



# Community Engagement for Adults with Cerebral Palsy

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### Abstract

Adults with cerebral palsy have the same desires as those without disabilities to create their own path to becoming independent, valued, and engaged members of their communities. Their goals can be difficult to achieve given the everyday challenges they face. As they transition out of the protected world of high school, they need to learn and manage a new set of laws, rules, and obstacles to achieving their goals. This chapter explores four key areas for adults with cerebral palsy as they pursue community engagement and independence. The four areas are transportation, home

health and support services (including attendant care), postsecondary education and work, and vocational services. Each section includes scientific literature and many other resources for both consumers and providers. A case scenario is also included that integrates each of these four areas, including challenges and solutions, from the perspective of an adult with cerebral palsy.

### Keywords

Adults with cerebral palsy · Community participation · Independent living · Employment · Assistive technology

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## Introduction

Adults with cerebral palsy (CP) have the same desires as those without disabilities to create their own path to becoming independent, valued, and engaged members of their communities. Their

goals can be difficult to achieve given the everyday challenges they face. As they transition out of the protected world of high school, they need to learn and manage a new set of laws, programs, and rules for achieving their adult life goals. There are various obstacles but there are also many private and public programs and social supports that are available to adults with CP to assist them with their goals. However, accessing them successfully requires knowledge, advocacy skills, coordination, and perseverance. Adults with CP have grown up with a disability, so most received services as children and adolescents, which are often (although not always) more coordinated than those available to adults. Transition from high school to the adult world for those with CP provides an opportunity for services and programs to be introduced or initiated but the adult service system is not as coordinated as the one that the youth or adolescent leaves behind at high school graduation. Some people with CP can manage these systems and programs independently or with occasional guidance, but others need more episodic or ongoing support. These are the same systems often needed by adults with disabilities that have been acquired in adulthood, but since this is all new and unfamiliar to them, they can be even more difficult for them to understand and manage. In some situations, adults with an acquired disability are involved with comprehensive discharge planning from medical and rehabilitation facilities that can be very helpful and can refer people to needed services.

There are a number of key areas that people with CP and their caregivers need to consider when planning what is needed to achieve desired life goals. This chapter explores four of these key areas for adults with CP as they pursue community engagement and independence. These are transportation, home health and support services (including attendant care), postsecondary education and work, and vocational services. Each section includes scientific literature and many other resources for both consumers and providers. A case scenario is also included that integrates each of these four areas, including challenges and solutions, from the perspective of an adult with CP.

## Goals and Environment

Social services and programs for adults with CP are designed to offer education, resources and opportunities for individuals to live their best lives based on their interests, strengths, and abilities. These services should, ideally, maximize the person's potential and abilities by providing the supports needed to participate fully within their community. This is true for both adults with CP and other lifelong disorders, as well as for those who have acquired disabilities in adulthood. However, adults with CP have experienced and worked within many programs and systems long before graduating from high school and entering adult life as opposed to people with disorders acquired in adulthood. Adults with CP have experienced more coordinated pediatric health care and education, often entering the service system through early intervention and children's hospitals and outpatient clinics. They and their families have had the advantage of having many "eyes" on them at various time points, at home, in school, and in the community.

People with CP have a wide variety of strengths and needs. They have had years to learn about both of these as they have evolved over time. They and their families and other caregivers have had opportunities to learn about advocacy and how to work with the pediatric, educational, and governmental systems. This is in contrast to people who have acquired disabilities in adulthood, who are beginning, as adults, to learn what is available to them, and how to advocate successfully for themselves and access appropriate programs, at the same time as they are learning about their disability. The adult service world is very different from the pediatric one. It is less comprehensive, more complex, and often fragmented, and takes time, knowledge, and skill to navigate.

Service needs often change over time, suggesting that they should be revisited over time and reconfigured when necessary to maximize abilities; however, not all programs have that flexibility. Young adults with motor disabilities described how social services and programs intended to assist them can actually be detrimental

by emphasizing a disability-based approach rather than focusing on the environmental adaptations and services needed to maximize their ability to work toward their goals (Darrach et al. 2010). Despite these issues, there are many groups – both governmental (local, state and federal) and private – that offer supports to individuals with CP depending on what they need to meet their goals of living meaningful and satisfying lives. Each has its own focus, personnel and requirements but all should empower the person by using an individual strength-based approach that has some flexibility depending on current needs. It is important for adults with CP to be involved in the conversations about services for them and to advocate for the services they need, using a service coordinator or other advocate to assist them if necessary. There are various advocacy agencies that can provide this help. Services and programs also change over time, so it is also important to seek out updated information. This chapter will focus on certain key social and vocational services, while recognizing that there are others that are beyond the scope of this chapter. The social services that will be discussed include transportation, home health and support services, assistive technology, and home and workplace accommodations. The vocational services discussed are training and supported employment and post-secondary education. Each of these life issues for individuals with CP will focus on how the service can impact community engagement and independence. The chapter will also discuss current literature and end with a case study to illustrate how an adult with CP and his caregivers navigate the social service and vocational systems to put appropriate and needed supports in place for him to achieve the quality of life that is important to him.

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## Techniques and Evidence of Effectiveness

### Transportation

Having accessible and reliable transportation is a key requirement for adults with CP to live with personal choice and independence in and beyond their own communities. For many people with CP,

the ability to travel for work, school, and medical appointments and to participate in social, leisure, and community and civic activities, such as voting, is dependent upon the availability of appropriate transit resources. Transportation is also critical for developing and sustaining social relationships, and for achieving happiness and a good quality of life. This is especially important because loneliness has been identified as a concern for some adults with CP (Balandin et al. 2006). In 2015, the US Department of Transportation (DOT) issued a policy statement affirming a commitment to the development of an accessible transit system so that all Americans can have equal access (<https://www.transportation.gov/sites/dot.gov/files/docs/accessibility-policy-statement-July-29-2015.pdf>). However, appropriate transportation can be difficult to find, coordinate and fund and is often described as an obstacle to community participation and independent living, rather than a facilitator (Scheer et al. 2003). This can be particularly true in rural areas where there are fewer public transit lines, and people may need to travel further to work and other social or medical appointments. A national study conducted by the United States Department of Transportation, Bureau of Transportation Statistics in 2003, indicated that 1.9 million people with disabilities never leave their homes, and of those, over 25% (560,000) indicated that they are homebound due to transportation difficulties (Bureau of Transportation Statistics 2003). Since the passage of the Americans with Disabilities Act (ADA), accessibility to transportation has improved; nevertheless, significant barriers are still reported. Access to transportation for people with disabilities is different depending on geographical location. Bezyak et al. (2017) surveyed 4161 people with disabilities who described a number of barriers to transportation. In urban areas, they reported issues with lack of knowledge by drivers, a failure to alert passengers of upcoming stops, poor driver attitudes, and lack of space in wheelchair accessible areas. In rural areas, the main problem was difficulty becoming eligible for paratransit. Almost half (47%) of those surveyed indicated that public transportation systems were inadequate to meet their needs for timely and efficient transportation (Bezyak et al. 2017).

