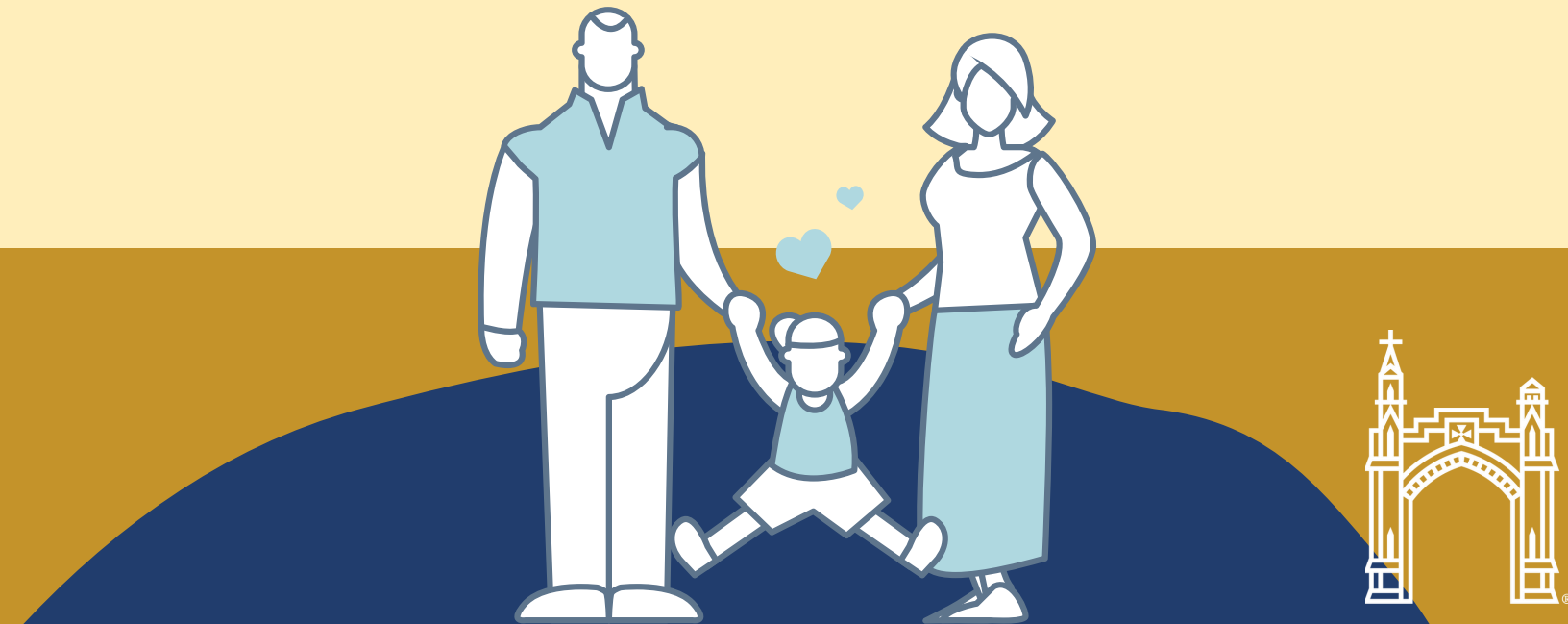
Caregiver Resources For People With Intellectual And/Or Developmental Disabilities (RAIDD Booklet)

Lena Conway, OTS



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This resource booklet is the intellectual property of Misericordia University and was developed by an occupational therapy graduate student as part of her capstone experience under the mentorship of Dr. Ariana Belles, OTD, OTR/L, CHT. This booklet takes an occupation-focused approach and was designed to support and educate caregivers of PWD. The aim of the booklet is to equip caregivers with practical strategies and valuable insights to navigate their role more effectively, foster meaningful engagement, and enhance the quality of life for both themselves and the individuals they support. This booklet is intended for informational purposes only and does not constitute medical advice. Always consult a qualified healthcare provider before making any health-related decisions. The author makes no guarantees about the accuracy, completeness, or reliability of the information provided. They are not responsible for any consequences, including injury or harm, resulting from the use or misuse of this content.

Note on Language: Language is continuously evolving, and the terminology used in this document reflects the author's knowledge at the time of writing but is subject to change. The term "people with disabilities" includes individuals with intellectual and/or developmental disabilities. The phrases "higher" and "lower functioning" are outdated and will instead be referred to as "high" and "low support needs." Additionally, "special needs" will not be used, as it is no longer considered appropriate. The majority of autistic individuals prefer identity-first language rather than person-first language; therefore, a variety of terms will be utilized to respectfully refer to autistic individuals.

This booklet has been created in accordance with the laws and regulations of the Commonwealth of Pennsylvania. Please note that laws and regulations may vary by state, and it is essential to refer to the specific rules governing the state in which you reside.

For any questions or concerns about this booklet, please reach out to conwayL1@misericordia.edu or abelles@misericordia.edu

Meet The Author



Hello! My name is Lena Conway and I am a graduate occupational therapy (OT) student at Misericordia University. I'm currently in the implementation phase of my capstone project, which focuses on supporting caregivers of individuals with disabilities. My project involves the creation of a resource booklet as well as hosting a resource fair to better assist caregivers to navigate their role of caring for people with disabilities across the lifespan. I am hopeful that this booklet will be a valuable tool for caregivers by offering information and support with their important role.

My passion for working with the disabled community began when I was eight years old through a program called Buddy Baseball. My father became the commissioner unexpectedly and I quickly immersed myself in the supportive environment. It was a place where people were celebrated, no matter their abilities. I began as a player and I gradually took on more leadership roles, while still promoting inclusion and helping others. This experience provided me with lifelong friendships as well as taught me the importance of inclusion. Being a part of a kind and caring community at a young age shaped who I am and how I view the world. Buddy Baseball confirmed my desire to dedicate my life to helping this underserved population.

Throughout high school and college, I continued to follow my passion through unified sports and a program aimed at fostering socialization among young adults with disabilities. Although I was proud to advocate and support this community, I also began to recognize the significant challenges individuals with disabilities and their families face. Many of my friends were also approaching the age where they would "age out" of the educational system, which caused stress and uncertainty for many of their families. The transition to adulthood, including planning for the future and finding stable jobs, often felt unclear. Information was not always easy to find, which added stress to an already challenging situation.

After discussing these challenges with family and friends, I developed the idea for this booklet as a way to assist caregivers in planning for the future of people/person with disabilities (PWD). My goal is to provide a free and accessible resource that can help to ease some of the uncertainty associated with navigating these important transitions as well as provide much needed guidance.

Purpose

There are limited resources available for individuals caring for PWD (Naidoo et al., 2017; Rabaey et al., 2021; Silaule et al., 2024; Smythe et al., 2020; Grigorovich et al., 2016). Current research has shown that clearer explanations and information about available opportunities can make a significant difference in caring for PWD (Papay & Bambara, 2014). This booklet will provide education on the role of OT and caregivers of PWD, various ways to plan for the future of the PWD, and how to optimize both caregivers and the PWD's quality of life. Through a comprehensive approach, caregivers will learn how their roles and responsibilities associated with taking care of PWD can be best supported.

Taking on the responsibility of caring for PWD can be overwhelming and challenging at times. This booklet also aims to create a sense of emotional support by providing information about healthy ways to manage stress and the importance of prioritizing your needs. It is important to always remember that you can not fill from an empty cup, meaning you must prioritize your own wellbeing before assisting others. This booklet will also briefly discuss self-care strategies to better support people with their caregiver roles and responsibilities. Through an evidence-based workbook, caregivers may feel more confident and empowered to provide better care and support for PWD. The resource booklet will help caregivers feel more knowledgeable about their specific situation and ultimately, help to reduce feelings of frustration and social isolation (Rabaey et al., 2021; Singogo et al., 2015).

OT is a healthcare profession that addresses many populations across the lifespan. OTs focus on engagement of meaningful activities, or occupations, to help individuals actively participate within their own lives. Regarding the role of caregivers, OT practitioners not only focus on the PWD's occupations, but also how their desired tasks can be included in the role of the caregiver. OTs are equipped to work with families and caregivers to assess their skills and ability to support the PWD and ultimately their well being. Education regarding the diagnosis, available community resources and services, and coping strategies related to activity participation, are all methods within the OT scope of practice. OT has been shown in the literature to be an effective way to better support caregivers of PWD. Through the use of a personal approach, OTs give people the opportunity to actively participate within their own care to increase their satisfaction with their overall therapy (Grigorovich et al., 2016; Naidoo et al., 2017; Rabaey et al., 2021; Smythe et al., 2020).

OTs can address PWD and caregivers in various settings including schools, hospitals, vocational programs, clinics, residential settings (ie. skilled nursing facilities), and other community-based settings (Haertl, K, 2014).

The broad term of “client” is now considered to include the person, organization, and population (American Occupational Therapy Association [AOTA], 2020). Therefore, an OT is able to address the patient’s physical, mental, and emotional needs as well as other individuals involved in their care, such as a caregiver, family member, or spouse. This is important to recognize because some caregivers and PWD may engage in co-occupations. A co-occupation is considered to be a meaningful activity to the PWD that is completed with two or more individuals and one that shares “a high level of physicality, emotionality, and intentionality” (AOTA, 2020, p. 9). Co-occupations may be essential in the daily lives of PWD, but they can also reduce the time caregivers have for their own important activities. Although occupational deprivation can manifest differently among caregivers, it can negatively impact many areas of their lives including employment, ability to complete self-care, sleep, coping challenges within the educational system, and limited personal leisure time (Bhopti et al., 2019; Dalvand et al., 2015; Halliwell et al., 2021). Managing occupations for both a PWD and yourself can be extremely challenging and can lead to a lack of physical and mental restoration (Halliwell et al., 2021). When caregivers are unable to feel satisfied with the completion of their own daily activities, feelings of stress and frustration can set in. With that being said, it is important to recognize the severity of not engaging in occupations that are personally meaningful.

Caregivers may also find it difficult to access community resources and opportunities for PWD, which can cause a lack of participation in meaningful occupations (Rabaey et al., 2021). Caregiver barriers to future planning can include a lack of knowledge regarding what is needed for PWD and where to obtain it, a lack of information increasing stress and frustration, difficulties navigating various services due to fragmentation, economic barriers that exist both individually and systemically, and policies that create additional challenges for caregivers (Silaule et al., 2024). Information to support caregivers is not readily available and the continual discrimination against this population can increase caregiver burden as well as challenges for the PWD (Silaule et al., 2024). Stigma surrounding PWD can also make it challenging for caregivers to access resources and find necessary help (Rabaey et al., 2021; Silaule et al., 2024). The inability to complete meaningful activities due to being in a marginalized population can negatively impact caregivers’ ability to care for PWD (Rabaey et al., 2021). Current research has shown that single mothers in rural areas can experience negative attitudes from community and family members causing feelings of abandonment and shame (Silaule et al., 2024). Mothers may also feel an increase in marginalization and isolation, which contributes to the unfair treatment of caregivers and PWD (Rabaey et al., 2021; Singogo et al., 2015). Stigma has been proven to have a negative effect on caregivers and their ability to provide care for PWD, making it important to target and address feelings of vulnerability within the community. PWD are a population that is more vulnerable to sexual, physical, and psychological abuse, making PWD more susceptible to being exploited (Naidoo et al., 2017).

Social marginalization can also lead to a lack of accessible educational and public resources in the community (Naidoo et al., 2017). Caregivers may also feel socially isolated and marginalized due to the stigma their loved one is facing (Naidoo et al., 2017). Overall, family caregivers are an overburdened and under-recognized group within our healthcare system, making community interventions necessary to better support caregivers of PWD (Charles et al., 2017).

Current best practice relating to people with intellectual and/or developmental disabilities stresses the importance of considering the individual's quality of life as well as personal preferences within their everyday lives. Quality of life has to do with personal satisfaction and well-being, as it relates to physical, mental, psychological, and emotional areas of one's life. Although quality of life is a broad focus area to consider, it is important to recognize that an individual's perception can be an important factor and determinant. An example of personalized care can be allowing PWD to have a say in their place of residence, use of money, and choices in daily activities and occupations (Haertl, 2014). Through the focus of "achieving health, well-being, and participation through engagement in occupation," OTs are able to address the growing needs of PWD and their caregivers (AOTA, 2014a, p. 4).

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1

Future Planning Options



Relevant Laws & Policies

Understanding various laws relating to people/person with disabilities (PWD) is essential to protect and promote equality among all people. Over the decades, there have been many laws and acts created to protect the wellbeing of PWD regarding housing, education, employment, and public accommodations and services. It is recommended that caregivers seek more in-depth information from outside sources, as thorough information regarding this topic is not covered within this booklet. Below is a general overview of several important laws relating to PWD and accessibility of various services and opportunities within society.

❶ Americans With Disabilities Act (ADA)

ADA was enacted in 1990 with the main purpose of prohibiting discrimination against PWD in employment, transportation, public accommodations, government activities, and communications (ADA, 2020). ADA is divided into five main titles:

- **Title I: Employment** - Employers must accommodate PWD in the workplace and not discriminate against employment or related opportunities, such as the hiring or termination process (ADA, 2020).
- **Title II: Public Services** - State and local government funded programs must be accessible to individuals with disabilities (ADA, 2020).
- **Title III: Public Accommodations** - Non-profit organizations and businesses must remove accessibility barriers, such as providing a wheelchair ramp (ADA, 2020).
- **Title IV: Telecommunications** - Equal television and telephone access for people with hearing and speech impairments (ADA, 2020).
- **Title V: Miscellaneous** - Unlawful practice and legal violations regarding individuals with disabilities (ADA, 2020).

❷ Fair Housing Act

The Fair Housing Act was enacted in 1968 and amended in 1988 with a goal of prohibiting housing discrimination on the basis of age, sex, race, color, religion, disability, national origin, and familial status. Housing considered in this act includes state and local government housing, federal housing receiving financial assistance, and private housing. This act also ensures house owners make reasonable exceptions to provide PWD an equal opportunity for housing (ADA, 2020).

❸ Individuals With Disabilities Education Act (IDEA)

For eligible children with disabilities, public schools must provide a “free appropriate public education in the least restrictive environment appropriate to their individual needs” (ADA, 2020, p.1). Based on the needs of the child with disabilities, the publicly funded school may be required to develop an individualized education plan (IEP) to best fit the needs of the individual. A knowledgeable team will then create the IEP in collaboration with the PWD and caregiver, with a review process annually. If the parents of the child disagree with the IEP, they have the ability to request a due process hearing or appeal the state agency’s decision, if applicable in the state in which they reside (ADA, 2020).

❹ Rehabilitation Act

The Rehabilitation Act prohibits discrimination against PWD who are in programs that are conducted by federal agencies or who are receiving federally funded assistance. Federal employment

and employment under federal contractors are also considered in this act. Although there are several sections included in this act, this booklet will only discuss Section 504, as it relates to discrimination against people with a qualifying disability. Individuals may not be denied benefits, excluded from, or subject to discrimination in any federally funded activity or program receiving federal financial assistance (ADA, 2020). Reference supplemental links at end of chapter for more information and clarity.



Legal Independence

For PWD, legal independence at the age of eighteen marks a transition where they can separate from their parents or caregivers, provided they demonstrate the necessary competence. This shift means that they are no longer under the control of others, allowing them to make their own choices and take responsibility for their actions. On the positive side, legal independence can empower PWD by granting them equal rights and fostering greater inclusion in society. However, the concept of independence for an eighteen-year-old with a disability can raise concerns for families. Many worry about whether their child is capable of making sound decisions independently and fear the potential legal consequences (Brown et al., 2017). Each caregiver should reference information on legal independence that is specific to the state in which they reside.

The 18th birthday of a child with special needs marks the beginning of significant changes regarding the benefits and services they can receive. In the United States, most children who turn 18 become adults in the eyes of the law, which means they are legally responsible for their choices and actions. If you or your child has been receiving various state and federal services, benefits, and accommodations, it's essential to understand what those changes are. We've put together the top five issues that are helpful for you to know. *This post was authored by SNA member Margaret A. Graham, Esq. of Pregenzer, Baysinger, Wideman & Sale PC. Margaret practices in the areas of elder law, specifically in representing individuals and families in the appointment of guardians and conservators for the elderly or disabled as both the petitioning attorney and Guardian ad Litem, estate planning, probate, and fiduciary litigation*[1].

[1] About this Article: We hope you find this article informative, but it is not legal advice. You should consult your own attorney, who can review your specific situation and account for variations in state law and local practices. Laws and regulations are constantly changing, so the longer it has been since an article was written, the greater the likelihood that the article might be out of date. SNA members focus on this complex, evolving area of law. To locate a member in your state, visit Find an Attorney. Reprinted with permission of the Special Needs Alliance – www.specialneedsalliance.org

Decision Making

Once an individual turns 18 or, in some states, 19, they are presumed to have the capacity and ability to make their own health care and financial decisions. This means that parents no longer have the authority to make these decisions for their child or even to be involved in these decisions without the express consent of their child. In some cases, a child may have sufficient capacity to execute a power of attorney (most frequently a parent) once they turn 18. The power of attorney is allowed to do things for the newly turned adult, such as apply for benefits, open a bank account, help the individual with their decision-making or make decisions on the individual's behalf when appropriate. Court involvement is not required to become a power of attorney but does require that the individual requesting one understands the document that outlines this arrangement.

If the individual does not have the capacity to execute a power of attorney, then a guardianship proceeding may be necessary. Court involvement is required to obtain guardianship. In most states, the court will decide if a person lacks the capacity to care for themselves or make decisions regarding their own care. Parents should not assume that their child cannot make their own decisions and should not assume that as the parent of a child with a disability, they will be able to act as they always have in making decisions. Instead, it is important to consult an experienced attorney to determine what is in the individual's best interest and the best way to offer protection and as much independence as possible.

Changes in Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a federal government program that provides cash assistance to low-income individuals who are disabled, blind, or elderly and have limited income (i.e., money earned from work, received from other sources, and receiving free food or shelter) and few assets. SSI is a cash program. Every eligible individual gets the same amount of money each month regardless of the nature of the qualifying disability, the level of their needs, and the city and state where they reside. SSI eligibility rules form the basis for most other government program rules.

