



ADULT *Transition* **TOOLKIT**



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INTRODUCTION

It is normal to feel overwhelmed and emotional, thinking about your child with Angelman syndrome turning 18. There is so much that comes with adulthood. It can be intimidating facing the uncertainty AND all the paperwork. You don't have to face this alone. We, at the Foundation for Angelman Syndrome Therapeutics (FAST), will be here to support you and help answer your questions as best as we can.

It can be a complicated process. There are rules, agencies, and even a new vocabulary you will need to know. Learning about the actions you will need to take may relieve some stress. Most importantly, knowing the steps and understanding your adult child's rights, will assist you when applying for the financial support that your adult child is entitled to. This knowledge will help you get the needed support so your adult child can live their best life.

There are people you can ask for help. At your child's school, there are teachers, guidance staff, and parents of older children who have been through the process and can offer advice. There may be other local agencies they can refer you to for more extensive assistance.

Every person with Angelman syndrome is unique, so there is no one size fits all plan for transitioning to adulthood. The approach you take and the decisions you make regarding their transition to adult life should be based on your individual child's strengths and needs.

We at FAST hope you can use this toolkit as a starting point to help break down the tasks and make this milestone in your child's life go as smoothly as possible. Get a notebook to keep good notes, your favorite pen, and let's begin!

FAST would like to thank Juli DelMonego and Tracy Carreola for their tireless dedication to the Angelman community and for their assistance with the drafting of the Adult Transition Toolkit.

Starting with the program that will fund most of your child's adult needs — your state's Medicaid Waiver program.



Juli



Tracy ♥

CHECKLIST

FAST ADULT TRANSITION ACTION PLAN CHECKLIST

We at the Foundation for Angelman Syndrome Therapeutics (FAST) have put together an action plan to assist with navigating the important tasks when transitioning into adulthood. The FAST Adult Transition Toolkit provides more in-depth explanations of the items below. Please read the Toolkit first and then use the Action Plan Checklist to keep track of the various steps.

Decision Making/Health

- ☐ **Meet with your child's current physician-** ask if you will need another doctor once your child turns 18; if yes, ask for recommendations.
- ☐ **Ask your child's current physician about HIPAA.** Ensure that once your child turns 18, you will still be able to speak and make decisions on your child's behalf.
- ☐ **Download and print the HIPAA form for your state** and confirm with your child's physician that your child's "mark" or signature is sufficient on the form. (HIPAA form in the quick reference guide).
- ☐ **Find a good family or elder care attorney** in your state to assist you with determining options for making decisions on behalf of your child once they turn 18, (SDM, guardianship, medical proxy, etc.)
- ☐ **Obtain a state ID card.**

Selective Service

- ☐ **Male Only-** This can be done online using the link provided under Selective Service in the toolkit.

Registering to Vote

- ☐ You can **register your child to vote** using the link within the toolkit.

Services/Transition from School

- ☐ **Check your child's Medicaid Waiver status.**
 - >> Your child is **already on a Waiver**, ensure there is nothing else you need to do once your child turns 18.
 - >> Your child is **on a Waiver waitlist**, inquire about crisis status, and apply.
 - >> If you have **not yet applied for a Medicaid Waiver** - do so now.
- ☐ Consult your **IEP transition team** on job training, day programs etc. and check each option out to find the best fit for your child.
- ☐ **Inquire about Vocational Rehabilitation** to see if your child will qualify. See the link under "Vocational Rehab" in the quick links page in the toolkit.

Money

- ☐ **Supplemental Security Income** - gather documents and make an appointment with Social Security.
- ☐ **Open a representative payee account.**
- ☐ Apply for the **Supplemental Nutrition Assistance Program** for your child.
- ☐ **Set up an ABLÉ account** if needed.
- ☐ If you would like to set up a **special needs trust**, find an attorney that specializes in special needs trusts.

STATE MEDICAID WAIVER PROGRAM

What is a Medicaid Waiver?

If your child already receives Medicaid Waiver services, you can skip the next section that explains what the Medicaid Waiver program is. You may not need to do anything when they turn 18 to keep them in the program. Some states have different Medicaid Waiver programs for children and adults. Check with your state's Medicaid Waiver office <http://medicaidwaiver.org/> to see if you need to re-file for your adult child.

The Medicaid Home and Community Based Services Waivers (HCBS WAIVER) help provide services to people in their home and community instead of in a hospital, nursing home or institution. In the past, people with disabilities could only receive Medicaid funding for supports if they were in an institutional setting. Medicaid Waivers, as they are commonly called, allow states to provide services to people who need Long Term Services and Supports (LTSS) in a community setting (like their family home or a supported living home) instead of a nursing home, or institution. For more information on HCBS Medicaid Waivers see the following link: www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/

Medicaid Waiver Details

The Medicaid Waiver is the program that pays for most adult services for our kids with AS, such as:

- Personal care assistance
- Respite
- Transportation
- Support in community activities
- Adult day programs



Contact your state's Medicaid Waiver office regardless of whether or not your child currently has the Waiver.

