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.*

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)
			/ /
			/ /
			/ /
			/ /

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 offce .	☐	☐
We know where to get care when their doctor's offce 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