Both users and their caregivers often cite transportation as a barrier to attending medical appointments and social engagements, to arriving and leaving work on time, or getting to work at all. Transportation services may be provided by State Vocational Rehabilitation (VR) agencies to enable individuals to participate in work services and training. If an individual has a vehicle or access to a vehicle, the state VR agency, under the rehabilitation technology service provision, may provide funding to adapt that vehicle to enable the individual to be transported. Examples of these adaptations are hand controls, swivel chairs, lowered floors, tie downs, and ramps. State VR agencies do not purchase the vehicles themselves for individuals, and obtaining the financing to buy the vehicles can also be a substantial barrier. Those seeking employment need to carefully consider transportation needs when looking for a job in a particular location because the lack of appropriate transportation can be a barrier to employment (Cook and Burke 2002; Magill-Evans et al. 2008), even if the person desires to work in that particular job (Rutkowski and Riehle 2009).

It is often difficult to find accessible public transportation for those who are unable to drive, or can drive but do not have access to a vehicle, or who do not have family members or caregivers who can drive them. Depending on where the individual lives, public transportation, although mandated to be accessible through the Americans with Disabilities Act, is often problematic. Even if individuals can use public transportation lines, buses and trains are not always equipped for wheeled mobility and stops may not be near destinations, like medical offices and work. Adults with a family friend, direct support care staff, or other adult to drive them describe the need to schedule their own appointments around those individuals' schedules, making unexpected medical or other visits particularly difficult (Scheer et al. 2003).

People who use transportation services designed specifically for those with disabilities, such as the paratransit system, often describe them as unreliable. Then can require several days to a week of advance booking, effectively restricting

social and work flexibility (Darrah et al. 2010; Scheer et al. 2003). Adults with significant restrictions in motor skills and leisure activities indicated that adapted transportation is essential to the accomplishment of these activities (Boucher et al. 2010), and the lack of transportation can also be a barrier to starting new leisure activities (Usuba et al. 2015). For those using wheelchairs, education about how to use them in and around transportation is critical for safety and efficiency, and not all wheelchair users, caregivers, and other healthcare providers have the education they need to use best practices for wheelchair transportation safety (Brinkey et al. 2009). Standards for wheelchairs and wheelchair use during transport are available through several sources including RESNA ([www.resna.org](http://www.resna.org)), University of Michigan Transportation Research Institute (<http://wc-transportation-safety.umtri.umich.edu/wts-standards>) and the Transportation Code of Federal Regulations (45 C.F.R. § 37 (2017)).

There are a number of funding or partial funding options for transportation solutions depending on the specific service needed and the individuals' eligibility. Public transit lines often offer reduced fares for people with disabilities, but such fares are frequently limited to off-peak hours. There are also cases in which individuals with CP may not be able to access any funding for transportation and may need to be creative with sharing or contracting for rides with transportation companies. For all of these services, there are federal rules and regulations as well as additional rules at the state level. Therefore, it is important for individuals to learn what is available in their own state. For public transit and paratransit systems, fares are posted online and may be paid by the rider, or in some cases, by Medicaid, if the rider is enrolled. States may have reduced fares available. Non-emergency medical transportation (NEMT) is a benefit for eligible Medicaid beneficiaries for transport to and from non-emergent Medicaid providers for medical appointments. Again, it is often reported that this transportation can be unreliable. The Centers for Medicare & Medicaid Services (CMS) provides multiple

documents on their website [www.cms.gov](http://www.cms.gov) that explain benefits, programs, and eligibility requirements. Transportation costs may also be covered by a Home and Community Medicaid waiver, so those individuals who currently have waiver funding, or are planning to apply for it, should check the waivers available in their state for transportation services and funding. A Medicaid waiver, which is funded by a combination of federal and state dollars, provides an individual with a disability the supports that are needed to live successfully in the community thereby “waiving” the old rules that provided those supports only in institutional settings.

All 50 states have waiver programs, but each state offers different waivers and waiver services for various populations. The Medicaid website lists all state waiver programs at: <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>. Eligibility is determined by functional and financial criteria. People with CP might qualify for waiver services if they need services to live independently and safely in a community setting that could otherwise be provided in a long-term care facility. When a person enrolls in a waiver, they receive a supports coordinator, who is an individual who helps the waiver participant define and access the supports and services they need to live independently. Transportation is one of a number of available waiver services. For those pursuing the purchase of an adapted van, there may be state grants, low-cost loans, or other programs available such as the Alternative Financing Programs which will be further discussed in the Assistive Technology section of this chapter. These programs are open to all people regardless of the type of disability or health condition. However, programs will vary as to the amount of money that can be borrowed as well as the terms and conditions of borrowing. It is also possible for an individual to obtain a low-interest loan from their bank or credit union depending on their credit worthiness. There are currently no state grants available to fund the purchase of the vehicle chassis, but there may be grants for the adaptations needed. To find such programs it is important for individuals to do a

thorough search at the time they look to make a purchase, either by themselves or while working with the assistance of a supports coordinator or case manager.

Another good starting reference for information about transportation is the Coordinating Council on Access and Mobility (CCAM) ([www.transit.dot.gov/ccam](http://www.transit.dot.gov/ccam)). This is a federal governmental interagency initiative established in 2004, to bring transportation services together under one website to improve services for people with disabilities, those with low income and older adults. The CCAM website provides an extensive resource library for those with disabilities and their caregivers to explore and find federal agencies and programs that can support transportation needs. However, actual services can vary widely across different geographical areas because funds for these programs are administered by states and local municipalities, potentially limiting availability. The United Cerebral Palsy Association ([www.ucp.org](http://www.ucp.org)) also provides a number of informational websites related to travel and transportation including air, land, wheeled mobility, and accessibility.

The ADA requires that public transportation organizations that operate public transit services in a particular geographical area (called fixed route services) also provide complementary accessible services for those with disabilities. These are called paratransit services, which are operated by various transit companies under different names in different states and different regions. There are specific detailed rules and regulations regarding all aspects of the federal administration of paratransit services that can be found at the following link: 49 CFR Part 37- Transportation Services for Individuals with Disabilities (ADA). Specific transit providers in different localities may have some different rules but must follow the basic rules and regulations set forth in the federal guidelines. Paratransit is an “origin to destination service” (49 C.F.R Section 37.129(a)) and is a service that is meant to be more flexible than public transit lines. These services can assist those with CP to get to and from work as well as other community activities and must provide

services to adults with disabilities on an individual basis to be certain that the origin to destination requirement is met (Federal transit administration <https://www.transit.dot.gov>).

Those seeking paratransit services must be determined to be eligible, which is determined by an application process. The applicant must also have a physician certify the need for paratransit services. A person with a disability may also need a personal care attendant (PCA) to successfully and safely ride complementary paratransit service or a fixed route transit lines. This must be approved through the application process. Personal care attendants are not allowed to be charged a fee on paratransit when riding with a person paying a fare but may be charged when riding a fixed route transit line. The rules regarding PCAs riding fixed route transit vary from state to state.

