

This is a peer-reviewed, accepted author manuscript of the following research article:  
McGill, O., & Robinson, A. (Accepted/In press). Recalling hidden harms: autistic experiences of childhood Applied Behavioural Analysis (ABA). *Advances in Autism*. <https://doi.org/10.1108/AIA-04-2020-0025>

## 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

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3 if gentle prompting is used rather than aversive techniques.” (Autism Canada, 2020). The  
4 implications of such a statement are both misleading and misinformed. Autistic individuals who have  
5 undergone ABA as children and adults have expressed diverse accounts of their experiences. These  
6 anecdotal reflections embody the range of perspectives taken by those in academic and professional  
7 fields yet are perceived with little to no value. Outside of anecdotal evidence, Kupferstein’s (2018)  
8 work on increased Post-Traumatic Stress symptoms (PTSS) for those who partook in early ABA  
9 intervention examples the overlooked nature of ABA which those who promote positivity may  
10 (dis)miss.  
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20 While some may perceive ABA as misinterpreted (Morris, 2009), argument stems from  
21 experiences of intervention and the impact of forced behavioural intervention has upon the  
22 processes and development of self-perception. Adapting autistic behaviour and identity to meet  
23 those of typically developing (TD) peers is at the core of ABA opposition. Indeed, current research  
24 has suggested ABA as causing a severe level of trauma from childhood participation (Kupferstein,  
25 2018). Autistic individuals continue to highlight the suffering felt through ABA’s inability to  
26 acknowledge the negativity inflicted through forceful coercion (see, for example, Kedar, 2011; "My  
27 experiences with ABA", 2017). Such a conclusion raises further doubt as to both the efficacy of early  
28 intervention as well as the long-term implications and impact on participants. While arguments put  
29 to those who oppose ABA claim methods and approaches have changed ("The Controversy Around  
30 ABA", 2019), opposition to ‘current’ ABA mirrors autistic attitudes to intervention (Klein, 2002) and  
31 ‘cures’ (Harmon, 2004) from nearly two decades ago. So many coming forward and indicating the  
32 harms for autistic children, which they themselves have experienced, to improve for the next  
33 generation is indicative of a disparity. Yet, with many being ignored or dismissed as ‘radicals’, ‘too  
34 autistic’ or ‘not autistic enough’ to speak for their own community, the bridge between academia  
35 and community is further fractured. To begin re-building these bridges, we seek to work alongside  
36 autistic reflections of ABA in order to bring voice into empirical constructs. Translating voice into  
37 academic comprehension of ABA in terms reflected by the autistic community addresses a vitally  
38 unaddressed gap in current research knowledge.  
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## 55 **Method**

### 56 *Purpose and aim*

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

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

### 44 *Procedure*

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

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12 Both interviews were conducted by OM and verbatim text was transferred to a word  
13 document following the completion of the interviews. Questionnaire responses were extracted from  
14 the online instrument. The data was organised into responses to 11 exploratory questions. Question  
15 1, participant 1, followed by Question 1, participant 2 until all responses to question 1 had been  
16 collated. At this point it was noted that two participants significantly differed from the majority and  
17 these two participants were collated and analysed separately. The same procedure carried out for  
18 question 1 was repeated with question 2 to collate all participant responses and this was replicated  
19 for all questions.  
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29 We used an essentialist or realist epistemological approach (Braun & Clarke, 2006). Such an  
30 approach allowed us to gain an insight into the nature of participants experiences and  
31 understanding of their own identities As we were interested in the meanings, realities, and  
32 experiences associated with autistic adults' recollections of early childhood ABA, taking a realist lens  
33 to interpret the reflections of participants was vital. As autistic participants were reflecting on their  
34 childhood experiences, thematic analysis was applied to better explore these perspectives (Braun  
35 and Clarke, 2006). The analysis was conducted by AR and consisted of six stages: familiarisation with  
36 the data, generating initial codes, searching for themes, reviewing themes, defining and naming  
37 themes and producing the report. Firstly, each question transcript was read, with AR noting  
38 potential themes and impressions of the data. Next, initial codes were generated based on the  
39 transcripts; these codes were then combined into preliminary themes. Finally, these themes were  
40 reviewed and refined, and extracts that illustrated them selected.  
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### 52 *Trustworthiness*