It is very important that your family member with AS be on the Medicaid Waiver.

The Medicaid Waiver program requires a written plan of action, developed, and regularly modified to meet the needs of a specific person. The plan includes:

- Short and long-term goals
- Activities that address the goals
- Time frames for reaching them
- Who is responsible for carrying out the plan

STATE MEDICAID WAIVER PROGRAM

A Medicaid Waiver enrolls your child in Medicaid Health Insurance, which will pay for:

- Health care (doctor's appointments, ER/hospital visits, etc.)
- Durable medical equipment (wheelchairs, walkers, etc.)
- Prescription medicines
- Supplies (diapers, pads, etc.)
- Co-pays if your child is included in your private health insurance

The ability to have paid supports and services depends on a funding source, such as the state Medicaid Waiver. It is very important that your family member with AS be on the Medicaid Waiver.

Who provides Medicaid Waiver services?

Home health agencies that accept Medicaid Waiver can provide services, such as personal care and respite. There are adult day and supported employment programs for people with developmental disabilities that are funded by the Medicaid Waiver. Caregivers can go through a state certification process to become a Medicaid Waiver provider. They can then operate a service provider agency or work independently.

Many states allow parents to hire their own support staff for their child through an option known as Self-Determined or Consumer-Directed Care. As the employer, it would require you to find your employees, train, and supervise them. An agency will provide support, case management, and oversight.

In many states, you, or another family member are allowed to be a paid caregiver for your own child.

Is the Medicaid Waiver program the same everywhere in the US?

No, every state has its own system for running and funding their Medicaid Waiver Programs. A Medicaid Waiver does not transfer from state to state.

States usually have many Medicaid Waiver programs. Some are for the elderly. Some are for people with only physical disabilities, only developmental or intellectual disabilities, or both physical and developmental disabilities. Your state's Medicaid Waiver office will have a list of programs and who qualifies for each.

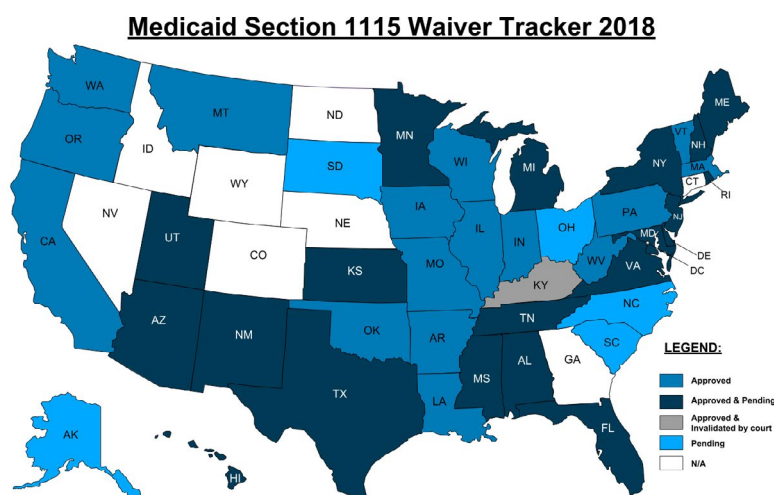
STATE MEDICAID WAIVER PROGRAM

Will my child automatically be enrolled in a Medicaid Waiver?

It is possible for your child to be eligible for Medicaid Waiver services but not receive them because of a lack of funds. Some states fully fund one or more of their Medicaid Waiver programs, so that all people who qualify get their needed services paid for. Most states do not adequately fund their Medicaid Waiver Programs, especially those that provide extensive services for people like our children with Angelman syndrome who have medical, physical, and developmental disabilities. Depending on where you live, your child with AS may wait years for services to be fully funded. It is important you get your child on the Medicaid Waiver waiting list in your state, if there is one, as soon as possible.

If you have to wait for a slot to open up for the right Medicaid Waiver for your child, your state may have a Medicaid Waiver program that meets some, but not all, of your family's needs.

Your first step is to contact your state's Medicaid Waiver office to find out the process for enrolling your child in a Medicaid Waiver program. You can find the phone number for your state on this website <http://medicaidwaiver.org/> or your school will be able to give it to you.



Source: <https://advocacy.epilepsy.com/MedicaidWaivers>

IEP TRANSITION PLAN



The Transition Plan in your child's Individualized Education Plan (IEP) is where you plan for your student's future. You should start planning for the transition to post-school activities at 14, or during high school, at the latest. The goal under the Individuals with Disabilities Education Act (IDEA) is for schools to prepare students for post-secondary education, vocational training, community participation, employment, and independent living.



