

# **ADULT SERVICES FOR AUTISM**

**BY HOLLY BORTFELD**

# PRESENTER

Holly Bortfeld is a single mother of 2 adults with ASD. A long-time homeschooler living in PA, Holly has been doing biomedical treatments since 1998 and now owns a homestead farm for men with autism.

Located in York County, PA, Felton Homestead is a private biomed-friendly intentional residence where the residents require a strict dietary program and have similar medical and safety needs. The resident farmers grow as much of their own food as possible, learn skills to care for animals, garden, preserve, cook and much more.

Follow us at <https://www.facebook.com/FeltonHomestead/>



# **(DON'T) TAKE NOTE**

My slides are very heavy in details, but they will be available for download from the NAA website after the conference, so you don't need worry about writing down all this material.



# WHAT WE'LL COVER

- When The Bus Stops Coming
- Insurances: Medicaid, Medicare and Private Insurance
- Funding the Future: SSI, SSDI, Special Needs Trusts and ABLE Accounts
- Disability Employment Programs
- Housing
- Waivers: What are they?, PA Waivers
- Guardianship and Power Of Attorney
- Where to Start: Age 16-18
- Glossary and Acronyms
- Recommended PA Links



# WHEN THE BUS STOPS COMING

- When your child graduates, ages out or leaves school, what will he or she do all day long? Some typical choices are:
  - Go to college or other higher learning
  - Work or volunteer
  - Attend a day program (if you can find one)
  - Sit around your house
- Day programs are few and far between, rarely are geared towards autism and don't generally accept those with behaviors, medical issues, or toileting needs.
- Caregivers – Will you be able to find capable staff (we're in a massive staffing crisis)? Will you as a parent need to quit working to stay home with your child?
- Funding – How will you pay for programs, activities, housing and staff?
- How will your child be transported? Who pays for that transportation?
- Community – What is there to do in your local community?
- Parent-created programs – When there is nothing appropriate for your child, are you willing and able to create what they will need?
- All of these issues need to be discussed and addressed in the Transition IEPs.





# NECESSITY IS THE MOTHER OF INVENTION

- Parent-created programs – When there is nothing appropriate for your child, are you willing and able to create what they will need? Many parents in PA (and all around the world) have been paving the way, creating what their kids need. If you have an idea for a business, program or housing opportunity, you can likely find a similar parent-built business for inspiration and guidance. Some parent-created options here in PA are:
  - Perkiomen Valley Brewery
  - Heart Stone Coffee
  - New Avenue Foundation
  - Our Community Cup Coffee
  - Felton Homestead
  - Hope Springs Farm
  - Tuckerboys Noveltees
- Whether it's a full-fledged program or a pieced together plan for only your child, parental involvement is critical.



# MEDICAL INSURANCE COVERAGES

- There are a 3 main insurance types for adults
  - Private Health Insurance
  - Medicaid
  - Medicare



# PRIVATE INSURANCE

- If you have insurance through your employer, as long as you are employed there, your **medically-dependent** child can stay on your insurance, past age 26.
- <https://tacanow.org/family-resources/dependent-disabled-adults-continuation-of-private-health-care-coverage/>
- When your child has multiple insurances, such as private insurance through your employer, Medicaid and Medicare, Medicaid will always be payor of last resort, so all other insurances you may have would have to pay or deny service before Medicaid will pay.
- PA has mandated autism coverage through Act 62.
  - <https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Act-62.aspx>





# MEDICAID

- Medicaid is a federal and state program that helps with medical costs for some people with limited income and resources. Medicaid also offers benefits not normally covered by Medicare, including nursing home care and **personal care services**. Medicaid recipients may include low-income adults, their children, and people with **certain disabilities**.
- If you qualify for even \$1 a month of SSI, you will get full Medicaid.
- Medicaid can pick up what your insurance company doesn't pay, including co-pays. Also, if your HMO has strict limits to the number of visits, Medicaid would kick in and pay after those visits have been exhausted, if you are using a Medicaid provider.
- All states have Medicaid (income-dependent) or and most have Medwaiver (not income-dependent) plans available to children with ASD.



