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A familiarization protocol facilitates participation of children with ASD in electrophysiological research

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Abstract:	This paper includes a detailed description of a familiarization protocol, which is used as an integral component of a larger research protocol, including collection of electroencephalography (EEG) and event related potentials (ERPs). At present, the systems available for collection of high-quality EEG/ERP data make significant demands on children with developmental disabilities, for example, those with an autism spectrum disorder (ASD). Children with ASD may have difficulty adapting to novel situations, tolerating uncomfortable sensory stimuli and sitting quietly. Our familiarization protocol uses evidence-based practices (EBPs) to increase research participants' knowledge and understanding of the specific activities and steps of the research protocol. The tools in this familiarization protocol are a social narrative, a visual schedule, the Premack principle, role-playing, and modeling. The goal of this familiarization protocol is to increase understanding, agency and potentially reduce anxiety for child participants, resulting in greater likelihood of successful completion of the research protocol, including the collection of EEG/ERP data.
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Question	**Response**
If this article needs to be "in-press" by a certain date, please indicate the date below and explain in your cover letter.	

January 4, 2017

To Whom It May Concern:

Please find attached the manuscript titled “A familiarization protocol facilitates participation of children with ASD in electrophysiological research”. This manuscript presents steps used to increase the likelihood of successful participation in research, for children with autism spectrum disorders.

In this manuscript, we provide the steps to creating a set of evidenced based practice tools, to familiarize and increase understanding of a research protocol that includes electroencephalography. Followed by a demonstration of how to implement these tools, to increase participant understanding and decrease participant anxiety. We report that these are efficacious tools in allowing researchers to gather data from a population that is highly researched with electroencephalography. We look forward to hearing from you and working with you on this manuscript.

Very best,

Jacqueline Turcios (for Cook, Rispoli, Irwin, and Landi)

TITLE:
A familiarization protocol facilitates the participation of children with ASD in electrophysiological research

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KEYWORDS:
Autism; developmental disorders; research; EEG data collection; visual schedule; social narrative.

SHORT ABSTRACT:
Electrophysiological research is an important tool for identifying biomarkers of developmental disorders, including autism spectrum disorders (ASD), but data collection in these populations remains challenging. This work presents a familiarization protocol to accompany research that includes electroencephalography (EEG) to improve the likelihood of collecting EEG data from children with ASD.

LONG ABSTRACT:
This paper includes a detailed description of a familiarization protocol, which is used as an integral component of a larger research protocol to collect electroencephalography (EEG) data and event-related potentials (ERPs). At present, the systems available for the collection of high-quality EEG/ERP data make significant demands on children with developmental disabilities, such as those with an autism spectrum disorder (ASD). Children with ASD may have difficulty adapting to novel situations, tolerating uncomfortable sensory stimuli, and sitting quietly. This familiarization protocol uses evidence-based practices (EBPs) to increase research participants' knowledge and understanding of the specific activities and steps of the research protocol. The tools in this familiarization protocol are a social narrative, a visual schedule, the Premack principle, role-playing, and modeling. The goal of this familiarization protocol is to increase understanding and agency and to potentially reduce anxiety for child participants, resulting in a greater likelihood of the successful completion of the research protocol for the collection of EEG/ERP data.

INTRODUCTION:
Autism spectrum disorders (ASDs) are neurodevelopmental disorders characterized by a constellation of social communicative difficulties and restricted, repetitive patterns of behavior[1,2]. As the number of identified individuals who meet the criteria for ASD increases, so does the desire to better understand the neurological underpinnings associated with ASD. Experts have suggested that future research should include the development of processes for the early detection of atypical brain function, which may then lead to interventions to support the brain systems hypothesized to impact social behavior[14]. In particular, this research uses temporally sensitive neuroimaging approaches—namely, electroencephalography (EEG) and event-related potentials (ERPs)—to assess audio-visual (AV) speech perception in children with typical development and those at-risk for ASD and other developmental disabilities. The use of electrophysiology techniques, both EEG and ERP, will provide a better understanding of the neural bases for both typical and atypical AV speech perception across development. This research approach includes the analysis of both continuous EEG data and ERPs. Because ERPs are time-locked, multi-trial-averaged portions of the EEG, this paper will discuss procedures for the collection of EEG data.

To ensure that this work is as representative of the population as possible, individuals with ASD who present with varying degrees of social, cognitive, and language ability are included as participants. At present, the systems available for the collection of high-quality EEG data make significant demands on children with developmental disabilities. Examples of behaviors that individuals with ASD may have difficulty with include adapting to novel situations, tolerating uncomfortable sensory stimuli (*i.e.,* wearing an EEG cap), and sitting quietly. These difficulties may be linked to the individual's sensory processing challenges, his/her disconnect in social perspective-taking, potential cognitive difficulties, and insistence on sameness. Collectively, these characteristics may impact a child's ability to comply with the required tasks that comprise the research activity[1]. Therefore, it is important to develop research protocols that support the children's strengths and accommodate their limitations to facilitate the participation of children with ASD. The goal is to assist children with ASD in completing research activities, without duress and in a manner that leads to useable neurobiological data.

The current work is part of a larger study on eye gaze and neural response to audiovisual speech in children with language and social disabilities, including children with ASD[11,12]. The primary experimental protocol involves multiple behavioral assessment sessions, as well as one simulated and one real EEG data collection session. Details of the EEG and ERP processing and analysis will not be discussed here; see Harwood *et al.*[9] for the ERP data processing protocols.

The focus of this paper is a familiarization protocol designed to address the challenges of getting children (particularly those with developmental disabilities such as ASD) to engage in neurobiological research. As in many research studies of this type, participants must complete a variety of standardized assessment tasks in addition to participating in EEG data collection. Due to the challenges that individuals with ASD face when coping with novel environments, tolerating uncomfortable sensory stimuli, and sitting still for extended periods of time, strategies must be developed to increase participant understanding of the research activities. Increased understanding and agency will increase the participant's ability to successfully complete all research activities. Importantly, this protocol provides multiple opportunities for each participant to make an active decision regarding his/her participation, with a clear ability to opt out and, by monitoring the emotional state throughout the experiment, continuing consent in ensured[4].

