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Dillenburger, K., & Keenan, M. (2023). Autism and Behavior Analysis: From Dissonance to Dialogue. *International Electronic Journal of Elementary Education*, 15(3), 199-208.
<https://doi.org/10.26822/iejee.2023.292>

Published in:
International Electronic Journal of Elementary Education

Document Version:
Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

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Autism and Behavior Analysis: From Dissonance to Dialogue

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Received : 19 November 2022
Revised : 20 January 2023
Accepted : 8 March 2023
DOI : 10.26822/iejee.2023.292

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Abstract

Questions about human behavior and diversity have captured the attention of scientists from a wide range of philosophical stances for centuries. While behavior analysts would argue that natural science is an enlightening perspective when applied to the understanding of the human condition, at times arguments within certain campaigns would prefer Applied Behaviour Analysis (ABA) to be banned or abolished. In this paper we discuss some of the roots of this stance and suggest a way forward based on what are basically complementary views on the goals enshrined in rights-based practice.

Keywords:

Natural Science, Behavior Analysis, Human Diversity, Autism Diversity, Discrimination

Introduction

Exclusion in all its many guises is an ugly thing and, in this paper, we discuss consequences that arise for autistic individuals who have particularly high support needs (American Psychiatric Association, 2013; Lord et al., 2022), if applied behavior analysis (ABA)-based services were abolished or excluded (Graber & Graber, 2023). We argue that countering exclusion and ensuring real inclusion requires dialogue and genuine empathy.

Autistic self-advocates commonly report the consequences of discrimination, ableism, a normalizing agenda, being viewed from a medical rather than a social model, and misunderstandings concerning support needs (Tarvainen, 2019). Until the 1980s, autism was not officially recognised (Volkmar et al., 1988) and profoundly autistic people (Lord et al., 2022) were considered unreachable or unteachable and commonly confined to a lifetime in institutional care (Gómez-Durán et al., 2014). Those who presented with challenging behavior were exposed to electroconvulsive therapy (ECT) and/or physically and pharmacologically restraint (Nielson et al., 2021; Schnitzer et al., 2020).

While this situation seems not to have changed in some countries (Buivydaite et al., 2017; Lipinski et al., 2022), in the 1960s, behavior analysts in the USA were the first professionals who were able to show that profoundly autistic individuals were not "unteachable," but that they could be taught and



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ISSN: 1307-9298

that they could learn (Ferster & DeMyer, 1962). They applied the principles of behavior formulated by the science of behavior analysis to design environments that facilitated skills development for persons who had been exposed to long-term care in designated institutions. Since then, the field of applied behavior analysis (ABA; Baer et al., 1968, 1987) has grown, particularly with regards to supporting autistic individuals (Surgeon General, 1999). So much so, that today ABA is viewed as providing the basis for “gold standard” interventions used to support individuals on the autism spectrum (Koegel, 2011; Lovaas, 1987; Smith & Eikeseth, 2011). With such a high profile, it is not surprising that for some, the abbreviation ABA practically became a synonym for a method of autism intervention (Chiesa, 2006; Dillenburger & Keenan, 2009).

In the meantime, disability advocates achieved some success in their fight against discrimination, health disparities, and ableism (Borowsky et al., 2021; Nario-Redmond et al., 2019; Tarvainen, 2019; Thorne & Barr, 2022), including extensive ratification of the United Nations Convention for the Rights for Persons with Disabilities (UNCRPD, 2006). As for autistic people, the fight for awareness, acceptance, and equal rights continues to be shaped by autistic self-advocates, mainly through the newly formed neurodiversity movement (Leadbitter et al., 2021a, 2021b; Silberman, 2015) as well as families of children with profound autism (Unumb, 2013).

But somewhere along the way, something has gone wrong. The special and supportive relationship between behavior analysts and profoundly autistic individuals and their caregivers that was built on deeply rooted care and trust in science appears to have been hijacked by an anti-ABA movement that views the discipline of ABA as abusive, causing post-traumatic stress, being ableist, and promoting a normalizing agenda (Kupferstein, 2018; Milton, 2012; Sandoval-Norton & Shkedy, 2019; examples of shockingly bad practice by poorly trained professionals can be found on YouTube). The focus of this paper is to discuss how those who have dedicated their lives and their science to helping people (i.e., behaviour analysts; cf., APBA, 2017) are being singled out and accused as protagonists of all of society's ills with regards to maltreatment of individuals with autism.

