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# The Autistic Perspective: Interviewing Autistic Adults on Lived Experiences with Behavior Modification and How It Has Shaped Their Communication

Lighla R. Whitson  
*University of Arkansas-Fayetteville*

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The Autistic Perspective: Interviewing Autistic Adults on  
Lived Experiences with Behavior Modification and How It Has Shaped Their Communication

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science in Communication Sciences and Disorders

by

Lighla R. Whitson  
Lyon College  
Bachelor of Science in Anthropology, 2012

May 2023  
University of Arkansas

This thesis is approved for recommendation to the Graduate Council.

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Christine Holyfield, Ph.D.  
Thesis Chair

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Rachel Glade, Ph.D.  
Committee Member

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Kimberly Frazier, Ph.D.  
Committee Member

## **Abstract**

The use of behavior modification (BM) based treatment, the best-known example being Applied Behavior Analysis (ABA), is established as an evidence-based practice for promoting communication and other outcomes for Autistic individuals. As such, many Speech Language Pathologists (SLPs) use it in their practice to target various forms of communication. Among many autistic advocacy groups, however, ABA and other BM informed therapies are often described as a detriment to mental and emotional health. Organizations such as the Autistic Self Advocacy Network (ASAN) have come out against the practices and recommend finding different approaches to teaching communication skills.

Much research is needed to understand this disconnect between the scientific and clinical community's understanding of BM based therapy as an effective, evidence-based therapy model, and the experience of autistic advocates as traumatic. As a small, early step in the large amount of research needed, this study takes a qualitative, phenomenological based approach, using semi-structured interviews to gain insight into the lived experiences of autistic individuals who were recipients of BM based intervention. The results of this study have the potential to illuminate future research directions, help therapists develop a more comprehensive understanding about the effects of BM on the lives of autistic individuals, and begin the work of building common priorities between the clinical and autistic communities.

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## Context

### Introduction

Many Speech Language Pathologists (SLPs) use Behavior Modification (BM) methodology in their practice, whether knowingly or unknowingly, through the use of positive reinforcement, extinction behaviors, and non-corporal punishment (*i.e.* withholding or confiscating preferred objects). Speech therapists often work with Board Certified Behavior Analysts (BCBA) therapists as part of a child’s interdisciplinary team and many private therapy companies include Applied Behavior Analysis (ABA) services, the most well-known example of BM based treatment, alongside occupational, and physical therapy.

According to an article on ABA from the American Speech-Language-Hearing Association (ASHA), “Descriptions of ABA as an instructional methodology appear throughout the seminal literature of speech-language pathology” (Schwartzman et al., 2021, as cited in *Applied Behavior Analysis and Communication Services*, n.d). The author of the article goes on to say that ABA can be a complement to SLP provided communication interventions if used in natural contexts (*Applied Behavior Analysis and Communication Services*, n.d.).

Autistic advocacy groups, however, often offer a different perspective. Many Autistic adults cite long term trauma resulting from ABA or other BM informed therapy and a lot of Autistic led organizations such as the Autistic Self Advocacy Network (ASAN) report that therapies focused on reducing autistic behaviors hurt autistic people without teaching any of the skills needed for navigating the world with disabilities (*What We Believe*, n.d.). With BM treatment methodology woven throughout our practice, as SLPs, it’s important that we understand fully how it affects Autistic individuals from their perspective.



## **Note about Language**

This study uses identity-first language, rather than person-first language, to refer to participants and other members of the autism community. This is in accordance with the expressed preference of the autism community in general and of the participants of this study in particular. More information on identity-first language can be found on the Autistic Self Advocacy Network website, <https://autisticadvocacy.org/about-asan/identity-first-language/>.

Additionally, many Autistic individuals who are active in the community have expressed a preference for the first letter of Autistic to be capitalized, similar to the Deaf community, to reflect that autism is part of their identity. Although not all Autistic individuals share this preference, several participants in this study did, therefore the word Autistic will be capitalized throughout.

Three of the study participants frequently refer to ABA even when discussing other forms of therapy such as speech or occupational therapy or when discussing certain teachers' classroom management styles. Among many circles, ABA has come to have a more generalized meaning that refers to any form of BM styled treatment. The subject of this study is not solely on ABA therapy, but rather on the use of behavior modification therapy in a variety of setting and treatment types.

## **Purpose**

The goal of this research is to better understand the impact of BM informed practices on Autistic recipients, particularly its impact on their communication, and to receive advice from members of the population on the best ways to proceed in the future. Given that Autistic individuals are the ones who have the actual experience participating in BM therapies and given that every clinician engages in practice to support – rather than harm – their clients, research is

urgently needed to understand the experiences of autistic individuals with BM treatment. This understanding, and the dissemination of this knowledge, is the goal of this study. While additional research is needed, the information gathered here represents an early step in a much-needed dialogue to ensure that therapies maximize communication and quality of life outcomes for all Autistic individuals.

## **Background**

Behavior Modification was first popularized by B.F. Skinner in his book *The Behavior of Organisms* published in 1938. The premise, based on his study of the behavior of animals, was that behaviors could be shaped directly through the use of operant conditioning, the use of rewards to positively or negatively reinforce good behaviors and the use of positive or negative punishment to discourage bad ones. The positive and negative terms do not reflect morally on the stimuli, but rather refer to whether the inducement is present or absent (B.F. Skinner, 1938). For example, a positive reinforcement could be the introduction of a treat for a toddler and a positive punishment might be that the child is spanked for eating too many sweets. A negative reinforcement, meanwhile, might be the removal of curfew for a well-mannered teen while a negative punishment would be the removal of TV or phone privileges if they abuse that leniency. In a 2022 article published in the National Library of Medicine, Scott et al. remarked that BM intervention is primarily used to target the reduction of “maladaptive behavior” and mentioned that it is often a key part of “externalizing behavior disorders” such as Attention Deficit Hyperactive Disorder (ADHD), autism, or Oppositional Defiant Disorder (ODD). The authors noted that some initial resistance is to be expected and a poorly enforced behavior plan can lead to worsening behavior. Overall, however, they found that BM therapy can achieve goals by modifying the way the individual thinks and how they feel about themselves. They particularly

found ABA to be an effective treatment approach with Autistic individuals (Scott et al., 2022). The study did not, however, use Autistic input as a metric when determining its efficacy.

Applied Behavior Analysis (ABA), the most well-known form of BM therapy, was developed primarily by Ivar Lovaas, who founded the Young Autism Project in 1970. The project was a result of behavioral studies he had done with Sidney Bijou, which was heavily influenced by the work of B.F. Skinner (DeVita-Raburn, 2016). In a speech, Ivar Lovaas stated that the emphasis of the treatment program was to “make the child look as neat and appropriate as possible” and that they attempted to “suppress the more severe or grotesque forms of self-stimulatory behavior by the use of aversive stimuli” and reasons that “(it) is obviously very embarrassing for people to be in the company of a child who jumps up and down and ritualistically slaps his arms in front of his face” (Lovaas, 1970). The clear implication being that the self-soothing behaviors of the child were modified primarily for the comfort of others. The Autistic Self Advocacy Network has published an ethical guidance brief that examines therapy based on the goals targeted and who they ultimately benefit, the client or society (Rodríguez-Roldán, V, 2021). It describes ABA in a similar manner to Lovaas’ initial description as “a model of intervention focused on changing the external behaviors of autistic children, with the goal of making an autistic child look and act non-autistic”. Therefore, there does not appear to be a lack of shared understanding about the goal of behaviorism between the Autistic and academic communities. There does seem to be a disconnect, however, about whether the goal of BM therapy is a worthwhile one that should be pursued in the first place, and what the effects of BM based treatment are on the Autistic individuals who are recipients of it.

In recent years, there have been many innovations in BM based approaches. ABA has shifted almost entirely away from the punishment framework, and new variations in therapy style

such as pivotal response training and play-based, child-led interactive models, have supplanted the previous one-behavior-at-a-time methodology of old ABA models. Therapy based on the revised models is often referred to as “New ABA” (DeVita-Raburn, 2016). Though children today may experience a different form of ABA than autistic adults who were children in previous decades, their insights still hold valuable information into ensuring clinical practice is a meaningful and positive experience for all individuals. Despite the change in certain practices, “New ABA” is still viewed as problematic by many Autistic advocacy groups. According to Autistic self-advocate Kaylene George, this is primarily due to the continuing emphasis on compliance and on reducing overtly autistic behaviors, the continued use of external motivators, and the high number of hours (George, 2019). One study participant who is looking for treatment for his own son commented that “the problem with the supposed new ABA (is that it’s) just like the old ABA that I went through.”

## **Objectives**

The objectives of this study are as follows:

1. Gather phenomenological data on lived experiences with BM via semi-structured interviews with Autistic adults.
2. Qualitatively measure the data using established coding methods as outlined in Johnny Saldaña’s book, *The Coding Manual for Qualitative Researchers*.
3. Present the major themes and subthemes identified during the coding process with supporting text from the original transcripts.
4. Extrapolate from the presented data about long-term effects BM may be having on some therapy recipients.

5. Postulate potential future avenues of research with the goal of broadening the type and volume of data to allow for a more full and accurate picture that can lead to future industry changes.

## **Methods**

### **Methodological Framework**

This phenomenological study consisted of semi-structured interviews examining the lived experiences of Autistic adults within the context of participation in some form of behavior modification (BM) based treatment. The goal of phenomenology is to capture lived experiences and derive meaning from them (Finlay, 2011). Additionally, qualitative, interview-based research provides greater flexibility and allows the interviewer to develop greater reciprocity with the participant and to follow up on relevant participant responses (Kallio et al., 2016). Given that the primary purpose of this study is to give autistic individuals a platform to share their opinions and experiences with ABA and/or BM based therapies, an interview-based, phenomenological style of research was determined to be the best-suited research design.

According to a systematic review of qualitative semi-structured interviews, the semi-structured interview method is most suitable when examining the perceptions and opinions of individuals on issues that are complex or emotionally sensitive by allowing the focus to be on the most meaningful issues for the individual participant resulting in a greater diversity of perspectives within a structured context (Kallio et al., 2016). For this reason, it was also determined that a semi-structured interview would best serve the purposes of the study.

### **Data Collection Methods**

Members of the autism community, in partnership with the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) organization, consulted on the content and

wording of interview and survey questions. AASPIRE advocates for and assists with the creation of more ethical, inclusive research using the principles of Community Based Participatory Research (CBPR). They connect members of the autism community with academics seeking to do research about the population resulting in studies that are the product of an equal partnership between the researcher and the community members. Although time constraints did not allow for this paper to be a full collaboration, important feedback from Autistic individuals was used to modify the interview and survey questions to increase accessibility and decrease the possibility of trauma responses in participants triggered by the sensitive nature of the discussion topic. Example documents from the AASPIRE team were also used to make recruitment materials more accessible and increase participant understanding of rights and expectations.

