



Bridging the Gap: A Guide for Adults with Autism.

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November, 2021

To Our Readers and Supporters:

The diagnosis of Autism Spectrum Disorder (ASD) exploded in our country, from roughly 1 in 2,500 children in 1990 to 1 in 54 in 2021, according to the Centers for Disease Control. As more and more children were diagnosed, the focus of services for individuals diagnosed with ASD has been on early intervention and special education services – and justifiably so, as research and results have proven better outcomes for ASD individuals who receive services as soon as possible in their developmental journey.

But one thing is certain. Children with ASD grow up to be adults with ASD, and services and supports are not nearly as well-defined or guaranteed for adults as they are for children. This Guide is the effort by the Autism Society Greater Harrisburg Area (ASGHA) to provide a roadmap to the available services and supports for our families and individuals in the transition from youth to adult.

We express our great appreciation to Jim Zoerkler, former ASGHA board member, who wrote the vast majority of this Guide. Tom Hassell, an adult with ASD and longtime ASGHA board member, contributed several sections with his invaluable life perspective. Board member Tom Flynn contributed writing and editing efforts to this Guide.

We intend for this Guide to be a living document and will update it periodically. Please bookmark our website, autismharrisburg.org, and email your thoughts, comments and suggestions to the Board at contact@autismharrisburg.org.

Sincerely,

Autism Society Greater Harrisburg Area

Introduction

The focus of this Handbook is to provide information and resources for adults with Autism Spectrum Disorder (ASD) once they achieve adulthood. Since a successful transition to adulthood begins in early childhood, the beginning of the Handbook briefly discusses the preparation for transition to adulthood. We want to be sure that they, and as any child, are adequately prepared to achieve their full life potential throughout their lifespan. Keep in mind that ASD individuals spend a greater portion of their life as adults than as children.

Preparing for transition to adulthood: Early years

With any child, the formative years (birth to age 8) are a critical period for development of intelligence, personality, and social behavior. This is also the time when many children are first diagnosed.

One of the biggest challenges for families with children on the spectrum is becoming socially isolated due to the child's behavior during family gatherings and public situations. Since appropriate social behavior is vital to living successfully as an adult, the possibility of social isolation needs to be addressed early. Initially, avoid situations that guarantee a meltdown.

Try different, low-risk situations that offer opportunities for success and easy exit if a problem develops. For example, go to a fast-food restaurant where your son or daughter can become accustomed to eating around non-family members and to the activity in a restaurant. Begin developing independent living skills by encouraging him or her to order their food and, when ready, pay for their meal. Once there is a comfort level with dining at a fast food restaurant, go to a restaurant with table service. Go during non-peak hours so the noise level is lower and when the service should be quicker.

Be creative in finding other low-risk activities and always have a strategy for handling inappropriate behavior.

1. Set realistic goals based on the child's abilities and strengths. A Pennsylvania public school student receiving special education will have an Individualized Education Plan (IEP) with

specific educational goals. More general, realistic goals should be set at home that supplement and support the IEP goals. Keep notes of what your child does well and areas where he or she struggles. The “home” goals may include basic life skills, such as: brushing teeth, picking up toys, greeting visitors, making a bed, doing laundry, and learning to use a microwave. Break down the skills they struggle with into smaller steps that they can complete. When all the smaller steps are completed combine them into the whole task.

2. Encourage self-advocacy. Self-advocacy is a fundamental skill for independent living as an adult. Independent ASD adults must be able to speak and act on their own behalf. The teaching of self-advocacy should begin early in childhood with simple opportunities for exercising self-advocacy. The example cited earlier of ordering a meal at a fast food restaurant is an early step in the self-advocacy process. As your son or daughter matures, step back and encourage him or her to become less dependent on you. They need to become more a part of the decision-making process as they mature. Keep in mind, individuals mature at a different rate and there may be a delay in maturity.

Teen years (before 18)

By Pennsylvania law, a transition plan must be formalized in the IEP at age 14. The Pennsylvania Training and Technical Assistance Network website (PaTTAN.net) offers a "Planning for the Future" site and checklist. When working with this checklist or similar documents, adjust the age brackets to reflect where your child is developmentally. It is not unusual for an ASD child to lag behind their peers in development. For this reason, some checklist items may need to be delayed until the child’s cognitive development catches up.

As a child transitions into adulthood, parents/caregivers may need to expand the daily living tasks to include cooking skills, management of medications, money management, adult hygiene, and doing laundry. Do not rely entirely on the high school’s transition plan to teach these skills.

As a parent or caregiver, no one knows your young teen better than you. This is the time to advocate for transition support based upon your insight into the student’s abilities, likes, dislikes,

sensory issues, etc. For example, the student expresses an interest in cooking. However, this may not be a good career option since they are very sensitive to cooking smells.

Up to this point, parents and/or caregivers have been the ones teaching independent living skills. This is not the time to give up and turn the responsibility over to the school district. You need to remain a vital part of the process and work with the school district to be sure that what is being taught in school is being reinforced at home. While the transition plan is written primarily for action by the school district, it should be a partnership where you have an active role in implementing the transition plan outside of school.

Adolescence can be a period of isolation for any teen. However, it can become even more isolated for those on the spectrum due to social awkwardness, bullying, peer pressure, lack of self-esteem, etc. During this period, it is important to find opportunities to socialize with extended family members, clubs for teens, church groups, or just generally going into the community by going shopping, attending movies, community events like fairs or festivals, or spending time in a park.

One of the more difficult times for parents and caregivers is determining which behavior is “teen” behavior versus behavior due to the diagnosis. Many times, they are similar, i.e. isolation, rebelling against parents/caregivers, anger. Remaining supportive and maintaining good communication with the teen is critical during this developmental stage.