For those 18 and over to be eligible for SSI, there must be a medically determinable physical or mental impairment (including an emotional or learning problem) that:

- Results in the inability to do any substantial gainful activity; and
- Can be expected to result in death; or
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

If your child received SSI benefits before their 18th birthday, you can expect the standards under which they receive them to change. Before 18, the Social Security Administration (SSA) attributes part of both parents' (legal guardians') income to their child's resources to determine their child's eligibility. Upon the child's 18th birthday, the parents' income is no longer considered when determining the means-based eligibility limits.

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Therefore, many people with disabilities who did not qualify as a minor will qualify for SSI as an adult because only the adult applicant's income and assets are being used to determine their financial eligibility.

Educational Transition

If your child is being educated through your state public school system, in most states, they will be working toward either receiving a diploma or certificate upon graduation. Beginning in 9th grade and throughout your child's time in high school, during your IEP meetings, you should be discussing *with* your child the best course of action to pursue. If you both determine that your child will pursue a diploma, they may then choose to pursue continuing education through college, university, or trade programs. Often these institutions can provide accommodations for students like in their IEP if the student qualifies.

If you and your child decide that they should pursue a high school certificate, depending upon their level of capacity and need, the child may be able to continue in a transitional program in their high school even *after* they complete their senior year. These programs typically focus on life skills, including financial literacy, social engagements, employment preparation, and similar activities. Most children in this program are permitted to remain in the program until the end of the school year in which they turn 22 years of age (or 21 in some states).

Finally, some children may choose to seek employment after high school. Your local Vocational Rehabilitation Services provider should also be involved in the IEP meeting and will be able to guide your child through the process of seeking employment.

Supports in Living Arrangements

Once a child with a disability turns 18, they may choose or qualify for different living arrangements depending on the services they already receive. For example, if your child is receiving therapy services at school, where will they receive these services once they transition out of school? This could be through a *Medicaid Waiver* or private insurance.

Qualification for respite services may look different as well. If your child is limited to a specific number of hours of care each week, the hours may be sufficient if your child is in school for much of the day. However, the hours may be insufficient if your child is no longer eligible for public education. Also, programs in your area may require participation at times that are not workable for your child if they continue to live at home. It is essential to understand all of the benefits and options available to your child before deciding living arrangements and services after they complete high school.

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Financial Protections

It is important to consider financial protections for a person with disabilities as early as possible. You do not need to wait until your child is close to turning 18 to start this process. You can begin protections by considering a special needs trust and updating your estate planning documents, so an inheritance does not terminate your child's governmental benefits. Other ways to protect your child's income and resources are through an ABLE account and a Representative Payee for Social Security. Once your child is no longer in the educational system, these two protections can become particularly helpful.

ABLE accounts allow an individual to maintain some income and resources above the amount typically allowed for recipients of governmental benefits to help them continue to receive those benefits. It can also allow your child the opportunity to have some financial independence and learn to manage their own finances without the risk of significant financial losses or abuse. There are limits on how much can be deposited into an ABLE account each year and on what the funds from the account can be used. ABLE accounts are also a good tool when used in combination with a Special Needs Trust to provide financial protection and independence for your child.

The Social Security Administration (SSA) will determine who will serve as the payee for your child's Social Security benefit. SSA may decide that your child is able to serve as their own payee or may appoint a Representative Payee for your child. This decision is made with the Social Security representative assigned to your child's application. It is important that a Representative Payee not commingle their assets and your child's Social Security Benefits. Therefore, a separate bank account in your child's name will be necessary for them to receive their benefits.

The top five changes we listed are meant to serve as a starting point in navigating your journey as an adult or parent of an adult with disabilities. For more information, please check out the resource links below or contact the *Special Needs Alliance* for help finding an attorney that can guide you.

- National Guardianship Association: https://www.guardianship.org/
- Social Security Administration, SSI information: https://www.ssa.gov/ssi/
- Medicaid – Link to State Profiles: https://www.medicaid.gov/state-overviews/state-profiles/index.html
- ABLE National Resource Center: https://www.ablenrc.org

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Decision Making

Supported Decision Making

Supported decision making for PWD is a growing movement that allows PWD to have control over their lives, which can help to positively affect their quality of life and overall well-being (Brown et al., 2017). The supported decision making model centers around PWD using their support system of family members, professionals, and trusted friends to provide them with information regarding the areas of discussion. Then the PWD is able to utilize that information and make their own educated decisions (Laurens et al., 2021). The three main areas of focus for supported decision making include enhancing a person's ability to make decisions, the environment and how it is supporting or hindering their decision-making ability, and what supports may be needed to best assist the PWD (Brown et al., 2017).

For PWD, it is extremely important to let the person have the ability to make or contribute to their own decisions. Although this can be challenging at times, it is important to remember that the decisions will impact their life so if they would like to be included, they should be a part of the process. Some ways to assist PWD with the decision making process can include simplifying information that is more complex, utilizing visual schedules or supports with routine tasks, implementing stress management techniques, or finding the just-right challenge to push the PWD enough but not to the point of frustration. Although these may be appropriate for some PWD, everyone is different and it is important to learn more about the PWD and what assist level they may need. Determining if the environment is supporting or hindering the PWD is another important aspect to decision making. For example, if the individual feels overwhelmed by the noise or lighting in the room, it may make it more challenging for them to focus and make sound decisions. It is important to always consider environmental factors and how that may positively or negatively impact the PWD. Lastly, it is important to consider what you can do as a caregiver to best support the PWD. Although supports will vary based on the needs of the individuals, some examples may include fidget toys for sensory regulation, flowcharts for visual simplification, and memory aids to ensure completion in a timely manner.

Supported decision making can be informal, such as people seeking advice from friends or family, or it can be formal. Many states have adopted statutes to formalize supported decision making through written agreements. Typically, a formal supported decision-making agreement will include:

- The PWD name and name of supporters
- The duration of the agreement (or specified no end date)
- The type of information that can be accessed by supporters (educational, medical, etc.) and
- Any other required documents to release information, such as HIPAA for medical information (Special Needs Alliance [SNA], n.d.)

Power of Attorney

A power of attorney is a formal document that provides legal authority for an individual to make decisions regarding another person's finances, medical care, or property. The requirements for a power of attorney varies in each state so it is important to look up additional requirements in the state the PWD and caregiver reside (SNA, n.d.). This information is also a general outline of the specifics of a power of attorney. It is recommended to reach out to a lawyer or expert in the field, as thorough information regarding this topic does not fall within OT expertise.

The purpose of a power of attorney is to appoint a designated individual to assist the PWD with decisions relating to physical or mental health, finances, or other decisions. In most cases, a power of attorney is effective immediately, meaning that the agent (person who is authorized by the principal to have ability to make decisions or take actions on behalf of the principal) is able to act on behalf of the principal (person who directs another person to act on their behalf) as soon as the power of attorney is executed. There are several types of power of attorneys including a durable power of attorney, which continues to be valid if the principal becomes either partially or fully incapacitated. A power of attorney that is not durable means that the document only authorizes the agent to make decisions on behalf of the principal when they are able to direct or authorize the agent's actions. Therefore, if the principal becomes incapacitated, the agent will lose the ability to make decisions on the principal's behalf (Disability Rights Pennsylvania [DRP], 2018a).

For a power of attorney to be valid …

- The principal must have capacity;
- It must be in writing;
- It must be signed by the principal; and,
- It must be notarized and may require a witness (SNA, n.d.).

It is important to consider all of the nuances and legalities surrounding a power of attorney and how it will impact you and the PWD. Therefore, it is recommended to seek legal advice from an expert in the field, such as an estate planning attorney, elder law attorney, certified financial planners, etcetera.

Guardianship

Guardianship in the context of disability has to do with a PWD turning eighteen and them having the legal ability to make their own decisions. Guardianship is a way to appoint someone to make decisions on behalf of a PWD who lacks the ability or capacity to make their own decisions. It is important to understand that having legal guardianship over an individual may not be in the best interest of the PWD. This information is also a general outline of the legalities surrounding guardianship. It is recommended to reach out to a lawyer or expert in the field, as thorough information regarding this topic does not fall within the OT scope of practice.

Typically, guardianship laws are created to allow for incapacitated individuals to be a part of the decision making process as much as possible. Although definitions may vary by state, within Pennsylvania, an incapacitated adult refers to an adult whose "ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that [they are] partially or totally unable to manage [their] financial resources or to meet essential requirements for [their] physical health and safety" (DRP, 2018b, pp. 4-5).

Guardianship laws also attempt to help and support individuals with meeting basic needs relating to health and safety, protection of their own rights, financial management, and maximizing their abilities. Guardianship is meant to be utilized in the least restrictive way to support PWD across the lifespan (DRP, 2018b). There are many nuances to guardianship and therefore, it is important to fully understand the pros and cons associated with the formality prior to determining what is best for your personal situation. Caregivers may consider seeking guardianship over a PWD if they are unable to make informed decisions about their own health, personal care, or finances due to a physical or cognitive impairment. Guardianship may also be considered if the PWD is at risk of being exploited, neglected, abused, or taken advantage of. Additionally, guardianship may be sought out if no less restrictive alternatives, such as a power of attorney, are available (DRP, 2018b).

Drawbacks of seeking out guardianship can include timely involvement in the court system, loss of autonomy for the PWD, and risk for potential abuse. First, guardianship requires a court order which can be a timely and expensive process. Guardianship can also negatively impact a PWD's autonomy due to removing their ability to make decisions independently. Lastly, guardianship can be abused if not supervised properly. There is an increased risk of exploitation by the legal guardian so it is vital that the chosen guardian will always keep the PWD's best interest in mind (DRP, 2018b).

Transition Planning

Although the transitional phase may look different for PWD, this period will likely occur between the ages of eighteen to twenty-six, when the support services within the educational system can no longer be utilized. The transition period refers to the progression from a more supportive and enriched environment, such as family life, to a more independent adult life. Three different types of transitions concerning people with intellectual disabilities have been highlighted in the literature - bureautic, family life, and status transition (Kanthasamy et al., 2024).

- Bureautic transition has to do with the shift between various supportive professional services for people with intellectual disability and their families. When considering the transition out of the formal education system, this transitional period relates to the integration into community-based services.

Family caregivers are then likely to have one of four relationships with the adult-service professionals who are assisting the PWD with the transition - surrender, abandonment, engagement, and assimilation. Surrender has to do with heavily relying on professional opinions, causing the caregivers to somewhat blindly follow the professional advice without a full understanding of what they are recommending. This can cause caregivers to take on a more dependent and passive role in the transition process, which can ultimately negatively impact the quality of life of the PWD. Abandonment relating to the transitional process is when a parent or caregiver feels that the professionals are not providing either enough information or placement opportunities to the PWD, causing the caregiver to feel that the care of their child is falling solely on them. This can be an extremely stressful feeling for the caregiver, however it is important to recognize that resources are available to support you and the PWD, they may just be located in an alternative place. Engagement with the transitional professional refers to creating a collaborative partnership in which both parties share responsibilities to ensure the optimal transition for the PWD. With this professional relationship, both the caregiver and professionals are able to create a healthy working relationship while also keeping the best interest of the PWD in mind. Lastly, assimilation relates to parents or caregivers becoming gradually more involved in the decision making process of the PWD's transition. It can be challenging to take on the responsibility of planning for a PWD's future. Therefore, it is important to discuss with the PWD about what they would like to do after high school and utilize resources in your community to best support you and the PWD (Kanthasamy et al., 2024).

Family life transition has to do with the changes in both daily routines and responsibilities that result from the PWD completing their educational program. School programs provide a structured schedule for PWD and with the transition into community-based services, the schedule of the PWD will likely be unpredictable and at times unreliable. This transitional phase for caregivers can be time consuming and frustrating, making it vital for caregivers to be flexible with the new schedule and familial role changes (Kanthasamy et al., 2024).

Status transition is when a PWD transitions from childhood to adulthood through achieving milestones, such as turning 21, obtaining a job within the community, or moving out of a family home to live a more independent life . Within this transitional phase, the level of supervision of PWD can significantly change, causing caregivers to have concerns regarding the vulnerability of the PWD. Although this can be a significant change for the caregivers and their role, all people should have the ability to try new opportunities, despite their physical or mental capabilities (Kanthasamy et al., 2024).



Permanency Planning

The life expectancy of adults with intellectual disabilities is increasing towards the life expectancy of the general population but this aging is not considered to be healthy (Coyle et al., 2016; Lin et al., 2016). The unhealthy aging of individuals with intellectual disabilities is likely due to ageism and negative attitudes surrounding old age, lack of best possible health and social care, diagnostic overshadowing, a lack of knowledge surrounding this population, and healthcare disparities (Lin et al., 2016). Both the government and disability services need to acknowledge the growing needs of PWD, such as their advancing age and increasing care needs related to their aging caregivers (Lin et al., 2016). Family caregivers are likely providing "emotional, informational, and practical support" to allow for a successful future for their loved one (Lin et al., 2016, p. 267). Permanency planning for PWD has to do with long-term planning to ensure stable and consistent care throughout the entirety of their lives. Permanency planning aims to provide a plan for continued care, services, and support throughout the transitional periods of life, such as the transition into adulthood and older adulthood. Many contributions and aspects of services can make it challenging for caregivers to adequately plan for the future of PWD. Coordinating services at multiple levels to ensure continuity and collaboration among all levels of care can help to provide optimal service coordination to PWD and their caregivers (Hill, 2012). It is also important for caregivers to understand the purpose and roles of services, such as respite programs, home-assistant programs, transportation supports within the community, and recreational programs. Having a better understanding of supportive services available can help to better assist caregivers and ultimately PWD.

Optimizing Future Planning

Importance of Health Management

Due to the limited access of resources within the community, PWD are more likely to have lived in poverty, have higher levels of obesity due to easy access to unhealthy foods, and participate in less physical activity when compared to the general population. Providing PWD with resources to promote better health outcomes is necessary to optimize their quality of life and overall well-being. PWD are considered to be a more vulnerable population to physical conditions, such as diabetes or asthma, which can increase their health risk. Optimal disease management includes early detection through screenings as well as preventative health programs. As a caregiver, you can ask the PWD's primary care doctor about healthcare screenings and opportunities in the community to optimize physical and mental health. You can also find and utilize local community resources, such as senior centers, town halls, religious gathering centers, libraries, and mentorship programs to promote health management for PWD (Liao et al., 2021).

Ableism, which is when people give privilege to able-bodied individuals, can also affect PWD access and experience with health services related to reproductive health and well-being (Biggs et al., 2023). Although ableism and reproductive health can look vastly different depending on the individual and their specific needs, some examples can include "lack of health care practitioner training on caring for people with disabilities, disability stigma, inaccessible health care facilities, nonexistent adaptive equipment and skilled language interpreters, and overall substandard quality of care" (Biggs et al., 2023, p. 2). Although intervention strategies will vary based on the specific individual, occupational therapists are able to address reproductive health concerns among PWD by providing education on contraceptives, menstrual hygiene, and stigma surrounding sexuality, adaptive equipment and tools for menstrual care (period underwear, modified menstrual cups), safe and comfortable positioning, and education on the importance of routine healthcare assessments. For more information on reproductive health management and intimacy for PWD, refer to Chapter 5.

Adults with intellectual and/or developmental disabilities (IDD) face health inequities not solely due to their medical diagnosis but also because of social factors, including reduced income, lack of education, and social isolation, and environmental factors such as transportation barriers and lack of access to resources and providers (Williamson et al., 2020). Within the current literature, community-based resources have supported caregivers of PWD as well as individuals with IDD by increasing self-efficacy and enhancing their overall health (Gitlin et al., 2023; Grigorovich et al., 2016, Smythe et al., 2020; Williamson et al., 2020). Building self-efficacy for PWD is important for making them feel more comfortable with making life decisions, navigating various obstacles, and overcoming challenges that arise within everyday life.

Barriers to Future Planning

Although there are resources available to better address the nuances of creating a future plan for a PWD, barriers may arise. The literature has highlighted "emotional demands, inertia, lack of information, lack of communication among family members, support needs of individuals with IDD, conflicts between individuals with IDD and their family members, siblings balancing their own lives, and systemic barriers" as obstacles that may arise when planning for the future of a PWD (Lee & Burke, 2020, pp. 101-103). Creating a care plan can be emotionally demanding for the caregiver, which can cause increased uncertainty, stress, loneliness, and caregiver burden. Due to the challenges of planning, caregivers may experience one or more of these feelings, highlighting the importance of taking care of yourself. Practicing stress management techniques, educating yourself on available resources, developing a support network, and prioritizing your own self-care can all help to make the planning process more manageable. Inertia refers to caregivers and PWD believing that it is too early in the process

to begin worrying about planning. Although siblings and caregivers may think that long-term planning is not necessary, it is important to start the process early because applications for trusts, housings, and financial assistance can take substantial amounts of time. The lack of information among family members and caregivers is another barrier to executing an appropriate plan for the future. Research has highlighted that there is an absence of clear information regarding financial, legal, and post-school options, and employment for caregivers of PWD. Although resources do exist, it is hard to locate tools as well as know where to find information. That is why it is important to consult an expert in the field, such as a transition specialist, occupational therapist, or case manager, to best support you with the planning process. Being able to locate and utilize necessary resources to optimize planning outcomes is important, however not communicating this information among family members can create an additional barrier. Ensuring that all family members are on the same page is an important consideration, as the needs of the PWD may change. Recent literature has shown that families often assume that the caregiving responsibilities will "fall to the siblings of individuals with IDD [intellectual and/or developmental disabilities]...however, parents often did not discuss planning with siblings" (Lee & Burke, 2020, p. 102). The lack of communication between parents and siblings may be related to not wanting to "burden" their offspring, however it is important to have open lines of communication to ensure all parties are on the same page regarding the PWDs care (Lee & Burke, 2020, p. 102).

