leading by example can promote the development of healthy exercise habits and routines in your adolescent with Down syndrome. This can be done by exercising and participating in activities with your adolescent just the two of you or as a family. For example, you may go for a walk in the park or participate in a sporting activity, anything that the participants find fun and get you moving.

- It may help to schedule or set time aside to exercise and get moving as a family by either putting it on a calendar or setting an alarm. By creating a habit and routine of exercising, it will likely increase health and well-being in your adolescent and your family.

(Chicoine, 2013)

SLEEP

- Getting good sleep also promotes general health and well-being in your adolescent with Down syndrome along with good nutrition and exercise.

- In order to promote good sleep hygiene and habits you may consider:

    - Creating a routine to help your adolescent get ready for bed and help get up in the morning. This may include making a visual schedule or routine checklist for your adolescent to follow in order to promote developing and following a sleep routine.

    - Going to bed and getting up at the same time every day on both weekdays and weeknights can help your adolescent get good sleep and create a sleeping schedule. This can help provide structure and create a routine for your adolescent to promote a regular sleep routine to get good, quality sleep.

    - Not using electronics, such as a TV, a computer, a tablet, or a phone may help your adolescent get good, quality sleep.

(Chicoine, 2013)

BEDTIME ROUTINE CHECKLIST:

☐ Take a shower or bath

☐ Put on pajamas

☐ Wash face

☐ Brush teeth

☐ Read a book

☐ Write down or share a good thing from the day

☐ Take a drink of water

Possible Concerns

This section contains some possible concerns that you may have that were found in recent literature along with suggestions on who to see to address these concerns and resources that you may find useful. The following are some of these possible concerns:

- Ineffective preparation and communication by healthcare providers regarding the you adolescent’s transfer from pediatric to adult health care providers
- Inadequate system support in place for your adolescent
- Concern about your adolescent’s adult healthcare providers’ ability to provide the necessary care
- School system not providing the help your adolescent needs to make this transition
- Lack of others’ understanding about you and your adolescent’s needs
- Limited community inclusion opportunities for your adolescent that could lead to social isolation

(Franklin et al., 2019)

People who may be able to help you address these concerns:

- Teachers with extensive special needs expertise that have worked with your adolescent or other adolescents with disabilities over time
- Knowledgeable case managers, home and community services personnel, and community guides from an organization in the community, such as The ARC. These resources may be able to provide support to work on goals across settings.

Resources that may be able to help you address your concerns:

- Students with Disabilities Preparing for Postsecondary School
    - https://www2.ed.gov/about/offices/list/ocr/transition.html

- Transition Planning for Students with Disabilities: Online Resources for Transitions
    - https://dredf.org/special_education/training_materials/Transition-Resources-List-5-14-12.pdf

- Peer support from other parents of adolescents with Down syndrome or an intellectual disability as it is an important source of hope, motivation, and connection to other resources

(Franklin et al., 2019)

Chapter 9:

Housing

Figuring out where your adolescent with Down syndrome is going to live after they graduate from high school can be a stressful decision. The goal of this chapter is to provide you with information and resources to make the decision that is right for you and your adolescent.

Housing

There can be a lot of planning involved as there are many different things to take into consideration when you are looking into options and making a decision. You may find it helpful to reach out to other parents who have made or are going to make this decision for their adolescent as they have gone through or are going through the same process you are. It may also be beneficial to talk to your adolescent's IEP team, a counselor or social worker, and therapists to get their input and resources. Most importantly, is to talk to your adolescent about what they want and their thoughts about where they want to live after high school. Knowing what they are thinking and taking it into account is important as this decision will greatly affect them during this transition period. If the decision is to move out of their family's home, it can be a big adjustment as their daily habits, routines, roles, and responsibilities will change.

(North Dakota Department of Human Services, 2016)

What Should I Take into Consideration?

The following are some questions to ask and issues to consider when you are planning where your adolescent will live after completing high school:

- ☐ What do you and your adolescent want for their life?
- ☐ What is your adolescent going to do after high school?
    - ☐ Are they going to pursue post-secondary education, get a job, etc.?
- ☐ What town/state are they going to live in?
    - ☐ What resources/supports are available here?
- ☐ Financial:
    - ☐ How much will it cost for housing?
    - ☐ Where will the money to pay for housing come from?
    - ☐ How will they manage their money?
    - ☐ How will they pay for groceries, medical bills, support services, and other living expenses?
- ☐ How much help does your adolescent need to complete:
    - ☐ Tasks that they need to do every day
    - ☐ Time management
    - ☐ Budgeting/money management
    - ☐ Laundry
    - ☐ Shopping
    - ☐ Meal preparation
    - ☐ Self-care tasks such as using the bathroom, showering, and dressing
    - ☐ Regulating their emotions
    - ☐ Problem-solving, decision-making, self-efficacy, and advocating for themselves

- ☐ Logistics:

- ☐ How will your adolescent get around the community?
- ☐ How will they get their groceries?
- ☐ How will they get their meals?
- ☐ What support services they will benefit from, if any?
- ☐ How do I set up support services?
- ☐ How will they schedule appointments?
- ☐ How will they get to their appointments?

When Should I Start Planning?

Planning for where your adolescent will live post-secondary can take some time to figure out which option you want to pursue, how to pay for it, and actually getting it lined up. Therefore, it would not hurt to start thinking about it while your adolescent is in high school and taking actions to start the process while they are in their last year or two of high school. This way you have enough time allotted to figure out all of the logistics and to ensure something is lined up.

(North Dakota Department of Human Services, 2016)

What are my Options?