Once a student leaves school, there is a dramatic loss in services. Keep in mind – there is no federal mandate for adult services for individuals with ASD. There are very few services for those between the age of 18 and 21. Carefully consider the loss of support services when contemplating your child leaving school at age 18. Many parents have been stunned by the lack of support services once their young adult leaves high school.

Turning 18

When your child turns 18, they are legally considered an adult and are subject to the laws and regulations that apply to adults. Young adults can be subject to jail sentences for infractions that would have resulted in a slap on the wrist before turning 18.

Without taking appropriate steps, parents lose the right to make decisions for their child and lose the right to access private records. For more information, go to the Legal Documents section.

Legally an adult: implications

Selective Service - all young men turning 18 are required to register for the Selective Service. Failure to do so can result in a fine up to \$250,000 or up to 5 years in jail.

Medical Records - If you want to see your 18-year-old's medical records, you will need to have her/him sign a release form at each medical and mental health provider's office. Your young adult must consent to giving you access to the records.

If your child agrees to authorize you to make health care decisions for her/him, document it by consulting an attorney to draft a durable power of attorney. Options are to have it 1) only apply when they are incapacitated, or 2) apply even when they are not incapacitated.

Educational Records - The Family Educational Rights and Privacy Act (FERPA) is a federal law that affords parents the right to have access to their children's education records, the right to have the records amended, and the right to have some control over the disclosure of personally identifiable information from the education records. When a student turns 18 years old, or enters a postsecondary institution at any age, the rights under FERPA transfer from the parents to the student ("eligible student"). Unlike other states, the age of majority for special education in Pennsylvania is 21. In the case of a Pennsylvania high school student over the age of 18 with an IEP, the parent still has access to educational records, participate in IEP meetings, and sign the

IEP. The exception to the rule in Pennsylvania is if the student can clearly demonstrate that she/he is emancipated.

Registering to vote - Young adults can register to vote when they turn 18.

Jury duty - As an adult, an 18-year-old can be selected for jury duty.

Corruption of minors - Once an individual turns 18 they are treated as an adult in the legal system and can be criminally charged for offenses for which they might not have been prosecuted when they were minors. Corruption of minors by providing or the perception of providing alcohol, illegal drugs, encouraging illegal acts, statutory rape all can have serious consequences. Since many of those with ASD may not have the social awareness to understand the consequences of their behavior, parents and caregivers need to help the young adult understand and avoid situations that could place him/her in jeopardy of being accused of corrupting a minor.

Social Security Supplemental Security Income

Supplemental Security Income (SSI) provides monthly financial assistance to those with limited income and financial resources. In 2021, the maximum amount of SSI benefit is \$794 per month for an individual, depending on their living arrangements.

Supplemental Security Income (SSI) - Child Under 18

Disabled children who have limited income and resources (i.e. savings) may be eligible for SSI. Contact Social Security to determine if the parent's and the child's income and resources are within the eligibility limits and to start the application process.

SSI Redetermination at age 18

Rule #1. Always keep records of conversations with Social Security staff. Record their name, time and date, and description of what was discussed.

Rule #2. Always send documents to the Social Security Office by certified mail so that you have proof of mailing and so that you can track the delivery of the documents online. Print the page showing the document was delivered for your records.

If a child received SSI prior to the age of 18, she/he will go through a redetermination of benefits process upon turning the age of 18 to determine if she/he is severely impaired. The criteria for severe impairment are more stringent for an adult than it is for a child. Consequently, not all young adults will continue to receive SSI as an adult if it is determined their impairment does not meet the adult criteria.

The steps in the redetermination process are:

1) Social Security sends the parents and child/young adult a letter notifying them of the start of the redetermination process.

A meeting is set up with the parents and child/young adult in the local Social Security Office to begin determining the severity of the disability. While the percentages vary by state, 65% to 70% of the SSI applicants are denied initially. This is the meeting where you will need to provide as much information as possible to justify your son/daughter's disability as an adult.

The information provided needs to support their disability and how it affects their ability to function as an adult. You and/or your young adult, if over the age of 18, will be asked permission to contact teachers, doctors, therapists, and other service providers to gather information on how the disability would affect the young adult's ability to function in the work place and live independently.

Give examples of how they are at home. Do they need prompts to remember to shower, clean up after themselves, and take medications? How are they socially? Do they have any friends? Are they

reluctant to meet new people? Talk to the doctors, therapists, teachers, and other service providers. Remind them to provide not only “clinical” type information to Social Security, but also an evaluation of how their behavior and diagnosis may inhibit their ability to attend higher education institutions and/or find employment. In their opinion, will they need special accommodations after high school in college and/or employment?

2) The Bureau of Disability Determination (BDD) reviews all the information gathered from you and others to determine if your son/daughter meets the Social Security adult disability criteria.

This is where there is a shortcoming in process. As a student, your child may have done very well with considerable support. BDD may only use that information to project how he or she may perform in an employment situation. This may not provide an accurate picture of how they will perform in a job or post-secondary school setting. These adult settings may not have similar support and different demands on their performance. This is where documentation of your child’s/young adult’s behavior in and out of the classroom are needed to support his or her ability to function in daily life without support.

SSI denials need to be appealed as quickly as possible and within 60 days of receiving the denial letter. There are four levels of appeal:

- 1) Reconsideration
- 2) Hearing by an administrative law judge
- 3) Appeals Counsel
- 4) Federal Court

To appeal successfully, you will need to provide additional information about the disability that was not in the initial application. The local Social Security office can help with the appeals. Many people whose applications were denied are represented by an attorney. When retaining an attorney, select one that has expertise in Social Security disability appeals.

