Attachment – 2 ORCA Item Tracking Matrix from 2 Rounds of Cognitive Testing among Caregivers of Individuals with Angelmen Syndrome

Communication Domain (or #)	Round 1 Wording	Round 2 Wording	Post Round 2 Wording	Reason for Change
Gestures/Signs Definition	When we say gestures or signs, we mean an arm or body movement with specific meaning. Gestures or signs could be formal (like American Sign Language) or informal (a gesture that only your child uses or was modified by your family). Pointing would be considered a gesture.	When we say gestures or signs, we mean an arm or body movement with specific meaning. Gestures or signs could be formal (like American Sign Language) or informal (a gesture that only your child uses or was modified by your family). Eye gaze, pointing and head nodding would be considered gestures.	No further changes	In Round 1, many caregivers asked if eye gaze and head nodding counted as gestures. We added these two behaviors to clarify the meaning of gestures. The re-worded definition worked well in Round 2.
Word/Word Approximation Definition	When we say words or word approximations we mean noises with a specific meaning(s). These can be actual words like "mama" or word approximations like "ba" meaning "bubbles".	When we say words or word approximations we mean noises with a specific meaning(s). These can be standard **words** like "mama" that other people can understand, or **word approximations** that are part of a word like "ba" meaning "bubbles". Names for people would be considered words or word approximations.	No further changes	In Round 1, participants had a hard time discerning the difference between words and WA. We changed the words definition to clarify we meant understandable or universal words. We also bolded and underlined each term so they could be more easily distinguishable. Many caregivers also asked if names would count as words or WA, so this item was also added to the definition. The modification worked well in Round 2.
Augmentative and Alternative Communication Devices Definition	When we say AAC devices, we mean anything that you child uses to assist in their communication. The device could be high tech (like an application on an iPad or a Dynavox) or low tech (like picture boards).	When we say AAC devices, we mean anything that your child uses to assist in their communication. The device could be high tech (like an application on an iPad or a Dynavox) or low tech (like picture boards). When we say **symbols**, we mean words, pictures or numbers on your child's device.	When we say AAC devices, we mean anything that your child uses to assist in his/her communication. The device could be high tech (like an application on an iPad or a Dynavox) or low tech (like picture boards). When we say **symbols**, we mean words, pictures or numbers on your child's device that he/she	In Round 1, participants mentioned that we ask about symbols in subsequent questions, but do not define what we mean by "symbols" in the original AAC definition. This wording was added to the definition and worked well in Round 2. However, participants in both rounds were selecting this modality, even if the child was not using the device in a meaningful or intentional

			intentionally selects to communicate something to you.	way. Therefore, we added a note about intentionality to the definition after Round 2.
1A - # of gestures/signs	How many individual gestures/signs does your child use regularly? ☐ _____	In the past 30 days, how many unique gestures/signs did your child use? ☐ 1-3 gestures/signs ☐ 4-6 gestures/signs ☐ 7-9 gestures/signs ☐ 10-15 gestures/signs ☐ 16-20 gestures/signs	In the past 30 days, how many individual gestures/signs did your child use? ☐ 1-3 gestures/signs ☐ 4-6 gestures/signs ☐ 7-9 gestures/signs ☐ 10-15 gestures/signs ☐ 16-20 gestures/signs	In Round 1, participants expressed that they would prefer ranges because many did not know the exact number of gestures/signs their child uses (some filled in ranges on the questionnaire itself). Therefore, ranges were added as answer options. We changed "individual" to "unique" in hopes of assisting caregivers in recalling the number of gestures. However, "unique" did not perform well in Round 2, as participants interpreted this word as modified or made up gestures/signs that are unique to the child. The ranges performed well so in the final version we reverted to "individual gestures/signs" while keeping the ranges as the response option.
1B – stringing gestures/signs together	Does your child string gesture/signs together to communicate one message? ☐ No ☐ Yes If yes, how many gestures/signs will your child string together to communicate one message? ☐ _____	In the past 30 days, did your child string gestures/signs together to communicate one message (example: "I want banana")? ☐ No ☐ Yes If yes, on average, how many gestures/signs did your child string together to communicate one message (example: "I want banana" would count as 3 gestures/signs)? ☐ 2-3 gestures/signs ☐ 4-5 gestures/signs ☐ More than 5 gestures/signs	In the past 30 days, did your child put gestures/signs together to communicate one message (example: "I want banana")? ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time If yes, on average, how many gestures/signs did your child put together to communicate one message (example: "I want banana" would count as 3 gestures/signs)? ☐ 2-3 gestures/signs	We added an example after Round 1 to clarify the meaning of stringing. Participants were also confused about how to count the number of signs/gestures their child strings together, so we added a note after the example in the second question for participants to reference. The example and counting instructions worked well in Round 2. Participants in Round 1 were thinking about one instance where their child strung together gestures/signs, so "on average" was added to capture only the number