Although it may depend on your location and what is available in the town or state that your adolescent is going to reside in post-secondary, the following are options that may be available to consider:

- ☐ Living at home- Having your adolescent live at home post-secondary would provide them with continued family support and a familiar environment. If extra help during the day is needed, it is an option to have a home health aide and/or homemaker come into your home to provide their services and help you. A home health aide would provide assistance to complete personal cares such as bathing, hair care, dressing, eating, toileting, transferring, completing eye and skin care, taking vital signs, exercising, performing catheter cares, and managing medications. A homemaker would provide assistance with environmental maintenance tasks such as preparing meals, dusting, vacuuming, cleaning the floors, changing linens, doing laundry, managing money, and assisting in using the phone, reading, and sending mail.

- ☐ Supported Living- Supported living services will provide your adolescent with support in their own home or apartment setting. These services may include, but are not limited to, instruction in budgeting, shopping, laundry, and other tasks that your adolescent may be completing daily. Support is often provided on an intermittent basis and generally less than 20 hours per month.

(North Dakota Department of Human Services, 2016)

- ☐ Group home- A community group home will provide your adolescent with training in community integration as well as social, leisure, and daily living skills (North Dakota Department of Human Services, 2016)

- ☐ Residential Facility- By living in a group residential facility, your adolescent will receive a continuous active treatment program. This program includes training, health services, and related services to help them function with as much independence and staff determination as possible.

(North Dakota Department of Human Services, 2016)

Chapter 10:

Finances

Finances

When you and your adolescent with Down syndrome start planning for their life post-secondary, money may be a concern and determinant of where your adolescent goes and what they do. The goal of this chapter is to provide you with information and resources to help you plan financially for your child's future.

General Financial Information

According to the National Down Syndrome Society (2021), financial wellness is a term that means you live within your means, feel comfortable with your future, are prepared for unforeseen circumstances, and are able to indulge yourself once in a while. Providing financial support for your adolescent with Down syndrome can be a daunting, stressful, and challenging task, especially with the various benefits they may be eligible for and the legalities that go with receiving them. Having information about the options available to you and your family as you begin financial planning for your adolescent's transition post-secondary can ease some of the stress and help give you peace of mind knowing that you have a plan in place.

It is highly recommended that you learn about and create a Special Needs Trust and ABLE Account to provide financial assistance for your adolescent with Down syndrome. You may find it helpful to talk to a financial planner or advisor that specializes in Special Needs Trusts and ABLE Accounts.

(National Down Syndrome Society, 2021)

YOUR PERSONAL FINANCES

In addition to managing or assisting your adolescent's with managing their finances, you also have your own finances to manage. You may consider consulting a financial planner to advise you on your own personal finances. You may also consider consulting with a special needs financial planner to assist you in planning and managing your adolescent's finances.

A resource that you may find helpful in managing your own finances is a financial wellness guide from the National Down Syndrome Society, written in collaboration with Voya Cares, titled *Financial Wellness: A Guide for Individuals With Disabilities, Their Families, and Caregivers*. This guide contains information that you may find helpful in locating resources and information as it relates to raising an adolescent with Down syndrome. There are sections that cover information regarding the following topics: government and workplace benefits, financing education, financial planning, Special Needs Trusts, ABLE Accounts, and overall financial wellness. This PDF can be found at the following websit:

→ https://www.ndss.org/wpcontent/uploads/2021/01/FinancialWellnessGuide_1_2021.pdf

(National Down Syndrome Society, 2021)

PAYING FOR POST-SECONDARY EDUCATION

→ Visiting the college website or talking to the financial office at the college/s that your adolescent is interested in can provide you with more information on what is available at the school.

Grants and Scholarships- Financial assistance that does not need to be repaid. An example is the Federal Pell grant that gives up to $5,815 a year to a low-income student

Work-Study- A program at a majority of colleges where your adolescent would work somewhere on campus to earn money to put towards their education

Low Interest Loan- Would allow your adolescent to borrow money to pay for their education that have to be paid back with interest

Free Application for Federal Student Aid (FAFSA)- Provides access and consideration for the above options to pay for post-secondary education and is free to apply for.

- ❑ For assistance to fill out the FAFSA: https://fafsa.ed.gov/help.htm
- ❑ For more information: https://studentaid.ed.gov/fafsa/filling-out

(National Down Syndrome Society, 2021; U.S. Department of Education, 2020)

Resources

Housing:

- ☐ The Arc
- ☐ Department of Housing and Urban Development (HUD)
- ☐ Habitat for Humanity
- ☐ Home of our Troops if a family member is a veteran
- ☐ VA home loans for disabled veterans (VA Loans) if a family member is a veteran

Paying for College:

- ☐ Good website to find financial resources: https://thinkcollege.net
- ☐ List of scholarships and financial aid that your adolescent with Down syndrome may quality for: https://thinkcollege.net/media-types/webpage

- ☐ In addition to the resources above, you may want to look at the financial and scholarship information that applies to the specific college that your adolescent is looking at attending.

(National Down Syndrome Society, 2020; U.S. Department of Education, 2020)

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Chapter 11:

Legalities

Legal Dimensions Regarding Health Care Decisions:

When your adolescent is nearing the age of 18 in this transition period, you may start wondering:

- Who is going to make the decisions, including decisions regarding health care, for my adolescent after they graduate high school?

You may find the following information in this section about your options and legal dimensions regarding legal guardianship as well as alternative options to guardianship helpful when determining who will be your adolescent's legal guardian after they graduate.

Guardianship

Guardianship according to the U.S. National Council on Disability (2019) is a state legal process where a court can eliminate a few, or many, rights relating to legal, financial, and personal decision-making from the individual to another person who is called their guardian or conservator. However, before considering guardianship as an option for your adolescent, supports for decision-making should be tested and found inadequate prior to taking this option into consideration as it is the most restrictive option for your adolescent.

