Carolina Institute for Developmental Disabilities
Angelman Syndrome Clinic Questionnaire

Return completed questionnaire, diagnostic genetics report, and any additional information to:

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OR
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Child/Individuals's Name_____ **Birthdate**_____
Last First MI

Gender_____ Race/Ethnicity_____

Name of Person(s) Completing Questionnaire_____ Date Completed_____

Relationship to Child/Individual _____

Address_____

Phone Number _____ Email_____

Primary Insurance _____ Policy Holder_____

Secondary Insurance_____ Policy Holder_____

Date of Angelman syndrome (AS) diagnosis_____ Age at time of AS diagnosis_____

Etiology of AS (*check one*): ☐ Deletion (class ☐1 / ☐2) ☐ Uniparental Disomy (UPD) ☐ UBE3A mutation
☐ Imprinting Center Deficit (ICD) ☐ Other _____ ☐ Unknown

***Where** and **by Whom** was the diagnosis made*_____

PLEASE ATTACH A COPY OF THE DIAGNOSTIC GENETIC REPORT
**Please note: appointments will not be scheduled until a diagnosis of Angelman syndrome has been confirmed*

CIDD AS clinic offers comprehensive services with up to seven professional disciplines available. However, the full comprehensive clinic has a long wait list. It is possible to be seen sooner if fewer professionals are needed. In order to streamline our services for you and your loved one, please rank your top three to five priority needs.

☐**Seizure Management** _____
☐**Behavior Management** _____
☐**Genetic Counseling** _____
☐**Communication** _____
☐**Feeding/Nutrition** _____
☐**Developmental/Learning Ideas** _____
☐**Physical Therapy Consultation** _____
☐**Occupational Therapy Consultation** _____
☐**Sleep Issues** _____
☐**Family Support/Social Work** _____

OR

☐**I would like a comprehensive assessment with all professional disciplines**

I would be available to attend the clinic on short notice. ***Please contact me in the event of a cancellation or other appointment opening.*** ☐ **Yes** ☐ **No**

Parent/Caregiver 1:
Full Name _____
Relationhip to child/individual:_____
Date of Birth_Click or tap to enter a date._Place of Birth_____
Highest school grade completed_____Degree_____
Current Place of Employment:_____
Job/Title:_____

Parent/Caregiver 2 *(write N/A if not applicable)***:**
Full Name _____
Relationhip to child/individual:_____
Date of Birth_Click or tap to enter a date._Place of Birth_____
Highest school grade completed_____Degree_____
Current Place of Employment:_____
Job/Title:_____

With whom does the child/individual with AS live? Please check all that apply.
☐ Biological parent(s) ☐ Biological mother only ☐ Biological father only

☐ Parent and Step-parent ☐ Parent and Domestic Partner ☐ Parent and Adoptive Parent

☐ Adoptive parent(s) ☐ Foster parent(s) ☐Residential/Group Home

☐ Other (specify):_____

Please provide the age and relationship to the child/individual for each person who currently lives in the same home with your child/individual with AS

Age	Relationship to Child/Individual

Household/Family's annual income: ☐ under $10,000 ☐ $10,000 to $14,999 ☐ $15,000 to $24,999

☐ $25,000 to $34,999 ☐ $35,000 to $49,000 ☐ $50,000 to 74,999 ☐ Over $75,000

FAMILY HISTORY:

Note below if any of the child/individual's **biological ("blood")** relatives have had any of the following conditions:

Condition	Siblings (include half siblings)	Father	Father's Family	Mother	Mother's Family
Autism/ PDD	☐	☐	☐	☐	☐
Convulsions/Seizures	☐	☐	☐	☐	☐
Neurologic Disorders	☐	☐	☐	☐	☐
Aggressive/Violent Behavior	☐	☐	☐	☐	☐
Alcoholism/Substance Abuse	☐	☐	☐	☐	☐
Depression	☐	☐	☐	☐	☐
Anxiety	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

If "other," please explain:_____

II. Child/Individual's Medical Information

Birth weight:_____ Birth Length: _____Total number of weeks of pregnancy: _____

How was your baby delivered: ☐ vaginally ☐ by Caesarean section

Were there any labor or delivery issues? ☐ **Yes** ☐ **No** if "yes", please explain:_____

_____

Was the child/individual placed in the NICU? ☐ **Yes** ☐ **No** if "yes", please explain: _____

_____

Check any of the following that the child/individual had in the first month of life:

☐ Breathing problems ☐ Convulsions ☐ Skin rash ☐ Jaundice (yellow) ☐ Infection

☐ Deformity ☐ Excessive crying ☐ Injury ☐Feeding difficulty ☐Other:_____

Has the child/individual ever been seriously ill? ☐ **Yes** ☐ **No** *If yes, with what?*_____

Has the child/individual had any serious injuries? ☐ **Yes** ☐ **No** *If yes, what kind?* _____

Is the child/individual currently on medication? ☐ **Yes** ☐ **No** *If yes, please indicate:*

Medicine	Dates taken	Dosage	Reason prescribed

Does the child/individual have any current medical concerns? ☐ Yes ☐ No *If "yes" please explain*

_____

_____

Does the child/individual have a history of seizures? ☐ Yes ☐ No

If "yes" Age of Onset_____ How often does he/she have a seizure?_____

Please provide any additional information about the child/individual's seizures: _____

