

## **Chapter 18: Challenging Behaviour(ists) – Neurodiverse Culture and Applied Behaviour Analysis**

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*'In the history of autism studies, expertise has been claimed by many differing academic schools of thought, practitioners, parents, quacks and so on. Yet, the one voice that has been traditionally silenced within the field is that of autistic people themselves.'*

(Milton, 2014)

### **Introduction [A-head]**

The Neurodiversity Movement has expanded knowledge, awareness and acceptance of identity through celebrating autism and positive portrayal of autistic lives. Vivaly moving from the long-publicised idea of tragedy, Autistic-led organisations and charities continue to advocate for awareness and change while combating negative and stereotyped views of autistic people. Extensions of autistic and neurodiverse advocacy have begun to question the methods and perceived need for early and behavioural intervention. In particular, the debate around the use of approaches from Applied Behavioural Analysis (ABA) has been fought vigorously on both sides. Autistic experiences frame an eloquent movement against behavioural intervention from lived experiences, while an exuberant evidence-base from case studies, reports and group research argue the case for ABA's efficacy. From its broad evidence base, ABA has been continually seen as the 'gold-standard' for autism interventions. Such conclusions suggest ABA as having a positive impact on developing skills and improving quality of life. Despite the improvements seen in targeted behaviours through applying behavioural conditioning, the long-term impact of ABA remains unexplored from the perspective of the participants. Peer-reviewed literature draws on examples of high-quality methods and outcomes, particularly exemplified in the *Journal of Applied Behaviour Analysis*. It could be argued, however, that the sources of these conclusions portray a practitioner's view of ABA as effective through limited reports rather than based on a collective conclusion drawn with the input of participants. In this chapter I aim to explore the debate between the autism community and ABA advocates. I will address the perspectives of apologists, parents and the vitally needed autistic expertise in understanding the unexplored long-term impact of Applied Behaviour Analysis. The chapter will also discuss the current debate on ABA outcomes within empirical literature and the need for autistic voices to form a vital part of future research outcomes.

### **Neurodiversity: a celebration [A-head]**

Since its inception, the neurodiversity movement has promoted the celebration of autism, and other developmental conditions, as a difference inseparable from the individual. First explored by Judy Singer (Ortega, 2009; Singer, 1999), the movement firmly challenges the idea of causality and cure, as promoted by the medical model (Kapp *et al*, 2013). For many, celebrating individuality and positivity in identity (Baker, 2011; Jaarsma & Welin, 2012) creates an understanding of neurodiversity as *human diversity* rather than tragedy in difference. Unfortunately, the continued focus on cause and cure from medical perspectives and the projection of autism as 'tragedy' have

increased eugenics-focused research (Orsini & Smith, 2010) meaning the removal of funding for vital support networks for many autistic people (Pellicano & Stears, 2011).

There is a growing need for research to create a developed and critical understanding of autistic experiences and invest in research which impacts the daily lives of autistic people. Looking to recent research, the debate around terminology in addressing those who are diagnosed or identify as autistic represents the steps future research should endeavour to take – positioning identity-first language compared to ‘person first’ terminology used to address identity (Orsini & Smith, 2010; Kenny *et al*, 2016) as preferred by many, while acknowledging individuality in identity for those who prefer person-first. The use of identity-first language has been expressed by a large percentage of those in the autism community in the UK as favourable over the medically preferred person-first language (Kenny *et al*, 2016). However, Kenny’s (2016) research also reflects on the need to understand and respect individual preferences in identity language. A small step, such research moves forward, indicating a broader acceptance and awareness of the autistic voice through identity and the value that involving autistic individuals within autism research has in helping us understand issues which are meaningful to their lives. Bringing autistic voices and experiences into academia and political policies creates stronger rooted evidence, based on the expertise of autistic individuals (Milton, 2014).

