Transition of Care
TOOLKIT

angelman™
SYNDROME FOUNDATION

Introduction

The **Angelman Syndrome Foundation (ASF) Transition of Care Toolkit** serves to empower caregivers and healthcare providers as they transition an individual with Angelman syndrome from pediatric to adult healthcare. This is a critical step for those affected by Angelman syndrome and their families, requiring thoughtful planning, informed decision-making, and access to tailored resources. Recognizing the complexities of this process, this toolkit was designed to address the unique challenges faced by the Angelman community.

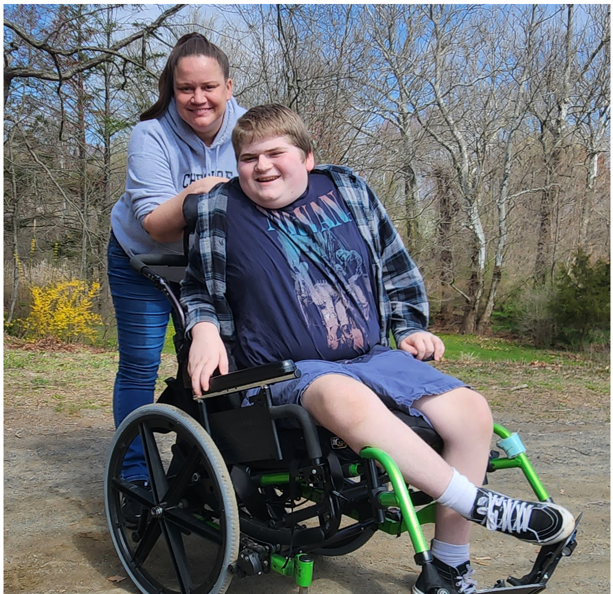
Developed collaboratively, this toolkit incorporates insights from both the ASF Adult Taskforce – a passionate group of parents and advocates with firsthand experience supporting adults with AS, and the ASF Adult Working Group - a team of physicians specializing in the care of adults with AS. This collaborative effort ensures a comprehensive and practical guide that reflects both lived experiences and clinical expertise. To further enhance its impact, the toolkit will be integrated within the ASF Clinical Network, a worldwide network of healthcare providers and multidisciplinary clinics that specialize in caring for patients with Angelman syndrome. By deploying this resource across ASF clinics and pediatric hospitals, this toolkit will equip families and providers with the tools, strategies, and best practices they need to streamline transition processes, improve communication between care teams, and establish a seamless continuum of care to support individuals with AS in achieving the highest possible quality of life during and after their transition to adult care.

This toolkit is not just a guide—it is a testament to ASF's commitment to supporting families through every stage of life and advocating for the specialized care individuals with AS deserve. ***Together, we can navigate this journey with confidence and ensure a brighter future for our loved ones with Angelman syndrome.***

This work was made possible with the vision and leadership of **Wilfreda Lindsey, MD, MS** and the generous financial support provided by the **Child Neurology Foundation**.

Email **info@angelman.org** with questions about this toolkit.

Disclaimer: This document is only intended to be a guide for the transition process. It is not intended to substitute medical advice or replace forms that may be required by an individual provider.



The Angelman Syndrome Foundation Transition of Care Toolkit including fillable forms for each resource found in this toolkit can be found online at Angelman.org/resources/transition-care-toolkit

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Caregiver Guide

How to Use this Toolkit & Important Information to Know

Welcome! If you're reading this, it's clear you're deeply committed to ensuring the best possible health journey for your loved one with Angelman syndrome—and that kind of dedication matters. This toolkit was developed with insights from parents, caregivers, and clinicians supporting adults with Angelman syndrome bringing together the most trusted recommendations, tools, and resources. It was created with caregivers like you in mind: those navigating the complex transition from pediatric to adult healthcare with courage, love, and determination. Before diving in, we invite you to read a few quick tips on how to get the most out of this resource.

TIP 1 *You own this process – make it work for you.*

As the caregiver, you are leading your loved one's healthcare transition with the support and guidance of your healthcare providers. This toolkit is yours to use in whatever way works best – print it and build a binder, or create a digital version with links you can easily share with providers. Use it as a collaborative tool to keep everyone on the same page and to advocate confidently for your loved one's needs.

TIP 2 *Use this guide alongside clinical care, not in place of it.*

This toolkit is meant to support the transition process by helping you feel more informed and confident—but it is not a replacement for medical advice, diagnosis, or documentation required by your care team. Always consult your healthcare provider or care coordinator when making medical decisions.

TIP 3 *Start by exploring the big picture.*

Before diving into specific forms or tools, take time to review the full toolkit. You'll find resources tailored for both caregivers and providers, along with practical steps and recommendations that can guide you through a successful transition. Familiarizing yourself with the full range of topics will help you prioritize what's most relevant for your family.

Differences in Adult Care Settings

Advice directly from Angelman syndrome parents and caregivers.

Across all systems - medical, educational, and community - resources begin changing drastically as your child becomes a legal adult. Learn "the system" in advance.

Medicaid, Medicare, SSI, and Waivers	Your child's current services and coverages may change as they become a legal adult. Talk to your pediatric care coordinators about what you may need to do in advance to ensure a smooth transition.
Private Insurance	If your child is on your plan, confirm until what age they remain covered and any changes that may occur to in-network providers and out-of-pocket expenses.
Services & Equipment	Know what durable medical equipment (e.g. wheelchairs, bracing, AAC devices), therapies, and medications are covered under each plan your child is on.
Resources	Join social media groups, listservs, or community groups for recommendations, shared experiences, and tips on local adult providers and resources.

The adult healthcare world may not feel as warm or coordinated as pediatric care, but with a proactive mindset, documented history, and thoughtful selection of a support network, you can create a strong system of care that may last many decades. Build relationships and choose locations accordingly.

Locations	Unlike pediatric specialty care experiences often found in hospitals, most adult specialty practices occur in private, office-based settings. Seek provider locations that are co-located or in close proximity to labs, imaging, and other services.
Multidisciplinary Staffing	Most pediatric specialty clinics are co-located with other specialists and offer ancillary therapies. Most adult specialty clinics are not and will need to refer out to other specialists and ancillary therapies. If available for adults in your region, consider ASF Clinics, specialty clinics, or medical home models.