In summary, transportation is a critical service for community participation for adults with CP and is part of the ADA. However, in many communities, delivery and funding of transportation services are problematic. This section provided a summary of the current issues regarding transportation and a number of resources that can help any adult with CP find, apply for, and receive services. It is very important to remember that resources change often and vary state by state. If assistance is needed, information advocacy may be available through social service agencies like The Arc ([www.thearc.org](http://www.thearc.org)), local affiliates of the United Cerebral Palsy Association ([www.ucp.org](http://www.ucp.org)), and other local organizations and disability rights groups.

## Home Health and Support Services

This section will discuss both health and other support services that may take place in the home but are also important for the individual with CP to access community activities of their choosing, such as work, health and other appointments, volunteer work, visiting friends and family, leisure and recreation, and social events. Although many adults with CP are completely independent in their daily lives, there are others who need support

at varying levels. Support may be for activities of daily living (ADL), including basic personal activities such as dressing and personal hygiene and/or for instrumental activities of daily living (IADL), which are more complex skills used in everyday life such as using a telephone and making medical appointments (Frisch and Msall 2013). IADLs also include social and recreational activities, either at home or in the community, and are important for meaningful community participation and personal choice. For adults with CP who need these services, they are essential to successfully live in their homes and participate in their communities safely and efficiently. For some individuals with more significant mobility limitations, particularly those people whose motor skills are classified at GMFCS level IV or V, support services are needed for many daily life activities as soon as they transition out of school and their family homes into community living or to postsecondary education. In the United States, most of the long-term care and support is delivered by unpaid family members or friends ([www.KFF.org](http://www.KFF.org)), but there are other avenues for long-term care as family members age or are otherwise unable to provide the care that their adult children with CP may need.

These support services are known by several designations, including Personal Care Attendants (PCA), Assistant Attendant Care, Direct Support Personnel (DSP), or home health aides. There is abundant literature about the positive effects of participation in the community for mental and physical health as well as independence and self-efficacy (Crawford et al. 2008; Dattilo et al. 2008). Usuba and colleagues (Usuba et al. 2015) reported the second most common barrier to participation in leisure time physical activity by adults with CP who live in the community was lack of time with attendant care. Some adults with CP indicate that they are lonely, particularly if they do not work or have never worked (Balandin et al. 2006). Some of the other factors that have been suggested to impact social interaction are communication difficulties (Balandin et al. 2006, Ballin and Balandin 2007; Cooper et al. 2009), lack of satisfactory community participation and social connectivity, and, potentially, a change in residence

that can take an individual away from family and friends (Ballin and Balandin 2007). Social support can take a number of forms and has been shown to be important to adults with CP (Horsman et al. 2010). Having friends and social networks at home and in community venues include family, housemates, church, and clubs. Adults with CP who were interviewed about loneliness indicated that these social networks at home and in the community are important for socialization and support (Ballin and Balandin 2007) and may be dependent upon their attendant care to access successfully. Some of these individuals with CP, but not all, talked about their care staff as friends, as people they socialize with while still acknowledging that they are paid as attendant care staff. Others felt that developing friendships with staff can be difficult and risky particularly if there is significant turnover (Ballin and Balandin 2007).

Being a PCA is a very important and demanding position. It is critical that attendant care staff allow individuals with CP to make their own choices regarding important decisions in their lives. Attendant care staff must also treat individuals with CP with dignity and respect. There are no federal training requirements for direct care support staff who are paid by public funds, which is mainly through Medicaid, so training requirements vary from state to state (Marquand and Chapman 2014). However, PCAs should receive ongoing and appropriate education and training about the general issues of disability as well as the specific issues related to CP, and particularly for the individual they are supporting. There are many potential areas of education and training and different curricula that should be included for staff depending on the needs of the client. Examples of these for the caregiver working with someone with CP are how to lift clients safely and comfortably; how to use and care for adaptive equipment; how to administer medication and control infections; how to handle emergency situations; how to provide basic personal care such as bathing, eating, dressing, and oral hygiene; how to communicate effectively with clients with intellectual disabilities and/or communication difficulties; how to manage behaviors that may arise; how to respect client choice and

client privacy; and how to take clients out into the community for appointments, social recreation, and leisure. Staff may work for an agency or can be hired directly by clients or their families. Training should be ongoing and revisited over time. If a direct support staff member is hired directly by the client or family, either the staff member or client will need to seek out training and education, which can be provided by a variety of human services agencies or state agencies. State certifications may also be available for direct care staff and may be required to work for agencies that bill Medicaid or Medicare for their services.

Generally, skilled home health care, such as nursing, physical, occupational, or speech therapy, is provided on a temporary basis and the amount of service provided and payment depends on the funding source. This may be for a specific episode of care, such as postsurgical or postinjury care, or can be for episodes of increased pain, decreasing function or other needs that may arise as the individual ages. Either Part A or Part B of Medicare can pay for home health care, both skilled and nonskilled, but only on a temporary basis and not for long-term care (also called “custodial” care), which includes ADL needs like dressing and bathing. If Medicare will be paying for these services, they will generally be provided by individuals who are employed by agencies who must be Medicare-approved. Adults with disabilities who are on the Social Security Disability Insurance (SSDI) program also have Medicare benefits even though they are younger than age 65, which is the time when people without disabilities are eligible. There are some individuals who have both Medicare benefits and Medicaid benefits, the latter because of they are low income or eligible for waiver services. These people have what is termed “dual eligibility,” so benefits coordination between these plans, which can be complex, is important for individuals or caregivers to understand and put into place. Advocates who are employed by agencies and service coordinators who are part of the Medicaid Managed care plans that cover the individuals can help with this benefits coordination.

For intermittent health care support in the home, private insurance plans paid for by the

consumer or through employment, or insurance such as Medicare advantage plans that are paid for by the consumer, can fund these services. Since Medicaid services are different from state to state, it may also pay for these services depending on in which state the person is living. Medicare does not pay for long-term or 24-h care, or personal care or homemaker services which adults with CP who have significant disabilities may need ([www.medicare.gov](http://www.medicare.gov)). Medicare also does not pay for attendants to take people out of the home to participate in their communities. In these cases, a different funding mechanism is necessary. For those individuals with CP who have low incomes, Medicaid is the primary funder of this kind of long-term care and support (Reaves and Musumeci 2015) through waivers, as discussed in the last section. For those people who are not covered by waivers, there may be other funding mechanisms such as through Medicaid or individual budgets funded by State Divisions of Developmental Disabilities (DDD). Similar to waivers, there is generally a supports coordinator the individual meets with to map out services and supports necessary to live in the community. Not all states have this funding mechanism, but for those that do (legislatively designated as “Developmental Disability” states as opposed to Intellectual Disability states), individuals can qualify depending on their level of disability. These services and the funding for the cost plays a very important role in the lives of people with CP who want to live as independently as possible but who may need ongoing support in the home and in the community.

### **Assistive Technology and Home and Workplace Accessibility Accommodations**

#### **Assistive Technology**

Assistive technology (AT) is another important component for supporting a rewarding life for many adults with CP. AT can make it possible for someone to live more independently at home, participate in the community, go to school or work, and excel in those activities. Individuals with disabilities can exercise choice in their daily

lives with more autonomy and be less dependent on family members and caregivers with the use of AT. There are many types of AT, but this section of the chapter will focus on AT laws and funding, AT solutions for the home and the workplace, and vehicle adaptations.