IDEA states that the IEP must include a section called Transition Planning at the age of 16, in addition to their other annual IEP goals. The transition plan has three parts:

- A description of the student's strengths and interests
- Measurable goals focused on the student's life after high school
- Transition services needed to achieve these goals



By law, your student with AS has to be included in this planning. **The transition plans should include a coordinated set of activities that prepare children with AS to "lead productive and independent adult lives, to the maximum extent possible," according to IDEA.**

Make sure to include goals for instruction on skills that will help your child in the future: problem-solving, decision making, and choice making. Make sure the supports your child will need to achieve these goals is in the transition plan. For more information about transition services in the law, see <https://ldaamerica.org/transition-planning-requirements-of-idea-2004/>

Many adults with Angelman syndrome will need significant supports to participate in community life, workplace, and volunteer activities. The supports will likely be addressed in the transition plan.

This is a good article from Autism Spectrum News on transition planning for people who will still need substantial supports in adulthood: <https://autismspectrumnews.org/next-stop-adulthood-a-framework-for-effective-transition-planning-for-students-with-severe-disabilities>

TRANSITIONING FROM SCHOOL TO ADULT LIFE

Until age 22, students are entitled under IDEA to receive a “free appropriate public education” (FAPE). After age 21, however, they are no longer entitled to any of the services or rights under IDEA.

Your child is not guaranteed a placement in any adult day program or supported employment program, and those programs are not required to provide the supports you are used to, like an IEP, 1:1 support, therapies, etc.

Ask your IEP team for a list of the agencies and programs in your area that work with adults with developmental disabilities (DD). We encourage you to visit and explore these programs and sites. Ask questions:

- What supports do they offer?
- What are the criteria for accepting clients into the program?
- Who funds the program?

If you find programs or activities that you feel will suit your child’s needs, get their name on a waiting list, if there is one, for the programs that you and your child with AS prefer.

If you are unable to enroll your child in one of these programs, or there are no programs available where you live, or you choose not to enroll them in a program, there are other ways to fill your child’s day with meaningful activities in the community.

Check into local non-profit agencies, churches, city parks programs, or for volunteer opportunities at places such as the Humane Society, food banks, or museums, that your child can participate in with assistance you provide. (See the information on Self-Determined Or Consumer-Directed options under the question, “Who provides Medicaid Waiver services” above, on how to get the 1:1 support your child may need.)

Person-Centered Planning

The transition plan should be driven by your child’s desires, preferences, strengths, and challenges. This is the theory behind person-centered planning. (*AutismSpeaks.org*)

Community-Centered Living

Visit the Administration for Community Living to see how Centers for Independent Living make community living possible for people with disabilities across the nation.

TRANSITIONING FROM SCHOOL TO ADULT LIFE

HOW DO I START PLANNING FOR MY CHILD'S TRANSITION FROM HIGH SCHOOL?

Person-Centered Planning and Community-Centered Living The 1999 US Supreme Court decision known as Olmstead is one of the most important Civil Rights decisions for people with disabilities in US history. The Supreme Court ruled that people with disabilities have the right to receive state-funded supports and services in the community, rather than institutions.

Individuals with disabilities can now receive home and community-based services through their state's Medicaid Waiver. They have the right to self-determination, have greater control over their community-based services, and more power in making decisions that affect their lives.

Just like in the IDEA, where there is a requirement that the student be in the "least restrictive environment," under Olmstead, there is an obligation to serve people with developmental disabilities (DD) in the least restrictive, most integrated environments.

Vocational Rehabilitation (VR, VocRehab) is a federal-state program that helps people with disabilities train for and achieve their career goals.

The VR program is administered by the federal Dept. of Education's Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration. You can invite VR representatives to take part in your child's IEP meeting to discuss transition services. You apply for services at your local VR office. A VR counselor works with people with disabilities to determine if eligible to receive Voc Rehab services. Find your local Voc Rehab office at <https://askearn.org/state-vocational-rehabilitation-agencies/>



Quick Links Resource Page

Please refer to the Quick Links Resource Page at the end of the Toolkit for links to information on:

Person-Centered- Planning, including Circles of Support, Planning Alternative Tomorrows with Hope (PATHS), Making Action Plans (MAPS), and Group Action Planning (GAP). These are all tools to do future planning, so a person with a disability has self-determination, which will help them to assume greater responsibility and control in their life.

LEGAL MATTERS

Like everyone else, when a person with Angelman syndrome turns 18 years of age, they are legally considered an adult and have all the rights and responsibilities that come with adulthood.

This means that parents may no longer have the right to see their child's school or medical records. Parents might not be allowed to give permission for medical care; to speak to doctors, Medicaid, insurance companies, or other agencies; or even pick up prescriptions, without the express permission of their adult child.