The National Professional Development Center on Autism and the National Autism Center are two organizations that have developed clear criteria for the establishment of evidence-based practices for individuals with ASD[16,22]. The protocol for the current research project used these criteria to identify, select, develop, and implement specific interventions that are applicable to addressing the challenges individuals may face in successfully participating in the research activities. The specific interventions from these sources include social narratives, visual supports in the form of a visual schedule, role-playing, and modeling[22]. In addition, the protocol includes an application of the Premack principle[18]. The Premack principle involves following a low-preference activity with a high-preference activity[13,18], providing a short, clear connection between the expected behaviors of the individual to the reward. For example, if a child answers questions for 10 min, he/she is then able to play with a preferred toy for 10 min.

Prior research suggests that social narratives are an effective intervention for children with ASD who exhibit disruptive behaviors[19]. Social narratives provide background and information about the context of a situation as a means of providing increased understanding related to social expectations. Most social narratives include expected activities, possible perspectives of others involved, and ways to interact with other people during structured activities (see Figure 1 for an example of the social narrative used here). Social narratives have been shown to reduce anxiety and support an individual with expectations in the new situation[15].

A visual schedule can be effective in helping children with ASD to cope in novel social situations[20]. Visual supports in the frame of a schedule provide individuals with ASD a static reference to aid in predicting upcoming activities (see Figure 2 for an example of the visual schedule used here). In addition, the removal of activities as they occur supports an understanding of the passage of time and provides a concrete visual representation of the session. Without this visual representation, individuals with ASD may become anxious if they are unable to conceptualize how much time has passed and how much time is left in an activity or session. A visual support that allows the participant to express his or her emotions may also be useful in allowing the participant to more easily cope with different emotion (see Figure 3 for an example of an emotion-rating scale).

Role-playing and modeling provide an opportunity to view and practice new situations for individuals with ASD. The process of rehearsal provides clarity about the expected behaviors and further reduces anxiety for these novel scenarios[8,22]. Role-playing, including modeling, provides the individual with a clear opportunity to practice and make a decision regarding his/her choice of participating or opting out of a particular activity (see Figures 5 and 6 for examples of role play and modeling with a toy bear and the child wearing the cap).

Some individuals with ASD and/or other developmental disabilities may not have developed the maturity or cognitive capability to clearly understand research tasks. Indeed, there is an ethical dilemma surrounding the participation of vulnerable groups due to their difficulties with comprehension in complex social situations and the impact this has on informed consent[17]. However, processes have been developed to better ensure informed consent without undue pressure[4,17]. For example, visual symbols and bullet points with simple explanations are provided here, and participants are asked if they agree to participate in the study as an ongoing process[3]. To facilitate the understanding of individuals with developmental disabilities, a protocol must be developed that both aligns with study goals yet adheres to ethical guidelines, including the subject choosing to participate without persuasion or undo pressure[6].

PROTOCOL:
All procedures have been approved by the appropriate research ethics committee at Yale University, with consent from participants.

1. Create a social narrative

[Place Figure 1 here]

Note: Sections 1, 2, and 3 present the tools that were developed for the familiarization protocol.

1.1. Create a social narrative that includes images and a short description of each step of the research protocol created by the researchers, starting with consent and ending with compensation (if applicable) and a short explanation.

Note: When possible, the image used should have high iconicity (iconicity refers to the degree to which a symbol represents its referent)[3] to facilitate the understanding of the participant. Follow the steps for developing the social narrative (adapted from Myles, Trautman, and Schelvan)[15].

1.1.1. In the social narrative, describe in sequential order the research activities from the participant's perspective. Write the story in first-person or second-person language and use either present or future tense.

1.1.1.1. In the description, include: a) where the activity will occur; b) what the participant will do; c) what the researchers will do; d) why the participant will complete each activity; and e) the possible thoughts or feelings of the researchers or the parents, if applicable (*i.e.,* "we're happy that you came;" "calm when you wait for directions;" or "Mom is happy that you can help.")

1.1.2. Select pictures that are iconic to use within the social narrative to increase the understanding of the participant (*i.e.,* the building, the room, the EEG cap, and the researchers).

1.1.3. Place the social narrative into a presentation software (*e.g.,* PowerPoint), including the iconic pictures. Use the presentation mode to show the narrative to the child as a story on a computer, or present it as a printed version.

1.2. Send the social narrative to the parent/caregiver by mail or email before the participant comes to the research appointment.

1.2.1. Ask the parent or guardian to read the social narrative to the participant at least 3 times before the first visit of the research study.

2. Create a visual schedule

[Place Figure 2 here]

2.1. Create a visual schedule that outlines each activity of the research protocol. Ensure that the visual schedule includes different cards, with pictures that represent each activity and a one- to three-word description printed under each picture (adapted from Hodgdon)[10].

2.1.1. Within the visual schedule, include a card with a picture that represents a break, along with the written description, “Take a break.”

2.1.2. Within the visual schedule, include a card with a picture that refers to being finished or all done; this card may include the word “stop” or “finish” printed in red font.

Note: The activities outlined in the visual schedule should be the same as those described in the social narrative. The written language and pictorial representations provided through these two tools should be consistent.

3. Create emotion-rating scales

[Place Figure 3 here]
[Place Figure 4 here]

3.1. Create a scale that depicts a range of 5 emotions, with pictorial representations and/or written words. Select emotions that are relevant to supporting the participant with engaging in the activities in the given research protocol (*i.e.*, emotions related to anxiety, pleasure, disgust, *etc.*).

Note: The emotion vocabulary and selected icons should match the developmental levels of the participant (adapted from Dunn-Buron and Curtis)[7].

3.1.1. Include an action that the participant may complete to maintain positive emotion in one column and label it “What I can do” (see Figure 3).

3.1.2. Include a smiley or picture of a face in a separate column and label it “How I feel.”

Note: All five emotions listed under the “How I feel” column should correspond with the “What I can do” column (*i.e.,* on the “How I feel” column, “I am confused and getting irritated” would correspond with “Ask to take a break” under “What I can do.”)

3.2. Create a Likert-type scale for rating emotions to be used by the researcher (see Figure 4) (adapted from the Positive and Negative Affect Schedule (PANAS))[21].

Note: Below are the steps to follow when implementing the familiarization tools over two visits to complete the research protocol.