Availability of Care Coordination	Pediatric care often has more built-in coordination services. While many adult primary care practices do have care coordination services, the way you access these services may be different. You may need to specifically ask for a care coordinator or social worker to be assigned to assist with care coordination.
Provider Shortages	Adult neurologists, specialists with experience in AS or intellectual and developmental disabilities, and adult-focused PT/OT/speech therapists may be harder to find. Start searching early for adult options or clinics that treat across the lifespan.
Relationships Matter	Seek new providers that trust your caregiving instinct and value the family as part of the team. Encourage new providers to practice a family-centered approach of shared decision-making with parents and caregivers.
Request Modifications and Offer Workarounds	When making appointments, request longer appointment times because shorter time is usual in adult settings. You may need extra time for wheelchair transfers, removing orthotics, diaper changes, etc. Offer new providers reminders and requested workarounds for adherence to care (e.g. virtual visits to cover all discussion components of the appointment in advance to make the on-site appointment time more efficient).

You know your loved one best. Your expertise is still important, valuable, and necessary in adult healthcare.

Advocacy is Constant	Adult systems are often not as equipped for rare neurogenetic disorders as pediatric systems. Be prepared to explain Angelman syndrome, share details about your loved one, and clarify your role as a caregiver. This is crucial to making appointments, refilling prescriptions, etc.
Keep Copies of Legal Documents on Hand	Time alone with your loved one is likely to be expected for at least part of the adult visit. This is legally required for confidentiality for individuals over age 18 unless they give permission for others to be present, or guardianship/conservatorship papers are provided. Make sure to have copies of your legal documents at all visits.

PRO TIP!

Many ASF Clinics serve both pediatric and adult patients. To learn more about an ASF Clinic near you, visit angelman.org/asf-clinics.

In addition to care that is specific to Angelman syndrome, your loved one should receive preventive care screenings that are recommended for all adults by the *United States Preventive Services Task Force (USPSTF)* or similar body in your country.

Questions to Ask *BEFORE* Transferring Care

Begin integrating these questions into your child's appointments as early as 12 years old.

Transition Planning Process

- Can we schedule a transition planning visit specifically to review next steps?
- Can I work with you to prepare a medical summary and emergency plan for my child? I have forms in this Toolkit to assist us.
- What have other families in similar situations struggled with during this transition?
- Are there any red flags or warning signs I should watch for once we make the switch?

Medical Records, Privacy, and Consent

- Before my child turns 18, what information about privacy, consent, and access to Electronic Health Records (EHR) do we need to learn about, and what actions need to be taken?
- Will you send my child's medical summary to the new adult doctor(s), and may I also have a copy?
- Who should new providers contact if they need clarification on our child's history?

Adult Care Providers and Referrals

- What kinds of doctors in adult care does my child need?
- Can you explain the types of specialists who will take the lead in the pediatric care world compared to the adult world (Example: Who covers muscle tone, pain, sleep, etc.)
- Do you have any suggestions for adult doctors, or multidisciplinary clinics, for my child to transfer to who have experience with AS or similar neurogenetic conditions? Primary Care? Neurology? GI/Nutrition? Therapy (PT/OT/ST)? Psychiatric/behavioral health? Etc.

Medical Continuity During Transition

- If you, as a pediatric provider, continue to see my child after age (18, 22, 26, etc.) but our insurance changes, will we still be able to see you?
- Before the initial visit can be made to the adult doctor, will you still refill their medicines and treat them for acute care needs?
- Will you be available for questions after we've transitioned out of your care?

Notes:

Medications, Devices, and Authorizations

- Will any of our child's medications or medical devices require new authorizations in adult care?
- Are there any medications or treatments that adult providers may be unfamiliar with?
- What DME (durable medical equipment) support will need to be renewed or transferred?

Insurance, Financial, and Support Services

- Do you know if our state offers transition case management or care coordination services for adults with developmental disabilities?
- Can you connect us with a hospital social worker to help with adult Medicaid, waiver programs, or SSI planning?
- Are there any parent networks or support groups you recommend for transition-age families?

Emergency and Hospital Care Planning

- Can we discuss a planned hospital admission versus an ED situation during the transition at specific ages (18, 21, 22+)? Where do we go and who do we call?

Questions to Ask When Selecting New Providers

- Have you worked with individuals with Angelman syndrome or similar neurogenetic or developmental disabilities before?
- Do you accept Medicaid and/or our private insurance? Are there services you commonly provide that are not covered by our insurance?
- How do you handle communication - do you offer email, patient portals, or phone calls for non-urgent questions?
- What hospital or health systems are you affiliated with in case of emergency or inpatient needs?
- Do you offer longer appointment times for patients with complex medical or communication needs?
- Will you help coordinate referrals to adult neurologists, GI specialists, or others as needed?
- Is there a social worker, case manager, or care coordinator in your office or network who can support patients with disabilities?
- How do you prefer to receive outside care summaries (from pediatric providers, therapists, etc.)?

Notes:

To Do’s & Questions *AFTER* Transferring Care

When Scheduling New Appointments

- Ensure all paperwork is completed prior to your appointment.
- Request the first appointment of the day or right after lunch as these times doctors are less likely to be behind, thus decreasing wait time.
- Suggest things that will help regulate your loved one like removing white coats.
- Request one room to have all activities done if possible (i.e. intake, scheduling appointments, etc.)
- Request additional time to allow transfers from wheelchairs, removing braces, etc.

Before Your First Visit with a New Provider

- Ensure receipt of the transfer package including **Provider Guide, Provider Master List, Medical Summary, Goals of Care, Emergency Plans, About Me, and Legal Documents.**
- Ensure receipt of any clinical records shared
- Share the **Angelman Syndrome Foundation Clinical Care Toolkit**, particularly for providers less familiar with AS.
- Write down a list of questions and concerns you have before seeing your new doctor.
- Keep your child’s health insurance card with you always.
- Keep copies of your legal caregiver documentation with you at all appointments.