If your child/young adult is currently receiving SSI benefits, they may continue to receive the benefits in some circumstances if a request to continue benefits is received by Social Security

within 10 days of receiving the denial letter. Be aware, all or a portion of the continued benefits may have to be refunded to Social Security if appeals are lost.

SSI - Adult (over 18) that did not have SSI as a child

Rule #1. Always keep record of conversations with Social Security staff. Record their name, time and date, and description of what was discussed.

Rule #2. Always send documents to the Social Security Office by certified mail so that you have proof of mailing and that you can track the delivery of the documents on line. Print the page showing the document was delivered for your records.

Contact the local Social Security office to make an appointment to start the application process. Unlike the cases of children where the child's and parent's income are used to determine eligibility, only the young adult's income is used to determine financial eligibility. So, if the only reason your child younger than 18 did not receive SSI is because your combined incomes were too high, they may be eligible for SSI as an adult.

Prepare for the appointment by gathering the information discussed in the "Redetermination at age 18" section above.

Social Security Continuing Disability Review

Rule #1. Always keep record of conversations with Social Security staff. Record their name, time and date, and description of what was discussed.

Rule #2. Always send documents to the Social Security Office by certified mail so that you have proof of mailing and that you can track the delivery of the documents on line. Print the page showing the document was delivered for your records.

Periodically, the Social Security Administration will conduct a Continuing Disability Review to confirm the disability still exists. This review seems pointless to many since ASD is a lifelong

condition. However, it is imperative that a complete, proper and timely response be made to the request for information.

When completing the Medical Conditions section, list not only the official diagnosis, but also any conditions reflective of autism. Examples are: only likes limited number of foods, educational problems, hygiene problems in social environment, and vocational challenges. This is where keeping records of the young adult's medical, mental health and therapy histories, appointments and anything that relates to her/his diagnosis is invaluable.

Even though behavioral health treatment may not be required on an ongoing basis, it is good to visit a psychiatrist and/or therapist a couple of times a year to keep their records open. By doing so, you may list the provider as an active provider on the review form to help defend the autism diagnosis as still being appropriate.

List any provider the young adult/adult visited in the past year including:

- 1) Eye doctors
- 2) Allergists
- 3) Family doctor
- 4) Dentist
- 5) County Mental Health/Intellectual Disability Agency Case Management or the agency the county uses for case management, i.e. Service Access Management (SAM)
- 6) Office of Vocational Rehabilitation
- 7) Supported employment agency, i.e. AHEDD
- 8) Include any waiver services the young adult/adult is receiving. (i.e. Adult Autism Waiver)

Several weeks after the initial questionnaire is returned, a second questionnaire (Functional Report-Adult) will be received from the Department of Labor. Consider calling the Department of Labor to establish a rapport with the caseworker handling the file and to answer any questions you may have about the questionnaire.

If the young adult/adult cannot complete the questionnaire, it is acceptable for a parent or caregiver to complete the report as a third party. When speaking to the caseworker, tell them you will be completing the form and provide the reasons why. Be very thorough and descriptive when completing this report.

Three to four weeks after returning the Functional Report, Social Security will send a letter with the decision on the continuation of benefits.

If benefits are denied, immediately begin the appeal process. Return the form requesting an appeal immediately. Do not wait to consult an attorney or advocate before returning the form. Return the form first to prevent missing the deadline. Then retain an attorney or advocate.

Ticket to Work

Ticket to Work (www.ssa.gov/work) is a free program for disabled individuals aged 18 to 64. Participation in the program is voluntary. The program is designed to assist Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) beneficiaries to find meaningful employment that may lead to a career. A key goal of the program is to enable the beneficiary to become financially independent. Most individuals with a disability will likely qualify for the program. Participants in the program retain their Medicare and/or Medicaid.

Participants in the program that make expected progress with employment or educational goals are not subject to periodic medical review of their disability.

An individual can access the Ticket to Work Program through the state Vocational Rehabilitation services, which may partner with an Employment Network (EN) to provide the service. If the individual has a SAM case manager, the case manager can assist in working with Vocational Rehabilitation and/or the EN.

Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP)

The AAW and ACAP programs were created by the Pennsylvania Bureau of Supports for Autism and Special Populations (BSASP) to provide services to adults with ASD who are not being served by any system. The AAW is available statewide. The ACAP is available in Dauphin, Chester, Cumberland, and Lancaster Counties.

Adult Autism Waiver - The goals of the AAW are:

- 1) Increase the person's ability to care for themselves.
- 2) Decrease family/caregiver stress.
- 3) Increase quality of life for both the person and the family.
- 4) Provide specialized supports to adults with autism spectrum disorder based on need.
- 5) Help adults with autism spectrum disorder reach their employment goals.
- 6) Support more involvement in community activities.
- 7) Decrease crisis episodes and psychiatric hospitalizations.

The AAW is for individuals 21 and older. As of January 1, 2020, individuals interested in applying for the AAW must contact their county Mental Health/Intellectual or Developmental Disability (MH/IDD) office. BSASP no longer maintains an interest list of individuals for the AAW.

For more information about the enrollment process, call BSASP at 1-866-539-7689 or visit the AAW website at <http://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Autism-Services.aspx>.

Individuals can also begin the application process online by going to the Department of Human Services' Information Referral Tool at humanservices.state.pa.us/irt.

The individual must meet the income and resource requirements for Medical Assistance (Medicaid) at the time the AAW application is completed. If the applicant is not currently receiving Medical Assistance, a form to request Medical Assistance will be included in the application

packet. BSASP will contact the local County Assistance Office to confirm the applicant's eligibility for disability coverage.