AT has been shown to be effective to improve independence, function, and community participation in people with disabilities in the USA and other parts of the world (World Health Organization Press 2011) and to be beneficial for those living in the community using AT for everyday activities (Hammel et al. 2002). In older adults with physical disabilities, AT has been shown to assist in preventing functional decline and decreasing caregiver support. Adults with physical disabilities, including people with CP, were given AT for home ADLs and IADLs and compared to a group not provided with AT at both 12 and 24 months. Results indicated a slower progression in functional decline in those using AT and significantly more independence with tasks which decreased the need for personal care support (Wilson et al. 2009). Mortenson et al. (2013) found similar results after providing AT to a group of older individuals with physical disabilities and their caregivers. Those users who received AT reported significantly higher accomplishment and performance satisfaction and decreased difficulty with selected activities performed with their caregivers. Caregivers reported a decreased burden during the same selected activities with users (Mortenson et al. 2013). Adults with physical disabilities and mobility limitations may use mobility devices such as walkers and canes. These devices have also been shown to improve walking ability and feelings of safety while walking in this group of adults; however, they need to be used properly to avoid an additional risk of falling due to their potential destabilizing effect and the physical demands of using them (Bateni and Maki 2005). Although this study included elderly people with physical mobility deficits and did not include adults with cerebral palsy, it is reasonable to consider that some of these issues may be similar for adults with CP who wish to walk and need assistance.

Children with CP are required to be provided with AT at no cost, if needed to assist them to meet their education-related goals and objectives in school, as part of their Individual Educational Plans (IEP) under the Individuals with Disabilities Education Act (IDEA) as of 2004. This legislation also provides for AT training for school personnel who are working with children who are using AT. Students who are not eligible to receive special education under IDEA, may still be able to receive AT in school under Section 504 of the Rehabilitation Act of 1973 (known as the Rehab Act), if it is needed to meet their educational goals. However, adults who have aged out of school need to find other mechanisms for funding their AT. The federal Assistive Technology Act of 1998, amended in 2004 (also known as the “AT Act”) defines assistive technology as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” [PL 108–364, 118 Stat, 1710 § 3(4)] (Public Law 108–364: Assistive Technology Act of 1998, 2004). This law also defines assistive technology services as including evaluation, acquisition, maintenance, repair, coordination with other service providers, and training and technical assistance among others [PL 108–364, 118 Stat, 1710 § 3(5)] (Public Law 108–364: Assistive Technology Act of 1998, 2004). There is a wide range and scope of AT devices – so wide so that it can be difficult for a practitioner to figure out which device(s) can best meet the needs of the individual. The solution is to examine the functional need that is identified and then look for the AT that will best address that need.

AT can be categorized into different types. Categories include (1) Durable Medical Equipment (DME), such as wheelchairs, scooters, walkers, lifting devices, hospital beds, and bath chairs; (2) Home adaptations or modifications, such as widened doorways, roll-in showers, ramps; (3) Vehicle adaptations, such as tie-downs for wheelchairs, ramps, lowered floors, and hand controls; and (4) general AT devices, such as hearing aids, augmentative communication systems, stair glides, seat lift chairs, phones

that are compatible with hearing aids or have large buttons or are voice-activated, and smart home technology.

These distinctions are important to understand because there are different possible funding resources depending on the types of AT needed. For example, health insurance policies, including Medicaid and Medicare, will often pay for Durable Medical Equipment (DME). Waiver programs, vocational rehabilitation, and some non-profit foundations may pay for home adaptations or vehicle modifications. Smart home devices, if classified as AT, are a covered service under many of the waivers because these devices help individuals with disabilities to live safely and more independently in their home.

AT should not be planned, ordered, or used in isolation. The adult with CP and family members and/or other caregivers should be part of the conversation about the AT before it is ordered and during the time it is being used. Additionally, there are AT services that can and should be used when purchasing and using AT. Each state and territory in the United States has an AT program created and funded under the federal AT Act of 1998, and amended in 2004, as mentioned above. These programs are administered through the Administration for Community Living’s (ACL) Center for Integrated Programs, Office of Consumer Access and Determination within the US Department of Health and Human Services. ACL maintains a richly sourced website at <https://www.acl.gov/programs> with information on programs for community living, assistive technology, employment, grants for AT for State Programs, and many other disability-related topics. Basic information on state and territory AT programs, their activities and programs, leadership activities, and state partners can be accessed through ACL and are listed at: [www.catada.info](http://www.catada.info). Each state has a somewhat different focus, but all states have a combination of AT demonstration programs, AT equipment lending libraries, AT reuse programs, and state financing activities. Most programs provide training opportunities as well as Information and Assistance services.

As part of the AT Act, Congress also provides annual grant opportunities for states and nonprofit

organizations to establish and expand Alternative Financing Programs (AFPs). Alternative financing includes several mechanisms for attaining AT such as low interest or no interest loans. Currently 42 states and US territories operate such programs. Alternative financing programs are important because they can provide loans to people who would not qualify for financing from traditional banks or who could not afford the high-interest rates and short repayment periods associated with such loans on those rare occasions when they are made available. Programs vary from state to state. Here are two examples of the types of programs states may provide: the Pennsylvania Assistive Technology Foundation (PATF) (<https://patf.us>) is a nonprofit Community Development Financial Institution that provides education and financing opportunities for the purchase of AT. PATF provides Information and Assistance about possible funding resources. It also has three loan products, including credit-building “mini-loans” (0% interest with no fees) for purchases under \$2000 and low-interest, guaranteed and non-guaranteed loans, with no fees, for larger AT purchases (up to \$60,000). PATF also reports repayments to the credit reporting bureaus so that borrowers have an opportunity to increase their credit-worthiness. PATF also provides financial education opportunities for people with disabilities and their families so that they can learn new skills and be more in control of their financial future. PATF and the National Disability Institute (NDI) work with the FDIC, Consumer Financial Protection Bureau, and the National Endowment for Financial Education (NEFE) to provide scenarios and disability-specific information in their financial education materials.