4. Visit 1: Social, cognitive, and language assessments

4.1. Greet the participants and bring them to an area with various toys (see Figure 5) in a designated “play area.” Ensure that the participant is comfortable within the setting.

[Place Figure 5 here]

4.2. Show the participant the 5-point emotion-rating scale (see Figure 3) and ask them to point to the picture that best represents how they feel.

4.3. Ask the participant how they feel and support the participant in saying "I feel _____," while pointing to the corresponding emotion on the scale (see Figure 3).

4.3.1. If the participant selects a 1 or 2, move to step 4.4. If the participant selects a 3 or 4, ask the participant to follow the suggested action under the "What I can do" section (see Figure 3).

4.3.2. Give the participant 5 min to follow the suggested action.

4.3.3. After 5 min, ask the participant rate how they feel, again. If they select 1-3, continue the session. If they select 4 or 5, end the research appointment and ask the participant to decide to come back on a different day or not to come back at all.

Note: See step 3 for creating the emotion-rating scale. The researcher is to rate the participant's emotions on a separate scale at the same time (Figure 4) to ensure that the participant is appropriately rating their emotion state.

4.4. Sit next to the participant and read and review the social narrative with them (see Figure 1). Say "we will look over all the games that we will be playing today; ask me questions if there is a game that you are not sure of."

4.5. Following the review of the social narrative, assess the participant's emotional state and readiness to continue with the research by asking, "How do you feel?" while showing them the self-rating emotion scale (Figure 3).

4.5.1. At the same time, ask the research assistant to use a separate scale to rate the participant (see Figure 4) to ensure that some of the anxiety (if any) has been reduced.

4.6. Hand a consent form to the parent and read the assent form with the child participant (if they cannot read it independently).

4.7. Ask the participant if they would like to continue and complete the activities described in the social narrative.

4.8. Ask the participant to sign the consent form.

Note: The participant should only be asked to sign if they agree to participate. If the participant says no, offer to read the social narrative again to ensure that the participant understands the requests being made.

4.9. Introduce the participant to the visual schedule, stating, “These (pointing to visual schedule pictures) are all of the games that we will be playing today. At the end of each game, you can take down the card for that game.”

4.9.1. Point to the “Take a Break” card and say, “You can also use this card if you need to take a break;” point to the “STOP” card and say “or this card if you do not want to play any more games for today.”

4.10. Arrange the schedule so that all social, cognitive, and language assessments are completed prior to the final activity.

4.10.1. Periodically, at the discretion of the researcher and based upon the attending behavior of the participant, implement a modified use of the Premack principle by stating, “Remember, first (activity name), then you may take a break.”

Note: This modified version of the Premack principle involved giving the child the preferred activity after the third attempt, even if the child did not complete the less preferred activity. Therefore, the participant is compensated for their time even when they do not complete the experiment.

4.11. Once the participant has completed half of the assessments, evaluate the participant’s emotions using both emotion-rating scales (as described in step 4.5); ensure that the participant maintains a level 1 or 2 emotion rating prior to continuing activities.

4.11.1. If the participant is at a higher level on the self-rating emotion scale, follow the action on the scale under the “What I can do” section.

4.12. EEG data acquisition simulation.

[Place Figure 6 here]

4.12.1. Introduce the participant to a stuffed bear (or doll, or any other toy of choice), and model the use of the EEG cap (see Figure 6) on it. Read to the participant, the section in the social narrative that describes use of the net to the participant.

4.12.2. Show the participant how the cap is placed on the bear’s head. Allow the participant to touch the cap and interact with it by placing it on the bear’s head (if needed).

4.12.3. Apply a modified version of the Premack principle by saying, “First, try the net cap. Then, you will be given a gift card.” If the participant says no, suggest the “First, then” statement one more time. If the participant says yes, continue to step 4.12.4.

4.12.3.1. If the participant continues to say no, compensate the participant for their time (if applicable). If the participant agrees to wear the cap, continue to step 4.12.4.

4.12.4. With a tape measure, measure the participant's head circumference to determine the cap size. After this initial measurement, measure from a location on the back of the skull (inion) to a location between the eyebrows above the nose (nasion), and from the right to left ear (using the tragus).

Note: This is done to identify the scalp vertex reference point for the placement of the Cz electrode. These steps are designed to be as similar to the actual acquisition protocol, which uses this procedure to maximize similarity of electrode placement across the scalp across participants.

4.12.4.1. Mark the vertex reference point with a washable magic marker.

4.12.4.2. Soak the appropriate-size net in water with a potassium chloride solution and baby shampoo.

4.12.5. Place a towel around the participant's neck to prevent water from dripping on their clothing. Tell the participant to close their eyes while the net is being placed on their head.

4.12.6. Adjust the cap on the participants' head so that it is comfortable for the participant (see Figure 7). Once the net is placed on the head and adjusted, let the participant known that they can open their eyes.

[Place Figure 7 here]

4.12.7. Have the participant practice wearing the cap and sit in front of a screen to watch a movie for at least 10 min (see Figure 8). If this step is completed successfully, invite the participant to come back for a second appointment.

[Place Figure 8 here]

Note: Participants had to wear the net for approximately one hour during the actual research appointment. However, breaks were built into the experiment every 3 minutes.

4.13. Following the final activity, assess the participant's emotions one last time (Figures 3 and 4) to ensure that level-1 or -2 emotion has been maintained throughout the protocol and that wearing the cap did not increase anxiety and/or decrease the participant's level of comfort.

Note: If any anxiety is present, the researcher should assist the child in following the suggested actions in the self-rating emotion scale (Figure 3).

5. Visit 2: EEG data collection

Note: As an integral part of the familiarization protocol, throughout the span of the experiment, a research assistant should code the participant's state (*i.e.,* whether they alert or appears anxious; see Figure 4), and participants should provide a self-rating of their emotional state by pointing to a visual representation on an emotion scale (Figure 3).

5.1. Present the participant with a social narrative that describes the steps of the second appointment. Ask the participant if they are willing to wear the cap and mention, "like you did last time;" (see step 1.1.1 for creating the social narrative).

Note: If the participant says yes, proceed to step 5.2. If the participant says no, repeat step 5.1 with the parent in the room. If the participant continues to say no, end the experiment.

5.2. Present the participant with a visual schedule that includes all the EEG data collection procedures (*i.e.,* measuring the head, wearing a towel, and placing the net on the head).