When your adolescent turns 18, they will become their own legal guardian unless your request, through a court hearing, to be granted legal guardianship. This process is initiated by a family member, a government agency, or a service provider filing a petition to the court with jurisdiction. Once this petition is filed, the following steps will take place:

(U.S. National Council on Disability, 2019)

- ☐ A notice that the petition has been filed is commonly sent to the involved parties.
- ☐ An attorney will be appointed to represent the allegedly incapable person.
- ☐ A capacity evaluation will be performed.
- ☐ Then, a court hearing will take place.
- ☐ If guardianship is appointed, letters of guardianship will be drafted.
    - ☐ Under state law, the responsibilities of the guardian may involve presenting a guardianship plan and submitting initial and annual reports, to the court.
    - ☐ In most cases, the appointed guardianship will last until the individual under guardianship passes away OR the individual has their legal rights restored.

It is up to you, as the parental caregiver, to determine if taking these steps is appropriate for your adolescent as you know them the best and what they are capable of. However, there are alternatives to legal guardianship that you can take into consideration as well if you do not want to pursue this course of action. You have to do what you think is right for you and your adolescent.

(U.S. National Council on Disability, 2019)

Alternative Options

There are alternative options to guardianship available which will be discussed in this section. Alternative options to legal guardianship include but are not limited to the following: health care surrogates, representative payees, trusts, and joint ownership.

These options are typically less restrictive for your adolescent than guardianship and may consist of services and supports that will allow the needs of your adolescent to be met without having a legal guardian in place. Other services and supports may include but are not limited to: voluntary participation in services for money management, in-home care, case management, delivery of food and prescriptions, and person-centered planning. Utilizing these decision-making supports for your adolescent may be a good alternative to take prior to pursuing legal guardianship as these options promote self-reliance, self-sufficiency, and self-empowerment in your adolescent with Down syndrome.

- Health care surrogates- People who are given the power to make healthcare decisions for someone through durable power of attorney for health care or operation of state law.
- Representative payees- People who receive payments, such as Social Security Disability or Supplemental Security Income for someone who is not able to manage their own finances.
- Trusts- Arrangements where a trustee typically manages money or property for the beneficiary, or receiver, of this money or property.
- Joint ownership- Two or more people co-own a property or manage a bank account and permits one co-owner to manage the other’s share as their own if they are not able to do it themselves.

(U.S. National Council on Disability, 2019)

NOTES

CONTACTS

Name/Relationship	*Contact Information*

Chapter 12:

Taking Care of You

Your Needs

So far, this manual has mainly focused on planning for and meeting the needs of your adolescent; however, your needs as a parental caregiver of an adolescent with Down syndrome transitioning out of high school are equally important to identify and address to help ease the stress you are probably experiencing as you work through this transition. The goal of this chapter is to help you identify and address your needs as a parental caregiver physically, mentally, and emotionally.

Your Feelings

Throughout this process, it is more than likely that you will experience a variety of emotions that may vary throughout the day or each day. Some days you may feel happy, encouraged, motivated, informed, hopeful, grateful, loved, and appreciated while other days you may feel stressed, anger, frustration, guilt, resentment, depression, fear, uninformed, and denial. It is 100% NORMAL to feel some, most, or all of these emotions as you and your adolescent work through this transition process.

Being Assertive

There may be times where it may be hard for you to care for your adolescent to meet their needs when yours are not being met. As the saying goes, “It’s hard to pour from an empty cup.” Therefore, it is important that your needs are being met to fill your “cup” in order to fill your adolescent’s “cup.” This is where being assertive can help you meet your needs as well as your adolescent’s. Being assertive is a means of open, respectful communication that projects confidence and can help get your needs met.

(Alabama Parent Education Center, n.d.; Lancer, n.d.)

The following are assertiveness skills called the 6 C's by Lancer (n.d.):

1. Congruency- Your body can project emotions that you don't say, accordingly, having the option to sincerely impact your opinion, feel, and mean is significant.
2. Courtesy- You want to engage who you are conversing with without having them feel like you are venting to them or scolding them. Constructive criticism that is delivered to others is the most effective.
3. Conciseness- Getting to the point is usually effective. Beating around the bush can show insecurity or lack of knowledge.
4. Clarity- Be direct and clarify statements of how you think, feel, need, or want. Try not to ask questions or give hints. For instance try saying, "I'd prefer to go out for dinner this evening." rather than "Would you like to go out for dinner?"
5. Cognizance- In other words you must hear in order to be heard. To be an effective communicator, tune in and respect what others need to say and how they feel. A tip is to summarize and repeat what the other individual has said as this shows you are tuning in, you give it a second thought, and you are interested in what they need to say.
6. Claim Yourself- This can be hard to do as you need to take responsibility for your opinions, considerations, emotions, and needs. Utilizing "I" statements such as "I think" or "I feel" to get across how you are thinking or feeling.

Using these assertiveness skills can help you communicate how you are thinking, feeling, and what you need in order to help get your needs met and fill your "cup."

(Lancer, n.d.)

Building Support

Having support through this transition process is vital to help you find information and resources as well as cope with emotions as you navigate with your adolescent through this transition. The type of support that you want, or need, can vary person to person. Some examples of people who can provide support for you include family, friends, healthcare professions, support groups, and other parents going through a similar experience as you are. You may find it helpful to utilize the assertiveness skills that were discussed in the section above to communicate how you are thinking, feeling, and what your needs are as well as to ask for support and what kind of support you want or need at the moment. American Academy of Pediatrics recommends local parent support groups as a resource for learning about doctors, therapists, schools and local developmental programs in your community.

- The following link is a link to a program called Parent to Parent which is a program of parents supporting parents who have a child with developmental delays, disabilities, and special health needs: http://fvnd.org/nd-parent-to-parent/

Support can also come through receiving support services such as family support services like respite care, supportive home care, and family care. Short-term respite care may be provided by family support services when your adolescent's parents, guardians, or caregivers are absent to provide care. Support home care provides a specialized trained caregiver to work with your adolescent's parents, guardians, or caregivers when additional help is necessary to meet their needs. Family care is out of home support that is provided in a licensed family home.