Questions to Ask at First New Provider Appointments

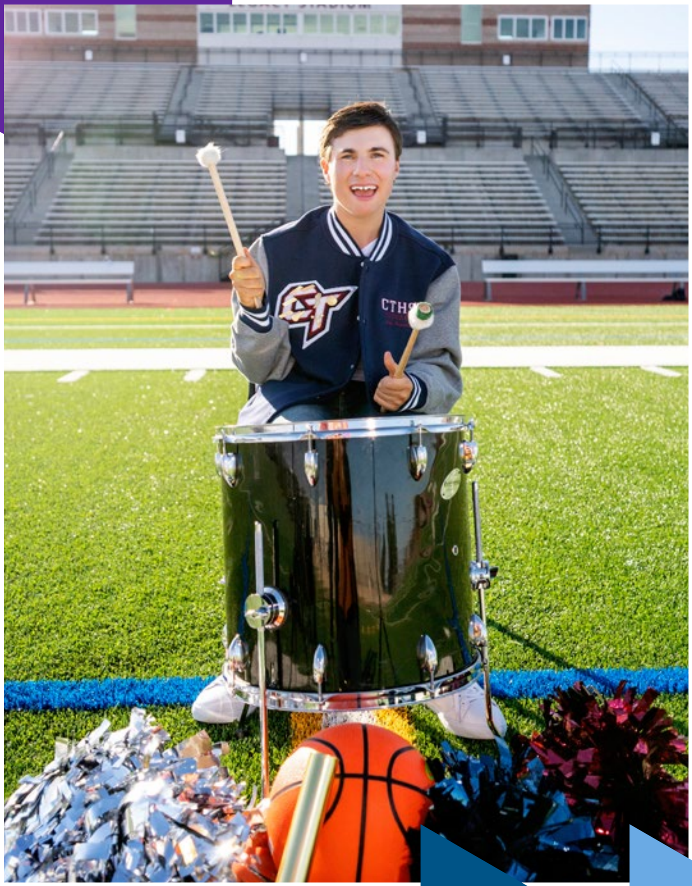
- Have you had a chance to review our Transition of Care Toolkit? Is there anything you’d like to discuss further?
- Are you familiar with our current medications or treatment protocols (e.g. seizure medications, sleep aids, etc.)?
- Will you continue to prescribe the same medications if they are effective or do you follow a different prescribing approach ?
- Can you help coordinate or re-establish PT/OT/Speech therapy services if needed?
- What is the best way to schedule routine and urgent appointments?
- Can you help us connect with local or regional services for adults with disabilities (e.g. day programs, DME providers, respite, or residential facilities)?

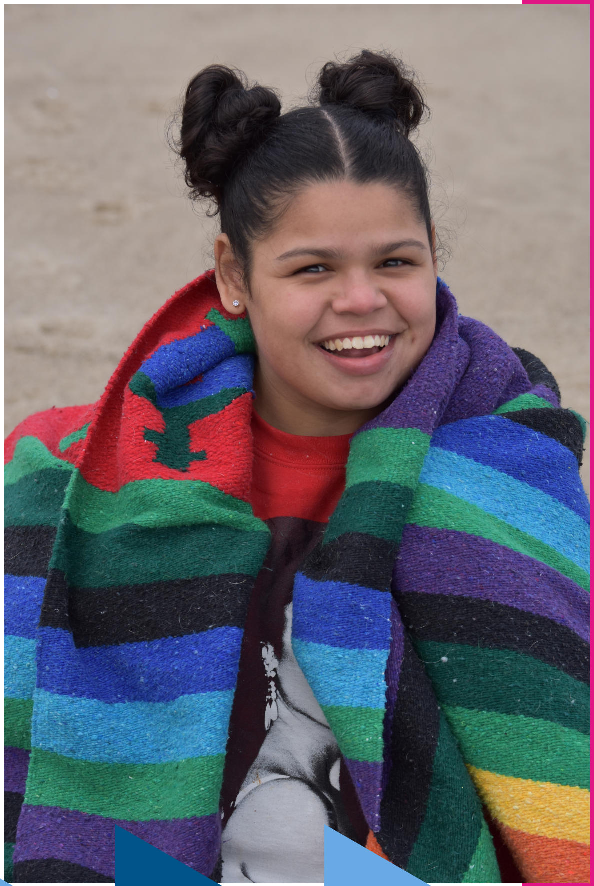
Notes:

Transition to Adulthood Resources

The Angelman Syndrome Foundation offers a variety of resources to navigate your journey with Angelman syndrome. Visit Angelman.Org/Resources to search for videos, podcast episodes, educational content, and more by subtopic, life stage, or even location. A few key resources that may assist in your loved one with AS's transition to adulthood include:

- AS Grows Up (Website)
- Adult Housing & Champions (Website)
- Transition to Adulthood Checklist (Resource)
- The Comprehensive Care Binder (Resource)
- Adults with Angelman Syndrome FAQ (Resource)
- Angelman Syndrome in Adulthood (YouTube Playlist)
- Moving to Adult Healthcare Toolkit (Resource)
- GotTransition.Org (Website)





Provider Guide

How to Use this Toolkit for Patients with Angelman Syndrome

Thank you for your commitment to supporting individuals with Angelman syndrome. Your willingness to learn, listen, and provide compassionate care makes a profound difference in the lives of your patients and their families.

If a caregiver has shared the Angelman Syndrome Foundation (ASF) Transition of Care Toolkit with you, it likely means you're working with someone who is not only deeply invested in their loved one's wellbeing but also eager to partner with you. Caregivers of individuals with Angelman syndrome often serve as the primary coordinators of care, advocates, historians, and communicators for their loved ones. By choosing to engage with this resource, you're taking an important step in building a collaborative, person-centered care plan—one that honors the caregiver's knowledge and the patient's unique needs.

The transition of care from pediatric to adult-based healthcare is a critical phase for patients with Angelman syndrome, their families, caregivers, and providers. The Provider Guide is designed to support healthcare providers in how to use the toolkit effectively to ensure a smooth, informed, and well-coordinated transition. The toolkit centralizes essential information and serves as a resource to streamline communication and continuity of care.

Purpose and Scope

This toolkit is designed to be a comprehensive resource managed by the caregiver with the support of their providers. It has been created to help guide both parties through the complexities of transitioning from pediatric to adult care by centralizing crucial data including:

- An extensive review of the patient's medical history including all diagnoses, medications, allergies, and past surgeries or procedures
- Emergency care plans
- Past and current provider details

How Providers Should Use the Toolkit

Before Transition	• Use the toolkit to review important patient information and specific needs related to the care of the patient. • Engage in family and caregiver education. As a provider, it is essential to ensure that the family, caregivers, and the patient (as much as possible) are involved in the transition process. The toolkit includes sections designed to help caregivers understand what to expect during the transition, how to manage ongoing care, and when to reach out for specialized help.

During Transition	• Pediatric providers, use this toolkit as a prompt to help caregivers create a centralized document to pass medical information to the adult care team. It should be shared by caregivers with their loved ones' new adult providers to help them understand the patient's unique needs and ongoing treatments or therapies which need to be continued and/or adjusted. • Help caregivers keep care plans updated and reflective of adult-specific needs by reviewing and documenting necessary information (e.g. medication adjustments, changes in care protocols, or a specialized approach to symptoms management in adults with AS).

After Transition	• Attempt to maintain clear and open channels of communication between the pediatric and adult care teams. The toolkit is designed to help maintain continuity of care and facilitate ongoing discussions about the patient's evolving needs. • Prompt caregivers to update toolkit with changes in the patient's medical condition, new treatments or emerging symptoms in order to maintain a current record that both pediatric and adult teams can rely on as the patient's care evolves.