			☐ 4-5 gestures/signs ☐ More than 5 gestures/signs	their child consistently strings together. We also added ranges because participants were providing ranges in the open response option in Round 1. These modifications worked well in Round 2. "Stringing" could not be easily translated according to our translatability review; therefore, we changed stringing to "put together". This change worked well in the second half of Round 2 interviews. We also changed the response options to the first question after Round 2 to make it consistent with other stringing questions.
1D – pairing sound and gesture together		In the past 30 days, did your child pair a gesture/sign with a sound in order to communicate something to you? ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time	No further changes	Many participants in Round 1 mentioned their child often pairs multiple modalities together to communicate one message. The communication experts on our team stated that pairing a sound with a gesture could represent a more advanced level of communication, therefore we added this question in hopes that it would help detect improvements in communication over time. This question worked well after initial implementation.
# of word approx.	How many word approximations does your child have? ☐ _____	In the past 30 days, how many unique word approximations did your child use? ☐ 1-3 word approximations ☐ 4-6 word approximations ☐ 7-10 word approximations ☐ More than 10 word approx.	In the past 30 days, how many individual word approximations did your child use? ☐ 0 word approx. ☐ 1-3 word approx. ☐ 4-6 word approx. ☐ 7-10 word approx.	In Round 1, participants expressed that they would prefer ranges because many did not know the exact number of WA their child uses (in addition, some filled in ranges on the questionnaire itself). We changed "individual" to "unique" for Round 2 in hopes of assisting

			More than 10 word approx.	caregivers in recalling the number of WA their child uses. However, "unique" did not perform well in Round 2, as participants interpreted this word as modified or made up sounds that are unique to the child. The ranges performed well so in the final version we reverted to "individual WA" while keeping the ranges as the response option. A 0 response option was added half way through Round 2 because one participant noted it might be possible that a caregiver could select words/word approximations initially (in question #1), but their child may only use one or the other. This modification worked well for the remainder of Round 2.
# of words	How many words does your child have? ☐ _____	In the past 30 days, how many unique <u>words</u> did your child use? ☐ 1-3 words ☐ 4-6 words ☐ 7-10 words ☐ More than 10 words	In the past 30 days, how many individual words did your child use? ☐ 0 words ☐ 1-3 words ☐ 4-6 words ☐ 7-10 words ☐ More than 10 words	In Round 1, participants expressed that they would prefer ranges because many did not know the exact number of words their child uses (in addition, some participants filled in ranges on the questionnaire itself). We changed "individual" to "unique" for Round 2 in hopes of assisting caregivers in recalling the number of words their child uses. However, "unique" did not perform well in Round 2, as participants interpreted this word as modified or made up sounds that are unique to the child. The ranges performed well so in the final version we reverted to "individual words" while keeping the ranges as the response option.

