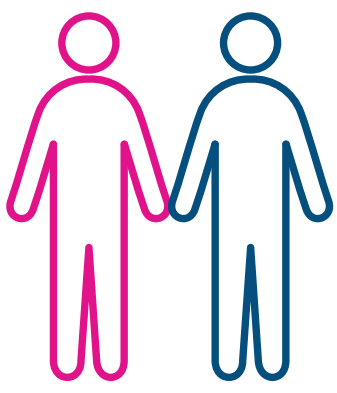
angelman SYNDROME FOUNDATION

The Comprehensive Care Binder

For _____



1

General Information

General Info

Name: _____

Address: _____

_____

Birthdate: _____ SSN: _____

Guardian/Conservator #1: _____

Address: _____

_____

Email: _____ Phone: _____

Guardian/Conservator #2: _____

Address: _____

_____

Email: _____ Phone: _____

Insurance Coverage

Does the individual with AS have any of the following:

- ☐ Private Insurance
- ☐ Medicaid
- ☐ Medicare
  - ☐ Part D Coverage

    Extra help for prescription costs:
    https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/lower-prescription-costs
- ☐ Dental Insurance
- ☐ Vision Insurance

Include copies of all insurance cards with Member ID/Number, Group Number, Policy Holder and Policy Holder DOB

Additional Information

*Is Secondary Insurance provided by a Deeming Waiver? ◯YES ◯NO

If YES, be sure to include renewal process and as much information as possible about this process (attach separately).

Are there any regular meetings in regards to insurance and/or waivers? ◯YES ◯NO

Medicaid Support Coordination

Who manages Medicaid? _____

Who is the support/service coordinator? _____

Medicaid Support Coordination

Where does the individual with AS reside? (Home, Group Home, Assisted Living Center, Other)

_____

Name: _____

Address: _____

_____

Room Number: _____ Phone Number: _____

Guest Policies: _____

_____

Cost: _____ How Is It Funded? _____

House Director Name and contact info: _____

Company Name and contact Info: _____

Day Program

Does the individual with AS attend a Day Program? (Include Name of Program, Address, Director, Company)

_____

_____

_____

_____

How is it Funded? _____

Transportation Information to and from Day Program. _____

List of current caregivers:

Name	Role *(parent/sibling/teacher/nurse/bus driver/respite)*	Phone	Email

Medical Information

Documents

- ☐ Copy of Birth Certificate
- ☐ Genetic Diagnosis Test Results
- ☐ Vaccine Record
- ☐ Past Medical History, including but not limited to seizure log, surgeries, hospitalizations, major illnesses, medications (past and present), previously prescribed meds that were ineffective, seizure protocol and seizure action plan.

General Doctors/Physicians/Specialists

Primary Physician: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Dentist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Sedation Needed: _____

Dental Insurance: _____

Questions: _____

Future Dental Procedures? _____

Other: _____

General Doctors/Physicians/Specialists

Neurologist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

GI Doctor: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Ophthalmologist : _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Glasses Perscription? _____

Vision Insurance: _____

Questions: _____

Future Eye Exams/ Procedures? _____

Other: _____

General Doctors/Physicians/Specialists

Orthopedist : _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Reason for Visits: _____

Questions: _____

Accepts Insurance: _____

Other: _____

Specialist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Specialist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Additional Info:

Therapies

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Medications/Prescriptions

Name *(Generic or Brand)*	Dosage	Frequency	Quantity *(30/90/120 day supply)*	Cost	Pharmacy	Purpose	How is the medication taken?	Preparation Type: *(pill, capsule, liquid, chewable, sprinkle, etc)*	Comments/Notes: *(ex: does it need to be brand necessary)*

3

Adaptive Equipment/DME (Durable Medical Equipment)

List any adaptive equipment, devices and durable medical equipment (i.e., walker, wheelchair, car seat/harness, C-Pap machine, orthotics, iPad, communication device, glasses, etc.)

Adaptive Equipment/ Device	Who Prescribes?	How is it funded?	Who is involved? *(ex: prescription from doctor or therapist?)*	Additional Information:

4

Important Personal Care Information

Important Personal Care Information

Include information regarding your adult individual with AS personal care and hygiene.

Examples include but not limited to:

– Incontinence service for adult diapers and pads

- Name & contact info of company:
- How often do you need to order?

– Hair cuts

- Where does your individual with AS get his/her hair cut?
- Frequency?

– Nail Trim

- Who cuts individual's nails?
- How often?
- Tips:

– Information on shaving (male and female).

– Things to frequently check on (whether individual lives at home or in residential setting):

- Skin assessment: any irritated spots, or infected bumps?
- Frequency of bowel movements
- Changes in behavior
- Changes in appetite

Additional Information:

5

Weekly Schedule

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

6

Regular Reporting Requirements

Important Personal Care Information

If required:

Representative Payee Report (ex: filed annually with Social Security Administration.
Reflect that his/her income goes toward his/her portion of the mortgage, if applicable)

– Incontinence service for adult diapers and pads

• May change when custodial parent draws SS benefits

• If Representative Payee becomes incapacitated or passes away,

Social Security needs to be notified immediately.

– Annual report for Guardianship / Mental Hygiene Commission (VARIES BY STATE)

– Medicaid Recertification (varies by state in frequency/need)

Additional Information:

7

Financial Information

Financial Information – Include any account that directly impacts the individual with AS

Bank/Savings Account: _____

Name(s) on Account: _____

Banking Institution: _____

Specific Location that you currently use: _____

Account Number: _____

Routing Number: _____

**or attach voided check*

Who Manages account? _____

What are asset limits to this account? _____

**Balance for Bank/Savings and SS/SSI needs to remain below a certain amount as not to disqualify him/her from any Waiver program and Medicaid.*

ABLE Account: For more information visit https://www.ssa.gov/ssi/spotlights/spot-able.html

Name/s on Account: _____

Banking Institution: _____

Account Number: _____

Routing Number: _____

Beneficiary: _____

**Include document about Rules of an ABLE account—especially maximum deposit limits AND what it can be used for. Varies by state.*

Special Needs Trust

Name/s on Trust: _____

EIN: _____

Rules Related to Trust: What can it be used for and tax information

_____

Accountant and/or Attorney Name and Contact Information

_____

Financial Information – Include any account that directly impacts the individual with AS

SS/SSI Account/Deposit: _____

Amount deposited each month: _____

Where is SS/SSI Deposited: _____

Rules for SS/SSI Direct Deposit: _____

Who is Representative Payee: _____

**Balance for Bank/Savings and SS/SSI needs to remain below a certain amount as not to disqualify him/her from any Waiver program and Medicaid. For more information visit https://www.ssa.gov/benefits/ssi/*

Other Insurance Policies:

8

Legal Documents & Paperwork

Legal Documents and Paperwork

– Birth Certificate

– State ID Card

– Passport

– Social Security Card

– Copies of updated Wills for Parents of Individual with AS

– Guardianship Paperwork

– Medical Power of Attorney for Parents

– Trust Documents and Information that Benefit Individual with AS

– Past Tax Return info filed yearly and/or Contact Info of Accountant

– Copies of Any Waiver Documents

9

Employee Payment Process

Part 9: Employee Payment Process *(If Applicable)*

10

List & Contact Information of Close Family/Friends

List and Contact Information of Close Family/Friends

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____