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55 Throughout the analytic processes, OM and AR met regularly to discuss data, codes,  
56 examples, and themes. Discrepancies were addressed through each author taking the same  
57 elements being analysed and critiqued and remodelled until consensus was reached. Finally,  
58 credibility checks were conducted by eliciting feedback by presenting the analytical framework to  
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3 ABA discussion and autism/ABA research groups. AR did not seek to go beyond what had been  
4 written or said during the interviews. To ensure a limiting of potential bias and trustworthiness in  
5 the analysis OM read over the analysis separately before the final consensus were met. Therefore,  
6 we can be reasonably confident that the researcher's knowledge and experience of working in the  
7 Autism field did not impact on the data coding process.  
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## 15 **Findings and Discussion**

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

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36 This theme encapsulates adult reflections of early childhood experiences of ABA, subsuming  
37 three subthemes. The majority spoke of being harmed by the methods used from such experiences.  
38 Each of the participants (n=10) indicated a sense of 'training' or negativity from the repetitive nature  
39 of the therapy.  
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#### 44 *Subtheme 1.1: Repetitive Schooling with Physical Intervention*

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46 Half of the participant's reflections (n=5) expressed that the intervention was contingent on  
47 repeating certain tasks in order to avoid punishment: "I was punished by having to do it again, and  
48 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  
49 the way they wanted the first time. If it's not done right the first time the treats were removed and  
50 you [were] punished by repeating the act or skill or reaction over until you get it right" (P14).  
51 Participants also indicated the use of physical intervention to forcefully engage them with the  
52 therapy: "I was physically restrained, kept from using the toilet, force fed" (P2).  
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#### 59 *Subtheme 1.2: Trained Like an Animal to Perform*

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

### 12 13 14 15 16 17 18 19 *Subtheme 1.3: Whose Empathy Problem is this?*

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

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34 Interpersonal exchanges in ABA have been critiqued, with outcomes suggesting that the  
35 manner taken by therapists reflecting outside perceptions of the intervention (Callahan et al, 2019).  
36 In this first theme a clear discourse lies between the therapist approaches and the understanding of  
37 participant autonomy. One of the core components of behavioural learning and intervention is  
38 consistency and repetition (Mohammadzaheri et al, 2014). The method of learning through ABA is  
39 built on a teach/reward strategy to adapt behaviour (Grindle & Remington, 2005). Such approaches  
40 were perceived as being *Trained Like an Animal to Perform*. The idea of forced change and 'training'  
41 resonates with previous thinking proposed by some of the Autistic Community (Milton, 2012).  
42 Practitioners, however, perceive 'training like an animal' as a misconception of practice (Potterfield,  
43 2013). Though individuals may interpret certain methods differently, the impact participants felt  
44 cannot be labelled as misconceptions of practice. The connotations of being *trained* reflects being  
45 somehow not 'good enough' and less than TD peers, while being labelled as different can negatively  
46 influence self-perceptions (Hodge et al, 2019). With the behavioural changes focused on autistic  
47 behaviour, participants indicated the need to change themselves as inhibiting a positive formation of  
48 identity. The *Hidden Harms* of a strained, negative development of identity are exemplified by  
49 participants.  
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## *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 being 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, "I'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.



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3 Ableism is the exclusion and diminishing of the value disabled and neurodiverse individuals through  
4 a complex system of oppression which holds them to account on the strengths of able and  
5 neurotypical individuals (Rauscher & McClintock, 1996; Hehir, 2002). Ableism is in no way a new  
6 phenomenon, in either literature or social practice. Hehir (2007) highlighted the discrepancies which  
7 ableism has the potential to create, particularly in educational settings where the risk is run that  
8 pupils support would focus on their disability rather than education. These detrimental impacts on  
9 identity extended beyond the language used by therapists to the approaches used. Participants also  
10 reflected anger, believing ABA removed and internally ableised their autistic identity. Difficulties in  
11 identity formation are not unique to autistic individuals, though many 'must deal with the social  
12 world as if they were not disabled' (Gray, 2002, 735), masking their neurodiversity. The approaches  
13 participants experienced fuelled the anger and negative self-perceptions from an early age.  
14 Negativity expanded from the consistent feeling of oppression and rejection of neurodiversity from  
15 their intervention experience, with the negative self-perception developing and staying with  
16 participants throughout their younger years. Jones et al (2015) suggest individuals make "meaning of  
17 their diagnosis through self-awareness of their own unique characteristics and behaviours in  
18 comparison with others" (2015, pg. 1500). Further, Jones' participants drew on their strengths in  
19 looking to their self-perception(s). If negative perception of autistic *impairments* is pushed on  
20 autistic participants, then the conclusions reached here are entirely plausible.  
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### 37 *Theme 3: Lack of Self-Agency Within Inter-Personal Exchanges*