Participants were recruited nationally via recruitment posts (see **Appendix B, Figure B1**) on social media platforms and discussion forums. No participants were excluded based on race, ethnicity, gender identity, sexual orientation, or communication modality. The only requirements beyond familiarity with the subject matter was a willingness to participate and the ability to respond independently to the interview questions either verbally or via an alternative or augmentative method. Facilitated Communication was not permitted to improve study validity and ensure Autistic voices were not being usurped. Interested parties were directed via the recruitment posts to a pdf with additional information on the purpose and methodology of the study as well as instructions for signing up (see **Appendix B, Figure B2**). Participants contacted Lighla Whitson via email and were sent information on study confidentiality, potential risks/benefits, and participants' rights (see **Appendix C**) that had been pre-approved by the University of Arkansas Institutional Review Board as well as step-by-step instructions for the

installation and use of a free Zoom account. Participants selected an interview time via a doodle poll and completed a 10-question survey on relevant demographics (see **Appendix D**).

Interviews were conducted remotely via video conferencing software with the maximum level of privacy controls. The interviews allowed for the participants' preferred communication modality to provide the greatest degree of accessibility. Interviews were recorded and kept on password-protected storage software in keeping with the regulations of the primary researcher's Institutional Review Board. The use of video conferencing software reduced costs, and allowed for a larger and more diverse participant pool, while also being more flexible and convenient for participants (Gray et al., 2020). Research done on video conferencing interviews has found no difference in quality from that of face-to-face interviews (Cabaroglu et al., 2010; Deakin & Wakefield, 2013) and when given the option, the majority of participants expressed a preference for remote interviews (Sedgwick & Spires, 2009). Given the recent prevalence of COVID-19, this format also allowed for a greater level of safety and comfort for both the interviewer and the participants and reduced the possibility of distorted speech, when communicating orally, by removing the necessity of wearing masks.

At the beginning of the interview, participants were briefed once again on the purpose of the study, the ways in which their information would be kept confidential, the format of the interview, and the expected length. Given the sensitive nature of the topic of discussion, participants were advised of potentially triggering topics that may be addressed and given a chance to specify if there were any topics they would prefer to avoid. None of the participants requested avoidance of any particular subject matter. Participants were then given the chance to ask additional questions prior to the beginning of the interview (Turner, 2010).

There were three primary sections of interview questions (see **Appendix E**). The first section included questions about general BM or ABA experiences. Examples of questions included: time spent in therapy, the way therapy was conducted, types of reinforcement, feelings about overall therapy techniques, and feelings about their therapists. The second set of questions related specifically to communication and speech therapy. Examples of questions included: how they felt BM practices affected their communication abilities overall, if they attended speech therapy and how it related to other BM specific therapies, whether Augmentative and Alternative Communication (AAC) devices were made available if needed and how well they were trained on them. The final section was more open ended with participants being given time to talk about other aspects of BM and their therapy that the more focused questions hadn't touched on as well as an opportunity to discuss their thoughts on the future of ABA and similar BM influenced therapies, as well as to give any advice they thought would be helpful for therapists to know.

## **Participants**

Although Autistic individuals are not the only ones to receive ABA therapy, the therapy is overwhelmingly recommended when a child first receives an autism diagnosis. Therefore, ABA and BM therapy affects autistic individuals disproportionately to people with other types of "impairments" for whom behavior modification is typically recommended. Additionally, the most vocal groups decrying the practices of these treatment types are autistic advocacy organizations such as the Autistic Self Advocacy Network (ASAN) and Autistic Inclusive Meets (AIM). For these reasons, the study specifically targeted autistic individuals who had previously participated in ABA and/or other BM therapies.

Seven individuals requested additional information and four individuals agreed to participate. Additional information on participant demographics can be found in Table 1. Rather



than refer to patients by their names or by participant numbers, pseudonyms were chosen at random to protect participants anonymity without losing sight of their humanity. The pseudonyms selected were Caitlyn, Diane, Ashton, and Maggie. One thing that was not included in the demographic survey but was discussed during the individual interviews was the setting in which the participants received BM. Caitlyn and Diane both experienced BM in the school setting. Caitlyn indicated that her classroom teachers practiced behavior modification and Diane specified that she had received occupational and speech therapy that used the behavior modification methodology. She also specified that one of her classes that was focused specifically on communication and job preparedness was modeled on behavior modification-based therapies. Maggie received home ABA therapy that also included activities in the community. Ashton was made a ward of the state and placed in a lockdown institution from the ages of 14-17 during which time he received group therapy, Cognitive Behavioral Therapy (CBT), covert therapy, as well as others. He also specified that behavior modification was used by all of the staff for every part of daily life.

**Table 1. Participant demographics**

Pseudonym	Age Range	Race	Gender Identity	Location of treatment	Age range during therapy	Hours per week	Need for AAC	Support Needs on an average day
Caitlyn	36-45	Caucasian	Mentally Agender Girl	Oregon, Missouri	15-20 / Unsure	Unknown	None	Pre-prepared meals and grocery shopping, assistance with laundry, legal guardian handles financials.
Diane	26-35	Caucasian	Female	Canada	0-10 and 15-20	1-3	None	A support person at all times
Ashton	46+	Caucasian	FTM (female to male transgender)	Virginia	10-20	Unknown	Currently Uses: Gestures, pen/paper, Fingerspelling (asl), AAC app, typing	Support needs vary. Sometimes includes executive functioning support and ADL support with food prep, dishes, and laundry. Often forgets hygiene tasks. Co-morbid conditions require additional support. Beyond that would prefer not to say.
Maggie	26-35	Caucasian	Female	Wisconsin	0-10	Unknown	Previously used: Sign Language	Declined to answer.

Age ranges were used rather than specific ages to better protect participant's anonymity.

Current age range options included 18-25, 26-35, 36-45, and 46 or older. Diane and Maggie fell within the 26-35 age range, Caitlyn fell within the 36-45 age range, and Ashton fell into the 46 or older age range. Given that ABA, the most well-known example of BM based therapy didn't become prevalent until the late 1970s, it was not deemed necessary to specify beyond the age of 46. Age ranges were also used to indicate when the participants took part in BM based treatment to account for the likelihood that most participants would not remember exact ages. The options

included 0-5, 6-10, 10-15, 15-20, and 20+. Participants could also select “I don’t know.” Caitlyn was unsure about the specific years but specified that she did attend between the ages of 15-20. Diane attended therapy between the ages of 0-10 and 15-20. Ashton attended between the ages of 10-20, Maggie attended between the ages of 0-10.

Most participants weren’t sure of how many hours they attended therapy. Diane specified that she attended around 1-3 hours weekly and Ashton clarified during the interview that he was constantly exposed to BM practices while institutionalized, but did not know the exact number of hours per week he would have attended therapy. All of the participants were Caucasian and received therapy in various parts of the US and Canada. Diane and Maggie identified as female, Caitlyn as a mentally agender girl, and Ashton as a transgender male. Given that he was misgendered during his adolescence when therapy was taking place as well as much of his early adulthood, Ashton felt that the specifics of his gender identity were relevant to include.

Participants were asked to describe their general support needs on an average day. Caitlyn specified that she required support to prepare meals, grocery shop, and complete additional activities of daily living (ADLs). She also indicated that her financials were handled by her legal guardian. Diane said that she requires a support person at all times, which she clarified during the interview was largely due to a lack of short-term memory. Ashton said his support needs varied daily but listed some support needs such as for executive functioning, memory, and completion of certain ADLs. Maggie declined to answer.

### **Analysis Methods**

Johnny Saldaña’s book, *The Coding Manual for Qualitative Researchers*, published in 2009, was used as reference for method of coding and thematic isolation. Participant interviews were transcribed with the assistance of the transcription software Otter.ai. Initial transcriptions

were automated followed by two rounds of review by Lighla Whitson to check for accuracy and to remove any identifying information. Analytic memos were created and consulted throughout the information gathering and analysis procedures. Coding was done manually, without the use of online Computer-Assisted Qualitative Data Analysis Software (CAQDAS). *In-vivo* codes, which use the participant's direct language, were selected to ensure the codes would embody their true voices and to help identify key repeating phrases. Descriptive codes, single words or short phrases used to describe the overall topic, were selected for improved clarity and to encompass broader ideas that could be more easily applied across participants.

Pre-coding was done by highlighting the most relevant data and important quotes. The initial round of coding split the data into smaller segments for more nuanced interpretation. The initial codes were mostly *in-vivo*. The second round of coding was done on larger "lumps" of data for more broad analysis to give a more generalized view of the information as a whole. These codes were a mix of *in-vivo* and descriptive. Initial, nuanced codes were combined in this step. The third, and final round of coding before thematic analysis, was done to reduce redundancy in the codes and create a more cohesive picture of the data as a whole, rather than as four individual sets. In this step, codes that were rarely used were eliminated and the rest were grouped under larger umbrella codes. These were mostly descriptive in nature.

Thematic analysis was done based on the final set of about 50 broad codes that each encompassed several more nuanced ones on a related topic. Codes were sorted according to general relatedness that fell mostly along the lines of initial question divides (*i.e.* codes about communication, BM in general, advice for the future). Codes were then evaluated for relation to others within a general topic (*i.e.* codes about disguising or changing behaviors, codes about therapists) and these became the 5 main themes of the study. Finally, codes within themes were

grouped based on relationship to one another to form subthemes (*i.e.* the codes social skills, “being understood,” and “wanting to understand” were grouped into a social communication subtheme). In the end five major themes and 17 subthemes emerged. These were named descriptively but given a corresponding direct quote from the initial *in-vivo* codes. Additional quotes were isolated from the transcripts and sorted based on their relatedness to the individual themes and subthemes.

### **Reflection on Potential Biases**

However well-intentioned and however many precautions are taken against bias, problems can still arise from factors beyond an investigator’s control. Reflexivity, the procedure of reflecting on and reporting potential biases is important for study validity. Researchers should be utilizing reflexivity continuously starting before data collection or analysis and continuing after study completion (Darawsheh, 2014). Researcher identified possible biases will be expanded upon below with additional information on steps taken to attempt to mitigate them.

***Selection Bias*** When searching for places to post flyers seeking participants, many of the discussion boards and social media groups for Autistic self-advocacy had requirements for membership that included a promise not to post anything pro-ABA. While this is, in and of itself, a good metric of the general opinion of the autism community on ABA and BM practices, it may cause the pool of potential participants to skew mostly in a more negative direction. To counter this, attempts were made to post the flyers in a wide range of locations and with a variety of groups. Inquiries were made with organizations that are anti, pro, and neutral on the topic of ABA. Flyers were posted with a wide range of hashtags on Instagram and Tumblr with no specifically negative or positive connotations.

**Negativity Bias** Negative events or feelings tend to invoke stronger reactions and a higher likelihood of generating responses. In the same way that a person who has a terrible meal is more likely to leave a scathing review than someone who has had a perfectly adequate one is to leave a kind one, so too is a person who had a traumatic experience more likely to join a study like this one. Of our four participants, two had very strong negative feelings about their experiences, one had mildly negative feelings about their experiences, and one had mostly ambivalent but slightly positive feelings about their experiences. While this may not be a truly representative sample, it does span a wide range of reactions, demonstrating that the study is not totally biased to a negative response.