While in his early writings Milton (2012) could be viewed as one of the leading denigrators of ABA, more recently he has sounded much more conciliatory and even seemed to hint at the solution when he discussed the double empathy problem (Milton, 2018):

...when people with very different experiences of the world interact with one another, they will struggle to empathise with each other. This is likely to be exacerbated through differences in language use

and comprehension. (Theory of double empathy section, para 1)

In order to balance a debate that generally is dominated by the views of autistic self-advocates, we offer an insider view of the perspective of behavior analysts who aim to help profoundly autistic people. What follows is an overview of our personal story as behavior analysts and the struggles to address the imbalance in discussions that could prevent profoundly autistic individuals receiving the kinds of supports that our science can offer.

Recently, we learned that the 3-year-old child we met in 1997, and whose parents we introduced to the discipline of ABA all those years ago, passed his driving test and he got a job in the open employment market. To be honest, that touched us deeply, more in fact than when he was awarded his Master's degree in American History a few years earlier. Before we met him, he had been assessed by all the usual health and allied health professionals, none of whom (according to reports by his parents) were able to help him acquire even the most basic skills. According to their clinical assessment reports, he was never going to learn to speak in full sentences and was destined for an institution. Together with his mother and other parents, we established the charity “Parents Education as Autism Therapists” (PEAT; the title was chosen by parents). During the subsequent 20+ years, PEAT helped hundreds of families build important life skills for their children, we co-authored the first book about ABA and autism in Europe (Keenan, Kerr, & Dillenburger, 2000) that has been translated into German and Japanese (Keenan, Kerr, Dillenburger, et al., 2000), we co-produced a multilingual multimedia online ABA training platform that has been translated into ten languages (German, Spanish, Dutch, Italian, Swedish, Icelandic, Norwegian, Czech, Portuguese, Canadian French, with Greek and Japanese in progress; Simple Steps, 2013), and we collaborated in a range of large scale research projects (Dillenburger et al., 2010, 2015; Keenan et al., 2010; 2022)

These are remarkable achievements inspired by a small parent-led charity that was established and provided services for over 20 years without any support from government. What is even more remarkable is that this charity was set up in Northern Ireland, in a context where their community has been torn apart by violent conflict over many years (Dillenburger, 1991, 2007; Fargas-Malet & Dillenburger, 2016), and their story continues to be one of struggle against prejudice, discrimination, and repression, as oftentimes the language used to caricature ABA (as ableist, abusive, prejudicial, discriminatory, and pushing a normalizing agenda), is itself ableist, abusive, prejudicial, and discriminatory (e.g., Baron-Cohen, 2014; Kupferstein, 2018; Sandoval-Norton & Shkedy, 2019).

Here is the problem. As behavior analysts, we think differently from most other people. As scientists, we avoid mentalistic pseudo-explanations for behaviour (APBA, 2016; Chiesa, 1994; Green, 2016; Skinner, 1953b; Thyer, 2009; Thyer & Myers, 1999; Thyer & Pignotti, 2010). Instead, our *raison d'être* is the discovery of fundamental principles of behavior. We investigate the intimate relationship between environmental contingencies and behavior. The language we use to describe these relationships is full of what sounds like "jargon" to those who are not familiar with the science. A point to make here is that in any other science the terms scientists use may appear strange, cold, alien, even overly technical (Keenan & Dillenburger, 2000). This is because the terms scientists use are short-hand for discussions with other scientists, and therefore they have to be defined very carefully. As Milton (2018) realised, there are "differences in language use and comprehension" (Theory of double empathy section, para 1) that can hinder communication between people with different experiences, as would be the case between scientists and non-scientists.