# MEDICAID (CONT.)

- You can have BOTH Medicaid and Medicare at the same time. You can even have private insurance as well as both Medicaid and Medicare.
- Medicaid can be your sole insurance or a supplemental insurance, but it will always be payor of last resort, so all other insurances you may have would have to pay or deny service before Medicaid will pay.
- Medicaid does not provide the recipient any cash assistance and will not reimburse any bills. They will only make direct payments to Medicaid-approved providers.



# PENNSYLVANIA MEDICAID

- In PA, we have a “loophole” for children with disabilities, including autism, called the PH-95 Waiver. Any child under 18 with a disability diagnosis can apply and receive Medicaid, regardless of household income.
- <https://paautism.org/resource/medicaid-health-insurance-ph95/>
- You will need to renew your application every year. You can do it online, but experienced parents will tell you to HAND-DELIVER the application to your local county office.
- When your child turns 18, your local county Medicaid office will ask you to apply for SSI and provide proof of determination to them. Adult Medicaid funding comes from a different pool than child Medicaid funding so they will need to change pools behind the scenes, but it will not affect your Medicaid benefits.
- The bad news – once your child ages out of EPSDT at 21, Medicaid only covers rehabilitative care for a 3-month period every calendar year to receive therapies such as PT, OT and Speech every year.
  - **Rehabilitative therapy** seeks to help a patient regain a skill or function that was lost as a result of injury or sickness.
  - **Habilitative therapy** is a type of treatment or service that seeks to help patients develop skills or functions that they were incapable of developing on their own.



# MEDICARE

- Medicare is the federal health insurance program for:
  - People who are 65 or older
  - **Certain younger people with disabilities**
  - People with End-Stage Renal Disease
- The different parts of Medicare help cover specific services:
  - *Medicare Part A (Hospital Insurance)*
    - Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.
  - *Medicare Part B (Medical Insurance)*
    - Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services.
  - *Medicare Part D (prescription drug coverage)*
    - Part D adds prescription drug coverage to:
      - Original Medicare
      - Some Medicare Cost Plans
      - Some Medicare Private-Fee-for-Service Plans
      - Medicare Medical Savings Account Plans
- These plans are offered by insurance companies and other private companies approved by Medicare. Medicare Advantage Plans may also offer prescription drug coverage that follows the same rules as Medicare Prescription Drug Plans.



# MEDICARE (CONTINUED)

- If you have SSI, you will have Medicaid. If you get SSDI, you will be moved to Medicare. You can have both Medicaid and Medicare with SSDI, but not SSI.
- <https://www.medicare.gov/>
- 1-800-MEDICARE (1-800-633-4227)
- 2022 monthly premium for part B is \$170.10.
  - <https://www.medicare.gov/your-medicare-costs/part-b-costs>
- Medicare Savings Program – if your child gets SSDI, they can likely qualify for MSP to cover the monthly premiums.
  - <https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/medicare-savings-programs>
- Medicare doesn't cover most dental care, dental procedures, or supplies, like cleanings, fillings, tooth extractions, dentures, dental plates, or other dental devices. Medicare Part A (Hospital Insurance) will pay for certain dental services that you get when you're in a hospital. Part A can pay for inpatient hospital care if you need to have emergency or complicated dental procedures, even though the dental care isn't covered.



# FUNDING THE FUTURE

- Unless you happen to have millions of dollars sitting around (if so, you're buying dinner for us all), you will need to become well-versed in how to fund your child's future:
  - SSI
  - SSDI
  - Special Needs Trusts
  - ABLE Accounts





# SSI

- Supplemental Security Income (SSI) is a Federal income supplement program. To qualify you must be:
  - Over 65, blind or disabled **AND**
  - Has limited income and limited resources (and some other stuff).
- If your child is under 18, SSI counts the household income and resources.
- If your child is over 18, SSI only counts his/her income and resources.
  - Wait until the month following your child's birthday to apply as SSI is a once-per-month cycle.
- \$2000 is the maximum assets in the child's name unless it's in a trust.
- Under age 18, SSI considers autism a "presumptive diagnosis" as disabled, which means as long as you have the autism diagnosis and documentation, and meet the financial criteria, your child will qualify.
- Over age 18, SSI is based on QUALITATIVE IMPAIRMENT, meaning that even if you have a diagnosis, if the SSI caseworker, or the doctors feel your child COULD work with proper supports, he/she may be denied.