_____

III. Developmental History

PHYSICAL SKILLS:

At what age did your child? *(Write "not yet" when appropriate.)*

_____roll over _____sit without support _____crawl _____pull to standing _____walk alone

_____eat with a spoon _____copy printed letters _____bladder train _____bowel train

_____climb stairs _____ride a tricycle _____run _____skip _____ride a bicycle

What concerns do you have about the child/individual's physical / motor development? _____

_____

Has the child/individual lost a previous skill? ☐ **Yes** ☐ **No** *If yes, please explain:*_____

_____

COMMUNICATION AND HEARING:

How is the child/individual's hearing? ☐ good ☐ poor ☐ none ☐ inconsistent ☐ uncertain

Child/individual's main communication methods: ☐ gestures ☐ crying ☐ noises/sounds ☐ spoken words

☐ sign language ☐ AAC system (please specify type of AAC system): _____

At what age did your child? *(Write "not yet" when appropriate.)*_____make single sounds _____babble

_____use single words ☐combine words in short phrases

Did the child/individual begin to use words and then stop? ☐ **Yes** ☐ **No** *If "yes," at what age?*_____

What are your primary communication concerns? _____

_____

IV. School and Intervention Services Information

Is the child/individual with AS currently in school, preschool, or daycare? ☐ **Yes** ☐ **No**

If yes, where?_____

Current/highest grade completed _____

Does the child/individual with AS have an Individualized Family Services Plan (IFSP), Individualized Education Plan (IEP), or an Individual Service Plan (ISP)? ☐ **IFSP** ☐ **IEP** ☐ **ISP**

Does the child/individual have Special Education Category? _____

Is the child/individual currently receiving therapy services? ☐ **Yes** ☐ **No** *If "yes," please indicate:*

Service	School Based	Hrs/Week	Private	Hrs/Week
Occupational Therapy	☐		☐	
Physical Therapy	☐		☐	
Speech & Language Therapy	☐		☐	
Behavior Therapy	☐		☐	
Other:	☒		☐	

If not in school, does the child/individual participate in a day or work program? ☐ **Yes** ☐ **No** *If yes, please describe:* _____

oes the child/individual participate in any recreation / leisure activities? ☐ **Yes** ☐ **No** *If yes, please describe:*_____

V. Behavior Information

Do you, or anyone else, have any concerns with the child/individual's behavior? ☐ **Yes** ☐ **No** *If "yes," please describe:* _____

_____

Who generally disciplines your child? _____

What methods are used? _____

How successful are the discipline methods? _____

Does the child/individual have behavioral tantrums (outbursts)? ☐ **Yes** ☐ **No** *If "yes," please circle the response that best describes the frequency and severity of characterisitics of your childs tantrums:*

	(0) not a problem	**(1) mild problem**	**(2) moderate problem**	**(3) severe problem**
1. Biting	☐0	☐1	☐2	☐3
2. Kicking	☐0	☐1	☐2	☐3
3. Screaming	☐0	☐1	☐2	☐3
4. Whining	☐0	☐1	☐2	☐3
5. Throwing objects	☐0	☐1	☐2	☐3
6. Hitting	☐0	☐1	☐2	☐3
7. Other:	☐0	☐1	☐2	☐3

What causes these behavioral outbursts? _____

_____

_____

Does the child/individual have a preference for one cargiver (over others)? ☐ **Yes** ☐ **No** *If "yes," please explain:* _____

_____

_____

_____

Does the child/individual display agitation upon someone coming between them and their preferred caregiver? ☐ **Yes** ☐ **No** *If "yes," please explain:* _____

_____

_____

Does the child/individual display agitation if the preferred caregiver attends to someone else or attempts to leave the child/individual for any amount of time? ☐ **Yes** ☐ **No** *If "yes," please explain:*

_____

_____

_____

Does the preferred caregiver expierence anxiety/fear when leaving the child? ☐ **Yes** ☐ **No** *If "yes," please explain:* _____

_____

_____

Does the child/individual display agitation upon breaking gaze (eye contact) with the preferred caregiver? ☐ **Yes** ☐ **No** *If "yes," please explain:* _____

_____

_____

VI. Family and Community Supports

What are the child/individual's strengths?_____
_____
_____
_____

What are the child/individual's interests?_____
_____
_____
_____

What are the child/individual's family's strengths?_____
_____
_____
_____

What are the current stressors (e.g., marital, parenting, lack of support, financial) in your family? _____
_____
_____
_____

Does the child/individual receive Social Security Disability? ☐ **Yes** ☐ **No**

Does the child/individual have Medicaid? ☐ **Yes** ☐ **No** Medicare? ☐ **Yes** ☐ **No**

Does the child/individual have the NC Innovations Waiver (NC Residents) ☐ **Yes** ☐ **No**

What supports is the child/individual receiving (e.g., respite, in-home skill building, skilled nursing care, community networker, etc.)?_____
_____
_____
_____

What supports are other family members receiving (e.g., family support, faith-based community, other community support groups, sibling groups, individual or family therapy)?_____
_____
_____
_____

What questions do you have for the CIDD Social Worker/what supports do you need? _____
_____
_____
_____
_____