Note: See step 2.1 for creating a visual schedule; a picture depicting a break is included. Periodically offer the participant the opportunity to take a break to maintain comfort and compliance.

5.2.1. Measure the participant's head circumference and then identify and mark the vertex reference point for the Cz electrode, following the steps outlined in step 4.12, above.

5.2.1.1. Mark the vertex reference point with a washable magic marker.

5.2.1.2. Soak the net in water with a potassium chloride solution and baby shampoo.

5.2.2. Place a towel around the participant's neck to avoid water from dripping on their clothing. Tell the participant to close their eyes while the net is being placed on their head.

5.2.3. Position the appropriate-size cap on the participant and ask them to sit in a comfortable position.

5.2.4. Once the ERP waves can be seen on a computer screen, ask the participant to blink and move their hands and feet. Then, have the child look at the distortion that is created in the ERP waves when they move.

5.3. Start the stimulus presentation and ask that the participant sit very still, "like a statue;" point to a visual sign that shows a child sitting still, along with the text, "sit still, like a statue." Use the Premack principle as needed.

Note: See step 4.9 for the use of the Premack principle.

5.4. After completing the EEG portion of the experiment, provide the participant with the promised compensation and thank them for their participation.

REPRESENTATIVE RESULTS:

As part of a series of studies on eye gaze and audiovisual speech perception, an initial cohort of 25 participants with ASD and average IQs (n = 25, 19 boys, 6 girls, mean age = 10.25 years) was recruited using a similar EEG protocol. 72% of the children in this previous cohort completed the EEG protocol. In the current cohort, 15 participants with ASD were run, 12 of whom (n = 15, 11 boys, 4 girls, mean age = 9.4 years) completed the familiarization protocol and completed the full EEG acquisition protocol. Three of the 15 participants (all boys, mean age: 8.11 years) did not complete the familiarization protocol and were not able to complete the EEG acquisition protocol.

[Place Figure 9 here]

FIGURE AND TABLE LEGENDS:

Figure 1. Social narrative. A sample social narrative, read to the participant prior to the first appointment and by the researcher prior to initiating the experiment and obtaining consent.

Figure 2. Visual schedule. A sample visual schedule, presented to the participant after obtaining consent and before initiating the first step of the experiment, as well as before and after the completion of each activity.

Figure 3. Self-rating emotion scale. A sample self-rating emotion scale, which is used by the participant to rate his/her state of emotion. The researcher uses a separate scale to rate the participant's emotion.

Figure 4. Researcher rating scale. A scale used to make sure that the participant's rating is consistent with outward observed behavior. This scale is to be completed by a researcher that is in the room with the child participant.

Figure 5. Welcoming the participant to the visit. Researcher playing with participants, familiarizing them to the environment and getting them accustomed to the context.

Figure 6. Bear used as sample for wearing the net. Demonstration of the bear wearing the net, allowing the participant to explore wearing the net and holding the bear while it wears the net, done before the participant is asked to wear the net.

Figure 7. Placing the EEG net on the participant. The researcher capping the participant to practice wearing the net; this is the role-play portion of the protocol, when the participant wears the towel.

Figure 8. Adjustment of the EEG net. The participant is wearing the net while the researcher adjusts it to make sure that the participant is comfortable.

Figure 9. Completion of EEG. Representation of the number of participants that completed the experiment, with and without the use of the familiarization protocol.

DISCUSSION:

The familiarization protocol outlined above applies evidence-based practices (EBPs) to increase the likelihood that child participants with ASD will be able to complete multiple testing sessions and EEG data collection. Prior to the implementation of the steps in this familiarization process, participants were unable to complete all components of the EEG research acquisition protocol. Preliminary data from this study show that all participants who engage in the familiarization protocol were able to complete the full EEG data collection.

The critical steps that were implemented include the provision of a social narrative and visual schedule, the use of the Premack principle (reinforcement) and modeling/role playing, and the desensitization to the EEG cap. Social narrative and the visual schedule make the protocol expectations and steps clear to the child, from the beginning of study enrollment to the completion of the study. Reinforcement helps the child persist through the tasks and provides a sense of mastery. Role playing and desensitization allow the child to try out unfamiliar equipment and novel sensory experiences. Finally, through the use of emotion-rating measures, the researcher ensures ongoing consent while engaging child participants in assessments and challenging experimental tasks.

Given the tools used for this protocol, a number of modifications can be made to accommodate for the varied backgrounds of the participants, relating to chronological age, mental age, and level of communicative competence. To account for a wide range of emotions that may be experienced during the research protocol, investigators may utilize the researcher rating scale to adapt the self-rating scale used by the participant. The language of the social narrative and the language of the visual schedule should align with the desired research schedule and match the cognitive and/or chronological level of the participants. Changes to these tools can include adding higher-level vocabulary for older participants or images with higher iconicity for younger participants. The activities outlined in either the visual schedule or social narrative can be changed, if necessary. For example, if participants are required to sit still for long periods of time, practicing sitting still, in the form of a game, may be beneficial. The protocol can also be modified to include a toy reward at some point in the experiment, as young children may find this more rewarding than money. Lastly, parents can be asked to bring a preferred toy of the child, to be used as a reward and to apply the Premack principle. However, when using a preferred toy, researchers must be cautious that the toy does not become a distraction during the experiment.

A potential limitation of the familiarization protocol is that it is constrained by the understanding of the language embedded in the procedure, which may limit its use for individuals with very poor receptive language skills. The quality of implementation of the described tools (*i.e.,* social narratives) can impact the accuracy or fidelity of the familiarization protocol. Finally, this paradigm uses a soft-sponge electrode cap, which is designed to be child-friendly; as such, the results of 100% participation after familiarization may not generalize fully

to protocols that use gel-based EEG data collection systems, which require scalp abrasion, or other data collection methods that entail greater physical or emotional discomfort.

While children with ASD are highlighted here as the population of study in this project, these principles can be used with young children in general, including those with other developmental disabilities, as well as those with typical development. Furthermore, although this procedure was designed for combined behavioral and EEG data collection, it could be easily adapted for use in other experimental protocols that have multiple visits and methodologies and that require participants to adapt to different contexts. For example, social narratives, visual schedules, and emotion-rating scales could be included, along with mock scanning sessions, in combined behavioral and MRI protocols. Furthermore, these elements, in addition to the cap familiarization procedure, could be augmented to allow for familiarization with near-infrared spectroscopy (NIRS) probe placement.