**Confirmation Bias** Researchers, like anyone, have opinions on topics that can sometimes bias how they approach a study and cause them to try and find information that fits their world view rather than accurately relating the data without bias. To mitigate the chances of this, the questions were phrased in a neutral manner or with a corresponding positive for every negative and *vice versa*. Additionally, interview questions were reviewed by four members of the autism community with varying life experiences of their own and all recruitment material was presented in a neutral manner without specific targeting. During the interview, participants were encouraged to elaborate on their own ideas, but apart from asking questions or attempting to clarify previous responses, the interviewer spoke minimally.

## **Results**

In general, the participants described experiences ranging from benign or mildly upsetting to traumatizing. Maggie said that she enjoyed her therapy about half of the time depending on who her therapist was and that she found it somewhat helpful in social interactions and communication. The determining factor in whether or not she enjoyed therapy appeared to

be the level of control she had and how well the therapist listened to her. Caitlyn described how her diagnosis was hidden from her and presented only as a bad thing. She shared feelings of frustration at teachers and family members never embracing who she was and always trying to change Caitlyn against her will. Two of the participants, Diane and Ashton, explained how the heavy emphasis on compliance in their therapy left them susceptible to predators and caused them to put other's needs over their own well-being. Both described feelings of being trapped in therapy that wasn't helpful or appropriate for them and attributed to their BM modeled treatment only harm. Ashton, in particular, painted a grim portrait, describing being made a ward of the state after suffering abuse at the hands of his father when his mother couldn't afford to care for him and his siblings. He was locked up with criminals in an institution at the age of 14 with no ability to escape the therapists and doctors and no control over anything in his life. Each of the interviewees have had unique experiences with BM treatment models and have shared their valuable insight to allow therapists and researchers opportunities for growth.

After analysis of the data, five themes were most predominate, and each encompassed several additional subthemes. A list of themes and sub-themes can be found in Table 2. They were derived from a combination of *in-vivo* and descriptive codes. They are presented descriptively for clarity and cohesiveness but with the supporting quotes from the interviewees to demonstrate origins and to increase study validity. The five themes include: Long-Term Trauma, Impact on Communication, Conformity, Impressions of Therapists, and Recommendations. Each theme and subtheme are presented below in greater detail with a breakdown of individual participants responses and with additional supporting text from the transcripts.

**Table 2.***Themes and Subthemes*

<b>Themes</b>	<b>Subthemes</b>
<u>Long-Term Trauma</u> <i>"I get PTSD when I see it"</i>	<ul style="list-style-type: none"> <li>▪ Conditioned Behaviors <ul style="list-style-type: none"> <li>○ <i>"That was so embedded in growing up was, 'you do this, you get that'"</i></li> </ul> </li> <li>▪ Emphasis on Compliance and a Loss of Autonomy <ul style="list-style-type: none"> <li>○ <i>"They teach you to walk away, but you aren't actually allowed to walk away"</i></li> </ul> </li> <li>▪ Ableism and Self Doubt <ul style="list-style-type: none"> <li>○ <i>"What ended up coming out of that is what I now know is a whole lot of internalized ableism"</i></li> </ul> </li> <li>▪ Emotional Burnout and Disassociation <ul style="list-style-type: none"> <li>○ <i>"Now I live in a constant state of burnout"</i></li> </ul> </li> <li>▪ Misdiagnosis and Delayed Diagnosis of Autism Due to Trauma <ul style="list-style-type: none"> <li>○ <i>"it took me like 10-12 years to get a diagnosis"</i></li> </ul> </li> </ul>
<u>Impact on Communication</u> <i>"It really did hurt my communication"</i>	<ul style="list-style-type: none"> <li>▪ External Validation of Communication Style <ul style="list-style-type: none"> <li>○ <i>"Even just communicating with friends, it was all graded"</i></li> </ul> </li> <li>▪ Emphasis on Spoken Language <ul style="list-style-type: none"> <li>○ <i>"I was so conditioned that you have to talk"</i></li> </ul> </li> <li>▪ Social Communication <ul style="list-style-type: none"> <li>○ <i>"I just didn't understand 90% of it, so I couldn't really communicate because I didn't know what was going on"</i></li> </ul> </li> </ul>
<u>Conformity</u> <i>"It's like they care so much about the society thing"</i>	<ul style="list-style-type: none"> <li>▪ Masking <ul style="list-style-type: none"> <li>○ <i>"Even if no one's around, I still feel the pressure to pretend that I'm just a regular adult like anyone else"</i></li> </ul> </li> <li>▪ Changing or "Curing" Autism <ul style="list-style-type: none"> <li>○ <i>"In their point of view, it wasn't me they were changing...and I thought it was a part of me (autism)"</i></li> </ul> </li> <li>▪ Stimming Eradication <ul style="list-style-type: none"> <li>○ <i>"The more I tried not to stim, the more I struggled"</i></li> </ul> </li> </ul>
<u>Impressions of Therapists</u> <i>"ABA either can or cannot be abusive...depending on the agency and the therapists"</i>	<ul style="list-style-type: none"> <li>▪ Well Meaning Therapists <ul style="list-style-type: none"> <li>○ <i>"The intent was definitely love"</i></li> </ul> </li> <li>▪ Therapists Causing Harm <ul style="list-style-type: none"> <li>○ <i>"The way they were going about it was harmful"</i></li> </ul> </li> <li>▪ Reinforcement Practices <ul style="list-style-type: none"> <li>○ <i>"I hate the phrase natural consequences...they neatly bastardized that"</i></li> </ul> </li> </ul>
<u>Recommendations</u> <i>"That's the problem with the supposed new ABA, that's just like the old ABA that I went through"</i>	<ul style="list-style-type: none"> <li>▪ The Future of BM based therapy <ul style="list-style-type: none"> <li>○ <i>"I think you can't reform ABA. I think it has to be completely dismantled"</i></li> </ul> </li> <li>▪ Change the System, not the Person <ul style="list-style-type: none"> <li>○ <i>"You have to meet halfway and hopefully that can kind of bridge a gap...just one person trying to bridge the gap, I don't think is fair"</i></li> </ul> </li> <li>▪ Listen to Autistic Individuals <ul style="list-style-type: none"> <li>○ <i>"Us Autistics have a voice too"</i></li> </ul> </li> </ul>



## **Theme 1: Long-Term Trauma**

All interviewees described some amount of lasting harm when discussing their experiences with BM though the degree varied. When asked about any ongoing impact from therapy, Maggie responded that the therapy continued to impact her “just a teeny tiny bit,” specifying that this was mostly in the form of occasional masking. She did note, however, that she was familiar with many Autistics who consider ABA “clinical torture,” something she ascribed primarily to compliance training. She also compared those types of therapy to conversion therapy for homosexuals, which was also designed by Ivar Lovaas. Caitlyn listed two layers of specific trigger words that had been used frequently as rebukes and that now cause her to become upset. The first layer, being words like “immature” and “childish”, she was able to list. The second layer are more triggering to the point of Caitlyn not wishing to explicitly say the words themselves, electing to instead spell them out. Diane and Ashton described the most damaging long-term impacts of the behavior modification they received to the point of having episodes of PTSD and constant burnout.

### ***Sub-theme: Conditioned Behaviors***

When describing an ongoing lack of internal motivation, Diane explained it “was so embedded in growing up was, ‘you do this, you get that.’” For her, it is still a struggle to enjoy things for their own sake rather than waiting for some form of reward or affirmation. She recounted being given incentives as rewards for doing “better” as judged by the therapist. This was echoed by other participants who described gaining positive attention or small rewards from therapists when they performed well and a total lack of response when they did not. For some this was something they appreciated and didn’t see as harmful. Maggie fondly described appearing in a newspaper article in which her therapist tested her on various things and would

pat her on the head and tell her “very good” when she completed a task as directed and how he would do funny impressions for her as a reward.

Though that was a happy memory for Maggie, Diane looked back on a similar experience with one of her teachers, who would give her stickers, with less appreciation. “In hindsight, I’m very resentful because it taught me if you perform, people will love you. If you don’t, no one will care.” That desire to gain love and approval through performance contributed to Diane’s lack of internal motivation, but it also had an even more damaging consequence. She said that the “do this and you get that” mentality was “already part of who (she) was” when, at a young age, a sexual predator used a similar technique to get her to do what they wanted. “I knew it was wrong, but at the same time, I was like, I have to do it or I won’t get to watch my show.” This assault she explicitly linked to BM based therapies and the behaviors therapists had conditioned into her.

***Sub-theme: Emphasis on Compliance and a Loss of Autonomy***

As demonstrated by Diane’s experiences, one of the most dangerous conditioned behaviors is compliance and the giving over of autonomy to another person. All the participants listed this as a damaging element of the BM based treatment they received, albeit in varying levels of magnitude. Maggie attributed her preference for one of her therapists to the amount of choice he gave her and the fact that he listened to her and took her feelings into account. A piece of advice she gave to therapists was to not “count on the client or whoever, you know to be compliant at the drop of a dime.” Caitlyn talked gratefully about a teacher who had taken the time to try and understand what she loved about her stims and didn’t try to simply force her to obey as others had done.

Ashton described the rigid rules he had to live by when in the institution and how he couldn't escape and couldn't refuse anything, at least not without consequences. The therapists might have said the right things, but their actions were the lessons that stuck. "They teach you to walk away, but you aren't actually allowed to walk away." After leaving the institution and going to college, he describes being raped by a classmate, something that it took him a long time to recognize for what it was. "they set me up" he said "to end up in a situation where I was raped...being raped is directly related to the ABA." Ashton began dating his rapist out of a desire to please. Eventually, he ended up marrying his rapist after becoming impregnated. His husband was very controlling, but no one had taught him that he has autonomy. That he can say no, can leave regardless of what the abuser might want. In fact, he had been taught the exact opposite. "It (referring to therapy) teaches them to get out of their comfort zone when their gut says something's not right. They get taught how to ignore that because they're doing what's in the best interest of this other person." He did manage to escape his abuser, but it took several years and giving up contact with his daughter to do it.

***Sub-theme: Ableism and Self Doubt***

One potential consequence of therapy that is designed for correcting deficits and flaws can be a lowered sense of self-worth and internalized self-doubt. This topic was not specifically addressed by Maggie or by Caitlyn, but the other two participants talked about it at length. Ashton talked about being "gaslit" into thinking that any problem that occurs is his fault. He said that "if I was struggling, it was something wrong with me. It was something I had to fix in my thinking." He described the challenges he faced transitioning out of the institution and into regular schooling caused by self-doubt and exacerbated by being labeled as "emotionally disabled" on his Individualized Education Plan (IEP). When he was in pain, if it wasn't

something easily apparent, it was brushed off as attention seeking. That doubt is something he internalized, and it caused him to delay seeking medical attention when it was needed. He said that “what ended up coming out of that (referring to therapy) ...is a whole lot of internalized ableism,” that he is still struggling with today.