Successful transition requires collaboration among a team of healthcare providers. Providers should encourage dialogue amongst all involved aiming to address all aspects of the patient's healthcare. The toolkit is not a stand-alone solution, but a collaborative tool that should be used in conjunction with discussion among:

- Pediatric specialists
- Adult providers
- The patient and his/her caregivers

Advice Directly from Angelman Syndrome Expert Providers

Avoid Diagnostic Overshadowing: A diagnosis of Angelman syndrome does not automatically explain new or changing symptoms. Common medical issues should always be ruled out first. If a patient with AS presents with changes in behavior such as increased agitation, social withdrawal, or increased drowsiness consider underlying illness, pain, or discomfort and evaluate as appropriate. Behavioral shifts are often signs of medical problems that the patient may be unable to verbally express.

Familiarize Yourself with Common Medical and Developmental Features of AS: Individuals with AS often experience seizures (which may lessen with age), sleep disturbances, gastrointestinal issues, gait abnormalities and ataxia, and limited or nonverbal communication. A consistently happy demeanor is characteristic but should not be mistaken for an absence of distress. It is important to distinguish typical AS behaviors, such as frequent laughter or hand-flapping, from signs that may indicate pain or discomfort.

Monitor Changes Over Time: Avoid assumptions that the patient’s current state is his/her permanent baseline. Individuals with AS can continue to make gains with appropriate support. Further, they may decline if unrecognized medical needs go unmet. Encourage caregivers to track changes in seizure activity, motor skills, mobility, sleep, GI function, feeding tolerance, and communication efforts over time . Longitudinal monitoring and caregiver input are essential for determining whether or not interventions are beneficial.

Engage the Patient at Every Encounter: People with AS often have strong receptive language skills. Always assume competence. Speak directly to the patient rather than talking at, through, or around the patient, or only speaking with the caregiver. Always explain what you're doing even if the patient does not respond verbally. If he/she uses an AAC device (e.g., tablet or communication board), ask how it works and allow extra time for responses.

Be Adaptable: To the best of your ability, create a supportive, sensory-considerate setting. Schedule longer visits when possible, avoid unnecessary physical handling or restraint, and minimize triggers such as harsh lighting, crowded or noisy waiting areas, and long delays. Be flexible. For instance, care may be more effective if the patient is seated with a caregiver or even on the floor.

Foster Collaborative, Lifelong Care: Caring for an individual with AS requires ongoing partnership. It is important to trust the caregivers' insight; they are your most valuable diagnostic ally and are often the first to notice subtle changes in behavior, mood, appetite, or sleep that may indicate an underlying issue even when exams and labs appear normal. Collaborate with specialists, support access to AAC, durable medical equipment, therapies, and community resources. Emphasize proactive wellness care—not just crisis management—to help your patient thrive.

Stay Curious! Angelman syndrome is rare and complex, but families value providers who take the time to ask questions, seek resources, and remain open to learning. A curious, informed approach builds trust and leads to better care.

Advice from Caregivers: What We Wish Providers Knew

Caregivers are experts in their loved one's care—and they want to be treated as respected partners on the healthcare team. Here's what they want you to know:

- **We know our child best.** If something seems off—even subtly—we often notice it first. Please take our instincts to heart, even if tests or vitals seem normal.
- **We want to work with you.** At home, we're juggling medications, seizures, feeding schedules, insurance paperwork, adaptive equipment, and more. We've had to become experts in Angelman syndrome, and we're here to collaborate—not to control.
- **We want to build a relationship, not just get through an appointment.** Compassion, flexibility, and curiosity from providers go a long way. When you speak directly to our loved one, ask questions, and show a willingness to learn, it builds trust.
- **We're in this for the long haul.** This isn't just a transition—it's a part of our journey. When you show you're in it with us, it gives us strength and hope.

The transition of care for patients with Angelman syndrome requires thoughtful planning, clear communication, and an ongoing commitment to high-quality care. By using this toolkit, healthcare providers can help ensure that the patient's journey from pediatric to adult care is as seamless and supportive as possible. This guide should be used alongside the toolkit to help healthcare providers navigate the process with confidence, providing the best care for the patient while addressing the needs of their families and caregivers.

Clinician Resources & Support

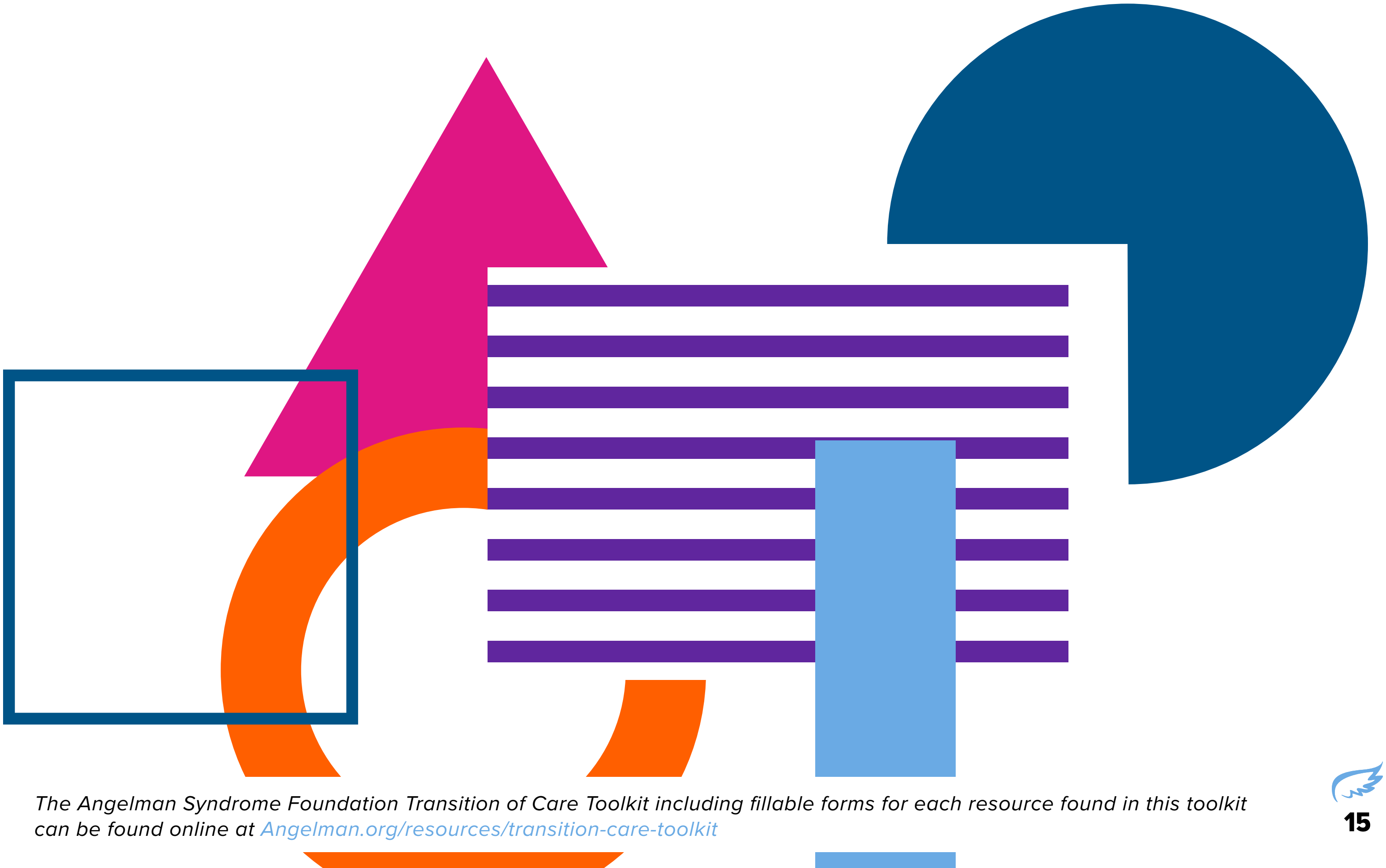
- **Training and Education:** Various organizations including the Angelman Syndrome Foundation and the Child Neurology Foundation offer related educational resources. Providers should take advantage of training opportunities related to Angelman syndrome to stay up-to-date with the latest research and best practices in care by subscribing to relevant newsletters and becoming familiar with the resources available.
- **Emergency Care Planning:** One of the critical components of this toolkit is ensuring providers are aware of emergency care plans. These should be reviewed regularly to ensure they are appropriate for the patient as he/she ages and care needs change.