The Idaho Assistive Technology Project (IATP) (<https://idahoot.org>) is housed within their state AT program. The IATP Finance Program also has a low-interest, guaranteed and non-guaranteed, loan program for amounts that range from \$500 to \$10,000. Staff also provide consumers with financial education opportunities. There is a downloadable listing of each state APF at: <https://patf.us/who-we-are/>

Other potential sources of funding for AT include State vocational rehabilitation (VR)

services, private insurance, Medicaid and Medicare, or other human services charitable organizations. State VR offices fund AT that is related to improving the ability of an individual to prepare for, attain, and keep employment. Depending on the specific plan, private insurance may pay for DME that is deemed “medically necessary.” Medicaid can be a funding source for people who are eligible due to low income and resources but generally only for equipment that is “medically necessary.” Medicaid can also fund AT for individuals on waiver services as already discussed or through the Supports Programs through the State Divisions of Developmental Disabilities (DDD) or Human Services. But again, these programs and what they provide are different from state to state and waiver to waiver, so consumers, family members, or other caregivers need to find out what is available in the state in which they live. If a person with CP is already on Medicaid for health insurance, on a waiver, or a client of a state DDD, case managers in those programs can assist with more specific information about Assistive Technology. Medicare may fund AT under the category of DME under Part B. For a detailed list of funding sources, the following website will be a helpful place to start: <https://www.atia.org/at-resources/what-is-at/resources-funding-guide/>

### **Home Modifications and Accessibility Adaptations**

Home modifications, by definition, make a physical or structural change to a home and can include many different types of AT depending on the needs of the user. Examples of modifications for inside the home are lowered kitchen counters, stair railings, stair lifts, roll-in showers for wheelchair users, expanded doorways, and automatic door openers and door sensors. These modifications can range from the simple and inexpensive to the complex and expensive. Examples of modifications outside the home include ramps, porch lifts, and railings for steps into and out of the house. These are important to enable access to the neighborhood and transportation. After examining data on the effectiveness of home

modifications for 266 individuals who used public funding in England, Wales, and Northern Ireland, researchers confirmed that these expenditures made users feel more independent and confident and improved their health and well-being. Benefits came from both minor (handrails and grab bars) and major adaptations (bathroom modifications). The authors did find that there can be problems with home modifications, particularly with larger changes, but the research demonstrated that good results can be obtained even with major home modifications when all family members, including the individual with a disability, were part of the planning decision-making process and the integrity of the home was considered (Heywood 2001).

### Other Assistive Technology Devices

Other AT devices, including sensory devices, tablets, and other communication devices, are an integral part of life today. These devices make it possible for people to hear and see, communicate and interact with others, learn, and play. Telecommunication devices can remove barriers to participation in everyday life. They provide opportunities for people to access and relay information, keep in touch with family and friends, access medical personnel, search for and apply for employment and educational opportunities, and keep safe in the event of an emergency. In 2010, Congress passed P.L. 111–260, the Twenty-First Century Communications and Video Accessibility Act (CVAA). This law was passed to ensure that persons with disabilities have access to and can fully use technology for communication and equipment that is current, including video programming. This includes online video closed captioning, access to the internet, use of mobile and other phones, mobile phone internet browsers, and other communication devices and services. This also includes electronic messaging, instant messaging, and video programming and communications (Federal Communications Commission Consumer Guide 2016). The law also required that the FCC keep a clearing house for information on accessible devices, which can be found at [\[services/mobile-devices/region-na/all-manufacturer/all-blind-features/all-cognitive-features/all-hearing-features/all-mobility-features/all-physical-features/page-1-of-5/show-100/\]\(https://ach.fcc.gov/products-and-services/mobile-devices/region-na/all-manufacturer/all-blind-features/all-cognitive-features/all-hearing-features/all-mobility-features/all-physical-features/page-1-of-5/show-100/\). Consumers can use this website to look for specific features they are interested in or to look at the specifications for products such as wireless phones, smart TVs, and mobile apps. This law also provides for manufacturers and service providers to develop options for consumer accessibility or to ensure that products are compatible with equipment already used by the consumer with a disability and for a complaint process if consumers have accessibility issues. This does not mean that there is funding for all of these devices and services for people with disabilities; however, there are programs for people with low income to access services such as support services for telecommunication accessibility issues. Consumers with disabilities should contact their service providers for assistance for specific issues.](https://ach.fcc.gov/products-and-</a></p></div><div data-bbox=)

Technology is changing rapidly and there are now devices that are affordable, easy to purchase, and can make lives much easier than were not available even 5 years ago. This is evident in the types of smart home devices an individual with CP can use to improve the quality of life at home and make home living more efficient and safer. Examples of these are the Amazon Echo (aka Alexa)<sup>®</sup>, Google Home<sup>®</sup>, and the Nest<sup>®</sup> devices used for home or office device control. These are voice- or app-controlled devices that can be used to perform daily tasks and can be used in conjunction with smart home appliances and devices already on the market. Smart home appliances can be purchased and paired with the Echo<sup>®</sup> for the person who has limited mobility or manual dexterity. Some of the tasks these devices can do are playing music, making telephone calls, controlling the TV, answering questions, and contacting a friend or relative in case of a fall or in the event that the person needs help. Some of these devices require additional apps and set up, but they can still be installed fairly easily (Metcalf 2017; Sperling 2017). There are also several different voice-activated adaptive telephones to allow people to use the phone hands free.

## Workplace Modifications

The ability to find and sustain employment in the community is critical for people with CP for a myriad of reasons. Work makes people feel like a valued contributor to society; it allows people to learn skills, gain independence, and to lessen their economic dependence on public funding and programs. It also provides opportunities for community inclusion and socialization. This is true for adults who have acquired a disability in adulthood as well. Depending on the type of disability, a change in work life may need to be considered. People with CP, as a group, have high un- and underemployment, which will be discussed in the next section in more detail. But rehabilitation technology in the workplace – which can include AT devices and services and rehabilitation engineering services to reduce barriers in work areas – have been shown to increase the odds of employment (Huang et al. 2013). Title I of the Americans with Disabilities Act (ADA) requires an employer to provide reasonable accommodations in the workplace so the person with the disability can have an equal opportunity to secure employment and to be successful in their work environments. In 2012, the US Government asked the National Academies of Sciences, Engineering and Medicine to organize a group of experts to collect data from the existing literature, the public, and recognized experts to analyze specific devices and services to better understand: (1) their availability to consumers with disabilities, (2) how they are being selected and used, (3) whether employers provide access to them, (4) costs for all aspects of equipment use, (5) who is using the AT devices and services and to what extent, and (6) how they have impacted success in the workplace. The published report (Jette et al. 2017) is available as either a summary or a full pdf report at no cost or can be purchased in paperback or E-book formats, at this website: <http://nationalacademies.org/hmd/reports/2017/promise-of-assistive-technology-to-enhance-activity-and-work-participation.aspx>. There are a number of important conclusions from this report. To summarize, AT devices that provide accommodations can be positive moderating factors for success in the

workplace, but they need to be correctly prescribed and used. Even so, depending on other environmental factors and personal factors, AT may not fully remove the limitations experienced by the user. The Academy also found significant variability in availability of AT both in terms of geography and funding, causing some individuals to lack access, which can affect workplace performance. Funding models also vary, with some agencies providing a greater range of devices and technologies than others. They also stressed the importance of education on AT, but AT development is advancing at such a rapid rate that it difficult for service providers and others to stay informed. Additionally, to best understand how successful a device is for a particular individual, professional evaluation needs to consider the personal, environmental, and societal factors at play (Jette et al. 2017). The report also discussed the need for more research to better understand the impact of AT on inclusion and work.