Similarly, Diane recounts “sitting for hours and hours just trying to do something I knew I wasn’t capable of” and a feeling of complete defeat by the end of the day. She explains that she was instilled with the idea that anything can be overcome if you work hard enough to accomplish it, leading her to feel that her “failures” were all her fault and not the result of her neurodivergence or any of her co-morbid conditions. Even as an adult, she says that she still beats herself up for not being able to work a normal job like others can, despite knowing it’s not a matter of effort, but of ability. She talked about trying so hard but no matter how hard she tried, “nothing ever changed.” The effort it would take to work on these tasks would tax her to the point that she was unable to learn anything the rest of the day.

***Sub-theme: Emotional Burnout and Disassociation***

As Diane pointed out, the amount of work it takes to succeed, or even to try and succeed at therapy tasks can be very taxing. She described crying during homework and being constantly overwhelmed. That feeling of emotional burnout was something she shared with both Caitlyn and Ashton. Caitlyn described becoming overwhelmed and crying when she had too much homework and said that, after her diagnosis, accommodations were made for her in her classes to reduce the amount of work assigned and reduce the possibility of burnout. Ashton talked about how therapy aimed at breaking down ADL tasks into smaller components frequently backfired with him. His ADHD allowed him to break things down into tiny composite parts, but then the sheer number of steps involved in a task overwhelmed him. He also explained that being given a

chance to play with the caveat that work would resume afterwards didn't really allow for a true brain break because all his brain was doing during that break was asking "when are they going to ask me to do that homework again?" He cautioned therapists against seeking so many hours for therapy with kids that are already overwhelmed with what they have to do at school. Even five or ten hours he said could be too much for children who have a lower threshold already for overwhelm and trauma and that have been working hard all day at school. "If I'm burned out at the end of the day, but you're still making me work...I can't escape."

***Sub-theme: Misdiagnosis and Delayed Diagnosis of Autism Due to Trauma***

Apart from Maggie, all of the participants were misdiagnosed or went undiagnosed until late adolescence or adulthood. Caitlyn described finding out about her diagnosis in high school and being excited to learn about the way her brain works differently, even if the adults in her life weren't all equally excited about the discovery. She talked about how the diagnosis was hidden from her and how her differences were downplayed at first. She was told she had Asperger's Syndrome (a now outdated term for autistic people with fewer support needs), which her mom described as the "kind to have" if you "have to have it", referring to autism. She found out that Asperger's was a form of autism when she overheard her mom discussing it in another room.

Neither Diane nor Ashton got their diagnoses until well into adulthood. Diane was misdiagnosed with short-term memory loss as a child. She does not have any short-term memory storage, which is one of the primary reasons she needs so much support for specific tasks. The diagnosis caused her to be put into occupational therapy despite the fact that nothing they targeted would be able to address the issue. She was constantly frustrated during therapy and described being scared that getting an autism diagnosis would cause her to be placed in therapy again. "I never wanted the diagnosis, I was more scared of the diagnosis than being jobless." In

the end it took over 10 years and her daughter being diagnosed as being on the autism spectrum before she sought out a diagnosis for herself.

Ashton also only sought a diagnosis for himself after one of his children was diagnosed, though he still didn't receive it until nine years later, getting his official paperwork in August of 2022. He had been misdiagnosed as bipolar while in the institution, but that was never a diagnosis he accepted, and he fought to be taken off the medication after reading the side effects. He had been given the additional diagnoses of ADHD and ODD causing any difficulties he had to be ascribed to his being defiant or confused. As a result, the doctors never recognized that he was on the autism spectrum despite numerous signs. He was especially scornful of functioning labels, saying sarcastically "my IQ was off the charts, so I was too smart to be autistic." He also described the discrepancies in the labels given to his children, noting that his son is classed level 3 but occasionally makes eye contact, which causes some to label him high functioning, while his daughter is considered high functioning but still struggles with some of the common milestones that her peers had long ago mastered, such as potty training.

## **Theme 2: Impact on Communication**

Communication was a major focus of the study, and all participants were asked to discuss the impact of BM on their communication. Communication in this context refers to all forms including oral/spoken language, using an AAC, using sign language, writing, and social communication. Neither Caitlyn nor Maggie described a major impact on their communication as a result of BM, but Maggie did report that her therapy helped slightly with speaking more purposefully/learning social skills while Caitlyn noted that she was sometimes discouraged from talking about preferred subjects by teachers. Diane and Ashton both reported that therapy hurt their communication in various ways. The main topics touched on were rigid rules for

communication and the requirement that communication meet standards of external validation, an emphasis on using spoken language over alternative methods, and the impact on their social communication overall.

***Sub-theme: External Validation of Communication Style***

One reoccurring topic of discussion was the emphasis on “appropriate” communication and the need to acquire external validation of communication in order for it to be approved. Ashton remembered having to “learn to justify every single thing to somebody else’s satisfaction.” He recounted how he was required to modulate his tone and volume, look the conversation partner in the eye, and to never interrupt. He said that he had to keep his voice “meek” to avoid people thinking he was upset or rude but noted that no one listened when he spoke gently because it wasn’t important enough, so no one ever listened either way. If he tried to get attention by physically tapping someone’s arm, he was chastised for invading their space and if he spoke without maintaining eye contact, he was ignored. He passionately spoke about how he “cannot stand being interrupted” due to the double standards the therapists had when instructing him on how to communicate appropriately. “I wasn’t allowed to (interrupt), but it was okay for everybody to cut me off because they wanted clarification or to make sure my thinking process was okay.”

Diane recalled how her speech therapy frequently targeted unhelpful and difficult tasks such as rapidly switching between French and English and a lot of emphasis on instant recall that requires short-term memory to accomplish. She talked about how worn out she would be after so much code-switching and how the skill seemed to her to be of little use. She also discussed a communication class she was required to attend in 11<sup>th</sup> grade during which every interaction was assessed and graded for “proper communication,” including informal chatting with friends.

“Those topics they didn’t see as productive conversation, they would deduct for.” She said that she had never considered herself to be unsocial prior to that class with the implication that the focus on graded communication reduced her ability to be social. One of her friends, she remembered, had an IEP stating he would talk a lot and had a specific pattern of speech that was part of his diagnosis, but the IEP was ignored, and points were docked for improper speech as well.

***Sub-theme: Emphasis on Spoken Language***

In that same communication class, Diane said that there was a heavy emphasis on verbal conversation and recounted how students were deprived of AAC devices to prevent them from “what they believed was drawing” while trying to communicate with peers. It was thought this deprivation would encourage the student to speak verbally. There was also a heavy emphasis on stim reduction and standing still when speaking because it was distracting. This rendered Diane basically mute since she needed to “move to comprehend” and she had “always moved around or stimmed” while talking.

Ashton, who sometimes goes non-speaking, said that his experiences at the institution “really did hurt (his) communication” because of the heavy emphasis on spoken communication. He currently uses a combination of writing/typing, drawing, fingerspelling ASL letters, and AAC applications to communicate when he is unable to communicate orally. As his son cannot read, he tries to conserve his vocal language to use with his children and uses his alternatives during most of the day. When asked if he was ever given access to AAC or if any alternatives to spoken language were addressed while he was in the institution he responded with a scoffing “Are you kidding me?” He was allowed to learn sign, he said, but not to use it personally because he wasn’t Deaf. He is currently fighting a similar battle for his son. They’d found an SLP who was



receptive and open to AAC use but said that she had left after only one year at the school. He was told by another therapist that his son “didn’t really need AAC” and cautioned that his son wouldn’t learn to talk if he didn’t start speaking verbally during those brain plasticity years, despite all evidence to the contrary. Another occupational therapist used withholding practices and tried to require his son to label the “blue crayon while looking her in the eye before he could have it to draw.” In advice to SLPs and other therapists, he thoroughly denounced withholding of AAC devices as prizes or their use only in discrete trials with very specific targets. If the child doesn’t use it in those situations, it’s not because they don’t need it, but rather because the therapist has turned them off of it, he explained.

Alternatively, Maggie described a much more positive experience with the targeting of communication in her therapy. She explained that when she was first diagnosed with autism, which she indicated was at a young age, she “didn’t really speak too purposefully” and that one of the primary focuses of her therapy was to learn to talk. She uses only spoken language now but at the time was taught additional ASL signs to supplement her verbal communication and said that the therapists used “a little bit half and half, like sign language and verbal.” She did not feel that she was ever lacking in resources and found the combination of verbal and sign language adequately met her needs. According to her parents, she was speaking normally with purposeful meaning by the age of five or six, which she attributes to the ABA that she received. She did say that she attended speech therapy while in school but couldn’t remember any specifics about it.

***Sub-theme: Social Communication***

In social communication as well, Maggie felt that the therapy she received helped her “a teeny tiny bit” to communicate more clearly with her peers and to understand them as well. She

specified learning social skills as one of the most helpful parts of her therapy. When asked what kinds of social communication exercises she remembers doing, she referred to a scene in the Temple Grandin movie in which her aunt had pictures of faces with a variety of emotions and asked her to label the pictures based on the emotion. This, she said, was very similar to what she learned. She also vaguely remembered discussing ways of dealing with conflict and interacting with people in specific scenarios.

Caitlyn was mostly ambivalent about the subject of social communication training. Her vision limitations made reading expressions or holding eye contact irrelevant and in general described her social skills as being good without therapy. She did, however, indicate that some teachers discouraged her from talking too much about preferred topics such as her favorite colors because other people wouldn't be interested. She described making a story about something she loved and the feeling of disappointment when no one else liked it. When the interviewer asked if her hesitance to share her interests was as a result of something she was taught, Caitlyn said that she had "kind of learned over the years. Like some things my mom didn't like or some things other people didn't like or that kind of thing."

Diane described the feeling of not understanding 90% of what her peers were discussing and being unable to communicate as she didn't know what was going on. She said something that would have been helpful for her is having someone who could explain what was going on in simple terms. Someone to explain the games other children were playing, for example, so that she wouldn't have had to either play by herself or stumble through attempting to figure out how an activity was done on her own. She specified not forcing an autistic individual to take part if they didn't want to, but helping them communicate enough to join or to inform the other kids about how the game could be modified so that she could be integrated into the group. "Then I

would have been able to make better friendships at a younger age, knowing I had someone beside me to go ‘what are they playing?’”

Ashton talked about how many of his interests didn’t correspond with those of his female peers because he was interested in boy things but was forced to be female presenting at the time. “It made it really hard for me to get other people to understand what I was saying, and that’s one that still haunts me.” There was a lot of focus on forming “proper relationships” and preparing him for adulthood. However, Ashton said he didn’t actually learn the things they thought they were teaching him because “if they had taught me the skills they thought they were teaching me, it (the rape) would not have happened...I would have recognized that this person was dangerous.” Instead, he was taught to be affable and thus he kept tolerating controlling and abusive behavior, putting himself into unsafe situations in order to “have friends and be social.”