- **Current Best Practices:** The Angelman Syndrome Clinical Care Toolkit has been developed in close collaboration with leading medical professionals. It is based on the most current scientific evidence and clinical experience, providing a trusted resource that can support and empower healthcare providers in their care of individuals with Angelman syndrome. Included are:

    - **Standards of Care**
        - A multidisciplinary approach and consensus statement to establish standards of care for Angelman syndrome (Duis et al, 2022) PMID: 35150089

    - **Epilepsy Management**
        - Low glycemic index treatment for seizures in Angelman syndrome (Thibert et al, 2012) PMID: 22779920
        - Myoclonus in Angelman syndrome (Pollack et al, 2017) PMID: 29555100
        - Seizure treatment in Angelman syndrome: A case series from the Angelman Syndrome Clinic at Massachusetts General Hospital (Shaaya et al, 2016) PMID: 27206232

    - **Additional Resources**
        - Clinical Guidance for the Treatment of Seizures in Angelman Syndrome
        - Management of Non-convulsive Status Epilepticus in Angelman Syndrome
        - Preparing Your Individual with Angelman Syndrome for General Anesthesia
        - Aspiration Prevention in Angelman Syndrome
        - General Anesthesia Best Practices
        - Angelman Syndrome Foundation Resources: Videos, podcast episodes, educational content, group support, and more



Transition Readiness Assessment

Intent

This Transition Readiness Assessment is designed to assess a young adult with Angelman syndrome (AS) and their caregivers' readiness for transition from pediatric to adult healthcare. It aims to:

- Help caregivers, providers, and patients navigate the tools provided in the ASF Transition of Care Toolkit
- Identify what caregivers and providers already know about the health and healthcare needs of the patient with AS
- Bring to light potential gaps in knowledge, services, or resources that may be needed for a successful transition to adult healthcare
- Encourage discussion about the differences in the models of care between pediatric and adult providers

Instructions

This assessment should be maintained and updated annually by the parent or caregiver with input from your loved one with AS and with the support of their healthcare providers. Expert Angelman syndrome (AS) providers and caregivers of adults with AS suggest building your Transition of Care plan, beginning with this assessment, as early as 12 years old with a goal to complete it by the age of 18.

Suggested Timeline

Age 12 - 13	Age 14 - 15	Age 16 - 17	Age 18+
Initiate transition of care conversations with your providers. • Do your providers have Transition Policies in place? Age cutoffs ? A system in place for adult referrals? Etc. • Talk with your providers about the expectations of both caregivers and providers during the transition. *See questions in Caregiver Guide for more suggestions.*	**Begin to develop your Transition of Care Toolkit.** • Start with pieces of the Provider Master List, Provider Transfer Plans, and Medical Summary. • These tools will likely not be done in one visit, but rather updated and added to every year. • Take the Transition Readiness Assessment annually to identify any potential gaps in knowledge, services, or resources needed.	**Review and Update your Transition of Care Toolkit.** • As your loved one nears 18, begin finalizing earlier Toolkit pieces, begin working on Goals of Care, Emergency Care Plans, and consider consulting a lawyer or learning more about guardianship, medical decision-making, and financial planning. • Begin establishing relationships with adult providers. • Continue taking the Transition Readiness Assessment annually.	**Finalize and begin Implementing your Transition of Care Toolkit in Adult Care** • Use the Toolkit to ensure continuity of care as you transfer to adult providers, ensuring they receive all necessary information from both the pediatric provider and the caregiver. *See questions and to-do's in Caregiver Guide for more suggestions to establish relationships with adult providers.*

The Angelman Syndrome Foundation Transition of Care Toolkit including fillable forms for each resource found in this toolkit can be found online at Angelman.org/resources/transition-care-toolkit

Last Update: / /

Patient Name: ____

Date of Birth: ________________________ Current Age: __________

Primary Diagnosis: ____________________________________

Primary Caregiver Name: ________________________________

Relationship to Patient: ________________________________

Email: ________________________ Phone: ________________

Transition Confidence Scale

Please circle how ***confident*** you feel in ***your*** ability to take care of ***your loved one's*** health care.

Not Confident ☐ Somewhat Unconfident ☐ Neither Confident nor Unconfident ☐ Somewhat Confident ☐ Confident ☐

Supporting Caregiver(s)

Having supporting caregivers that can support the primary caregiver when needed helps ensure continuity of care. They should receive up-to-date copies of your Transition of Care Plan as they are made. Supporting Caregivers may be good Emergency Contacts when asked in new provider paperwork.

