Introduction

The autistic voice is increasingly present in writing over the last decade, being drawn into mainstream cultural awareness (Straus, 2013) and influencing the turn of inclusive research (Fletcher-Watson et al, 2019). Since the publication of Pelicano’s *A Future Made Together* (2014), the progression of including autistic voices in both research and outcomes has expanded. The vitality of these voices has created a developed comprehension of autistic lives from the perspective of lived expertise (Milton, 2014), highlighting the need for voices to be further included in progressing vital and relevant research. Early behavioural intervention is one such area, seen as critical for the development of positive life outcomes (Dawson et al, 2012). Researchers claim early intervention using behavioural conditioning develops a solid foundation for participants learning retention (Dennis et al, 2013; Ismail et al, 2017). Current controversy exists surrounding perceptions of the need for early intervention. From an outsider perspective it would seem those who form part of the debate would fit into one of two sides; those who assert early intervention as a necessity for autistic children and those within the autistic community who see these interventions as having a detrimental impact on autistic identity. Not all members of the autistic community would suggest early intervention to be negative, while not all practitioners would suggest a cohesive positive outcome for each child who participates in these interventions.

Applied Behavioural Analysis (ABA) is one such intervention which faces a level of scrutiny. Behavioural learning within ABA is founded on Reinforcement, Punishment, Extinction and Repetition (Mohammadzaheri et al, 2014), promoting learning through replication of targeted behaviours modelled by the therapist, with reinforcers reducing potential distractors interfering with learning. Further, efficacy is viewed through short term outcomes, with long term outcomes rarely explored. Long-term (4-4.5 year) outcome studies concluded strength in the application of long-term learning retention of children through ABA techniques (McEachin et al, 1993; Sallows & Graupner, 2005), though impacts further into adolescence and adulthood remain unexplored. Research portrays the ways in which ABA is attempting to become more adaptive in going beyond its original parameters (Dixon, et al, 2019). Moving to address other areas where participants may face distinct challenges, such as IQ and areas of more complex skills, examples the flexibility ABA is moving towards. Research such as Dixon’s may highlight a perspective of positivity from behavioural intervention, though there are greater complexities to the understanding of early interventions. Some Autism focused institutions focus on the positive outlook of ABA. Indeed, Autism Canada go so far as to state “There are no known negative effects of the ABA approach. This is especially the case
if gentle prompting is used rather than aversive techniques.” (Autism Canada, 2020). The implications of such a statement are both misleading and misinformed. Autistic individuals who have undergone ABA as children and adults have expressed diverse accounts of their experiences. These anecdotal reflections embody the range of perspectives taken by those in academic and professional fields yet are perceived with little to no value. Outside of anecdotal evidence, Kupferstein’s (2018) work on increased Post-Traumatic Stress symptoms (PTSS) for those who partook in early ABA intervention examples the overlooked nature of ABA which those who promote positivity may (dis)miss.

While some may perceive ABA as misinterpreted (Morris, 2009), argument stems from experiences of intervention and the impact of forced behavioural intervention has upon the processes and development of self-perception. Adapting autistic behaviour and identity to meet those of typically developing (TD) peers is at the core of ABA opposition. Indeed, current research has suggested ABA as causing a severe level of trauma from childhood participation (Kupferstein, 2018). Autistic individuals continue to highlight the suffering felt through ABA’s inability to acknowledge the negativity inflicted through forceful coercion (see, for example, Kedar, 2011; ”My experiences with ABA”, 2017). Such a conclusion raises further doubt as to both the efficacy of early intervention as well as the long-term implications and impact on participants. While arguments put to those who oppose ABA claim methods and approaches have changed (”The Controversy Around ABA”, 2019), opposition to ‘current’ ABA mirrors autistic attitudes to intervention (Klein, 2002) and ‘cures’ (Harmon, 2004) from nearly two decades ago. So many coming forward and indicating the harms for autistic children, which they themselves have experienced, to improve for the next generation is indicative of a disparity. Yet, with many being ignored or dismissed as ‘radicals’, ‘too autistic’ or ‘not autistic enough’ to speak for their own community, the bridge between academia and community is further fractured. To begin re-building these bridges, we seek to work alongside autistic reflections of ABA in order to bring voice into empirical constructs. Translating voice into academic comprehension of ABA in terms reflected by the autistic community addresses a vitally unaddressed gap in current research knowledge.

Method

Purpose and aim
The current research set out to understand the long-term outcomes of autistic adults recalled early childhood experiences of ABA. Currently, little exploration has been made to grapple with autistic individuals’ experiences of ABA outside of online blogs and videos. Debates on the purpose of ABA (Milton, 2012) and the possibility of trauma (Kupferstein, 2018) from participation developed new directions in understanding and interrogating ABA as an intervention for autistic individuals. There is a distinct need to understand how autistic individuals have experienced ABA beyond anecdotal reflections. Building on the need to balance the debate while developing an empirical evidence base requires listening to autistic expertise through experience (Milton, 2014). Placing the autistic voice at the centre of the research, an interpretative, descriptive method was required. Thematic analysis was used to grapple with and understand the long-term impacts of participants experiences (Braun and Clarke, 2012).

Participants

Participants were 12 autistic adults. Adults were eligible to participate in the study if they: (1) were diagnosed as autistic; (2) were 18 years or above; (3) had engaged in ABA as a child for a minimum of 6 months; (4) were willing to share their experiences in a questionnaire or interview. Twelve autistic adults were eligible to take part. One respondent was excluded as they represented a parental view (participant 11): “It’s up to us parents to decide” and “I can easily talk to other parents about it and help them in getting more info”. Another was omitted as the therapy lasted less than 1 month (participant 3). Two participants indicated a co-occurring Intellectual Disability diagnosis (participants 4 and 13). The majority of the participants were from the UK, USA and Canada. Participant characteristics are shown in Table 1.

INSERT TABLE 1 HERE

Procedure

Participants were recruited via existing contacts within the research team and through adverts placed on social media within both autism advocacy and ABA advocacy organisations. Information sheets were provided to eligible participants at least 24 hours before consent for interviews was sought, and only those who subsequently gave full informed consent joined the study. Before accessing the questionnaire, participants were required to indicate having read the information sheet and understood the process of consent. Participants were interviewed via instant messenger using live text interactions and questions following the same sequence as those on the
questionnaire. Interviews were conducted using this method as participants chose to partake in non-face-to-face interviews for their own comfort and accessibility.

**Data Analysis**

Both interviews were conducted by OM and verbatim text was transferred to a word document following the completion of the interviews. Questionnaire responses were extracted from the online instrument. The data was organised into responses to 11 exploratory questions. Question 1, participant 1, followed by Question 1, participant 2 until all responses to question 1 had been collated. At this point it was noted that two participants significantly differed from the majority and these two participants were collated and analysed separately. The same procedure carried out for question 1 was repeated with question 2 to collate all participant responses and this was replicated for all questions.

We used an essentialist or realist epistemological approach (Braun & Clarke, 2006). Such an approach allowed us to gain an insight into the nature of participants experiences and understanding of their own identities. As we were interested in the meanings, realities, and experiences associated with autistic adults’ recollections of early childhood ABA, taking a realist lens to interpret the reflections of participants was vital. As autistic participants were reflecting on their childhood experiences, thematic analysis was applied to better explore these perspectives (Braun and Clarke, 2006). The analysis was conducted by AR and consisted of six stages: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. Firstly, each question transcript was read, with AR noting potential themes and impressions of the data. Next, initial codes were generated based on the transcripts; these codes were then combined into preliminary themes. Finally, these themes were reviewed and refined, and extracts that illustrated them selected.

**Trustworthiness**

Throughout the analytic processes, OM and AR met regularly to discuss data, codes, examples, and themes. Discrepancies were addressed through each author taking the same elements being analysed and critiqued and remodelled until consensus was reached. Finally, credibility checks were conducted by eliciting feedback by presenting the analytical framework to
Findings and Discussion

Data were organised into themes and subthemes, with the final thematic framework presented in Table 2. Five themes, comprising fifteen subthemes, were identified. The five major identified themes are as follows: (1) ‘Behaviourist methods create painful lived experience’, which explores the methods and impact of early experiences of behaviourist approaches; (2) ‘Erosion of true actualizing self’ which recognises the gaslighting impact of ones developing self; (3) ‘Lack of self-agency within interpersonal exchanges’ which recognises longer-term impact living with experience; (4) ‘Self-healing and compassion’ which recognises the journey of recovery; and (5) ‘Hear my angry voice’ which explores activist messages.

INSERT TABLE 2 HERE

Theme 1: Behaviourist methods create painful lived experience

This theme encapsulates adult reflections of early childhood experiences of ABA, subsuming three subthemes. The majority spoke of being harmed by the methods used from such experiences. Each of the participants (n=10) indicated a sense of ‘training’ or negativity from the repetitive nature of the therapy.

Subtheme 1.1: Repetitive Schooling with Physical Intervention

Half of the participant’s reflections (n=5) expressed that the intervention was contingent on repeating certain tasks in order to avoid punishment: “I was punished by having to do it again, and again and again. In ABA when they say you get a reward if you do it, they mean you get it if you do it the way they wanted the first time. If it’s not done right the first time the treats were removed and you [were] punished by repeating the act or skill or reaction over until you get it right” (P14).

Participants also indicated the use of physical intervention to forcefully engage them with the therapy: “I was physically restrained, kept from using the toilet, force fed” (P2).

Subtheme 1.2: Trained Like an Animal to Perform
The majority of participants expressed (n=7) being forced to engage/‘perform’ certain acts or tasks in order to appear like their neurotypical peers. “They trained me like a dog to act like a neurotypical or else” [...] “I had [to] be perfect, socially. No one was allowed not to like me, I wasn’t allowed to not like anyone” (P9). Feeling dehumanised, whilst suppressing autistic identity, was stated by one participant “I was treated more like an animal than a person, they tried to stop me stimming (which I need to do to stay calm/prevent meltdowns/express myself)” (P14). Another participant demonstrated feeling ‘trained’ by reinforcers and their interests: “If I complied, they complimented in a condescending manner and gave me what I liked, just as you would to a puppy” (P13).

Subtheme 1.3: Whose Empathy Problem is this?

This subtheme contained reflections of what was described as a two-way empathy problem. Most participants reflected (n=7) feeling misunderstood and having their communication misinterpreted, “When they told me I was being shocking on purpose. That I was lying about what I felt, was unjust just because I was "being lazy" and didn’t want to do my therapy” (P9). Further, one participant illustrated their reflections of being left with a singular communication method, “I shut down quickly and was non-verbal yet they treated me as verbal and didn’t try to find alternative ways to communicate” (P7).

Interpersonal exchanges in ABA have been critiqued, with outcomes suggesting that the manner taken by therapists reflecting outside perceptions of the intervention (Callahan et al, 2019). In this first theme a clear discourse lies between the therapist approaches and the understanding of participant autonomy. One of the core components of behavioural learning and intervention is consistency and repetition (Mohammadzaheri et al, 2014). The method of learning through ABA is built on a teach/reward strategy to adapt behaviour (Grindle & Remington, 2005). Such approaches were perceived as being Trained Like an Animal to Perform. The idea of forced change and ‘training’ resonates with previous thinking proposed by some of the Autistic Community (Milton, 2012). Practitioners, however, perceive ‘training like an animal’ as a misconception of practice (Potterfield, 2013). Though individuals may interpret certain methods differently, the impact participants felt cannot be labelled as misconceptions of practice. The connotations of being trained reflects being somehow not ‘good enough’ and less than TD peers, while being labelled as different can negatively influence self-perceptions (Hodge et al, 2019). With the behavioural changes focused on autistic behaviour, participants indicated the need to change themselves as inhibiting a positive formation of identity. The Hidden Harms of a strained, negative development of identity are exampled by participants.
Theme 2: Erosion of True Actualising Self

This theme encapsulates adult reflections recalling how they experienced a sense of losing their sense of who they were which contained three subthemes. The majority of participants (n=7) experiences told a story of feeling a gradual loss of their sense of self and self-identity.

Subtheme 2.1: Shutting Down of the Real Autistic Me:

Many participant reflections (n=7) spoke of disengagement with their sense of self and autistic identity, “(ABA) changed the way I act, react, or interact with the world...The aim was to force a square peg into a round hole, instead of being ok with who I am. ...Better to stay safe and isolated, than rejected” (P6). Expression of being “taught that being able to fool people I was neurotypical was my best goal in life” (P10) followed troubling reflections of impact on self-perception. Another participant indicated how this removal of their autistic identity impacted both in sensory and physiological terms; “They physically made me sit the way they demanded without caring that it hurt. Once I was tied up for rocking” (P13).

Subtheme 2.2: Mental Health and Trauma:

This second subtheme contained reflections pertaining to mental health and wellbeing, with participants believing (n=7) ABA as having a causal impact on negative mental health, “I now have clinical depression as a result of experiencing ABA” (P2). A further four participants stated, “it gave me PTSD” (participants 4, 6, 8 & 13). Another participant reflected the long-term impacts of this experience, as illustrated here, “l’ve turned into an anxious person afraid of consequences” (P10).

Subtheme 2.3: Rejecting, Self-Loathing:

The majority of participants reflections (n=7) in the third subtheme referred to being left with feelings of self-rejection and a sense of self-loathing as a consequence of their experience of ABA. This self-loathing developed as a consequence of the forceful nature of ABA, “This is traumatic, it created internalized ableism, self-loathing” (P8). In agreement with this forceful nature, another participant indicated how this had an impact to their confidence and self-worth, “extreme poor self-esteem due to self-loathing forced” (P2).

The second theme to arise from our cohort’s reflections were the impacts of trauma which participation in ABA have had upon them. While short-term positive outcomes of ABA have been conceptualised (Dawson & Burner, 2011), little attention has been given to the long-term impacts.
Ableism is the exclusion and diminishing of the value disabled and neurodiverse individuals through a complex system of oppression which holds them to account on the strengths of able and neurotypical individuals (Rauscher & McClintock, 1996; Hehir, 2002). Ableism is in no way a new phenomenon, in either literature or social practice. Hehir (2007) highlighted the discrepancies which ableism has the potential to create, particularly in educational settings where the risk is run that pupils support would focus on their disability rather than education. These detrimental impacts on identity extended beyond the language used by therapists to the approaches used. Participants also reflected anger, believing ABA removed and internally ableised their autistic identity. Difficulties in identity formation are not unique to autistic individuals, though many ‘must deal with the social world as if they were not disabled’ (Gray, 2002, 735), masking their neurodiversity. The approaches participants experienced fuelled the anger and negative self-perceptions from an early age. Negativity expanded from the consistent feeling of oppression and rejection of neurodiversity from their intervention experience, with the negative self-perception developing and staying with participants throughout their younger years. Jones et al (2015) suggest individuals make “meaning of their diagnosis through self-awareness of their own unique characteristics and behaviours in comparison with others” (2015, pg. 1500). Further, Jones’ participants drew on their strengths in looking to their self-perception(s). If negative perception of autistic impairments is pushed on autistic participants, then the conclusions reached here are entirely plausible.

Theme 3: Lack of Self-Agency Within Inter-Personal Exchanges

The third main theme encapsulates experiences of loss of self-agency with a need for masking within interpersonal exchanges as a consequence of their childhood experiences and this contained three subthemes.

Subtheme 3.1: Left Voiceless and Mute:

This first subtheme contained participant reflections (n=4) the referred to them becoming voiceless or muted throughout the ABA process. One participant highlights this removal of any sense of agency through the process, “Entirely coercive. ABA controlled all aspects of reinforcers and aversives [sic], completely. I had no choice” (P4). Similarly, another participant indicated the forceful nature of this removal of agency and voice, “The conversation was over when and only when they said it was over” (P9).

Subtheme 3.2: Dependency with an Enduring Fear:
The majority of participants reflections (n=7) in this second subtheme referred to how ABA was believed to create dependency based upon accompanying fear. One participant illustrates this dependency and continued vulnerability in the following, “the focus on compliance made it harder for me to say no to people who hurt me later” (P12).

Subtheme 3.3: Pretending to be Someone Else:

This third subtheme reflected the need for pretence following the intervention, with some participants (n=3) describing the need for masking and camouflaging their identity. One participant reflected the fear and reasoning for this, “I am no longer capable of being myself around others. Outside of my own control I observe them and make a person that they will most likely enjoy. I actively change myself around others to a staggering degree” (P9). Another explained how they felt “ABA made it much harder to make friends, because I was spending so much time trying to pretend to be someone I’m not that I could never really connect to people” (P13)

The autistic adults in this study demonstrated how they believe their mental health has been affected by their ABA participation. The findings call in to question the cost of interventions, moving from short-term outcomes to refocus on potential long-term impacts of harm and trauma. Reflections of trauma, anxiety and forced change are troubling, highlighting the discourse between the reported outcomes of the intervention and participants own experiences as having a level of risk which remained unseen to practitioners. Indeed, this is not the first investigation to bring together ABA participation and mental health impacts. Kupferstein (2018) concluded heightened criteria for PTSS for those who had previously participated in ABA intervention. While critiques of Kupferstein’s approach and conclusions suggest potential bias and a difficulty in interpreting which were the autistic voices in their research (Leaf, Ross, Cihon & Weiss, 2018), Kupferstein’s research builds on the foundations of autistic narratives of trauma and forced change. In addition, there are different stakeholders with vested interests in ABA. Indeed, those involved in the Leaf critique of Kupferstein hold a vested interest in the positive outlook of ABA as practitioners and/or teachers of the intervention (Chown et al, 2019). Kupferstein’s interest lies with projecting the impacts of ABA which are in serious dearth within research.

Theme 4: Self-Healing and Compassion

This fourth main theme contained reflections by participants that marked the realisation that they had been psychologically damaged by their earlier childhood experiences, but this
triggered a process of self-recovery. This level of self-realisation and compassion, was drawn by participants as a sense of self-acceptance, moving beyond the loss and building anew.

**Subtheme 4.1: Who Am I Really?:**

Within this first subtheme there is a beginning awareness portrayed in participants reflections (n=3) as they start to question the change in themselves through contemplation of their involvement with ABA, “I’ve turned into an anxious person afraid of consequences (good or bad). And I got depressed and lost my interests which were used as reinforcer.” (P10). Another participant here illustrated how their daily life has become impacted to the difficulty of completing mundane tasks, “I stress when I do things like dishes when it should just be a very simple task” (P13).

**Subtheme 4.2: Searching to Recapture My Autistic Self:**

This second subtheme contained participants (n=3) reflections of the tensions experienced in challenging the ableist concepts forced upon them while understanding and exploring a new emerging sense of self and autistic identity. Reflecting on the difficulty of this self-recognition, P12 indicated, “I still feel ashamed of who I am. Rationally I know that being autistic isn’t wrong, it’s just a different way of thinking”. Further reflections highlighted how, “Nobody can see the emotional and mental scars that have been caused by the trauma and damage done by ABA” (P14). Finally, P10 acknowledged repairing the psychological damage they experienced “shaming and ableist thinking was hammered into my brain from the time I was a preschooler. In recent years, I’ve begun undoing the damage on my own.”.

**Subtheme 4.3: Rediscovering my Lost Loves:**

Within the third subtheme, participants (n=3) expressed a movement towards engaging with their interests which they had lost (through either repression or use as a reward system) during their intervention. One participant reflected on rediscovering a lost love through a simple item and the impact this had upon them, illustrated here, “a small laptop for them to use and take home...and I got one as well; my lifesaver. I hid them then stayed up at night playing on it. Most crucial point of my life” (P13).

Within our participants reflections, there remained an ableist overtone from both the practitioners and intervention. The persistent and pervasive discourse which participants indicated reflected an ableist approach adopted within the intervention. Both their self-perception and value they believed they held were drastically damaged following their participation. The focus, from participants outlook, remained on their inability (impairment from the medical perspective) and
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changing them to appear and act more like TD children. The need for strengths to be acknowledged and a focus on instilling skill or educating individuals has been highlighted in outside literature (Herir, 2007). There remains a clear need for a change in the ABA field when approaching and understanding autism, particularly as its rhetoric lies within an ableist focus of autism as an impairment or deficit does little to understand individual differences (Shyman, 2016). The longevity of internalised ableism long outlasted the intervention itself, with participants expressing the negative self-perceptions these created. Through a complex system of self-reflection, self-acceptance has taken place in later years, progressing beyond the harm and internalised ableism to an understanding of their autistic self’s. The overarching theme of *Hidden Harm* suggests that it isn’t what is widely reported and seen within practice which impacts participants, rather the long-term aspects which remain broadly unexplored.

**Theme 5: Hear My Angry Voice**

The fifth main theme referred to an emerging collective strength of voice with a strong message and insistence to be heard, which subsumed three subthemes. These messages moved towards a movement of activism which was opposed to the philosophy of ABA and a desire for recognition of a strengths-based approach for all autistic people.

**Subtheme 5.1: We Reject ABA with Your Ableist Philosophy:**

Within this first subtheme, over half of the participants (n=6) expressed their rejection of the ABA philosophy and processes, whilst demanding autism acceptance. “Stop trying to fix us. Short-term "success" isn’t worth the long-term PTSD” (P8) reflects the broader consensus of participants. Angry rejection of ABA’s philosophy and aim were consistent across the six participants reflections; “It is a bogus intervention which should not be recommended to autistic people if they are not adults and are not capable to fully understand the methods which will be used on them and the risks of them for their own well-being” (P11).

**Subtheme 5.2: See my Strengths:**

Within this second subtheme participants’ reflections (n=3) were indicative of the need to move towards a strengths based philosophy, “focus on affirming what's good about autism along with helping to develop skills to navigate our society” (P11), “The best approach would be to see what goals the autistic kid has, let them direct the skill they want to learn, and to understand that the way autistic people think isn’t bad” (P12). Further, P14 highlights the need to build upon the
interests of the individual to bring out these strengths, “not all of us grow up to be like Dr. Sean Murphy on the good doctor. Some of us do. It’s all about interest environment and how their taught”.

Subtheme 5.3: Nothing Without Us Means Autistic Led:

The third and final subtheme referred to the need for adaptation in the involvement of autistic individuals in the intervention, with more than a half of participants (n=6) calling for autistic adults’ involvement for the protection of younger, vulnerable autistic children. “Have Autistic adults teach Autistic children. They would know the children, and what’s best for the children in a far better and far more humane capacity” (P9), with P8 extending to “Have autistic adult mentors to guide parents in selecting any therapies”.

In this study we have reported on autistic adult’s childhood experiences of ABA. The autistic voice is a form of lived expertise, a knowledge-base which research should seek to embody yet is consistently overshadowed in favour of other methods (Milton, 2014). The current research findings gave voice to ‘Recalling Hidden Harms of Early Childhood Experiences of ABA’ as an emergent core theme. Participants expressed a sense of harm and living with the long-term painful experiences following childhood intervention. From these painful experiences expressed, a challenge arises to the practice and success of intensive ABA (Fein et al, 2013; Orinstein et al, 2014). As shown in theme 5, there remains a need for future research to embody and understand the strengths of autistic individuals partaking in ABA intervention. Expressions of harm from participation poses a strong ethical issue to the practice of behavioural intervention, especially considering most autistic children who become involved use non-verbal communication or become selectively mute in stressful scenarios. Such a position of power over vulnerable children may create an environment where self-doubt festers, leading to the possibility of an intrinsically harmful long-term impact, with the sense of anger participants expressed beginning at an early age.

While many of our participants reflected upon the negative outcomes they experienced, two individuals reflected upon the positivity they felt ABA has given them. Given only two positive reflections met the qualifying parameters of the research, the data wasn’t of a large enough quantity to warrant a robust thematic evaluation similar to the Hidden Harms theme. Despite the shortcomings in our numbers of positive reflections, there were distinctive similarities to the suggested empirical outcomes of ABA. Both participants highlighted the efficacy of their participation: “ABA taught me some amazing social skills and coping methods” (P1). What forms the basis of positive outcomes for ABA is adapting and changing participant behaviours in a positive
manner (Ho, Stephenson & Carter, 2015). Through reflections of positive experiences, these two participants have highlighted what they perceive as vital to their own developments. Both participants indicated ABA helping to regulate and remove self-harming to ensure support for their mental and physical wellbeing: “ABA stopped harmful disfiguring behaviours when nothing else could” (P5); “it stopped a harmful behaviour that would have had lifelong negative effects if allowed to continue” (P1). Suggested outcomes are reflected throughout ABA research (Sallows & Graupner, 2005), with these participants becoming part of the wider narrative on a positive model of ABA. Finally, both participants also highlighted an acceptance of their autistic selves with ABA forming part of this positive outlook: “Sure, I'll always be autistic but I'm in control of myself and my life. And that's due to ABA” (P1); “I'm in control of myself and my life. And that's due to ABA” (P5). These reflections support both the empirical outcomes of ABA and the outside anecdotal evidence given from parent and other autistic individuals (“ABA Success Stories - Child Autism UK - releasing potential”, 2019). While only two accounts, stock should be taken from these accounts which require further research alongside those who reflect negative outcomes.

Limitations

Though autistic researchers have written on the perceptions and impacts of ABA (Kupferstein, 2018; Milton, 2012), the voices of autistic participants of behavioural intervention have been consistently unexplored. The authors used contacts within the autistic community and autistic organisations in the UK to promote and recruit participants for the research. Of course, there are those in the autistic community who challenge and advocate against ABA due to their own participation, just as there are those who’s experiences mean they now advocate for others to undergo ABA. The authors shared the research recruitment through both autistic and ABA organisations, as well as widely on social media in an attempt to gain a broader sample. Additionally, recruitment taking place online through both ABA and autism organisations creates the potential for bias in our sample. Through the anonymous questionnaire approach there is potential that more participants may have been attracted to reflect on their negative experiences rather than positive, though this may be a more poignant reflection on the ABA outcomes which have, until now, remained unexplored.

While our results are powerful reflections of participants experiences, our sample size remained small. Many reasons may account for this, though some responses to our research indicated not wanting to 'give advice on torturing other autistic children' and helping to develop
better ‘training methods’. Such statements reflect not only the future research which is needed, but the discord between the autism community and practitioners and advocates of early intervention. While our sample has allowed the conclusion of negative experiences, the application of our outcomes may not apply to broader samples though provides a novel development in the current knowledge of behavioural intervention. There lies a need for further research to develop the understanding of autistic individuals’ experiences of ABA.

We must also highlight that the experiences of our participants may not reflect all current ABA practice as these reflections are looking back over 18 years. That, however, does not invalidate our participants experiences and the potential for autistic children to experience such negativity. We must also highlight the differing understanding of good or positive outcomes. Stakeholders may hold different views on what positive ABA outcomes are. Our participants perceive autistic participants becoming indistinguishable from TD as a wholly negative outcome while others may perceive such development as positive.

Conclusion

Our research is the first to present a thematic analysis of ABA experiences during childhood. The smaller cohort size has allowed an intense, in-depth comprehension of the long-term impacts behavioural intervention may have upon participants. Core reflections of Hidden Harms suggest a broadly unexplored impact upon the autistic participants of behavioural intervention. The reflections of our participants demonstrate that continued research is vital to developing a critical understanding of autistic experiences and perspectives in the area of early intervention. We call for a change in practice to acknowledge and involve the autistic voice when practicing ABA as well as short and long-term follow up on the lasting impact of early intensive intervention. We also call for researchers to engage with those who are experts by experience. Foremost, we advocate for a development of methods to capture the autistic voice, particularly those most vulnerable to having their voice ignored or supressed.