### **Theme 3: Conformity**

“It’s like they care so much about the society thing.” The sentiment behind Caitlyn’s quote was echoed across every interview. The topic that all participants agreed on the most was the detrimental effect of a heavy emphasis on conformity. The feeling that they had to hide how they really felt for the sake of other’s comfort, the need to change or be cured to fit in to society, and attempts to stop harmless self-soothing techniques were all common themes throughout the interviews.

#### ***Sub-theme: Masking***

Masking, also known as camouflaging, is a term used to describe the practice of suppressing behaviors and acting “appropriately” and it has been tied to higher levels of depression and suicidal ideations (Cage & Troxell-Whitman, 2019). Cage and Troxell-Whitman’s study determined that autistic individuals who masked were nearly three times as

likely to suffer from depression as non-autistic individuals. For the most part, Caitlyn said that the attempts to get her to mask were largely unsuccessful, for which she was glad, but that didn't mean that they didn't leave a mark. Teachers didn't understand why she preferred to be herself rather than hide it away and let people find out about her differences only later.

Ashton, on the other hand said he'd "learned very well how to mask." He talked about putting on a happy face and only ever being allowed to show happiness. When he finally left his husband, he said, no one in his family had any idea there had been problems despite years of dealing with abusive and controlling behaviors. He talked about therapy equating yes with happy, including using a smiley face for yes on AAC devices, and advised teaching all emotions as equally acceptable and letting kids feel how they feel. Diane had a similar experience in therapy, stating that she couldn't show her true emotions during the sessions. She continues to feel the pressure to pretend and hide that she is different even when there isn't anyone to witness it.

### ***Sub-theme: Changing or "Curing" Autism***

Beyond simple masking of emotions and behaviors, many participants discussed attempts to outright change their personality to help them better adapt. Ashton spoke about his inability to express his true gender identity and the attempts to make him act like a girl. He said that they accepted homosexuality, but he wasn't allowed to be a boy without them claiming he was confused or being defiant. Maggie spoke less about specific experiences and more generally about efforts to "cure" autism. She said, "we're going to be autistic all in life, and that really, that's okay." She was against the search for a cure saying there shouldn't be one and talked about some of the controversy surrounding Autism Speaks, which she referred to as the PETA of autism, because it is focused on finding a cure rather than on encouraging acceptance.

Caitlyn spoke the most on this subject and it seemed to be the most impactful topic to her. She brought it up again and again throughout the discussion. “It’s kind of like they don’t like you being how you like being,” she said after affirming that she liked all of who she was, including her neurodiversity. She said that if a person is doing something harmful, that’s a good reason to change them, but doing it for society’s acceptance wasn’t right. She talked about others not understanding that changing the autism meant they were changing a part of her that she didn’t want to go away. She also talked about the loneliness of being the only one to like who she truly was inside and the relief she felt when she found other advocacy groups that embraced uniqueness.

***Sub-theme: Stimming Eradication***

One particular thing that therapists frequently tried to change was the participants attempts to self-stimulate or stim. These generally manifest as repetitive movements such as hand-flapping, rocking, or fidgeting with objects. Although it’s not unique to autism, it is very common for Autistic people to stim, especially when experiencing strong emotions. Many describe it as something calming when they’re anxious (Deweerd, 2020). Maggie in particular talked about how she used stimming to calm herself and asserted that it was a natural thing that didn’t need to be stopped. She recalled her therapists telling her “quiet hands” whenever she began to stim.

Stimming is usually an ingrained behavior that is uncomfortable to try and stop, especially as it causes extra anxiety while at the same time removing the person’s method of dealing with stressors (Deweerd, 2020). Diane shared how trying to stop just made it worse. Caitlyn recalled being told to stim in her room where no one could see it. She said that they tried to ruin stimming for her, but that, happily, they did not succeed. She recalled most of her

interactions with therapists and teachers being negative when it came to stimming but did discuss one teacher who noticed her stims and acknowledged why she was doing it, while still gently redirecting her when it wasn't possible to continue stimming at a particular moment.

#### **Theme 4: Impressions of Therapists**

Participants were explicitly asked about their therapists. Specifically, about their feelings on the therapists' intentions, the kinds of practices they used, and what impact overall their therapists had on them. Overall, most thought that the therapists were good people trying their best with bad information but, for the majority at least, these well-intentioned individuals ultimately did more harm than good. This section will also take a look at some of the specific reinforcement practices they used and what impact those had on the participants and their relationships with their therapists.

##### ***Sub-theme: Well Meaning Therapists***

“The intent was definitely love.” Diane spoke about her well-meaning therapists and how they truly were trying their best and never meant to harm anyone. In the end, however, the only therapist she remembered with any fondness was the one who ended all of her therapy when they recognized that it wasn't addressing her needs and was simply causing her frustration. Caitlyn had a similar impression, saying that the therapists thought they were helping but to her, they just weren't. Ashton mentioned that some people might get into the profession for power and authority, but said he believed most of them get into this to help people. He talked about the fact that the therapists are doing exactly what they're trained to do and it's all they know to try. He referred several times to BM being cultish due to both its pervasiveness and the total faith its practitioners have in it. He also said it didn't hurt that BM therapy is big business with good job security making it all that much more alluring.

Maggie spoke positively about the majority of her therapists, saying most are “just really awesome.” She even noted that there is one she’s still friends with to this day. That therapist came up several times in discussion and seemed to be one of the primary factors behind her enjoyment of therapy. Maggie talked about how he paid attention to her likes and dislikes and didn’t try to force her to do anything she didn’t want to do. She talked about going out into the community with him and getting to do things she enjoyed. The level of autonomy seemed to be the most consistently discussed factor that singled him out from other therapists.

***Sub-theme: Therapists Causing Harm***

For all their good intentions, half of the participants still said that the things they did caused real and lasting harm. Neither Caitlyn nor Maggie talked much about personal negative experiences with therapists. Maggie mentioned that some therapists weren’t so good with her and that there were times she really didn’t enjoy therapy. She mentioned “bawling (her) eyes out” in some initial sessions but said it got easier as she got to know the therapists better. In the end, she was of the opinion that “ABA either can or cannot be abusive...depending on the agency and the therapists,” demonstrating that who is conducting the therapy and how makes a big difference in how it is perceived.

Diane discussed her resentment and said the therapy was abusive and did nothing but cause long-term trauma. She didn’t seem to blame her therapists for not knowing about the damage BM practices could cause when she was younger, because there wasn’t much if any information about the long-term effects or people coming out saying it has given them PTSD. Therapists practicing nowadays, however, can’t hide behind their ignorance, according to Diane. Given the research that has begun coming out and the advocacy groups that are speaking out against the practice, therapists should be listening and open to change. She maintained that “once

you know that it can cause harm, continuing after that point is then purposefully harming somebody.”

Most alarmingly, both Diane and Ashton equated their therapists with the sexual abusers they encountered in other parts of their lives. Diane said it was hard for her to see the difference between what the therapists did to obtain her love and attention and what the assaulter did. “They’ll (both) use what you’ve liked to get you to do what they want you to do.” Ashton acknowledged that therapists wouldn’t like to be equated with sex offenders, but said “ultimately, the gentlest techniques are quite literally grooming, it meets the dictionary definition.” Dictionaries do vary in their definitions with most making intent to cause harm a requirement. However, the actual behaviors listed as being associated with grooming a person include conditioning over time with the use of gifts or flattery (Dictionary.com, n.d.) that is similar in many ways to the techniques practiced in most BM treatment approaches. He advises that therapists should listen to their gut rather than their training when it comes to practices that they don’t feel right about performing.

***Sub-theme: Reinforcement Practices***

Most of the issues interviewees had with their therapists had less to do with them and more to do with the way they practiced. The BM treatment model follows Skinner’s original operant conditioning design. Although none of the participants reported receiving physical punishment or shock treatments, as Ashton said, “it doesn’t mean there wasn’t punitive things.” He described hiding in a laundry basket for hours while confined to his room to cause the staff to think he’d run away. The act of defiance got him additional consequences, but it was the only bit of autonomy he had left. He told one of his doctors that if he knew the consequences and was willing to accept them, then he was doing exactly what he’d been taught. Ashton and Diane both



described mostly negative punishments, meaning the removal of a preferred item to elicit the target behavior. Ashton would frequently be denied TV rights or other privileges that the therapists referred to as natural consequences, a phrase he said they'd "neatly bastardized." Diane talked about being separated from peers or being unable to go outside and play. In one class, the teacher physically blocked her off from the rest of the room with dividers.

Diane also discussed positive rewards being used as reinforcers, but the act of withholding rewards when she didn't accomplish the task was a type of punishment in and of itself. This is something Caitlyn also found frustrating. With a great deal of emotion in her voice, she described a teacher withholding a gift, that a fellow student had brought her from Germany, to serve as inducement to finish all of her work. A gift that wasn't the teachers' to give or keep that someone brought for her knowing Germany was one of her favorite topics of discussion, was used as a bartering tool. Even years later, this clearly had a profound effect.

## **Theme 5: Recommendations**

The Participants were all asked about what they thought the future of BM based therapies should be and about any additional advice they would like to offer therapists. The two main types of advice that came up across multiple interviews was the idea that the Autistic individual shouldn't be the only one responsible for changing, and the importance of listening to Autistic voices. Additional advice included avoiding compliance based training, and being honest and direct about deficits and treatment methods.

### ***Sub-theme: The Future of BM Therapy***

Opinions were split on the topic of what the future of BM informed therapy should be. Caitlyn and Maggie offered up specific advice about certain things they'd like changed in ABA and similar treatment methods, but neither had any comments about the future of the practice in

general. In contrast, both Ashton and Diane said that ABA and BM based approaches cause too much harm and aren't helpful enough to keep. They don't believe it can be saved with a few changes in practice and recommended that it be completely done away with. Ashton mentioned what was needed wasn't a whole new approach, but a "completely different outlook." A total overhaul of how the world thinks about therapy and what the goals of that therapy should be. He recommended funding be shifted away from BM therapies and into speech, art, music, and horse therapy. He and Diane both have children on the spectrum and discussed the challenges they faced finding services and the funds to pay for them. Ashton referred to it as the "Disability Tax". Diane discussed a more humanistic approach to therapy and implementing additional resources for Autistic adults after they've aged out of services as children.