Name	Relationship	Contact (email/phone)	Transition of Care Toolkit Shared (Date)
			/ /
			/ /
			/ /
			/ /

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Transition of Care Master Checklist

Assessing progress towards completing your comprehensive transfer of care package for future adult healthcare providers.

	In Progress	*Completed*	
Provider Master List	☐	☐	Date: / /
Medical Summary	☐	☐	Date: / /
Provider Transfer Plan(s)	☐	☐	Date: / /
Goals of Care	☐	☐	Date: / /
Emergency Plans	☐	☐	Date: / /
Legal Documentation	☐	☐	Date: / /
Communicated with Pediatric Provider about End of Service Date	☐	☐	Date: / /
Communicated with Adult Provider about Transfer	☐	☐	Date: / /
Immunizations Sent to Adult Provider	☐	☐	Date: / /

Understanding Young Adult's Health

Please check the box that applies to you right now. Note that "We" refers to the primary parents/caregivers and the individual with Angelman syndrome.

	Yes, we know this.	*We'd like to learn more.*
We know their medical needs.	☐	☐
We can tell other people what their medical needs are.	☐	☐
We know what to do if they have a medical emergency.	☐	☐
We have an emergency care plan documented.	☐	☐
We know the medicines they take and what they are for.	☐	☐
We know what they are allergic to, including medicines.	☐	☐
We can name and have documented 2-3 people who can help them with their health goals.	☐	☐

	Yes, we know this.	*We'd like to learn more.*
We and 2-3 people know and can find their doctor's phone number.	☐	☐
We and 2-3 other people have access to this Transition of Care Toolkit including their medical summary, emergency plan, and goals of care.	☐	☐
We and 2-3 other people can find necessary health information (e.g. insurance card, allergies, medications, provider list, etc.)	☐	☐
Before a visit, we think about questions to ask.	☐	☐
We have a way to get to their doctor's office .	☐	☐
We know where to get care when their doctor's office is closed.	☐	☐
We know how to ask for a form to be seen by another doctor/therapist (i.e. referral).	☐	☐
We know where their pharmacy is and what to do if they run out of medicines.	☐	☐
We know where to get a blood test or x-rays if the doctor orders them.	☐	☐
We have a plan so they can keep their health insurance after 18 or older.	☐	☐
We know what we need to do to establish legal guardianship and/or conservatorship to ensure they have support with healthcare decisions.	☐	☐

Additional Comments/Notes

Provider Master List

Intent

This document is intended to keep up to date on all current and future providers.

Patient Name: ______________________ Date of Birth: ______________________

Primary Caregiver Name: __________________________ Last Updated: / /

Medical Providers

Specialty	Current Pediatric Provider	Adult Provider
Primary Care Provider (PCP)	Name: Role: Phone:	Name: Role: Phone:
Neurology *(epilepsy, movement, sleep)*	Name: Role: Phone:	Name: Role: Phone:
Dietitian/Nutrition	Name: Role: Phone:	Name: Role: Phone:
Gastroenterology	Name: Role: Phone:	Name: Role: Phone:
Rehabilitation Medicine	Name: Role: Phone:	Name: Role: Phone:
Orthopedist/Orthopedic Surgeon	Name: Role: Phone:	Name: Role: Phone:
Psychiatry	Name: Role: Phone:	Name: Role: Phone:

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Medical Providers

Specialty	Current Pediatric Provider	Adult Provider
Dental	Name: Role: Phone:	Name: Role: Phone:
Ophthalmologist	Name: Role: Phone:	Name: Role: Phone:
Other:	Name: Role: Phone:	Name: Role: Phone:
Other:	Name: Role: Phone:	Name: Role: Phone:
Other:	Name: Role: Phone:	Name: Role: Phone:

Therapists

Specialty	Current Pediatric Provider	Adult Provider
Occupational Therapy	Name: Role: Phone:	Name: Role: Phone:
Physical Therapy	Name: Role: Phone:	Name: Role: Phone:
Communication/AAC	Name: Role: Phone:	Name: Role: Phone:
Behavioral Therapist/BCBA	Name: Role: Phone:	Name: Role: Phone:

Therapists

Specialty	Current Pediatric Provider	Adult Provider
Other	Name: Role: Phone:	Name: Role: Phone:
Other	Name: Role: Phone:	Name: Role: Phone:
Other	Name: Role: Phone:	Name: Role: Phone:

Other Important Contacts

Specialty	Current Pediatric Provider	Adult Provider
Social Work	Name: Role: Phone:	Name: Role: Phone:
Care Coordination	Name: Role: Phone:	Name: Role: Phone:
Respite Providers	Name: Role: Phone:	Name: Role: Phone:
Other	Name: Role: Phone:	Name: Role: Phone:
Other	Name: Role: Phone:	Name: Role: Phone:
Other	Name: Role: Phone:	Name: Role: Phone:

Provider Transfer Plan

Intent

The Provider Transfer Plan is designed to ensure clear communication about transition policies and protocols between pediatric providers and caregivers.

Instructions

Caregivers should request each relevant provider (i.e. pediatrician, neurology, gastroenterology, etc.) help complete a Provider Transfer Plan to ensure they have clear expectations of how the process will work and identify key information each provider wants to be passed along to future adult providers.

Specialty: ______________________________

Provider Name: ______________________________

Clinic/Location: ______________________________

Email: ______________________________

Phone: ____________________ Fax: ____________________

Patient Information

Patient Name: ____________________ Date of Birth: ______________

Current Diagnoses Treated: ______________________________

Former or Resolved Diagnoses Treated: ______________________________

Transition Complexity: Low Moderate High

Notes:

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Transition Policy & Planning

☐ Practice policy on transition discussed/shared with caregivers and youth.

Date: / /

Notes:

☐ Communicated with caregivers and youth transition goals and prioritized actions to include in their Transition of Care Plan.

Date: / /

Notes:

☐ Discussed with caregivers the level of support we provide after the patient has started care with their adult provider (e.g. answering new provider's questions, consult with caregivers if they have concerns about their new provider, etc.)

Date: / /

Notes:

☐ Timing of transition has been discussed.

Date: / /

Notes:

☐ Adult provider has been selected.

Provider Name: ______________________________

Contact Information: ______________________________

First Appointment Scheduled For: / /

☐ Pediatric provider records/notes have been sent to the new provider.

Date: / /

Notes:

Additional Comments/Notes:

Medical Summary

Intent

This Medical Summary is intended to provide a consolidated, yet comprehensive, summary of a person with Angelman syndrome's most important medical history highlights.