When BSASP receives the completed forms and the applicant is determined to still be eligible for consideration for the AAW, BSASP will contact the applicant or their representative to set up an in-person functional assessment interview. This is the final step in determining eligibility. This interview takes place in the home or a place convenient to all parties. Parents and or the caregiver may participate in the interview. It is recommended that a parent(s) or caregiver be present during the interview to provide their insight. The functional assessment centers on the following areas:

- 1) Self-care
- 2) Understanding and use of receptive and expressive language
- 3) Learning
- 4) Mobility
- 5) Self-direction
- 6) Capacity for independent living

Before the functional assessment interview, spend some time developing examples of the applicant's level of functionality in each of the categories. Do not hesitate to interject with your comments about your observations/experience of the applicant's strengths and weaknesses.

The evaluator conducting the assessment will complete the report with their assessment recommendation. BSASP will notify the applicant or their representative of the final eligibility decision.

If the decision is favorable, BSASP will provide information on the various agencies that act as supports coordinators. A supports coordinator will meet with the applicant and their representative to help determine the level and nature of supports required. The supports coordinator will also provide information on the various service providers in the area. A service provider or providers will then be selected from that list.

The Adult Community Autism Program (ACAP) is similar to the Adult Autism Waiver. Like the AAW, those 21 years old and older are eligible. The application process is the same as the AAW.

1) Call 1-866-539-7689 (toll-free number) and follow the prompts to select the Adult Autism Waiver, or

2) Apply online by visiting the Information Referral Tool (IRT): humanservices.state.pa.us/irt

The major differences between ACAP and AAW are:

1) Unlike the AAW, the ACAP is also the participant's health plan. It combines physical and behavioral health with home and community-based services. Medications remain covered through Medical Assistance.

2) The ACAP is only available in the Pennsylvania counties of Chester, Cumberland, Dauphin, and Lancaster. The AAW is statewide.

Other Waiver Programs

The state's Office of Developmental Programs (ODP) manages three waiver programs for people with intellectual disabilities and/or autism - the Consolidated Waiver, Person/Family Directed Support (P/FDS) Waiver and the Community Living Waiver. Due to changes made by ODP starting July 1, 2017, persons with an autism-only diagnosis are eligible for any of these waivers.

Previously, a person had to have a diagnosis of intellectual disability or intellectual disability and autism to access these waivers.

These programs are different than the Adult Autism Waiver or the Adult Community Autism Program, which are managed by the Bureau of Supports for Autism and Special Populations (BSASP).

There is an important difference between the waivers offered by ODP and those offered by BSASP. ODP does not have an age limit on its waiver programs, while the BSASP programs are for adults age 21 or over.

How to apply

The waivers are managed through the County Office of Mental Health and Intellectual Disabilities (MH/ID). To begin the process, contact your county office to make an appointment to determine eligibility. A person must have a diagnosis of intellectual disability or autism; must meet an intermediate care facility (ICF) level of care threshold; and must meet Medicaid eligibility requirements.

Consolidated Waiver

The Consolidated Waiver is designed to help a person with an intellectual disability or autism live more independently in their homes or communities. The Consolidated Waiver offers residential, community integration, employment and behavior support services. There is no individual financial limit on the Consolidated Waiver.

Person/Family Directed Support Waiver

The P/FDS Waiver is also designed to help individuals live independently in their homes or communities. The P/FDS Waiver does not offer residential services; however, most of the non-residential services in the Consolidated Waiver are also available in the P/FDS Waiver. There is a \$33,000 annual individual financial limit on the P/FDS Waiver.

Community Living Waiver

ODP began to offer the Community Living Waiver on Jan. 1, 2018. It is also designed to help individuals live more independently in their homes or communities. It offers limited residential services through the Supported Living and Life Sharing models, and also offers most of the same

services in the Consolidated and P/FDS Waivers. There is a \$70,000 annual individual financial limit on the Community Living Waiver.

ODP Waivers Information

More information about ODP's waivers can be accessed at:

<https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Intellectual-Disabilities-Services.aspx>

Adult Challenges

Transitioning to primary care and mental health providers who care for adults

Providers expect patients 18 and older to make decisions on their healthcare and mental health treatment. Legally, a parent or caregiver cannot make these decisions without a properly written Power of Attorney (POA) (see discussion on Powers of Attorney). Most pediatricians stop seeing patients once they reach age 21, some do so at age 18. Ask the pediatrician to recommend physicians and other providers who are familiar with treating ASD adults.

Community Living

Most ASD adults live with their parents or other caregiver. This is due to a general lack of affordable, supported housing. Throughout the country, several housing complexes for Autistic adults have been developed in recent years. The Autism Housing Development Corporation in the Pittsburgh area and Madison House Foundation located in Maryland are examples of the complexes. Generally, the rental costs in many complexes are usually unaffordable for those on a limited income and/or there are limited units available.

An option is for a parent or group of parents is to purchase a house for their adult children to rent. Whether it is a parent or group of parents that purchase the house, it brings with it all the responsibilities of being a landlord and, perhaps, disagreement with other parents in the group about the operation of the house.

Other housing options that are available include:

- 1) Group homes
- 2) Adult foster care

3) Section 8 housing

4) Supported living

For information on the housing options available in your area, contact your county's Mental Health/ID housing coordinator or, if receiving waiver services, your supports coordinator.

Employment

Per a Drexel University study, young adults with ASD have more difficulty finding and retaining jobs than their peers with other disabilities. More effective preparation for work during the transition process and the proper level of employment support increase the success rate.

Supported employment is an individualized plan/strategy for seeking employment and providing the appropriate level of on-the-job coaching support.

There are several levels of supported employment:

1) Competitive Integrated Employment may be suitable for someone that has the skills and the capability to perform a job in a competitive, integrated setting with minimal support from the start. There is no long-term support provided.