You have legal decisions to make regarding your child's future. What you decide to do depends on the ability of your child to make and communicate their own decisions. Whatever you decide, **you must go through a legal process.**

We can provide you with information on some of the options, but **it is NOT a substitute for legal advice.** And, like Medicaid Waiver programs, each state has its own laws and processes.

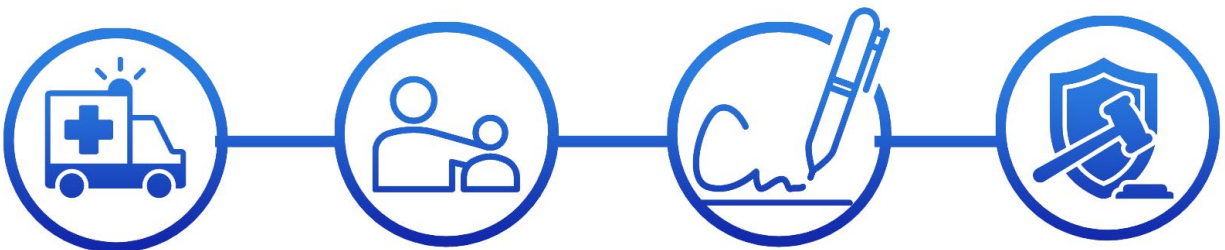
It is especially important that you consult with professionals — lawyers, financial planners — who can assist with these legal issues well BEFORE your child turns 18. If you did not, this is a perfect time to get started!

In addition to what help we can offer, we recommend that you ask the school and/or other parents for advice on how to get started. You can contact your state's disability agency or The Arc for guidance, lists of providers, etc. You can find your state and local contact information at <https://thearc.org>.

QUICK LINK RESOURCES

for federally funded
assistance programs
in each state.

There will be changes in the following areas when your child becomes an adult.



LEGAL MATTERS

Health Care

According to the Health Insurance Portability and Accountability Act (HIPAA), after they turn 18, you will no longer have access to your child's health information unless your child signs a waiver giving you permission. The following link contains a generic HIPAA release form: www.caring.com/forms/hipaa-release-form/free-hipaa-release-form.pdf. Most medical providers have their own forms. Many medical providers have a printable HIPAA on their websites.

Once your child reaches the age of 18, they may have to transition from a pediatrician to an adult primary care physician. They may have to move to adult specialty doctors, such as neurology and gastroenterology, instead of using the Pediatric Clinics they have received care from in the past.

Speak to your child's doctors about when, or if, they must transfer to adult providers. If your child is on the state Medicaid Waiver for insurance, your state may require them to transition to adult Medicaid, and services and coverage may change. Under the Affordable Care Act (ACA) of 2010, insurers must cover dependents on a parent or guardian's insurance plan up to the age of 26. Some private insurance companies will continue to cover a dependent of any age with a disability. Check with your insurance provider to determine the exact coverage.

Decision-Making / Guardianship

A person, regardless of their disability, should keep as many rights and responsibilities as possible. This means that a person should stay in control of their life as much as they can. There are various decision-making alternatives for adults with developmental disabilities, from Supported Decision-Making to Full Guardianship.

Not all of these require a ruling from a judge or court, but they all require legal expertise. We recommend that you talk to someone who can explain the legal ramifications of different decision-making options in your state for your adult with AS.

Many people with a disability need some degree of help in making decisions about their health, finances, where they live, etc. Each state laws that decide:

- Who requires help in making these decisions?
- What types of decisions will they need help with?
- How much help do they need?
- Who will provide the help?

You will need the assistance of a legal professional to begin this process.

... CONTINUE FOR YOUR OPTIONS

LEGAL MATTERS

WHAT ARE THE OPTIONS IN DETERMINING HOW MUCH SUPPORT MY CHILD NEEDS? (...continued)

Supported Decision Making

Allows an adult with a disability to make his or her own decisions with the help of trusted supporters. SDM does not take away any rights, responsibilities, or decision-making power from the person with a disability.

The individual chooses people to be a part of his or her support network. The individual can remove or add a supporter at any point.