				A 0 response option was added half way through Round 2 because one participant noted it might be possible that a caregiver could select words/word approximations initially (in question #1), but their child may only use one or the other. This modification worked well for the remainder of Round 2.
Stringing words or WA together	Does your child string words or word approximations together to communicate one message? ☐ No ☐ Yes If yes, how many words or word approximations will your child string together to communicate one message? ☐ _____	In the past 30 days, did your child string words or word approximations together to communicate one message (example: "I want banana")? ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time If yes, on average, how many words or word approximations did your child string together to communicate one message (example: "I want banana" would count as 3 words/word approximations)? ☐ 2-3 word or word approximations ☐ 4-5 word or word approximations ☐ More than 5 word or word approximations	In the past 30 days, did your child put words or word approximations together to communicate one message (example: "I want banana")? No changes to second question.	An example was added after Round 1 to clarify the meaning of stringing. Participants were also confused about how to count the number of words/WA their child strings together, so we added a note after the example in the second question for participants to reference. The example and counting instructions worked well in Round 2. Participants in Round 1 were thinking about one instance where their child strung together words/WA, so "on average" was added to capture only the number their child consistently strings together. We also added ranges because participants were providing ranges in the open response option. These modifications worked well in Round 2. "Stringing" could not be easily translated according to our translatability review; therefore, we changed stringing to "put together". This worked well for the remainder of Round 2.

# of AAC symbols	How many symbols does your child use regularly? ☐ _____	In the past 30 days, how many symbols did your child use? ☐ 1-10 symbols ☐ 11-20 symbols ☐ 21-30 symbols ☐ More than 30 symbols	In the past 30 days, how many symbols did your child intentionally use? ☐ 1-10 symbols ☐ 11-20 symbols ☐ 21-30 symbols ☐ More than 30 symbols	In Round 1, participants expressed that they would prefer ranges because many did not know the exact number of symbols their child uses (some participants filled in ranges on the questionnaire itself). Therefore, we added ranges and they worked well in Round 2. In Round 2, some participants were counting symbols that their child randomly/unintentionally uses. Therefore, we added "intentionally" to clarify we want the # of symbols their child uses in a meaningful, consistent way.
Stringing AAC symbols together	Does your child string symbols together to communicate one message? ☐ No ☐ Yes If yes, how many symbols will your child string together to communicate one message? ☐ _____	In the past 30 days, did your child string 2 or more symbols together to communicate one message (example: "I want banana" could count as 2 or 3 symbols depending on how your child's device is set up)? ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time If yes, on average, how many symbols did your child string together to communicate one message? ☐ 2-3 symbols ☐ 4-5 symbols ☐ More than 5 symbols	In the past 30 days, did your child put together 2 or more symbols to communicate one message (example: "I want banana" could count as 2 or 3 symbols depending on how your child's device is set up)? If yes, on average, how many symbols did your child put together to communicate one message? ☐ 2-3 symbols ☐ 4-5 symbols ☐ More than 5 symbols	We added an example after Round 1 to clarify the meaning of stringing. Participants were also confused about how to count the number of symbols their child strings together, so we added a note after the example for participants to reference. The example and counting instructions worked well in Round 2. Participants in Round 1 were thinking about one instance where their child strung together symbols, so "on average" was added to capture only the number their child consistently strings together. We added ranges because participants were providing ranges in the open response option. The modifications worked well in Round 2.

				"Stringing" could not be easily translated according to our translatability review; therefore, we changed stringing to "put together". This worked well in the second half of Round 2 interviews.
Requesting AAC device	If their device is not around, does your child let you know that they need their device to tell you something? (could be eye gaze, gesture/sign for device, word/word approximation, etc.) ☐ No ☐ Yes, but not consistently ☐ Yes consistently	In the past 30 days, when their device was not around, did your child let you know that they need their device to tell you something or request something? (Could be eye gaze, gesture/sign for device, word/word approximation, etc.) ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time	In the past 30 days, when his/her device was not around, did your child let you know that he/she needs his/her device to tell you something or request something? (Could be eye gaze, gesture/sign for device, word/word approximation, etc.) ☐ No or only once ☐ Sometimes ☐ Yes, almost all the time ☐ Not applicable	We added "request something" to add specificity to the question to assist caregivers to recall specific scenarios where their children may have requested their device. Prior to adding this phrase, participants were frequently thinking about their child going to get the device, rather than using another mode of communication to request the device. Not applicable was added after Round 2 because some caregivers stated that their children wear the device via a harness so they would never need to request the device.
Turn Taking		Next we want to know how you have a back and forth conversation with your child. We are interested in the number of turns he/she takes in conversations. The next example shows 2 turns taken: **Caregiver:** What do you want for breakfast? **Child:** [Points to cabinet for oatmeal] **Caregiver:** What do you want in your oatmeal?	Next we want to know how you have a conversation with your child. We are interested in the number of turns he/she takes in conversations. The next example shows 2 turns: **Caregiver:** What do you want for breakfast? **Child:** [Points to cabinet for oatmeal] **Caregiver:** What do you want in your oatmeal?	We added this question after Round 1 per the suggestion of our SLP colleagues. They stated it is an important aspect of pragmatic communication. Changes were made to this question after Round 2 because participants were confused by the phrase "back and forth", so it was removed. We added a 0 response option because some participants said their child cannot do this activity or have not done it in the past 30 days and we needed to account for this.