# SSI, CONTINUED

- 2/3 of people who are denied on the first round, win on appeal, so if you are denied, APPEAL.
- The clock on payments starts on the day you file so no matter how long SSI takes to review your case, how long appeals take, or how long they investigate a Special Needs Trust, you will get monthly payments back to the date of application. If it's a large lump sum, you will want to put it in a trust or ABLE as soon as you receive it, so your child doesn't go over the income/asset limits.
- The 2022 maximum monthly SSI payment is \$841.00. COLA increase in 2022 was 5.9%
- You NEED to charge your child Rent or "Room and Board" to get the most SSI possible. It must be in writing, and you provide this to SSI at application. Rent/R&B cost should be no more than 72% of the SSI maximum.
  - "Room and Board" includes a fixed rate for food.
  - Rent only would leave your child eligible for food stamps based on his income alone but all food must be bought and prepared separately.
  - PA Rent Rebate Program for renters or homeowners with disabilities. It sets aside 50% of the renter's SSI/SSDI income, and rebates are \$500-650 per month. <https://mypath.pa.gov/>  
<https://www.revenue.pa.gov/>



# SSI, CONTINUED

- SSI calculations are a bit like Common Core – they are way too complicated and make zero sense to anyone who has ever done math.
- SSI calculates household expenses and divides by people in the house. Then if the SSI payment maximum is not enough to cover your child's portion, they DECREASE (Say what now?) the payment and consider it a gift of “in-kind support” from the parent to the child.
- Do not allow your child's account or the Representative Payee account, to go over \$2000 or you will be forced to give it back to SSI.
- If your child is under 18 and your household income or resources change, you must report it to SSI or they may penalize you.
- It takes 2-5 months generally to be approved for SSI.
- <https://www.ssa.gov/ssi/>



# HOW TO APPLY FOR SSI

- You can apply online or on the phone. However, experience shows us it's far better to do the pre-qualification via telephone, then go to the meeting in person at your nearest office. **1-800-772-1213**.
- Unless instructed otherwise due to covid, you must bring your child to the appointment unless you can present a doctor's note of why they are too ill to attend. Unless their behavior is a danger to themselves and others, bring them and someone who can keep them busy, take them for a walk, or take them back home while you finish the appointment. It doesn't hurt for the SSI caseworker to see that your child is significantly impaired.
- Bring COPIES of all the necessary documents. Most SSI offices will take them and scan them and hand them back to you, but some will keep the documents for their files. Rarely, you will get someone who tells you that SSI will send requests for the files to the doctors and therapists you name but give them the copies anyway.
  - **Less than 20%** of all SSI forms sent to practitioners and schools are ever returned to SSI and most of those are incomplete. This can adversely affect your ability to get SSI without having to appeal.



# WHAT TO BRING TO YOUR APPOINTMENT

- Most recent IEP. If your child is out of school, bring an IEP from his/her final year
- Something that shows your child had a diagnosis before they turned 16. Can be an IEP, ISP, doctor's diagnosis, etc.
- Most recent ISP
- Most recent psych evaluation that includes Axis scores and or/IQ
- Doctor's diagnosis
- Therapist evaluations (speech, OT, PT, etc.)
- Rent or Room and Board agreement
- List of utilities and mortgage/rent, taxes (school, local, municipality) for household expenses
- Name, date, social security numbers for all people living in the house
- If your child has a bank account, savings bonds, life insurance, bring statements. (If they total over \$2000, you will be denied)
- Any unpaid medical bills from the past 3 months
- Documentation of any hospitalizations from the last year
- Contact information (names and addresses) for all doctors and therapists your child has seen in the last 5 years