2) Supported employment differs from competitive integrated employment in that the individual receives continuous support as long as they hold that job. The level of support may be reduced as tasks are mastered.

3) Customized employment personalizes the working relationship between employee and employer. The job customization should satisfy the needs of both parties.

4) Secured or segregated employment is typically found in "sheltered workshops" where only disabled individuals are employed in a supervised setting.

The level of support provided must be aligned with the individual's capabilities and the complexity of the job. Some may succeed at a less complex competitive employment position

without support while they may require supported employment in a position with more complexity. Also, bear in mind the ability of the individual to stay on task.

Matching the individual's skills, interests, and abilities to the job is critical for success regardless of the level of support. Traditional hiring practices fit the employee into the employer's requirements. The chances of a successful employment outcome occur when employee's abilities and limitations are considered. Try to find an employer who is willing to make reasonable modifications that better align the job requirements to the employee's capabilities.

Many times, sensory issues stimulated by the work environment can lead to poor job performance. Before committing to an employer, determine if there are noises, smells, lighting conditions, or other environmental factors that could trigger a sensory issue. Also, how will the employer support the employee when there are issues involving fellow employees?

The following sections on Vocational Rehabilitation and Employer Networks discuss the various employment services available. If the individual receives waiver services through BSASP or ODP, supported employment may be available.

Vocational Rehabilitation

Most states, including Pennsylvania, have an Office of Vocational Rehabilitation (OVR) that assists individuals in preparing for, obtaining, and maintain employment. OVR either provides services directly or through an outside organization.

OVR can assist eligible individuals with admission to the Hiram G. Andrews Center in Johnstown. The center offers several training programs on site, independent living skills development and transition to employment support.

Other services provided by OVR include:

- 1) Diagnostic Services: Medical, psychological, and audiological examinations and tests used to better understand the disability and the need for specific types of services.

2) Vocational Evaluation: Aptitude, interest, general ability, academic exams, work tolerance, and "hands-on" job experience used to understand the young adult's vocational potential.

3) Counseling: Vocational counseling will help the young adult to better understand his/her potential, to rely on his/her abilities, to set vocational goals and change them when necessary, to develop successful work habits, and to begin a satisfying career. Counseling is available throughout the duration of rehabilitation program.

4) Training - Education to prepare the young adult for a job including, but not limited to, basic academic, vocational/technical training, college, on-the-job training, independent living skills, and personal and work adjustment training.

5) Restoration Services - Medical services and equipment such as physical and occupational therapy, wheelchairs, and automobile hand controls can be provided to enable the young adult to pursue and achieve employment.

6) Placement Assistance - Counseling, job-seeking programs, job clubs, and job development used to increase the individual's ability to get a job.

7) Assistive Technology - Assistive technology includes a wide range of devices and services that can empower persons with disabilities to maximize employment, independence and integration into society.

8) Support Services - Other services are provided for eligible persons if they are necessary to start and maintain employment.

The OVR office directory can be found on the Department of Labor & Industry website: dli.pa.gov.

Employment Networks

Employment Networks (EN) are organizations that have an agreement with Social Security to provide support to disabled individuals in finding and retaining suitable employment. The individual has the right to select the EN that best matches their needs. The EN will assign a job coach to aid in preparing for a job search, interviewing, securing a job, and on the job training. The

EN can also help with the Social Security Ticket to Work program to assure that employment earnings do not jeopardize Social Security benefits. See the earlier section on the Ticket to Work program.

Employment Networks (i.e. AHEDD and the Disability Rights Network) can be accessed through OVR or through a county case manager.

Post-secondary education

The post-secondary education choices are primarily vocational school or college. Whether the final decision is vocational school or college, the thought process is similar for selecting the appropriate school/college.

Students must look at the top three schools they wish to attend for their chosen field of study. Literally there are thousands of colleges or universities to choose from. All schools have loan departments to help pay for four-year colleges. Students should apply for federal and state aid by filling out the Free Application for Federal Student Aid (FAFSA), which is accessed at studentaid.ed.gov/sa/fafsa. Individuals receiving services through OVR or ODP might be eligible for educational support services. Filling out a FAFSA application might be a requirement for access to those services; check with your OVR counselor or waiver supports coordinator for more information.

The Individuals with Disabilities Education Act (IDEA), which ensures a Free and Appropriate Public Education (FAPE) for school-age children with disabilities through age 21, does not apply for students attending postsecondary institutions (colleges, universities, community colleges, and vocational schools). Thus, these institutions are not bound by federal or state law to offer educational accommodations.

While more institutions are offering more services to students with disabilities, those services can differ widely. It is vital that the student and his/her parents/supporters look closely at each school and ensure they understand the supports available.

The Pennsylvania D.R.E.A.M. Partnership assists individuals with intellectual disabilities (including autism) with post-secondary education. The partnership works with selected colleges to post-secondary education opportunities and scholarships. Go to dreampartnership.org for more information.

If your son or daughter is on the spectrum, what type of school should he or she look for? The first thing they should look for is whether the school has a disability office that will help them throughout their school career.

Second, check to see if the school has accommodation programs to assist your child with help with note taking in class or recording of all classes, a personal guidance counselor, and/or untimed tests. Also, the school should meet disability standards that are required with the Americans with Disabilities Act. There are many schools across the country that have such programs for students with disabilities. There are many colleges in Pennsylvania that provide accommodations. Examples of Pennsylvania colleges are: Messiah University, Millersville University, Misericordia University, Penn State University, Harrisburg Area Community College and Lebanon Valley College.