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DISCLOSURES:
The authors have no disclosures to report.

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Figure 1

Click here to download Figure Figure1.png

I will watch a video of this man speaking, his name is Larry.

During the video I will sit quietly and listen to instructions

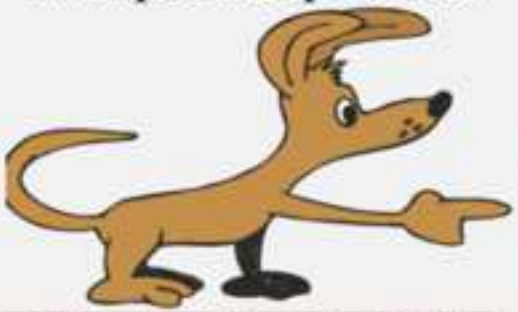
After the video I will be paid for my time!

Figure 2

Click here to download Figure Figure2.png

I will put words in a sentence.

I will point to pictures.



I will name pictures.

I will make designs with blocks.

I will be able to take many breaks.

I will find a picture to fit the pattern.

I will repeat words and sentences.

I will try on a funny net hat and watch a video, just like Junior Bear.

Figure 3

Click here to download Figure Figure3.png

	How I feel	What I Can Do
5	I feel scared and I am ready to finish. 	I can ask to come back another day
4	I feel upset and I am very nervous. 	I can ask to take a break
3	I feel confused, I am getting irritated. 	I can take some deep breaths and get a stress ball
2	I feel okay, but I am anxious. 	I can ask for help
1	I am doing great I feel good about myself 	I can keep going

Figure 4

Click here to download Figure Figure4.png

Listening to Faces
Circle the Location: SCSU or Haskins
Participant Number: _____

Pre-Research Activities
Participant Appears:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Interested					
Distressed					
Excited					
Upset					
Scared					
Enthusiastic					
Proud					
Irritable					
Alert					
Nervous					
Attentive					
Jittery					
Active					
Afraid					

Participant Self Rating on the 5-Point Scale _____

Post-Social Narrative
Participant appears:

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
Interested					
Distressed					
Excited					
Upset					
Scared					
Enthusiastic					
Proud					
Irritable					
Alert					
Nervous					
Attentive					
Jittery					
Active					
Afraid					

Participant Self Rating on the 5-Point Scale _____

Figure 5

Click here to download Figure Figure8.png

Figure 6

Click here to download Figure Figure5.png

Figure 7

Click here to download Figure Figure6.png

Figure 8

Click here to download Figure Figure7.png

Figure 9

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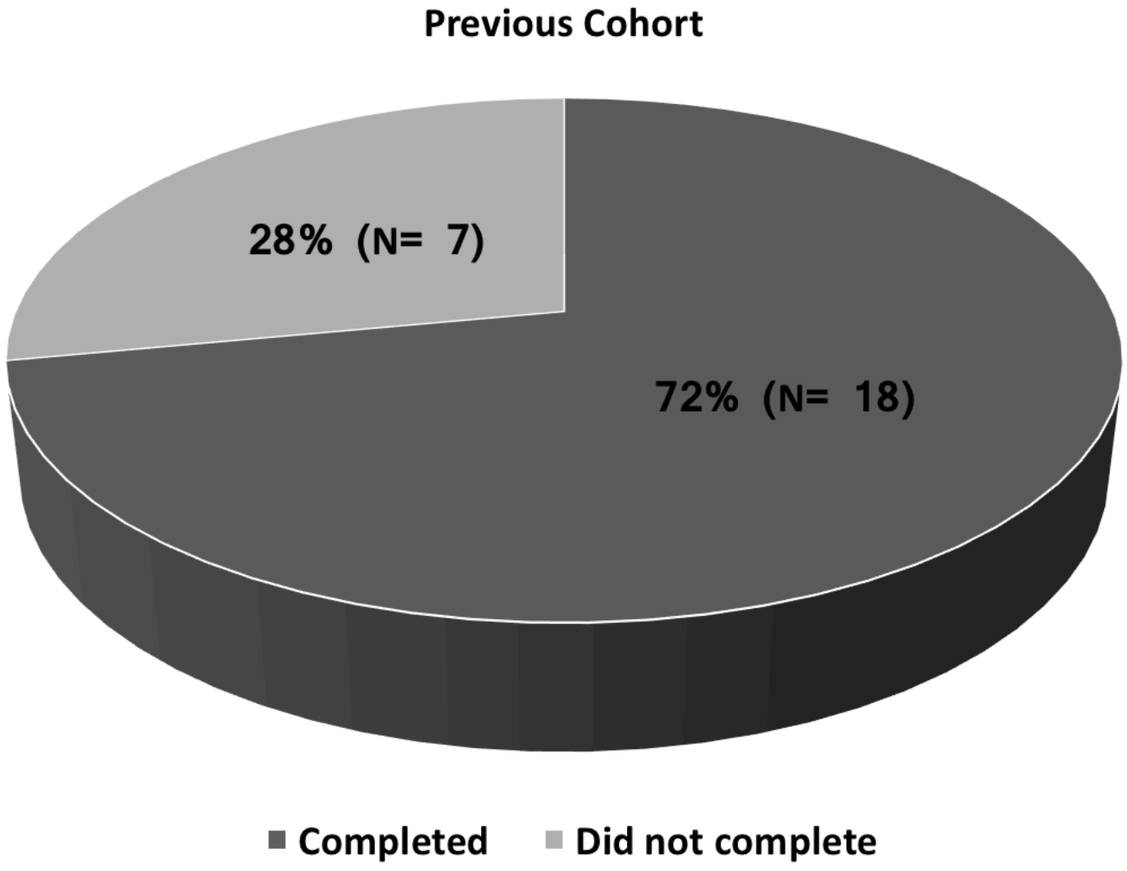