# SSDI

- **Social Security Disability Insurance (SSD or SSDI)** is a payroll tax-funded federal insurance program. Like SSI, it is managed by the Social Security Administration and designed to provide income supplements to people who are physically restricted in their ability to be employed because of a notable disability. SSD can be supplied on either a temporary or permanent basis, usually directly correlated to whether the person's disability is temporary or permanent.
- The Social Security disability insurance program pays benefits to workers and certain family members if you worked long enough and paid Social Security taxes. Eligible family members can include a spouse, divorced spouse, child, **a disabled child, and/or an adult child disabled before age 22.**
- While a disabled (nonblind) person applying for or receiving SSDI cannot earn more than \$1,350 per month by working, a person collecting SSDI can have any amount of income from investments, interest, or a spouse's income, and any amount of assets. Beneficiaries can receive up to \$3345 per month in 2022.
- You cannot have both SSI and SSDI unless your SSDI payment is very low. If your child was receiving SSI but becomes eligible for SSDI, they will be changed over.
- You don't apply for SSDI, you apply for SSI and if you qualify for SSDI instead, they will move you over.





# SPECIAL NEEDS TRUSTS AND ABLE ACCOUNTS

- **You will need one of these.**
- Because Medicaid and SSI have income and resource restrictions, you will need to open either a Special Needs Trust or at least an ABLE (Achieving a Better Life Experience Act) account to be able to save any money in their name for their future.
- A SNT requires a lawyer and can cost thousands to set up.
- An ABLE account has low start up and monthly fees but has a lower cap than a SNT.
- <https://www.ablenrc.org/> has free webinars, state comparison charts and more.
- Make sure your family and friends who may want to gift or help your child puts the money into either an ABLE or SNT. This includes life insurance policies (parents, grandparents, etc).
- <https://tacanow.org/family-resources/legal-planning-special-needs-trusts/>



# DISABILITY EMPLOYMENT PROGRAMS

- Whether a disability is temporary or permanent, if you are able, you can still work, but there are limits to how much you can earn and still receive SSI/SSDI or other benefits.
- To be eligible for disability benefits, a person must be UNABLE to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. Non-blind: \$1,350 per month  
<https://www.ssa.gov/oact/cola/sga.html>
- **If you exceed the income limits, SSA will take the money back.**
- Report all changes to income. The SSA don't play!
- The 4 programs are:
  - PASS - Plan to Achieve Self-Support
  - TTW – Ticket To Work
  - MAWD - Medical Assistance for Workers with Disabilities
  - OVR – Office of Vocational Rehabilitation



# PLAN TO ACHIEVE SELF-SUPPORT (PASS)

## What is a PASS?

- It is an SSI provision to help individuals with disabilities return to work.
- If you receive SSI or could qualify for SSI after setting aside income or resources so you can pursue a work goal, you could benefit from a PASS.

## How does a PASS help someone return to work?

- PASS lets a disabled individual set aside money and things he or she owns to pay for items or services needed to achieve a specific work goal.
- The objective of the PASS is to help disabled individuals find employment that reduces or eliminates SSI or SSDI benefits.

- <https://www.ssa.gov/disabilityresearch/wi/pass.htm>



# TICKET TO WORK & MAWD

- **The Ticket to Work and Self Sufficiency** (Ticket) program is a Federally-funded employment program designed to provide Social Security disability beneficiaries (i.e., individuals receiving Social Security Disability Insurance and/or Supplemental Security Income benefits based on disability) the choices, opportunities and support they need to enter the workforce and maintain employment with the goal of becoming economically self-supporting over time.
- <https://yourtickettowork.ssa.gov/>
- **Medical Assistance for Workers with Disabilities** (also called “MAWD”) is a state health insurance program for individuals who have chronic health problems and are working. MAWD is often a good option for individuals who have too much income to qualify for other categories of Medical Assistance (MA) but who nonetheless need health insurance. MAWD provides comprehensive health insurance coverage and, compared to other MA programs, MAWD has high income and resource limits. It also has flexible work and disability requirements.
- <https://paautism.org/resource/medical-assistance-health-disabilities/>



