

**In-depth Interviews with Parents/Caregivers of Children with Angelman Syndrome:
Communication Abilities
Interview Guide Version: 1/28/19
Pro00101207**

Date of interview: _____

Participant ID number: _____

Interviewer's name: _____

Interview Start Time (24-hour clock): ____:____

Thank you for taking the time to participate in this study. For this interview, we want to discuss your child's communication abilities. Your answers to our questions will help us develop a questionnaire that will assess how your child both communicates and understands communication. This questionnaire is planned for use in future clinical trials to find treatments for individuals with Angelman Syndrome.

The interview will take about an hour. We are first going to discuss what typical communication looks like for your child and the ways in which they communicate with you. I'm also going to ask about different situations and people they might communicate with, and how they show you that they understand you and others. Finally, we are going to talk about how their communication has changed as they've grown older.

Please note that individuals with Angelman Syndrome have a range of communication abilities. During this interview, I am going to ask about different types of abilities, but it is not expected that your child will be able to do everything I describe. If I ask about something that your child is not able to do or has not done before, you can simply tell me that your child is not able to do that and we will move to the next question.

Please remember that there are no right or wrong answers. You are the expert on your child, and we are interested in your perspective and experiences. Your participation is completely voluntary, and you can choose to take a break at any time or stop the interview entirely.

I would like to audio record the interview because I want to make sure I don't miss any of your comments. If you don't want the interview audio recorded, I will take detailed notes during the interview instead. The recording will be stored securely and eventually destroyed after we publish the study's findings.

Do I have your permission to record this interview?

☐ **Yes**

☐ **No**

Do you have any questions for me so far about the interview?

[Begin recorder]: This is participant ID *[Insert Participant ID number here]* on *[Date]*.

[Goals for Questions #1-2: Build rapport with caregiver and start to learn about typical and atypical communication for the child.]

1) Who does your child communicate with on a typical day?

Probes:

- What kinds of things does your child communicate about?

2) What are your child's communication strengths?

Probes:

- What do they do well?

[Goal for Question #3-4: Learn about typical gestures and their context of use. Expressive.]

3) How does your child use facial expressions to communicate with you?

Probes:

- Please describe the different facial expressions your child uses to communicate.
- How do they use eye contact to communicate?
- Do facial expressions change when communicating with different people?
Siblings? Strangers?

4) What types of gestures does your child use to communicate with you?

Note to interviewer: Gestures can include Sign Language or less formal gestures, like pointing, informal signs, etc. Please probe on each gesture the caregiver mentions.

Probes:

- Please describe the different gestures your child uses.
- At what age did your child start using gestures to communicate?
- Can you describe to me what each gesture means? The intended goal of each gesture?
- How often do they use gestures?
- How many gestures/signs do they have?
- When do they use the gestures (i.e., do they use them to direct or request action)?
- Does the meaning of the gesture stay the same (consistent)?
- Does one gesture have multiple meanings?

[Goals for Question #5-6: Learn about typical vocalizations and their context of use. Expressive.]

5) What types of sounds does your child use to communicate with you?

Note to interviewer: Sounds can include things like grunts, babbling, etc.

Probes:

- How often do they make these sounds?
- At what age did your child start using sounds to communicate?
- When do they use sounds?
- Can you describe what each sound means? The intended goal of each sound?
- Can you give me examples of the types of sounds they use?
- Do the meanings of the sounds stay the same?
- Do certain sounds have multiple meanings?

6) What types of words does your child use to communicate with you?

Note to interviewer: Please let the caregiver answer without a prompt. If they need a prompt: "Words don't need to be full words. Words can include syllables, word approximations, or any vocalization that has a consistent meaning."

Probes:

- How often do they use words?
- At what age did your child start using words?
- Have they ever used words?
- About how many words do they have? Please will you list all the words they have?
- When do they use words?
- Can you describe what each word means? The intended goal of each word?
- Do the meanings of the words stay the same?
- Do certain words have multiple meanings?
- Do they ever string sounds and words together? Tell me more about that.

[Goal for Questions #7-8: Learn about assistive devices, their context for use, and how helpful parents believe them to be. Expressive.]

Next, I would like to ask you some questions about the types of aided communication devices your child uses, such as a tablet.

Note to interviewer: Respondent may have already answered many of these questions so adjust questions and probes as needed.

7) What types of devices does your child use to help them communicate?

Note to interviewer: Devices could be "high tech" like iPads, ACC devices, or speech generating devices. Or "low tech" like pictures, binder, etc.