Conflict among family members and the PWD can also be a barrier to successful long-term planning. A common concern among this population is PWD not having enough control to make their own decisions throughout their lives. This can be problematic as families believe they are doing the best they can for the PWD, however the individual wants more control over their lives. Although caregivers may play an important role in the care and planning process of a PWD, it is always important to listen to the PWD as well as consider their viewpoints. Siblings having to balance their own lives is another barrier for the future planning of PWD. For PWD whose parents have passed away, siblings may be overseeing their care and planning for the future, however having families of their own, can make it challenging to balance everything within their life. Having a demanding job, children to care for, and other life stressors can make it difficult to prioritize proper planning. Lastly, systemic barriers such as a lack of resources, experts in the field, funding, and difficulty with navigating the system can also contribute to ineffective long-term planning.

Interventions to Facilitate Future Planning

To better support caregivers with the future planning of a PWD, there are trainings, programs, and tools that have been created and deemed effective. Below are several caregiver training programs and resources:

- ***The Quality Living 10-Year Plan*** aims to "empower and resource carers and people with disability to proactively plan for how they can optimize their quality of life over the next 10 years" (Craig & Cartwright, 2015, p. 303). This program included information sessions, workshops, as well as an intensive training program. The two information sessions inform PWD and their caregivers on the importance of planning for the future and executing the plan effectively. Following the information sessions were eight workshops where PWD and caregivers filled out the "Futures Plan" and "Personal Portrait" documents. The last phase of the program included training for caregivers from expert staff, to best support them with executing the care plan. Although this is a relatively new program that has only been run several times, caregivers can utilize these resources to better support PWD with future planning (Craig & Cartwright, 2015). For more information, refer to The 10-Year Plan for Quality Living for People with Disabilities and their carers under supplemental links at the end of this chapter.

- ***Transitioning Together*** is "an 8-week program designed to reduce family distress and improve social functioning for adolescents" with high functioning autism spectrum disorder (ASD) (DaWalt et al., 2018, p. 251). The program findings showed significant improvements regarding parental depressive symptoms and problem solving skills as well as socialization skills among the participants with ASD (DaWalt et al., 2018). The program consisted of two "individual family joining sessions, 8 weekly parent and teen group sessions, and ongoing resources and referrals" (DaWalt et al., 2018, 255). The joining sessions are meant to build rapport and better understand family goals through various activities and the weekly group sessions were to educate parents and adolescents with ASD on various skills. The parent group aimed to help with problem solving skills, whereas the adolescent group incorporated learning activities to increase socialization and problem-solving skills. Overall, the findings of the program suggest benefits on caregiver well-being, relationships between the caregiver and adolescent, as well as social outcomes for the individual with ASD (DaWalt et al., 2018). For more information on this program, refer to the supplemental links at the end of this chapter. Currently, The Boston Medical Center is recruiting participants for a research study implementing this program so if you are interested, refer to that link at the end of this chapter.

- ***The Future is Now*** is a curriculum and training manual that addresses people with developmental disabilities and their families by encouraging communication and information to best support joint

future planning (DeBrine et al., 2009). The goal of this curriculum is "to have families prepare a letter of intent that describes their relative's desired future living arrangement, community role, and lifestyle preferences, and specifies the available resources, needed supports, and action steps to achieve these outcomes" (DeBrine et al., 2009, p. 1). The training consists of five two and a half hour sessions that include breakout training parts for both caregivers and people with developmental disabilities. Research has shown that families who participated in this training "were more likely to prepare a special needs trust and to initiate planning for future living arrangements" (DeBrine et al., 2009, p. 1). The training also significantly reduced feelings of caregiver burden and promoted autonomy among people with developmental disabilities. The training manual was updated in 2009 and now contains "instructions for planning the training, facilitator's guides, workbooks for families and people with disabilities, and assessment tools along with a CD-ROM (DeBrine et al., 2009, p. 1; Heller & Caldwell, 2006). For more information on the training manual or curriculum, please refer to the supplemental links at the end of this chapter.

- ***Preparing for the Future: The Lifetime Assistance Program of Arc Greater Twin Cities*** is an initiative planning process with a website that "provides reliable information and practical assistance to families and individuals with I/DD on areas such as person-centered planning, decision-making, housing options, financial planning, establishing daily activities, and making social connections" (Roehl & Sedlezky, n.d., p. 1). The website also provides information for professionals, family, and friends on how to best support PWD (Roehl & Sedlezky, n.d.). Webinars are also offered for professional development (contact futureplanning@thearc.org for more information on additional resources and trainings). For more information about what this program has to offer caregivers with future planning resources, please refer to the supplemental materials at the end of this chapter.
- **The Institute for Community Integration** discusses many resources and tools to better support caregivers with future planning. For more information about the many programs and resources, please refer to the supplemental materials at the end of this chapter.
- **The Sibling Leadership Network** also offers a variety of resources for adult siblings who are assisting PWD with future planning, finances, caregiving, death and end of life care, grief and loss, self-care, and who may identify in the Black, Indigenous, and Other People of Color (BIPOC) community (Sibling Leadership Network, 2025). For more information, refer to the supplemental links at the end of this chapter.

As a caregiver, it is important to keep an open mind about new resources, programs, training, or opportunities that have the potential to benefit you and the person you care for. Research has shown that parents who participated in future planning interventions had "increased knowledge

and access to formal resources for planning, … reduced caregiving stress" and depressive symptoms, increased competency and problem-solving abilities, as well as new ways to meet parents in similar situations (Lee & Burke, 2020, p. 103). Research has also shown that caregivers were not the only population positively affected by these future planning interventions. PWD had "greater access to out-of-home activities, extension of supportive networks, skill development, increased self-determination skills, and attention to neglected health issues" (Lee & Burke, 2020, p. 103). This allowed for increased health outcomes among PWD, highlighting the importance of beginning the process of future planning early rather than later. Although some of these programs and training may not directly discuss the importance of long-term planning for a PWD, the skills and education provided can help to better support caregivers with their role in the management of care of a PWD (Lee & Burke, 2020.



Supplemental Links



DISABILITY RIGHTS GUIDE:

HTTPS://WWW.ADA.GOV/RESOURCES/DISABILITY-RIGHTS-GUIDE/

NATIONAL GUARDIANSHIP ASSOCIATION:

HTTPS://WWW.GUARDIANSHIP.ORG/

SOCIAL SECURITY ADMINISTRATION, SSI INFORMATION:

HTTPS://WWW.SSA.GOV/SSI/

MEDICAID – LINK TO STATE PROFILES:

HTTPS://WWW.MEDICAID.GOV/STATE-OVERVIEWS/STATE-PROFILES/INDEX.HTML

ABLE NATIONAL RESOURCE CENTER:

HTTPS://WWW.ABLENRC.ORG

SPECIAL NEEDS ALLIANCE (ATTORNEY INFORMATION):

HTTPS://WWW.SPECIALNEEDSALLIANCE.ORG/

THE 10-YEAR PLAN FOR QUALITY LIVING FOR PEOPLE WITH DISABILITIES AND THEIR CARERS (APPENDIX A AND B):

HTTPS://WWW.RESEARCHGATE.NET/PUBLICATION/284281535_A_10-YEAR_PLAN_FOR_QUALITY_LIVING_FOR_PEOPLE_WITH_DISABILITIES_AND_THEIR_CARERS

Supplemental Links

TRANSITIONING TOGETHER PROGRAM (TABLE 2- PARENT SESSION AND GOALS):
HTTPS://PMC.NCBI.NLM.NIH.GOV/ARTICLES/PMC5762411/#FN-GROUP1

TRANSITIONING TOGETHER PROGRAM:
HTTPS://WWW.AUTISMSPEAKS.ORG/NODE/160534

TRANSITIONING TOGETHER PROGRAM RECRUITMENT BOSTON MEDICAL CENTER: HTTPS://WWW.BMC.ORG/AUTISM-TRANSITION-STUDY

THE FUTURE IS NOW CURRICULUM INFORMATION: THE COST FOR A SOFTCOVER OF THE MANUAL IS $80 PLUS SHIPPING AND HANDLING (EMAIL RRTCADD@UIC.EDU FOR PURCHASING INFORMATION):
HTTPS://PUBLICATIONS.ICI.UMN.EDU/IMPACT/23-1/THE-FUTURE-IS-NOW-TRAINING-INDIVIDUALS-WITH-DISABILITIES-AND-FAMILIES-IN-FUTURE-PLANNING

PREPARING FOR THE FUTURE- THE LIFETIME ASSISTANCE PROGRAM OF ARC GREATER TWIN CITIES INFORMATION:
HTTPS://PUBLICATIONS.ICI.UMN.EDU/IMPACT/23-1/PREPARING-FOR-THE-FUTURE-THE-LIFETIME-ASSISTANCE-PROGRAM-OF-ARC-GREATER-TWIN-CITIES

Supplemental Links

PREPARING FOR THE FUTURE: THE LIFETIME ASSISTANCE PROGRAM OF ARC GREATER TWIN CITIES INFORMATION:
HTTPS://PUBLICATIONS.ICI.UMN.EDU/IMPACT/23-1/PREPARING-FOR-THE-FUTURE-THE-LIFETIME-ASSISTANCE-PROGRAM-OF-ARC-GREATER-TWIN-CITIES

THE ARC PLANNING FOR THE FUTURE RESOURCES:
HTTPS://ARCMINNESOTA.ORG/WP-CONTENT/UPLOADS/2022/03/FREE-RESOURCES-FOCUS-ON-THE-FUTURE.PDF

THE ARC FUTURE PLANNING FOR PWD POWERPOINT PRESENTATION:
HTTPS://WWW.ADVANCINGSTATES.ORG/SITES/DEFAULT/FILES/A-11%2OFUTURE%2OPLANNING%2OARC%2OAIRS%2OPRESENTATION.PDF

THE ARC CENTER FOR FUTURE PLANNING HOMEPAGE:
HTTPS://FUTUREPLANNING.THEARC.ORG/

INSTITUTE FOR COMMUNITY INTEGRATION (ALL PROGRAMS AND MATERIALS ON LEFT-HAND SIDE):
HTTPS://PUBLICATIONS.ICI.UMN.EDU/IMPACT/23-1/MAKE-YOUR-VOICE-HEARD-UNTIL-THE-VERY-END

Supplemental Links

SIBLING LEADERSHIP NETWORK (ADULT SIBLING RESOURCES):

HTTPS://SIBLINGLEADERSHIP.ORG/RESOURCES/RESOURCES-FOR-ADULT-SIBLINGS/FUTURE-PLANNING/

THE ARC HOUSING INFORMATION:

HTTPS://THEARC.ORG/POLICY-ADVOCACY/HOUSING/

2

Transition From School To Work



Transitional Challenges

Addressing Transition & Associated Challenges

The transition of people/person with disabilities (PWD) from high school to adulthood is a critical focus area to consider to better support PWD across the lifespan. The focus on transitional periods has been growing and evolving, however more resources and services are needed to address people of all abilities. Transition services were authorized by The Individuals with Disabilities Education Act (IDEA), which was reauthorized in 2004. The reauthorization of IDEA made it so PWD must have transition planning in place prior to them turning 16 years of age. This reauthorization also aligns with the No Child Left Behind Act of 2001, which has to do with states holding school systems accountable for how PWD "perform on standards-based assessments and postschool outcomes" (Wehman, 2013, p. 60.) These legal efforts in combination with recent federal publications allowed for more detail-driven goals for transitional services, which should also be included in the individualized education plan (IEP). Having more specific guidelines for supported transition has allowed PWD to have more assistance with their transition from the school system to adulthood (Wehman, 2013).

Challenges can arise in the transitional period, as it can be multifaceted based on the needs and desires of the PWD. Challenges can also arise, due to mental health needs, long-term conditions, or life-limiting diagnoses (Medforth & Boyle, 2023). Recent research has found that monitoring treatments of chronic conditions, identifying effective health promotion strategies, addressing health needs, developing health and wellness programs, and improving access to general specialized programs can help to reduce health disparities among this population (Anderson et al., 2013). Implementing these strategies into personalized transition planning may help to better support PWD with the transition from school to adulthood as well as help to ease caregiver stress. It is also important to consider that PWD should be provided with equal opportunities to interact with their teachers and peers. Having high expectations for PWD can help teachers and caregivers to have greater access to inclusive activities and opportunities that can help to improve their ability to adjust to new environments (Wehman et al., 2013). Assisting PWD in school classrooms is the new expected standard, which helps to promote inclusivity and the development of necessary life skills for the future, such as financial literacy. It is now known that "students will not develop competency… when excluded" (Wehman et al., 2013, p. 62).

Caregiver and family support has been found to play a pivotal role in the transition process of PWD. Due to the potential complex needs of individuals with intellectual and/or developmental disabilities (IDD), caregivers commonly need to assist with activities of daily living (bathing, dressing, grooming) and instrumental activities of daily living (feeding, shopping, cooking, and medication management) (Lindstrom et al., 2011). Due to the continued need to support individuals with IDD, family caregivers can easily become overburdened. Family caregivers of seniors with complex needs are an important yet overlooked group within healthcare that continually faces caregiver burden and stress (Charles et al., 2017). Because of the individualized nature of caring for individuals with IDD, caregivers require multifaceted support to continually assist a PWD. The care required will depend on the setting the individual is in, the family structure and geographical location, as well as the unique and personalized needs of the individual (Charles et al., 2017). Regarding the transition process, caregivers may find themselves responsible for understanding what opportunities the school system provides, what employment options are available, and continually advocating for the PWD to receive support throughout the transition process. A caregiver who understands the rights of the PWD has a significant advantage over someone who is unaware of what services are readily available (Lindstrom et al., 2011).

The Office of Vocational Rehabilitation (OVR) can be a good resource for PWD and their families to navigate available employment and educational opportunities. Typically, a career goal will be discussed, and services will then be provided based on the PWD's overall need (Disability Rights Pennsylvania [DRP], 2018c). Although this can look different for each person, some examples of services can include "counseling, job assessments, training and education, job placement, and other support services" to promote functional independence (DRP, 2018c, p. 9). For more information regarding OVR and if the services are right for you, please reference OVR's website at the end of the chapter under supplemental links.

Other transitional services that can help ease stress among PWD and their caregivers can include instructional training, related service information, life skill training, community resource experiences, and employment training (DRP, 2018c). This is not an extensive list of transitional services, and it is recommended that you consult your PWD's IEP team to learn more about available services and resources specific to your personal needs.

Day Habilitation

What is it?

Day habilitation focuses on building "community living skills of people with IDD by increasing their capacity to perform activities of daily living" (Friedman, 2016, p. 245). Day habilitation programs can occur in various areas within the community, except for at the PWD's area of residence (Inclusa, 2021). A person-centered plan can allow for the incorporation of day habilitation services to better support the PWD as well as include therapy that may be beneficial to the individual, such as physical, occupational, or speech therapy (Inclusa, 2021). With the focus of increasing independence among PWD through various skill development, the goal is to better support them with integration into a community setting (Gerken & Baumgartner, 2023). Although day habilitation programs can offer a structured routine with personalized support and opportunities for socialization, "there is no baseline for programs to adhere to as the United States lacks federal rules and regulations for day hab[ilitation] programs" (Gerken & Baumgartner, 2023, p. 51). This causes variations of services between states, which can result in a lack of comprehensive services for PWD. One of the main critiques of day habilitation programs is that they are not socially integrated, which is not the current best practice for PWD (Friedman, 2016). Day habilitation programs are also less cost-effective when compared to more integrated programs (Friedman, 2016). Community-based nonwork programs have also been growing in popularity, however community integration can be limited due to disability-specific programs occurring within the community (Friedman, 2016). Although the programs may be run within a community-based setting, if individuals are not interacting with members of the community, the socialization aspect is somewhat lost. There is also literature being published that supports that nonwork programs are shifting attention away from employment among the disabled community (Friedman, 2016). Some agencies are even beginning to consider community-based nonwork programs as more of an alternative to work than a supplement (Friedman, 2016). While day habilitation and community-based nonwork programs offer both benefits and challenges, it's essential to prioritize what's best for the PWD and take their unique circumstances into account.

Person-Centered Focus

Incorporating the interests of the PWD is crucial to making nonwork or habilitation programs more meaningful and effective, as it aligns with their preferences and desires. The belief that incorporating special interests into employment leads to limited engagement and participation for PWD is incorrect. In reality, a strengths-based approach recognizes and leverages the interests of people with disabilities, enhancing both their involvement and performance. Incorporating special interest areas into transition planning can include a four-step process to identify and improve skill areas within the educational system and prior to employment (Bross & Travers, 2017).

❶ Preferance Assessments

- The first step of the skill identification process is to use preference assessments to identify special interest areas of the PWD. Professionals within the school district, such as occupational therapists (OTs), can use "open-ended questions, questionnaires, rank-ordering activities, paired-choice (i.e., forced-choice), assessments, or ecological observations" to learn more about the individual's preferences (Bross & Travers, 2017, p. 76). Utilizing more individuals within the identification process can also allow for more information to be gathered, which can help to narrow down interest areas (Bross & Travers, 2017).

❷ School Resoures & Personal Interest

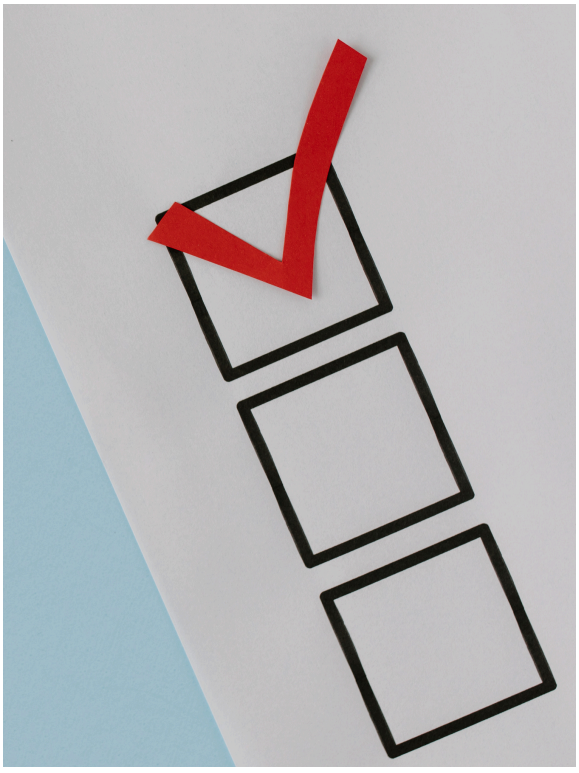
- The second step has to do with determining what people, experiences, and locations within the school environment align with the special interests of the PWD. This can be done through surveying the school environment and asking teachers, parents, friends, and family members of the PWD about possible job training opportunities that align with their specific interests areas (Bross & Travers, 2017).