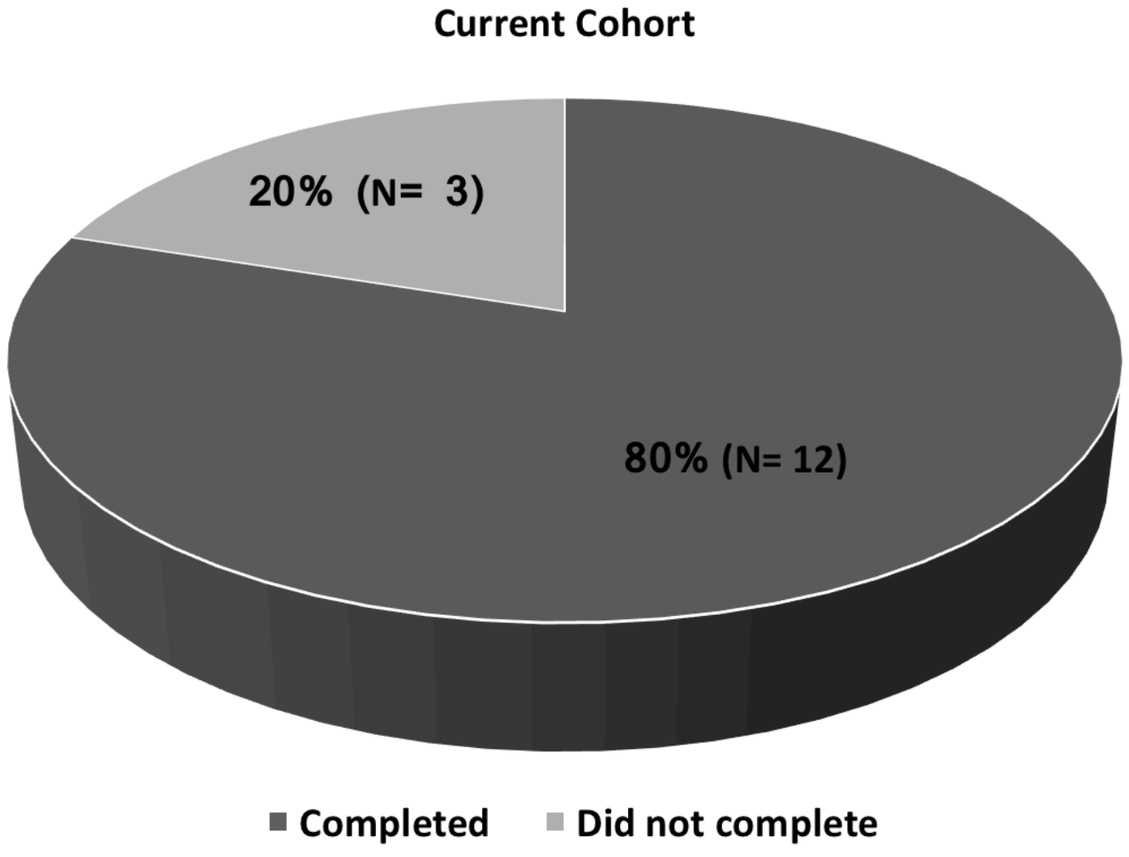

* Note: in the current cohort, those participants that did not complete EEG did not receive the familiarization protocol.

Excel Spreadsheet- Table of Materials/Equipment

Click here to download Table of Materials/Equipment Turcios_JoVE_Materials.xls

Name of Material/ Equipment	Company	Catalog Number	Comments/Description
Electroencephalography Net	Electrical Geodesics Incorporated	EGI 300 Series Amplifier	

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Author(s): Jacqueline Turcios, M.A., Barbara Cook, EdD., Taylor Rispoli, B.A., Julia Irwin, PhD., & Nicole Landi, PhD.

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Below you will find your suggestions and guidance to improving this manuscript, followed by a reply to each comment and suggestion. I thank you all very much for taking the time and effort to review this manuscript and for providing your guidance.

Very Best,
Jacqueline Turcios

Changes recommended by the JoVE Scientific Review Editor:

• Please take this opportunity to thoroughly proofread the manuscript to ensure that there are no spelling or grammatical errors.

- *Thank you for your comments. Please see the changes made to the manuscript described in response to your comments as well as reference to the line items that are relevant to the suggested changes.*

• **Abstracts:** Please re-word the Long Abstract to more clearly state the goal of the protocol.

- *Changes in wording have been made to the long abstract, so that it states that the familiarization protocol was created in order to reduce anxiety and increase the likelihood of successful participation in research.*

• **Protocol Language:** Please ensure that all text in the protocol section is written in the imperative tense as if you are telling someone how to do the technique (i.e. "Do this", "Measure that" etc.) Any text that cannot be written in the imperative tense may be added as a "Note", however, notes should be used sparingly and actions should be described in the imperative tense wherever possible.

- *We have reviewed the protocol to ensure that it is in imperative language.*

• **Protocol Detail:** Please note that your protocol will be used to generate the script for the video, and must contain everything that you would like shown in the video. **Please add more details to the following protocol steps.** There should be enough detail in each step to supplement the actions seen in the video so that viewers can easily replicate the protocol. Please ensure that all additional details in the protocol section are written in the imperative tense, as if you are telling someone how to do the technique (i.e. "Do this", "Measure that" etc.).

1) 4.2: Please check the figure reference, this should likely be figure 3.
   Number changed in line 253.
2) 4.3: Please check the figure reference.
   Now step 4.4, image reference has been repaired, thank you.

3) 4.4: How is this assessed? Do you ask them participants to rate themselves on the emotion rating scale as in 4.2? You state "both emotion-rating scales", but only one scale is present.

   Now step 4.5. The second scale will be attached as a figure; figure 4. Further explanation on how to use the scales is now described on step 4.5, line 276.

4) 4.5: Is the consent form presented to the child or the guardian?

   Now step 4.6. Clarification has been made under this item, see line 281.

5) 4.9: You state "both emotion-rating scales", but only one scale is present. Again, is this performed as in 4.2?

   Again, the second scale is now available as a newly attached figure.

6) 4.10.1: Do you read this out to the participant? If not, it should likely be un-highlighted.

   Yes, the social narrative is read to the participant. Now stated in the text 4.12.1, line 321.

• **Protocol Numbering:** Please adjust the numbering of your protocol section to follow JoVE's instructions for authors, 1. should be followed by 1.1. and then 1.1.1. if necessary and all steps should be lined up at the left margin with no indentations. There must also be a one-line space between each protocol step.