		Child: [uses device to say] Strawberries In the past 30 days, about how many conversational turns did your child take during one conversation? ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more	**Child:** [uses device to say] Strawberries In the past 30 days, about how many turns in conversations did your child have during one conversation? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more	Even with the modifications, participants had difficulty with what counted as a communicative act and a turn in conversation. As such, this question will be reevaluated after the cross-sectional study.
Seek Attention	Does your child <u>make a specific noise</u> to seek attention?	Did your child <u>make a specific sound</u> to seek attention?	No further changes	We changed noise to sound per the suggestion of the SLP on our team and to be consistent with our definitions.
Seek Attention	Does your child <u>use a specific gesture/sign</u> to seek attention?	Dropped	No further changes	This item was dropped because many participants ignored the word "specific" in the question. Our intention was for participants to think about dedicated signs to seek attention, however this question did not elicit those responses. Our SLP colleagues also confirmed it is unlikely that children would be using modified gestures or signs to seek attention, as it is not a common way for anyone to seek attention.
Seek Attention	Does your child <u>use a device</u> to seek attention?	Did your child <u>use a specific symbol on a device</u> to seek attention?	No further changes	"Specific" was added to this item after Round 1 because some participants mentioned that their child might press random buttons on their device to get attention. However, we are only interested in times when the child is intentionally selecting a specific symbol that is being consistently used by the child to seek attention (like "look at me!")

Direct Attention		Did your child <u>use a specific symbol on a device</u> to direct your attention?	Did your child <u>use a symbol on a device</u> to direct your attention?	The term "specific" was dropped from this item after Round 2. Children can direct attention to a multitude of things using a symbol on their device. "Specific" was unnecessary here since most caregivers set up the device for the specific needs of the child and their speech therapy goals.
Direct Attention	Does your child <u>use a gesture/sign **and** a word (or word approximation) together</u> to direct your attention?	Did your child <u>use a gesture/sign **and** a sound together</u> to direct your attention?	No further changes	Many participants in Round 1 said their child does not use words/WA but does use gestures and sounds together frequently. After consulting with our SLP colleagues, they also suggested changing words/WA to sounds, as a child who uses words/WA would probably use those alone to direct attention and sounds would be more appropriate here. This suggestion is also reflected in the data we collected.
Direct Attention	This question is asking if your child uses language to direct your attention. This could be in specific ways, like signing "ball" for you to look at the ball. Your child could use gestures/signs, specific vocalizations (i.e. words or word approximations), or symbols on their device.	These questions are asking if your child used language to direct your attention in the past 30 days. This could be in specific ways, like signing "ball" for you to look at the ball.	These questions are asking if your child used language to direct your attention in the past 30 days. This could be in specific ways, like using sign language to say "ball" for you to look at the ball.	After Round 1, we decided to take the modalities out of the instructions because participants said it was repetitive to see the modalities in the directions and the questions. In Round 2, participants were mistaking "signing" to mean pointing. For our purposes, pointing is not considered "labeling". Therefore, we changed it to "sign language" to be more specific.
Direct Attention	Does your child <u>use a gesture/sign, word or word approximation, or device</u> to let you know **specifically** what they want you to see?	Did your child <u>use a gesture/sign</u> to **label** specifically what they wanted you to see?	Did your child <u>use a sign</u> to **label** specifically what they wanted you to see?	After Round 1, we decided to split this question into 3 questions because participants stated it would represent a significant improvement