In fact, while the everyday language we inherit from our parents has its role in everyday life, it interferes with the precision required by science (Skinner, 1953b) and thus does a poor job for scientists (Chiesa, 1994; Moore, 2013a). Take for example, the term "behavior." In everyday use of the term, it refers to "the way in which one acts, especially towards others," oftentimes meaning "bad behavior" (e.g., "Did the children behave?;" Cambridge University Press, 2020). In contrast, when behavior analysts talk about "behavior," we define the term behavior as the "interaction of the organism with their environment," both, historically as well as currently (Cooper et al., 2007; Phelps, 2007). We talk about lifelong "learning histories" as well as "cultural meta-contingencies" that impact on present behavior (Glenn, 1988, 2004). This holistic view of behavior includes private behavior (what happens inside the skin, e.g., thinking and feeling; Skinner, 1977; Keenan & Dillenburger, 2022 *Mentalism Chapter*) as well as public behavior (e.g., moving and speaking; Skinner, 1953a, 1957). The image of a stream or river is helpful here. We cannot talk about a river without referencing both the water and the banks through which it flows. Likewise, behavior analysts consider that the skin does not separate us from the world, but it connects us to it. This is a completely different way of viewing the world in which we live, with major implications for understanding the process of living where a typical lifespan can be over 2,208,988,800 s. Called the behavioral stream, the process of living is viewed as a stream of experiences accumulated throughout one's lifetime (Keenan & Dillenburger, 2022, *Behavioural Stream and Private Events chapter*).

There is no formal "diagnosis" for our way of being, nor should there be. As behaviour analysts we are just

different, with diverse views within our community. The science we employ to study behavior is attracting more people from around the world (see ABAI, 2022; APBA, 2016). Yet, we are being told by some (e.g., the neurodiversity movement) that we are wrong in what we are doing, even alleging that we are causing harm and abusing vulnerable children on the autism spectrum (Sandoval-Norton & Shkedy, 2019). They demand that everyone (and that includes behavior analysts) conform to their normalizing agenda and their way of doing things (Milton, 2012).

As mentioned previously, when behavior analysts study the behavioral stream, the goal is to increase awareness of how behavior is affected by environmental contingencies. This is a formidable task and the methods that have been developed have enriched lives in a wide range of areas (see Cambridge Centre for Behavior Studies, 2022; Heward et al., 2022). Sharing the findings from behavior analytic research is not without its problems. When autistic children experience severe challenges, commonly parents seek guidance on how to design experiences for their children in order to facilitate the emergence of confidence and independence. In other words, parents need to learn how to implement "interventions" with precision and fidelity. Behavior analysts have developed many strategies for designing bespoke experiences that straddle education and health issues. Denying either the existence of the principles of behavior or their relevance to education and health is simply not an honest way to proceed.

In contrast to North America, where there are laws to ensure ABA-based interventions are available to those who need them (Unumb, 2013), in Europe the misinformation about ABA disseminated by people not trained in the science has resulted in ABA-based services generally not being endorsed by governments (Keenan et al., 2022). In fact, some parents report that they have been threatened with the removal of all autism services if they continued with their ABA-based home programs (Dillenburger et al., 2015). Intriguingly, these threats occur even though their children are making progress at home and are learning skills that they did not learn at school (Larsson, 2021). Keenan (2016) pointed out that this kind of anti-ABA perspective implies that parents who seek to improve their awareness of how best to educate their children should apologise to their children. Maybe they should say things like "We didn't know that by educating you, by preparing you for the future, we inadvertently did not 'accept you as you are?'" (Keenan, 2016, p. 10). Or maybe they are supposed to say to their children:

Please forgive us for designing experiences for you to have fun, for toilet-training you, for helping you make friends, for supporting you to manage your self-injury, for teaching you to communicate, for giving you the

skills to make choices and convey your individuality, and for expressing our love for you in numerous other practical ways. We did not know that this could be interpreted negatively, as trying to change who you are or as trying to make you 'normal' (Keenan, 2016, p.10).

Those who perpetuate myths about behavior analysis are missing the point completely if they consider these parental apologies to be necessary. On one hand they dismiss the whole science because they object to the idea of "deliberately doing something to change a person" (i.e., education). Yet in the next breath, they propose to engage socially with a person in applied settings in the hope that the person be supported or empowered (i.e., changed). The additional layer of awareness provided by the science of behavior analysis in relation to the effects of environmental changes is considered an anathema. What is truly very sad about this situation is that it impacts directly on the benefits to be derived from awareness of how environmental contingencies contribute to the outcomes of education.