Tom Hassell, Autism Society of the Greater Harrisburg Area Board member and a leading self-advocate, describes his college experience:

“I, myself attended College Misericordia now (Misericordia University) which has a program called the alternative Learners Program for those that have a learning disability. The program through which I was able to earn my Bachelor of Science Degree in Business Administration. The program

started during the summer, which gave us a start to learn about this special program. The A.L.P. program is under the direction of Dr. Joseph Rogan; each student would attend regular college courses. Each of us in the program had note takers which we would receive after each class. Each of us had their own guidance counselor you would see once a week or more to go to if you needed help in any class. There were also untimed tests which you would take out of class which would you would take in your counselor's office. In conclusion I would highly recommend parents take a hard investigate these types of academic programs for their autistic young adult if they truly want to go to college.”

Transportation

Many ASD adults do not have a driver's license. Consequently, transportation can be a major impediment to employment, social activities, and receiving health/mental health care. Those that live in urban areas may have access to regularly scheduled public transportation. However, those that live outside of urban areas struggle to find a reliable, safe mode of transportation. It is not unusual to rely on family and friends to get around. One of the benefits of the waivers offered by ODP and BSASP is that the service provider can fill in much of the gap.

Most counties in Central Pennsylvania offer reasonably priced shuttle bus services via Capital Area Transit (cattransit.com) or RabbitTransit (rabbittransit.org) for doctor's appointments, places of employment, and shopping.

Other available services include:

1) Commuter Services of Pennsylvania assists clients in finding carpools.

<https://pacommuterservices.org/carpool/>

2) Uber and Lyft

County Mental Health

The county is a resource for some adult services and should be one of the first agencies contacted upon completion of high school. To locate the agency in your county, go to:

<http://www.mhdspa.org/Pages/Local-Contacts.aspx>

They will determine eligibility for county services, assesses the need for behavioral health treatment or other services, and make referrals to other programs that may benefit the individual.

County agencies are the gatekeepers for local services. They also may provide funding for supported employment once the Office of Vocational Rehabilitation 90-day period of funding expires.

Medicaid/Medical Access

In Pennsylvania, individuals who qualify for SSI automatically receive Medicaid/Medical Access. Medicaid/Medical Access provides health care coverage and includes coverage for speech, physical, and occupational therapy, as well as behavioral health services. Individuals receiving Medicaid/Medical Access do not pay any premiums, deductibles, or copays for physical and mental health.

Medicaid eligibility is required in order to receive most services, including services provided under the waivers.

If your child or young adult does not automatically receive Medicaid/Medical Access through SSI or doesn't qualify for SSI, contact your county's Department of Human Services (County Assistance Office) to determine if he or she is eligible for Medicaid/Medical Assistance.

If your child or young adult has private health insurance, the private health insurance is the primary payer of covered expenses and Medicaid/Medical Access is secondary. If there is no private health insurance, then Medicaid/Medical Access is primary and pays the full amount of covered medical/mental health bills.

After an individual is on SSI for two years they are then eligible to receive Medicare in addition to Medicaid/Medical Access. If the young adult has private insurance, consider dropping the private insurance for the young adult if all their medical/mental health providers accept Medicare/Medicaid.

If the individual is employed and meets the state's income requirements, they may be eligible for Medical Assistance for Workers with Disabilities. The premium is five percent of monthly income.

Medicare

The young adult normally is automatically enrolled into Medicare Parts A (Hospital) and Part B (Medical) by the Social Security Administration after they have been receiving SSI benefits for 2 years. Medicaid/Medical Access will pay the Medicare Part A and Part B deductibles and copays. If the young adult also has private health insurance, the private health insurance pays after Medicare and before Medicaid/Medical Access. Consider dropping the private insurance on the young adult if all their medical/mental health providers accept Medicare/Medicaid.

In addition to Medicare Parts A and B, the young adult will need a separate Part D, Medicare Prescription Drug Coverage, if they are not covered by a private prescription drug plan provided by a parents/guardian's employer. Check with your employer's Human Resources Department to obtain written documentation that the prescription drug plan they provide is consider "credible" coverage by Medicare. If it is not credible coverage, a separate Medicare Part D Plan will need to be obtained to avoid a lifetime premium penalty.

In many cases, SSI recipients are automatically enrolled in Medicare Part D Plans with Extra Help, which means for most young adults Medicare pays part of the cost of their prescriptions. Extra Help also pays part or all of the Part D premium.

If the young adult does not have "credible" Part D Prescription Drug coverage or does not have Extra Help, they will need to purchase a prescription drug insurance plan. Contact the county Area Agency on Aging office and request an appointment with an APPRISE counselor to assist in selecting and enrolling in the most cost-effective Part D plan.

Medicare beneficiaries typically pay a monthly premium for Medicare Part B, which is automatically deducted from their monthly Social Security check. SSI recipients in Pennsylvania may qualify for the Medicare Savings Program, which pays the Medicare Part B premium.

Role of private health insurance

Medicare and Medicaid are typically the health insurance providers for ASD adults. Coverage for prescription medications and mental health/behavioral health is normally included in the Medicaid coverage. With full Medicare and full Medicaid coverage, private insurance coverage to supplement Medicare and Medicaid coverage may not be necessary. However, not all providers (doctors, psychologists, psychiatrists, hospitals) accept Medicare and/or Medicaid. If the individual's provider does not accept either Medicare or Medicaid, the choices are limited:

- 1) A new provider that accepts Medicare and/or Medicaid will need to be found.
- 2) Pay for the provider services out of pocket.
- 3) Purchase a private health insurance plan that the provider accepts.

If the individual is not eligible for Medicaid and retains Medicare coverage, there are physical/mental health insurance plans and Part D prescription medication plans available to replace Medicaid. Contact the county Area Agency on Aging for an appointment with an APPRISE counselor who will assist in determining the plan or plans that best fit the individual's circumstances. The service is free of charge and there is no incentive for the counselor to recommend one plan over another.