# OFFICE OF VOCATIONAL REHABILITATION

- Vocational Rehabilitation is a federal program, delivered (and named) a little differently in each state.
- You should start working with OVR during transition IEPs (age 16) but can work with them privately at any age.
- The Pennsylvania Office of Vocational Rehabilitation, or OVR, provides vocational rehabilitation services to help persons with disabilities **prepare for, obtain, or maintain employment**. OVR provides services to eligible individuals with disabilities, both directly and through a network of approved vendors. Services are provided on an individualized basis. The OVR counselor, during face-to-face interviews, assists customers in selecting their choice of vocational goals, services and service providers. An Individualized Plan for Employment (IPE) is developed, outlining a vocational objective, services, providers and responsibilities.
- Certain services are subject to a Financial Needs Test (FNT) and may require financial participation by the customer.
- Counseling and guidance, diagnostic services, assessments, information and referral, job development and placement, and personal services such as readers or sign language interpreters are provided at no cost to the individual. Also, by law OVR customers receiving Social Security benefits for their disability (SSI, SSDI) are exempt from OVR's Financial Needs Test.
- <https://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/OVR-Office-Directory.aspx>



# HOUSING

- There is a vast shortage of housing in the US for the epidemic numbers of people with autism who are starting to age out.
  - To date, only 19% of people with autism have ever lived outside their family home.\*
  - 87% currently live with their parents.\*
  - 1.2 MILLION people with ASD live with parents OVER THE AGE OF 60.\*
  - More than 40% of adults with ASD will need 24-hour care, lifelong.\*
- There is a tsunami of adults coming and the states are horribly unprepared. Parents will need to pick up the slack by creating their own housing opportunities. There is help for families:
  - Autism Housing Network – Resources to help you start or find housing for your child  
<http://www.autismhousingnetwork.org/>
  - HUD Housing Assistance - [https://www.hud.gov/program\\_offices/comm\\_planning](https://www.hud.gov/program_offices/comm_planning)
  - Housing Resources - <https://tacanow.org/family-resources/housing/>

\*Stats from Autism Housing Network





# WHAT IS A WAIVER?

- In terms of disability services, a waiver means “to waive the income/cost and still provide a service”.
- The most common are **Home & Community-Based Services 1915(c) Waivers**
  - Within broad Federal guidelines, States can develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.
  - States can offer a variety of unlimited services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose “other” types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.
  - <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html>
- To find the waiver programs in your state, just do a websearch for your state and autism waivers or Medicaid waivers”.



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>Community Living Waiver</b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Community-Living-Waiver.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Community-Living-Waiver.aspx</a></p>	<p>*No age limit for intellectual disability or autism.            *Developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8            *Require an ICF/ID or ICF/ORC level of care            *Individual cost limit of \$85,000 per person per fiscal year.</p>	<p>*Employment Services (job finding and job coaching)            *In-Home and Community Support            *Companion            *Community Participation Support            *Respite            *Shift Nursing            *Therapies            *Behavioral Support            *Assistive Technology            *Home and Vehicle Accessibility Adaptations            *Transportation            *Life Sharing            *Supported Living</p>



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>Community HealthChoices (CHC) Waiver</b></p> <p>Formerly “Independence” and “CommCare” Waivers</p> <p><a href="https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/CHC-Main.aspx">https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/CHC-Main.aspx</a></p>	<ul style="list-style-type: none"> <li>*Age 21 or older with a physical disability</li> <li>*Meet nursing facility level of care criteria</li> <li>*Wish to receive long-term services and supports in own home or another community setting</li> </ul>	<ul style="list-style-type: none"> <li>*Daily Living Services*Assistive Technology</li> <li>*Environmental Adaptations</li> <li>*Cognitive Rehabilitation Therapy Services</li> <li>*Employment Services</li> <li>*Home Delivered Meals</li> <li>*Transportation Services</li> <li>*Personal Assistance Services</li> <li>*Pest Eradication</li> <li>*Respite</li> </ul>