Social media has a huge offering of autistic expertise on their daily lives and experiences. Social discussion pages such as ‘Ask Me I’m Autistic’ and ‘Autistic Allies’ allow autistic individuals to express their experiences while helping them to learn and gain knowledge through other people’s lived experiences. From these and additional advocacy groups, opposition to techniques and philosophies that use behavioural modification can be expressed in a safe environment. ABA uses progressive learning progression to develop the communication and behavioural presentation of participants, approaching autism as a condition to be influenced or changed intervention. The aim to change or ‘cure’ autistic participants demonstrates a reductive understanding of autism in its attempts to reduce and remove anxiety reducing self-soothing techniques (e.g. stimming) (Lowery, 2017). Moving to negate the need for stimming and self-autonomy requires an engagement with those who are impacted by such reductive approaches to understanding. Viewing autism as removable (and, in some groups, requiring change) runs counter to the philosophy of acceptance and the celebration of the Neurodiversity Movement, bringing into focus the reason for challenging such ideologies.

### **Lived expertise [A-head]**

The societal barriers faced by many autistic individuals show the need for a deeper understanding and acceptance of autism. Autistic self-advocates, academics and other members of the autism community have highlighted the need for autistic voices to be heard, acknowledged and valued in matters which impact not only their lives, but the lives of all autistic individuals. In no way an easy challenge, autistic accounts have elucidated what had been coined as *impairments* or *deficits* as *difference* and part of the *autistic identity*. Autistic advocates and academics have built different inroads to understanding autistic lives. Comprehending the barriers in communication between autistic individuals and neurotypical individuals, Milton (2012) conceptualised these through the Double Empathy Theory, while Woods (2017) highlights shortcomings of the social model of disability in promoting autistic identity. From the side of autistic advocacy, promoting understanding

and acceptance of autistic identity and promoting knowledge (Agony Autie/Sara Jane Harvey) and challenging 'autism cures' and pseudoscience (Autism Inclusive Meets/Emma Dalmayne) are only a fraction of the knowledge to be drawn from autistic identity and the autism community.

Despite the positivity being represented by autistic viewpoints, there are still those who would challenge and oppose neurodiversity as an identity and as a movement. The medical model of disability continues to conceptualise autism in terms of deficit, impairments and inability (Jaarsma & Welin, 2012). Such a perspective creates environmental approaches where early intervention is not only palatable, it is seen as a vital necessity. The need for early and behavioural intervention stems from ABA literature which frames autistic children as only developing social skills, increasing quality of life and forming meaningful relationships (Dawson, 2008; Warren *et al*, 2011) through behavioural intervention. We remain at a societal and cultural level where autistic individuals face an increased vulnerability in terms of professional/medical practice and intervention(s). Conclusions reached by the OHCHR ('Discrimination against autistic persons, the rule rather than the exception – UN rights experts', 2015) conceive that such intensive intervention could be classed as violating basic human rights, as many approaches aren't based on strong, robust science. For many who both practice and advocate for early intervention, the practice-based evidence and literature provide evidence that applying behavioural modification techniques are necessary to autistic children's development.

The techniques and approaches synonymous with ABA have been challenged as being abusive, torturous and as leaving many who have been through the intervention with post-traumatic stress symptoms (Kupferstein, 2018). Applied Behaviour Analysis aims to target, change and remove certain behaviours, while promoting the learning of new skills, social awareness and improving overall communication, knowledge and quality of life (Foxy & Meindl, 2007; Dillenburger & Keenan, 2009). For those who explore ABA's approaches in depth, perceptions of its effectiveness and the outcomes it achieves differ on either side of the ABA debate. From a behavioural perspective, intervention is needed to allow autistic children to progress socially, behaviourally and academically. Many autistic individuals have heavily disputed the need for such intervention, as the functions of some behaviours, such as stimming, aid in necessary anxiety reduction, self-regulation and expression (Nolan & McBride, 2015). The difficulty arises in ABA when such self-regulation may be seen by some behavioural therapists as unnecessary or distractive to learning (Dillenburger & Keenan, 2009) and are therefore targeted for change or removal. The semiotics and need for stimming have been consistently discussed by autistic individuals – particularly within Yergeau's (2012) video 'I Stim, Therefore I am', and Agony Autie's YouTube content. Both advocates define and show the power of stimming for an individual's expression and identity. What forms part of the perceived need for ABA intervention relates to such misinterpreted *challenging* or *complex behaviour*.