Instructions

With the support their primary care and specialty providers, caregivers should update this document regularly. This can be shared with healthcare providers and supporting caregivers as needed to ensure a person with Angelman syndrome's entire care team is aware of these very important components of their health care needs.

About Angelman Syndrome

Angelman syndrome (AS) is a rare neuro-genetic disorder that occurs in one in 15,000 live births. People with Angelman syndrome have developmental problems that become noticeable by the age of 6 – 12 months. Other common signs and symptoms usually appear in early childhood like walking and balance disorders, gastrointestinal issues, seizures and little to no speech. Despite these symptoms, people with Angelman syndrome have an overall happy and excitable demeanor. An individual with AS will light up a room with their smile and laughter.

Patient Name: ______________________ Date of Birth: ______________________

Primary Caregiver Name: ______________________ Last Updated: / /

Diagnoses & Management

Pertinent Active Diagnoses:
Prioritize list of active issues for Individual with Angelman syndrome (epilepsy, behavior, constipation, sleep, etc.)

Inactive or Currently Resolved Diagnoses:
E.g. kidney stones, sleep apnea, pneumonias, etc.

Primary Care Provider

Name and Contact Information

Emergency Contact(s)

Name and Contact Information

Important Details or Recommendations

A brief summary of the most important things one would need to know about managing this person's health.

Current Medications

Medication Name	Dose	Frequency	Pharmacy

Prior Medications

Medication Name	Dose	Frequency

Functional Information

Below is general information to better understand this person with Angelman syndrome's strengths, challenges, communication methods, and preferences.

Cognitive Skill Level:

Adaptive Skill Level:

Communication Skill Level:

Communication Method:

Type of Adaptive Equipment:

Diet:

Food Texture:

Food Intolerances:

Ambulatory (fully, with assistance, non-ambulatory, etc.):
Sleep Concerns:
Safety Concerns:
Behavior Concerns:
Shower/Bath/Hygiene:
Dental Hygiene:

Best Learning Method:
Things That Make Me Happy and Things I Enjoy:
Things That Frustrate or Upset Me:
Additional information:

Allergies

Allergies:	Reactions:

Medications & Procedures to Avoid

Medications / Procedures (List):	Why?

Prior Surgeries, Procedures, and Hospitalizations

Date	Details

Vaccine Administration Record

Vaccine	Administer Date	Details

Goals of Care

Intent

Goals of Care has been designed to ensure your healthcare team understands what is most important to you and your loved one with Angelman syndrome. It is essential for your providers to know your loved one's medical needs but also the values and priorities you hold for their care now and in the future.

Instructions

Use the prompts below to help think beyond standard medical care while establishing your "Top Goals" list. Consider overall quality of life and what health and wellness goals will help your individual with Angelman syndrome thrive, not simply survive their journey with Angelman syndrome. This document may be edited often as new goals arise and former goals are achieved.

Example Goal

Goal

Maintaining seizure control.
For this patient, this means we only tend to see breakthrough myoclonic seizures in times of illness. Historically, a bridge medication during illnesses has prevented the return of grand mal seizures.

Issues/Concerns/Potential Barriers

Prior to gaining control of seizures at the age of 14, patient experienced dangerous grand mal seizures that often resulted in falls, injuries, and regressions that significantly effect patient's overall wellbeing. Caregiver can often see signs of increased neurological behavior before actually seeing breakthrough seizures appear. It's critical that providers trust caregiver instinct on this and help us establish an emergency seizure action plan and regular plan for medication/dosing assessments.

Actions Needed

- *Ensure new provider is aware of seizure history, medications that did/did not work, and signs of increased neurological activity often identified by caregiver.*
- *Understand provider process to receiving a timely appointment/request for medication adjustments if needed.*
- *Ensure all caregivers and medical providers are aware of the Emergency Seizure Action Plan and, if needed, post-seizure recovery expectations (e.g. physical therapy may be needed to address potential mobility regressions due to a fall, etc.)*

Progress/Notes

- *New adult neurologist appointment scheduled for ____________.*
- *Pediatric neurologist has prepared a comprehensive seizure history and seizure action plan to share with new provider.*
- *Caregiver has prepared notes and questions for new provider.*

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Patient Name: ______________________ Date of Birth: ______________________

Primary Caregiver Name: ____

Relationship to Patient: ______________________ Phone: ______________________

Last Updated: / /

Please consider the following questions as you develop Goals of Care to share with your providers.

- **What are your primary goals for your loved one's care as they transition into adulthood?** This may include things like maximizing quality of life, managing specific symptoms, or ensuring independence and autonomy in certain areas.
- **What are your loved one's most important values and preferences?** For example, are there specific activities, comforts, or routines that are particularly meaningful to them? Are there things they enjoy or want to continue doing as they grow older?
- **Are there any medical or care priorities that you feel are particularly important?** This might include managing certain health conditions, minimizing discomfort or pain, or focusing on mental or emotional well-being.
- **How involved would you like to be in your loved one's care decisions moving forward?** Do you prefer to be the primary decision-maker or are you comfortable with your loved one being involved with decision making or working with a healthcare team to make decisions together?
- **What concerns or challenges do you foresee in your loved one's future care, and how can your providers help address those?** This could include worries about healthcare access, navigating adult care systems, or managing specific aspects of the condition as it progresses.
- **Are there any cultural, religious, or personal beliefs or practices that should be considered when making decisions about your loved one's care?** We want to ensure that care is aligned with your family's values and beliefs.
- **Do you have any specific wishes or concerns about end-of-life care planning?** If you would like, this can include preferences for interventions or comfort care if the patient reaches a terminal stage.
- **What support or resources would be helpful to you and your family during this transition?** Your providers are there to give guidance and ensure you have the resources you need, whether it's emotional, logistical, or financial support. Think about what might be helpful to ask prior to your appointments.

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Goal	Issues/Concerns/Potential Barriers

Actions Needed	Progress/Notes

Emergency Care Plans

Intent

Emergency Care Plans are a critical resource designed to ensure the primary caregiver, any supporting or secondary caregivers, and health care providers have clear communication and understanding of what must be done in case of an emergency.

Instructions

Caregivers should work with their healthcare team to establish emergency care plans for any major risks to the individual with Angelman syndrome's health.