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>Adult Community Autism Program (ACAP)</b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/ACAP.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/ACAP.aspx</a></p>	<ul style="list-style-type: none"> <li>*21 years or older</li> <li>*Diagnosis of Autism Spectrum Disorder (Autistic Disorder, Childhood Disintegrative Disorder, PDD-NOS, Asperger Syndrome or Rett Disorder)</li> <li>*Require Intermediate Care Facility (ICF) level of care</li> <li>*Be able to live in a home or community setting without 16 hours or more per day of awake staffing and supervision</li> <li>*Not have behaviors that are dangerous to yourself or others or that could cause harm to property</li> </ul>	<ul style="list-style-type: none"> <li>*Physician, ICF, psychiatric, nursing facility, hospice services</li> <li>*Dental, vision, speech, podiatry, chiropractic services</li> <li>*Medical supplies and equipment</li> <li>*Health promotion and disease prevention services</li> <li>*Targeted case management</li> <li>*Mental health crisis intervention services</li> <li>*Adult day habilitation services</li> <li>*Homemaker services</li> <li>*Residential &amp; behavioral support</li> <li>*Respite care</li> <li>*Supported employment</li> <li>*Community transition services</li> <li>*Environmental modifications</li> <li>*Assistive technology</li> <li>*Family counseling</li> </ul>



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b><u>Adult Autism Waiver (AAW)</u></b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Adult%20Autism%20Waiver.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Adult%20Autism%20Waiver.aspx</a></p>	<ul style="list-style-type: none"> <li>*Age 21 or older</li> <li>*Diagnosed with Autism Spectrum Disorder (Autistic Disorder, Childhood Disintegrative Disorder, PDD-NOS, Asperger Syndrome or Rett Disorder)</li> <li>*Meet Intermediate Care Facility level of care</li> <li>*Provides Housing Funding</li> </ul>	<ul style="list-style-type: none"> <li>*Assistive technology</li> <li>*Behavioral health services</li> <li>*Community inclusion</li> <li>*Community Transition Services</li> <li>*Counseling</li> <li>*Day &amp; residential habilitation</li> <li>*Environmental modifications</li> <li>*Family counseling &amp; training</li> <li>*Job assessment and finding</li> <li>*Nutritional consultation</li> <li>*Occupational therapy</li> <li>*Respite</li> <li>*Speech/ language therapy</li> <li>*Supported employment</li> <li>*Supports coordination</li> <li>*Temporary crisis services</li> <li>*Transitional work services</li> </ul>



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>Person/Family-Directed Support (P/FDS) Waiver</b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/PFDS-Waiver.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/PFDS-Waiver.aspx</a></p>	<p>*No age limit for intellectual disability or autism.            *Developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8            *Require an ICF/ID or ICF/ORC level of care            *Individual cost limit of \$41,000 per person per fiscal year (Supports Coordination and Supports Broker are excluded from this limit. There are also some exceptions for employment service.)            *Certain services must be delivered by EPSDT before 21.  <a href="http://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf">www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf</a></p>	<p>*Employment Services (job finding and job coaching)            *In-Home and Community Support            *Companion            *Community Participation Support            *Respite            *Shift Nursing            *Therapies            *Behavioral Support            *Assistive Technology            *Home and Vehicle Accessibility Adaptations            *Transportation</p>





# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>Consolidated Waiver</b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Consolidated-Waiver.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Consolidated-Waiver.aspx</a></p>	<ul style="list-style-type: none"> <li>*No age limit for intellectual disability or autism.</li> <li>*Developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8</li> <li>*Require an ICF/ID or ICF/ORC level of care</li> <li>*No individual cost limit per year on services</li> <li>*Certain services must be delivered by EPSDT before 21.</li> </ul> <p><a href="http://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf">www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf</a></p>	<ul style="list-style-type: none"> <li>*Residential Habilitation</li> <li>*Employment Services (job finding and job coaching)</li> <li>*In-Home and Community Support</li> <li>*Companion</li> <li>*Community Participation Support</li> <li>*Respite</li> <li>*Shift Nursing</li> <li>*Therapies</li> <li>*Behavioral Support</li> <li>*Assistive Technology</li> <li>*Home and Vehicle Accessibility Adaptations</li> <li>*Transportation</li> <li>*Life Sharing</li> <li>*Supported Living</li> </ul>