### **Who is challenged? Who is complex? [A-head]**

Looking at the longstanding evidence-base of ABA, the approach towards 'severe' and challenging behaviour is well documented (Newcomb & Hagopian, 2018). Through the many ways in which autistic individuals are 'characterised', categorised and labelled, the use of the terms such as 'challenging behaviour' and 'complex' is constant, confusing and aggravating for many. Challenging behaviour is summarised as '*culturally abnormal behaviour(s) of such intensity, frequency or*

*duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities'* (Emmerson, 2001, p3). Further examples include aggression, self-injury and stigmatised behaviour (Nicholls *et al*, 2019). Factoring into the definition of *challenging* and *complex*, what is actually being expressed and communicated by the individual can be consistently misunderstood or ignored through the methods applied by ABA. Confusion, frustration, sensory or information overload, alongside a pressured environment where the participant has little to no control, may cause fight or flight reactions that are seen as non-compliance or as *challenging behaviour*.

In looking to my current writing, I feel it important to address two key elements which resonate with the problematic nature of the ABA debate; the 'Double Empathy Problem' and defining behaviour. Interactions and equal reciprocation are reliant on each individual comprehending the motions and interplay of the interaction. In the context of socialising, understanding meaning and cues from the other individual is vital for communication to be understood (Milton, 2012). In interactions between autistic individuals and the neurotypical (NT), there is a tendency to bypass the communication of the autistic individual in favour of the 'normal', and this creates problems in reciprocity as equality isn't met, being a 'double problem'. Understanding from both parties is critical to attaining understanding and social comfort for both individuals. Recent research has also highlighted the differences and difficulties between neurotypes in terms of communication. Autistic individuals don't face issues of double empathy in neurodiverse circles, whereas such issues can arise while in neurotypical circles. Despite this logical thought process, ABA takes a less inclusive stance. Behaviour is interpreted by the behaviour analyst who may hold preconceived notions as to which behaviours and communication methods are acceptable. Tying in with Double Empathy highlights the problematic outset of the therapy. Commencing the intervention under the communication style of the analyst begins with the autistic participants seeing their own communication style as wrong, potentially having a detrimental impact on their sense of self. Given that the majority of autistic individuals who participate in ABA are children who may not use verbal communication and don't get to make the choice of participation, the approach's intensity can have damaging and lasting implications for future mental health (see Kedar, 2011 & ABA Controversy Autism Discussion UK, 2017).

The second element of this section looks to behavioural interpretation and defining 'problem' or 'challenging' behaviour. Conclusions on what warrant this definition include 'physical aggression, self-injury... disruption' (Horner *et al*, 2002, p423). Given that behaviour can reflect emotion, communication or self-expression, judging 'autistic behaviours' relating to frustration or confusion as aggression reduces an individualised understanding on the part of the neurotypical therapist. The (mis)translation of behaviour through a neurotypical lens further stigmatises and labels the behaviour. Through the (mis)translation of behaviour in ABA, the shattering of equality in the communication between therapist and participant highlights the concept of Double Empathy within behavioural modification techniques. In a similar manner, the use of *complex* to describe autistic individuals can also serve to remove some of the difficulties professionals are facing in passing responsibility onto the person being supported. Emotion, reaction, expression and stimming can all be attributed to labelling an individual as *complex* or *challenging*, though *who* is challenged is rarely accounted for. The complexities of social language, cues and trends can be difficult for many to follow (Crompton, 2019 – *Neurodiverse Interaction*). Reflections from members of the autism

community have stressed the differences in social language between neurodivergent and neurotypical communities. Catherine Crompton's recent research on social interactions highlighted that there is a *difference* in social cues and understanding between autistic people and autistic-to-neurotypical people. Though novel in terms of academic conclusions, the outcomes mirror what the autism community has been saying for some time. The *complex* and *challenging* labels placed on autistic individuals serve to bolster the perceived need for behavioural intervention, while advocacy from the Neurodiversity Movement suggests that more mentored and autistic-led approaches are a far more constructive.

### **ABA: a discourse in 'right'? [A-head]**

Following noted guidelines (e.g. NICE guidelines), many professionals call for early intervention for autistic children in order to create conditions for the best possible quality of life and well-being. Within the 'gold standard' of these approaches, ABA is supported by a significantly large quantity of research, much of which advocates and promotes the effectiveness and need for behavioural intervention. Some challenge the veracity of these claims, questioning the lack of engagement with and input from autistic participants, with autistic individuals who speak out against ABA labelled as a minority (Davison, 2018). Practices within ABA that are heavily criticised by anti-ABA groups are those which focus on removing soothing and self-managing (Gibson & Douglas, 2018) through the use of punishment (also seen as a reward system) (Cook, 2018; Leaf *et al*, 2019). Despite the growing number of voices speaking out against ABA, there remains a stable lobby from behavioural therapists, parents and professionals promoting the effectiveness of ABA.

Many behavioural therapists have reflected on the positive benefits they believe their work and intervention has brought the children they have supported (e.g. ABA4ALL). A growing number of behavioural therapists continue to promote the apparent positive impact of ABA on children's quality of life, social interactions and personal progression. Such value placed on ABA lies with the intensity and individualisation of the methods applied. Through consistent repetition and reinforcement of tasks, participants learning development can be enhanced. Developing participants' skills while being adaptive, focuses on improving the participants' ability to learn new skills and replicate these in their daily lives. Empirical outcomes support the adaptability of ABA as having positive impacts on participants (Fein *et al*, 2013). For each individual partaking in ABA, the method is individualised by the Board-Certified Behavioural Analyst to ensure the child is achieving core learning developments that are central to their needs (Leach, 2010; Reichow & Volkmar, 2010). As neurodiverse individuals, we can look at the impact of high intensity intervention and see the continued reductivist misinterpretation of our personal processes. The veracity of ABA as being able to incorporate an understanding of the individual, while continuously forcing change, has galvanised the challenge to behavioural intervention.

### **Progressing culture: voice versus veracity [A-head]**

Cultural understandings of the application of ABA (and the need for intense interventions) are heavily influenced by the understanding society has of autism and how it perceives or imagines autistic lives. For many, the stereotyped and stigmatised image of 'Rain Man' or Dr Sean Murphy

encapsulate the binary and closed perceptions that society at large has of autistic individuals. Many don't, or indeed can't, envision the autistic academic, the activist, the parent, the employee, the company owner, as stigma tells them that autistic individuals can't be things. Despite such reductive thought, the development and recognition of autistic culture has grown vastly in the last two decades, from the beginnings of cultural developments changing the public's recognition of autistic individuality (Dekker, 1999) to having a vital impact on research and outcomes (Kenny *et al*, 2016; Ellis, 2017; Spiel *et al*, 2017). Evaluating the efficacy of ABA within different cultures is impacted by a number of factors; the social perception of autism; the 'need' to change behaviour; and where the behavioural adjustments will target learning (Keenan *et al*, 2010).

Though cultural awareness of autism has continually grown, there is simply little to no record within empirical data on the personal effects and impacts felt by the autistic individuals who have participated in ABA. The short-term outcomes concluded through longitudinal research (Fenske *et al*, 2005) suggest a positive relationship between behaviourally applied skill learning and improved social awareness. These alone begin to form a strong enough argument to advocate for consistent ABA intervention for autistic children. There are those autistic individuals who have flourished following ABA, those who find it detrimental and those who oppose the changing of autistic children to 'fit in' and pass as neurotypical. Autistic people are diverse and individual. Why, then, is one intervention seen as the 'gold standard' for such a diverse group? In the perpetual debate on the need for ABA intervention, there are people whose experiences have driven them to either side. Rarely addressed are those whose attitudes towards early intervention have changed through their personal experiences and those of autistic adults and children.

### **Apologists and parental perspectives [A-head]**

*'The underpinning of cultural discord in relation to ABA can be seen fundamentally within debate between the autistic community and academic outlooks, with some ABA practitioners reversing their views on the overall effectiveness and impacts of the intervention.'* (Socially Anxious Advocate, 2015)