(North Dakota Department of Human Services, 2016)

Family Building and Connecting (BAC) Framework

This approach includes strategies for you and your family members to use in order to build a supportive environment around your adolescent with Down syndrome. To accomplish this, you have to rely on yourselves and your established network of relatives and close friends. People who have used this approach rarely contacted professional agencies to help build their social support network.

The following strategies were found to be used by families to build support networks:

☐ Create peer opportunities- Enabling your adolescent to meet peers around their age both with and without disabilities
☐ Modify living environments- Creating or modifying environments to provide opportunities for your adolescent to be more independent while they continue to live with you and their family
☐ Ensure family care continuity- Involving your adolescent's siblings to help take on the responsibility of supporting them when you are not able to do so

Using connecting approaches include family members utilizing strategies to connect their adolescent or adult with Down syndrome to professional support services. Some connecting strategies include the following:

☐ Bridge builders- Connecting your adolescent to social support networks outside of their family. Bridge builders are professions that create connections between someone with Down syndrome and external opportunities and services.

(Roll & Bowers, 2019)

❑ Organizing family-independent living- This approach differs from the first approach as it includes supported living arrangements in the community rather than at home with you and their family. This planning process for moving out of the family home includes making financial arrangements and finding a roommate along with care services as necessary that will support your adolescent and be a good fit.

❑ Sharing responsibilities- Family members who are interested in using the connecting approach often decide to share responsibilities with people outside of their family network instead of maintaining the full responsibility. Sharing this responsibility may not always be easy, however, it is important for your adolescent to be able to be apart from their family as well as for you as their family to learn to trust people who are outside of your family network.

(Roll & Bowers, 2019)

Managing Stress

Stress is a common feeling that is experienced among parents or guardians of adolescents who have a disability, especially as they start planning and navigating through the post-secondary transition process.

Stress can affect every person differently and is detected through symptoms displayed in your body, mind, mood, and behavior.

- Knowing what the signs of stress are
- Being able to identify them
- Knowing how to cope with stress
- Being aware of how to prevent stress are all key in managing your stress.

The first step is to know what your signs of stress are. Stress can manifest in physical, mind and mood, and behavioral signs. Some examples of physical signs of stress are:

- Headaches, fatigue, difficulty sleeping, and chest pains

Examples of mind and mood signs of stress include:

- Becoming irritated or angry easily
- Feelings of worry and anxiety
- Feeling overwhelmed
- Lacking motivation
- Feeling depressed or sad

Examples of behavioral signs of stress include:

- Changes in appetite
- Increased alcohol or drug use
- Avoiding responsibilities
- Withdrawing in social situations

These are all examples of how you may feel when you are stressed. Being able to identify your signs of stress can help you prevent, prepare for, and manage your stress to the best of your abilities by recognizing when you are feeling stressed. You can do this by pinpointing the sources of your stress. Then, you can set up strategies to manage your stress to help you work through these feelings and emotions while continuing to build and strengthen your relationship with your adolescent.

Knowing how to effectively cope with your stress is vital as feelings of stress can affect how you are thinking, feeling, and acting towards others. It can also help you work on filling and keeping your "cup" full. An example of how to cope with stress is practicing strategies such as "Living in the Moment." The following are the 4 steps to complete in order to execute this strategy:

1. Identify the problem or source of your stress
2. Think about or research what your options are to cope with this stress
3. Decide what option you want to carry out
4. Evaluate how your decision is working in the future

To help prevent stress, there are many different options that you may find beneficial to prevent feeling stressed. Some examples are scheduling some alone time regularly to do activities that you find enjoyable such as:

- Reading a book
- Taking a warm bath
- Going for a walk
- Watching your favorite tv show or movie.

(Alabama Parent Education Center, n.d.)

Find something that you enjoy doing and that you find relaxing and then let yourself enjoy doing it. Having alone time is necessary to maintain good health, improve your mood and productivity, and prevent feeling stressed.

Eating healthy and following an exercise plan can also help reduce feelings of fatigue and irritability as well as lower your risk for certain diseases and health complications. In conclusion, there are many benefits to preventing stress for your overall health and wellbeing.

Mindfulness

Being mindful means to maintain awareness of your surrounding environment, thoughts, feelings, and bodily sensations through a gentle, thoughtful, and non-judgmental lens to bring awareness to your thoughts and feelings to be present in the moment. In addition to becoming more present, mindfulness can help reduce stress.

Mindfulness can be achieved through performing a variety of relaxation techniques such as:

- Deep breathing
- Meditation
- Gentle stretches/yoga/movements

A mindfulness-based stress reduction (MBSR) program is an approach that you can utilize when you are feeling overwhelmed while planning for, going through, and anticipating challenges for your adolescent's post-secondary transition.

This program focuses on empowerment, non-judgmental interpretation of events, and acceptance of your present situation by using mindful meditation practices and gentle stretching.

(Bazzano et al., 2015; The Greater Good Science Center at the University of California Berkeley, 2019)

A MBSR program is structured with teaching mindful meditation practices, gentle yoga/movements, mindfulness and stress theory, and group discussions. This program can help strengthen:

- Your inner psychological resources
- Build psychological resilience
- Help with accepting your current situation
- Increase patience of uncertainty.

Your Quality of Life

Quality of life is your life satisfaction as well as your health, how you function, as well as social and economic factors. Your feelings of life satisfaction may vary day to day and that is okay.

It is normal to feel happy and satisfied with your life one day and then feel unhappy and dissatisfied with your life the next, especially during a stressful period of time, such as:

- Your adolescent’s post-secondary transition
- Time management
- Financial management
- Social participation
- Leisure participation

(American Occupational Therapy Association, 2020; Mayo Clinic, 2020; The Simple Dollar, 2020)

Time management is the ability to use your time effectively and productively to get done what you need to. This may include:

- ➢ Prioritizing tasks
- ➢ Making to do lists
- ➢ Establishing a daily routine
- ➢ Making a schedule
- ➢ Multitasking once in a while. For example, while your clothes are in the washer or dryer, you have time to complete other tasks on your to do list around the house before switching loads or folding laundry.

When it comes to prioritizing, **it is okay to say no** to events, tasks, or requests that you simply do not have time for in order to get done everything that you need to.

Financial management is the ability to pay your bills, keep track of your money, and financial planning to manage your finances. Reviewing your finances regularly by keeping track of your spending as well as any out-of-pocket expenses for your adolescent can help manage your finances. Setting a budget for your family to follow may also be helpful.

Social participation is spending time with other people through joining a support group and seeking social support. A support group can provide validation and encouragement as well as problem-solving strategies for difficult situations as the people in this group understand and get what you are going through. This is a great way to meet and create meaningful friendships that also provide support.

(American Occupational Therapy Association, 2020; Mayo Clinic, 2020; The Simple Dollar, 2020)

Social support can include:

- Staying connected with friends and family that can offer non-judgmental emotional support
- Setting aside time throughout your week to connect with these people is important, even if it is simply meeting a friend for coffee or a walk or a phone call

Leisure participation is taking part in activities that you enjoy. Active or physical leisure activities have been shown to lead to immediate as well as long-term increases in positive affect, self-esteem, sense of belonging, and happiness. Active or physical leisure activities involve:

- Working out
- Playing sports
- Going for a walk

Social leisure activities involve:

- Interacting with others at family gatherings
- Support groups
- Other social events

Mentally stimulating leisure activities involve cognitive engagement involve:

- Crossword puzzles
- Sudoku
- Reading
- Card and board games

Participating in any of the activities mentioned may help alleviate some feelings of stress.

(Mayo Clinic, 2020; Mihaila et al., 2017)

Available Services for You

- Family system programs follow a systems approach that focuses on parents' internal variables, such as stress, depression, or coping with the news.
- Positive behavior support approach has been developed to promote parenting practices related to behavior management.
- The National Down Syndrome Society advocates for people with Down syndrome at a Congressional level in order to secure funding for research and social programs that will provide support in school, home, and in the workplace.
- The National Down Syndrome Congress is a major national organization that provides support to parents through providing information and holding conferences.

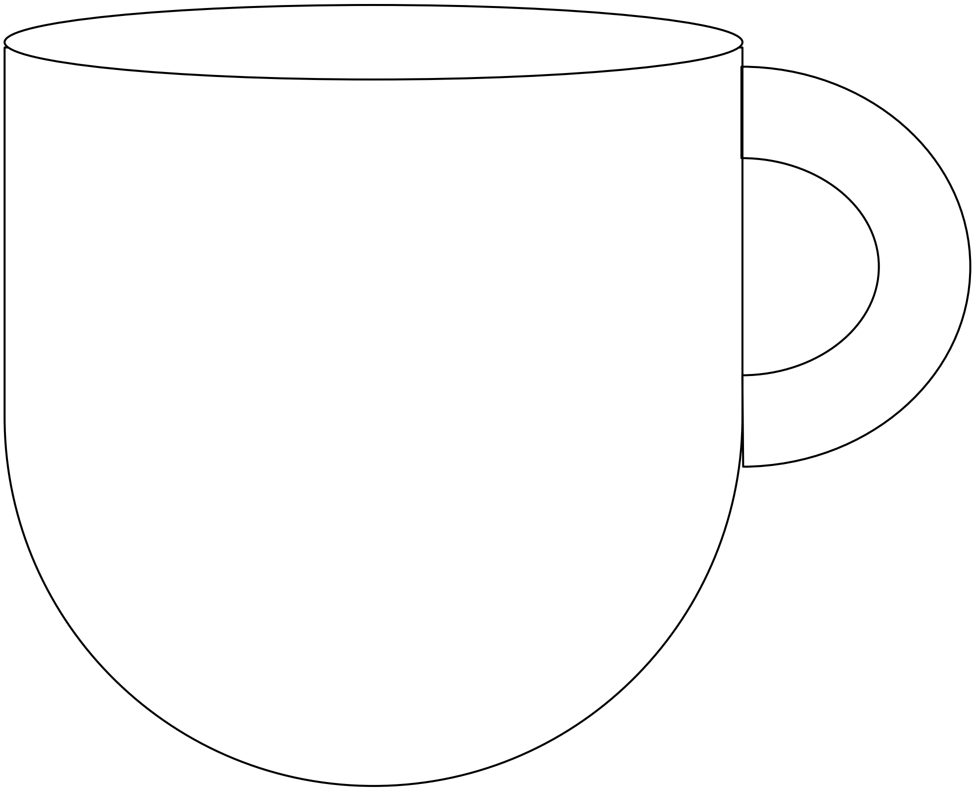
(The National Academies of Sciences Engineering Medicine, 2016)

Additional Resources

- Band of Angels- World's largest provider of non-medical information on Down syndrome.
- Global Down Syndrome Foundation (GDSF)- International non-profit offering a variety of resources in areas of research, medical care and education
- International Down Syndrome Coalition (IDSC)- Access to educational opportunities
- National Association for Down Syndrome (NADS)- Provides parent with support, self-advocacy programs, resource referrals, public awareness, conferences and retreated for students with Down syndrome and their families
- National Down Syndrome Congress- Provides resources for families alongside a self-advocates program
- National Down Syndrome Society- Providing advocacy for individuals with Down syndrome
- Ruby's Rainbow- Supports the educational dreams of students with Down syndrome by providing scholarships, supplying housing resources about available education programs and sharing success stories.

(Writers, 2020)

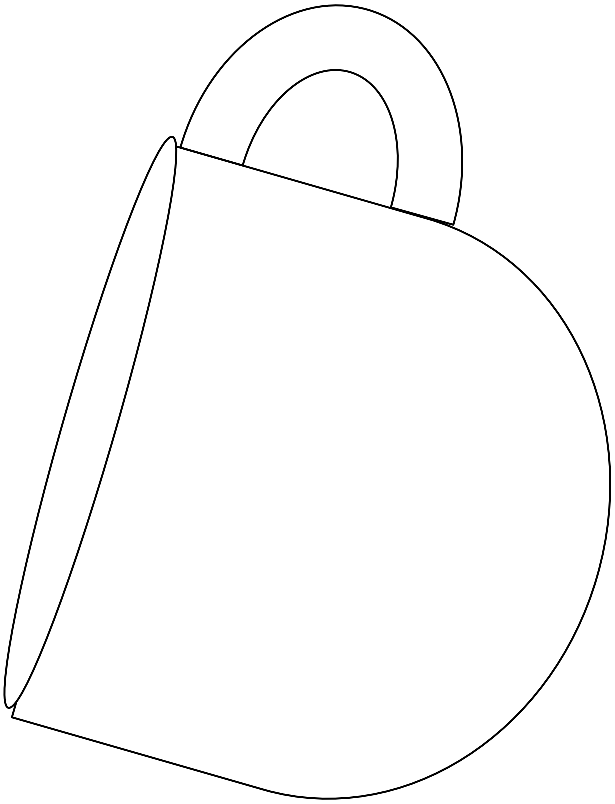
WHAT FILLS YOUR CUP?



Ideas:

Hug Someone
Read/Watch TV
Act of Kindness
Doing a Hobby
Taking a Walk/Hike
Listen to Music/Podcast
Write
Call a Loved One
Play with a Pet/Child
Get Coffee with a Friend

WHAT EMPTIES YOUR CUP?



Ideas:

Stress

Feeling Alone

Not Eating

Not Getting Enough Sleep

Life-Changing Event

Being Tired

High Expectations

Conflict

Working Through Stress

Body

If you're experiencing…

- Headaches, sleeping problems, sick, stiff/sore/tense muscles, fatigued, tired, skin issues, stomach problems, sweating

Try…

- Progressive muscle relaxation, yoga, breathing techniques, meditation

Mind

If you're feeling…

- Anxious, worried, forgetful, indecisive, negative, panicked, problems with thinking and judgement

Try…

- Visualization, meditation, focus on your surroundings, work through why you are stressed, go to a safe space, looking at the positives

Emotions

If you're feeling…

- Irritable, lonely, hopeless, angry, racing thoughts, worried

Try…

- Work through why you are stressed, meditation, yoga, deep breathing

Behavior

If you're feeling…

- ➔ Appetite change, substance use, insomnia, clumsy, more/less social

Try…

- ➔ Work through why you are stressed, deep breathing, meditation

Reminder:

Having concerns about your adolescent with Down syndrome during this postsecondary transition is NORMAL. Worrying about your adolescent with Down syndrome during this transition is also NORMAL. Your adolescent is about to go through a period of change, and you want the best for them, for them to be happy, and to make a successful transition into life after high school. This manual is intended to help you navigate through this transition period for your adolescent with Down syndrome as well as help you take care of yourself and attend to your needs during this time. You are doing great :)

Contacting the Authors

Feedback, suggestions, and questions are always welcomed and appreciated to ensure we are providing you with relevant and useful content as we are beginning to pilot this manual. To contact the authors of this manual please use one of the following email addresses:

- → kalindi.rachey@gmail.com
- → hailsnjohnson@gmail.com

You may also complete the survey on the next page and email it to one of the above email addresses to provide feedback to the authors and continue to improve the usability and utility of this manual.

Thank you for using our manual :)

Survey

1. What are your thoughts on the manual?

2. What information did you find helpful in this manual?

3. What information would you recommend adding to this manual?

4. What other recommendations do you have to improve the usability and utility of this manual?

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Appendix A: Definitions

Definitions

- **Adolescence-** Typically the developmental stage that occurs between the ages of 12 and 18 with late adolescence occurring between ages 17 and 21 (Arnett, 2000; Radzik, Sherer, & Neinstein, 2020; Vroman, 2015)
- **Down's Syndrome-** Happens when someone has either a full or partial supplemental copy of chromosome 21 ("What is Down," n.d.). Some of the more common physical characteristics may include low muscle tone, smaller build, an upward slant to their eyes, and a single deep crease across the center of their palm ("What is Down," n.d.)
- **Guardianship-** A state legal process where a court can eliminate a few or many rights relating to legal, financial, and personal decision-making from the individual (U.S. National Council on Disability, 2019)
- **Healthcare Transition-** A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young

adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems (Department of Health, 2006)

- **Quality of Life-** wellbeing experienced when individuals basic needs are met and they have the opportunity to pursue and achieve goals in major life settings (van Heumen, & Schippers, 2016)
- **Self-Care-** The ability to promote health and wellness through personal hygiene, nutrition, lifestyle, environmental and socioeconomic factors, and self-medication (WHO, 2019)
- **Transition-** The process of moving from the protected life of a child to the autonomous and independent life of an adult (Leonard et al., 2016)

Appendix B:

Licensed Developmental Disabilities Service Providers in North Dakota

Licensed Developmental Disabilities Service Providers in North Dakota

Bismarck

- **Day Habilitation**
  - Community Options for Residential & Employment Services, Inc.
  - KAYD Home Care, LLC
- **Individual Employment Supports**
  - Community Options for Residential & Employment Services, Inc.
- **In-Home Supports**
  - Community Options for Residential & Employment Services, Inc.
  - KAYD Home Care, LLC
- **Parenting Supports**
  - Community Options for Residential & Employment Services, Inc.
  - Support Systems, Inc.
- **Prevocational Services**
  - Community Options for Residential & Employment Services, Inc.