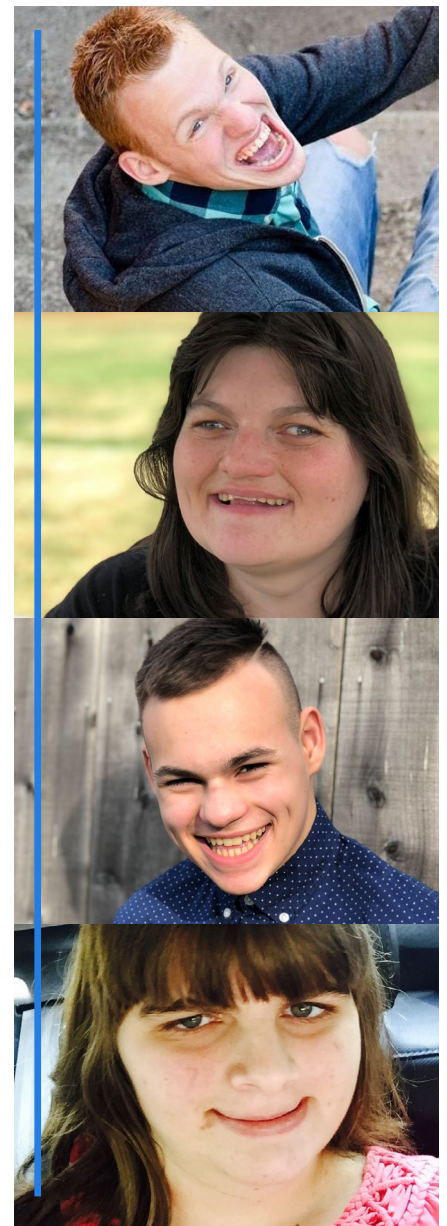
Sometimes a person completes and signs a written document or a support agreement. The chosen support people would also sign this agreement. The agreement explains the role of the support people.

People can use SDM on its own or in combination with other alternatives to guardianship.

For more information about SDM, visit:
www.supporteddecisionmaking.org.

This website has a page under “In Your State” that gives you the option to click links to resources in your state-supported decision on making AND the Guardianship laws in each state.

The following link will take you to the registration for a free online course called “Finding the Right Fit: Decision-Making Supports and Guardianship”
<https://eji.courtllms.org/catalog>.



LEGAL MATTERS

WHAT ARE THE OPTIONS IN DETERMINING HOW MUCH SUPPORT MY CHILD NEEDS? (...continued)

Health Care Proxy

A HCP is a legal document that can be used instead of a durable power of attorney when a person needs medical decision-making assistance.

It allows an adult to choose a trusted person to make medical decisions for the adult if they are unable to do it themselves. The person can complete a health care proxy without involving the court system.

Not all states allow the option of a Health Care Proxy. You will have to check the laws in your state to see if that is an option.



[CLICK HERE](#) for an example of a Health Care Proxy from the state of Florida authorized under FL Statute.



[CLICK HERE](#) for the Declaration of Medical Proxy Document

Durable Power of Attorney

A DPA is a legal document. It allows an adult to choose a trusted person to manage the adult's money, property, and business affairs when the adult is unable to do so.

The person with a disability must understand the legal document and sign it. They must have the capacity, meaning the ability, to appoint someone as their Power of Attorney. He/she may also revoke or undo the durable power of attorney. The Courts are not generally involved.

Conservatorship appoints a Conservator that manages the finances of a person with a disability but does not make personal or health decisions for the person.

A **Representative Payee** is a person or an organization that manages certain government benefits for an individual when that individual cannot safely do so. The Social Security Administration (SSA) can appoint a representative payee to manage a person's Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) funds.

LEGAL MATTERS

WHAT ARE THE OPTIONS IN DETERMINING HOW MUCH SUPPORT MY CHILD NEEDS?

The representative payee can only manage the individual's government benefits (SSI and SSDI) and cannot control an individual's other money or property. For more information, go to www.ssa.gov/payee or call your local SSA office.

Guardianship is a legal process involving the Probate Court. If a parent wants to continue to make all decisions for their child when they turn 18, they must become their legal guardian.

Guardianship should be considered only after less restrictive options have been explored. It takes away an individual's decision-making rights and responsibilities and gives this authority to another person. The guardian makes decisions for the individual with disabilities.

Court-ordered Guardianship gives one person the authority to make decisions on behalf of another person whom a court has deemed to be "incapacitated." A guardian can be removed or replaced via a petition to the court. The following link contains information on guardianship laws in each state:

www.supporteddecisionmaking.org.

There are several types of guardianship, two of which we will discuss here:

LIMITED GUARDIANSHIP

allows the guardian to make decisions only in specific areas, such as medical and educational. This type of guardianship allows the individual to make certain decisions on their own and retain some rights.

FULL GUARDIANSHIP

also called Plenary Guardianship allows the guardian the power to exercise all legal rights and decisions on behalf of an individual. The court may appoint full guardianship only after finding the individual is "incapacitated." That means the individual has been found to be incapable of handling personal decisions, consenting to medical procedures, or handling finances.

Every state handles guardianship differently. Each state has its own definition of limited and full guardianship; requirements for the courts; and laws governing evaluations, need for attorneys, and specific rights they limit.

SUPPLEMENTAL SECURITY INCOME

Supplemental Security Income (SSI) is monthly income from the federal government's Social Security Administration (SSA) to support people who have never been able to work due to a significant disability and who have limited or no income.