# PENNSYLVANIA WAIVERS

Waiver	Functional Eligibility Requirements	Services Provided
<p><b>OBRA Waiver</b></p> <p><a href="https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/OBRA.aspx">https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/OBRA.aspx</a></p>	<ul style="list-style-type: none"> <li>*Persons with developmental physical disabilities</li> <li>*Disability results in at least 3 substantial functional limitations</li> <li>*Disability manifested prior to age 22</li> <li>*Age 18 or older</li> <li>*Disability is expected to continue indefinitely</li> <li>*Requires ICF/ORC level of care</li> </ul>	<ul style="list-style-type: none"> <li>*Daily living services</li> <li>*Environmental adaptations</li> <li>*Assistive technology</li> <li>*Community integration services</li> <li>*Respite services</li> <li>*Transportation</li> <li>*Supported employment services</li> <li>*Prevocational and educational services</li> </ul>



# GUARDIANSHIP AND POWER OF ATTORNEY

- Guardianship provides the parent the ability to safeguard their child and make medical and financial decisions for their child.
- Without guardianship, you have no legal rights to information about your child, or their care.
- Guardianship generally costs \$1-3K if it's uncontested, using a lawyer.
- You CAN file for guardianship without a lawyer, just paying court fees. Do a web search for your county and "orphans court guardianship" to find forms.
- PA now has a statewide online guardianship tracking system that is mandated for all guardians. You will need to fill out 2 short forms every year and submit them online.
- POA costs \$400-800 through a lawyer. It generally limits your role to just a specific thing, like legal or financial and unlike guardianship, your child can revoke it at any time (even if they don't understand they are doing it). If your child cannot advocate for themselves, guardianship should be considered.
- Orgs like SSI do not recognize POA.
- <https://tacanow.org/family-resources/preparing-for-adulthood/>



# WHERE TO START – AGE 16-18

- At diagnosis/move to PA:
  - Apply for Medical Access (Medicaid) and begin services.
  - Apply for a Consolidated/PFDS Waiver waiting list.
  - Open an ABLÉ or SNT.
- Age 16:
  - Start annual Transition IEPs at school (include OVR).
- Age 17:
  - Start gathering docs you will need for SSI.
  - Apply for OVR if not already included in IEP.
  - Get a state ID card and passport for your child.
  - Start prepping for college, if applicable.
- Age 18:
  - Apply for SSI.
  - Open a Representative Payee bank account for your child's SSI payments.



# GLOSSARY AND ACRONYMS

- ASD – Autism Spectrum Disorder
- AWC – Agency with Choice
- BSC – Behavioral Specialist Consultant
- CAO – Community Assistance Office
- CHC – Community Health Choices
- CLA – Community Living Arrangement
- CLE – Common Law Employer
- COLA – Cost of Living Adjustment
- COMPASS – Website for Pennsylvanians to apply for services
- DSP – Direct Support Professional
- EHC – Enhanced Home and Community
- EPSDT – Early and Periodic Screening, Diagnostic and Treatment
- HCBS – Home and Community Based Services
- HTTSS – Housing Transition and Tenancy Sustaining Services (ODP Comm 083-18)



# GLOSSARY AND ACRONYMS

- ISP – Individualized Support Plan
- LIHEAP – The Low-Income Home Energy Assistance Program
- MA – Medical Access (aka PA Medicaid)
- MCO – Managed-Care Organizations
- MLTSS – Managed Long-Term Services and Supports
- ODP – Office of Developmental Programs
- OLTL – Office of Long-Term Living
- OVR – Office of Vocational Rehabilitation
- PUNS – Prioritization of Urgency of Need for Services
- SB – Supports Broker
- SC – Supports Coordinator
- SIS – Supports Intensity Scale (SIS) Assessments for ODP Waivers
- SSP – Support Service Professional
- TSS – Therapeutic Support Staff