Probes:

- How long has your child been using the device(s)?
- At what age did they start using assistive devices?
- How often do they use the device?
- Is the device your child's primary mode of communication?
- In what setting does your child use the device?
- Does your child initiate the use of the device? How so?
- In what ways does the device help your child communicate?

8) How has your child's usage of the device changed over time?

Goal for Questions #9-13: Identify typical communication skills. Expressive.]

For the next set of questions, I am interested in specific ways your child communicates with you. As discussed earlier, children have a range of communication abilities and it is okay to tell me that your child cannot do something.

9) Please describe how your child refuses something they don't want.

Probes:

- How would they refuse a book or toy?
- How would they refuse an action, such as not wanting to stay seated?
- Does this behavior change depending on what they are rejecting?
- What circumstances affect how or when your child refuses/rejects?
- How do they communicate "no"? How do they communicate "yes"?

10) How does your child ask for attention?

Note to interviewer: Attention/interest/level of engagement can include physically approaching something, gestures, pulling, etc.

Probes:

- When does your child ask for attention?
- How does your child show interest in other people?
- How does your child show interest in an object?
- Is this action specific to gaining attention?

11) We are very interested in the specific ways your child expresses himself or herself. These next set of questions are about specific scenarios:

(a) How does your child let you know they need to go to the bathroom?

(b) How does your child let you know that they are hungry or thirsty?

(c) How does your child request an object, like a book or toy?

- How does your child request something they don't have any of, so they need to tell you exactly what it is they want? Such as a favorite toy?
- How does your child request something they have some of, but want more? Such as markers or food?

12) How does your child direct your attention, like if they want you to look at something?

Probes:

- How does your child show you something?
- How do they draw your attention to an action? To an object?

13) How does your child use challenging behaviors to communicate?

Note to interviewer: These behaviors can include things like biting or hitting. These behaviors could be exhibited when the child is refusing, requesting, or something else.

[Goal for Question #14-16: Identify social communication skills. Pragmatic.]

14) How does your child comment?

Note to interviewer: Comments can be non-verbal and include facial expressions (like raised eyebrows), eye contact, etc.

Probes:

- How does your child tell you about something you didn't see?
- Does your child let you know they are thinking about something?
- How does your child tell you about an event?
- How does your child show you that they like something? Don't like something?

15) How does your child greet people?

Probes:

- How do they greet you?
- How do they greet other family members?
- How do they greet strangers?

16) How does your child make choices?

Probes:

- How do they indicate preferences?

[Goal for Questions #17-19: Identify typical communication skills. Receptive.]

Now we will discuss how you communicate with your child.

17) How do you get your child's attention?

Probes:

- How do they respond to your voice?
- How do they respond to their name?
 - Does their facial expression change?
- How has their response to your voice changed as they've gotten older?
- How does their response change in certain situations?

18) How do they respond to someone they aren't familiar with trying to get their attention?

19) What other things affect your child's ability to respond to you?

Probes:

- How do they respond to directions or requests?
- How do they respond to the name of familiar objects? Do they look at the person or thing?
- How do they respond to simple routine commands? Like a bath, do they start to undress?
- Are there routine games that your child knows? Like peek-a-boo?
- Describe circumstances when their response is better or worse.
- Can your child identify objects when given choices? For example, blue versus green? A horse versus a cow?
- When is your child least successful in their communication? More successful?

Finally, we will discuss global communication questions.

[Goal for Question #20: To identify the stability/variability of communication in this population]

20) How has communication between you and your child changed over time?

Probes:

- As your child has gotten older, how have their communication abilities changed?
- When did their communications change?
- Were the changes fast or slow?
- When you do see changes, over what time period do changes typically occur?
- How have people helped you measure this change?
- Once a new communication skill is learned, does it stick around? Did you need to keep working on it?
- What happened to other skills during this time?
- As a parent, what has changed in how you support your child's communication?

[Goal for Question #21: Define what meaningful improvement in communication looks like.]

21) What would a meaningful change in communication look like for your child?

Probes:

- What improvements in communication skills would you like to see for your child?
- Why?

22) We know many different things can affect communication skills and abilities. How easy or hard is it for you to access the therapy your child needs?

Note to interviewer: This is an optional question, time-permitting.

Probes:

- What things affect this access?

23) Can you think of anything else that you would like to share with me that you think is important for us to know about your child's communication abilities?

Thank you so much for talking with me today. Your thoughtful responses will help us to develop a better questionnaire.

After we've finished all of the interviews, we will analyze everyone's responses and create a summary report. Would you like to receive the summary report via email?

☐ **Yes**

☐ **No**

[Stop recorder]

Interview Stop Time (24-hour clock): _____: