"I Was Taught That My Being Was Inherently Wrong": Is Applied Behavioural Analysis A Socially Valid Practice?

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Abstract: *While an ongoing passionate controversy over the use of Applied Behaviour Analysis has been raging on the Internet in online forums and blogs, little has been written about the issue in the professional literature. We discuss this debate and report the results of a pilot study conducted with autistic participants who have had experience with Applied Behaviour Analysis. It was discovered that there are different understandings and definitions about what ABA actually is. The results highlighted that ABA means different things to different people, and some participants who experienced ABA as children view the practice negatively and feel that it causes trauma. The importance of the consideration of social validity when choosing behavioural interventions for students with disabilities is highlighted, as ABA researchers do not often ask people experiencing the therapy how they feel about it. The main recommendation was that those who use ABA should ask students with disabilities how they feel about the treatment and listen to them when setting treatment goals.*

Key words: *Applied Behaviour Analysis, social validity, disabilities, behaviour, autism.*

I. Introduction

This article is the result of a few years of us meditating and discussing, often passionately, how we feel about the contradictory experiences with Applied Behavioural Analysis (ABA) expressed on one hand by autistic people, and on the other hand by their parents and teachers. While parents (Shepherd, Csako, Landon, Goedeke, and Ty 2018) and teachers (Miramontes, Marchant, Heath Allen and Fischer 2011) tend to be satisfied with the procedures and effectiveness of ABA therapy in improving autistic children's behaviour, autistics themselves tend to be increasingly vocal on social media about the damaging effects ABA has had on their lives. As special education teacher educators, we were conflicted by the tension between the well-established evidence base for using ABA to improve students' skills, and by statements of autistics about ABA destroying their lives. This article is both a report of a research study in which we interviewed and surveyed people with disabilities about their experiences with ABA as well as an exploration of the various definitions of ABA and a discussion about the importance of determining the social validity of any behavioural intervention.

It is our belief that part of the debate has to do with misuse and misunderstanding of behavioural support terms and definitions. Therefore, the following sections explore ABA, along with the popular practices and frameworks that it underpins, whose terms are often used erroneously used interchangeably.

Note about language: While we prefer using people first language (person with autism), in recognition of the bloggers, people who posted online and the autistic participants in our study, we use the terms autistic and autistic people/person instead of person first language.

II. Applied Behaviour Analysis

Applied Behaviour Analysis (ABA) is the most popular early childhood autism intervention recommended by professionals (CDC 2015). Before any discussion of ABA can be had, one must consider its definition. Cooper, Heron, and Heward (2013) provide the most popular and widely accepted definition of ABA:

> *Applied behaviour analysis is the science in which the principles of the analysis of behaviour are applied systematically to improve socially significant behaviour and experimentation is used to identify the variables responsible for behaviour change* (22).

To expand upon the definition above, Cooper et al. (2013) suggest that in order to be considered ABA, a practice must have six components or principles: (a) be guided by scientific inquiry, (b) all procedures are described and implemented in a systematic, technological manner, (c) any behaviour change interventions must

be derived from the basic principles of behaviour, (d) focus on socially significant behaviour, (e) elicit a meaningful improvement in important behaviour, and (f) analyse the factors responsible for improvement.

While acknowledging the existence of the definition above, autistic scholar Williams (2018) claims that the overall driving goal of ABA is to "produce a child that is indistinguishable from a normal child" and describes ABA as a technique that is used daily over months or years with the goal of eliminating autistic traits in preschool age children (echolalia, motor stereotypes, sensory behaviour) with the assumption that this will enable the child to attend mainstream schooling.

After reading many similar opinions and definition in the online autistic literature, we concluded that when autistics speak of and define ABA, they are referring to the Lovaas Approach, or applied behavior analysis autism early childhood intervention. This approach was designed specifically for autistic children, unlike ABA, which was meant to support any students with challenging behaviour and includes many different practices.

III.   The Lovaas Approach

The Lovaas Approach is also known as Early Intensive Behavioural Intervention or EIBI. It is named after O. Ivar Lovaas, who began developing methods to treat young autistic children in the 1970's. His approach is based on a system of reinforcement and punishment, underpinned by operant conditioning. It involves up to 40 hours a week of one-on-one training with a young child, lasting for up to 2-3 years or more. At the time of its inception, the program was focused on making children as 'normal' as possible - eliminating flapping and other stims, teaching eye contact and hugging. At the time of its introduction, autism therapy consisted mostly of institutionalisation. The idea that the Lovaas method could produce results without institutionalisation made it very attractive to parents, bearing the responsibility for most of the decision-making regarding interventions for their autistic child (Shepherd et al., 2018).

Techniques used in the Lovaas approach include pivotal response treatment (PRT) and discrete trial training (DTT). PRT is a play-based method that targets improving "pivotal" development areas instead of individual behaviours. The pivotal areas include motivation, self-management, and initiation of social interactions (Autism Speaks n.d.). It's based on the idea that changes in pivotal responses would spark widespread progress in other developmental areas and is used to support the development of communication and language skills, increasing positive social behaviours, and the elimination of disruptive self-stimulatory behaviours.

According to Autism Speaks (2018), DTT is a structured ABA technique that breaks down skills into small, "discrete" components. A trained ABA therapist teaches these skills one by one. Along the way, trainers use tangible reinforcements such as food or toys to reward children for displaying desired behaviour. DTT is often confused with ABA - many times when people speak about ABA therapy, they are actually speaking of DTT (Autism Speaks 2018).

At its onset, Lovaas' therapy included both aversives, such as slaps and shocks, as well as positive reinforcement, most typically in the form of food. Over time, due to criticism and research, the aversives were eliminated. ABA is considered by many today to be the gold standard for the behavioural treatment of autistic children (Applied Behaviour Analysis Program Guide n.d.). The training program can be quite costly, up to nearly $100,000 per year, but is often at least partially covered by government and private insurance schemes (Yell and Grasgow 2000) when other treatments are not. This has contributed to its popularity (Shepherd et al., 2018).

IV.   Positive Behaviour Support

According to Carter (2010), the PBS approach is an expansion of ABA that highlights the importance of the environment and how behaviours interact with it. This approach was in response to increased emphasis on improving behaviours that positively affect the well-being of the individual receiving services, individualised services and supports and increased skills of the person receiving the intervention.

PBS is multi-tiered system of behavioural support that uses data to understand what maintains an individual's challenging behaviour. PBS can be defined as "a general term that refers to the application of positive behavioural interventions and systems to achieve socially important behaviour change" (Sugai et al. 2000, 133). This definition alone makes the distinction that while grounded in ABA theory, PBS is concerned with the human side of behaviour change. Miramontes et al. (2011) suggest that PBS is a collaborative system that relies on stakeholder participation and has the philosophy that humanistic values should inform empiricism.

Horner and Sugai (2018), developers of PBS, make the distinction between PBS and ABA by saying on one hand that PBS is a framework and does not support a specific science or approach, it involves many different practices from different places as long as they are socially valid and evidence based. On the other hand, they

acknowledge that ABA underpins PBS. They suggest that the overarching strength of PBS is the marriage of values with science, and values should always lead. The goal is to improve the quality of life for the consumers of PBS. This is accomplished by supporting students to reduce behaviours that pose a barrier to learning, working, living and participating in typical contexts. The effectiveness of PBS should be measured by whether the support received results in a valued improvement in an individual's quality of life. This is where the concept of social validity comes into play.

V.   Social Validity

At the heart of the ABA debate lies the argument that just because a program is effective does not mean that it is appropriate or should be implemented, particularly if the procedures and goals are not acceptable by the individual receiving the treatment. There may be other interventions that produce similar results while being more acceptable and less intrusive (Carter 2010).

The term social validity was coined from literature in the field of behaviour analysis, but both the term and concept have been adopted in other fields, and even renamed. This resulted in a plethora of terms and a lack of consistency of how the original term is used, as well as its definition and how to measure and evaluate it. Wolf (1978, 207) originally defined social validity as "the social significance of the goals of treatment; the social appropriateness of the treatment procedures; and the social importance of the effects of treatments."

To measure social validity, the people who are implementing, receiving, or consenting to a treatment are asked their opinions about the treatment (Carter 2010). This information is then used to make decisions about the future use of the treatment. By including social validity into its practice, ABA can combine the objective and subjective and in doing so, use science to improve people's lives while at the same time making them happier (Marchant, Heath, and Miramontes 2013). Ensuring social validity is crucial to the survival of ABA. One aspect of social validity should be to obtain feedback from the individual receiving the treatment about aspects they liked or disliked (social validity assessment). If someone likes and accepts a program, they are more likely to follow it and find it relevant (Carter 2010).

Unfortunately, as reported by Miramontes et al. (2011), few studies about ABA and PBS report results of social validity measures, and those that do fail to report on the three areas suggested by Wolf (1978): social significance of treatment goals, social appropriateness of procedures, and social importance of outcomes. Worse, it is difficult, if not impossible, to locate studies in which the consumers of ABA were surveyed about the social validity of the treatment, its procedures, and its goals. Williams (2018) argues that it is this lack of autistic voice that allows the perpetuation of behavioural interventions that are behaviourist and mechanical rather than based on self-determination theory. He further explains that the autistic community rejects behaviourism due to its wilful ignorance of the emotional impact of ABA on children. Further, the traumatic effects of ABA have been documented through personal testimonies online, disability scholarship, and social media campaigns.

VI.   The ABA Controversy

Social media, online forums, and blogs are rife with arguments against ABA made by autistics. Autistic individuals who have experienced ABA therapy believe that they should have a voice in what treatments are administered to autistic children. The blog, *ABA Controversy Autism Discussion* (2017) and the Facebook page *ABA Controversy Autism Discussion UK* summarise evidence to support adult autistics having a voice in the treatment of autistic children. The author likens ABA to a cult movement, very much aligned with the medical model of autism, viewing autistic children as something that needs to be fixed. The blog lists 13 other pro-autism organisations that officially position themselves against ABA.

The Autistic Self-Advocacy Network (ASAN 2019) is one of the world's largest self-run autistic associations. They are developing resources to support autistic people to widen services beyond ABA. The services include: social communication, sensory integration, emotional regulation, and adaptive skills. ASAN state that "Until now, much advocacy for coverage of "autism interventions" has focused on purely behavioural approaches, like Applied Behavioural Analysis (ABA). These interventions can be inappropriate or even harmful, and exclusive focus on coverage for behavioural interventions can result in limited access to evidence-based and emerging models that focus on improving relationships, communication skills, and development of skills that are meaningful to individuals' quality of life."

ASAN has included ABA in its core position statements, saying they are opposed to behavioural programs that focus on normalisation rather than teaching useful skills. They cite the UNCRPD's guiding principle of respect for the right of children with disabilities to preserve their identities - to support the notion that autistic children should not be told that their natural behaviour is wrong and they cannot be accepted as they are.

Several postings from former ABA therapists who now actively argue against the practice can be found online. One example of this is the Socially Anxious Advocate (2015), the author of which is an ABA therapist that left ABA because she listened to the voices of autistic people in regard to ableism. She feels that since ABA affects autistic lives first and foremost that it is crucial that we listen to what they are saying. She also recognises that many forms of therapy are called ABA (in order to be eligible for insurance) but are not. She lists DTT, Natural Environment Training (NET), and errorless teaching. She also describes a variety of concerns about ABA therapy that she shares with autistic people: (a) explicit aversives, (b) withholding food, breaks, and affection, (c) only very small breaks in 5-8 hour days, (d) misunderstanding of motor apraxia (looks like child is not complying but in reality the mind cannot make the body follow a command), (e) behaviourists have too much power, (f) the use of verbal and physical prompts to prevent children from stimming, (g) the routine use of physical restraints for children engaging in violent or destructive behaviours, and (h) presuming children are not competent and therefore not providing an adequate means of communication. These sentiments are echoed on Birdmadgrrl (2017), another blog authored by a former ABA therapist.

Another complaint about ABA therapy is its intense nature (Lynch 2019). Most ABA therapy involves children as young as 3 and consists of 35-40 hours per week. Detractors claim that ABA programs often set goals meant only to 'normalise' children, not support them in acquiring useful skills to improve their quality of life (ASAN, 2019; Controversy Autism Discussion 2017). Devita-Raeburn (2016) claims that ABA has a predatory approach to parents, telling them that ABA is their only chance for their children to have a normal life. ABA is also often the only treatment that is funded by government subsidies or insurance companies.

Autistic academics and researchers are beginning to work on providing an evidence base that suggests Lovaas' ABA therapy has serious negative effects on the children that participate in it. Kupferstein (2019) used an online questionnaire to survey 460 autistic adults and caregivers of autistic children and noted post-traumatic stress syndrome in nearly half of the participants who had participated in ABA therapy, while 72 percent of those who were not exposed to ABA therapy were asymptomatic. Interestingly, the majority of respondents were female, which is not consistent with autism prevalence statistics and should be looked at in future studies. It should be noted that Kupferstein's description of ABA is aligned with Lovaas' model rather than the definition provided by Cooper et al. (2013) and used by schools and educators implementing PBS.

Kupferstein's (2019) study was also criticised by Barrett Leaf, Ross, Cihon and Weiss (2019) for methodological and conceptual flaws including, leading questions, a non-validated survey, bias, and an incomplete description of interventions. Autism researchers and advocates Chown, Hughes, Leatherland, and Davison (2019) penned a letter to the editor of *Advances in Autism,* pointing out that Kupferstein's study was unfunded and completed in her own time, while Barrett Leaf et al.'s study was funded by the Autism Special Interest Group of the Association for Behavior Analysis International. They also defended Kupferstein's hypothesised link between ABA and post traumatic stress syndrome by stating that hypothesising is part of doing good research and her findings, at the very least, justify concerns about such a link. They advocated for Kupferstein and her findings to be taken seriously by the academic community.

There is little in the online space from non-professionals promoting ABA as an effective therapy for autistic children, but what is out there is typically written by parents (Parenting with ABA n.d.; Rigden 2019; Walsh 2011). Rigden (2019) is an autistic blogger with two autistic children. He states that breaking down tasks into basic steps to make a complete activity understandable through the use of ABA just makes sense. He is very critical of the ABA detractors, calling them a small but loud and militant part of the autism community and accused them of trying to, "bully, harass, and intimidate anyone who speaks positively about ABA therapy." He also claims that the groups focus on lies and misinformation from outdated or disproven studies. He refutes the groups' claims of torture and child abuse by iterating that professionals use and adhere to the ABA principles. He passionately defends the ABA professionals who work with their son as loving and caring human beings.

Academics, practitioners, and professional organisations have responded to criticisms of ABA by dismissing them as myths (Carrero 2015; Dillenberger and Keenan 2009). First and foremost, they argue that ABA was never meant to be used only with autistic children, that it is a science for use with anyone who has challenging behaviours - based on a set of principles that guide interventions, regardless of type, or even presence of disability (Dillenberger and Keenan 2009). They add that many common strategies used with students with emotional and behavioural disorders, including function-based interventions, are based on the tenets of ABA (Carrero 2015). Proponents of ABA claim that searching the disability categories: emotional/behavioural disorders, learning disabilities, intellectual disability, traumatic brain injury, visual impairments, blind, deafblind, hearing impairment, deaf with the term ABA results in a number of peer reviewed articles for each, and Briesch and Daniels (2013) conducted a study on using ABA interventions with general education students.

Briesch and Daniels (2013) point out that ABA processes are not only used to eliminate challenging behaviour, but also to increase socially appropriate behaviour as well as social, academic, and daily living skills. Lastly, Dillenberger and Keenan (2009) recognise that terminology is often confusing, with many people using

the term ABA to describe DTT, when it is its own separate intervention, based on the tenets of ABA. Carrero (2015) sums up the professional argument for ABA with the belief that students deserve to have professionals who support them be qualified to critically analyse their practices and provide individual support based on data generated by the individual student.

VII.   Methodology

Compliance with ethical standards. Permission to conduct this study was sought from and granted by the Human Ethics Advisory Panel of authors' affiliated institution. The authors ensured that there were no potential conflicts of interest, as the surveys were delivered online and were completely anonymous. Participant information and consent were provided at the beginning of the survey, with a button participants clicked to indicate that completing the survey online implied their consent.

Research design. Qualitative inquiry "attempts to understand, interpret, and explain complex and highly contextualised social phenomena" (Kamberelis and Dimitriadis 2005, 17). When adopting this approach, researchers assume that reality is subjective and knowledge, as well as knowledge producing processes are context specific (Lyons 2008). Qualitative research also aims to describe and explain individuals' experiences, and the meanings and practices resulting from their experiences (Creswell 2013; Kamberelis and Dimitriadis 2005; Miles, Huberman, and Saldaña 2019). Therefore, we employed a qualitative research design to examine the experiences of autistic individuals who have undergone ABA, and its social validity.

Research instrument. We initially planned to use interviews as the main method of data collection. However, several potential participants suggested that the questions also be made available as a survey, as autistic participants would most likely feel more comfortable with a survey than a face-to-face interview. We took that advice on board, converted the interview questions into open-ended survey questions, and made the survey available online via *Survey Monkey*. All but one participant chose the survey over the interview. A copy of the survey is available from the first author upon request.

Data analysis. We used inductive content analysis to analyse the data (Elo and Kyngäs 2008). Two of us (the second and the fourth author) conducted open coding of the completed surveys. Differences were resolved in discussion, and agreement was reached. The first author reread the open coding results, and suggested minor changes to the codes. The second and fourth author then proceeded to the next stages of coding, i.e., we gradually grouped the codes and emerging categories, and in the process of abstraction grouped the categories into themes. The involvement of all authors in this process was crucial as it enabled investigator triangulation and peer checking (Brantlinger, Jimenez, Klinger, Pugach, and Richardson 2005). At times we had different opinions during the data analysis process. In reaching an agreement, we engaged with alternative explanations of the data. This plurality of our perspectives greatly enhanced self-questioning, and thus our self-reflexivity (Archibald 2016).

Participants. There were 17 people who took part in the study; however, some participants chose not to share their demographic information. In terms of gender, there were six females, four males and one transsexual participant in this survey; with the remaining six participants not indicating their gender. The participants' age ranged between 18 and 47 years, with the mean age of 30.9 years (all participants provided their age). Fourteen participants indicated their employment status – five were employed part-time, four were employed full-time (one self-employed), two were studying and three were unemployed. The participants in this study were from 4 continents – seven from the USA, three from Australia, one from Germany and one from South Africa. The remaining participants decided not to share their country of residence.

Twelve participants indicated their disability categories (some choosing more than one) – seven were autistic, one had a learning disability, three had emotional and behavioural disorders and/or ADHD, one had anxiety, and one had sensory processing disorder. Eleven participants shared the age when they were diagnosed with their disability. Seven were diagnosed before the age of 10 years (five by the age of 5 years); two were diagnosed before they were 20 years old; and two in their thirties. Six participants opted not to share this information.

VIII.   Results

The main themes resulting from this study include: (1) Perceptions of ABA treatment by people with disabilities; (2) Practitioners and parents; and (3) Autistic identity. It should be noted that we have assigned a pseudonym to each participant to preserve their anonymity.

Perceptions of ABA treatment by people with disabilities. This theme consisted of the following categories: (i) Defining ABA; and (ii) Effects of ABA on people's lives.

Defining ABA. Many participants described ABA as a system of "rewards and punishments", where punishments were very common. For example, John described this perception of ABA in the following way: "A "therapy" using punishments and rewards to obtain desired behavior from a subject. The subject almost never

chooses which behaviors are "desirable" and which are not." George shared the following experience with the punishments from his ABA therapist:

> As for punishments that could be anywhere from screaming 'No' at me if I didn't do what she wanted - which is dead set terrifying. She might like physically pick me up and move me to where I needed to go. She was like, if ever I was stimming the code phrase for that was quiet hands so if I was stimming too much she'd sort of physically grab hold of me and like pin my hand at my sides and slow count for three seconds and then let it go. And if that kept happening that's sort of when the bigger punishment would come. And her favourite thing was sensory aversives. For me it was ridiculously sensitive to noise. So for me, she would start playing the noise she knew I wouldn't like or whatever it was... it was like a toy snail that rocked and made music and she knew I didn't like the noise it made so she would play that to punish me.

Participants described experiences where therapists, rather than respecting their sensory sensitivities, targeted them for change. This was well demonstrated by George's experience. His ABA therapist wanted to, "de-sensitise me, but then let's just say she was like trying to desensitise me to a new texture, if I didn't like that and would try to get away, then she'd play a noise as punishment." George then continued with an advice to ABA therapists:

> … sensory aversion should go in the bin, right bloody now. I don't know if she does know and didn't care but that was excruciatingly painful like running a feather up my arm like she liked to do that was like running a blade along my skin, but she could get away with it because it didn't cause physical pain. And so, I think that if any ABA therapists hear this, or anything, then stop using sensory aversives.

Eight participants perceived ABA as compliance training, a power tool used by neurotypical population to dominate and change them. For example, Justine, stated that "ABA is compliance training through coercion. Non autistic people decide what is right or wrong and then train autistic people to behave in whatever way they deem right." Peter went even further in stating that ABA is a:

> Pavlovian torture method that attempts / succeeds in removing an autistic's brain functions and replaces their normal functions with those of the dominant culture, which often creates a dissonance that is resolved by chemically castrating the mind in order to achieve maximum conformity. Coercive. Leads to PTSD [post-traumatic stress disorder]. Can lead to chemical addictions.