		Did your child <u>use a word/word approximation</u> to **label** specifically what they wanted you to see? Did your <u>child use a symbol on a device</u> to **label** specifically what they wanted you to see?		in communication ability if their child could do these behaviors with other modalities. Our SLP colleagues also said these separated questions could be a place to show growth in communication ability. This change worked well in Round 2. We also added the term "label" after Round 1 because participants were not understanding that we were looking for the ability to name or label something to direct attention to it; the term "specifically" was being overlooked. Label performed moderately well in Round 2. However, participants in Round 2 were again talking about pointing as "labeling something". We dropped gesture from the first question to clarify we are only looking for sign language. We will reevaluate these items after the cross sectional study.
Refusal	Does your child <u>turn their head away or push an object away</u> when they do not want it?	Did your child <u>turn their head away, push an object away, or throw an object</u> when they did not want it?	No further changes	Participants in Round 1 thought throwing should be added to this item instead of the kick item. Throwing was not considered a challenging behavior in this population because children often have motor control issues. This change worked well in Round 2.
Request	Does your child have <u>a distinct "yes" (shaking head, sign, or symbol on device)</u> that they use when they want something or are agreeing with you?	Dropped	No further changes	This item was dropped because our SLP colleagues clarified that there are many ways to confirm agreement and it does not necessarily represent an

				improvement in communication ability.
Request	Does your child <u>use a device</u> to ask for an object they want?	Did your child <u>use a symbol on a device</u> to ask for an object they wanted?		"Symbol" was added to be consistent with our definitions and other related items. This modification caused no problems in Round 2.
Request	Think about how your child lets you know that they <u>want something that is not in the same room or that they cannot see.</u> Does your child ask for a specific object they want (like a snack, a person, or a toy), <u>even if the object is not around?</u>	Think about how your child let you know that they <u>wanted a specific object</u> (like a book, toy or food) <u>that was not in the same room or that they could not see.</u> Did your child ask for a specific object they wanted, <u>even if the object was not in sight?</u>	Top instructions did not change. Did your child <u>go and get a specific object he/she wanted</u>, even if he/she could not see the object? Did your child <u>use a gesture/sign, word/word approximation, or symbol on a device</u> to ask for a specific object he/she wanted, even if he/she could not see the object?	In Round 1, participants were overlooking the word "specific" and were describing how their child requests things they cannot see, but the caregiver does not always know exactly what the child wants. Caregivers were also often just describing their child getting up and getting what they want, which is an adaptive behavior rather than true communication. We modified this question in Round 2 so that "specific object" would be in the instructions (and underlined). "Not around" was also being misinterpreted as "not in reach", so this was changed to "not in sight". Even with our changes in Round 2, these issues still persisted. After Round 2, we decided to create two questions in order to clarify meaning. We will evaluate these items after the cross sectional study.
"More"	Does your child have <u>a specific gesture/sign, word/word approximation, or symbol on their device</u> that they use to ask you for "more" of something?	Did your child <u>use a specific gesture/sign</u> to ask you for "more" of something? Did your child <u>use a word/word approximation, or symbol on a device</u> to ask you for "more" of something?	No further changes	After Round 1, this question was broken into 2 questions to make it consistent with the other item set structures (per our SLP colleagues' recommendations). Specific gesture/sign became its own item because our colleagues confirmed that this is a lower communicative

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				ability than using words or a device. Words and symbols on a device can be universally understood, making those modalities more advanced. This modification caused no problems in Round 2.
Choices	If you give your child options <u>with words only</u> (without showing them choices), does your child choose what they want?	If you gave your child options <u>with words only</u> (without showing them choices), did your child choose what they wanted using a specific gesture/sign, word/word approximation, or symbol on a device?	No further changes	After Round 1, modalities were added to this question because participants were counting when their child "gets up and goes to get the choice" (which we are not counting towards communication ability). This modification worked well in Round 2.
Sick/Hurt		Please tell us how your child <u>let you know he/she was not feeling well, were hurt, or were sick.</u>	Please tell us how your child <u>let you know he/she was not feeling well, were hurt, or were sick.</u> If your child was not hurt or sick in the past 30 days, please select N/A.	N/A response option was added after Round 2 because many participants said their child had not been sick or hurt in the past 30 days. Adding N/A allows us to differentiate between a child who has been ill and unable to do this activity and a child who has not been ill. We will evaluate this modification after the cross sectional study.
Sick/Hurt	Does your child <u>cry, fuss or lay down</u> to tell you that they are not feeling well?	Did your child <u>cry, or fuss</u> to tell you that they were not feeling well?	No further changes.	We dropped "lay down" after Round 1 because after discussing with our SLP colleagues, they said laying down is not necessarily true communication (just a means to an end or self-soothing behavior).
Sick/Hurt	If you ask your child "what hurts", does your child <u>tell you the name of the body part that hurts?</u>	Did your child use a gesture/sign, word/word approximation, or symbol on a device to <u>name the body part that hurt?</u>	Dropped.	In Round 1, participants were interpreting "tell" as using only verbal words to name the body part. Therefore, we changed "tell" to "name" and added modalities to clarify the meaning. "Name" did not