❸ Special Interest Plan

- The third step is having the special education teacher or educational team create a plan that incorporates the identified special interests into meaningful activities to help generalize various skills. The Special Interest Area (SIA) Planning Form can be included in the IEP and transition plan by including the student's daily schedule, goals, and training of special interest skills (Bross & Travers, 2017). For more information on the SIA Planning Form, refer to the supplemental materials at the end of this chapter.

❹ Evaluation

- The fourth and final step is evaluating if the special interest focused interventions were effective for the PWD. Data collection should occur by the special education teachers or the educational team, to determine if the instruction provided was effective. Progress monitoring can also be utilized by defining the target skill, determining how the PWD could use the target skill before and after the intervention, and data collection to help draw a conclusion regarding the student's progress and what other supports may be needed (Bross & Travers, 2017).



Transition Across The Lifespan

According to C. Marfisi [2], transition through the lifespan can be categorized into three main areas of transition: adolescence, adulthood, and older adulthood. When considering adolescence with disabilities, it is important to remember that all individuals are growing and developing in different ways. The only constant within an adolescent's life is change, so it is important that caregivers take time to understand the PWD as well as provide empathy towards them. This then allows for the PWD to feel more comfortable with vocalizing their questions and concerns. It is also important to remember that PWD will likely have the same needs and desires as their able-bodied peers, with the main difference being that parents or caregivers may be too helpful or overprotective. This can cause a shift in the relationship and resistance to form, due to the PWD wanting the same opportunities as their able-bodied peers. PWD may also have more issues to consider, such as the transition out of the school system and the accessibility not aligning with their desires. Therefore, it is always important to include the PWD in these decisions, as the plan will impact their life so they should have the ultimate say (C. Marfisi, personal communication, January 28, 2025).

With the transition to adulthood, PWD who are higher functioning are commonly concerned with employment opportunities as well as how they are going to be able to live on their own. Although the individual may still require some assistance from their family or caregivers, they will likely want to be seen as being capable of living on their own. Home health agencies are an option to support PWD with daily living skills, however some agencies may be better equipped to work with someone with physical disabilities when compared to others. Adulthood for PWD can also be challenging if the individual would like to pursue partnerships, such as marriage. Challenges can arise when living within a marriage, such as wanting to start a family. A PWD should be encouraged to have open conversations with their partner about being married to someone with a disability as well as parenthood, if that is desired in the future (C. Marfisi, personal communication, January 28, 2025). For more information on relationship building and intimacy, please refer to Chapter 5.

The transition to older adulthood can be challenging due to the multi-faceted nature of aging and the potential new needs of the PWD. Depending on the PWD, they may or may not want assistance from their family. Some families may be willing to provide care, whereas others may feel that they did not sign up for a life committed to caregiving. It is important to remember that there is no right or wrong answer to this situation and that people may hold different opinions on the situation. Regarding various living options, skilled nursing facilities may be an option, however the PWD may not desire this outcome. If the PWD desires to live on their own, home health services may be a possibility, however these services can be unreliable, leaving the PWD vulnerable (C. Marfisi, personal communication, January 28, 2025). For more information on future living arrangements, please refer to Chapter 6.

[2] Carol Marfisi has her masters degree in rehabilitation counseling in education. She has taught at Temple University for 22 years in disability rights and history and has been an active disability rights advocate. Verbal permission was given to utilize this information.

Although smooth transitions for a PWD will vary depending on their interests, values, and goals, several aspects can help to facilitate a better transition such as a strengths-based approach, incorporating meaningful assessments, maintaining high expectations, and viewing the process from multiple perspectives. First, as stated previously, it is important to always consider the strengths of the individual and how they would like to utilize those strengths to best support them throughout their life. Whether that is within employment, recreational opportunities, or life skill programs, the PWD is more likely to participate in a transition plan that aligns with their interests. Meaningful and relevant assessments can also be utilized by the transition team to better understand a PWD with more severe disabilities with what their strengths and weaknesses are as well as how they can use those strengths throughout their life. With any PWD, it is important to have high expectations for their future, despite their possible challenges. All individuals are different and dwelling on what they are unable to do can lead to a more negative outlook on life as well as negatively impact their quality of life. You may be surprised by how much the person you are caring for is able to do! Lastly, it is important to consider the transition for the PWD from multiple perspectives, as people who are less knowledgeable about the situation may provide inappropriate suggestions (Carter et al., 2014).



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Supplemental Links

THE SPECIAL INTEREST AREA PLANNING FORM INFORMATION:

HTTPS://RESEARCH.EBSCO.COM/C/GJUHFO/VIEWER/PDF/AZSQJO5SLF?ROUTE=DETAILS&AUTH-CALLID=F9C8DB55-7441-98EC-8BD0-E336EFE9925D&AUTH-CALLID=43F3053D-E3D8-9460-B3A8-33415500BE12

TRANSITION TO ADULTHOOD GUIDE:

HTTPS://WWW.DISABILITYRIGHTSPA.ORG/WP-CONTENT/UPLOADS/2018/07/TRANSITIONTOADULTHOODGUIDEFORTRANSITIONAGEINDIVIDSANDFAMILIESCHONEMARCH2018.PDF

STATE VOCATIONAL REHABILITATION AGENCIES:

HTTPS://RSA.ED.GOV/ABOUT/STATES

3

Social Supports & Recreational Opportunities



Socialization & Leisure Activities

Social participation and leisure activities are both considered to be life activities in which people, groups, and populations engage. Social participation has to do with communicating with individuals to ultimately promote social interdependence (AOTA, 2014b). For people/person with disabilities (PWD), the level of intellectual disability and the presence of mental illnesses can both have significant effects on an individual's ability to socialize (Djordjevic et al., 2020). PWD may also have a restricted social life that limits their leisure and physical activities (Djordjevic et al., 2020). Physical activities not only help to improve one's health, but they can also help to promote socialization among individuals (Djordjevic et al., 2020). Leisure activities refers to tasks that people are motivated to engage in that are not related to sleep, work, or self-care (AOTA, 2014b). Leisure activities are unique to the individual and focused around what brings them joy. Watching television is an example of a leisure activity and like anything, it is important to do it in moderation. A recent study found that when compared to people without disabilities, disabled individuals watched television twice as often (Erbaş et al., 2021). This may be because they spend more time at home or they have less socialization opportunities. Although watching television may be a favored leisure activity for PWD, it is important to prioritize other activities as well.

For PWD, access to social gatherings and some leisure activities can be challenging due to several factors, such as transportation, cost, physical limitations, and exclusion. Throughout history, the disabled community has faced social exclusion within society as well as "inaccessibility to basic services, cultural and social activities, close social circles and economical fields" (Erbaş et al., 2021, p. 2). This in turn can act as a second disability due to the limited opportunities related to their interest areas. This cycle is important to consider because having an active life and engaging in socialization helps to reduce the risk for chronic disease among PWD. A recent study done in The United States indicated that almost half of PWD that were physically inactive did not participate in any form of physical activity, causing the rate of chronic disease to be 50% or more for those not engaging in an active lifestyle (Erbaş et al., 2021). Therefore, it is important to encourage PWD to take part in physical activities because it can help to reduce chronic illnesses and potentially lead to having higher life satisfaction and more energy. Physical activity also helps PWD suffer less from secondary health related issues, such as a cold or fever. Cardiovascular health and sleeping habits will also likely improve with physical activity (Erbaş et al., 2021).

Current research has helped to determine what barriers have the potential to hinder PWD's participation in physical activities (Erbaş et al., 2021). The first barrier includes environmental, social, and physical factors, such as the lack of supportive friends and family, transportation difficulties, and the lack of reliable facilities (Erbaş et al., 2021). The second barrier is

individual factors, such as disability status and financial challenges (Erbaş et al., 2021). Other common barriers to physical activity participation among PWD is the lack of physical abilities and economic factors (Ayan & Ergin, 2017). People with intellectual and/or developmental disabilities (IDD) are 4.5 times more likely to not engage in physical activities, as they are often not provided with beneficial exposure to education regarding health promotion (Williamson et al., 2020). Many PWD often become socially isolated from their communities and require socialization opportunities to reintegrate into society (Naidoo et al., 2017). Discrimination among PWD and their caregivers can negatively impact their quality of life and overall well-being. Access to competitive employment is another important aspect of participation for people with IDD and although this is understood, limited employment opportunities exist for PWD (Williamson et al., 2020). Although these are some barriers that PWD and their caregivers may face, it is important to remember that everyone is different and that their barriers may differ. It is also essential to identify potential obstacles when planning for a PWD's future to ensure the most effective and suitable plan for them.

As a caregiver for this population, it can also be challenging to help the PWD locate the right recreational activities for them. This can lead to the caregiver experiencing feelings of isolation accompanied by depression, anxiety, and increased stress about what may or may not be best for the PWD (Erbaş et al., 2021). The continued stress over access to these opportunities for PWD can negatively impact the caregiver's quality of life, and it is therefore important to prioritize both the PWD and the caregiver's overall well-being (Erbaş et al., 2021).

Community Mapping

Community mapping is the "process of discovery" that "allows the 'mapper' to develop new understandings about a specific geographical area that can assist his or her quest to uncover valuable community resources" for themselves or others (Ordoñez-Jasi & Myck-Wayne, 2012, p. 32). Resources can include therapy services, family support groups, educational opportunities, and various health services. Community mapping is a way for the transitional team to identify opportunities to ultimately support and achieve the functional goals of PWD.

Although mapping the community can look different based on the individual conducting the information, typically they will utilize photos, videos, written field notes, observations, and communal interaction to better understand available resources. Teachers and program specialists can then use the information to help develop knowledge regarding resources to best support PWD and caregivers. Increasing the knowledge of various resources can help with creating a stronger sense of community as well as foster community relationships (Ordoñez-Jasi & Myck-Wayne, 2012).

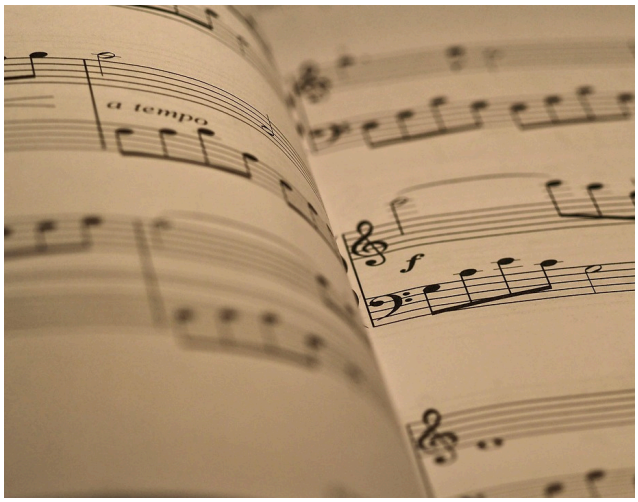
Community mapping falls within the scope of occupational therapy (OT)practice, meaning that an OT can help PWD by first identifying what community resources are present to best support them. Services and resources that can support PWD may include therapy services, employment programs, recreational opportunities, and public areas within the community that are accessible. The identified resources can help PWD with the completion of activities of daily living to ultimately promote a more meaningful lifestyle. Community mapping can also help an OT identify and understand potential barriers for PWD in the community. It is important that possible obstacles are considered when planning for the future of PWD because barriers, such as accessibility, stigma, and discrimination, can negatively impact the way in which an individual is able to safely interact with their environment. An OT can then help to determine if adaptive or compensatory strategies are needed to best support the individual with the completion of activities within the community. OTs are also able to advocate for necessary change, such as accessible assistive technology (AT) or the presence of elevators for accessibility. Community mapping allows OTs to better support PWD with their integration into society by organizing various outreach programs that align with the interests of the PWD. OTs are also able to use a holistic and personalized approach that is meaningful to the interest areas of the PWD. Through a person-centered approach and identification of community-based resources, the PWD and their caregiver will have more information regarding the community resources available to them. If community mapping is of interest to you or a PWD, you can discuss with the transition team or local OTs in your area to learn more about how they may be able to specifically address your needs (Ordoñez-Jasi & Myck-Wayne, 2012).

Recreational Opportunities

Although recreational opportunities and activities will vary based on the PWD's interest areas and where they reside, this booklet aims to touch upon several recreational programs that have been proven in the literature to benefit PWD. The two main areas that will be discussed include art-based programs and outdoor recreation.



Art therapy includes music, dance, and drama related programs, however access to these programs can be limited among PWD (Mino-Roy et al., 2022). Art therapy allows PWD to fully express themselves in an accepting environment, which has the potential to increase their overall life satisfaction (Mino-Roy et al., 2022). Art therapy also can help PWD to form relationships with other individuals as well as to improve social inclusion (Mino-Roy et al., 2022). Music therapy includes a wide array of interventions, such as group singing, music production and appreciation, and playing an instrument (Giummarra et al., 2022). Although the results vary based on the type of musical intervention and population, music therapy has helped to decrease disruptive behaviors and anxiety, increase self-esteem, and help with self-expression and emotional control (Mino-Roy et al., 2022). Music therapy has also helped PWD with improving emotional reactions and motivation, building autonomy, and improving quality of life and social relationships. Although music therapy can be beneficial, current research is unclear on the benefits of music therapy among this population in a community-based setting (Giummarra et al., 2022; Mino-Roy et al., 2022). Although the physical component of dance therapy may not be desired by everyone, positive effects have been reported among people with intellectual disabilities such as increased balance, cardiovascular endurance, muscle strength, and range of motion in joints (Mino-Roy et al., 2022). Dancing also helped to improve "interaction, imitation, emotional expression and regulation but did not affect social skills, self-other awareness, empathy, cognition, communication, or psychological wellbeing" (Giummarra et al., 2022, p. 20). For PWD, participation in drama programs has also been associated with increased skills such as increased acceptance among peers, relationship building, social inclusion, friendship development, increased engagement, reduced isolation, and leisure activity participation (Giummarra et al., 2022). Communication skills and learning, problem-solving, creativity, attention and concentration, self-awareness, impulse control, and decision-making also improved with participation in drama programs (Giummarra et al., 2022; Mino-Roy et al., 2022). Art-based activities are also important to consider as a form of art therapy, as they focus on building artistic skills to create art with guidance from artists with or without disabilities (Giummarra et al., 2022). Participation in art-based programs has helped to increase a sense of belonging, social inclusion, socialization, friendships, engagement, improved quality of life, confidence, and happiness (Giummarra et al., 2022). Overall, art therapy can be beneficial for PWD who have an interest in the arts or who could benefit from the development of various skills relating to improving life satisfaction.



Outdoor recreational activities are considered to be leisure activities that are done for either relaxation or enjoyment (AOTA, 2014b). Although there are dozens of outdoor activities that PWD may choose to engage in, this booklet focuses on leisure programs and various physical activities and sports. Leisure programs relating to recreation may include nature-based programs and structured programs, such as community walks or self-help programs (Giummarra et al., 2022). As mentioned previously, leisure activities are important for incorporating joy and relaxation within one's life. For PWD, leisure recreational programs have "improved social connectedness, relationships, interpersonal relationships, personal growth, confidence, wellbeing, self-determination, and empowerment, and reduced loneliness and depression" (Giummarra et al., 2022, p. 22). Physical activity and sports involvement has also been shown to be effective in reducing chronic illnesses among the disabled community (Erbaş et al., 2021). As previously mentioned, incorporating physical activity into a PWD's routine can have several health benefits that can result in higher life satisfaction (Erbaş et al., 2021). For PWD, being a part of physical activities/sports can help to maximize their physical health as well as help to increase their independence and peer socialization (Erbaş et al., 2021). Recent literature considered PWD who did and did not participate in sports, and it was determined that those who played a sport had higher levels of self-respect, socialization skills, and a positive difference in behavioral issues when compared to PWD who did not participate in sports (Erbaş et al., 2021).



Although physical activity is recommended, it is important to consult a physical activity specialist (physical therapist, occupational therapist, primary care physician, etc.) prior to having a PWD engage in strenuous physical activity (CDC, 2024). Everyone's physical health and capabilities are different and certain disabilities can cause health systems to work differently than able-bodied peers (CDC, 2024). Several organizations such as Special Olympics and The National Center on Health, Physical Activity, and Disability (NCHPAD) has free online resources to best support caregivers and PWD with physical activity and nutrition planning. Please reference the end of this chapter for several supplemental links relating to free physical activity programs and health-related resources (CDC, 2024).

Driving

Within the United States, close to half (45%) of households are considered to be located in low population density areas, making it important to own and be able to safely operate a vehicle (Randall et al., 2021). With that being said, "private vehicles are used for practically all (91.4%) commutes to work" and although that is not a significant challenge for most adults, it can increase challenges for PWD who live in rural areas, who cannot safely operate a car, or for those who are unable to access public transportation due to living in a rural area (Randall et al., 2021, p. 191). PWD are considered to be the population with the lowest rates of employment and living independently (Randall et al., 2021). The inability for PWD to access community resources can make it increasingly difficult for PWD to hold jobs, live on their own, and integrate into society. Although learning how to drive may be an option for a PWD, it is highly dependent on their physical and cognitive abilities as well as their desires. Studies have shown that there are two prominent ways for PWD to learn new skills: systematic instruction and prompting (Randall et al., 2021). Systematic instruction helps to break down tasks into smaller and more manageable steps by incorporating scaffolding (Randall et al., 2021). Scaffolding is when someone provides feedback to the individual until they achieve mastery with the new skill (Randall et al., 2021). This can help PWD to break down large tasks and focus on smaller steps, to ultimately achieve mastery. Prompting can also be used to provide physical, visual, or auditory cues to help the PWD achieve the desired outcome or behavior (Randall et al., 2021). Verbal prompting has been shown to have positive effects with maintaining task focus and appropriate responding among PWD (Randall et al., 2021). New research has shown that one in three people with autism spectrum disorder (ASD) will earn their driver's license by the age of 21 (Curry et al., 2018). Although there is a common misconception that PWD are unable to drive, it is important to consider the individual's needs and desires prior to making a conclusion about what they can and cannot do.

Driving simulators are an option to help PWD be exposed to basic driving skills prior to learning more challenging skills, such as maintaining the speed of the vehicle (Chee et al., 2019). Once someone has mastered both basic and more advanced driving skills, the dangerous and potential life-threatening scenarios can be safely introduced (Chee et al., 2019). One benefit of driving simulators is that the level and instruction can be customized to the individual's preferences and assistance levels, unlike an on-road program (Randall et al., 2021). Driving simulators can provide PWD with a safe learning environment prior to a more challenging on-road program (Randall et al., 2021). Although obtaining a driver's license and being able to safely operate a car can help PWD to potentially maintain employment, live independently, and be more immersed in the community, the PWD may not desire or be comfortable with the idea of driving or operating a vehicle.

If a PWD is unable to drive, it is common for them to rely on their parents or caregivers as their primary source of transportation (Randall et al., 2021). Although this may not be an issue for some families, other families may find this time-consuming and burdensome (Bross et al., 2024). Therefore, it may be beneficial to connect the PWD with community resources to help support transportation skill development. As mentioned previously, it is important for caregivers to navigate their options in order to receive state and federally funded support after the PWD is no longer a part of the special education system (Bross et al., 2024). Identifying community-based supports, such as "vocational rehabilitation [VR], centers for independent living [CILs], Social Security Administration, employment services, nonprofit organizations" as well as others can help caregivers and PWD learn more about what is available (Bross et al., 2024, p. 217). For example, CILs will commonly "provide transportation instruction, and VR can provide transportation to and from a job…however, personnel from different organizations, such as secondary schools and VR agencies, reported challenges with collaborating with one another" (Bross et al., 2024, p. 217). Although navigating these services can be challenging, PWD can benefit from a more organized and coordinated service delivery plan that focuses on ways to be safely transported around their community (Bross et al., 2024).

Supplemental Links

NATIONAL CENTER ON HEALTH, PHYSICAL ACTIVITY, AND DISABILITY (NCHPAD) 14-WEEK FREE PERSONALIZED NUTRITION AND PHYSICAL HEALTH PROGRAM:
HTTPS://14WEEKS.NCHPAD.ORG/

SPECIAL OLYMPICS FIT:
HTTPS://RESOURCES.SPECIALOLYMPICS.ORG/HEALTH/FITNESS/FIT-5?_GA=2.250654734.945859860.1584493348-1898712207.1501874855

DRIVE FOCUS APP (DRIVER SIMULATOR):
HTTPS://DRIVEFOCUS.COM/

NAVIGATING PUBLIC TRANSPORTATION GUIDE FOR PEOPLE WITH PHYSICAL DISABILITIES:
HTTPS://ELDERLYORDISABLEDLIVING.ORG/NAVIGATING-PUBLIC-TRANSPORTATION-WITH-A-PHYSICAL-DISABILITY/

CENTER OF DISEASE CONTROL PHYSICAL ACTIVITY GUIDE:
HTTPS://WWW.CDC.GOV/DISABILITY-AND-HEALTH/ARTICLES-DOCUMENTS/PHYSICAL-ACTIVITY-FOR-PEOPLE-WITH-DISABILITY.HTML#:~:TEXT=NCHPAD%20ALSO%20OFFERS%20A%2014,INCLUDING%20THEIR%20PHYSICAL%20ACTIVITY%20LEVEL

4

Financial Supports & Employment



Financial Support

Benefits & Services

❶ Intellectual/Developmental Disability (I/DD) Waiver

- An I/DD waiver is a federal or state program that is available to support people/persons with disabilities (PWD). The purpose of an I/DD waiver is to assist PWD with living in the community rather than in an institutionalized setting. Typically, an I/DD waiver falls under Medicaid and therefore, the benefits can vary greatly based on the state in which someone lives. The waiver can help with providing various support systems, such as physical therapy (PT), occupational therapy (OT), case management services, home health, and assistive technology (AT). An I/DD waiver can also assist in providing essential supplies for PWD, such as oxygen, feeding supplies, and incontinence products. It is important to understand that an I/DD waiver is typically not a cash program and that the eligible person will receive Medicaid as their health insurance, which can be used to cover the costs of hospitalizations, medications, and doctors visits. The eligibility for an I/DD waiver is based on financial need as well as the social security qualifying definition of "disability", though many states have a waiting list of months to years to obtain this waiver (Special Needs Alliance [SNA], n.d.). Although this can be a great option to support PWD, due to the competitive nature of the program, it is important to consult an expert in the field early to determine if this is right for your situation (SNA, n.d.). For more information, refer to the supplemental links at the end of this chapter.

❷ Supplemental Security Income (SSI)

- As discussed in Chapter 1, SSI is a federal program in The United States that provides financial assistance and resources to people who are blind, elderly, or who have a qualifying disability. All individuals who are eligible receive the same amount of money, regardless of the state they reside or their level of need. This program was created to assist individuals with little or no income, which refers to money earned from work, free shelter and food, as well as money received from other sources such as social security benefits, unemployment, and workers compensation. For a PWD who is over the age of 18, they must have a confirmed physical or mental impairment that either:

    - "Results in the inability to engage in substantial gainful activity; and
    - Can be expected to result in death; or
    - Has lasted and can be expected to last for a continuous period of not less than 12 months" (SNA, n.d., p. 12).

- For more information regarding SSI, refer to the supplemental links section at the end of this chapter.

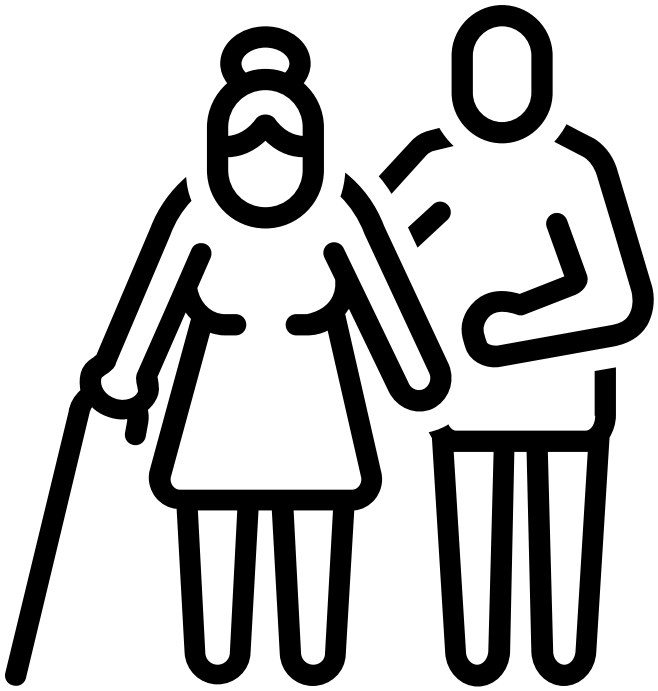
❸ Social Security Disability Income/Insurance (SSDI)

- SSDI is a federally-run program that supports PWD financially, but this program provides financial assistance to PWD who are unable to work due to their disability. This program is based on the individual's work history as well as their ability to earn money from employment. This federal program is not based on the financial need of the PWD, like SSI. To be eligible for the cash benefits from SSDI, the worker must be insured, meaning they must have recently worked enough quarters and paid social security taxes on their financial earnings. The amount from SSDI is based on the work credits that the worker has completed prior to becoming disabled (SNA, n.d.).

- Disabled Adult Child (DAC) is a type of SSDI benefit that is eligible to people who had a disability prior to them turning 22 years old and either "their parent is deceased or starts receiving retirement or disability benefits" (SNA, n.d., p. 12). Although the PWD is considered to be a legal adult, this is a child benefit because it is paid on behalf of the parent's social security earnings (SNA, n.d.). For more information regarding SSDI, refer to the supplemental links section at the end of this chapter.

❹ Care Management

- Ensuring optimal support and transition planning for PWD is important for individuals who would like to live at home after their caregivers are no longer able to provide care. With that being said, it is important to consider financial benefits and services early in the planning process, as some of these programs can take long periods of time to obtain. Refer to the transition planning section of Chapter 1 for more information regarding the process of planning for the future of a PWD.



Financial Arrangements

Special Needs Trust (SNT)

- A SNT is a legal arrangement for PWD to receive financial assistance without preventing them from getting government benefits, such as SSI. Due to the beneficiary not having ownership over the assets within the trust, they can still be eligible for other various benefit programs. The trustee is then able to use the assets to supplement the beneficiary's government benefits but not replace them. Typically, an SNT is used to cover the cost of activities that help to improve the quality of life of the PWD, such as social and leisure activities as well as hobbies. A SNT is a supplemental program, which can be beneficial for PWD (SNA, n.d.). More information regarding the various types and purposes of SNTs goes beyond the scope of this resource booklet, and readers are advised to refer to "The Special Needs Alliance" website for more information. The link is provided at the end of this chapter.

Achieving A Better Life Experience (ABLE) Accounts

- As previously discussed, ABLE accounts are "tax-advantaged saving accounts for individuals with disabilities and their families" (SNA, n.d., p. 17). The account is owned by the beneficiary and the income that is earned within the account is untaxed. Anyone can put after-tax money into an ABLE account, but they cannot deduct these contributions from federal taxes. With that being said, some states may offer state income tax deductions for the contributions made to an ABLE account. ABLE accounts can be beneficial, as many public benefits restrict PWD to $2,000 in resources, such as retirement and saving accounts. Therefore, it is important for PWD to remain under the $2,000 limit of resources to remain eligible for public funding (SNA, n.d.).

- To be eligible for an ABLE account, the disability had to have begun before the age of 26. Beginning January 1st of 2026, people whose disability began before the age of 46 will be eligible for an ABLE account. It is also important to note that individuals who are receiving SSI and/or SSDI will be automatically eligible for an ABLE account. Annual and lifetime contributions to ABLE accounts are also present, however the contribution amounts can vary based on if the PWD receives SSI or if they earn income (SNA, n.d.). More information regarding ABLE accounts goes beyond the scope of this resource booklet, and readers are advised to refer to "The Special Needs Alliance" website for more information. The link is provided at the end of the chapter.

Financial Management Strategies

Remedial Strategies

- A remedial approach to financial management falls within the scope of OT practice, as it aims to assist PWD with independently managing their financial responsibilities by targeting a lost function or skill due to their disability. One way that OTs do this is by supporting PWD with skill development related to money management. Although the management of money can include a wide array of skills and knowledge, it is important for PWD to first understand numbers and the value of money. For individuals with developmental dyscalculia, a learning disability that makes it more difficult for individuals to understand math and number skills, daily activities can be negatively impacted (Vigna et al., 2022). Although there is limited literature regarding developmental dyscalculia in adults, daily activities can become more challenging, such as managing money or seeking employment (Vigna et al., 2022). Current research has highlighted that "people with low numeracy have a lower range of work opportunities, lower salaries, poor financial well-being, and less access to internet technology (e.g., computers and cell phones)" (Vigna et al., 2022, pp. 4-5). For people with developmental dyscalculia and/or other disabilities, the management of money can be addressed through hands-on activities with money. These activities can include counting change, using cash for everyday tasks, and helping the PWD understand the value of money. Setting financial goals can also be a helpful remedial strategy that encourages numerical problem-solving, goal-setting, and the potential to monitor individual outcomes. Assisting the PWD by going to the bank can help the individual with developing financial literacy and awareness of their own financial affairs. If a PWD visits the bank with a caregiver or aide, it is important for the bank teller to address the PWD first, before speaking to the caregiver, to promote their autonomy and sense of financial independence. Financial counselors, benefit programs, and vocational rehabilitation services can also be helpful for PWD to be better supported with financial understanding. As discussed previously, financial resources such as ABLE accounts, SSI, and SSDI can be confusing due to the many factors, however having a trusted caregiver or financial advisor can help to ease the financial management process.

Adaptive and/or Compensatory Strategies

Adaptive or compensatory strategies aim to change or modify the task to promote participation among the individual. For financial management specifically, visual aids, prepaid cards, financial checklists, automated bill pay, and family/caregiver support are all examples of ways to modify the task to promote participation among PWD. Visual aids can be used for a variety of sequencing tasks as well as tracking financial spending through color-coding wants, needs, and spending categories. Visual reminders or timers can also be used to remind the PWD to pay bills, make a necessary payment, or to complete a financial task. Lastly, a visual chart can be created to show progress towards a financial goal as well as

track money spent over time. Visual aids can be beneficial to reduce stress surrounding important financial decisions. Prepaid cards are another way for PWD to manage sums of money with low consequences. Unlike a credit card, a prepaid card is able to have a determined amount of money uploaded on the card, which can reduce the risk of the individual overspending or using money that they do not have. Another adaptive strategy is using financial checklists to ensure that the PWD is completing necessary payments or financial tasks to reduce the risk of late payments and monetary fees. Automated bill pay can help PWD with paying bills on time, if they are forgetful or they are not responding well to other visual reminders. Lastly, the involvement of a caregiver or family member can help the PWD stay on track with their financial goals, while still promoting independence within their life. It is important to also consider that if any individuals are involved in the financial management of a PWD, it is important that the person is trustworthy and that they understand the financial needs of the PWD. Creating a document that highlights the roles of the caregiver/financial planner and PWD can be helpful to promote understanding of roles within the decision-making process.

Protection Against Financial Abuse

Although the definition can vary based on exploitative behaviors, financial abuse refers to taking an individual's property or money without permission, pressuring an individual to sign financial documents, controlling someone by withholding or limiting their money, and/or forcing someone to change their will or sell items (Ghaderi, 2024). Financial abuse can also include "pressuring an individual to withdraw money from the cash machine for them, borrowing money and never paying it back, and taking someone's pension, benefits or inheritance" (Ghaderi, 2024, p. 5).



Explicit financial abuse has to do with a situation where an individual is forced to pay for another person and implicit financial abuse has to do with a situation where a caregiver or provider does not allow a PWD to spend their money how they would like to. Although financial abuse can vary greatly based on the intention of the supporting individual, it is important to be aware of who has access to financial information for a PWD and possibly have someone oversee the finances to ensure ethics are being upheld (Ghaderi, 2024).

A recent study found that people with intellectual disabilities who "[spoke] up for themselves, [made] their own decisions, [gained] information to understand things better and [were] aware of their rights" had better chances of having and remaining in control over their lives because they knew how to protect themselves (Buhagiar & Azzopardi Lane, 2022, p. 1). Allowing PWD to have increased control and independence over their own lives can help to prevent financial abuse (Buhagiar & Azzopardi Lane, 2022). My Money Counts is an app that is currently being developed in conjunction with The Money Advice and Budgeting Services (MABS) and the Institute of Art, Design, and Technology (IADT) (Burke, 2024). This app aims to be a tool to help individuals with realistic money management, supporting personal safety, as well as promoting financial independence. My Money Counts is being specifically created for people with intellectual disabilities and cognitive impairments, including dyscalculia, which aligns with the positive role that AT can play within the lives of PWD (Burke, 2024). For more information regarding My Money Counts and MABS, refer to the supplemental links section at the end of this chapter.

Job Exploration Strategies

According to the 2023 United States Bureau of Labor Statistics, "for all age groups, the employment-population ratio was much lower for people with a disability than for those with no disability" (U.S. Department of Labor [DOL], 2023, p. 1). As mentioned previously, employment among PWD can be challenging due to many factors such as discrimination, stigma, and transportation (U.S. DOL, 2023). Despite the accessibility challenges to employment for PWD, job opportunities for PWD have been proven in the literature to help "[improve] quality of life and income, [enhance] self-confidence, [expand] social network, and a sense of community" (Lindsay et al., 2018, p. 634). A recent study demonstrated that youth with physical disabilities "had a wide variety of career aspirations that were influenced by special interests and exposure to certain professions" (Lindsay et al., 2021, p. 1661). Having more exposure to various career opportunities can support youth with a wider array of career options (Lindsay et al., 2021). The study also put forth how PWD may want to pursue a career, which highlights the importance of talking with the PWD prior to making conclusions about their job or lack thereof (Lindsay et al., 2021). With that being said, job exploration strategies can help individuals find and maintain employment opportunities.

Types of Employment

Vocational Rehabilitation

As mentioned in Chapter 2, The Office of Vocational Rehabilitation (OVR) can help to support both PWD and their families to better navigate the employment realm through vocational rehabilitation services. OVR is a state and federally funded program that is available to PWD in The United States as well as Puerto Rico. The overarching goal of OVR is to "support independence and provide career-related services to all eligible youth and adults living with disabilities" to access competitive employment (Dispenza, 2021, p. 677). The services provided are little to no cost to PWD, however the execution and delivery of services can vary based on geographical locations within the United States. Vocational rehabilitation services typically will include "career-related assessments and workplace evaluations, individual and group career counseling, specific trainings (e.g., job readiness, job search, social skills), case management and referral services, interpreter services, transition vocational services from high school to work or postsecondary education, assistive work technology, assistance with living conditions, and workplace accommodation evaluations" (Dispenza, 2021, p. 677). OVR has the ability to provide vocational rehabilitation services to PWD, however it is important to survey all community options as well as discuss with the PWD prior to determining what is best to meet their specific needs (Dispenza, 2021).

Apprenticeship

Although there are "apprenticeship-like" programs, this section will focus on a true apprenticeship program that meets specific criteria and standards, such as being registered with the U.S. Department of Labor (DOL) or various state apprenticeship offices. Registered Apprenticeship (RA) programs have specific criteria that need to be met:

- The apprenticeship is a paid employment opportunity where the PWD is hired by the employer,
- There are scheduled wage increases based on increased competency,
- An experienced mentor is present at the job site,
- Apprenticeship includes technical instruction related to the job, and
- The apprenticeship will result in the earning of an industry credential (Mitchell et al., 2023).