Many of these eight participants mentioned the negative reinforcement strategies used in ABA:

> ABA … (…) …makes a person under psychic compulsion not only mentally dependent from other people, but also make pliant to obey everything what is required from him under unspoken menace of negative consequences. … (…) …Compliance training … (…) …until I would be cooperative again … (…) …or being punished, i.e., being ignored or my belongings were removed or I received full prompts which I don't liked. I don't like being touched. (Alan)

> "…learning fast to do what they want all the time to avoid punishment" (Jacqui).

Martin even compared recipients of ABA to another marginalised population, people who are homosexual: "an abusive therapy intended to squash Autistic people and conform them to societal expectations, similar to gay conversion therapy."

George had some appreciation for teaching students to be compliant, however protested against mindless compliance. As he put it, "… mindless compliance - 'do what I say when I say' because I'm the authority voice you've got to do it - is dangerous, absolutely dangerous because then if someone in power wants to do bad stuff to you, you don't know how to say no and I've actually got into some situations where maybe I wouldn't have if I'd known how to say no." George also felt that it was ABA treatment that largely contributed for him not coming out as transsexual for substantial period of time: "I do think that ABA was part of the reason I didn't come out as trans for so long because there was this big emphasis on indistinguishability from peers and all this sort of thing if I come out as trans, I won't be indistinguishable, and not being indistinguishable is bad. So, I think that was part of what kept me in the closet for so long."

Effects of ABA on people's lives. Seven participants talked about the ways ABA treatment in childhood affected their lives. For Jacqui, ABA meant an ability to "fake normal for short periods of time", and she described ABA as "structured abuse in an institutional setting". She summarised the treatment in the following words: "sit still, never question, fake what you think they want so that you do not get any attention." As a result of ABA treatment, she had "nightmarish flashbacks, inability to trust people, constantly trying to please others because I know that is the only thing they want from me."

Alan blamed ABA for his addiction to alcohol:

> I am addicted to alcohol as many other people I know of after a life of ABA. Some died in their twenties and thirties. Some sort of homelessness while one can't cope healthily with other people and while trying to live as independently as possible.

In fact, Alan felt that as a result of ABA treatment in childhood, he also suffered post-traumatic stress disorder (PTSD). Alan was not the only one who referred to PTSD. Peter also referred to a: "Lifetime of haunting

nightmares, PTSD, lack of trust ...", as a result of ABA treatment in childhood; and Martin stated: "I suffer from PTSD. I find myself in distress and squashing my urges to stim or behave in a normal Autistic manner."

Being subjected to ABA treatment made Alan felt unloved and not accepted by his parents:

When I received ABA, I very often felt helpless and desperate, sometimes also furiously - because of what was done to me under ABA. I thought, my parents hate me. I did not understand what was wrong, why they were so othering, why they act differently to me than towards other people. I was taught that my being was inherently wrong. I now have to spend decades unlearning what they drilled into me. … (…) … They taught me that adults get to do whatever they want with me. That others get to decide what is right or wrong for me. That I don't matter. Which is bullshit.

George shared the further effects that ABA treatment had on his self-determination, as he felt that the only thing ABA taught him was to: "do what the nice authority voice tells you even if you're in pain because like it will cause you a whole lot more pain if you don't. And so later in life I've ended up not knowing how saying no to people because I'm like what the heck why should I bother, they're not going to listen anyway."

While John was also critical of ABA, he admitted that "…as a child, mimicking NT [neuro-typical] social norms made elementary school a little easier." Similarly, Monica, despite her criticism of ABA, stated: "It did help me to learn ways to respond to them normally, however the reward system itself - points - made me actively want to rebel against learning how to respond to them." For her, ABA as a therapy could be useful, if practiced "…in a manner that doesn't required being talked down to and without a point system. I would have liked to have someone explain to me the reason why these interactions were necessary."

Christine and Robert were positive about ABA treatment, with Christine defining ABA as "a positive way to change behaviors", and describing her experience with ABA stating "I enjoyed it". In her opinion, ABA helped her, as "… the teachers who used it taught me how to be a good person and responsible". Robert felt that ABA was important, because, "When you struggle with behaviour it is important to have a goal you are working on for a reason to behave, and to see your progress being tracked."