SSI is available for individuals over the age of 18 if the individuals meet the following definition of disability under the Social Security Administration: www.ssa.gov/ssi/text-eligibility-ussi.htm. Even if your child was receiving SSI benefits prior to turning 18, they will need to go through a redetermination process to maintain their SSI benefits as an adult.

Your child will have to choose a Representative Payee and set up a joint bank account in the child and representative payee's name. *(You will most likely be the Representative Payee. Your bank will assist you in setting up a joint account with your child.)*

Your child cannot have more than \$2,000 in cash or assets at any time, or their benefits may be compromised. If your child receives any amount of SSI money, they will automatically be eligible for the Medicaid Waiver.

Angelman syndrome is listed as a Compassionate Allowance. A Compassionate Allowance is a way to identify disorders and other medical conditions that by definition, meet Social Security's standards for disability benefits. <https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022600>



Your child cannot have more than \$2,000 in cash or assets at any time, or benefits will be compromised or reduced.

Even though Angelman syndrome is an automatic qualifying condition under compassionate allowance, sometimes the social security office will make you provide supporting documentation. As noted in the above link, "Adjudicators (the person evaluating your child's eligibility) may, at their discretion, use the Medical Evidence of Record or the listings suggested to evaluate the claim. However, the decision to allow or deny the claim rests with the adjudicator." You may need to provide further information on the diagnosis from doctors; IQ score; current IEP; and assessments of present functioning levels of speech, fine motor, and self-help skills.

The following link lists the identification documents required when you apply for SSI with your 18-year-old: www.ssa.gov/ssi/text-documents-ussi.htm

SUPPLEMENTAL SECURITY INCOME

The SSA requires originals of identification documents. Make copies of all documents before submitting them to the SSA office. The earliest your child will receive a SSI payment is one month after the application date, or one month after meeting eligibility. Keep good notes of all interactions with the SSA, including NAMES of employees and the dates you talked to them, what information you have given them, and what they told you.

Benefits for Children with Disabilities Booklet is a publication put out by the SSA for the parents/caregivers of individuals with disabilities who are eligible for SSI. www.ssa.gov/pubs/EN-05-10026.pdf

In order to get the maximum SSI benefit, you have to charge your adult child for their share of household expenses, including rent or mortgage, utilities, and groceries to live in your house.

Example C (www.ssa.gov/ssi/text-living-ussi.htm) is what would pertain to your child if they live in your home. The link also explains the SSA formula for reducing your adult child's SSI monthly amount, so you know what to avoid.

We have adapted the following example from the above SSA link (Example C) to make it more understandable.

When your child turns 18, they are considered a household of one. This is the way the SSA figures the SSI amount for that one person if they live in another person's household (yours) and share expenses:



*** Suppose you live with your parents and one sibling in a family home and your only income is SSI. There are four people in the household. The mortgage payment is \$700. The average monthly bills are \$200 for electricity, \$100 for water and sewer, and \$600 for food. The total monthly expenses are \$1600. Because there are four people in the household, your share of the expenses is \$400 per month.*

If you pay your full share of \$400 for the household expenses, there would be no reduction of your benefit and you would get the full \$783 in your SSI check.

*If you pay less than \$400, then you would be receiving in-kind support and maintenance. We would apply the one-third reduction rule and the \$783 would be reduced by \$261.00, so your SSI benefit would be \$522.00*** The link below gives information on how to obtain the maximum amount of SSI money

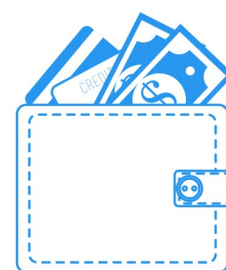
<https://farley1.com/maximizing-ssi-by-charging-rent-to-your-disabled-child.html>

OTHER CONSIDERATIONS

Supplemental Nutrition Assistance Program

If a person qualifies for SSI, they are eligible for the Supplemental Nutrition Assistance Program (SNAP) formerly known as food stamps. For information on federal SNAP, click the link below, then click the blue “Local Office” to find your individual state’s information.
www.benefits.gov/benefit/361of

If your adult child gets SNAP benefits, they will receive an Electronic Benefits Transfer (EBT) card. The card is used just like a debit card with a PIN number. Money loads onto the card monthly. You can write goals into your child’s IEP to help train them to use their EBT card at stores to purchase their own groceries. If your adult child moves to a group home or into a supported living residence, they will need SNAP benefits to pay for their groceries.