Acceptance in the community

Acceptance in the neurotypical community varies based on the level of an individual member of the public's understanding of autism. The more that parents, caregivers and advocates can raise the understanding that the word autism does not define an individual, and that everyone is unique. Involvement with social groups, church groups, civic organizations will help raise the level of understanding.

Friendships and romantic relationships

Friendships are built on the sharing of mutual interests. The challenge for some ASD adults is that they have a limited number of interests or some very unique interests that make it difficult for them to find someone with similar interests. Joining clubs that focus on a shared interest is a good way to meet new friends. Also, volunteering at organizations or events that share the individual's interests may open doors to new friendships.

Learning the social skills to appropriately interact with others is an important first step. Looking at the other person, not monopolizing the conversation, and showing an appropriate interest in the other persons likes and dislikes will help make others want to form a friendship.

Self-care

Self-care can be one of the major physical and/or behavioral challenges of ASD adults. Lack of self-care can be an impediment to a higher quality of life, overall health independent living, employment, and social opportunities. Some adults might not have the physical coordination or strength required to performing self-care tasks such as shaving, opening containers, cooking, using scissors, tying shoe laces, and similar tasks. Others might have the ability to perform self-care tasks, but they do not have the motivation to routinely care for themselves.

Self-care skills should be introduced as early as possible in an ASD child's life so that they can build and retain the skills into adulthood. Depending on the child's ability, parents and/or caregivers may need to frequently prompt the child or adolescent to brush their teeth, bath, use deodorant, or clean their room. Learning appropriate social interactions also is essential. Opportunities to interact with family members and members of the community at large should occur on a regular basis. They may require some level of support in performing the tasks.

Role of caregiver(s)

A caregiver's (parents) role is to be sure that the young adult can live their life as independently as possible. Once the young adult transitions out of high school, they lose many of the supports that were previously available to them through the "system". Caregivers now must find what limited support there is for Autistic adults. They may initiate finding employment support through agencies such as the Office of Vocational Rehabilitation, search for and assist in applying for higher education, research appropriate housing options.

Finding social activities

There are a limited number of social groups available for ASD adults. If possible, try to maintain into adulthood any friendships that were developed during high school. The Autism Support, Education, Resources and Training (ASERT) website, <http://www.paaautism.org/community/Support-Groups>, contains contact information for social groups available in each county. The Autism Society of the Greater Harrisburg Area (www.autismharrisburg.org) supports the Spectrum Friends group that meets regularly in the Harrisburg Area. Spectrum Friends contact information is available on the ASERT site. The Spectrum Friends group also maintains a Facebook page ([link](#)). There are national advocacy organizations that have local chapters; for example, the Autism Society (<http://www.autism-society.org>).

Joining local autism support groups can help one find other adults in the area, which can lead to social opportunities. Local support groups can also be found on the ASERT site. Also, look for local clubs that are geared toward similar interests. For example, if there is an interest in railroading, find a local model train club, or if there is an interest in Dungeons and Dragons, look for a group that plays D&D regularly or create a group.

Financial Planning

Whether you are an ASD adult, or a parent/caregiver of an ASD Adult, financial planning is tricky since you do not want to jeopardize the benefits received from Social Security, Medicaid, and waiver programs. A properly written financial trust and an ABLE account are two ways of planning for future financial needs. Consulting an attorney experienced in properly writing wills and setting up disability trusts is highly recommended to avoid jeopardizing benefits. ABLE savings accounts allow an individual to save money without jeopardizing SSI and Medicaid benefits. For more information on ABLE accounts, go to: <http://www.paable.gov>. The ABLE program was authorized by the Pennsylvania Achieving a Better Life Experience (ABLE) Act.

If a parent or caregiver is the Social Security Representative Payee, consider turning the Representative Payee responsibility over to a reputable organization. By having an agency as a Representative Payee, the record-keeping burden shifts to them. Also, if the parent or caregiver becomes incapacitated, there will be no disruption in disbursement of funds to landlords, credit card payments, etc.

Also, see the following topics: Parent's Last Will and Testament, and Power of Attorney.

Legal Documents

Guardianship

Guardianship allows a person or entity to make decisions for another person (wards).

Guardianships may not be appropriate for every situation. If in doubt about a guardianship, consult an attorney familiar with handling guardianships for the disabled.

Courts typically appoint a guardian (preferably a family member) when an individual is incapacitated or has a physical or mental disability and is unable to make their own decisions. The role of the guardian is not that of a caregiver, although a caregiver can also be a guardian. Guardianship is a tool that can be used when there are severe and long-term disabilities, when an individual cannot communicate verbally, support themselves financially, or live on their own. To the extent they can, wards are permitted to exercise independent living skills.

The powers of a guardian are limited to the powers needed to accomplish the tasks the ward is unable to perform on their own. Examples of powers:

- 1) Ensuring the ward's care
- 2) Financial decisions
- 3) Medical decisions
- 4) Ensuring medical and behavioral health services are properly maintained
- 5) Provide periodic updates to the court.

Parent's last will and testament

Regardless of one's assets, everyone should have a will!

A will is a legal document where an executor is named to settle the final finances of one's estate and to distribute property to those designated in the will. A will is also the document that can be used to set up a special needs trust for a disabled minor or adult child after the parents are deceased. The wording of a special needs trust must be written in a manner that avoids a situation where the disabled child/adult child could lose Social Security and Medicaid benefits. It is advisable to have an attorney that is well versed in special needs trusts to prepare a will that contains a special needs trust.