Hana (P5) described how she experienced ABA in her life circumstances: "I lived in several group home environments where reward and point systems were an everyday thing. Points for chores and good behavior. If you earn enough points you get to participate in fun trips to the movies, skating, bowling, etc.". She concluded that ABA made her aware of her behavior, however, "unfortunately I never really took it seriously. I wasn't interested in rewards and wasn't afraid of consequences for my actions." She further concluded: "I think ABA is a great tool for the teachers to have."

Practitioners and parents. The participants also talked about other people involved in ABA treatment. This mostly included parents, while five participants also talked about ABA therapists. Perceptions of ABA therapists were prevailingly negative and included Jim's belief that "ABA practitioners are professional child abusers. Yes, every damn one.".

In many participants' recollections, their parents found ABA therapy as very helpful. For example, Alan stated: "Although my parents kept saying I succeeded in being as other people after ABA, I am still autistic and if I wished I could live in a group home for severely autistic people, but I don't want to.". It seems that parental respect to the authority of a professional caused them to give more value to ABA therapists' approaches than to how their children felt about them and reacted to them. This is well documented in the following narrative of George:

… so mum was cleaning out the house and she grabbed this bell ball that [D] gave me and she shook it and she said: "Do you recognise this sound?" Well, did I ever. I felt like there were iron bands tightening around my chest and I felt like I couldn't breathe. All I could manage was "Oh no, not now, not her. I don't want to even think about her. Why? I seriously hated her." And mum said "Oh what was wrong with her? I liked her." And then she reminisced for ten minutes about just how much of a good therapist she was. And even laughed about the fact cos I said yeah I remember she had that god-damn walking snail and mum laughed and said aw yeah she used to like torment the shit out of you. She thought the whole thing just funny. Meanwhile … I'm here trying to breathe because like I could barely breathe because everything just came back in a rush and I had been trying to forget this and then here she is laughing because she thinks it's funny.

The participants in this study also made some recommendations for practitioners and parents about alternative approaches to ABA. Three of them suggested that students with disabilities should be taught the same way as other children; "organically, naturally, and in harmony with how my brain actually works" (Peter); and "by letting time take its course, and mastering social skills when I was ready." (John). Martin suggested that practitioners and parents should search advice from autistic people about how to teach them: "There are numerous websites and groups devoted to providing alternative techniques from Autistic People." Last but not the least, Alan called for self-determination, self-advocacy, acceptance, and allowance to make mistakes and learn from them:

I would be glad if the time was also admitted to me like to everyone else, discovering in my own pace and learning and making own decisions, and that absolutely harmless behaviour patterns are accepted, even if they are considered socially maybe as "not normal". …(…)… To make the experience with many different people that mistakes are quite normal and that they belong to human life and that one learns only by them and receives more knowledge - not by the so-called errorless learning.

Autistic identity. This is a recurring theme that ran through the open-ended surveys and one interview. It is a theme about power and powerlessness; about normalcy versus neurodiversity. Many participants felt that their identity as an autistic person was not respected; on the contrary, it was perceived as of a lesser value than being "neurotypical". Justine's perception summarises this well: "Non autistic people decide what is right or wrong and then train autistic people to behave in whatever way they before deemed right."

Some of the participants felt that people around them wanted to make them the same as their peers. This only reinforced the feeling of not being valued for who they were. Justine called for a change in education: "Stop trying to make us 'indistinguishable from our peers'. Teach us how to do the things we need and want to be able to do WITH our disability." For Joe being exposed to ABA was a symbol of not being accepted by his close ones. For him, ABA was "the way to get people to leave you alone is to do what they say. Comply or die. My parents crossed so many lines by ABA says ANYTHING is ok if it's "to fight autism"." Martin stated: "I would not wish for anything to be done to alter me. I am normal for an autistic person. I deserve acceptance as I have found it in adulthood."

IX.   Discussion

Overall, the majority of participants viewed ABA and the people endorsing its use (parents and therapists) in a negative light. Only two of the participants (Christine and Robert) viewed ABA as positive and/or helpful, and it is interesting to note that neither one of them identified as having autism, but a learning disability and an emotional behavioural disorder, respectively. This lines up with Rigden's (2019) observation that there is a group of autistic people rallying against ABA. The participants who had strong negative views about ABA spoke of repetition and working for rewards, which some disliked, but overall their biggest complaints were that the goals of the treatment were focused on making them seem neurotypical and eliminating their autism and that they had no agency in the treatment whatsoever. Many perceived this as having a negative lasting effect on their self-determination.