- **Residential Habilitation**
    - Community Options for Residential & Employment Services, Inc.
    - KAYD Home Care, LLC
    - Support Systems

Devil's Lake

- **Day Habilitation / Individual Employment Supports / Prevocational Services / Residential Habilitation**
    - Lake Region Corporation

Fargo

- **Day Habilitation / Individual Employment Supports / In-Home Supports / Prevocational Services / Residential Habilitation**
    - CHI Friendship, Inc.
- **Day Habilitation**
    - LISTEN Inc.

Grafton

- **Day Habilitation / Individual Employment Supports / Prevocational Services / Residential Habilitation**
    - Life Skills & Transition Center

Grand Forks

- **Day Habilitation**
  - Development Homes, Inc.
  - Grand Forks Growth & Support Center
- **Individual Employment Supports / Prevocational Services / Residential Habilitation**
  - Development Homes, Inc.
  - Success Unlimited
- **In-Home Supports / Parenting Supports**
  - Development Homes, Inc.

Jamestown

- **Day Habilitation / Individual Employment Supports / In-Home Supports / Prevocational Services / Residential Habilitation**
  - Anne Carlsen Center

Mandan

- **Day Habilitation / Individual Employment Supports / In-Home Supports / Parenting Supports / Prevocational Services / Residential Habilitation**
  - Easter Seals/Goodwill of North Dakota

Minot

- **Day Habilitation / Individual Employment Supports / Residential Habilitation**
    - Minot Vocational Adjustment Workshop dba KALIX
    - Rehab Services Inc.
    - REM North Dakota Inc.
- **In-Home Supports / Prevocational Services**
    - Minot Vocational Adjustment Workshop dba KALIX
    - REM North Dakota Inc.

Valley City

- **Day Habilitation / Individual Employment Supports / In-Home Supports / Prevocational Services / Residential Habilitation**
    - Open Door Center

Williston

- **Day Habilitation / Individual Employment Supports / In-Home Supports / Prevocational Services / Residential Habilitation**
    - Opportunity Foundation

Appendix C:

Foundational Skills for College and Career Learning Plan

Foundational Skills for College and Career Learning Plan

The Foundational Skills for the College and Career Learning Plan (CCLP) can be used to structure college experiences, including course work, employment, internships, on campus activities, volunteer and service learning experiences, and more. The CCLP is a goal setting and assessment tool designed to drive learning and productivity on campus, during internships and on the job. It can be used to structure the goal setting and to track and document the achievement of foundational skills. The CCLP may also be used as a planning document while developing the course of study, career goals, as a teaching tool for opening up conversations with students about the importance of foundational skills, and as an evaluation tool for providing ongoing evaluation and feedback on skill acquisition.

SECTION 1:

Foundational Skills identifies the skills common to college and career success. It is helpful to use this list of foundation skills as a guide when working with the student to develop their goals for the semester.

SECTION 2:

College & Career Characteristics Goal Setting provides an opportunity to identify characteristics specific to the college and work experience and to the student's personal development and transition goals.

SECTION 3:

Progress and Performance Review can be used to structure feedback and goal setting meetings regularly throughout the college and work experience, with the frequency of meetings to be decided by the faculty, staff, or supervisor with the student.

HOW TO USE THE COLLEGE AND CAREER LEARNING PLAN

STEP 1 Student should review the list of skills and characteristics in Section1 "Foundational Skills" and identify 2-4 skills that they would like to work on in a semester. They should work with their advisors, mentors and coaches to identify both the skills and the environment where they can achieve these skills.

STEP 2 Student should meet with faculty advisor or supervisor to set specific plans for how they will learn that skill. Use Section 2 "College & Career Characteristics Goal Setting" of the CCLP to list those plans.

STEP 3 Student meet with their advisor at least 2 or more times each semester to review performance and progress and set new goals as needed. Students can use Section 3 "Progress and Performance Review" to record their progress. The first review meeting (Review 1) should take place during the first few weeks of the semester to assess the level of achievement and set goals. The next review (Review 2) should be scheduled at that meeting to review progress. Student and advisor should write comments and sign the CLLP at each of the reviews.

SAMPLE FOUNDATIONAL SKILLS FOR COLLEGE AND CAREER LEARNING PLAN

Name: ______________________________ Advisor Name: ______________________________

Coach/Mentor Name: ______________________ Start Date: ______________________________

SECTION 1: SPECIFIC COLLEGE AND CAREER SKILLS

Instructions: Review the College and Career Skills that you want to focus on this semester, concentrating on skill areas that relate to your specific course of study and academic or career goals. With the assistance of a coach, mentor, advisor, select at least 2 goals that you want to work on this semester. You may also add an additional skill.