Ethical Statement

The study was granted ethical approval from the School of Education Ethics Committee at the University of Strathclyde. All participants were provided with full disclosure on the study.
References


Kupferstein, H., 2019. Why caregivers discontinue applied behavior analysis (ABA) and choose communication-based autism interventions. *Advances in Autism.*


### Table 1: Characteristics of the sample

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<td>USA</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>12</td>
<td>/</td>
<td>1997</td>
<td>5 years</td>
<td>Australia</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>13</td>
<td>3</td>
<td>1999</td>
<td>9 years</td>
<td>USA</td>
<td>Interview</td>
</tr>
<tr>
<td>14</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>USA</td>
<td>Interview</td>
</tr>
</tbody>
</table>
Table 2: Thematic Framework of Autistic Adults Experiences of Early Childhood ABA

<table>
<thead>
<tr>
<th>Thematic Framework of Early Childhood Experiences of ABA</th>
<th>RECALLING HIDDEN HARMS OF EARLY CHILDHOOD EXPERIENCES OF ABA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviourist methods create painful experiences</td>
<td>“I was physically restrained, kept from using the toilet, force fed”</td>
</tr>
<tr>
<td>Repetitive ‘schooling’ with physical interventions</td>
<td>“They trained me like a dog to act like a neurotypical or else”</td>
</tr>
<tr>
<td>Trained like an animal to perform</td>
<td>“I shut down quickly and was non-verbal yet they treated me as verbal and didn’t try to find alternative ways to communicate”</td>
</tr>
<tr>
<td>Whose empathy problem is this?</td>
<td></td>
</tr>
<tr>
<td>Erosion of true actualizing self</td>
<td>“I was trained to be nonautistic…I was taught that being able to fool people I was neurotypical was my best goal in life”</td>
</tr>
<tr>
<td>Shutting down of the real autistic me</td>
<td>“it gave me PTSD”</td>
</tr>
<tr>
<td>Mental health through trauma</td>
<td>“This is traumatic, it created internalized ableism, self-loathing”</td>
</tr>
<tr>
<td>Rejecting self-loathing</td>
<td></td>
</tr>
<tr>
<td>Lack of self-agency within interpersonal exchanges</td>
<td>“The conversation was over when and only when they said it was over”</td>
</tr>
<tr>
<td>Left voiceless and mute</td>
<td>“the focus on compliance made it harder for me to say no to people who hurt me later”</td>
</tr>
<tr>
<td>Dependency with an enduring fear</td>
<td>“it made it much harder to make friends, because I was spending so much time trying to pretend to be someone I’m not that I could never really connect to people”</td>
</tr>
<tr>
<td>Pretending to be someone else</td>
<td></td>
</tr>
<tr>
<td>Self-healing and compassion</td>
<td>I still feel ashamed of who I am. Rationally I know that being autistic isn't wrong, it's just a different way of thinking, but it's hard to shake all those years of</td>
</tr>
<tr>
<td>Who am I really</td>
<td></td>
</tr>
<tr>
<td>Searching for me, being autistic is</td>
<td></td>
</tr>
<tr>
<td>OK</td>
<td>people trying to force me to be someone different. “a small laptop for them to use and take home...and I got one as well; my lifesaver.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Rediscovering my lost loves</td>
<td></td>
</tr>
<tr>
<td>Hear my angry voice</td>
<td>We reject ABA with your ableist philosophy</td>
</tr>
<tr>
<td>We reject ABA with your ableist philosophy</td>
<td>“Stop trying to fix us. Short-term &quot;success&quot; isn’t worth the long-term PTSD”</td>
</tr>
<tr>
<td>Nothing without us means autistic led</td>
<td>focus on affirming what’s good about autism along with helping to develop skills to navigate our society</td>
</tr>
<tr>
<td>Put well paid autistic adult advocates on all behaviour change meetings to enforce no coercion</td>
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</tr>
</tbody>
</table>