			work well in Round 2 because caregivers were often just counting pointing as "naming". Therefore, this item was dropped.
Asking Questions	Does your child <u>use gestures/signs, words/word approximations, or their device</u> to ask you questions?	Did your child <u>use gestures/signs, words/word approximations, or symbols on a device</u> to ask you **simple** questions (example: Where's mommy?)? Did your child <u>use gestures/signs, words/word approximations, or symbols on a device</u> to ask you **complex** questions (example: Why do I have to brush my teeth?)?	No further changes	Participants in Round 1 thought this question was really broad and asked what types of questions we were looking for. In Round 2, we split this question into "simple and complex" questions and added examples so caregivers could see the difference between the two. This change worked well in Round 2.
Past Events	Think about how your child <u>tells you about past events</u>. For example, telling on a sibling or telling you about something that happened at school. Your child might tell you a story through gestures/signs, vocalizations, words or word approximations, or a communication device.	Think about how your child <u>told you about past events</u>. For example, telling on a sibling or telling you about something that happened at school. Your child might tell you a story through gestures/signs, words or word approximations, or symbols on a device.	No further changes	After Round 1, we dropped "vocalizations" to be consistent with our beginning definitions. We also changed "communication device" to "symbols on a device" to be consistent with our beginning definitions and other related items.
Past Events	Does your child <u>tell a story</u> (either true or untrue) that has a logical flow with beginning, middle, and end?	Did your child <u>tell a two-step story about one event that led to another</u>? (example: I ate apple, I threw up) Did your child <u>tell a story</u> (either true or untrue) that had a logical flow with beginning, middle, and end?	Did your child tell a <u>two-part story about one event that led to another</u>? (example: I ate apple, I threw up) Did your child <u>tell a story</u> (either true or untrue) that flowed logically with beginning, middle, and end?	Participants in Round 1 thought this question was really broad and our SLP colleagues upon review also thought this question could be a place to show growth. Therefore, we split this question into two questions for Round 2. This change worked well in Round 2, but some minor word changes were made after Round 2 to clarify meaning.
Greeting	Does your child use gestures/signs to say "hello" or "goodbye" to	Did your child <u>use gestures/signs to say "hello"</u> to people without you telling them to?	No further changes	Some participants in Round 1 said their child could only say hello to people without them telling their

	people without you telling them to? Does your child use words/word approximations, or their device to say "hello" or "goodbye"?	Did your child <u>use words/word approximations or symbols on a device to say "hello"</u> to people without you telling them to? Did your child <u>use gestures/signs to say "goodbye"</u> to people without you telling them to? Did your child <u>use words/word approximations or symbols on a device to say "goodbye"</u> to people without you telling them to?		child to, but their child could not say goodbye. Therefore, we split hello and goodbye greetings into separate questions. We also separated by modality to show growth. This modification worked well in Round 2.
Names for People		Did your child use a specific name, gesture/sign, or symbol on a device <u>for you or another primary caregiver?</u> Did your child use specific names, gestures/signs, or symbols on a device <u>for any other person (other than you or another caregiver)?</u>	Did your child use a specific name, gesture/sign, word/word approximation or symbol on a device <u>for you or another primary caregiver</u>? Did your child use specific names, gestures/signs, words/word approximations or symbols on a device <u>for any other person (other than you or another caregiver)</u>?	A couple participants in the beginning of Round 2 asked if we intended to exclude word or WA from these items and did not understand that "use a specific name" meant word. This modification was made half way through Round 2 interviews and worked well.
Self-Reference	Does your child gesture/sign, vocalize or use their device to say <u>"I", "me", or their name</u>?	Did your child use gesture/sign, word/word approximation or a symbol on a device to say <u>"I", "me", or their name in a sentence</u>?	No further changes	Some participants in Round 1 thought this question was asking if their child could identify their name or say their name, but we are interested in if a child can refer to themselves in a sentence (i.e. can the child refer to themselves in the first person). Therefore, "in a sentence" was added to make it clearer that we are interested in correct grammatical usage here.