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39 The third main theme encapsulates experiences of loss of self-agency with a need for  
40 masking within interpersonal exchanges as a consequence of their childhood experiences and this  
41 contained three subthemes.  
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#### 45 *Subtheme 3.1: Left Voiceless and Mute:*

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47 This first subtheme contained participant reflections (n=4) the referred to them becoming  
48 voiceless or muted throughout the ABA process. One participant highlights this removal of any sense  
49 of agency through the process, "Entirely coercive. ABA controlled all aspects of reinforcers and  
50 aversives [sic], completely. I had no choice" (P4). Similarly, another participant indicated the forceful  
51 nature of this removal of agency and voice, "The conversation was over when and only when they  
52 said it was over" (P9).  
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#### 58 *Subtheme 3.2: Dependency with an Enduring Fear:*



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3 The majority of participants reflections (n=7) in this second subtheme referred to how ABA  
4 was believed to create dependency based upon accompanying fear. One participant illustrates this  
5 dependency and continued vulnerability in the following, “the focus on compliance made it harder  
6 for me to say no to people who hurt me later” (P12).  
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11 *Subtheme 3.3: Pretending to be Someone Else:*  
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13 This third subtheme reflected the need for pretence following the intervention, with some  
14 participants (n=3) describing the need for masking and camouflaging their identity. One participant  
15 reflected the fear and reasoning for this, “I am no longer capable of being myself around others.  
16 Outside of my own control I observe them and make a person that they will most likely enjoy. I  
17 actively change myself around others to a staggering degree” (P9). Another explained how they felt  
18 “ABA made it much harder to make friends, because I was spending so much time trying to pretend  
19 to be someone I'm not that I could never really connect to people” (P13)  
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26 The autistic adults in this study demonstrated how they believe their mental health has been  
27 affected by their ABA participation. The findings call in to question the cost of interventions, moving  
28 from short-term outcomes to refocus on potential long-term impacts of harm and trauma.  
29 Reflections of trauma, anxiety and forced change are troubling, highlighting the discourse between  
30 the reported outcomes of the intervention and participants own experiences as having a level of risk  
31 which remained unseen to practitioners. Indeed, this is not the first investigation to bring together  
32 ABA participation and mental health impacts. Kupferstein (2018) concluded heightened criteria for  
33 PTSS for those who had previously participated in ABA intervention. While critiques of Kupferstein’s  
34 approach and conclusions suggest potential bias and a difficulty in interpreting which were the  
35 autistic voices in their research (Leaf, Ross, Cihon & Weiss, 2018), Kupferstein’s research builds on  
36 the foundations of autistic narratives of trauma and forced change. In addition, there are different  
37 stakeholders with vested interests in ABA. Indeed, those involved in the Leaf critique of Kupferstein  
38 hold a vested interest in the positive outlook of ABA as practitioners and/or teachers of the  
39 intervention (Chown et al, 2019). Kupferstein’s interest lies with projecting the impacts of ABA which  
40 are in serious dearth within research.  
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54 *Theme 4: Self-Healing and Compassion*  
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56 This fourth main theme contained reflections by participants that marked the realisation  
57 that they had been psychologically damaged by their earlier childhood experiences, but this  
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3 triggered a process of self-recovery. This level of self-realisation and compassion, was drawn by  
4 participants as a sense of self-acceptance, moving beyond the loss and building anew.  
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7 *Subtheme 4.1: Who Am I Really?:*  
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10 Within this first subtheme there is a beginning awareness portrayed in participants  
11 reflections (n=3) as they start to question the change in themselves through contemplation of their  
12 involvement with ABA, "I've turned into an anxious person afraid of consequences (good or bad).  
13 And I got depressed and lost my interests which were used as reinforcer." (P10). Another participant  
14 here illustrated how their daily life has become impacted to the difficulty of completing mundane  
15 tasks, "I stress when I do things like dishes when it should just be a very simple task" (P13).  
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20 *Subtheme 4.2: Searching to Recapture My Autistic Self:*  
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23 This second subtheme contained participants (n=3) reflections of the tensions experienced  
24 in challenging the ableist concepts forced upon them while understanding and exploring a new  
25 emerging sense of self and autistic identity. Reflecting on the difficulty of this self-recognition, P12  
26 indicated, "I still feel ashamed of who I am. Rationally I know that being autistic isn't wrong, it's just  
27 a different way of thinking". Further reflections highlighted how, "Nobody can see the emotional  
28 and mental scars that have been caused by the trauma and damage done by ABA" (P14). Finally, P10  
29 acknowledged repairing the psychological damage they experienced "shaming and ableist thinking  
30 was hammered into my brain from the time I was a preschooler. In recent years, I've begun undoing  
31 the damage on my own."  
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39 *Subtheme 4.3: Rediscovering my Lost Loves:*  
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42 Within the third subtheme, participants (n=3) expressed a movement towards engaging with  
43 their interests which they had lost (through either repression or use as a reward system) during their  
44 intervention. One participant reflected on rediscovering a lost love through a simple item and the  
45 impact this had upon them, illustrated here, "a small laptop for them to use and take home...and I  
46 got one as well; my lifesaver. I hid them then stayed up at night playing on it. Most crucial point of  
47 my life" (P13).  
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52 Within our participants reflections, there remained an ableist overtone from both the  
53 practitioners and intervention. The persistent and pervasive discourse which participants indicated  
54 reflected an ableist approach adopted within the intervention. Both their self-perception and value  
55 they believed they held were drastically damaged following their participation. The focus, from  
56 participants outlook, remained on their inability (impairment from the medical perspective) and  
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3 changing them to appear and act more like TD children. The need for strengths to be acknowledged  
4 and a focus on instilling skill or educating individuals has been highlighted in outside literature (Herir,  
5 2007). There remains a clear need for a change in the ABA field when approaching and  
6  
7 understanding autism, particularly as its rhetoric lies within an ableist focus of autism as an  
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9 impairment or deficit does little to understand individual differences (Shyman, 2016). The longevity  
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11 of internalised ableism long outlasted the intervention itself, with participants expressing the  
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13 negative self-perceptions these created. Through a complex system of self-reflection, self-  
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15 acceptance has taken place in later years, progressing beyond the harm and internalised ableism to  
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17 an understanding of their autistic self's. The overarching theme of *Hidden Harm* suggests that it isn't  
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19 what is widely reported and seen within practice which impacts participants, rather the long-term  
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21 aspects which remain broadly unexplored.  
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#### 25 *Theme 5: Hear My Angry Voice*