The anti-ABA stance generally is at odds with the science of behaviour analysis for a number of other reasons. Behavior analysis embraces the full spectrum of neurodiversity and there is no better evidence than the way it addresses the differing educational needs of each person in applied settings (Kazdin, 2010). To ensure that the focus is on the individual, we use single-system research designs to monitor changes in the behavioral stream (Keenan & Dillenburger, 2011) instead of using comparative group designs which commonly leave one group without support that may be desirable (e.g., NICE, 2013).

The result of the spread of misinformation is that a whole science has been branded as controversial (Parker, 2015) when the real controversy should revolve around the deliberate dissemination of misinformation. The misrepresentation is so pervasive in Europe that on one hand it is said that it would be wrong to invest in only one "thing" like ABA, while on the other hand it is argued that it is acceptable to invest in one "thing" called an "eclectic approach," even though there is evidence that ABA-based interventions are more effective than eclectic interventions (Howard et al., 2005, 2014). Unfortunately, no-one addresses the ethical questions that arise from the role played by the Dunning-Kruger effect (Benzel, 2022; Hofer et al., 2022) when misinformation and the associated caricatures of ABA form the basis of government strategies and policies (Dillenburger et al., 2014). Vyse (2022) is right when he says:

It is one thing to form a social movement in an effort to gain greater acceptance of and better supports for a group of people in need. It is quite another to do so at the expense of another group who is also in

great need. Helping people on the autism spectrum should not be a zero-sum game with gains at one end of the spectrum requiring losses at another. Unfortunately, the autism self-advocacy movement's attacks on ABA [applied behavior analysis] create just such a dilemma (The Death of Truth and Freedom section, para 3).

To ward off the onslaught of the anti-ABA perspective (Note: this language is often used by parents on the receiving end of misinformation), some have suggested that it might be best to change the name of ABA. This suggestion is truly symptomatic of the stresses to which parents are exposed. What other science has to contend with a name change as a strategy for managing the aversive consequences produced by discrimination and prejudice. One of the authors (MK) explains:

As a child who grew up in N. Ireland, I am familiar with many facets of prejudice. Raised by a Protestant mother and having a Catholic father, I experienced at first hand the damaging effects of misguided conclusions conceived in the shadow of myths. When visiting my grandparents, it was at times a surreal experience to cross from one perspective tainted by prejudice to the other perspective similarly tainted by a different kind of prejudice. I was exposed to exclusion and discrimination based on prejudice. In many walks of life during my childhood, Irish people were not welcome, as expressed in the sign in the window "No Irish".

Never did I imagine, though, that in my professional life those scenes from my childhood would be replayed. I should have known better. Behavior analysts are not welcome. The sign in the window should read "No ABA" or "No Behavior Analysts." In Shakespeare's play Romeo and Juliet, Juliet described the conflict between the rivaling families with the poetic words: "A rose by any other name would smell as sweet." The families of my own parents, and the families described by Shakespeare, were not able to break free from the experiences that shaped their beliefs in order to accommodate another with different experiences and consequently a different perspective.

Yet, many parents of children with autism have been able to break free from the misinformation and myths about ABA and as a consequence their children have benefitted greatly (e.g., ABA4All, 2022). Unfortunately, we have seen parents pushed to the point of exhaustion in defence of ABA in courts and tribunals fighting for their children's rights to have access to ABA-based interventions (Blakemore, 2021; Byrne & Byrne, 2000). Where else would this be allowed to happen? Where are the investigative journalists who want a human interest story, one about how health and education authorities peddle misinformation about a science in which they are not trained, while parents do what they can to defend a science which they evidently understand better than those professionals (Dillenburger et al., 2012)? The ethical drama that is played out in these situations simply is staggering and at the same time diabolical.

It is almost as if the parents are put on trial for being witches, inhuman creatures who are hell bent on harming their children. The truth is that these parents are heroes, mustering all of their love to defend the opportunity for their children to acquire skills that others believed they were unable to acquire. So much for equality of opportunity and disability rights. So much for the rights of their children to be regarded as people deserving of the opportunity to be guided by a science dedicated to bringing out the best in people through its accumulated understanding of the principles of behavior change.

