

In-depth Interviews with Communication Experts discussing children with Angelman Syndrome
Interview Guide Version: 12/5/18
Pro00101207

Date of interview: _____

Subject ID number: _____

Interviewer's name: _____

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

Thank you for taking the time to participate in this study. The overall goal for our research study is to design and to evaluate a questionnaire to assess communication ability in children and adults with Angelman Syndrome. The questionnaires will be completed by parents or caregivers and used in future clinical trials to evaluate treatment efficacy. We seek your expert input to help us understand the type and extent of communication ability in children, as young as 2 years, adolescents, and adults.

During this interview, I am going to ask you questions about how children with Angelman Syndrome communicate and understand communication. I also want your thoughts on what types of communication skills and abilities caregivers are able to observe. Also, we are interested in how these children's communication abilities and skills may change over time. We will finish with seeking your input on the questionnaire design itself. The interview will take about an hour.

There are no right or wrong answers. We are interested in your thoughts and experiences. Please remember that 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 before we start the interview?

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

- 1) Please define what “communication ability” means to you.
- 2) What are the different components that make up communication ability?
- 3) How does your definition change when considering communication ability in the context of individuals with Angelman Syndrome?

- 4) How do you assess communication ability in individuals with Angelman Syndrome?

Probe:

- Please tell me more about that approach.

- 5) What are the different levels of communication ability you see in individuals with Angelman Syndrome?

Probe:

- What are the range of communication modalities you see used by the individuals with AS that you work with?

- 6) What role does assistive technology play in improving communication with this population?

Note to interviewer: assistive technology can include low tech (e.g., pictures, cards) or high tech (e.g. tablets).

Now, let's talk about how parents or caregivers may assess their child's communication ability.

- 7) What are examples of communication that caregivers are good at noticing?

Probe:

- What is information you typically ask parents to give you?

- 8) What are examples of communication that caregivers are bad at noticing?

Probe:

- What are things caregivers may misinterpret? Such as problematic behaviors?

- 9) When caregivers share their observations of their child's communication abilities, what terms do they use to describe it to you?

Probes:

- Are they describing how frequently something is happening?
- How do they describe mastery of a communication ability?
- What terms are most helpful in understanding the child's abilities?

Now let's switch gears and talk about changes over time in communication abilities.

- 10) For individuals with Angelman Syndrome, how do communication abilities change as children get older?

Probes:

- What factors may affect change?
- During what ages or time periods does communication typically change?

So we've talked about changes over time, now let's talk about meaningful changes in communication abilities.

11) For children with AS, what does meaningful change in communication look like to you?

Probes:

- What factors are important when assessing meaningful changes in communication abilities in this population?
- What are some examples of meaningful change that you've seen in this population?
 - Do you have an example of meaningful change in expressive communication?
 - Receptive communication?
 - Pragmatic communication?
 - *[Other types brought up by expert]*?
- Are the meaningful changes you've seen consistent with the families' expectations?
 - Where is there agreement about meaningful change?
 - Where is there disagreement about meaningful change?
 - How have you had to manage caregiver expectations regarding improvements in communication abilities?
- Have you seen change that looked at first to be meaningful but ended up not being meaningful?
 - For example, a child with AS may say a new word they've never said before, but they never say that word again. What would that represent in terms of a change in the child's communication abilities?
 - What sporadic improvements in communication are seen in this population?

12) For a child enrolled in therapy, what types of improvements would you expect to see?

Probes:

- What does early skill acquisition look like in these children?
- What does skill mastery look like in these children?
- What happens to other skills when new skills are being acquired?
- Is there an amount of time when you would expect to see a change in communication abilities for children receiving therapy?
- How would this be different for a child not enrolled in therapy?

- 13) How are other communication abilities impacted when learning new communication skills?

Finally, I'm going to ask you some specific questions that will help us to design the new questionnaire.

- 14) Questionnaires use different reference periods to ask parents to recall their child's communications. For example, we might ask about the "past 4 weeks", "past 7 days" or the "past 24 hours". What time period would you would recommend we use?

Probe:

- Why?

- 15) You had talked about different types of communication ability [*interviewer should mention types discussed like expressive, receptive, pragmatic*]. How do the different types of communication ability overlap with each other?

Probes:

- How does change within one type of communication associate with changes in other types of communication?
- How helpful is having one score from the questionnaire to represent overall communication ability to assess change?
- How helpful is it to have a score for each type of communication ability to assess change?

- 16) Those are all of the questions I have. Is there anything else you would like to share with me about communication abilities or the development of our caregiver-reported questionnaire?

Thank you so much for taking with me today. Your answers will help us design a better questionnaire.

[Stop recorder]

Interview Stop Time (24 hour clock): _____: