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Conducting research with minimally verbal participants with autism spectrum disorder

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Abstract

A growing number of research groups are now including older minimally verbal individuals with autism spectrum disorder in their studies to encompass the full range of heterogeneity in the population. There are numerous barriers that prevent researchers from collecting high-quality data from these individuals, in part because of the challenging behaviors with which they present alongside their very limited means for communication. In this article, we summarize the practices that we have developed, based on applied behavioral analysis techniques, and have used in our ongoing research on behavioral, eye-tracking, and electrophysiological studies of minimally verbal children and adolescents with autism spectrum disorder. Our goal is to provide the field with useful guidelines that will promote the inclusion of the entire spectrum of individuals with autism spectrum disorder in future research investigations.

Keywords

behavioral assessment, electrophysiology, eye-tracking, minimally verbal autism spectrum disorder, research methods

Until recently, most published research studies on autism spectrum disorder (ASD) did not include older minimally verbal individuals. In 2010, the National Institutes of Health convened a workshop to address the needs and opportunities that would begin to fill this gap in the literature (Interagency Autism Coordinating Committee (IACC), 2011), which resulted in two publications: a paper on the challenges that need to be addressed in order to extend research to this end of the spectrum (Tager-Flusberg and Kasari, 2013) and a companion paper on best practices for behavioral phenotyping studies, focusing primarily on measures that can appropriately be used with this population (Kasari et al., 2013). Here, we expand the discussion on collecting data from minimally verbal school-aged children and adolescents in research settings with an emphasis on approaches that can optimize the likelihood of collecting high-quality data.

There is growing interest in studying older minimally verbal individuals with ASD, although there is no accepted definition for who would be included in this group. The term "minimally verbal" is used in cases in which an individual has very limited use of spoken, non-echoed or scripted language for the purpose of communication (Tager-Flusberg and Kasari, 2013); comprehension may also be severely impaired, although it is often not easy to evaluate in standardized ways (Kasari et al., 2013; Plesa Skwerer et al., 2015). Autism symptoms are typically quite severe, and minimally verbal individuals often exhibit a range of challenging and atypical behaviors (Tager-Flusberg and Dominick, 2011).

Within the tradition of applied behavior analysis (ABA), there are many published studies on minimally verbal individuals with ASD or intellectual disability (often not separated by diagnosis), based on single subject designs (e.g. Lionello-Denolf et al., 2008; Pierce and Schreibman, 1994; Wilkinson et al., 2009). This work has been important from an applied and educational perspective, but for the most part, it has not been included in mainstream research on ASD, largely because it has been presented and published in specialized outlets. Nevertheless, the approaches that have been developed by ABA researchers and therapists provide the foundation for the approaches we and other researchers follow in working with this population.

There is a pressing need to extend autism research beyond the more accessible verbally fluent individuals

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Table 1. Demographic information for participants by age.

	Younger participants (under 12 years) (*N* = 18)	Older participants (12 years and older) (*N* = 14)
Chronological age		
M (SD)	7.10 (2.3)	15.6 (1.9)
Range	4.4–11.11	12.9–18.7
Gender	*N*	*N*
Male/female	16/2	9/5
Race		
African American	0	1
Asian	2	0
Caucasian	10	12
Hispanic	0	0
More than one race	6	1
Ethnicity		
Hispanic	2	1
Non-Hispanic	16	12
Prefer not to respond	0	1

SD: standard deviation.

with whom most cognitive and neuroimaging research has been conducted. For example, rare genetic mutations are known to occur in at least 10% of the ASD population (Geschwind and State, 2015) and are often associated with more severe phenotypes, including limited or absent language. Expanding research to include minimally verbal individuals is critical for understanding how specific genes influence behavioral and neural phenotypes. Furthermore, minimally verbal individuals offer the opportunity to investigate the neurocognitive mechanisms that underlie speech and language development as well as many co-occurring and severe atypical behavioral patterns. Research in these areas will lead to the development of innovative behavioral, neural, or pharmacological interventions that are essential to address the serious needs of this population.

To achieve these goals, we must develop and refine our methods for collecting high-quality, reliable, and valid data from minimally verbal research participants so that we do not rely exclusively on secondary informants. As part of our National Institutes of Health (NIH)-funded Autism Center of Excellence (ACE) research program (approved by the Institutional Review Board at Boston University), we use a combination of assessments that provide us with deep phenotyping of children and adolescents with ASD. Our methods for conducting these assessments are grounded in ABA techniques (e.g. Fisher et al., 2011; Liuselli et al., 2008), but these have been adapted and modified for use in a research environment by examiners who have been introduced to ABA principles but not fully trained as ABA therapists. In this article, we focus on describing our methods for collecting standardized behavioral, experimental, eye-tracking, and electrophysiological (electroencephalography (EEG)) data.

Methods

Participants

We report here on 32 minimally verbal children and adolescents with ASD. Table 1 summarizes the demographic characteristics of this sample divided into younger (under 12 years of age; $n = 18$) and older (12 years of age and older; $n = 14$) participants who were between the ages of 4.4 and 18.7 years. This division into younger and older participants corresponds to whether we administered the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Module 1 or 2, for the younger group) or the Adapted ADOS (Module 1 or 2, for the older group).

We defined the participants as minimally verbal based on information provided by parents during the screening process, when they were asked to describe how their child communicated. We asked follow-up questions, if needed, to determine whether or not the child used phrase speech spontaneously (not just echoed) and in a variety of contexts.

The participants met criteria for ASD on the Autism Diagnostic Interview–Revised (ADI-R) and ADOS-2 (Lord et al., 2012) or Adapted ADOS (Hus et al., 2011), and diagnoses were confirmed by expert clinical judgment. In the younger group, 14 (out of 18) had or were continuing to receive ABA intervention; 11 out of 14 of the older participants had received ABA interventions.

We collected several parent-report measures of the participants' autism symptoms (ADI-R; Rutter et al., 2003), adaptive skills (Vineland Adaptive Behavior Scales-II;

Table 2. Descriptive characteristics of participants.

	Younger participants	Older participants
Vineland-II[a]	Mean (SD)	Mean (SD)
Communication domain	58.06 (12.9)	46.82 (9.23)
Daily living skills domain	62.94 (11.2)	51 (10.7)
Socialization domain	55.19 (8.7)	43.73 (6.2)
Adaptive behavior composite	58.20 (9.3)	46.18 (8.3)
ADI-R[b]		
Social total	26.76 (2.9)	26.73 (4.2)
Nonverbal communication total	12.20 (1.4)	12.5 (1.8)
Repetitive behaviors total	6.26 (2.1)	5.73 (1.7)
Aberrant Behavior Checklist[c]		
Subscale I: irritability (15)	12 (9.6)	9.17 (6.4)
Subscale II: lethargy (16)	11.88 (5.3)	8.1 (5.3)
Subscale III: stereotypy (7)	8.88 (4.5)	4.42 (3.9)
Subscale IV: hyperactivity (16)	20.1 (8.4)	13.25 (7.4)
Short Sensory Profile[d]		
Tactile sensitivity (7)	30 (1.86)	28.85 (4.32)
Taste/smell sensitivity (4)	14.44 (5.29)	15.46 (5.43)
Movement sensitivity (3)	13.44 (1.9)	13.54 (2.6)
Under responsive/seeks sensation (7)	20.19 (5.76)	22.31 (4.01)
Auditory filtering (6)	18.5 (2.97)	21.15 (4.2)
Low energy/weak (6)	24.63 (4.84)	22.69 (6.26)
Visual/auditory sensitivity (5)	18.38 (3.05)	19.54 (4.29)
Total	140.25 (13.66)	143.54 (20.54)
CASI-5 comorbidities[e]	*N* (%)	*N* (%)
ADHD inattentive	7 (41)	3 (23)
Specific phobia/social phobia	6 (35)	4 (33)
Compulsions	6 (35)	5 (42)
Motor tics	7 (41)	3 (25)
Vocal tics	9 (53)	9 (75)
Skin picking	2 (12)	5 (42)
Enuresis, encopresis	10 (59)	2 (17)

SD: standard deviation; ADI-R: Autism Diagnostic Interview–Revised; CASI-5: Child and Adolescent Symptom Inventory 5; ADHD: attention deficit hyperactivity disorder.

[a] The domain score on the Vineland-II are standard scores (mean: 100; SD: 15).

[b] The ADI-R domain totals are sums of converted raw scores (0–2). Higher values indicate increased autism symptom severity.

[c] The subscales of the Aberrant Behavior Checklist include a different number of items, noted in brackets for each subscale. The table presents raw scores based on ratings of 0–3. Higher values indicate increased problem behaviors severity. The fifth subscale, Inappropriate speech, does not apply to the minimally verbal sample tested in this study.

[d] The subscales of the Short Sensory Profile include a different number of items, noted in parentheses after each subscale label. The table presents raw scores based on ratings of 1–5. Lower values indicate increased sensory interest or aversion.

[e] On the CASI-5, the numbers (*N*) indicate the number of participants who met cut-off scores for the respective comorbidity. The comorbidities presented in the table were selected if at least one-third of the sample in either group (young and older) met cut-off criteria.

Sparrow et al., 2005), sensory symptoms (Short Sensory Profile; Dunn, 1999), aberrant behaviors (Aberrant Behavior Checklist; Aman et al., 1985), and comorbid psychopathology (Child and Adolescent Symptom Inventory 5 (CASI-5); Gadow and Sprafkin, 2015). These data are presented in Table 2 to provide some information about the parents' descriptions of the sample participants.

Procedures

In the following sections, we describe the process and procedures that we used to conduct our research.

Screening. Before enrolling participants, we conducted a detailed screening evaluation not only to ensure that participants met our inclusionary and exclusionary criteria but also to ask questions that prepared both the participant and the research team for the first lab visit. Parents provided information about their child's diet, preferred items and activities that could be used as rewards during the assessment, atypical or challenging behaviors, communication needs, sensory issues, attention span, and motivation to comply with task demands.

The information gathered during the screening process helped us prepare for the specific, individual needs of each

Table 3. Frequency of participants who engage in challenging behaviors: parent report and behavioral observation.

	Younger participants	Older participants
Aggressive behaviors		
Parent report and observed during visit	4	2
No parent report, but attempted during visit	6	5
Self-injurious behaviors		
Parent report and observed during visit	1	1
No parent report, but attempted during visit	3	2
Socially inappropriate behaviors (e.g. spit play, exposures, and inappropriate touching)		
Parent report and observed during visit	2	1
Other challenging behaviors (e.g. elopement)		
Parent report and observed during visit	5	5
No parent report, but attempted during visit	4	2

participant. We depended on the parents to provide us with a complete and accurate picture of their child prior to meeting them. Nevertheless, some participants surprised us with their actions or preferences; parents did not always report accurately during the screening process, perhaps because they did not anticipate how their child would act in the research environment or were concerned that their child would be excluded from the research. Table 3 summarizes the challenging behaviors reported by parents and/or observed during testing sessions.

Preparation for visiting the research facility. Given the complexity of testing minimally verbal participants, it is crucial to prepare for visits to the research facility. Once a family agreed to participate, we provided detailed information in advance about what would happen. We sent illustrated booklets to the family, introducing to them the examiners, testing rooms, specialized equipment (e.g. EEG cap), and the activities that would be carried out. The booklet was written for the parent but the design was also appropriate for the participants as it included many photos of the people and facilities, and we encouraged parents to review it with their child prior to the visit. It is possible that some of our participants may not have benefited from the booklet, given their cognitive and linguistic abilities.

The testing spaces were prepared in advance according to the individual needs of the participant as reported by the parents. Only essential materials, including measures, items (e.g. favored toy or tablet) to be used as rewards, break activities, and snacks were present (out of sight of the participant) to limit distraction. In the observation room, the one-way mirror was covered over for participants who were overly interested in peering at themselves or looking into the adjacent room. The most important concern was to ensure the participants' safety by minimizing the possibility the participant could wander out of the research facility and by limiting the availability of objects with which the participant could cause self-harm or harm to the examiner.

Testing sessions—general issues. There are many ways in which assessing minimally verbal participant differs from the standard approach used for collecting research data. In general, we based our approach on adaptations of ABA principles. We addressed antecedents (preventive measures) and consequences (reactive measures) to promote appropriate testing behavior and respond to interfering behaviors. The procedures were developed by a specialist (Board Certified Behavior Analyst (BCBA)/special education teacher) who trained the other examiners on basic ABA principles in a series of workshops and in guided feedback at regular meetings held before and after testing sessions. We summarize here some of the main modifications we incorporated into our research practices.

1. Typically, two examiners were present: one interacted and collected the data from the participant, while the second provided support by exchanging test materials with the examiner or redirecting the participant's attention to the task. We discussed with parents in advance whether the testing would run smoother with or without a parent or teacher/therapist present in the testing room.
2. To prepare the participant for the schedule of the visit and facilitate transitions from one assessment or activity to the next, we typically used visual schedules with photos, symbolic pictures, or words depending on the participant's abilities (Dettmer et al., 2000).
3. For the family's first visit, examiners began by orienting the participant to the environment and building rapport with the participant for 5–10 min prior to testing.
4. For individuals who regularly communicate via Augmentative and Alternative Communication (AAC; see Table 4), we incorporated their preferred mode of communication into the testing. Directions and information given to the participants were gauged to their level of attention and comprehension.

Table 4. Information about testing sessions for participants.

	Younger participants	Older participants
Number of visits[a]		
Mean (SD)	4.83 (1.47)	2.07 (1.07)
Range	2–7	1–5
Augmentative and alternative communication (ACC)		
Number of participants who used AAC	2	0
Types of rewards used		
Food/edible	16	7
Other	16	5
Use of visual schedules		
Number of participants	12	13
Use of timers		
Number of participants	2	4
Total adaptations during visits		
Mean (SD)	2.56 (0.92)	2.07 (0.83)
Range	1–4	1–3

SD: standard deviation.

[a] Participants under 12 years completed on average 8.44 (1.89) standardized behavioral assessments during their visits, while participants 12 years and older completed 3.71 (1.27) standardized behavioral assessments.

5. Different participants can tolerate testing sessions of different durations. Parents provided guidelines, but the examiners monitored the tolerance level of each participant and did not extend the testing time beyond that threshold. This sometimes resulted in completing one measure across two or more sessions, which, though not optimal from a psychometric perspective, was the best that could be accomplished with some participants. Typically, each session began with a non-stressful task that was expected to be well within the ability level of the participants so that there was an initial experience of success.
6. Throughout the testing session, positive feedback such as social praise and access to preferred items were provided to keep the testing on track. For some participants, it was helpful to provide them with a timer to monitor the length of the task and/or session. Breaks were scheduled into the session for a visit to the bathroom, time to engage in a favorite activity (e.g. riding on a scooter), or to offer a brief period of time in which no demands were placed on them. While these reduced the testing time, they also reduced the likelihood that the participant became frustrated or resistant to continued testing.
7. Despite our best efforts, some participants became distressed, tried to leave the room, refused to continue testing, or engaged in aggressive or destructive behavior. To address these episodes, several strategies were used such as redirecting the participant, changing the activity, offering a short break, or ignoring outbursts.

Not surprisingly, our minimally verbal participants required more visits to complete the assessment battery than either typically developing or verbally fluent participants with ASD. Table 4 summarizes the number of visits for our younger and older minimally verbal participants (who completed different numbers of measures) and the number in each group who required the supports and adaptations described here.

In the following sections, we provide examples of some of the specific approaches we developed for select portions of the research battery.

Behavioral testing. Despite the challenges involved in direct assessment of the minimally verbal participant with ASD, it is important to obtain detailed quantitative and qualitative evaluations of their current abilities that are not easily provided by caregivers. Here, we summarize our approach to collecting nonverbal intelligence quotient (IQ) scores using the Leiter International Performance Scale, Third Edition (Leiter-3; Roid et al., 2013).

Composite Leiter-3 IQ scores are calculated based on four subtests: Figure Ground, Form Completion, Classifications and Analogies, and Sequential Order. Each subtest involves an easel board and a combination of cards, blocks, and/or foam shapes. In its standard administration, the tester presents the Leiter assessment completely nonverbally, using gestures, pantomime, and facial expressions to convey the test instructions and to prompt a response. Each subtest includes training items to familiarize the participant with the task. During training trials, the examiner models accurate responses and corrects the participant errors to establish an understanding of the task.

We implemented modifications to the administration of the Leiter-3, which were applied during the training items to ensure that participants understood the task and throughout the test administration to maintain attention and on-task behavior. On Leiter-3 training items, most participants were unable to comprehend standardized test instructions or expectations conveyed via complex gestures and facial expressions, reflecting the nonverbal communication impairments that characterize ASD. To facilitate their understanding of the task instructions, brief verbal instructions were given (e.g. "Just one" or "Match") accompanied by gestures (e.g. pointing to the correct location). For participants requiring more support, we modeled the correct response and, if necessary, provided hand-over-hand guidance to complete a correct response. The administration of training items also allowed the examiner to assess and plan for the modifications that would likely be needed during test trials.

Additional modifications were used to maintain attention and compliance during test administration. Simple verbalizations, gestural prompts, and other visual cues were used to re-engage a non-responsive participant on a test trial, up to three times with 10-s intervals between prompts. When a participant was distracted by extraneous stimuli or engaged in repetitive behaviors, we provided access to preferred items to regain his or her attention. When repeating instructions was not effective, the examiner positioned the test materials directly in the participant's line of sight.

Another occasional modification was required when participants engaged in inappropriate use of the test materials, such as mouthing, visually inspecting, throwing, or destroying them. In these cases, the examiner withheld the stimuli while keeping them in the participant's sight and allowed access to only one card at a time. Finally, participants with fine motor difficulties that impeded them from putting cards into the block board slots were taught to respond by placing the card in front of the slot.

Using these modifications, we were successful in obtaining nonverbal IQ scores from 16 of the 18 younger participants (mean IQ: 74.9; standard deviation (SD): 15.5; range: 39–112) and from all 14 older participants (mean IQ: 56.2; SD: 16.6; range: 30–87).

Eye-tracking. The introduction of automated eye-tracking devices that require no language or explicit responses from a participant provides an opportunity for conducting experimental research with minimally verbal individuals with ASD (Tager-Flusberg and Kasari, 2013). To date, most of the published eye-tracking research has included either verbal individuals with ASD or infants (Falck-Ytter et al., 2013; Guillon et al., 2014). We recently published the first study using eye-tracking (and other) methods to assess lexical comprehension in minimally verbal individuals (Plesa Skwerer et al., 2015). In our ongoing research, we also use eye-tracking to investigate social information processing.

Our main consideration in choosing the Tobii T60 XL automated infrared eye-tracker was to minimize sensory and behavioral demands on participants while collecting reliable gaze data. This system requires no head-gear, offers several options for calibrating infants or other individuals with short attention spans, and has relatively high tolerance for head movements. We used a 5-point calibration and adapted the choice of calibration method (adult or infant) to each participant, obtaining 15 successful calibrations (out of 18) in the younger group and 12 (out of 14) in the older group, based on 1–6 calibration attempts, resulting in an overall success rate of 84%.

Our social information processing task, modeled after Chawarska et al. (2012), included two short videos depicting an adult carrying out a simple activity and engaging the viewer in conversation while in the background there were several interesting objects. The adaptations we developed were directed toward minimizing the participants' movements and maximizing their attention to the screen. Before calibration began, one examiner modeled the target behavior, sitting next to the participant, looking directly at the screen. If needed, a booster seat was used (with the younger participants) or a weighted blanket to minimize repetitive movements and fidgeting. Four of our participants used a "hands" prompt (a place card with an outline of two hands) on the table in front of the monitor to prevent them from obstructing their view with their hands. Participants were prompted to put their hands on the card and verbal reminders were used, as needed.

Two examiners were present: one examiner monitored the experiment on the computer, while the second stood behind the participant, sometimes gently resting her hands on the participant's shoulders to minimize rocking and prevent sudden movements; 10 of our participants benefited from this adaptation. About half of each group (six older participants and five younger) needed redirection and prompting to reorient to the screen several times during calibration and the task. The examiner who monitored data collection used the Live-viewer mode to observe the participants' looking behavior in real time and signaled to the second examiner to reorient a participant whose gaze wandered off screen.

The participants' compliance and interest in watching the movies varied. While several remained relatively still and attentive for the duration of the experiment, a few vocalized in protest, put their head on the table, dropped to the floor before being seated, or tried to hit and push over the monitor. In these cases, the eye-tracking session was ended and attempted again on a subsequent visit.

The adaptations we used were intended to minimize eye-tracking data loss. While some researchers adopt stringent criteria for including gaze data in statistical analyses (e.g. at least 80% validity), such constraints are not realistic and would bias any estimate of visual attention when working with minimally verbal participants. In the tasks described here, the data validity reported by the eye-tracker ranged between 1% and 86% in the younger group (mean: 41%), and between 4% and 97% in the older group (mean: 50%). In all, 5 of the 15 younger participants who calibrated successfully provided over 70% valid data, as did 6 of the 12 older participants. Instead of filtering out participants based on low validity, it is preferable to screen data for outliers within the group. This led to the exclusion of data from only two participants from the younger group and one from the older, resulting in 13 younger (72% of the entire group) and 11 older (almost 80%) with useful data for analysis.

Electrophysiology. With the advent of non-invasive technologies for investigating brain structure and function, many significant advances have been made in our understanding of the underlying pathophysiology in autism (e.g. Lainhart, 2015; Minshew and Keller, 2010). To capture neural processing of auditory information, we use electrophysiology (both EEG and event-related potential (ERPs)) because it is highly sensitive to the timing of cortical neural responses and can simultaneously measure basic hearing capacity without requiring any verbal instructions or responses from the participants.

We selected the 128 channel HydroCel Geodesic Sensor Net system (EGI, Eugene, OR) because it was designed to be suitable for a wide range of individuals from infants to adults. The accurate placement and set up of the "cap"—the flexible net system—can be completed in 5 min, and attaching the electrodes to the scalp does not require using alcohol to clean the face or sticky gels applied to the face and hair. Instead, the net that holds the electrodes, which end in soft sponges, is dipped into an electrolyte solution before being placed on the head. Thus, the main discomfort experienced is a feeling of moisture over the head and areas of the face.

The most challenging part of electrophysiological research is acclimating participants to all the steps involved in accurate placement of the electrode cap. Webb et al. (2015) have recently published guidelines for EEG research on autism. We provide here an expanded discussion of their methods from the perspective of our work with minimally verbal participants.

Central to our approach is "desensitizing" or acclimating participants to every stage in the process. For each stage, we followed the same steps: show, demonstrate on the examiner, introduce incrementally to the participant providing positive feedback until the participant is comfortable, and has achieved the goal for that stage. First, we acclimated participants to the room that houses the EEG equipment and the shielded testing booth until they felt comfortable with the general environment. For participants who were reluctant to enter the EEG booth, we used a stepwise procedure: first, they sat immediately outside of the booth with the door open; next, they sat inside of the booth with door still open and the lights on; finally, they were acclimated to sitting inside the booth with the door fully closed and lights off.

To select the correct size net and position the electrodes, we measured the participant's head circumference and marked the vertex. These stages required acclimating some participants, which sometimes took several trials. The next stages involved getting the participant to tolerate the net with practice nets, which do not have functioning electrodes or wires attached, beginning with getting the participant to wear the dry practice net. At first, we touched the net to the participant's head. Then, we fitted it loosely over the participant's head and gradually increased the actual placement until it fit snugly over the whole head. This took anywhere from a few seconds to several minutes to accomplish.

For participants who required lengthier training, we sent a practice net home with the parents and asked them to work with the child to tolerate putting it on and wearing it. Parents were instructed in the proper application of the net and were given written step-by-step instructions how to practice with the EEG net. They were asked to place the dry EEG net only three-quarters of the way on their child's head. In order to decrease participant agitation, parents were instructed to put the net on their child at least once before their next visit to the lab and only for a maximum of 5 min. Parents were also instructed to discontinue the at-home practice if their child became agitated or actively refused to wear the EEG net. Parents provided informal feedback on the success of their home practice when they returned to the Center for the next testing session. Of 32 parents who completed the home practice, 31 reported that their child could wear the net for 5 min.

Once the child tolerated the dry net, we introduced the wet practice net. If participants did not like the smell of the electrolyte solution, we began with water. Throughout this process, the examiner showed the net, modeled the cap placement, and then used praise and access to favorite items to reward progress. The end goal was for the participant to tolerate wearing the wet net without touching it for at least 5 min.

Once the participant was able to wear the wet practice net, we acclimated them to allowing us to add electrolyte solution to the electrodes using a pipette and to moving the individual electrodes around to ensure they were all in contact with the scalp in their correct position. The same steps were repeated with the testing net, which has a large bundle of wires that connect each electrode to the computer that collects the EEG. Once the participant was wearing the test net without signs of distress, he or she was ready to be introduced to the experimental testing. We prepared a video of the entire process and encouraged families to watch it with their children; the video also served as a support for parents who took home a practice net.

Table 5. Electrophysiological data collection procedures and outcomes.

	Younger participants (N = 16)[a]	Older participants (N = 13)[a]
Practice net sent home with parents		
Number of participants	12	10
Desensitization with dry practice net		
Attempted	16	12
Successful	13	9
Desensitization with wet practice net		
Attempted	13	8
Successful	12	8
Desensitization with real net		
Attempted	12	5
Successful	12	5
Hearing test (5 min)		
Attempted	12	10
Successful	10	9
EEG experiment (45 min)		
Attempted	10	9
Successful	6	9
Number of visits to complete EEG[b]		
Mean (SD)	3.33 (0.82)	1.78 (1.09)
Range	1–4	1–4

EEG: electroencephalography; SD: standard deviation.

[a] Three participants (two in the younger and one in the older group) were not given the opportunity to attempt EEG due to loss at follow-up.

[b] These numbers are for the 15 participants on whom experimental EEG data were collected.

We administered an auditory processing EEG experiment that required about 50 min to complete, including time to evaluate the participants' hearing using EEG. As participants listened to the experimental sounds, they were seated in front of a computer and were able to watch a video of their choice (usually one brought from home). This stage required acclimation to watching the video without sound. Prior to beginning the actual experiment, we also acclimated the participants to listening to the experimental tones.

Although EEG allows somewhat greater movement than other brain imaging methods, we included several adaptations to minimize movement, including chairs adjusted for height and width, and in some, we added geriatric side wings that provide close support for the torso and a weighted blanket to limit bouncing legs or squirming. During the experiment, one examiner sat in the testing booth to monitor behavior and to provide support by holding hands, adjusting wires, offering encouragement, and maintaining the comfort of the participant. If the participant became agitated, the examiner judged whether a short break or terminating the testing session was necessary.

Table 5 provides a summary of our success in the process of acclimating participants to the EEG portion of our research. Using the procedures described here, we successfully completed the EEG study on almost 40% of the younger children and almost 70% of the adolescents.

Discussion

Collecting high-quality research data from minimally verbal children and adolescents with ASD is an extremely difficult enterprise. Nevertheless, as noted in the introduction, it is imperative that we begin studying these minimally verbal individuals who, arguably, are in greatest need of novel interventions and other treatment approaches, given their multiple challenges in both behavior and communication.

We have summarized the methods that we have developed for collecting different types of research data from minimally verbal participants. Our approach is grounded in ABA: break tasks down into incremental steps, guiding participants with modeling and rewarding appropriate responses, and handling challenging behaviors using ABA techniques. The research team included examiners who had at least some background in ABA methods and prior experience with minimally verbal individuals with ASD. Nevertheless, there are important differences between ABA as developed and employed in educational settings and the application of the same techniques in a research setting. Researchers are not trying to teach the participant the correct response, whereas this is the main goal for teachers and other interventionists. We used training items and practice sessions to convey to our participants the tasks and expected responses, but when we administered test items, we were careful to stop modeling or reinforcing just the correct items.

Thus far, we have developed comprehensive approaches for the collection of a wide range of behavioral data, the administration of computerized and eye-tracking tasks, and conducting electrophysiological studies. The general approaches summarized here can also be extended to other types of data collection, including more challenging brain imaging methods such as magnetic resonance imaging (MRI) (e.g. Nordahl et al., 2010; Slifer et al., 2002) or the collection of DNA and other biological samples from saliva or blood.

We have been quite successful in our work, although as the data presented here show not all our participants were able to be calibrated for our eye-tracking studies or complete the electrophysiological research. In general, our older participants were relatively easier to work with. This may be because they have had more experiences with ABA and have spent more time in structured educational environments that make similar demands on them as we do in our research studies. Perhaps with more time and more research visits, we would eventually have been able to be achieve greater success with the younger participants. However, there are limits on the number of lab visits and time that we can ask of families and participants.

We sometimes find ourselves treading a fine line around issues of consent when participants refuse to continue testing or actively attempt to leave the testing room. We honor their initial expressions of refusal but then later try again to carry out the testing. To what extent should we encourage individuals who have limited means for expressing themselves to continue with a research procedure? We have relied on our own intuitions and are guided by the parents of our participants who typically encourage us and their children to continue with data collection. Still, it is not always easy to distinguish when a participant is experiencing transitory distress or discomfort and when that participant is actively unwilling to be involved in our research.

There are some potential research participants whose challenging and aggressive behaviors are quite extreme and who would thus pose a serious safety concern to themselves in the context of a strange environment and to the examiners and support staff. Although thus far we have not had to turn away potential participants, perhaps because their parents would not attempt to enroll them in a research study like ours, we are mindful that we would not be able to include the most severely challenging individuals. Excluding these individuals from research limits the generalizability of findings, and means that despite our best efforts to bring minimally verbal individuals into our studies, our research would still not represent the full spectrum of ASD. We hope that as treatment approaches for challenging behaviors and communication development advance, all research programs will be able to include every person with ASD.

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