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27 The fifth main theme referred to an emerging collective strength of voice with a strong  
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29 message and insistence to be heard, which subsumed three subthemes. These messages moved  
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31 towards a movement of activism which was opposed to the philosophy of ABA and a desire for  
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33 recognition of a strengths-based approach for all autistic people.  
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#### 35 *Subtheme 5.1: We Reject ABA with Your Ableist Philosophy:*

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37 Within this first subtheme, over half of the participants (n=6) expressed their rejection of the  
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39 ABA philosophy and processes, whilst demanding autism acceptance. "Stop trying to fix us. Short-  
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41 term "success" isn't worth the long-term PTSD" (P8) reflects the broader consensus of participants.  
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43 Angry rejection of ABA's philosophy and aim were consistent across the six participants  
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45 reflections; "It is a bogus intervention which should not be recommended to autistic people if they  
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47 are not adults and are not capable to fully understand the methods which will be used on them and  
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49 the risks of them for their own well-being" (P11).  
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#### 51 *Subtheme 5.2: See my Strengths:*

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53 Within this second subtheme participants' reflections (n=3) were indicative of the need to  
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55 move towards a strengths based philosophy, "focus on affirming what's good about autism along  
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57 with helping to develop skills to navigate our society" (P11), "The best approach would be to see  
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59 what goals the autistic kid has, let them direct the skill they want to learn, and to understand that  
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the way autistic people think isn't bad" (P12). Further, P14 highlights the need to build upon the

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3 interests of the individual to bring out these strengths, “not all of us grow up to be like Dr. Sean  
4 Murphy on the good doctor. Some of us do. It's all about interest environment and how their  
5 taught”.