The EBT SNAP benefits will also qualify your child with AS for other discounts and benefits, including free meals at school, discounted or free cell phone and service, possible discounts on a state ID card, 50% off Amazon Prime, (which includes free delivery of Amazon purchases, Amazon Prime streaming, free book, magazine, and music streaming, and depending on your state, the ability to order groceries online using your EBT card), and many other benefits. The following link gives information on how to apply for SNAP benefits in your state and also the extra benefits and discounts your child is eligible for with their EBT card in each state. <https://foodstampsnow.com/food-stamps-and-ebt>

Special Needs Trusts

A Special Needs Trust is used when someone wants to give money or property to a person with a disability but doesn’t want to jeopardize the person’s ability to receive SSI, Medicaid, SNAP, or subsidized housing.

A properly drafted special needs trust will allow the beneficiary to receive government benefits while still receiving funds from the trust. The funds in a special needs trust are intended to improve the quality of life for the beneficiary and may be used for items not provided by public benefits.

You need an attorney specializing in special needs trust to assist in properly setting up

OTHER CONSIDERATIONS



the trust. The attorney needs to make sure the trust will not cause your adult child to lose government benefits. Any income your child receives, such as child support, could reduce government benefits. This includes any life insurance policies, pensions, or IRA. Your child with Angelman syndrome should never be listed as a beneficiary; the beneficiary should be their special needs trust in order to preserve their Medicaid and SSI benefits.

ABLE Account

Achieving a Better Life Experience (ABLE) Act of 2014 is similar to a 529 education plan but allows families with individuals with disabilities to add money to an account that can grow tax-free. A person with Angelman syndrome that receives SSI would be eligible to establish an ABLE account.

The ABLE Act recognizes that there are significant costs involved in living with a disability. To receive SSI, a person must be low income. The ABLE savings account allows people with a disability to save money for the extra costs and largely remain eligible for SSI, Medicaid, HUD (federal housing benefits), and SNAP.

The earnings on an ABLE account are not taxed. The funds are generally not considered for SSI programs. For information on ABLE accounts see the ABLE National Resource Center, founded by the National Disability Institute, at www.ablenrc.org.

States have set differing limits for total allowable ABLE savings. For more information on ABLE accounts in your state, click this link <https://specialneedsanswers.com/able-accounts>

No matter where you reside, you can open an ABLE account in any state that accepts outside residents into their program. There may be a better option for your child from another state. To see a comparison of ABLE accounts in different states, check this site: www.ablenrc.org/compare-states.

GOVERNMENT DOCUMENTS

ID Card

Your child with Angelman syndrome will need a State ID card when they reach adulthood. They will need an ID for identification for medical appointments, to get a disabled parking permit, to prove state residency, and to fly on an airplane.

Beginning October 1, 2021, every air traveler 18-year-old and up, will need a REAL ID-compliant state photo ID to fly within the US, per the Dept. of Homeland Security REAL ID-compliant cards are marked with a star at the top.

To get a REAL ID card you will need to present your child's birth certificate issued by the county health department, or a valid Passport; social security card or official document with complete name and Social Security number; and 2 documents with proof of their address (can be mail from a governmental agency) to the local office that administers driver's licenses in your area.

In some states, if you present a letter that states the current dates of your child's SNAP benefit eligibility, the cost of the photo ID will be reduced.

Registering to Vote

Once your child turns 18, they can register to vote. For more information, click this link for your state. *(If you opt for full guardianship, your child may not be eligible to vote.)*
www.eac.gov/voters/register-and-vote-in-your-state

Registering for Selective Service (DRAFT)

A male who turns 18 in the US is required to register with the Selective Service System. Even though we have had an all-volunteer military since 1973, the Selective Service System remains to make sure that the military "draft" can be quickly resumed if necessary. In the event the US decided a draft was needed, men who registered would be examined to determine if they are capable of military service. To register online, use this link: <https://www.sss.gov/register/>

CLOSING

We hope that this Toolkit helps explain the steps and give you resources to help make the transition a little easier. You **WILL** get through this. Just think how much you've learned and done for your child with AS over the years!

Disclaimer: The Foundation for Angelman Syndrome Therapeutics, its employees, independent contractors, and volunteers (collectively, FAST) does not provide medical or legal services or advice. The information provided through the Toolkit is for general informational purposes only. FAST has not validated nor is it responsible for any third-party information obtained through links or references in this Toolkit. The user should use their own independent judgment and use this only as a guide. The Toolkit is not intended to be a full and exhaustive explanation of the law in any area, nor should it be used to replace the advice of your own legal counsel. Only your attorney can provide assurances and interpretation of information provided in the Toolkit that may be applicable to your particular situation. Access to the FAST Adult Transitioning Program does not create an attorney-client relationship as the information is merely informative.