# RECOMMENDED PA LINKS

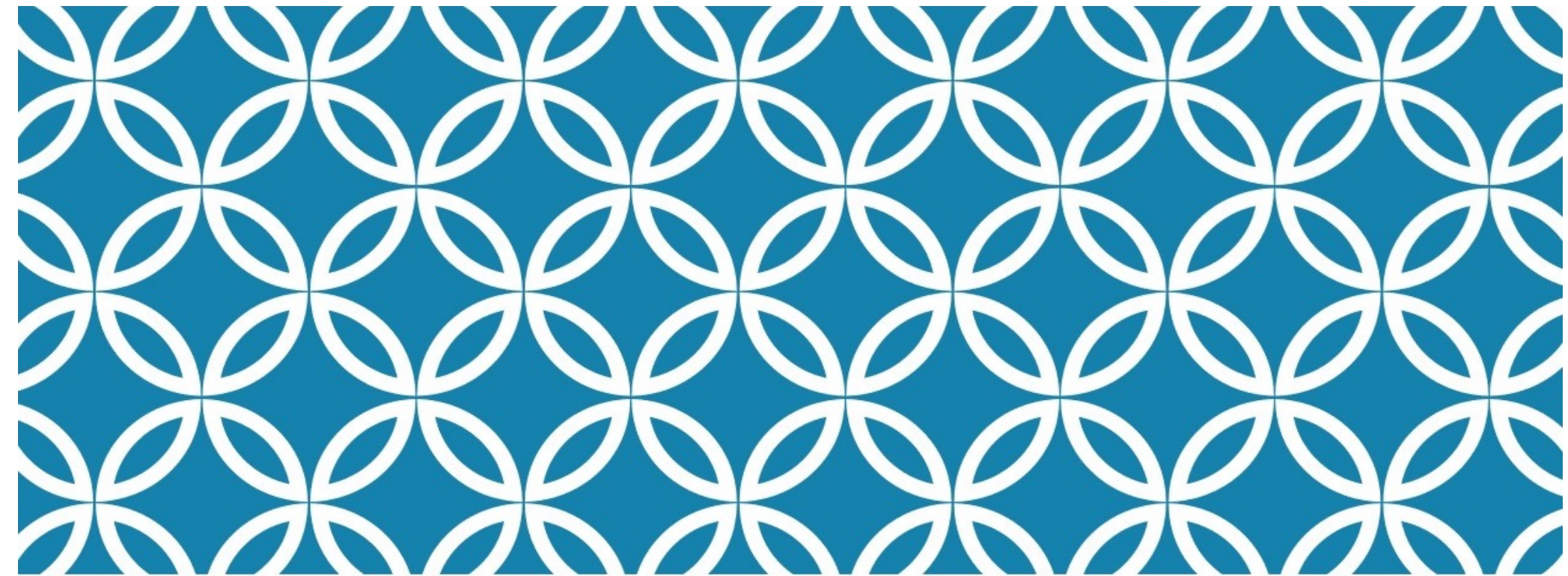
- PA Family Network (aka Vision For Equality) offers support and help for families navigating the system. <https://www.visionforequality.org/>
- Disability Rights of PA - <https://www.disabilityrightspa.org/>
- PA Health Law Project – PHLP provides free legal information and help to families for healthcare related matters including Medicaid and waivers. <https://www.phlp.org/>
- MyODP - You can sign up here to receive ODP bulletins that affect state programs. <https://www.myodp.org/>
- ASERT PA Autism Resources - <https://paautism.org/>
- Waiver plans overview- <https://www.dhs.pa.gov/Services/Assistance/Pages/Home-and-Community-Based%20Services.aspx>
- PA Families of 16+ (only) kids with ASD/ID - <https://www.facebook.com/groups/SEPaAutismFamilyMembersOfAdults/>



# TIME IS NOT ON YOUR SIDE

- Some days it feels like just yesterday that my kids were little. Then I remember they are already adults – soon to be 25 and 27. Time is not on my side. It's not on yours either.
- No one wants to put their kid in a “home”, but we cannot live forever, so for those of us - the majority of us - who do not have other family members who will care for our children after we're gone, we need to make plans that are appropriate for our kids to lead the happiest, healthiest lives they can.
- What happens to children when their parents are unable to care for them suddenly is almost invariably bad. Languishing for months in the ER, dumped into the first available bed in the state, fed garbage, pumped full of meds, neglected and misunderstood by those charged to care for your child is the most common outcome we see nationally.
- No one is going to do this for you. No one is coming to save you. You must do this for your child. It's not optional. The sooner you get started the better.
- As parents, we don't get to live forever, no matter how much we may want to. You NEED to get these services on board for your child. You need to make a plan, in writing. We're only getting older so start NOW, tomorrow may be too late.





**QUESTIONS?**