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9 *Subtheme 5.3: Nothing Without Us Means Autistic Led:*

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

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22 In this study we have reported on autistic adult's childhood experiences of ABA. The autistic  
23 voice is a form of lived expertise, a knowledge-base which research should seek to embody yet is  
24 consistently overshadowed in favour of other methods (Milton, 2014). The current research findings  
25 gave voice to ‘*Recalling Hidden Harms of Early Childhood Experiences of ABA*’ as an emergent core  
26 theme. Participants expressed a sense of harm and living with the long-term painful experiences  
27 following childhood intervention. From these painful experiences expressed, a challenge arises to  
28 the practice and success of intensive ABA (Fein et al, 2013; Orinstein et al, 2014). As shown in theme  
29 5, there remains a need for future research to embody and understand the strengths of autistic  
30 individuals partaking in ABA intervention. Expressions of harm from participation poses a strong  
31 ethical issue to the practice of behavioural intervention, especially considering most autistic children  
32 who become involved use non-verbal communication or become selectively mute in stressful  
33 scenarios. Such a position of power over vulnerable children may create an environment where self-  
34 doubt festers, leading to the possibility of an intrinsically harmful long-term impact, with the sense  
35 of anger participants expressed beginning at an early age.

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47 While many of our participants reflected upon the negative outcomes they experienced, two  
48 individuals reflected upon the positivity they felt ABA has given them. Given only two positive  
49 reflections met the qualifying parameters of the research, the data wasn't of a large enough quantity  
50 to warrant a robust thematic evaluation similar to the *Hidden Harms* theme. Despite the  
51 shortcomings in our numbers of positive reflections, there were distinctive similarities to the  
52 suggested empirical outcomes of ABA. Both participants highlighted the efficacy of their  
53 participation: “ABA taught me some amazing social skills and coping methods” (P1). What forms the  
54 basis of positive outcomes for ABA is adapting and changing participant behaviours in a positive  
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3 manner (Ho, Stephenson & Carter, 2015). Through reflections of positive experiences, these two  
4 participants have highlighted what they perceive as vital to their own developments. Both  
5 participants indicated ABA helping to regulate and remove self-harming to ensure support for their  
6 mental and physical wellbeing: "ABA stopped harmful disfiguring behaviours when nothing else  
7 could" (P5); "it stopped a harmful behaviour that would have had lifelong negative effects if allowed  
8 to continue" (P1). Suggested outcomes are reflected throughout ABA research (Sallows & Graupner,  
9 2005), with these participants becoming part of the wider narrative on a positive model of ABA.  
10 Finally, both participants also highlighted an acceptance of their autistic selves with ABA forming  
11 part of this positive outlook: "Sure, I'll always be autistic but I'm in control of myself and my life. And  
12 that's due to ABA" (P1); "I'm in control of myself and my life. And that's due to ABA" (P5). These  
13 reflections support both the empirical outcomes of ABA and the outside anecdotal evidence given  
14 from parent and other autistic individuals ("ABA Success Stories - Child Autism UK - releasing  
15 potential", 2019). While only two accounts, stock should be taken from these accounts which  
16 require further research alongside those who reflect negative outcomes.  
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### 30 *Limitations*