There are many people with CP who are working successfully and need few, if any, accommodations. However, for those who do need them, accommodations can be physical, such as accessible restrooms, enlarged doorways and ramps, or related to technology, such as accessible communication and software. Companies may also need to make policy adaptations that can include work hours, break times, and schedules (Accommodations 2017). The Job Accommodation Network (JAN), a technical assistance organization funded by the US Department of Labor, Office of Disability Employment Policy (ODEP), lists potential accommodations by disability, by topic, and by limitation on their website at <https://askjan.org/links/atoz.htm>. Prior to working out accommodations, there are a number of questions that need to be asked, including the specific type(s) of limitation(s), how the work and specific job tasks are affected, and how much education the employee's supervisor and other personnel need about CP and necessary and appropriate accommodations. Employers often need to know the best ways to provide accommodations for people with CP specifically, especially for those who have mobility and

communication needs (Huang et al. 2013). It is also important to be sure that the employee has been a part of the conversation about modifications. They are the most knowledgeable about their needs. If there is a job coach or advocate, that individual should also be involved in the discussion. Many accommodations do not require complex, expensive solutions, but there are some that do. Some of the accommodations listed by the JAN are for things like parking spaces closer to the door to the workspace, motorized carts for mobility over long distances, and close proximity to restrooms and lunch rooms. People with CP may also need the services of a job coach or personal care attendant, and this person would need physical space in the workplace near the individual they are serving. In some cases, reduced work time and extra rest times may be necessary if fatigue is a problem. Other accommodations that are listed include alternative keyboards, desk ergonomics, and adaptive telecommunications as discussed above. For individuals with cognitive impairments, accommodations could include specialized instructions, “carved out” parts of jobs (when the individual could not do the entire job), extra structure, and an onsite job coach to assist both the employee and employer. These support persons are funded by Offices of Vocational Rehabilitation for individuals who are eligible for their services. This will be discussed in more detail in the next section.

### **Postsecondary Education, Work, and Vocational Services**

Adults with CP can and should be able to enjoy a meaningful and satisfying life after high school graduation. School, work, career, and employment are goals for everyone, including those with CP. Most people want to work in some way. Work and volunteering gives people purpose in life, brings them into their communities, and can provide skills and social outlets. This section will discuss issues related to postsecondary education, career, and work and provide information and strategies on how people with CP can accomplish these life goals.

### **Postsecondary Education**

Postsecondary education is an appropriate option to build a career and one which is within the reach of many people with CP. Programs can be degree conferring in a university or community college, or more skill related such as in a technical/vocational school or technical skill certifications for specific jobs. Students should be sure to investigate their eligibility for scholarships and loans for certificate programs that do not confer a degree. If they are not eligible for scholarships or loans, vocational rehabilitation or waiver services may help to fund those programs. As high school students plan to transition to life after school, they should be planning their futures just like anyone who is nearing graduation. For people with CP, this can be a complex process and require support from the school special education personnel, the VR office, and other relevant agencies to determine the best solutions to any accommodations needed for campus living, mobility, transportation, communication, and academic life. When leaving the public educational system, postsecondary plans should be in place for immediate life after graduation, although they will likely continue to evolve as needs become more apparent and situations change. Some of the important laws that address postsecondary education that can assist students with needed accommodations and modifications are the Americans with Disabilities Act (ADA), The Assistive Technology Act (AT Act), already discussed above, and Section 504 of the Rehab Act. These laws also provide support for people entering the workplace which will be discussed in the next section. In terms of postsecondary education, all of these laws prohibit discrimination on the basis of disability and each covers different aspects of what may be needed by a student with CP on a college campus to be successful. It is helpful for students to be knowledgeable about these laws. In addition, the VR program can provide financial support to assist with educational expenses not otherwise covered, including those that are specifically disability related such as PCAs and other educational support services and personnel (U.S. Department of Education 2017).

Schools may not deny an individual admission as long as the person meets the basic requirements for admission, nor can a school charge a person with a disability more for their education than any other student who does not have a disability. Prospective students also need an understanding of their rights and responsibilities in requesting accommodations. First, the student should research schools that meet their academic needs, like any college-bound student; they should also research other issues about the school, including building and facility accessibility, physical layout of the campus, campus and surrounding transportation, academic supports, and other disability services and accommodations the schools provide. Students with disabilities talk about the value of having faculty members they can talk to who are knowledgeable about issues facing students with a disability (Dowrick et al. 2005) and having faculty mentors who can help when facing obstacles (Timmerman and Mulvihill 2015). All schools must provide basic disability services, but some may provide more of what an individual student is looking for and may be more welcoming to a student with a physical disability than others. For example, if a student wishes to live on campus and requires a PCA, this needs to be planned out in advance. This process will be different from the pre-college years, when, most often, the family provided most of the needed care. In this situation, the student will be responsible for finding the funding and hiring and training their attendant and working with that person on an everyday basis (Burwell et al. 2015). As was mentioned above, attendant care may be paid for through several funding options like Medicaid, a Medicaid waiver, VR, or privately. Hiring and training can be done through an agency or privately, but in either case, it is important for the student to know what they will need the attendant to do and the university physical environment, so they can hire the appropriate person and make sure they receive the correct training. If the student hires their own attendant, rather than using an agency, they need to be aware that they will need to take a larger role in the hiring process and may not have back up help if the PCA is unable to attend on a given day, unless the student has

planned for that. If the student is unable to do all of the hiring and training, this can be accomplished with the help of family and/or an advocate and/or VR counselor prior to the beginning of school. Additionally, if the PCA will be providing 24/7 care, the student should discuss and may need to negotiate where their PCA will live to be accessible to the student during the night hours. That will be illustrated in the case scenario. This is a process that will give students the opportunity to take more responsibility for their own lives, learn to self-advocate, and develop positive relationships with their attendants (Burwell et al. 2015).

After deciding which schools to apply to, the student must identify himself or herself to the school as a person with a disability in order to request accommodations. This is always a voluntary disclosure and can be difficult for the student, but in order to receive appropriate accommodations, this is an important first step, and an open dialogue is very helpful for successful inclusion into the college environment. This information is confidential and is handled by the school's Office of Disability Services. Each school will have its own process, but the process usually encompasses meeting with Disability office staff, providing documentation of the disability, and discussing needed accommodations and how they will be accomplished. Schools do not have to provide any and all modifications requested but need to abide by the laws that govern accommodations. Even if the process has gone well from the outset, there may be issues that come up, and students will need to advocate for what they need. If particular issues are not resolved satisfactorily, all schools must have a grievance process.

### **Work and Vocational Services**

Unfortunately, people with disabilities, including CP, have and continue to have high rates of unemployment and underemployment. The 2016 American Community Survey shows the percentage of employment for persons age 16 and older with disabilities to be 23.4%, compared to 66.8% for those with no disability (US Census Bureau 2016). Additionally, according to the Bureau of Labor Statistics 2016 Census data, adults over age 16 with disabilities are more likely than those

without a disability to be employed part-time rather than full-time (Bureau of Labor Statistics 2017). These data include people with CP as well as a number of other disabilities including intellectual disabilities, which sometimes may accompany CP. Adults with acquired disabilities, not just those with lifelong disabilities such as CP, may have these same issues. Some of the factors found to positively impact employment are gender (men are employed more than women), higher cognitive function, access to transportation, positive employer attitudes, and physical accessibility (Magill-Evans et al. 2008). Higher educational level has been found to predict employment in some studies (Huang et al. 2013; Murphy et al. 2000) but not others (Magill-Evans et al. 2008). Specific barriers limiting mobility and employment sites were identified by Berbrayer (2016). Participants in this Canadian study identified the lack of timely accessible transportation, limitations in the physical environment such as the dimensions and accessibility of restrooms, elevators and lunchrooms, and computer and telephone access as the main barriers to employment (Berbrayer 2016). Other job services, provided by the VR Offices, were found to be positive factors predicting employment. These were on the job training and support, assistance with job placement, follow-along services, and rehabilitation technology (Huang et al. 2013). Additionally, those who applied for employment after age 25 had a higher likelihood of being employed, suggesting the need for longer periods of education and training for people with disabilities than for those without (Huang et al. 2013).

Interestingly, SSI and SSDI cash benefits, along with other government disability benefits, can act as disincentives to accepting competitive employment particularly when the proposed job provides low pay and no, or very limited, employer-sponsored benefits, even if the individual wants to work at that job (Darrah et al. 2010; Murphy et al. 2000; Rutkowski and Riehle 2009). Restrictions on the amount of money individuals are allowed by the government to earn each month and still receive the benefits they need to survive often require that people work low-paying jobs so they will not lose those necessary benefits. In

some situations, people may choose to take a higher-paying job, thereby losing most or all of their disability benefits, but they have concluded that higher salary makes the trade-off worthwhile. However, if that same individual loses that higher-paying job, they will need to re-apply for their disability benefits. This applies to cash and supportive benefits like housing and food, but also to medical benefits like Medicare and Medicaid. To assist individuals with these issues, the Social Security Administration has developed work incentive programs such as the Ticket to Work program to help individuals stay employed while keeping social security benefits or to expedite reinstatement of benefits should employment be lost. Information about these programs can be found at <https://choosework.ssa.gov/about/work-incentives/index.html>. These are complicated programs and many people with CP and their families are often not adequately knowledgeable about these programs, what questions to ask and how to deal with the changes in the governmental systems, which happen frequently. Unfortunately, some of these programs, while well intentioned, can keep people under- or unemployed, so they won't lose benefits, even if they have a college degree or other certifications, therefore not attaining their goals of independent quality of life and perpetuating a cycle of poverty (Nye-Lengerman and Nord 2016; Darrah et al. 2010). People with motor disabilities such as CP describe high costs of living with a disability and the difficulty of living on low salaries even with government benefits (Darrah et al. 2010; Magill-Evans et al. 2008). It is important to be as knowledgeable as possible and to consult with VR Offices and employment specialists, supports coordinators, and other advocates who can assist people in these areas. Benefits coordinators and counselors can help people weigh the various options they need to think about when planning education and seeking employment. Even those with a college education may need the services of an employment specialist when seeking employment in their chosen field.

A new program that many people with CP may be eligible for is the Achieving a Better Life Experience Act (ABLE Act). ABLE accounts

are tax-advantaged savings accounts for individuals with disabilities. The monies in an ABLE account, within specific guidelines, are not counted as an asset so they are a “safe” way to save for qualifying expenses (e.g., housing, assistive technology, medical expenses, work, and transportation). If a person does not have an ABLE account, they are not allowed to have more than \$2000 in savings to retain their eligibility for SSI benefits or \$8000 to maintain their eligibility for waiver services (for most states.) With an ABLE account, however, they can save up to \$100,000 (with annual contribution limits of \$15,000) and still keep their benefits. In late 2017, Congress passed an amendment to the ABLE Act, the ABLE to Work Act. ABLE account owners who are employed are able to contribute an additional \$12,060 annually to an ABLE account above the \$15,000 annual contribution limit. For more information about the ABLE program, go to the National ABLE Resource Center, [www.ablenrc.org](http://www.ablenrc.org).

In 2014, President Obama signed The Workforce Innovation and Opportunity Act (WIOA) (P.L. 113–128) (1) . This is a very important law for people with disabilities who are seeking employment or postsecondary education opportunities. WIOA strengthens opportunities for community based, integrated employment and training by providing additional funding to State VR programs to encourage greater coordination between them and other organizations that provide assistance to people with disabilities. WIOA also provides for better transition services for youth exiting high school, including pre-employment activities such as internships and workplace job sampling as well as for assistance with postsecondary education planning and support for tuition and training (The Arc 2015).

Many individuals with CP will need and benefit from supported employment to access and maintain a job. Supported employment was introduced in the Rehab Act with the premise that everyone has the right to community employment, to have choice and control in their career and work life, to work with colleagues with and without disabilities, and to have access to the advantages of employment, including salary,

benefits, and enhanced personal satisfaction. Individuals must be approved by the state VR office for supported employment services, or services can be approved through the Division of Developmental Disabilities in DDD states. The services are often delivered by community agencies who have spent time developing relationships with the local community employers and know where they may be able to develop job opportunities to meet the needs and choices of the clients they are working with. Sometimes creative solutions need to be found to that take advantage of an individual’s specific strengths. This will be discussed in the case study.

Service needs are determined individually and include skill evaluations and interest inventories to help employment specialists assist the individual in deciding which jobs to apply for and in finding a good match between the individual and the business (Brooke et al. 1997). Supports can also include applications and interviews and on-the-job coaching as necessary for success in a paid position. The coach acts a liaison between the individual and the workplace to assist the individual with what they will need to be successful. This can include on-the-job training, AT and workplace modifications (as discussed above), assistance with mobility needs, and other job services. Some of the specifics will need to be negotiated between the employer, the client, and the agency. This is one of the reasons that relationship development between the VR agency and employer is an important part of the job of the employment specialist and job coach.

There are a number of characteristics of successful relationships between VR agencies and employers that are important to improving opportunities and outcomes for people with disabilities. For example, the employer and the VR agency must trust that each will be competent in their roles and will work well together and maintain the focus on the individual seeking employment. By doing so, they can ensure that the individual gets the support they need, no matter where that support comes from (Buys and Rennie 2001). Once the individual is doing well in the job, ongoing job coaching can be decreased and replaced with follow-along services as part of a job

monitoring situation. Eventually, these services should be phased out as the individual becomes more independent. Optimally, as that happens, workplace natural supports, which are informal supports from co-workers, will develop over time. While these supports assist a person with paid employment, they are not able to be used to support a person in a volunteer, unpaid position. However, Medicaid waiver funding may be able to support someone to volunteer in the community, since community integration and inclusion is a cornerstone of waiver funding. This can include a job coach, attendant care, and transportation. Volunteering can be an excellent way to integrate into the community, learn skills, and develop social relationships either on its own or as an adjunct to a part time job.

The following case scenario illustrates and integrates all the aspects of community living that have been discussed in the chapter.

### **Clinical Case Example**

Andrew is 26 years old and recently graduated from college with his Associate's degree in liberal studies. Andrew has cerebral palsy (spastic quadriplegia) and is a power wheelchair user. He has very limited ability to use his hands and is, therefore, dependent on others for assistance with all activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Andrew was able to attend college because of the supports he received from both the University and the PA Office of Vocational Rehabilitation (OVR). These two entities have a long history of working collaboratively so that students with disabilities have an opportunity to succeed in post-secondary education.