Academic and Career Habits

Skill	Characteristics
Attendance and punctuality	Maintains current course and work schedules Gets to class and work on time
Use of resources	Is aware of college supports (e.g.. counseling, career, library) Uses tutoring, coaching, mentoring, disability services as needed
Communication	Communicates clearly and can make others understand their meaning Checks for understanding such as asking clarifying questions Communicates with college faculty, supervisors, co-workers, residence hall staff, peers and classmates. When engaged in class or a conversation, talks on topic. Initiates greetings and conversations with peers and classmates.
Quality of work	Plans ahead to manage assignments Takes or knows how to get class notes Organizes class or work materials Maintains good study and work habits such as completing assignments, and asking for help if needed
Acceptance of direction and constructive criticism	Responds to valid requests. Listens to and evaluates feedback from peers, instructors, coaches, co-workers, and supervisors Changes behavior as a result of assessments or feedback, if necessary Accepts (OR understands) work performance assessments
Technological know-how	Follows email etiquette Uses office software (e.g., word processing, spreadsheets, slideshows) Uses cell phone to make calls, text and/or leave messages, as appropriate. Uses mobile device to manage and monitor course schedule, assignments and social activities Maintains social media accounts responsibly Uses on-campus learning management systems

Cultural Know-how

Skill	Characteristics
Commitment	Regularly attends class, job, and campus activities Follows through on assigned tasks to completion
Respect	Adheres to college, work, and social rules and expectations Demonstrates respect (as defined by culture/community) to peers, instructors, coworkers and supervisors Manages conflict, frustration or disappointment appropriately
Flexible attitude (or flexible thinking)	Learns the attitudes and expectations of new environments Creates and seeks solutions to problems Can generate alternatives and identify additional solutions
Responsible risk-taking	Considers ethical, safety, and societal factors in making decisions Applies decision-making skills to deal responsibly with daily academic, employment, and social situations
Interpersonal skills	Maintains reciprocal relationships with friends and peers Manages respectful interactions with professors and employers, friends and classmates. Engages in assigned group work during class.
Curiosity	Asks questions Asks or looks for new information Seeks new experiences
Awareness and use of resources	Uses a range of campus and community resources (e.g., career center, public transportation, health services) Knows how to find information

Balance of Multiple Roles

	Skill	Characteristics
	Persistence	Participates fully in academic task or project from beginning to end Problem-solves when there are barriers
	Responsibility	Creates and follows a daily/weekly schedule Can list places and times when best able to succeed at a task Can list places and times when least able to succeed at a task
	Collaboration	Coordinates with study/class/work partners Contributes to group assignments Performs a variety of roles within a group
	Independence	Completes familiar tasks at school or work without assistance Able to find and use needed resources
	Engagement	Participates in a variety of organizations and/or groups Is motivated to learn Demonstrates initiative in learning Demonstrates initiative in getting involved in activities

Self-Direction

	Skill	Characteristics
	Communicates needs	Asks for help, asks for clarification Uses campus and community resources
	Anticipates needs	Recognizes and communicates personal support needs Learns from experiences Identifies possible problems or challenges Takes initiative to solve problems
	Advocates for own needs	Knows of and uses campus and workplace resources Speaks up for self Expresses desires Articulates accommodation needs Requests accommodations when necessary Identifies own achievements Engages in self-reflection, recognizing own improvement and growth.
	Accesses health care	Schedules preventative and necessary medical appointments Manages prescription medication Uses campus fitness centers
	Manages personal finances	Deposits and withdraws funds (ATM, checking account) Pays bills on time Safeguards money from others Budgets funds effectively

SECTION 2: SPECIFIC COLLEGE AND CAREER SKILLS GOAL SETTING

Instructions: Choose the specific College and Career Skills that you want to focus on this semester, concentrating on skill areas that relate to your specific course of study and academic or career goals. With the help of a coach, mentor or supervisor, list those skills and identify how you will learn the characteristics associated with this skill. You may want to explain where you will learn this skill at either the college or in the workplace.

Specific College or Career Skills	How you will learn this skill
Skill #1	
Skill #2	
Skill #3	
Skill #4	

SECTION 3: EVALUATION OF PERFORMANCE AND PROGRESS

Instructions: Please meet with your advisor at least 2 or more times each semester to review performance and progress and set new goals as needed. The first review meeting (Review 1) should take place during the first few weeks of the semester to assess your level of achievement and set goals. The next review (Review 2) should be scheduled at that meeting to review progress.

Specific College or Career Skills From Section 1	Goals
Skill #1 Review #1 Date: Review #2 Date:	
Skill #2 Review #1 Date: Review #2 Date:	
Skill #3 Review #1 Date: Review #2 Date:	
Skill #4 Review #1 Date: Review #2 Date:	

Appendix D:

Permission Pages

Permission to Use Table in Chapter 5

U.S. Department of Education
Betsy DeVos
Secretary

Office of Special Education and Rehabilitative Services
Mark Schultz
Delegated the duties of the Assistant Secretary for
Special Education and Rehabilitative Services

August 2020
Initially issued January 2017

Other than statutory and regulatory requirements included in the document, the contents of this guidance do not have the force and effect of law and are not meant to bind the public in any way. This document is intended only to provide clarity to the public regarding existing requirements under the law or agency policies.

To obtain copies of this report:

Visit: https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2020.pdf

Availability of Alternate Formats

On request, this publication is available in alternate formats, such as Braille, large print or audiotape. Requests should be submitted to the Alternate Format Center by calling 202-260-0852 or by contacting the 504 coordinator via email at **ofo_eeos@ed.gov.**

Permission to Use the Worksheet in Appendix C

Hi Kalindi.

I am glad you found the tool and would like to include it as a resource. You have our permission to do that.

Good luck with your project!

Cate

Cate Weir

(she, her, hers)

Program Director, Think College National Coordinating Center

Institute for Community Inclusion

University of Massachusetts Boston

603-848-4901

www.thinkcollege.net

Permission to Share the Financial Wellness Guide from National Down Syndrome Society

Hi Kalindi and Hailey,

Thank you for reaching out. We would be happy for you to share information about the financial wellness guide with families in your community. Please make sure when you mention the guide that you state it was produced by the National Down Syndrome Society in collaboration with Voya Cares®. Please let me know if you need anything else!

Best,
Colleen Hatcher

Senior Manager of Community Relations
National Down Syndrome Society
p: 202 751 6013
w: www.ndss.org e: chatcher@ndss.org