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32 Though autistic researchers have written on the perceptions and impacts of ABA  
33 (Kupferstein, 2018; Milton, 2012), the voices of autistic participants of behavioural intervention have  
34 been consistently unexplored. The authors used contacts within the autistic community and autistic  
35 organisations in the UK to promote and recruit participants for the research. Of course, there are  
36 those in the autistic community who challenge and advocate against ABA due to their own  
37 participation, just as there are those who's experiences mean they now advocate for others to  
38 undergo ABA. The authors shared the research recruitment through both autistic and ABA  
39 organisations, as well as widely on social media in an attempt to gain a broader sample. Additionally,  
40 recruitment taking place online through both ABA and autism organisations creates the potential for  
41 bias in our sample. Through the anonymous questionnaire approach there is potential that more  
42 participants may have been attracted to reflect on their negative experiences rather than positive,  
43 though this may be a more poignant reflection on the ABA outcomes which have, until now,  
44 remained unexplored.  
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55 While our results are powerful reflections of participants experiences, our sample size  
56 remained small. Many reasons may account for this, though some responses to our research  
57 indicated not wanting to 'give advice on torturing other autistic children' and helping to develop  
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3 better 'training methods'. Such statements reflect not only the future research which is needed, but  
4 the discord between the autism community and practitioners and advocates of early intervention.  
5 While our sample has allowed the conclusion of negative experiences, the application of our  
6 outcomes may not apply to broader samples though provides a novel development in the current  
7 knowledge of behavioural intervention. There lies a need for further research to develop the  
8 understanding of autistic individuals' experiences of ABA.  
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14 We must also highlight that the experiences of our participants may not reflect all current  
15 ABA practice as these reflections are looking back over 18 years. That, however, does not invalidate  
16 our participants experiences and the potential for autistic children to experience such negativity. We  
17 must also highlight the differing understanding of good or positive outcomes. Stakeholders may hold  
18 different views on what positive ABA outcomes are. Our participants perceive autistic participants  
19 becoming indistinguishable from TD as a wholly negative outcome while others may perceive such  
20 development as positive.  
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## 29 **Conclusion**

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

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56 The study was granted ethical approval from the School of Education Ethics Committee at the  
57 University of Strathclyde. All participants were provided with full disclosure on the study.  
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*Table 1: Characteristics of the sample*

Participant	Age at intervention	Year of birth	Duration of ABA	Country of origin	Feedback method
1	5	1993	3 years	USA	Questionnaire
2	3	1995	7 years	USA	Questionnaire
3	/	1988	1 month	UK	Questionnaire
4	6	/		USA	Questionnaire
5	3	1998	7 years	UK	Questionnaire
6	3	1980	3 years	Canada	Questionnaire
7	14	1994	6 months	USA	Questionnaire
8	/	1965	10 years	USA	Questionnaire
9	/	1997	/	USA	Questionnaire
10	3/4	1980	15 years	Germany	Questionnaire
11	/	1980	/	USA	Questionnaire
12	/	1997	5 years	Australia	Questionnaire
13	3	1999	9 Years	USA	Interview
14	/	/	/	USA	Interview

Table 2: Thematic Framework of Autistic Adults Experiences of Early Childhood ABA

RECALLING HIDDEN HARMS OF EARLY CHILDHOOD EXPERIENCES OF ABA		
Behaviourist methods create painful experiences	<p><i>Repetitive 'schooling' with physical interventions</i></p> <p>Trained like an animal to perform</p> <p>Whose empathy problem is this?</p>	<p>"I was physically restrained, kept from using the toilet, force fed"</p> <p>"They trained me like a dog to act like a neurotypical or else"</p> <p>"I shut down quickly and was non-verbal yet they treated me as verbal and didn't try to find alternative ways to communicate"</p>
Erosion of true actualizing self	<p>Shutting down of the real autistic me</p> <p><i>Mental health through trauma</i></p> <p>Rejecting self-loathing</p>	<p>"I was trained to be nonautistic...I was taught that being able to fool people I was neurotypical was my best goal in life"</p> <p>"it gave me PTSD"</p> <p>"This is traumatic, it created internalized ableism, self-loathing"</p>
Lack of self-agency within interpersonal exchanges	<p>Left voiceless and mute</p> <p>Dependency with an enduring fear</p> <p>Pretending to be someone else</p>	<p>"The conversation was over when and only when they said it was over"</p> <p>"the focus on compliance made it harder for me to say no to people who hurt me later"</p> <p>"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"</p>
Self-healing and compassion	<p>Who am I really</p> <p><i>Searching for me, being autistic is</i></p>	<p>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</p>

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	<p>OK</p> <p>Rediscovering my lost loves</p>	<p>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.</p>
<p>Hear my angry voice</p>	<p>We reject ABA with your ableist philosophy</p> <p>See my strengths</p> <p>Nothing without us means autistic led</p>	<p>"Stop trying to fix us. Short-term "success" isn't worth the long-term PTSD"</p> <p>focus on affirming what's good about autism along with helping to develop skills to navigate our society</p> <p>"Put well paid autistic adult advocates on all behaviour change meetings to enforce no coercion"</p>

Advances in Autism