Andrew took advantage of many of the services offered to students with disabilities. He was allowed a reduced class load (2 or 3 classes a semester) throughout his time at the University. And the Office for Students with Disabilities provided note takers for each of Andrew's classes as well as tutors who assisted him with completing class assignments, writing papers, and studying for exams. OVR provided Andrew, and the other students who have disabilities, with attendant care in the dorm and with assistance at mealtime in the

University dining halls. OVR also provided all the students with disabilities with transportation services between the dorm, dining halls, and academic buildings – a “must” because of the amount of snow and arctic temperatures that occur in this region of PA as a result of the Lake (Erie) effect!

But once Andrew finished school, he started planning for the next stage of his life. He recognized that he would miss talking and visiting with his friends (so easy to do when living on campus) and attending all of the sporting events. But, Andrew's goals after graduation were to live in a home of his own in Pennsylvania and work part-time using his talents and interests so that he would have a career, not merely a job.

Andrew started to receive Supplemental Security Income (SSI) when he turned 18. It was then that he was considered an adult and only his income – and not his family's income – determined his financial eligibility for this program. Andrew also enrolled in one of the state's home and community-based waiver programs (“waiver”) at this time. He met the financial eligibility requirements because he was receiving SSI and he also met the functional eligibility requirements because of the severity of his cerebral palsy. When Andrew enrolled in a waiver, he was automatically enrolled in Medicaid.

So how did Andrew begin constructing his life after school? First, Andrew met with his supports coordinator for his waiver services. Together they planned what services Andrew needed to move home with his parents (both of whom work full-time) while he looked for an apartment. It was determined that he needed personal assistance services (“attendant care”), someone to help him with activities of daily living. He also needed community integration services (someone to help him re-integrate into the community as well as help him with finances) and transportation services (tokens for the Paratransit system.) Andrew's supports coordinator also advised him as to how to look for attendants and a community-integration specialist. Second, Andrew met with his Office of Vocational Rehabilitation (OVR) counselor. Because OVR's mission is to help people with disabilities obtain competitive

employment (i.e., a job with a salary of minimum wage or higher), OVR has contracts with agencies that can provide direct employment services. Andrew was quickly connected to one such agency. The employment agency developed a service plan with Andrew that included a skills assessment, career exploration, and job coaching. His employment counselor also recommended that Andrew use all of his networking abilities (as well as those of his parents) to connect with possible leads for a desired job. Andrew and his parents hosted a “Let’s Get Andrew a Lead” party. While twenty of their friends munched on goodies, they learned about Andrew’s interests and abilities. Ideas of where Andrew could look, and who he could talk with, flew around! By the end of the afternoon, Andrew and his employment counselor had a plan in place.

Andrew followed his new employment plan and he scheduled informational interviews. One of his connections was the local professional basketball team! After several interviews with the team’s vice-president of business operations and the team’s chief statistician, Andrew was offered a part-time job doing statistical research and as well as the opportunity to welcome members of the press before each of the team’s home games! This was a great opportunity! The job played right into Andrew’s strengths – a love of sports, the ability to research, a memory for details, and a joy in developing relationships.

So, how could Andrew make this work? First, he wanted to talk with his co-workers about his disability so they would have a greater understanding about cerebral palsy and, therefore, be more comfortable collaborating with him on projects. Andrew wanted to explain what he could do all by himself, and what his attendant would help him with. He also wanted his co-workers’ assistance with the redesign of the office layout so that he and his wheelchair would have enough room so that he could avoid bumping into others whenever he entered or exited the office. Second, Andrew wanted to meet his new supervisors along with his job coach. Andrew wanted to learn the details of his new job responsibilities, including what others had found to be the most reliable research sites and the format he would be expected to use when

he submitted his findings. He counted on his job coach to help him set up the systems he would need to do his job well. Next, during the interviewing process, Andrew was told that he could work from home from time to time – particularly when researching and charting previous players’ performances. He had a computer that was loaded with all of the necessary software, but he needed a computer table that his wheelchair could fit under so that he could sit closely and read the small print of newspaper articles and data sets. OVR agreed that his was a reasonable accommodation and they funded an adjustable table for Andrew.

Fourth, within a few weeks, Andrew discovered that he couldn’t rely on the public transportation system, Paratransit, to get him to work on time! So, Andrew talked with his OVR counselor and his counselor approved the agency’s paying for the adaptations needed for a new vehicle.

Andrew was referred to Pennsylvania’s Alternative Financing Program (AFP), Pennsylvania Assistive Technology Foundation, for a low-interest loan for the vehicle’s chassis. Andrew had good, albeit “thin” credit (he was paying back his student loan), so he qualified for a loan. Now, Andrew had the funding package he needed to get a new, reliable, adapted passenger vehicle! Andrew’s attendants are the primary drivers of his van. As part of Andrew’s interviewing process, he makes sure that successful candidates have a valid driver’s license, are good drivers, and have experience driving an adapted vehicle. The attendants don’t have to carry their own vehicle insurance on the van because Andrew’s insurance covers anyone he designates to drive him. Lastly, Andrew’s doctor also recommended that two pieces of equipment be added to his power wheelchair so that he could travel safely in his new van – a chest harness for stability and connectors on the wheelchair frame for the tie-downs to the floor. Both were approved by Andrew’s Medicaid carrier and the modifications were made to the wheelchair before the van was ready for delivery.

Now, finally, Andrew could focus on his goal of living in a home of his own! Andrew has a friend with a disability who also wanted to live

independently so after talking about their compatibility, they decided to be roommates. His community integration specialist (and parents) helped them develop a budget using a financial education book called *Cents and Sensibility: A Guide to Money Management* (Pennsylvania Assistive Technology Foundation fifth Edition 2017) so they could figure out how much they could afford for rent and utilities. Andrew and his friend developed a list of “musts” for their new apartment – it *must* be accessible and located in a safe area that has sidewalks; is near a pharmacy, store, restaurants, and a bank; has access to public transportation so that it’s easy for attendants to travel; is nearby to one set of parents; and, finally, is not too far from the sports stadiums. After searching for about 5 months, Andrew found the perfect place! He and his friend signed a multi-year lease – and their supports coordinator for their waiver services was able to amend their plans to include funding for a barrier-free shower and increased hours for attendant care. The increase in hours was necessary now that they were living independently and their parents could no longer provide some of their care.

Fast forward. It’s been a couple of years since Andrew transitioned to his new life after college. He has a new job that offers greater flexibility and a higher salary. He also receives SSI, but the amount varies every month depending on how much he earned the previous month. The neighboring business owners know Andrew and cheerfully greet him as he conducts business in their pharmacy, diner, or coffee shop. Finally, there was a recent ruling in federal court that provides a clarification to Title III of the Americans with Disabilities Act that ensures that Andrew, and others like him, are no longer required to pay an additional admittance fee for their attendant in order that he (Andrew) can attend and access sporting events, museums, and other public venues (Anderson 2016). This court decision can be found online at: <https://www.paed.uscourts.gov/documents/opinions/16D0367P.pdf>.

Suffice it to say, Andrew is living the independent life he dreamed of in his chosen community – and he is able to attend as many basketball, football, and baseball games as his budget allows.

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