			This modification worked well in Round 2.
Social Games or Activities	Think about any games you and your child might play together. For example, peek-a-boo, chase, or catch. Example: Does your child <u>play</u> games with you or others?	Think about <u>one</u> game or activity your child might have played with you or other people. Games could include peek-a-boo, chase, or catch. Activities could include swimming, playing with Play-Doh, or blocks. Example of change to all items in this domain: Did your child <u>play at least one game or activity</u> with you or others?	No further changes	Multiple participants in Round 1 struggled with this question because they were thinking about multiple games their child plays, and that they may do some of these things for one game only, but not all. Therefore, we added "think about one game or activity" to the directions. Parents of teenagers and young adults had trouble thinking of games they played with their child; therefore, we clarified in the directions that activities would also count. These modifications worked well in Round 2.
Response to Name	Does your child look at you or pause what they are doing <u>when you say their name</u>?	Excluding times when they ignored you, did your child look at you or pause what they were doing <u>when you said their name</u>?	No further changes	Multiple participants in Round 1 mentioned that their child does this "sometimes", but often the child just ignores them (but still understands their name is being called). Therefore, we added a sentence to the beginning of the question to ask parents to disregard times when their child ignores them. This modification worked well in Round 2.
Response to Directions	Please tell us how your child <u>responds to your directions</u>. This first set of questions asks about directions that are part of their <u>daily routine</u>.	Please tell us how your child <u>responded to your directions</u>. This first set of questions asks about directions that are part of their <u>daily routine</u>. Please exclude times when your child may have ignored you.	No further changes	Multiple participants in Round 1 saidd that their child "sometimes" responds to directions, but often times, the child just ignores them (but still understands the direction). Therefore, we added a sentence to the instructions to ask parents to disregard times when their child

				ignores them. This modification worked well in Round 2.
Response to Directions (Daily Routine)	Does your child respond when you tell them "no"? Does your child respond to certain words (stop, bath) when you say them?	Did your child respond when you told them "no" or "stop"?	No further changes	In Round 1, participants were thinking about stop and bath, not stop **or** bath like we intended. Many participants also wondered how many one word commands their child has to follow to count as consistently vs. not consistently. This item was subsequently dropped and "stop" was added to the no item because the two commands are similar.
Response to Directions (Daily Routine)	Does your child follow one-step directions that are part of their daily routine? (example: "Get your cup.")	Did your child follow one-step directions that are part of their daily routine? (example: "Get your cup" **or** "Let's take a bath")	No further changes	As mentioned above, the stop, bath item was dropped and we decided to add these two examples to other items. "Let's take a bath" was added here because caregivers said this is a very common one step direction they give their child.
Response to Directions (New)	Now think about how your child responds to directions that are new or not part of their daily routine. Example: Does your child follow one-step directions that are new or **not** part of their daily routine?	Now, think about how your child responded to new directions. Please exclude times when your child may have ignored you. Example of change to all items in this domain: Did your child follow one-step directions that were **new**?	No further changes.	Some participants in Round 1 said their child follows directions that are not part of their daily routine, but do not follow new directions. Therefore, we changed this item to reflect just new directions. This modification worked well in Round 2. We also had the same ignoring issue here and added a clause to the instructions asking caregivers to disregard times when their child ignores them. This modification worked well in Round 2.