***Sub-theme: Change the System not the Person***

Part of the humanistic approach Diane suggested was giving neurodiverse people a way to explain their differences and embrace them. To "be yourself and navigate the world" without needing to change for society's sake. She talked about social and communication breakdowns as being two sided and the need for attempts to be made on both sides to "bridge the gap" between neurotypical and neurodivergent ways of thinking. This was echoed by Caitlyn who advised therapists to be more accepting of neurodiversity and to look at changes that can be made to the environment itself before trying to change the way the individual reacts to it. Similarly, Maggie talked about being "sensory friendly" and used examples of reducing sounds or lights that are too stimulating. Ashton brought up some specific therapies that he had found helpful for his children, including Acceptance and Commitment Therapy (ACT) and the Ross Greene model of Collaborative & Proactive Solutions (CPS). He also particularly recommended increased use of AAC devices to help facilitate interactions and overcome communication breakdowns. "Speech

language pathology” he said, “has an excellent opportunity to be proponents for AAC, not (as a) last resort.” Before addressing behavior, he advised, working on total communication, and assessing AAC options. He discussed the importance of specialized training for SLPs in AAC use and the need for them to become knowledgeable about different high- and low-tech options. He did specify, however, that, in his opinion, PECS (the actual picture exchange program not low-tech picture boards) is BM, not AAC and he didn’t believe it facilitated communication.

***Sub-theme: Listen to Autistic Individuals***

Maggie put it best saying, “us Autistics have a voice too,” but the sentiment was one shared unanimously across all participant interviews. The most important piece of advice for any therapist according to each of them was to listen to Autistic input. Autistic advocates and individuals receiving treatment deserve to be heard. Beyond that, though, therapists need to learn and implement changes based on the feedback they receive. Maggie in particular stressed listening to both verbal and non-verbal communications about what the individual needs or wants instead of deciding for them and expecting them to get on board. Diane talked about the importance of really allowing the Autistic individual to lead and watching how they interact and communicate so that you can learn the best ways to engage with them. It should always be a choice, she said. “I don’t think they should be forced to communicate in a certain way.” Caitlyn brought up the importance of communicating honestly and openly with your clients. Finally, Ashton pointed out that the problem is that BM therapy isn’t being run by the people that actually need to be asked and emphasized listening to community advocates even when it’s negative.

## **Discussion**

Although there were a variety of experiences and opinions shared, there were a number of points upon which all participants reached a consensus. Specifically, the emphasis on compliance, the lack of autonomy, the focus on masking or altering Autistic mannerisms, and the disregard for Autistic voices were all denounced by the interviewees. The lingering trauma experienced by the majority of the participants and the vulnerability to abuse discussed by half of the interviewees is alarming and should give every therapist pause. The practices therapists employ have long-reaching and serious impacts on people's lives, both for the better and for the worse. The most positive outcomes reported by participants were help with communication and socialization. The most concerning outcomes reported were a connection between a BM treatment approach and increased vulnerability to predatory strategies without the ability to self-advocate.

One 2022 study with similar objectives and methodology to this one was conducted by Laura Anderson, and yielded results consistent with those found in our study. Anderson's study was also a qualitative phenomenological study based on interviews with seven Autistic individuals. Her study examined the impact of ABA specifically rather than the broader category of BM and did not examine the communication aspect of intervention impacts. Her results also found that participants reported long term harm as a result of ABA therapy and had similar specific complaints. Interviewee recommendations given to Anderson were also in accordance with recommendations voiced by participants in our study.

## **Limitations**

Potential study limitations and efforts made to mitigate them are discussed below. The primary limitations noted are a small sample size and a disproportionate degree of discussion by

the individual participants. Efforts were made to ensure that these limitations did not detract from the reliability of data extracted from the study, but they should be noted nonetheless.

***A Small Sample Size*** The sensitive nature of the discussion topic will necessarily reduce the number of participants to a certain extent. Lack of funding with which to provide adequate compensation also factored into the number of participants. Each participant was given a gift card for \$20, but several comments on posts indicated that this was considered insufficient given the high emotional cost the discussion could potentially have. Additionally, one person who reached out with questions but ultimately did not participate mentioned recent studies being conducted by organizations that benefited financially from BM therapies that were posting in similar discussion boards and targeting the same population, possibly causing potential participants to be more wary for fear of information misuse.

Efforts taken to mitigate this include posting multiple times in multiple places and using remote video conferencing software to broaden the pool of potential participants.

Recommendations vary for an adequate number of interviewees to reach data saturation, but the general minimum is around 5 or 6. Given that everyone has different experiences, a larger sample size would be preferred, however, there is still valuable information to be gained from even a single interview. Additionally, a similar study conducted by Anderson in 2022 had similar procedures and outcomes with seven participants, demonstrating interstudy reliability.

***Disproportionate Levels of Discussion*** In an interview-based study, there are a number of factors that influence overall percentage of participation by individual interviewees. In this study, some participants had an easier time communicating than others. Every effort was made to accommodate a variety of communication modalities. All participants ultimately elected to use spoken language, but their ability to do so with ease varied. The study also involved adults being

asked to recall things from their childhood, with some participants remembering in greater detail than others. Additionally, participants were being asked to discuss difficult subject matter that not everyone was equally comfortable doing. This meant that some participants answered fewer questions or answered in less detail. Attempts were made to elicit further information during the interview with follow up and clarification questions, but the body of text still varied a great deal between participants. To accommodate for this, attempts were made to ensure that all themes had at least been discussed to some degree by every participant.

### **Future Research**

The implications of the data presented have far reaching consequences and can be used to identify additional directions for critical areas of research. In general, it is clear that additional ethical evaluation of both new and established treatment approaches should be implemented across all areas of practice. Given that frequently long-term effects aren't immediately apparent, longitudinal studies that follow participants after therapy completion should be more common in therapeutic research. It is also apparent that there is an element of treatment that is not being properly assessed – the feelings of the participants. This type of evaluation should become an industry standard targeting both current and past recipients.

Additional research should be done in the area of BM models of therapeutic practice specifically as well. Further qualitative research with higher saturation is needed to get a more complete picture of both the Autistic individuals' varied experiences with BM based practices, as well as that of other impacted groups. Additionally, quantifiable research should be done on the long-term efficacy of different treatment approaches including BM models for comparison. This is not because efficacy outweighs ethical considerations, but rather to determine how effective the therapy actually is and what other therapies may be more effective without the issue of

ethical concerns. There should also be research done with more recent recipients of BM treatment as all of the participants received therapy at least 10 years ago or more.

Research should be done that seeks the opinions of professionals from a variety of settings and therapy types. Surveys could be conducted of current and former BCBAs, speech pathologists, occupational therapists, physical therapists, and teachers regarding their experiences with BM. This could evaluate the costs and benefits of BM informed practice as the professionals see them, as well as uncover alternative therapies or management methods that are being utilized. This would help to identify key elements that would need to be present in alternative therapies and may provide initial avenues of research into options already in use while identifying strengths and weaknesses of current therapy approaches.

## **Conclusion**

This study does not present a true representative sample, but the lessons derived from these individuals' stories are no less valid as a result. Their willingness to share their experiences, even the painful ones, gives therapists a unique opportunity to learn from someone else's mistakes. Best practices are constantly shifting and changing with the passage of time. No therapy is perfect and despite the best possible intentions, therapists will make mistakes, sometimes with horrifying consequences. No therapist wants to believe that they may have caused harm to the people they were trying to help, but continuing to ignore critical voices for fear of what their critique might reveal simply perpetuates harmful practices further and may lead to more individuals suffering needlessly. The most important thing is to listen to the people being treated, to reassess methodologies based on new information, and to find alternatives, when necessary, no matter how well established a practice might be. "Do the best you can until you know better. Then, when you know better, do better" (Maya Angelou).

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# Appendix A

## IRB Approval Letter

This appendix consists of an approval letter from the University of Arkansas' Institutional Review Board.

### Figure A1



---

**To:** Lighla Whitson  
**From:** Douglas J Adams Justin R Chimka, Chair  
IRB Expedited Review  
**Date:** 04/20/2022  
**Action:** **Expedited Approval**  
**Action Date:** 04/20/2022  
**Protocol #:** 2202386092  
**Study Title:** The autistic perspective: Interviewing autistic adults on their lived experience with behavior modification-based therapies and how it has shaped their communication  
**Expiration Date:** 03/03/2023  
**Last Approval Date:**

The above-referenced protocol has been approved following expedited review by the IRB Committee that oversees research with human subjects.

If the research involves collaboration with another institution then the research cannot commence until the Committee receives written notification of approval from the collaborating institution's IRB.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.

Protocols are approved for a maximum period of one year. You may not continue any research activity beyond the expiration date without Committee approval. Please submit continuation requests early enough to allow sufficient time for review. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study closure.

Adverse Events: Any serious or unexpected adverse event must be reported to the IRB Committee within 48 hours. All other adverse events should be reported within 10 working days.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, study personnel, or number of participants, please submit an amendment to the IRB. All changes must be approved by the IRB Committee before they can be initiated.

You must maintain a research file for at least 3 years after completion of the study. This file should include all correspondence with the IRB Committee, original signed consent forms, and study data.

cc: Christine E Holyfield, Key Personnel

## Appendix B

### Recruitment Materials

This appendix includes a figure used on social media for recruitment and the pdf potential participants were referred to for additional information.

Figure B1



**Autistic Input Needed**

**What:** 1 hour interview about the experience of autistic people with ABA and other behavior modification therapies (BMTs)

**Who:** Autistic adults who have experienced ABA or BMTs

**Where:** The comfort of your own home via zoom

**When:** We'll work with your schedule


**Why:** Help shape future practice

Scan the QR code or contact Lighla Whitson at [lwhitson@uark.edu](mailto:lwhitson@uark.edu) to learn more

**Make your voice heard**

## Figure B2

### The Autistic Perspective on ABA: Interview Study Information Sheet



This form has **INFORMATION** about being in a research study.

After reading the details, you can decide if you want to take part in the study.

You can change your mind about participating in the study **at any time**.

If you choose to join the study, please read the instructions at the end of this document.

#### Who is Doing this Research?

The study is being done by the representatives of the Speech and Language Pathology program at the University of Arkansas and has been approved by the university's review board.



**Lighla Whitson** (she/her) is the graduate student leading the study. She obtained her undergraduate degree in 2012 from Lyon College and a post-baccalaureate degree in Communication Sciences and Disorders in 2021 from the University of Arkansas. She is in her 2<sup>nd</sup> year of graduate school at the University of Arkansas.



**Christine Holyfield** Ph.D., CCC-SLP (she/her) is the faculty supervisor for the study. She is an Associate Professor in the Communication Sciences and Disorders department at the University of Arkansas.

**\*Consultation was given on study questions by four members of the autistic community.**

#### What is the study about?

The **purpose** of the study is to:

1. Hear the thoughts and opinions of autistic adults on Applied Behavior Analysis (ABA) and similar therapy techniques.
2. Learn how ABA and similar therapies have impacted the way those individuals communicate.
3. Shape future research to better understand the effects of these therapies on autistic individuals both during the therapy and later in life.

Figure B2 cont.

## Risks and Benefits

### Can anything bad happen if I take part in the study?

We do not expect anything bad to happen to you if you take part in the study, but there are possible risks.



Some of the questions in the study are about **experiences that might have been painful**, may **bring up difficult or traumatic memories**, and could potentially **trigger a traumatic episode**.