Example

Emergency Care Plans

Symptom or Diagnosis	Special Precautions
Patient has an allergic reaction to tree nuts which may be found in some nut milks, nut meals, and nut oils.	Allergic Action Plan: Mild symptoms can be an itchy or runny nose, few hives OR mild nausea or abdominal cramping. If there are mild symptoms from one system, give an adult dose of an oral antihistamine such as Benadryl, Claritin or Zyrtec or their respective generics. Closely monitor for worsening symptoms. If there are mild symptoms from more than one system, give epinephrine as soon as possible and call EMS. Severe symptoms are shortness of breath, wheezing, persistent cough, pallor or blue coloring, feeling faint, lightheaded or weak, diffculty breathing and/or swallowing, swelling of the tongue or lips, many hives and/or large areas of redness on the skin, repetitive vomiting or severe diarrhea. If severe symptoms, inject epinephrine immediately then call 911 and alert the dispatcher that you are witnessing an anaphylactic reaction. Wait with person until responders arrive. Alert caregivers/emergency contacts.
Patient has an increased risk of aspiration where food and fluids enter the lungs rather than the stomach after being swallowed.	Aspiration Symptoms: Choking, difficulty breathing, wheezing, pallor or turning blue. Aspiration Action Plan: If any of these symptoms are present after eating, check for a pulse and listen for breathing. Do not do a blind sweep. If you know how, perform the Heimlich. If you do not, call 911 immediately and stay with patient until responders arrive.

Patient Name: ______________________ Date of Birth: ______________________

Primary Caregiver Name: ____

Relationship to Patient: ________________ Phone: __________________________

Preferred Emergency Care Location: _______________________________________

Emergency Care Plans

Symptom or Diagnosis	Special Precautions

Last Updated: / /

Legal & Planning Documents

Intent

The Legal & Planning Documents section is a critical component of the ASF Transition of Care Toolkit, designed to help caregivers and families centralize and organize important legal paperwork that ensures the continuity of care and supports the patient's legal and financial needs as they transition into adulthood. This section is intended to provide a comprehensive, easy-to-access place for storing key legal documents that may be required by healthcare providers, guardians, and financial advisors. Proper legal planning is vital in ensuring that the patient continues to receive appropriate care and support, especially as they move from pediatric to adult services.

As patients with Angelman syndrome transition from pediatric to adult care, the role of caregivers and family members often shifts. Legal documents help ensure that caregivers have the authority to make critical decisions on behalf of the patient, particularly in areas of healthcare and finances. This section of the toolkit is designed to make it easier for caregivers to organize and manage these important documents.

Instructions

Use this resource to help keep track of your key legal and planning processes, documentations, links, points of contact, key dates, and notes. Consider using a calendar reminder system to keep track of annual renewals and determinations.

PRO TIP!

It is crucial that you keep documents suggested in this section in secure locations, whether that is as paper copies, digital scans, or both. Consider fireproof safes for paper documents and secure password-protected files for digital files. Do not include critical information (i.e. social security numbers) in this resource to prevent identity theft in the case your toolkit is shared with other caregivers or providers.

Essential Identification

	We have this on file	*Person Responsible for Safe Keeping*
Social Security Card	☐	
Birth Certificate	☐	
Photo ID or Government-Issued ID (if available)	☐	
Insurance Card (Medicaid, Medicare, private)	☐	

Guardianship and Alternatives to Guardianship

- If the patient has a legal guardian, a copy of the guardianship paperwork should be included.
- For those who do not have formal guardianship in place but may need it as the patient transitions to adulthood, include notes/documents related to alternatives such as power of attorney or supported decision-making agreements.

Healthcare Proxies and Advance Directives

- If the patient or their family has designated a healthcare proxy or decision-maker for medical decisions, includes copies of these documents.· This ensures that the adult healthcare providers can follow the patient's wishes and consult with the designated individual in the event the patient is unable to make decisions independently.

Medicaid, Medicare, Social Security (SSI/SSDI) & Waiver Documentation

- **Social Security (SSI/SSDI):** Award letter and benefit determination, recent annual renewal or redetermination forms, payee designation (if you are the representative payee), income and resource documentation (for eligibility purposes)
- **Medicaid/Medicare:** Approval letter and member ID, enrollment documents, Explanation of Benefits (EOBs) and notices, eligibility letters, service plans or individualized support plans (ISP), managed care provider assignments (if applicable), prior authorizations for durable medical equipment (DME), therapies, etc.
- **Medicaid Waiver & Long-Term Services:** Waiver enrollment confirmation and case manager contact, waiver service authorizations (e.g. Respite, day program, therapies, etc.) individualized service plans (ISP) or person-centered plans, service provider contracts or care agreements, receipts or records of waiver-related services (important for audits).

Financial and Special Needs Planning Documents

- **Trusts:** Copies of any special needs trusts, which are designated to protect the patient's eligibility for government benefits while allowing assets to be managed for their benefit.
- **Wills:** If applicable, include any legal wills that outline the patient's wishes for the future, including provisions for care or financial support after reaching adulthood.
- **ABLE Accounts:** Include documentation of any Achieving a Better Life Experience (ABLE) accounts, which allow individuals with disabilities to save money without effecting eligibility for government benefits such as Medicaid or Supplementary Security Income (SSI)
- **Other Financial Planning Documents:** Any documents related to long-term care planning, such as life insurance policies, government benefits eligibility, or financial support plans.

Legal & Planning Resources

AS Grows Up (Website)
Adult Housing & Champions (Website)
National Guardianship Association Affiliates by State (Website)
National Association of State Directors of Developmental Disability Services Agencies by State (Website)
MedicaidWaiver.Org (Website)
Long-Term Planning (YouTube Playlist)
Angelman Syndrome in Adulthood (YouTube Playlist)
Guardianship (YouTube Video)
ASF Family Fund (Resource)
Transition to Adulthood Checklist (Resource)
The Comprehensive Care Binder (Resource)
Home Modification Loan Program (Resource)
Financial Planning Q&A (Podcast)

The Angelman Syndrome Foundation Transition of Care Toolkit including fillable forms for each resource found in this toolkit can be found online at Angelman.org/resources/transition-care-toolkit

Resources & Additional Notes

For a comprehensive resource library, please visit Angelman.org/Resources. No matter where you are in your journey with Angelman syndrome, you'll find resources to assist every step of the way. Use filter to search by subtopics, lifestage, or even location to find information including, but not limited to:

- Educational content, videos, and podcasts on a variety of topics such as anxiety, sleep, dental, diet, behaviors, and more.
- Health care support including emergency medical considerations, general anesthesia best practices, genetics, PT/OT best practices, standards of care, epilepsy guidelines, advocacy in dental care, and more.
- Useful resources including comprehensive care binders, letter of medical need for safety beds, rare disease medical card template, About Me templates, etc.
- Specialized resources including financial/legal support, education/IEP support, community integration/inclusion support, AAC/communication, transportation, and more.

Additional Notes