QUICK LINKS RESOURCE PAGE

MEDICAID WAIVERS

State Resources:
medicaidwaiver.org

Home and Community-Based Services Waiver: cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/

PERSON-CENTERED PLANNING

PCP: inclusion.com/path-maps-and-person-centered-planning/

PCP: project10.info/DPage.php?ID=103

A Manual for Person-Centered Planning: rtc.umn.edu/docs/pcpmanual1.pdf

VOCATIONAL REHAB

askearn.org/state-vocational-rehabilitation-agencies/

IDEA TRANSITION PLAN

Transition Planning for Students with Multiple Disabilities:
autismspectrumnews.org/next-stop-adulthood-a-framework-for-effective-transition-planning-for-students-with-severe-disabilities

LEGAL MATTERS

Information from the Arc:
thearc.org

HIPAA Form: caring.com/forms/hipaa-release-form/free-hipaa-release-form.pdf

SUPPORTED DECISION-MAKING

Information for each state:
supporteddecisionmaking.org

Free online course:
eji.courtllms.org/catalog

HEALTH CARE PROXY

Sample Medical Proxy Law:
leg.state.fl.us/Statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0700-0799/0765/Sections/0765.401.html

Sample Health Care Proxy Form:
northfloridaopg.org/wp-content/uploads/2015/03/declaration_of_medical_proxy.pdf

GUARDIANSHIP

Guardianship Laws Per State:
supporteddecisionmaking.org

QUICK LINKS RESOURCE PAGE

SUPPLEMENTAL SECURITY INCOME

Benefits for Children with Disabilities Booklet:
ssa.gov/pubs/EN-05-10026.pdf

Representative Payee Info:
ssa.gov/payee

SSI Eligibility: ssa.gov/ssi/text-eligibility-ussi.htm

Compassionate Allowance: <https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022600>

Identification Documents Needed to Apply: ssa.gov/ssi/text-documents-ussi.htm

SSI Living Arrangements/Room and Board: ssa.gov/ssi/text-living-ussi.htm

Get Maximum SSI Benefits: farley1.com/maximizing-ssi-by-charging-rent-to-your-disabled-child.html

VOTER REGISTRATION

eac.gov/voters/register-and-vote-in-your-state

SELECTIVE SERVICE

sss.gov/register/

SNAP / EBT

What are SNAP Benefits:
benefits.gov/benefit/361of

How to Apply in YOUR State and Get Extra Benefits and Discounts via SNAP/EBT:
foodstampsnow.com/food-stamps-and-ebt

ABLE ACCOUNT

ABLE National Resource Center:
ablenrc.org

ABLE Account Info for Your State:
specialneedsanswers.com/able-accounts

Compare Different State's ABLE Accounts to Find the Best Option:
ablenrc.org/compare-states/



QUICK LINKS RESOURCE PAGE

FEDERALLY FUNDED ADVOCACY RESOURCES IN EACH STATE

Protection and Advocacy Centers

Protection and Advocacy Systems (P&As) work at the state level to protect individuals with disabilities by empowering them and advocating on their behalf. There are 57 P&As in the United States and its territories, and each is independent of service-providing agencies in their states. They protect the rights of persons with DD through legally based advocacy. Their function is to help individuals with DD to become independent, integrated, and included in their communities. “Find Your P&A” will take you to your state: www.ndrn.org

Parent Training and Information Centers

Parent Training and Information Centers (PTI) provide free information to families of kids from birth to age 22 who have a disability. You can learn more about your child’s rights at a parent center. Parent centers offer workshops and training sessions about IDEA, special education, and disabilities. They can also suggest ways to help kids at home who learn and think differently. You can call or email a parent center. Or you can visit a center in person. The people there can answer questions, give advice, or find the help you need.



Parent Training and Information Centers at a glance: understood.org/en/school-learning/special-services/special-education-basics/parent-training-centers-a-free-resource

Find the Parent and Training Info Center in your area: parentcenterhub.org/find-your-center

Developmental Disabilities Councils

State Councils on Developmental Disabilities (Councils) are federally funded, self-governing organizations charged with finding the most important needs of people with developmental disabilities in their state. Councils focus on empowering individuals through activities that teach self-advocacy skills and support self-determination. Councils also play a role as innovators in the development of person-centered systems.

State Council on DD Program Contacts: acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities

QUICK LINKS RESOURCE PAGE

Centers for Independent Living

Centers for Independent Living work to support community living and independence for people with disabilities. They operate on the belief that all people can live with dignity, make their own choices, and participate fully in society. They provide tools, resources, and supports for integrating people with disabilities fully in their communities.

Centers in each state: acl.gov/programs/centers-independent-living/list-cils-and-spils

National Network of University Centers for Excellence in Developmental Disabilities Education, Research & Service

Four core functions frame the UCEDD program

- Interdisciplinary pre-service preparation and continuing education
- Research, including basic or applied research, evaluation, and public policy analysis
- Information dissemination
- Community services, including direct services, training, technical assistance, and model demonstrations



Click “Program Links” on this site to show resources in your state: acl.gov/programs/aging-and-disability-networks/national-network-university