Isolated Words or Phrases	Does your child show you that they <u>understand a more complex message</u> that they overheard? (example: grandma is visiting next week)	Did your child show you that they <u>understood a more complex message</u> that they overheard? (example: Grandma is bringing cookies)	Dropped.	Participants in Round 1 struggled with the example we provided because they said their child does not understand the concept of time. They may tell their child grandma is visiting, but they were not sure if their child understands "next week". Therefore, we changed the example to eliminate the time issue. However, in Round 2, some participants were unsure if their child understands both concepts (grandma <u>and</u> cookies), while other participants were overinflating their child's abilities here. Interviewers know overinflating was occurring because when caregivers were prompted to provide examples of when they have seen this behavior, they could not provide any. Therefore, this item was dropped.
Understanding	<u>Are people familiar to your child</u> (parents, teachers, caregivers, siblings) able to understand your child's communication? <u>Are people **less familiar** to your child</u> able to understand your child's communication?	<u>In general, were people familiar to your child</u> (parents, teachers, caregivers, siblings) able to understand your child's communication? <u>In general, were people **less familiar** to your child</u> able to understand your child's communication?	No further changes.	After Round 1, we added "in general" to the beginning of these questions because participants expressed that different people who are familiar to the child understand their child to varying degrees. Therefore, we added "in general" so participants could think about this on average. We also added it to the question below to make it consistent.
Bathroom	Does your child let you know they <u>have gone</u> to the bathroom or that their diaper is dirty? Does your child let you know that they <u>have to go</u> to the bathroom?	Dropped		Questions about bathroom communication were dropped after Round 1 because many participants said they did not know if their child was truly communicating, or if they were just alerting them that they

				were uncomfortable. Also, many different families prioritized different toileting behavior and it was not feasible to account for every scenario in a way that differentiated improvement in communication ability.

Non-domain changes

	Round 1 Wording	Round 2 Wording	Post Round 2 Wording	Reason for change
Instructions	The goal of this survey is to get a clear understanding about how your child *typically* communicates. When you are answering the questions, please think about communication skills and behaviors that you have *personally observed.*	The goal of this survey is to get a clear understanding about how your child *typically* communicates. When you are answering the questions, please think about communication skills and behaviors that you have *personally observed*. Please use a ✓ or an X to mark your answers.	The goal of this survey is to clearly understand how your child *typically* communicates. When you are answering the questions, please think about his/her *intentional* communication skills and behaviors that you have *personally observed and your child initiates.* Please use a ✓ or an X to mark your answers. If something is not applicable to your child, please select "No or only once".	Multiple participants in Round 1 asked "how" they should complete the survey (i.e. filling in bubbles, using a check mark, etc.), so we added this to the instructions to make it consistent. In Round 2, all participants used a ✓ or an X to mark their answers. If something is not applicable to your child, please select "No or only once" was also added to these instructions and the directions before item set #3.
Recall period	The next set of questions are about <u>how</u> your child currently communicates in specific situations.	The next set of questions are about <u>how</u> your child communicated in specific situations over the past 30 days	No further changes	We added a specific recall period because we thought it would help parents focus on consistent communication behaviors they observe (and eliminate communication behaviors caregivers have not seen in a long time that are not consistent or frequent).
Response options	No Yes, but not consistently Yes, consistently	No or only once Sometimes Yes, almost all the time	No further changes	Participants in Round 1 struggled to reliably define the word "consistently". Some were interpreting it as frequency. Some were interpreting this as the primary modality their child uses. Therefore, more common response options were implemented and worked well in Round 2.

Skip Logic Instructions	Example: If you selected <u>GESTURES/SIGNS,</u> please answer questions 1A and 1B. If not, please skip to 1C.	Example of change to all skip instructions: If you selected <u>GESTURES/SIGNS,</u> please answer questions 1A and 1B. If not, please go to 1C.	No further changes	Our translatability review showed that "skip" was not easily translatable; therefore, we changed this to "go to" based off the company's recommendation.
Third Person Singular	Example: Did your child <u>cry or fuss</u> when they did not want an object?	Example of change to all items: Did your child <u>cry or fuss</u> when he/she did not want an object?	No further changes	Throughout the survey, we originally referred to the child as them, they or theirs. Our translatability review showed that the third person singular should be used in all verbs in the items when referring to the child. Therefore, all items referring to the child were changed to he/she/him/her. An example of the change is provided.