RA programs are highly structured and time-consuming commitments that require the apprenticeship to meet a minimum of 2,000 hours; 144 hours are to be related to technical instruction and additional required competencies. Although this work-based learning opportunity may not be appropriate for all PWD, RA can be a way for PWD to gain "market-

directed skills to prepare for, enter and advance their careers, in positions that are stable and offer good wages" (Mitchell et al., 2023, p. 258). Similar to other employment and job exploration strategies, PWD may face barriers to accessing and participating due to factors mentioned previously (reliable transportation, time, etc.). There are current initiatives being implemented at The Institute for Community Inclusion (ICI) at the University of Massachusetts Boston to help increase access to these programs for PWD (Mitchell et al., 2023). For more information regarding RA programs and ICI, refer to the supplemental links provided at the end of this chapter.

Supported & Custom Employment

Supported employment aims to support all PWD, including those with severe disabilities, with working in a competitive environment that includes able-bodied individuals. Current research has found supportive employment effective for individuals with psychiatric disabilities, I/DD, traumatic brain injuries, autism, as well as severe physical disabilities. Supported employment consists of four main features which include competitive employment, integrated settings, ongoing support, and people with severe disabilities. Competitive employment refers to job opportunities available in local communities that offer livable wages that are equivalent to those in the job market. An integrated setting refers to various job placements that do not separate or exclude PWD, such as having the PWD be a part of customer interactions. Ongoing support focuses on coaching and supervision to promote optimal participation within employment. For individuals with severe disabilities, supported employment can help with providing training on specific job tasks, placing individuals in an appropriate job setting, continual training, and personalized follow-ups. The ultimate goal of supported employment is to help the PWD advance in their job and retain new skills, to ultimately promote a sense of autonomy (Dispenza, 2021).

Customized employment uses an approach that meets the needs of both the employer and the PWD. The "job tasks, duties, and expectations are adapted to meet the needs of an employer, while taking into account the strengths, interests, and abilities of a PWD" (Dispenza, 2021, p. 678). The employment team for the PWD should be working closely with the employer, as they should be continually identifying ways to better support the employee. The support team of the PWD can also help to educate the employers on disability culture as well as ways to best assist the PWD (Dispenza, 2021).

Internship programs are another way for job exploration among PWD. For internships to be effective, it is extremely important that both disability departments and career staff collaborate with one another to ensure that the optimal internship experience is being created for the PWD (DiYenno et al., 2019). Internships can be beneficial for job exploration by allowing individuals to "discover their strengths and weaknesses in employment," prior to them beginning a job (DiYenno et al., 2019, pp. 149-150). Internships can also help with creating new socialization opportunities, developing new skills, as well as exposing individuals to new job experiences that can positively impact their search for employment in the future (Oswald et al., 2015).

Assistive technology (AT) refers to various types of equipment that can be used to support "people regain capabilities that they may have lost (rehabilitation) and for helping people develop new capabilities that allow them to cope more effectively (habilitation)" (Smith et al., 2024, p. 489). The two main areas relating to AT include high and low technologies. High technology refers to more complex and sophisticated equipment that typically are more expensive and harder to access, such as tracking devices, augmentative and alternative communication (AAC) devices, and smart tablets (Dispenza, 2021). On the contrary, low technology is easy to access, simple, and inexpensive, such as eating utensils or magnifying glasses (Dispenza, 2021). Regarding employment and job exploration, AT can be a way for a PWD to have better access to a physical or social environment, however it is important to thoroughly assess the needs of the individual and seek advice from an expert in the field prior to implementing any assistive technology with a PWD (Dispenza, 2021). For more information regarding AT and reasonable accommodations for PWD within an employment setting, refer to The Office of Disability Employment Policy (ODEP) information under the supplemental links section at the end of the chapter.

With employment or job exploration opportunities, it is also important to consider both the physical and social environment. For all individuals, a physical environment can support or hinder one's performance of job-related tasks. Lights, physical space, accessibility, noise volume, and geographical location can all play a role in how a PWD is able to interact with their environment and perform their designated responsibilities. The social environment can also play a role in how the PWD performs. If the individual is not comfortable or satisfied with their role within the organization, they may be less likely to participate (Ellenkamp et al., 2016).

Employment For People With High Support Needs

Although employment for a person with severe disabilities can be challenging to acquire, work experiences are considered to be the "best practice for youth with severe disabilities" (Awsumb et al., 2022, p. 22). Connecting a person with severe disabilities to paid employment opportunities within high school significantly increases their chances of future employment post-graduation. Although there is limited information about individuals with severe disabilities and employment, parents of PWD—including autism, intellectual disabilities, and multiple disabilities—were more likely to express concerns about work-related barriers compared to parents of those without disabilities. These barriers included "youth's underdeveloped employment and social skills, the unwillingness of employers to hire, overall minimal opportunities for employment, the lack of availability of services and supports after graduation, and the poor quality of employment preparation provided by schools" (Awsumb et al., 2022, p. 23). Unfortunately, many barriers can be identified and there is a continued lack of specific interventions to better target this underserved population (Awsumb et al., 2022).

The job opportunity and skill development strategies listed above can be applied and personalized based on the specific needs and desires of the individual with disabilities. Also, as caregivers, it is important to remain active in the employment process of the PWD to ensure the individual is safe, comfortable, and enjoying their newfound job.

The Family Employment Awareness Training (FEAT)

High family expectations can help to combat low employment rates among PWD (Carter et al., 2012; Francis et al., 2013;). In a study where parents had higher expectations for their child with disabilities to "definitely get a paying job," the child was five times more likely to gain employment after finishing high school (Carter et al., 2012, p. 15). Although having high expectations can help PWD with employment, it is also vital for caregivers to understand the transition process related to job opportunities and career exploration. FEAT was designed and created to "help families, professionals, and people with ISN [individualized support needs] develop high expectations for competitive employment and gain knowledge about employment services, supports, and resources (Francis et al., 2013, p. 45). Through a two-step training program, FEAT strives to increase competitive employment opportunities for PWD as well as knowledge among PWD, their families, and involved professionals (U.S. DOL ODEP, 2021). The FEAT will inform individuals on new and evolving ways to consider employment, other individual's experiences regarding employment, local resources, as well as how to maximize resources through several federal/state run programs (U.S. DOL ODEP, 2021). Although FEAT is a relatively new program developed in 2010 and it is only being offered in five states (Kansas, Rhode Island, Oklahoma, Nebraska, and Indiana), the program was successful in increasing expectations related to employment as well as resource knowledge (U.S. DOL ODEP, 2021). To learn more information regarding FEAT, reference the supplemental links at the end of this chapter.

Supplemental Links

PENNSYLVANIA CONSOLIDATED WAIVER (TYPE OF I/DD WAIVER):
HTTPS://WWW.PA.GOV/AGENCIES/DHS/RESOURCES/MEDICAID/WAIVERS/CONSOLIDATED-WAIVER.HTML

SOCIAL SECURITY INCOME INFORMATION:
HTTPS://WWW.SSA.GOV/SSI

SOCIAL SECURITY DISABILITY INCOME/INSURANCE INFORMATION:
HTTPS://WWW.SSA.GOV/BENEFITS/DISABILITY/QUALIFY.HTML

SPECIAL NEEDS ALLIANCE - SNT:
HTTPS://WWW.SPECIALNEEDSALLIANCE.ORG/THE-VOICE/YOUR-SPECIAL-NEEDS-TRUST-SNT-DEFINED-2/

SPECIAL NEEDS ALLIANCE - ABLE ACCOUNT:
HTTPS://WWW.SPECIALNEEDSALLIANCE.ORG/SPECIAL-NEEDS-101/ABLE-ACCOUNTS/

MY MONEY COUNTS APP INFORMATION: HTTPS://ILLUSTRO-IADT.FIGSHARE.COM/ARTICLES/THESIS/INVESTIGATING_USABILITY_AND_ENGAGEMENT_IN_A_MONEY_MANAGEMENT_APPLICATION_FOR_USERS_WITH_INTELLECTUAL_DISABILITY/25225982?FILE=44560700



Supplemental Links



MONEY ADVICE AND BUDGETING SERVICE: HTTPS://WWW.MABS.IE/EN/

REGISTERED APPRENTICESHIP INFORMATION:
HTTPS://CONTENT.IOSPRESS.COM/ARTICLES/JOURNAL-OF-VOCATIONAL-REHABILITATION/JVR230013

INSTITUTE FOR COMMUNITY INCLUSION:
HTTPS://WWW.COMMUNITYINCLUSION.ORG/

OFFICE OF DISABILITY EMPLOYMENT POLICY INFORMATION:
HTTPS://WWW.DOL.GOV/AGENCIES/ODEP

FAMILY EMPLOYMENT AWARENESS TRAINING (FEAT):
HTTPS://WWW.DOL.GOV/SITES/DOLGOV/FILES/ODEP/PDF/SSI_YOUTH_GROSS_FINAL_PROPOSAL.PDF

5

Relationship Building & Intimacy



Intimacy, Stigma, & Informed Consent

This chapter will discuss intimacy, informed consent, abuse, as well as ways to reduce inappropriate sexual behaviors. Sexual health and intimacy is a broad topic, and this resource booklet aims to give a brief overview to caregivers on ways to best support people/persons with disabilities (PWD) with their sexual desires. For more in-depth information regarding these topics, please refer to either the supplemental links at the end of this chapter or consult an expert in the area (primary care doctor, occupational therapist (OT), behavior therapist, counselor, etc.) to address the specific needs of the PWD.

As mentioned in Chapter 3, socialization is important to promote relationship building. Although it is understood that PWD should have equal opportunities to socialize and meet new people, they are more likely to experience loneliness and spend less time with their friends (Fulford & Cobigo, 2018). PWD who have been in intimate relationships have reported being physically intimate and having romantic feelings towards their partners. Although there is a stigma surrounding PWD and sexual intercourse, it is important to remember that every individual is different and some may desire physical intimacy whereas others may not. Caregivers can also play an important role with helping the PWD form and maintain relationships through continued support. Although caregivers have the ability to support various relationships for a PWD, they also have the ability to discourage physical intimacy. It is important to remember that PWD have the legal right to engage in intimate relationships at the age of eighteen if they provide informed consent. Therefore, it is important to discuss with a PWD about their desires and address them accordingly (Fulford & Cobigo, 2018). Some PWD may seek a partner to avoid loneliness; however, finding, building, and maintaining relationships can be challenging (Schaafsma et al., 2017). Healthy relationship building skills and sex education should be provided to all PWD, despite their current desires, as these may change in the future.

In a study conducted in 2018, it was found that “84% of the 360 participants with ID [intellectual disability] had been in a sexual relationship and 87% indicated they currently would like to be in a relationship,” which highlights the importance of providing support and education to this underserved population (Hole et al., 2022, p. 454). The literature has also shown that “sexual pleasure is an important aspect of relationships and sexuality for people with ID,” including “kissing, having a crush, sexual talk, ‘lovemaking’, anal intercourse, ‘playing doctor,’ marriage, dating, expressing ‘I love you,’ fantasy, masturbation, fellatio, vibrators, and pornography” (Hole et al., 2022; Turner & Crane, 2016, p. 687). Although sexual intercourse within western culture can be seen as taboo, it is important to recognize that people may want to engage in sexual relationships, so as a society, we should best prepare and support all individuals with these desires.

In some cultures, people once believed that intimacy among PWD actually caused the individual's condition. This idea was called Christian morality and "the fear of people with ID/DD's [intellectual disability/ developmental disability] reproductive potential to unleash a genetic scourge on society, were influencing factors in a decision to ban, outright, all sexual interaction between institutionalized people with ID/DD" (Onstot, 2019, p. 635). This was seen as a way to protect society. However, we now know that sexual liberation among this population is the desired goal and right of PWD (Onstot, 2019).

The stigma surrounding intimacy and disability stems from past beliefs and refers to PWD being "asexual, lacking sexual feelings and desires, or as sexually inadequate," thus contributing to PWD lack of autonomy and sexual rights (Fritsch et al., 2016, p. 88). The stigma of The North American "socio-cultural barriers may be more disabling than the physical impairment itself" (Esmail et al., 2010, p. 1148). Stigma has the ability to cause PWD to internalize the ideas of asexuality and negatively impact their desire, confidence, and ability to find a partner (Esmail et al., 2010). Sexuality is considered to be a "natural and very important aspect of [PWD's] health, well-being and overall satisfaction" and therefore, it is important to not alter one's self-concept in response to sexual stigma (Esmail et al., 2010, p. 1154).

Although there are no laws dedicated solely to PWD and marriage, the general constitution and civil rights of all Americans allows for marriage, no matter an individual's ability. The United States Constitution "guarantees a person's ability to make certain decisions in matters related to procreation, child rearing, contraception, marriage (including interracial marriage and same-sex marriage), and consensual sexual activity" (Santamaria, 2022, p. 1). Therefore, it is legal for PWD to get married and have children, if they provide consent and desire that outcome.

Each state has their own statutory language relating to consensual and non-consensual sexual contact for PWD, however most states consider "age, consciousness, and ability to understand the nature and consequences of the act" (Baladerian, 2022, p. 26). Some states also take into consideration the PWD's understanding of both the social and moral results related to having sexual intercourse with another individual. Because all states do not have uniform requirements surrounding informed consent, there is also not one standard assessment to measure one's ability to consent to having sex. Some states also consider the PWD's ability to internalize their values. Although these themes are usually included within the definition of sexual consent, it is important to fully understand the definition within the state that the PWD resides (Baladerian, 2022). It is also important to recognize that "people with IDD deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives" (American Association on Intellectual and Developmental Disabilities [AAIDD], 2024, p. 1). All individuals have the right to develop and maintain interpersonal relationships, whether those relationships are centered around friendships, sex, and/or emotional connections. For more information regarding informed and sexual consent, refer to The National Adult Protective Services Association in the supplemental links at the end of this chapter.

Sex Education In The Classroom

Although the requirement for sex education can greatly depend on the state in which the PWD lives, it is important that all individuals are receiving some form of instruction. Within the sexual and reproductive health service field, "research shows that PWD face outstanding unmet needs and... are more likely to be deprived from sex education programs" (Matin et al., 2021b, p. 2). People with intellectual disabilities have also reported having less formal and informal opportunities to learn about sexual education, when compared to their able-bodied peers (Matin et al., 2021b). Typically, PWD's knowledge about sexual health has to do with safe sex, use of condoms, contraception, and sexually transmitted infections (STI), however this information tends to be surface-level (Schaafsma et al., 2017). With that being said, information about safe sex also does not always translate to real-life situations and safe sexual behaviors (Schaafsma et al., 2017).

Although the improvement of sexual education programming will be dependent on the state and school district where the PWD resides, this booklet will discuss several broad opportunities to strengthen the approach to sex education for PWD. First, sex education should include "a broad range of topics and not exclusively focus on safe sex and prevention of STI's and unwanted pregnancy" (Schaafsma et al., 2017, p. 34). The approach to sex education should focus on increasing skill-building knowledge, the PWD's opinions, caregivers, and educator supports (Schaafsma et al., 2017). This can help to increase a broader range of



educational materials relating to sexual health within the classroom (Davies et al., 2022). Research also highlights the importance of education through multiple "learning activities" over a period of time, such as parents increasing carryover from what is being taught (Schmidt et al., 2020). As a caregiver of a PWD, you have the right to know what the school curriculum entails and if the classes are incorporating beneficial topics to meet the specific needs of the PWD. Other areas to consider are how online relationships, parenthood, and social media can influence the sexual desires of a PWD (Schaafsma et al., 2017). Although some educators may be well versed with understanding sexual health and PWD, providing the program with specific goals for the PWD relating to what they understand and want to know can help to create a more person-centered and appropriate sex education program for the PWD (Schaafsma et al., 2017). Although providing adequate knowledge to PWD is important, ensuring knowledge translation through skill performance and hands-on activities, such

as ways to ask for consent and safely utilizing contraceptives, can help to ensure skill acquisition and development. Also, having the programs include multiple session and booster courses can help to ensure the maintenance of knowledge over extended periods of time (Schaafsma et al., 2017). Overall, a successful sex education program should be "systematically developed using a theory – and evidence-based protocol" if the developers want the program to succeed (Schaafsma et al., 2017, p. 34).

Due to health inequalities and gaps within sex education, PWD "may experience higher rates of sexually transmitted infections" (Brennand & Santinele, 2022, p. 91). According to a recent study conducted in Canada, both men and women with any type of impairment had a higher likelihood of reporting an STI diagnosis (Brennand & Santinele, 2022). There was also a positive correlation between higher rates of STI and severity of disability, meaning that people with more severe disabilities were more likely to have a STI diagnosis (Brennand & Santinele, 2022). The group most impacted by STI were females with severe visual impairments (Brennand & Santinele, 2022). Another relatively recent study of 20 individuals with intellectual disabilities found that the general knowledge regarding STI was poor (Schaafsma et al., 2017). When asked about symptoms associated with STI, most individuals answered that you know when you are tested, however only three participants were able to vocalize symptoms such as pain and fever (Schaafsma et al., 2017). Although this was a relatively small study and more research is needed to determine the level of understanding related to STI and PWD, education regarding sexual health is needed to ensure optimal health and wellbeing. There is a need for individuals to have "STI [screenings], as well as the greater need for improved strategies to address the sexual health needs" of PWD, regardless of the type and severity of the disability (Brennand & Santinele, 2022, p. 91).

Women's Sexual Health

For women with disabilities (WWD) in the United States, both personal and healthcare system factors can affect access to maternity care (Matin et al., 2021b). Some personal factors can include attitudes, resources, and personality traits whereas healthcare system factors can include knowledge, healthcare provider's attitudes, as well as political factors (Matin et al., 2021b). Barriers to access maternal healthcare will likely vary based on location and socio-economic factors, highlighting the importance of reliable and affordable transportation (Matin et al., 2021b). WWD who live in rural areas may also face additional barriers to receiving sexual health support and services, such as breast cancer and cervical cancer screenings (Matin et al., 2021b). Physical challenges to gynecological exams may also be a concern for WWD. Various resources and strategies exist to better support healthcare providers with performing these exams as well as for caregivers who may struggle with advocating for proper healthcare among WWD. For more information regarding resources and strategies concerning sexual health, refer to the supplemental links at the end of this chapter.

Current literature has also identified that women with intellectual disabilities "have sexual desires and need specific supports to [have] a healthy sexual relationship" (Matin et al., 2021a). As mentioned in the previous section of this chapter, there is a lack of sexual education among PWD, which is a major issue for women in sexual relationships (Brennand & Santinele, 2022; Matin et al., 2021a). Sexual education programs should not only be adapted to the needs of the WWD, but they should also include caregivers within the process to ensure knowledge translation and carryover outside of the classroom (Matin et al., 2021a). The role of caregivers in sex education should not be overlooked, as the caregiver may have a good understanding of the specific educational needs of the PWD. Specifically for WWD, often times they have "a poor understanding of sexual knowledge that can lead to inappropriate behaviors and increase the likelihood of sexual abuse" (Matin et al., 2021a, p. 18). Evidence has also highlighted how parents are more likely to have conservative viewpoints regarding the sexual activity of WWD, specifically those with intellectual disability (Matin et al., 2021a). Providing WWD with the proper knowledge on how to navigate sexual relationships, can help to reduce unwanted outcomes of sexual intercourse, such as STI and unwanted pregnancies.





It is also important to recognize that some WWD feel that they have very little control over their own life decisions, including their sexual lives. For WWD who are living in a residential facility, the women's fertility is controlled by families and government policies. Instead of the WWD having autonomy over her own sexual life, she has to conform to what others want for her. Caregivers and family members can play a vital role with providing helpful information to the PWD about making decisions and developing autonomy over their own lives. Regarding sex-related education, some families may feel uncomfortable discussing these topics due to religious beliefs or sociocultural barriers. If caregivers are unable to provide adequate sexual health education for PWD, they should reach out to schools, therapists, or healthcare facilities to ensure they receive accurate information about safe sexual relationships (Matin et al., 2021a).

Caregivers may also have difficulties addressing sexual health information due to "inadequate training on this issue, conflicting parental wishes, lack of organizational policies, and lack of confidence" (Hole et al., 2022, p. 454). Therefore, as a family member or caregiver of WWD, it is important to identify supports within the community that can help assist with proper education on sexual relationships for this population. For more information regarding strategies to best support healthy sexuality among PWD, refer to the supplemental links at the end of this chapter.

Cognitive limitations among WWD can also leave individuals more vulnerable to STI, unwanted pregnancy, and sexual exploitation. Self-protection skills, such as "consent to sex and reporting the sexually abusive incidence should be taught" by either public or non-government organizations for WWD (Matin et al., 2021a, p. 18). Educating WWD on how to safely report concerns over sexual abuse could help to reduce feelings of stress in an already overwhelming situation. When educating WWD on sexual health, it is important to also consider their level of understanding so they are able to "attain the requisite knowledge to form relationships, understand sexual and romantic relationships, and practice safe sex when they choose this option" (Matin et al., 2021a, p. 1). Overall, as caregivers and family members of WWD, it is important to best support them with their sexual health as well as desires for sexual relationships.

Men's Sexual Health

Although there is limited research on men with disabilities (MWD) and sexual health, it is known that more men than women are affected by intellectual disability and there is a higher prominence of sexual abuse among MWD (Bollard, 2017; Malihi et al., 2021). Although understanding WWD's experiences and knowledge concerning sexual health is important, the sexual health of MWD should not be overlooked. When considering young men with disabilities, they were found to have a better understanding of sexual matters when compared to young women with disabilities (Baines et al., 2018). Although MWD may have a higher level of understanding relating to sex, that does not necessarily mean that this will translate to real life experiences (Baines et al., 2018). Within current research, it was found that "masturbation was the most common sexual behaviour" for MWD and that they are more likely to engage in the act than women with disabilities (Estruch-García et al., 2024, p. 512). The high frequency of men engaging in masturbation may explain why men have a higher level of sexual knowledge when compared to WWD (Estruch-García et al., 2024). Although masturbation may be seen as taboo within society, it is a way for individuals to meet their sexual needs. With that being said, caregivers can help to address this topic by having open conversations with the PWD as well as discussing where that behavior is and is not appropriate.

In a research study conducted in 2009, men with mild intellectual disabilities were engaging in risky sexual behaviors despite having adequate knowledge relating to sexual matters (Baines et al., 2018). With that being said, "people with intellectual disabilities looking for correct information on sex and contraception may" find it difficult to locate family planning clinics that can cater to their specific needs (Baines et al., 2018, p. 2). Within the literature, it was found that PWD were able to identify external body parts, however they found it difficult to identify internal body parts, such as the ovaries and testicles (Brkić-Jovanović et al., 2021). Although sexual intimacy among PWD is often overlooked, proper education is needed to ensure all people are being addressed, no matter their disability status.

Sexual vulnerability among men with intellectual disability is another important aspect to consider. Sexual vulnerability among MWD can include "people being coerced into sex, and the risks of seeking sex in public places" (Yacoub & Hall, 2009, p. 10). Although limited research is available regarding sexual matters relating to this population, past literature has shown that it is common for men with intellectual disabilities to have sex in public places and with other men (Yacoub & Hall, 2009). Increased rates of same-sex relationships among men with learning disabilities and autism has been supported within past literature, however more current research is needed to determine the current validity of those statements (Yacoub & Hall, 2009). For more information on the correlation of autistic individuals and identifying with the LGBTQIA+ community, refer to the supplemental links or John Strang's work.

For caregivers of men with intellectual disabilities, it is important to best support the individual by educating them on meeting partners in safer environments and utilizing contraceptives (Yacoub & Hall, 2009). Although having these conversations can be challenging, it is important to have open conversations to ensure safe sexual relationships.

Men with intellectual disabilities also tend to "experience less overprotection than their female counterparts," and increased access to opportunities without supervision can increase their risk of abuse (Tomsa et al., 2021, p. 13). Because MWD are less supervised within communities, they may experience higher rates of being alone in segregated contexts (Tomsa et al., 2021). With that being said, current literature has found that 27.5% of women and 50.8% of men were sexually abused within institutions (Tomsa et al., 2021). Although sexual abuse among MWD is not frequently discussed, unfortunately it does still occur. MWD are "more likely to report experiencing physical violence from family members... or friends ... than men without disabilities (Malihi et al., 2021). For MWD, it may be challenging for them to seek out help due to societal norms surrounding masculinity (Malihi et al., 2021). The disclosure of abuse is not an easy task, which highlights the importance of a strong support system, addressing societal norms, and providing proper education. Sexual health education is needed to not only help PWD understand the nuances of sexual relationships, but also to ensure that safe sexual practices are occurring nationwide.

Inappropriate Sexual Behaviors

Myths and stereotypes regarding PWD and sexuality are present within society, and they inevitably create barriers and stigma (Hole et al., 2021). This then can cause PWD to be at a "greater risk for sexual exploitation, disease, and/or mental health issues" (Hole et al., 2021, p. 454). Although people may think that PWD are asexual and not engaging in sexual desires, that is not the case. The number of people with intellectual disabilities in relationships and who are engaging in sexual intimacy is high, "with a prevalence ranging from 70.5% to 80.5% (Estruch-García et al., 2024, p. 512). Although sexual intimacy among this population should be accepted as a social norm, researchers have found that parents or staff of PWD have "chastised participants for physical intimacy, teased them when discussing sexual topics, and… participants' partners were not allowed to stay overnight" (Hole et al., 2021, p. 424). The overprotective and suppressive attitude towards PWD's relationships can negatively impact PWD and inevitably cause inappropriate or risky behaviors (Hole et al., 2021). A research study found PWD to engage in inappropriate sexual behaviors within residential settings because of the restrictive nature of staff members and the lack of privacy (Hollomotz & Speakup Committee, 2009). Inappropriate sexual behaviors, such as "disrobing, public masturbation, inappropriately touching others, publicly discussing sexual topics, and sexual arousal to atypical objects or individuals with potentially serious consequences," have also been observed in school age children as well as adults with developmental disabilities (Davis et al., 2016, p. 390).

Although inappropriate sexual behavior has been observed within the disabled population, it is important to recognize that most PWD will not engage in these behaviors. In a study including roughly 150 PWD, 9.3% touched their own private areas in public, 19.1% touched someone else's private area without consent, 6.3% discussed sexuality in a vulgar manner, 2.8% masturbated in public, and 6.3% had disrobed in public (Estruch-García et al., 2024). These behaviors are more common to be seen among PWD with higher support needs due to deficiencies in socialization and personal boundary skills (Estruch-García et al., 2024). It is also important to understand that children with developmental disabilities may have restricted access to instruction on appropriate behaviors during social participation with their peers, which can negatively impact their awareness of social factors relating to sexual health and behaviors (Davis et al., 2016). For PWD who engage in inappropriate sexual behaviors, it is also important to be aware of negative outcomes on the individual, such as social rejection, injury, and limited access to community participation (Davis et al., 2016). Currently, there is a lack of person-centered behavior targeted interventions relating to sexual behaviors with PWD, which can make it increasingly challenging for these behaviors to be properly addressed (Davis et al., 2016).

Although the prevalence of inappropriate sexual behaviors can vary between 6% to 28% among PWD, interventions to address these behaviors need to be openly discussed among various clinicians to promote acceptance and social awareness. Although there are interventions that have been utilized in the past, some are more effective than others. For example, differential reinforcement of alternative behaviors (DRA) has been successful with addressing inappropriate sexual behaviors among PWD in the past. DRA aims to identify the undesirable behavior (inappropriate sexual behavior), find a replacement behavior that is more socially acceptable and meets the same need, reinforce the alternative behavior, and not reinforce the undesired behavior. Although DRA with punishment has been proven to be effective with reducing unwanted sexual behaviors among PWD, it is important to understand that "unwanted sexual behaviors" is subjective based on the beliefs of the therapist addressing these concerns. Punishing a PWD for attempting to meet their sexual needs does not educate them on why the behavior is not okay. Punishment can also cause the individual to feel ashamed and potentially lead to a trauma response. The current literature highlights that punishment is not effective for behavioral interventions or that it is not as effective as other behavioral interventions. OTs aim to use functional ways address sexual needs in a way that best supports the individual without having to suppress feelings of sexual arousal.

Although person-centered functional interventions will vary based on the PWD's needs and desires, video modeling, sequencing cards, and visual aids can be utilized to assist the individuals with learning when and where it is socially acceptable to meet their sexual needs. It is also important to have open communication with the PWD to better understand and address their concerns (Falligant & Pence, 2020). In-depth information regarding inappropriate behavior interventions goes beyond the scope of this resource booklet.



For more information regarding person-centered interventions to address the sexual needs of PWD, consult an expert in the field (OT, case manager, behavior therapist, etc.) to determine what is best for the PWD. Also, please refer to the supplemental links at the end of this chapter for a free interactive educational resource regarding sexual behaviors, possible interventions, as well as family support.

Sexuality & Sexual Abuse

Like all individuals, "healthy sexuality best occurs through appropriate education, absence of coercion and violence, and developmental acquisition of skills to navigate feelings, desires, relationships, and social pressures" (Houtrow et al., 2021, p. 1). For PWD, it may be challenging for them to fully understand the nuances associated with sexuality and social constructs. Sexual satisfaction and intimacy are directly correlated with one's quality of life, making it an important topic of discussion. For a PWD who is seeking guidance or support with their sexuality, it is important as a caregiver to not instill judgement based on your own beliefs. Although you may have an opinion regarding their sexuality, it is ultimately the individual's decision. Healthcare providers can also help to educate PWD on sexual health if a caregiver is uncomfortable with having these open conversations. Like all individuals, PWD should be provided with ways to appropriately develop accurate knowledge relating to sexual health to ensure competency. Another way to provide PWD with knowledge regarding various sexual health topics is through the website AMAZE. AMAZE is a digital media platform that was created to assist young adults with medically accurate sex education topics. AMAZE also provides information on various ways for adults, parents, guardians, and educators with how to effectively communicate about sex and sexuality (Houtrow et al., 2021). For more information regarding AMAZE, please refer to the supplemental links at the end of this chapter.

Sexual violence and abuse is a public health concern that impacts all groups of people, no matter their ethnicity, religion, race, gender, or sexual orientation. According to the "2010 United States National Intimate Partner and Sexual Violence Survey (based on 16,507 respondents), both women and men with a self-reported disability (defined as physical, mental, or emotional problems) were at significantly increased risk of sexual coercion…and noncontact unwanted sexual experiences during the previous 12 months" (Basile et al., 2016, p. 931). Being pressured to have or engage in sexual acts can be both emotionally taxing and traumatizing. For WWD, sexual intimacy is not always pleasurable, as women are commonly fulfilling a passive role to "pleasure the penis" (Schaafsma et al., 2017, p. 33). Some WWD feel that this is necessary to maintain the relationship and satisfy men (Schaafsma et al., 2017). As a caregiver of PWD, it is vital to educate them on how to communicate their sexual desires to their partners, whether it is what the partner does or does not want to hear. It is also important to teach PWD on how to report sexual violence or abuse, to ensure their safety as well as their autonomy. Of PWD who have experienced and reported sexual violence, "43.5% of women and 60.0% of men never sought help" (Malihi et al., 2021, p. 329). People with and without disabilities should not have to engage in activities that they do not desire, and although that may seem obvious, it is important to vocalize this to PWD at a young age to ensure their safety in the future. As mentioned previously in this chapter, sexual abuse is more prominent among MWD, and as the severity of the intellectual disability increases, so does the risk for sexual abuse (Tomsa et al., 2021). PWD are an underserved population within many aspects of their lives. As a caregiver of a PWD, it is important that you or an expert in the area provides the individual with proper education on sexual health, safe sex, sexual abuse, and how they have the right to say no.

Supplemental Links

NATIONAL ADULT PROTECTIVE SERVICES ASSOCIATION ADDRESSING (NAPSA) CONSENT TO SEX FOR PWD: HTTPS://WWW.NAPSA-NOW.ORG/WP-CONTENT/UPLOADS/2020/05/2020-5-21-ADDRESSING-CAPACITY-TO-CONSENT-TO-SEX.PDF

AMAZE (DIGITAL MEDIA PWD CAN UTILIZE FOR INFORMATION ON MEDICALLY ACCURATE SEXUAL HEALTH INFORMATION): HTTPS://AMAZE.ORG/US/

SUPPORTING HEALTHY SEXUALITY RESOURCE AND FREE SELF - STUDY SEXUAL HEALTH COURSE: HTTPS://TASCC.CA/

CENTER FOR PARENT INFORMATION AND RESOURCES: HTTPS://WWW.PARENTCENTERHUB.ORG/

VANDERBILT KENNEDY CENTER PARENT GUIDE FOR PUBERTY FOR BOYS: HTTPS://VKC.VUMC.ORG/HEALTHYBODIES/FILES/HEALTHYBODIES-BOYS-WEB.PDF

VANDERBILT KENNEDY CENTER PARENT GUIDE FOR PUBERTY FOR GIRLS: HTTPS://VKC.VUMC.ORG/HEALTHYBODIES/FILES/HEALTHYBODIES-GIRLS-WEB.PDF

Supplemental Links

NATIONAL CENTER ON THE SEXUAL BEHAVIOR OF YOUTH:
HTTPS://WWW.NCSBY.ORG/RESOURCE-AND-EDUCATION

ATN/AIR-P PUBERTY AND ADOLESCENCE AUTISM RESOURCE TOOLKIT:
HTTPS://WWW.AUTISMSPEAKS.ORG/TOOL-KIT/ATNAIR-P-PUBERTY-AND-ADOLESCENCE-RESOURCE

INTERACTIVE RESOURCE GUIDE FOR SEXUAL DEVELOPMENT AND BEHAVIOR: HTTPS://WWW.VIRTUALLABSCHOOL.ORG/FOCUSED-TOPICS/SEXUAL-DEVELOPMENT-AND-BEHAVIOR-IN-K-12-STUDENTS/LESSON-1

SEXUALITY EDUCATION TOOLS AND RESOURCES
FAMILY LIFE AND SEXUAL HEALTH (FLASH) SEXUAL EDUCATION CURRICULUM: HTTPS://WWW.PLANNEDPARENTHOOD.ORG/PLANNED-PARENTHOOD-SOUTH-EAST-NORTH-FLORIDA/EDUCATION-PROGRAMS/FLASH#:%7E:TEXT=FAMILY%20LIFE%20AND%20SEXUAL%20HEALTH%20(FLASH)%20IS%20A%20COMPREHENSIVE%20SCIENCE,PREGNANCIES%2C%20STDS%20AND%20SEXUAL%20VIOLENCE.

DATE SMART PROGRAM:
HTTPS://STANFIELD.COM/PRODUCT/DATESMART/

CHILD PROTECTIVE PROGRAM:
HTTPS://STANFIELD.COM/PRODUCT/CHILD-SEXUAL-ABUSE-A-SOLUTION/

Supplemental Links

NATIONAL CENTER ON THE SEXUAL BEHAVIOR OF YOUTH:
HTTPS://WWW.NCSBY.ORG/RESOURCE-AND-EDUCATION

INTERACTIVE RESOURCE GUIDE FOR SEXUAL DEVELOPMENT AND BEHAVIOR: HTTPS://WWW.VIRTUALLABSCHOOL.ORG/FOCUSED-TOPICS/SEXUAL-DEVELOPMENT-AND-BEHAVIOR-IN-K-12-STUDENTS/LESSON-1

SEXUALITY EDUCATION TOOLS AND RESOURCES
FAMILY LIFE AND SEXUAL HEALTH (FLASH) SEXUAL EDUCATION CURRICULUM: HTTPS://WWW.PLANNEDPARENTHOOD.ORG/PLANNED-PARENTHOOD-SOUTH-EAST-NORTH-FLORIDA/EDUCATION-PROGRAMS/FLASH#:%7E:TEXT=FAMILY%20LIFE%20AND%20SEXUAL%20HEALTH%20(FLASH)%20IS%20A%20COMPREHENSIVE%20SCIENCE,PREGNANCIES%2C%20STDS%20AND%20SEXUAL%20VIOLENCE.

DATE SMART PROGRAM:
HTTPS://STANFIELD.COM/PRODUCT/DATESMART/

CHILD PROTECTIVE PROGRAM:
HTTPS://STANFIELD.COM/PRODUCT/CHILD-SEXUAL-ABUSE-A-SOLUTION/

JOHN STRANG AUTISM AND LGBTQIA+:
HTTPS://WWW.LIEBERTPUB.COM/DOI/10.1089/AUT.2023.0056.EDITORIAL

Supplemental Links

SOCIAL SKILLS AND BEHAVIORAL REGULATION RESOURCES:

HTTPS://DO2LEARN.COM/

SEXUAL WELLNESS YOUTUBE VIDEOS:

HTTPS://WWW.YOUTUBE.COM/@WATCHWELLCAST

PLANNED PARENTHOOD SEXUAL EDUCATION PROGRAM:

HTTPS://WWW.PLANNEDPARENTHOOD.ORG/LEARN/FOR-EDUCATORS

PLANNED PARENTHOOD TOOLS FOR TEENS:

HTTPS://WWW.PLANNEDPARENTHOOD.ORG/LEARN/TEENS/TOOLS-FOR-TEENS

SHEIDD REVIEW OF SEXUAL HEALTH EDUCATION CURRICULA FOR PEOPLE WITH DISABILITIES:

HTTPS://WWW.OHSU.EDU/SITES/DEFAULT/FILES/2019-08/REVIEW%20OF%20SEXUAL%20HEALTH%20EDUCATION%20CURRICULA%20DESIGNED%20FOR%20PEOPLE%20WITH%20DISABILITIES%208.2019.PDF

SIECUS COMPREHENSIVE SEX EDUCATION FOR YOUTH WITH DISABILITIES: HTTPS://SIECUS.ORG/WP-CONTENT/UPLOADS/2021/03/SIECUS-2021-YOUTH-WITH-DISABILITIES-CTA-1.PDF

Supplemental Links

RESPECT ABILITY SEXUAL EDUCATION RESOURCES:
HTTPS://WWW.RESPECTABILITY.ORG/RESOURCES/SEXUAL-EDUCATION-RESOURCES/

KENNEDY KRIEGER SEXUAL HEALTH AND IDD RESOURCES:
HTTPS://WWW.KENNEDYKRIEGER.ORG/SITES/DEFAULT/FILES/LIBRARY/DOCUMENTS/COMMUNITY/MARYLAND-CENTER-FOR-DEVELOPMENTAL-DISABILITIES-MCDD/SEXUAL%20HEALTH%20AND%20IDD%20RESOURCE%20HANDOUT.PDF

CENTER FOR PARENT INFORMATION AND RESOURCES ON SEXUAL EDUCATION: HTTPS://WWW.PARENTCENTERHUB.ORG/SEXED/

TALKING TO CHILDREN WITH COGNITIVE DISABILITIES:
HTTPS://WWW.BETTERHEALTH.VIC.GOV.AU/HEALTH/CONDITIONSANDTREATMENTS/TALKING-TO-CHILDREN-WITH-INTELLECTUAL-DISABILITIES-ABOUT-SEX#BHC-CONTENT

PHYSICAL LIMITATIONS AT OB/GYN:
HTTPS://CPRESOURCE.ORG/TOPIC/WOMENS-HEALTH/WHAT-KNOW-DURING-YOUR-OBGYN-APPOINTMENT

6

Potential Living Options





Considering where a person/people with disabilities (PWD) will live in the future is an important aspect of transitional planning. Residential environments are considered to be prominent social determinants of health that play a key role in optimizing one's quality of life. With that being said, "recent innovations and policy developments in the disability sector are now moving away from traditional congregated living settings and towards more individualized housing options" (Oliver et al., 2022, p. 1141). Individual housing for PWD not only aims to provide an increased sense of autonomy but also helps people to better immerse within the community. Allowing individuals with disabilities to have control over their housing choices fosters self-determination and empowers them to make decisions based on their own preferences and needs. Individualized housing has also been shown to positively influence socialization, mood, active participation within tasks, and challenging behaviors (Oliver et al., 2022).

Although long-term planning has been proven effective for PWD, caregivers have reported that they experienced challenges with supporting the complex needs of PWD (Lee & Burke, 2020). Transitioning a PWD to a new living environment can be overwhelming and challenging for caregivers and family members. One concern of parents and siblings was that there would be an increase in maladaptive behaviors that would negatively impact their new living experience (Burke et al., 2015; Rawson, 2010). For example, an individual may feel overwhelmed moving into a new environment, causing them to engage in self-injurious behaviors more frequently. This can negatively impact the safety of the PWD, as well as their ability to adapt to a new situation in a healthy manner. Another concern of family members were the nuances associated with aging (Lee & Burke, 2020). For any population, aging can be associated with various physical and mental changes. For PWD, changes such as limited mobility and dementia can require the individual to need additional support. Due to age-related factors, the future living plan may need to be altered to best support the new needs of the PWD. The last reason why family members were reluctant to plan for the future of the PWD was the fear of having to discuss parental death with the PWD (Baumbusch et al., 2017; Davys et al., 2015). Family members believed that the PWD had a limited understanding of death and they were therefore nervous to address this topic (Lee & Burke, 2020). Although this may be the case for the PWD, it is important to have these open and hard conversations. If the caregivers never address the loss of family members with the PWD, it will likely make it even more difficult when that time comes because they may not know what their future will hold. Although concerns exist regarding future planning for a PWD, it is important to consider how to effectively talk and listen to the PWD, as well as what possible living arrangements could best support the individual.

Types Of Living Arrangements

❶ Institutional Living

As mentioned previously, current best practice for PWD is to support them with individualized housing options instead of more segregated options (Oliver et al., 2022). As of 2020, “61% of people with IDD [intellectual and/or developmental disabilities] received long-term services and supports (LTSS) while living with a family member” (Residential Information Systems Project [RISP], n.d., p. 1). It was also found that “11% lived in a home of their own, 5% lived with a host or foster family, 15% lived in a group home shared by 6 or fewer people, and 8% lived in an IDD facility of 7 or more people, a nursing home or a psychiatric facility” (RISP, n.d., p. 1). Housing arrangements for PWD is considered to be a continuum, as each individual will have unique needs and desires relating to their living environment. There are four main stream housing options for PWD including institutions, group homes, living within the community with additional support, and living with family members (Oliver et al., 2022). Institutions are large residential centers for PWD that are predominantly closed (Oliver et al., 2022). Institutions were more prominent in the 20th century, although Medicaid was willing to pay for both institutional services as well as home/ community-based services (Mitra et al., 2022). It was not until the famous Olmstead versus L.C. case in 1999, where the United States Supreme Court came to the conclusion that unnecessary institutionalization was considered discrimination under the Americans With Disabilities Act (ADA) (Mitra et al., 2022). States were then able to provide reimbursement for community-based services for those with disabilities who would not benefit from being institutionalized (Mitra et al., 2022). The unmet social and community living outcomes of PWD were now able to be addressed through services provided within the community (Mitra et al., 2022). Institutions violate the basic human rights of PWD by limiting their autonomy, personalized care, and community integration. Although there is a recent push for community-based services for PWD, due to the gaps in community services for those with complex support needs, institutions still exist for PWD who are unable to live in the community. Institutions for PWD vary based on their specific needs. However, nursing homes, long-term care facilities, group homes, residential treatment centers, intermediate care facilities, psychiatric institutions, and assisted living facilities are all considered to be some form of an institution (RISP, n.d.). As of 2020, there are over 15,000 people with intellectual disabilities being served in large state-run facilities across 33 states (RISP, n.d.). Although state-run institutions do not typically provide the best care for PWD, unfortunately not all individuals with complex needs have people who are willing to take care of them throughout their lives. For more information regarding state-run institutions, refer to The Department of Developmental Disabilities or The Department of Health and Human Services website for the state in which the PWD resides.

❷ Supported Living & Group Homes



Supported living and group homes refer to smaller residential centers that have shared facilities and supports (Oliver et al., 2022). Supported living services (SLS) provide PWD with "support in home and in the communities" where they reside (Special Needs Alliance [SNA], n.d., p. 16). With SLS, PWD live in a house with 24/7 staff to ensure individuals are receiving support to promote safety for all (SNA, n.d.). With the closures of most institutions within The United States, group homes have become a popular alternative for housing support for PWD (Oliver et al., 2022). A relatively small Australian study with 30 PWD found that most of the people living in separate housing were happy with where and who they were living with (Fisher et al., 2021). Of the select few that were unhappy, it was because they did not have a say over where they wanted to live (Fisher et al., 2021). It is important as a caregiver to allow the PWD to be involved in the decisions about where they would like to live in the future. Although it may be unrealistic to accommodate all of the individual's desires, it is important to make the PWD feel that they have some control over their future.

The Australian study also found that most of the PWD included in the study preferred living with other people instead of living by themselves (Fisher et al., 2021). Sharing a house comes with several benefits, such as "economic savings… social gains from living with friends or peers…and benefits from having increased control over support arrangements" (Fisher et al., 2021, p. 66). Both formal and informal support were found to be important with ensuring success of shared arrangements (Fisher et al., 2021). Caregivers can play a vital role with supporting PWD through the transition to a new living arrangement. Although group homes offer more independence and autonomy for PWD, individuals are often "treated as service users or recipients of care" who have to live within the confinements of staff rules and expectations (Oliver et al., 2022, p. 1142). Several concerns have been raised about group homes, including the limited choices of residents relating to where they live as well as decreased participation and inadequate community engagement (Oliver et al., 2022). Also, PWD living in group homes are more susceptible to falling victim to abuse and neglect (Oliver et al., 2022). Due to these concerns, international trends are beginning to favor individualized housing options over group homes because community inclusion and self-determination are important factors to prioritize (Oliver et al., 2022). For more information regarding group homes and SLS in your community, consult The Department of Disability Services in the state the PWD resides and refer to the supplemental links at the end of this chapter.

❸ Independent Living

Independent living for PWD "provides support and services for individuals with I/DD so that they can live independently in their own home without 24/7 support" (SNA, n.d., p. 16). The goal of individualized housing is to "support people's choice and control over decisions that affect their lives" such as where they reside and what support they will receive (Oliver et al., 2022). The individual's choices can include small decisions, such as what meals they would like to eat, as well as larger decisions, such as what kind of external support they would like to receive (Oliver et al., 2022). Self-determination and autonomy have been directly correlated with one's quality of life, so giving a PWD control over their own housing arrangement (if possible), can help to promote increased life satisfaction (Oliver et al., 2022). Caregivers also play an important role with providing education and resources to best support PWD with living independently. Family members have mentioned their experience with locating appropriate rental properties, negotiating rental agreements, and helping to manage employed support staff as some of their responsibilities to best support continued independence (Oliver et al., 2022). While independent living has demonstrated better outcomes with participation in community activities, recreational opportunities, and control over decision making, group homes have demonstrated an increase in safety, health, money management, and planned activities (Oliver et al., 2022). More research is needed to determine the outcomes of individual housing arrangements for PWD (Oliver et al., 2022). For more information regarding individual housing arrangements, consult The Department of Disability Services in the state the PWD resides and refer to the supplemental links section at the end of this chapter.

❹ Family Living

The last mainstream housing arrangement for a PWD is to live with their family, companion, or a host family member, who can help to support the individual with day-to-day tasks (SNA, n.d., p. 16). Family living for a PWD refers to residing with family members "beyond the age when people would usually" move out (Oliver et al., 2022, p. 1142.). With this housing arrangement, the caregivers are aging, which can require additional planning for when the caregiver/s pass away. The relationship between family members and PWD is another important factor to consider, as this can either have a positive or negative effect on the empowerment of PWD within the community (Harrison et al., 2021). People with intellectual disabilities who received encouraging remarks from family members in social settings were more likely to develop higher self-esteem and a more positive self-image (Harrison et al., 2021). The current literature also suggests that "being close to family both figuratively and literally could improve the way people with intellectual disabilities felt about themselves" (Harrison et al., 2021, p. 988; Head et al., 2018). With that being said, living with family members who neglect or abuse PWD could result in devastating effects on the PWD (Harrison et al., 2021). Although family living may not be an appropriate or realistic option for all PWD, it is important for caregivers to consider the positives and negatives of all potential housing arrangements. For a PWD living with family members, they may have increased

access to emotional or physical support, safety, care coordination, and assistance with daily tasks. Although these support services will vary based on the needs and desires of the PWD, having a close relationship with family members or caregivers can help to better support the individual's complex needs through a person-centered focus. Although family living may have associated benefits for the PWD, it is also important to consider the possible negative implications, such as experiencing a loss of independence, reduced access to personal care (due to absence of training), limited privacy, and possible conflict with family relationships. Therefore, it is important to talk with the PWD to determine where they would like to reside in the future and weigh the pros and cons of each housing arrangement.

Planning For Independent Living

The life expectancy of adults with intellectual disabilities is increasing towards the life expectancy of the general population, highlighting the importance of planning for the future (Lee & Burke, 2020; Lin et al., 2016; Coyle et al., 2016). PWD are now outliving their parents, which is why future planning is currently a relevant and emerging topic within the IDD field (Lee & Burke, 2020). If planning options for the future are not considered, the PWD and family members are at "greater risk for negative outcomes such as inappropriate living conditions… and greater anxiety for families" (Lee & Burke, 2020, p. 94). A recent survey conducted by The Family and Individual Needs for Disability Supports (FINDS), found that about "54% of family caregivers reported that they did not develop future plans for their family members with IDD" (Lee & Burke, 2020, p. 94). And for the families who had conducted future planning for the PWD, the plans were not comprehensive (Lee & Burke, 2020). Another recent national study was completed regarding the prevalence of future planning and it was concluded that future planned activities included aspirational activities, such as locating an attorney (Burke et al., 2015).

Although aspirational planning is an important first step to consider, definitive future planning, such as developing a housing arrangement plan, is important to ensure the plan is properly executed when necessary. Although definitive planning is vital to support PWD with the future, the study found that this was infrequently completed by caregivers, potentially due to the lack of clarity and detail to properly execute the plan (Burke et al., 2015).

Future planning not only helps to better prepare parents with navigating housing arrangements for the PWD but also for their siblings (Coyle et al., 2014). Adult siblings of PWD "are the most likely people to be involved in the support of adults aging with I/DD, as parents die or become unable to provide care" (Coyle et al., 2014, p. 309). This is an important aspect to consider when planning for the future of a PWD, as siblings often have to pick up where their parents left off (Coyle et al., 2014). This can be an overwhelming and stressful time for siblings as they navigate the nuances and difficulties associated with finding permanent housing for the PWD if living with them is not an option (Coyle et al., 2014). Although some

siblings of PWD may not desire to be lifelong caregivers of their sibling with disabilities, two studies found that most siblings were willing to take on the caregiver role (Lee & Burke, 2020). The studies also found that when parents completed future planning early, it made the siblings feel less stressed and more willing to take on caregiver responsibilities (Lee & Burke, 2020). Therefore, as caregivers of a PWD, future planning not only helps to better support the individual with disabilities, but also other family members who may be involved in the long-term planning process.

The Technical Assistance Collaborative (TAC) currently has an ongoing data collection regarding the housing crisis of PWD (TAC, 2025). Their research has found that there is no housing market within The United States that supports individuals who live solely off of SSI without additional rental assistance (TAC, 2025). Due to the lack of affordable housing, many PWD have to live in nursing facilities or state hospitals, while others face the risk of homelessness or incarceration. (TAC, 2025). Although the housing crisis is due to numerous interconnected factors, since the ADA was passed in 1990, federal spending for various community services for PWD has tripled. However, federal money only covers a small portion of what is needed by states (Resnick & Blackbourn, 2009). Although federal standards exist for PWD, it is typically up to the individual state to determine services offered and the associated cost (Resnick & Blackbourn, 2009). As mentioned in Chapter 4, federal and state funding can be complex and often require significant planning for future housing and support services. More in depth information about government funding goes beyond the scope of this resource booklet. More information can be found in The Autism Speaks Opening Doors: A Discussion Of Residential Options For Adults Living With Autism And Related Disorders (page 35 to 39) (Resnick & Blackbourn, 2009). This resource briefly discusses various government funding options for several housing arrangements for PWD (Resnick & Blackbourn, 2009). Coordinating housing for a PWD can be a challenging and time-consuming process, so it is important to start this process early. It is also important to always consider how the PWD feels as well as their desires. If a housing plan is not person-centered, the individual's desires, abilities, and needs will not be adequately considered. This in turn can impact their ability to achieve independence, their safety and wellbeing, community integration, their financial situation, as well as their overall quality of life (Lee & Burke, 2020). For more information on housing insecurity, the housing market in your local community, and various resources and project initiatives, please refer to the supplemental links at the end of this chapter (TAC).



Supplemental Links



AUTISM HOUSING NETWORK:
HTTPS://WWW.AUTISMHOUSINGNETWORK.ORG/

OPENING DOORS RESIDENTIAL OPTIONS (FOR AUTISM AND RELATED DISORDERS):
HTTPS://WWW.AUTISMSPEAKS.ORG/SITES/DEFAULT/FILES/2018-08/OPENING_DOORS_RESIDENTIAL_OPTIONS.PDF

AMERICAN NETWORK OF COMMUNITY OPTIONS AND RESOURCES (ANCOR) (COMMUNITY SERVICES FOR PWD, INCLUDING RESIDENTIAL OPTIONS): HTTPS://WWW.ANCOR.ORG/

TECHNICAL ASSISTANCE COLLABORATIVE (TAC) (INFORMATION ABOUT AFFORDABLE HOUSING CRISIS FOR PWD):
HTTPS://WWW.TACINC.ORG/RESOURCES/PRICED-OUT/

THE ARC HOUSING INFORMATION: HTTPS://THEARC.ORG/POLICY-ADVOCACY/HOUSING/

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