If you **struggle with PTSD** and are worried about potentially triggering a PTSD episode, please **speak to a mental health professional before volunteering to participate**.

### What will I get from being in the study?



You will **make your voice heard by the academic community** and help **educate professionals** about your unique perspective on the most common type of therapy recommended for autistic individuals.

Your opinions could **help shape future research and the way future therapy is done**, benefiting many individuals in the autistic community in the future.

### Will I be paid for my time?

You will receive a **\$20 Walmart gift card** for participating.

- The gift cards will be sent electronically as digital codes that can be used online.
- You **WILL** receive the gift card even if you do not answer every question, ask to stop early, or ask to have your answers take out later.

## Information Use and Privacy

### How will my information be kept private?

We will do our best to keep what you say confidential (private) but we cannot promise total privacy.

What we will do:

- **No identifying information will be shared** about you such as your name or specific location, but some general information may be used such as an age range for people who participated and general information about location such as regional areas participants lived during therapy.
- **All information** will be kept on data software storage that is **password protected** and kept for 3 years before being deleted (due to state and federal laws).

### Will I be recorded?

All interviews **WILL** be recorded to make sure we are giving accurate information about your answers.

**You may choose to have your camera on or off.** Recordings will be transcribed into text and kept anonymous. **Your recorded interview will never be shared with anyone outside the study conductors.**

Figure B2 cont.

## Study Activities

### What will happen if I decide to be in the research study?



#### Short Online Survey

We will ask you to complete a **10-question survey** online with basic information about yourself and a few questions about your history with ABA.

The survey will be mostly **multiple choice** with a **few short answer** questions and should take no more than 10-15 minutes to complete.



#### Online Zoom Interview

We will schedule an interview with you to ask more detailed questions about your experiences with ABA. The interviews will be one-on-one online and done with the Zoom program. **You can choose to turn your camera on or leave it off.**

The interview will take about 30 minutes to an hour but will **NOT** go longer than 90 minutes.

You can answer questions **verbally**, via **chat**, or with an **Augmentative and Alternative Communication (AAC) device**. Questions can **NOT** be answered by **an interpreter**.

**You can ask to skip any question you do not want to answer or ask to take a break or stop at any time.**

### What will the interview questions be about?

The interview questions will be about:

- Your overall experience with ABA and similar therapies
- How it affected you when you were in therapy
- How it is affecting you now
- How it affected the way you communicate
- Your general opinion on ABA and similar therapies



## Figure B2 cont.

### Can I change my mind about letting you use my information?

**Absolutely!** If at any time you **decide you do not want us to use the information** you gave us in the interview, you can let us know by **contacting Lighla Whitson** at [lwhitson@uark.edu](mailto:lwhitson@uark.edu).

**We will stop** using or sharing your information **on the day that we get your message**. However, by that time, we may have already used or shared information we collected before we knew that you had changed your mind. Any publication done before your request will **NOT** be changed to have your answers removed.

### What Now?

#### I want to join the study! How do I get started?

Great! We are so excited to have you join us!

Here is what you will need to do to join:

1. **Contact** the principal investigator Lighla Whitson at [lwhitson@uark.edu](mailto:lwhitson@uark.edu).
2. **In your email include:**
  - a. Your name (Can be just your first name or a nickname)
  - b. That you would like to be interviewed for the study
  - c. The email address you would like us to use to contact you
  - d. Your phone number if you are comfortable sharing it (This will be used only if there is a problem on the day of the interview)
  - e. Which method you plan to use to join the meeting (step 6)
  - f. Any questions or concerns you have about the study
3. **Look** for the response email from Lighla. She will usually respond within **2 business days**. If you do not see a response within 2 days, please **check your spam/junk folder** and **send a follow up email**.
4. **Choose** a time slot at <https://doodle.com/bp/lighlawhitson/aba-study-interview>. **Please pick a date that is at least two days after the date of your email.** (ex. If you email Lighla on 9/5/22, please choose a time slot for 9/7/22 or later).
5. **Complete** the 10-question survey at <https://forms.gle/XTmE14JpDbkEDah78> before the date/time of the interview or ask to do the survey with assistance during the interview.
6. **Prepare** for the Zoom meeting:
  - a. **Option 1: Create a free Zoom account** (if you don't already have one) and **install** the Zoom software on a laptop or a computer with a microphone (unless you are choosing to use chat for your responses instead). **Instructions will be emailed to you.**
  - b. **Option 2: Call in from your cell phone** at the scheduled time using a provided phone number, meeting number, and passcode. This option does not have a chat function and would require oral responses. **Instructions will be emailed to you.**
7. **Find** a quiet room with good internet and **join** the Zoom chat **at the scheduled time** of your interview **using the link or phone number emailed to you when you signed up on Doodle**. Please make sure you have **set aside an hour and a half** for the interview. Most will not go longer than an hour, but it may go up to 90 minutes at the longest.
8. **That's it!** Your gift card codes will be emailed to you **within 24 hours after the interview**.



## **Appendix C**

### **Participant Handout**

This appendix contains information given in handout form to participants after they expressed a desire to participate in the study. The handout was first approved by the Institutional Review Board at the University of Arkansas and contained information about what to expect during and after the study, as well as information on how to contact a neutral party on the review board to discuss any concerns they may have about the interviewer or the way the study was conducted.

#### **Introduction**

Thank you for your interest in participating in our study entitled “The Autistic Perspective: Interviewing autistic adults on their lived experiences with behavior modification-based therapies and how it has shaped their communication.”. Below you will find additional information on the purpose and format of the study as well as potential risks, compensation, and your rights as a participant.

This study is being led by Lighla Whitson, Graduate Student in the Speech and Language Pathology Program at the University of Arkansas. The Faculty Advisor for this study is Dr. Christine Holyfield, Ph.D., CCC-SLP, Professor in the Communication Sciences and Disorders Department at the University of Arkansas.

#### **Purpose**

The purpose of this research is to examine the thoughts and opinions of autistic individuals on Applied Behavior Analysis (ABA) and other behavior modification (BM) based treatments and how they feel it has impacted their ability to communicate. By documenting the

lived experience of autistic individuals, we hope to shape future research and help to better understand the effects of these therapies on communication and other outcomes for autistic individuals.

### **What is involved in the study?**

We will ask you to give your honest answer to questions about your experiences with ABA or other BM during an interview conducted remotely via a video conferencing software. You may choose whether to enable your camera or not. The interview will last about 30 – 60 minutes and will be recorded. You may answer using whatever communication method you prefer as long as you are able to answer independently.

### **Risks**

You will be asked to recount your previous experiences with therapy which may or may not have been painful or traumatic for you. Therefore, you may experience some discomfort in the course of the interview from reliving difficult memories. If there are any questions you would prefer not to answer or if there is any point at which you would like to pause or end the interview, you may do so at any time.

You are not required to answer any question that makes you feel uncomfortable. If there is a question you would like to skip, please let the interviewer know. All participants who complete the interview will receive full compensation regardless of the number of questions answered.

## **Benefits**

There are a few potential benefits for participants. In participating, you will be given the opportunity to make your voice heard by the academic community. This can be a liberating feeling and provide a sense of catharsis. You will also have the satisfaction of knowing that your opinions will help shape future research and possibly the way future therapy is conducted. The information from this study may, therefore, benefit many autistic individuals in the future.

## **Compensation for participation**

Participants will receive \$20 in the form of digital codes for Walmart gift cards in compensation for your time spent assisting us with this study. These codes will be sent via e-mail and no address will be required.

## **Audio/Video Recording**

All interviews will be recorded to ensure your thoughts and opinions are accurately represented. You may choose whether or not to have your camera enabled for the interview. Recordings will be transcribed into text and stored electronically. Participants not willing to have audio recordings of their answers will not be eligible to participate.

## **Taking Part is Voluntary**

Your participation in this study is entirely voluntary. You may choose to withdraw your participation at any time. If you choose not to participate in the study, please let the researchers know as soon as possible.

If you would like your interview responses to be removed from the study, you may contact the interviewers at any time before publication and make a written request to have your responses deleted.

## **Confidentiality and Data Security**

Please be aware of the following regarding your confidentiality and the security of your data.

- All information collected will be kept confidential to the extent allowed by law and University policy. No identifying information will be used in any publications or reports resulting from this research.
- All personal information that could be used to identify you will be removed from the data presented in the study. Only general information such as age range, sex, and general location (i.e. the state you lived in while receiving therapy) will be used.
- Signed consent forms will be kept separate from the survey data and the two will not be connected.
- All data will be stored securely on data storage software which is password protected. Records will be kept for three years after the study is completed in accordance with state and federal laws. While we will do everything we can to ensure the safety of your information, we cannot guarantee against interception of data stored electronically.

## **IRB Approval and Contacts for questions or problems**

This study has been reviewed and approved by the University of Arkansas' Institutional Review Board (IRB). The IRB has determined that this study meets the ethical obligations required by federal law and University policies.

If you have questions or concerns regarding this study please contact the Principal Investigator Lighla Whitson at [lwhitson@uark.edu](mailto:lwhitson@uark.edu) or Dr. Christine Holyfield, Ph.D., CCC. at [ceholyfi@uark.edu](mailto:ceholyfi@uark.edu) or at 479-575-8655 .

If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) Coordinator at 479-575-2208 or at [irb@uark.edu](mailto:irb@uark.edu). It is recommended that you save a copy of this handout for future reference.

Thank you again for your participation!

All the best,

Lighla Whitson

## Appendix D

### Demographic Survey Questions

This appendix consists of survey questions for participants about their general demographics both now and at the time of receiving therapy. The survey was administered via Google Form.

1. Please select the best answer to describe your age:
  - a. 18-25 years old
  - b. 26-35 years old
  - c. 36-45 years old
  - d. 46 years old+
  - e. Would prefer not to say
  
2. Please select the best answer to describe your race/ethnicity:
  - a. White
  - b. Hispanic
  - c. Black/African American
  - d. Asian
  - e. American Indian or Alaska Native
  - f. Native Hawaiian or Pacific Islander
  - g. Mixed race

- h. Other
  - i. Would prefer not to say
3. Please select the best answer to describe your gender identity:
- a. Male
  - b. Female
  - c. Non-Binary
  - d. Would prefer not to say
  - e. Other...
4. Please tell us the state where you currently live. If you live outside of the U.S. please tell us the country. (If you would prefer not to answer, please put "I would prefer not to say.")
5. Please tell us **ALL** of the states and/or countries where you lived during ABA or a similar therapy. (If you don't remember all of them or aren't sure you can list the ones you remember and/or say "I don't know." If you would prefer not to answer, please put "I would prefer not to say.")
6. Please select **ALL** age ranges during which you went to ABA therapy in the past:
- a. 0-5
  - b. 6-10
  - c. 10-15

- d. 15-20
  - e. 20+
  - f. Don't know
7. How many hours per week did you attend therapy on average? If it changed, please select the amount of time that best matches how often you went for the longest period of time. (i.e. If you attended therapy for 3 hours a week for 2 years and 10 hours per week for 5 years, please select 8-11)
- a. 1-3 hours per week
  - b. 4-7 hours per week
  - c. 8-11 hours per week
  - d. 12-15 hours per week
  - e. 16-19 hours per week
  - f. 20+ hours per week
  - g. I Don't know
8. Do you use any type of communication other than oral speech?
- a. Yes
  - b. No, but I did in the past
  - c. No, and I never did
  - d. Would prefer not to say



9. If you answered A or B to number 3, please tell us what types of communication you use or have used in the past. (write in the space below)
  
10. Please describe your support needs on an average day. (If you would prefer not to answer, please put "I would prefer not to say.")