When asked how they would explain what ABA was to someone who did not know, several of the participants gave answers according to their perceptions (e.g., Pavlovian torture, abusive therapy, compliance training) without actually explaining what therapy they experienced. This leaves the question of what approach to ABA therapy they experienced- was it DTT? The Lovaas Method? This ties in with the observations of Autism Speaks (2018) and Dillenberger and Keenan (2009), who concede that there is often confusion around what the actual definition of ABA is.

Another factor to consider is that the participants' memories in this study go back to almost two decades ago, when knowledge of autism was not as advanced as it is today, and some of the approaches to treatment incorporated aversives and other treatments that are no longer used today. For example, George underwent painful sensory desensitisation treatment, but the DSM-V (2013) now acknowledges sensory sensitivities as one of the core characteristics of autism. Also, prior to 1998, there were no formal qualifications for an ABA therapist; there is now a formal board certification for ABA therapists (Behavior Analyst Certification Board, 2019).

Several of the participants spoke about experiencing post-traumatic stress disorder (PTSD) as a result of their experiences with ABA as children. This is aligned with Kupferstein's (2019) findings. The two participants without autism not only did not suffer from PTSD, but also found ABA helped them. This replicates what has been discovered in the literature that provides a strong evidence base for the use of ABA and PBS (Briesch and Daniels 2013; Carrero 2015; Dillenberger and Keenan 2009). This brings the concept of social validity into play. There is a distinct possibility that while ABA-based interventions such as PBS are effective interventions for some children, that some of the practices could prove to be harmful to others.

As stated earlier, one of the issues surrounding ABA research is the lack of assessment of social validity of both the treatment goals and practices. Another glaring omission is that while the scant social validity research surveyed parents, teachers, and clinicians, none of those asked the most important group - the consumers. Recent consumers of ABA-type therapies should be surveyed about their experiences and their effects. This would include people with a variety of disabilities.

More research needs to be conducted to determine the efficacy of alternate treatments to Lovaas' methods of intervention for young autistic children. This will hopefully increase the number of interventions that are covered by governments and insurance companies, thus increasing the choices for parents, who make these early front-line decisions (Shepherd et al. 2018).

Many of the autistic participants mostly struggled with feeling unloved and not accepted the way they are. They felt they needed to be changed in order to be deemed worthy of society. ABA therapy was just a series of compliance drills to them, without any logic or explanation of why they need to learn skills. This is another social validity issue - although Lovaas' early childhood therapy has evidence of effectiveness in changing behaviour, what is the cost to autistics' self-worth and self-determination?

X. Strengths and Limitations

The main strength of this study is that it sought the voices of autistic people. It was borne of our interests as both researchers and practitioners. We feel that we have presented a balanced view of what exists on the ABA controversy in the popular and professional literature.

The main limitation is that although we consulted an autistic colleague about this study, and although two of us identify as having a disability, neither identifies as having autism. Future research should include an autistic research team member. The sample of participants was relatively small. Kupferstein's (2019) study had a much larger sample size. As recruitment was conducted mostly through social media, it should be noted that several of these sites actively recruit participants for studies on ABA in order to promote abolishing the practice. For example, a posting on the Facebook page *ABA Controversy Autism Discussion UK* states, "If you have used ABA on your child and then saw the light and would like to feedback your experience in a research project, please get in touch with the contact in the advert." Therefore, it is more likely to hear voices of autistic people who had negative experiences, than those who might have had positive ones.

The majority of participants were autistic. Because ABA and PBS are so widely used in schools globally, future studies should include participants with a variety of disabilities, particularly emotional and behaviour disorders. Lastly, all of the participants were adults, with a mean age of 37 years. This poses two limitations. First of all, the respondents were relying on their memories of interventions they participated in decades ago. Secondly, ABA practices may have evolved since they experienced their various therapies. The solution to this would be to survey children and young people who are currently experiencing ABA therapy.

XI. Conclusion

There has been much controversy over the use of ABA among autistic individuals on online forums and blog, yet the social validity of ABA remains largely unexplored among researchers. This pilot study revealed that while parents generally find ABA to be an effective therapy for their child, most participants who have had experience with ABA view it in a negative light. Although ABA may be effective in changing one's behaviour, it is essential to consider its social validity when determining its effectiveness as an intervention.

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