As cultural change has edged its way forward, the Neurodiversity Movement and autistic voices have drawn attention to factors not previously acknowledged or explored. As autistic reflections of ABA participation have become more involved in current thought and debate, some advocates and practitioners have changed trajectories through these reflections mirroring their own experiences in practicing behavioural intervention. Labelled as *apologists*, these individuals have reflected heavily on what they believe to be *malpractice*. One former-therapist (birdmadgrll, 2017) spoke of her belief that her time practicing ABA supported the learning development of the autistic children she worked with. In time, her view of the positive impact of the approach changed, through being consistently forced to decide between the communication and needs of participants and applying the behavioural intervention. Hers is not the only such account. Others, such as *Why I Left ABA* (2015), have described feeling abusive for punishing behaviour that is a natural reaction to stress and fear, and forcing the continued participation of the child. Many children are typically exposed to the intervention through parental consent, not their own. Many children are therefore placed in a very intense environment from which they are (typically) unable to leave of their own accord and have their enjoyments taken away in order to be used as rewards, without being aware of the process or having a choice as to whether they take part. From these apologists, a certain backing and insight

into the 'behind closed doors' approaches of some (not all!) behavioural therapists has progressed the argument put forward by many from the autism community.

Beyond apologists and reflections on the need for change, many parents have also become opposed to and advocate against ABA following their child's intervention. Some have moved their advocacy online and promote the need for autistic-led methods (see ABA Controversy Autism UK on Facebook). Zurcher's (2012) account brings to light the misunderstanding that can be seen between the autistic child and the therapist. In their account, there were several discrepancies between their child's participation (or rather disengagement) with the intervention and how this was interpreted by the therapist. Such (mis)interpretation places many non-verbal individuals at a further disadvantage as communication is set by the therapist. Further, those who become selectively non-verbal during high stress environments can be viewed as *non-compliant*, placing the child at fault rather than the therapist's approach (Zurcher, 2012). For those parents who reflected on their reasons for removing their children from ABA intervention, there are similarities to Zurcher's (2012) issues. Parents may see their child's attempts at communication not being recognised or acknowledged and being in a state of distress throughout the processes of ABA. In turn, they themselves are told to accept these stresses as part of the process, leading many parents to turn their backs on the intervention. As is argued, however, these techniques may be used only by the minority of therapists. Given the broad application of ABA, there will be those whose understanding of autism as inability may increase the risk of their participants' stress. Misinterpretation, or admonishing, of communication which lies outside the parameters of the therapist's learning makes participants vulnerable, stressed and potential voiceless. In turn, these individuals may be forced to comply to ensure they complete the sessions, learning to survive rather than thrive.

Opposingly, some parents remain focused on the need for ABA and its perceived benefits, leading some to suggest that ABA is of more benefit to parents than autistic children. Much of the debate from parental perspectives is founded on two factors. First, it has been suggested that those who speak out against ABA are either *not autistic enough* to have warranted an intervention, therefore having no real knowledge of its workings. Second, that those who advocate through their own experiences are only able to communicate their experiences *because of* ABA intervention. There are also some members of parental and professional groups who suggest that those who are in advocacy and academia should not be involved in these debates. Such ideology reflects the idea that the Neurodiversity Movement is not representative of non-verbal individuals (Clements, 2017). Such views do little to calm the ferocity of the debate. These instead fuel ableism and the repression of autistic voices, while failing to acknowledge that the advocacy and positivity of the Neurodiversity Movement community is made up of more than those who use verbal communication. Many have indeed failed to acknowledge the empowerment that online and social media forums offer non-verbal advocates. Additionally, many fail to understand the empowerment that can come from augmented and alternative communication technology, which allows non-verbal autistic voices to advocate and be heard. Significantly, those who have been through ABA have been able to express their experiences on the elements they have found unfavourable (e.g. Kedar and Lowery).

**ABA and autism: (un)acknowledged outcomes [A-head]**

Differences in attitudes towards the intensity of ABA reflect the substantial elements of the debate between the autistic community and empirical research. Depending on the beliefs about a participant's needs, the intervention can use a highly intense level of therapy of up to 40 hours a week. Despite the push from ABA literature and the Behaviour Analyst Certification Board that there is a need for this level of intensity, intervention-focused literature suggests that 25 hr/wk. has as significant an impact as 40 hours (Warren *et al*, 2011). Despite the argument for lowering hours, much of the debate deriving from the experiences of the autistic community challenges the need for children to experience such intensity. Additionally, several social media sites aim to facilitate discourse between pro and anti-ABA voices, promoting autistic reflections and opinions in order to inform behavioural intervention practice (Autistics and BCBA's for a Reformed ABA), while autistic individuals have used blogs and other mediums to express their experiences.