## Appendix E

### Interview Questions

This appendix consists of interview questions and scripted language for the introduction of the participant to the interview process and to specific interview topics. Underlined text represents scripted language. The bolded questions that were numbered with Arabic numerals were always asked. Additional questions designated by Roman numerals or letters were used as follow up questions depending on what the interviewee said.

#### **Introduction:**

“Thank you for joining me. My name is Lighla Whitson, and I am the principal investigator for this study. I’m going to go over a few details with you and then we’ll begin. This interview is being recorded for transcription purposes.”

I’m going to ask you some questions and you can take as much time as you need to answer and share as much or as little detail as you feel comfortable with. Some questions may be too personal or too difficult to talk about. Please know that answering any question is your choice. You are not required to answer anything you are uncomfortable with and you may choose to skip any question. There are a few questions that ask about particularly traumatic experiences (such as punishments and restraints). Would you like me to avoid those types of questions?

If you would like to take a break or stop the interview at any time, please let me know. If you answer something and later decide you don’t want your answer included, please let me know as soon as possible. If you let me know before the study is published, I will remove your response from our records. Your gift card will be given to you no matter how many questions

you do or do not answer even if you choose to leave the interview early or ask to have your answers taken out of the study.

The interview will probably take about 30 minutes to an hour, it may go a bit longer but will not exceed an hour and a half.

Do you have any questions before we get started?"

"If you don't have any (more) questions, Let's get started."

### **Interview Questions:**

#### ***Section 1 – General Questions about ABA Experience***

I'm going to ask you some general questions about your personal experience with ABA. Please answer with as much detail as you feel comfortable sharing. Based on your answers, I may ask some follow-up questions to better understand you or to expand on your answer. If you're not sure how to answer, feel free to ask me to rephrase.

**1. Please tell me what an average ABA session looked like? What kinds of things did the therapist ask you to do?**

- i. Did you do a lot of work at a table, play games, play on a jungle gym, play with toys?
- ii. Was it in your home or at a clinic, at a school, or in a different setting?
- iii. What were the goals of the therapy?
  - i. Sitting still?
  - ii. Getting used to things touching your skin?

- iii. Listening to directions?
- iv. Stopping stimming like hand flapping or running in circles?
  - a. What were some examples of stims they tried to stop?
- v. Making eye contact?
- iv. Were there any positive/negative instances that come to mind?
- v. Did you feel like you got to do things you wanted to or was it always what the therapist wanted?
- vi. How hard was it to do the things you were asked to do? Did it ever feel painful or make you uncomfortable?
- vii. Were you ever restrained?
  - i. Do you feel comfortable sharing some of the details about the situation?  
For example, why you think they chose to restrain you and what was going on at the time?
  - ii. How do you feel this impacted you as a child?
  - iii. How do you feel this impacts you now?
- viii. What ways did they use to motivate you?
  - i. Did they offer sweets or toys?
  - a. Looking back, how do you feel it impacted you?
  - b. Did they ever hold things just out of reach as an incentive?

ii. Did they ever use punishment?

a. What did that punishment look like?

a. Were they physical?

b. Did they withhold things from you?

**2. What kind of effect did ABA have on your life while you were in therapy? When did you stop therapy?**

i. Did it help you develop any skills?

ii. Did you think it was useful at all while you were there?

iii. Did it help you at school/work or did it make school/work harder?

iv. Did it make things easier or harder for you at home?

v. Did you feel like you were wasting a lot of time or did you feel like it was useful?

vi. Did it cause you to have a lot of anxiety or stress or depression or was it something you looked forward to?

vii. Did you feel like you had to mask (meaning pretend to be neurotypical)?

i. Was that mostly in therapy, outside of therapy, or both?

viii. Do you think it helped you or hurt you or both?

**3. What kind of effect does ABA have on your life now? Do you think it's still impacting your life? In a good way or a bad one?**

i. Do you think you have more/less anxiety, stress, or depression because of ABA?

- ii. Do you feel like you continue to mask(meaning pretend to be neurotypical)?
    - i. Is that something you think has been helpful for you or has it hurt you?
  - iii. Has it helped you to get work or made it more difficult?
  - iv. Does it help you to understand and get along with coworkers or made it more difficult?
  - v. Are you still using any skills you learned in ABA?
  - vi. Do you have any trauma responses like flashbacks or trouble sleeping because of thoughts about your experiences?
  - vii. Do you continue to feel like you have to do things that make you uncomfortable for other people like making eye contact?
4. **How would you describe your relationship with your ABA therapist or therapists if you had more than one? Is there a main person you can think of that worked with you for a long time? Do you remember much about your therapist(s)?**
- i. Can you tell me about some specific experiences you had with a therapist? Things they did that you remember well?
  - ii. Did you have several different ABA therapists?
    - i. About how many would you say?
    - ii. Did you like some of them better than others?
    - iii. Did any seem to help you?
    - iv. Did any cause you harm?

- iii. Did you have a mostly good or bad relationship with your therapist or a mix of both with different therapists?
- iv. Did they help you at all or did any cause you specific harm?
  - i. Did you think they were trying to help you when you were a child even if they didn't succeed or did the opposite?
- v. Did they hurt you?
  - i. Physically, Mentally, or both?
- vi. Did they seem mean or nice to you as a child?
- vii. Did it feel like they listened to you or ignored you?

## ***Section 2 – Questions about ABA and Communication***

The next few questions I ask will be specifically about how ABA has affected your ability to communicate with others and about any speech therapy you might have had in addition to ABA. By communication I mean any form of communication including oral/spoken language, using an AAC, using sign language, writing, and social communication.

### **5. How do you feel ABA impacted your ability to communicate? Do you think it helped you understand others or made it more difficult? Did it help you make others understand you or make it more difficult?**

- i. Did ABA do anything to work on communication with you?
- ii. Did your therapist work on social communication like reading faces or body language?

- i. Was this helpful or harmful for you?
- iii. Did you discuss things like big and small problems?
  - i. Do you feel like that made it easier or harder for you to express your feelings about problems?
  - ii. Do you think it helped you at all to identify different levels of problems or did it cause more problems?
- iv. Did you talk about ways to cope with emotions or how to deal with conflicts with other people?
  - i. Were those strategies helpful/harmful for you?
- v. Did it help you understand other people's emotions or make it harder?
  - i. Does it still?
- vi. Did it help you express your feelings to other people or make it harder?
  - i. Does it still?
- vii. Did ABA help you make friends or did it make it harder?
- viii. Do you think you do better or worse at job interviews or in the workplace because of things you learned in ABA
- ix. Do you feel like you couldn't tell people your true feelings or be your true self because of ABA or did it help you be more true to yourself?

**6. Did you also have speech therapy? Could you tell me a little about what your sessions were like?**



- i. Did you enjoy speech?
  - i. Did you like it more than ABA, less than ABA, or about the same?
- ii. Did it seem similar to ABA or was it different?
  - i. Did they use similar ways of motivating you like offering sweets or toys?
  - ii. Did they work on similar skills?
  - iii. Did your ABA therapist and speech therapist work together in the same place or separately?
- iii. How did you feel about your speech therapist?
  - i. Did you feel like they listened to you?
- iv. Do you think speech was helpful or harmful for you?
- v. Was there anything you didn't like about speech?
- vi. Is there anything you would like your speech therapist to have done differently?

**7. Were you encouraged to use other types of communication in ABA or in speech like using an AAC (communication device like an app on an ipad or a picture board) or sign language or did they focus only on oral/spoken language? Do you feel like you needed another way of communicating or that it would have been helpful?**

- i. What kinds of activities did they do with alternative communication methods?
  - i. Did they teach you sign or how to use an AAC?
- a. What kind of AAC did they teach you to use?

- b. How did they teach you?
  - a. Did they use hand over hand?
    - i. Was that helpful or did it make you uncomfortable
  - b. Did they take your device without asking?
    - i. Can you tell me about what it was like when they did that?
- ii. Were you encouraged **not** to use alternatives to oral/spoken communication?
  - i. Did they try to get you to stop or to reduce how often you use the AAC device or sign?
  - ii. Were you ever punished for using something other than oral/spoken communication?
    - a. What did that punishment look like?
      - a. Did they withhold things from you?
      - b. Was it ever a physical punishment like a spanking?
  - b. Can you tell me about what it felt like when they did that?
    - iii. How do you think it affected your ability to express yourself
- iii. Did they try different types of alternatives?
  - i. Did they try low tech options like PEC boards and high-tech options like iPad apps or just one?

- ii. Did they give up quickly if an alternative didn't seem effective right away?
- iv. Did you have enough access to your alternative communication method all the time?
  - i. Was it taken away at certain times like at lunch?
  - ii. Was it only available in school or certain classes or at therapy?
  - iii. Did other people know how to communicate with you via your AAC?
    - a. Did the therapist help train other teachers or your parents/guardians?
    - b. Did other people get angry about having to communicate that way or try to make you stop?

### ***Section 3 – Expansion***

The last few questions will be about your overall thoughts and advice you have for therapists and others.

- 8. What would you like therapists to know about therapy for autistic people? Is there anything you think we should do differently to better help autistic people?**
- i. Are there any specific things you wish therapists would do?
  - ii. Are there any specific things you wish therapists would stop doing?
  - iii. Are there any alternative therapies to ABA that you think would be better?
  - iv. How should therapists interact with autistic people?

- i. What should we know about the autistic community in general?

**9. What do you think the future of ABA should be? Is there any situation where it would be useful, should it be modified, or should it be gotten rid of entirely?**

- i. Would you ever consider enrolling your child in any form of ABA if you had one with autism?
  - i. What specific things do you think it would help with?
  - ii. What questions would you ask about a program before enrolling your child?
- ii. Do you think it should be gotten rid of?
  - i. Would you like to expand on that?
- iii. Do you think it could be good if it was changed?

**10. Is there anything else you would like to share with me today? Anything about your experiences or something you would like people to know?**

“That’s all I have for you. Thank you so much for taking the time to answer my questions. Do you still have your information sheet with my contact information?”

If yes: “Great. Please feel free to reach out with any questions or concerns.”

If no: “I’ll be happy to send that to you again. Is the best way to reach you still \_\_\_\_\_? Great.

I’ll send that out as soon as we’re done. Please feel free to reach out with any questions or concerns.”