- *Numbers have been adjusted to follow journal instructions. We have justified all text to the left. However, sub-steps cannot be entirely moved to the left, because this disrupts the numbering convention.*

• **Protocol Highlight:** After you have made all of the recommended changes to your protocol (listed above), please re-evaluate the length of your protocol section. There is a 10-page limit for the protocol text, and a 3- page limit for filmable content. Please see JoVE's instructions for authors for more clarification.

For continuity, 4.10.2 should be highlighted.

This is now 4.12.2 and it has been highlighted as, suggested.

• **Results:** Do you have data to show what percentage of children wore the net without the familiarization approach for comparison? Also, can the average wearing time be provided for all samples?

- *We have included an additional pie chart to show improvements in running participants through the protocol post-implementation of the familiarization protocol. See Figure 9. A note is included in line 360-361, mentioning the approximate wearing time of the EEG net during the actual experiment.*

• **Discussion:** JoVE articles are focused on the methods and the protocol, thus the discussion should be similarly focused. Please ensure that the discussion covers the following in detail and in paragraph form: 1) modifications and troubleshooting, 2) limitations of the technique, 3) significance with respect to existing methods, 4) future applications and 5) critical steps within the protocol.

- *The protocol now contains these headings, in order to insure that none of this information is missed.*

• **Figures:**: (change table to Figure)

1) Please ensure that figures are called out in the correct order. Currently 5 and 7 are referenced before 3.

   All images are now in the correct order.

1) Fig 3: How does the researchers scale look? How is it different from this?

   We attached a figure, Figure 4, so that you can see the scale that was used.

- *See Figure 4*

• **References:**Please make sure that your references comply with JoVE instructions for authors. Citation formatting should appear as follows: (For 6 authors or less list all authors. For more than 6 authors, list only the first author then *et al.*): [Lastname, F.I., LastName, F.I., LastName, F.I. Article Title. *Source*. **Volume** (Issue), FirstPage – LastPage, doi:DOI (YEAR).]

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   All journal titles have been abbreviated

2) Please include volume, issue numbers, and DOIs for all references.

   DOIs that were available have been included.

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All references to EGI have been removed from the protocol.

• Please use standard abbreviations and symbols for SI Units such as μL, mL, L, etc., and abbreviations for non-SI units such as h, min, s for time units. Please use a single space *between the numerical value and unit.*

- *We ensured that all reference to time units were changed as requested.*

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Comments from Peer-Reviewers:

Reviewer #1:

Manuscript Summary:

This manuscript by Turcios and colleagues discusses a pervasive but often under discussed aspect of ASD research-- how to consistently get good data from a vulnerable population while also ensuring that participants are comfortable and continuously consenting to the sometimes demanding research procedures. This protocol would be useful to inform not only EEG-specific experiments with children with ASD, but nearly any protocol with children who have any communication deficits or developmental delays.

Major Concerns:

I have no major concerns about this manuscript.

Minor Concerns:

- What is iconicity?

- *Thank you for making us aware of the need to clarify this. Iconicity refers to level with which an image matches the object that it represents. We have added a brief definition on lines 180-181.*

- It's stated that the visual schedule and social narrative should be consistent, but not in what way. Should the icons used be the same, etc.? For anyone who has heard of social stories/visual schedules but never made them, I think a little extra direction here would be helpful.

- *The visual schedule and social narrative should be consistent, in a way that the images and language, used in the two tools, are the same. See lines 219-221.*

- The protocol seems well suited for younger/less verbal children, but certain aspects (especially re-reading, multiple administrations of the emotion scale) may be less needed for older/more-verbal children (at the discretion of the researcher). Are there any adaptations the researchers would suggest for participants who are older children/quick to pick up the procedure? This might be useful as well in terms of control groups that are often included in these studies, TD children will likely benefit from some of these strategies but may not need all of them.

- *This certainly needed further clarification. Images and language can be adapted to appeal to children of different ages and cognitive abilities is now stated under "Modifications and trouble shooting," see lines 494-508.*

Additional Comments to Authors:
N/A

Reviewer #2:
Manuscript Summary:
The authors present a protocol designed specifically to assist researchers in adapting children with ASD to the demands of neuroimaging studies and participating in research protocols. The basic concepts presented, although not new, are presented in a logical manner and described in a stepwise manner with appropriate places for decision making by the subject to withdraw from further testing. I have two major concerns and a few minor comments listed below:

Major Concerns:
1)The emotions chart listed in the study is far too narrow and mostly focused on anxiety and fear. There are many other emotions that children may feel during testing which are more useful for the evaluator. For example: grumpy, impatient, angry, sleepy, frustrated, shy, excited, annoyed, unsure or embarrassed. Did the reviewers pick these five, very similar, emotions for a particular reason or could the chart be redesigned with more informative emotional states?

- *Thank you for making a note of this. The chart was designed in this manner because these are the emotions that were observed early in the research*

project. Children were coming in exhibiting anxiety about the steps of the procedure. Therefore, the focus of this protocol is to reduce anxiety. However, we recognize that there are more emotions that could arise in this context. Therefore, we have mentioned that the Researcher Rating Scale (see lines 501-505) can include other emotions in the self-rating scale in other research situations. For our study, these are the emotions that were consistently present in our participants.

2)At step 5.2.4 the authors tell the participant to "sit still like a statue" during the EEG reading. Although there has been extensive training during the early phases of study for putting on the sensor net, they have not suggested any training at all for sitting still. In fact, sitting still for 5-10min could be the most difficult task you can ask a child with ASD to perform. They should re-think this issue and add places in the protocol for playing a "sit still" game with visual cues.

- *This is a great idea and we have included it as a modification: see line 507-509.*

Minor Concerns:

1) The materials table could be just listed in a Methods section of the written portion of this article.*[Editor's Note: Please ignore this comment.]*

2) Table #1 is not useful - it should be a pie chart figure instead.
Thank you for the suggestion, we have reviewed this section to include pie charts from a cohort tested prior to the familiarization protocol and after adopting the protocol, see Figure 9.

3) What is the "stress brain" referred to in Figure 3? Also, check that the text matches the stated "what I can do" section of this figure - it does not.

- *A stress brain is a stress ball in the shape of a brain, is now changed to stress ball in a changed chart of the self-rating emotion scale, and now the language starts with "I can do." See modified image 3. Thank you.*

3) The section written after Table #1 and before the Discussion is confusing and should be re-written to some extent. For example, the sentence on line 448 implies that some of the boys "were unable to do so,…" but really they were unable to go to the appointment.

   a. *This paragraph has been changed. We are only including the information about the results and removed the phrase that you mention in this comment. Lines 466-473. It wasn't that they did not attend the appointment, but did not receive the familiarization protocol. Thank you.*

Additional Comments to Authors:
None

Reviewer #3:
Manuscript Summary:
This paper presents a familiarization protocol for involving children with ASD in EEG/ERP research. I am enthusiastic about this work being presented and that it will be a useful tool for many in the field. My main questions are those that relate to the generalizability of the procedures, and some instances where the rationale for certain decisions could be made more clear.

Major Concerns:
The authors use the term "EEG" throughout the paper, when it seems that their paradigm is actually an ERP study. It might be helpful early in the paper to describe how these terms will be used, as the suggestions are generally appropriate for both techniques.

- *Our current experimental approach includes analysis of both EEG and ERP, this is now explicitly stated. Further, we now clarify that because ERPs are extracted from the ongoing EEG, we will be referring to procedures for EEG data collection throughout the manuscript.*

The paradigm described is for kids of a generally moderate ASD severity level and of a certain age range. It would be very helpful to briefly describe which aspects of the protocol could be used in children who are older or younger, and more or less severe on the ASD spectrum.

- *Excellent point! This is now explicitly laid out at the end in the "Modifications and trouble shooting" portion, lines 495-510.*

Minor Concerns:
In the short abstract, the authors say that EEG is useful for identifying biomarkers. I think that this effort has not actually been very successful, and that EEG/ERP can do more than this. Consider rephrasing.

- *We agree with the reviewer, and we have changed our wording to refer to our broader goal of better understanding the neural bases of AV speech processing in typically developing children and those with developmental disabilities. Space limitations, and the focus on procedures for familiarization and preparation in the current manuscript, preclude a longer discussion of our approach and motivation for the use of EEG and ERP specifically.*

As I mentioned, several points could use a bit more explanation as to why the given approach is chosen. These include 1.1.3 (using powerpoint to show social narrative), the experimenter's rating of child's state (lines 351-354).
Adjust awkward wording in section 4.10.4.

- *Step 1.1.3, we added more explanation to say that it is in powerpoint mode so that it can be used as a story on presentation mode. Of course, other programs can be used as well.*

- *This is now 4.12.6 and the wording has been changed to read more clearly, see lines 352-354*

What is to be done if the child's comfort/anxiety is increased after wearing the cap? (4.11)

- *A note has been made to provide further instruction, see lines 367-368*

I have a few additional suggestions that many colleagues find helpful: soliciting information from the parent in advance about their child's likes and preferences. For example, a child who has a given interest can be rewarded with that interest. Parents can also bring a child's favorite movie, a stuffed animal or blanket, and extra layers to keep the child comfortable.
I also find it works well to never mention the effect of eye blinks on the data, as kids tend to think about it and blink more. I do find it helpful to show the child their EEG in real time and let them see how body motion or touching the electrodes make their brain waves go wiggly and hard for the researchers to understand.
It's likely that the research team may already employ these strategies given their expertise, and I defer to them to add these to the protocol as they see appropriate.

- *Thank you for your excellent suggestions, we have added some of these as consideration for modifications to the protocol in lines 499-514. Further, we do indeed show older children their EEG and the effects of movement, however we do not do this consistently as some, particularly younger and/or highly anxious children, are easily distracted by this, and we have tried to only include procedures that are consistently employed with every child.*

Additional Comments to Authors:
N/A

Reviewer #4:
Manuscript Summary:
Paper by Turcios et al provides recommendations on familiarization of the young participants with ASD with behavioral and EEG experimental protocols to improve

compliance and increase participation. The procedure can be applied to children with other developmental disorders and to typically developing young children.
This is a useful paper for those who works with developmentally disordered children. It may appear particularly instructive for the researchers who just start working with the ASD participants. Turcios formalizes the steps to increase compliance of the subjects, their satisfaction, and participation outcome, and suggest useful means, such as e.g. visual schedule of upcoming activities (Fig. 2) and 'How I feel' scale (Fig. 3). I think that the content of the paper can be used to produce a valuable educational video. I have just a few comments.

Major Concerns:
N/A

Minor Concerns:

1. The authors report the '% participation' outcome of their study that used this protocol. They though do not report IQs and autism severity of their participants. Please, do that since it would give the reader/viewer a better understanding of which group could benefit most of this approach.

    Thank you for pointing this out, we have noted that our participants had an average IQ.

2. Children with ASD may have difficulties understanding emotions. Do they have difficulties interpreting the 'How I feel' emotional scale? In what % of you cases there were discrepancies between subject's and researcher ratings?

    We did not do a discrepancy analysis. The purpose of using the pictures was to increase the child's understanding of the different emotions. We have now added the researcher scale as Figure 4, this scale was used to ensure that the outward state of the child showed that he/she wanted to continue participation. We did not come across a situation in which a child was unable to rate how they felt.

3. Figure 1 implies a monetary reward upon finishing the experiment. I wonder if is would be appropriate for all participants? Young children and those with developmental delay may prefer to choose a toy from a collection of small toys as a reward. This can be done during both the 1st and the 2nd visit to increase the motivation. The 'toy reword' does not exclude the monetary reward for the participating family.

    Great point. We have included a toy reward as a modification for younger children

4. It is a bit difficult to judge without the video how the familiarization takes place and how the participants use the means depictured in figures 2 and 3 in the experimental settings. I hope it will be clear from the video.

    We hope so too, thank you!

5. How do you use the 'How I feel' information (Fig. 3) with those children who cannot read? Would it be better to use the cartoons without the text printed?

    This is now more explicitly explained in steps 4.1 to 4.3. See the text below. In the manuscript these are lines 248-256.

- *Ask the participant to point to the picture that best represents how they feel on the 5-pt emotion-rating scale (see Figure 3).*
- *The researcher asks the participant "how do you feel" and supports the participant in saying "I feel _____." While pointing to the corresponding emotion on the scale (see Figure 3).*