Several self-authored experiences address many of the negative aspects of their ABA experiences. Much of the negativity focuses on the removal of autistic identity, self-preserving processes and the lack of connection to the individual as unique and having humanity beyond their diagnosis (Kedar, 2011; 2017). Such a disconnect forms part of the opposition to ABA (and behavioural therapies in general). Voicing personal experiences provides an evidence base for the challenges facing ABA. Together, these reflections build the foundations for opposing the treatment of autistic children in any context outside of physical illness. An argument could here be made, however, that the need to learn and remove dangerous behaviours, such as self-injurious behaviour or road safety, are effectively taught through ABA more quickly than other methods. The justification that children need to understand the concept of danger requires little argument, though the need for an intensive and potentially (mentally) damaging intervention is highly debatable. Regarding the required change within societal and professional attitudes towards autism, Lowery, in their reflection of undergoing ABA intervention states: 'We are different... it's who we are, and this should be respected' (2017). Their message portrays the need for an understanding of neurodiversity in order to move from a lack of respect or recognition of autistic participants agency and autonomy. Bringing such views into the processes of intervention would advance the well-being of autistic individuals considerably through self-acceptance of their strengths compared to negative societal perceptions of their weaknesses.

Looking to Kupferstein's (2018) seminal work on challenging the outcomes of ABA, her conclusions reflect the voices of autistic adults who have participated in early life ABA. The veracity of Kupferstein's work and findings has been criticised, and indeed will be for some time to come for those who advocate the efficacy of ABA. While critics look to the difficulty and effectiveness of diagnosing Post-Traumatic Stress Disorder and the possibility of bias within her work (Leaf, Ross, Cihon & Weiss, 2018), Kupferstein replicates the views and challenges put forward by autistic voices. On the other side of the argument, Kupferstein is simply looking to research that which the Autism Community has been suggesting for some time. Taking a stance on one side of such a long-standing debate would always impact the reception of her research, though it seems both sides wish to either completely exonerate or fully embrace her findings.

While many past participants have advocated against ABA, there are those who believe the intervention has advanced their development and lives and now promote and advocate in favour of ABA for autistic children. In comparison to Kupferstein's (2018) conclusions, these individuals feel that behavioural therapy has changed their lives in a positive manner. Some of these individuals

would give credit to the intervention for their ability to now voice and express their experiences. Further, ABA has allowed them to be part of the broader autism community, being in education and allowing them to seek 'meaningful' employment. It is these individuals who many groups (such as ABA4ALL) seek out in order to combat the vilification of the therapy, instead drawing their narratives as a reason for *all* autistic children to participate in ABA. One example lies in Lerner's blog, *How ABA Saved My Life*, reflecting on the positivity and enjoyment they experienced through the continued learning, self-development and reinforcement of their progression and the positive impact ABA had on their life. In addition to this positive promotion, these reflections from autistic participants mirror the success found in empirical conclusions within research: improvements in behaviour, social awareness, intelligence and communication skills (Lerner, 2019). For those opposing ABA, these individuals may be viewed as internally ableised, while those in support would hold these reflections up as evidence of the efficacy of ABA. There is no doubt that the debate will continue to be fought on both sides for some time to come. While autistic individuals rightfully advocate for the safety of the wider community, parents will continue to seek what is best for their children. The key lies not in a middle ground or no-man's land, but the empowerment of autistic voices. Continuing the examples of current research, behavioural therapists should seek to develop an understanding of autistic lived expertise to ensure inclusion, communication and consent are maintained.

### **What next? [A-head]**

The question for many of those looking for *better ways than ABA* is how to enable their voices to be heard and acknowledged with empirical research. Such an accomplishment would allow for the autism and ABA debate to be evidenced empirically, enlightening both sides of the debate. It is therefore the suggestion of the author that research which engages with autistic voices on both sides of the debate be conducted to further our knowledge of the consequences and efficacy of ABA, and to continue to promote the autistic voice. While conclusive academic evidence would bolster the understanding of outcomes, the fact remains that those who stand on either side of the ABA and autism debate are unlikely to be moved. It is only the experiences of autistic people who have experienced ABA who can truly understand and explain the long-term outcomes of ABA intervention and verbalise what is unseen by professionals and parents.