



TRANSITIONING
TO ADULTHOOD
checklist

NAVIGATING THE CHANGES WITH ADULTS
WITH ANGELMAN SYNDROME

A Checklist for Transitioning to Adulthood

This resource has been created to support families as they begin to work through transitioning their loved one. **We know this may not be a complete list, but hopefully a helpful tool to understand what needs to be considered, what you need to prepare for and where to go to get support.**

Please also note that every state is different in the level of support and resources they provide. If we have left anything out, please feel free to send it to us at info@angelman.org.

Prior to 12 Years be Working on These Things

(Also refer to the “First 100 Day Journey” resource.)

- If you have not already, begin the process of Early Intervention for your child. Check with your local county to set up an evaluation.
- Join a local advocacy group to help educate yourself on what you may need (the ARC, Easter Seals, Global Genes, NORD, EveryLIFE)
- IDEA (Individuals with Disabilities Education Act) Training
- Create a will and talk to someone about estate planning.
- Consider a Special Needs Trust and/or an ABLE Account.

12 – 14 Years

- Begin looking into vocational and/or recreational opportunities for your child. *Federal Guidelines are to have a written transition plan that includes the student strengths and preferences by the age of 16, some states are age 14. The student is invited to the IEP/Transition Planning Meeting. The Transition plan compliments the IEP, not replaces it.*
- Consider a Vocational Assessment.
- Complete a behavior plan—start by having a Functional Behavior Assessment by a board certified behavior analyst for tracking purposes.
- Understand the Medicaid waiver and learn about Long Term Care options in your state.
- Write/develop a personalized plan for your young adult (similar to an IEP, only for all aspects of their life), following the rules in place in your state.

16 Years

- Apply for a Non-driver ID Card. This will provide him/her with a convenient form of government ID.
- Plan an extensive transition plan in the IEP. *Pre-vocational skills, pre-community living skills, interest survey.*
- Consider options for guardianship. Additional legal and financial areas to consider: durable power of attorney, naming a representative and payee for governmental benefits, opening and maintaining a joint bank account, medical power of attorney, etc.

17 Years

- Prepare to assume Guardianship/ Conservatorship. *Will possibly need legal aid for this process. At minimum, guardian ad litem to represent your child.*
- Apply for SSI for your child. *This is what will qualify your child for Medicaid when he/she turns 18. Make sure the applicant does not have more than \$2,000 in assets (excluding primary residence). This benefit may be available to some individuals before the age of 18 if his or her family is low income or they live in an out-of-home residential setting.*
- If the adolescent is male, register for the Selective Service (the Draft). This is required by the government (but does not mean that the individual would actually be drafted) and failure to register can affect eligibility for services. www.sss.gov/register/who-needs-to-register/
- Write a Letter of Intent. It is important that you write a letter of intent, which explains your child’s abilities, support needs, services, current and future benefits. As well as your wishes for his or her future and who will support them either legally and/or as natural supports.

18 Years

- Apply for Adult Services with the supporting Federal Agency (DDS, Rehab, DMH).
- Take necessary steps to enact guardianship plan.
- Carefully track SSI funding received monthly.
- If you have not done so, write/develop a personalized plan for your young adult (similar to an IEP, only for all aspects of their life), following the rules in place in your state.
- Apply for Section 8 Housing.
- Apply for local and regional housing lists. Ask if there are any portable vouchers for the disabled population. There may be a 10 year waiting period, but it is VERY worth the wait.
- Consider transitioning from a pediatrician to an adult medical provider. Research options in your area. Check with your current medical team for suggestions or visit one of the 15q Clinic Network Clinics.
- For New Jersey residents, apply for Personal Preference Program.

21 Years

- The day after the 21st birthday should look exactly like the day before. Placements and funding should be in place.
- Apply for the Medicaid waiver program in your state. (Application age varies by state.)

Parent(s) Approaching Age 62 Years—

Need to make a decision regarding the best age for parent to begin receiving social security benefits. Consider the pros and cons for the parent and the child. It is very important for the parent to review his/her social security statement (info can be found on the social security website). Please click [here](#) to access a webinar to walk you through this process.

Child Approaching Age 26

Need to determine whether your child can continue to remain on your primary insurance plan if he/she is currently on it. This varies based on the state, the agency, and the policy. Research the following:

- Can my child remain on my primary insurance after age 26 since he/she has a disability?
- If so, what documentation/forms are needed to continue the coverage?

Support from Families for Families

We know that this process can be overwhelming for families. We have created adult champions that you can reach out to at any time to help you through this journey. Please see below for contact information.

Sue and Jeff Rossetti | Tinley Park, Illinois

suerossetti@comcast.net

We have two sons, Nathan, age 23 (UPD) and Kevin, age 26 (non-AS). We have been going to the ASF Walk in Chicago for 20 years and try to go the ASF Family Conferences whenever possible. Nathan is very sociable. He enjoys being out in the community and using his tablet. Most of all Nathan enjoys eating, whether it be at home, take out, or dining out!

Kathy Johnson | Michigan

Rhodes48652@yahoo.com

Kathy is the mom to Amanda 28, Angela 22 and Rocky 18, all of whom have the ube3a mutation. Kathy has worked tirelessly to make sure her kids live in their own home, with support staff to care for them. Kathy's expertise lies in helping parents build a successful self determination arrangement. She has been a speaker at the ASF Family Conference on how to train support staff, chipping away at the mountain to find services, and how to hire, train and keep support staff. She also is a speaker at conferences in her home state of Michigan. She advises professionals on how they can help support their clients with in-home supports and speaks to parents on how to run a self determination arrangement successfully.

Robin Wilkerson | Oxford, Mississippi

robin.r.wilkerson@gmail.com

My husband, Woody, and I have a daughter, Paige, who has Angelman syndrome. She is 26 years old and has the UPD transmission of Angelman syndrome. Paige has two older brothers who are both married and who have one child each. I am a retired nursing faculty and Woody is a retired speech language pathologist.

Leigh Sutherland | Chevy Chase, Maryland

leigh.sutherland@gmail.com

Leigh is the mother of a 32 year old Angelman (Deletion Positive) daughter, Alex. Leigh has been an active member of the Angelman and special needs community since Alex's AS diagnosis in 1993. The Maryland, DC, Virginia region has a large and supportive community of Angelman families with Angels from age 50 to newly diagnosed infants. We are here to help and support each other.

Shari Caspert | North Caldwell, New Jersey

scaspert@gmail.com

Shari Caspert is Mom to Matthew - (age 23, Deletion Positive), has been involved with the ASF since 1998. Her family's vast experience continues to serve the Angelman community, especially with issues surrounding the transition from school age to the adult world. Shari lives in Northern New Jersey with her husband, Mitchell.



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