Power of Attorney

Power of Attorney (POA) is another tool parents of adult children on the spectrum should have available. Normally, a parent(s), another family member, or caregiver is appointed as the attorney-in-fact and has the power to make decisions for the adult or child (principal). Be sure the POA contains provisions that give the person(s) that is designated as the attorney-in-fact the power to make health and mental health decisions. It is recommended that the POA be obtained as soon as the child turns legal age at 18. This is especially important in situations where the adult child might be inclined to refuse behavioral health treatment or admission to a mental health facility if needed.

Advanced Directives

Advanced directives, also known as living wills, are used to communicate one's desire regarding the extent of medical treatment to be provided at the end of life. The law applicable to advanced directives varies by state. One can draft his or her own advanced directive; however, it is advisable to consult an attorney to assure the directive is written in compliance with state law. It is

recommended that everyone have an advanced directive since it can serve as a guide to family members and caregivers in the event of a terminal illness or injury.

Resources

Conferences for self-advocates and caregivers

Attending a conference is a great way to learn more about a specific topic and meet other people who also have an interest in that topic. Here are some things you should know before you go.

1) Make sure you have completed the registration process before going to the conference. Most conferences require you to register and sometimes pay a conference fee, in advance. When you pre-register, be sure to tell the registration coordinator about any accommodations you may need (e.g., food allergies, seating in a certain part of the room, etc.).

2) Go to the registration table when you arrive to let the organizers know you are there. You may receive a schedule for the conference, a name tag so people know who you are with the conference, and any special instructions you may need for the conference. You may receive a meal ticket. This is often a good place to discuss any accommodations you may need for the conference. The registration table is usually near the front entrance of the building but if you cannot find it, ask one of the building staff with a name tag to help you find it.

3) The registration table is also a great place to go if you have a question or can't find a room you are looking for. The person behind the table will be able to answer your question or find someone who can if they don't know.

4) Be sure to wear your name tag for the entire conference.

- 5) Read the schedule to see where you should be at what times. If there is more than one session for a time block, you can pick which one you would like to hear the most and go to that one.

- 6) Before your first session starts, locate the rooms where the sessions you want to go to are being held, if there is enough time. This can help you feel more comfortable about where you are going.

- 7) Go to your first session a few minutes before it starts and sit in the seat that you like. If you think you may need to get up and leave the room to take breaks, consider sitting closer to the back of the room, or on the end of a row, so your movement does not distract the rest of the people in the room.

- viii. While the presenter is speaking write down any questions you may have about the presentation.

- 8) When the presenter is finished speaking or asks for questions, you can take this time to ask your questions by raising your hand and waiting to be called on by the presenter. You might only be able to ask one question because others in the room need a chance to ask their questions.

- 9) If you don't get all your questions answered during your session, ask the presenter if you can email or call him/her another day to finish asking your question.

- 10) The time between sessions is a good time to use the restroom if you need to.

- 11) During breaks, you can also try to start a conversation with someone who is also attending the conference. A good conversation starter is, "What session did you go to? What did you learn that was interesting?" Then share something you learned from the session you went.

- 12) Many conferences provide food and drinks as part of the event, and usually there is no extra cost to enjoy them.
- 13) Be sure to fill out any feedback forms they may request of you. Often this is required as proof of attendance or receive credits for attending the conference.
- 14) Remember, if you have any questions, ask the people behind the registration table to help you.
- 15) Enjoy the conference.

Behavioral Health Managed Care Organizations, i.e. PerformCare

Behavioral Health Managed Care Organizations replace the Medicaid health insurance company for mental/behavioral coverage management. They:

- 1) Pay providers for mental health/behavioral health services
- 2) Are available to help the Medicaid beneficiary locate appropriate providers and services.
- 3) Handle complaints/grievances concerning provider's care.

References

In addition to the websites reference in the text of the Handbook, the following sources were most helpful in providing background information. Hyperlinks were active as of September 2021.

Life Journey Through Autism, a Guide for Transition to Adulthood. Organization for Autism Research, page 27, published 2006

Transition to Adult Living in Pennsylvania-Transition Health Care Checklist-Revised 2012-

Pennsylvania Department of Health

<https://www.health.pa.gov/topics/Documents/Programs/Infant%20and%20Children%20Health/The%20FINAL%20Transition%20May%209%202013.pdf>

Apply for Disability Benefits- Child (Under 18); Social Security Administration;

<http://www.ssa.gov/disabilityssi/apply-child.html>

DRN WIPA Program - Disability Rights Network of Pennsylvania;

<https://www.disabilityrightspa.org/resources/#work-incentives-planning-and-assistance-wipa>

Supplemental Security Income (SSI) Benefits; Social Security Administration:

<https://www.ssa.gov/benefits/ssi/>

Employment Networks in Social Security's Ticket to Work Program; Social Security Administration:

<http://www.ssa.gov/pubs/EN-05-10065.pdf>

Ticket Overview; Social Security Administration: <http://ssa.gov/work/overview.html>

The Appeals Process - Social Security Administration: <https://www.ssa.gov/ssi/text-appeals-ussi.htm>

Family Education and Privacy Act: <https://www2.ed.gov/policy/gen/guid/fpco/pdf/ferpfaq.pdf>

Vocational Rehabilitation Services; Pennsylvania Department of Labor:

<http://www.dli.pa.gov/individuals/disability-services/ovr/pages/default.aspx>

Setting Goals for a Child with Autism: <https://www.autismsociety-nc.org/making-resolutions-setting-goals/>

Self Determination Housing of Pennsylvania: <http://www.sdhp.org/>

Dream Partnership: <http://dreampartnership.org/>

Guardianship of Incapacitated or Disabled Persons:

<http://family.findlaw.com/guardianship/guardianship-of-incapacitated-or-disabled-persons.html>