Clearly, those who are against ABA are not the only bastions of love for children. Nevertheless, ABA professionals who guide parents when educating their children continue to be maligned for doing so. It is worth stating that again in other words. Parents who have used the discipline of ABA to successfully empower their children and improve the quality of their children's lives have been criticised for doing so. They have been criticised because some people proposed that the evil world of ABA could never produce something positive. Indeed, they would consider these parents to have been duped into adopting a perspective that emphasises the importance of normalizing children, and not accepting their uniqueness. One of the authors (MK) elaborates:

When I hear that kind of misguided anti-ABA rhetoric, I find myself straddling the mindsets of both sets of my grandparents (one set from a Protestant background and one from a Catholic background). It was never possible for them to accept that something positive could emanate from the other camp. Of course, this was not always the case for them, but when it came to important matters that divided the community, they each held firm to how they had been taught to view their nemesis. My time growing up in a divided community has brought many stresses to me personally. But it has also educated me in showing how twisted logic is used to defend either position when it is challenged. There was a time in my childhood, for example, when one could have been challenged in the streets along these lines:

"Are you a Catholic or a Protestant?"

"I am an atheist"

"Are you a Catholic atheist or a Protestant atheist?"

There is no normalizing agenda at the heart of ABA. Apart from this correction, there is another misguided criticism that needs to be rebuffed. It is said that using ABA is tantamount to using a one-size-fits-all approach that ignores individual needs. This one-size-fits-all criticism is entirely misleading because there is indeed one thing that is used by the scientist/practitioner to guide the development of bespoke services, and it is called the scientific method. But this is entirely different from the kind of plug-and-play conceptualisation of one-size-fits-all conjured up by authorities who refuse

to invest in ABA. Surely it cannot be wrong to employ professionals who use the scientific method in the 21st century for designing bespoke services. Nurturing an individual using the scientific method so they can feel empowered by the acquisition of skills is an enlightened act of human kindness, not the act of a despot intent on removing their uniqueness (Keenan & Dillenburger, 2020).

To conclude, here is an example that illustrates what can be achieved with good quality ABA-based interventions. Following it is a contrived example of the sorts of criticism that have been levelled by others in the face of something that does not sit well with preconceived ideas about the nature of ABA. This case study was provided by Dr. Nichola Booth (personal communication):

A young boy, 8 years old, had a confirmed diagnosis of autism and was non-verbal. It was reported that he had excessive amounts of saliva that was impacting on his day-to-day social and educational experiences. At school he was being isolated from his peer group as he was rubbing the saliva over other children, teachers, classroom assistants and equipment. The same behaviors were happening at home to the point where his parents would not have visitors because their furniture was covered in dried saliva. His clothing was destroyed from being caked in dried saliva.

After medication failed, the parents went back to their GP. It was at this stage that they were told the next step would be a referral to a surgeon for an invasive operation where a piece of his mouth would be snipped to reduce or eliminate the extreme levels of saliva. Due to waiting times for this appointment, the parents accepted this and went home.

While waiting for the hospital appointment the parents decided to access the services of a behavior analyst for support, but nothing related to the saliva issue. The ABA professional came to the family home and carried out parental interviews and behavioral observations to determine what supports would be required. While carrying out the observation he noticed the behavior associated with excessive saliva production, especially the wiping of the saliva on all items and people within the room. This was raised as a potential issue to be addressed and it was then that the parents explained what had happened to date. The behavior analyst suggested that they could perhaps put a programme in place to see if this behavior could be reduced without the need for surgery. The parents agreed.

Following collection of data from additional observations, both at home and at school, a plan was developed. A sensory tray of all 'goo-like' items was made and placed in the main family room in the home. Alongside this, a visual sign for the tray was made available across the home environment for the child to access.

The parents were educated in how to identify when the excessive saliva related behaviors were about to occur – these included heightened vocalisations,

hand-stimming, and facial movements. When the parents saw these behaviors, they were immediately to prompt the child to point to the visual for the sensory table visual and then immediately redirect him to the sensory tray. He was then requested to 'play' and the parents modelled some of the playing behaviors for him with the items in the tray.

This strategy was implemented successfully in the home with the saliva related behavior reducing significantly before it was introduced in the school setting. The end results was that surgery was no longer required and the behavior had decreased with the child being fully reintegrated back into school and other social events.

A Critique of this Case Study

It is awful that the child was not accepted for who he was by both the medical professional and the ABA professional! Instead, they each attempted to normalize him, one using drugs and then proposing an invasive surgical procedure. The ABA professional was more deceptive and hood-winked the child into changing his behavior, thereby refusing to acknowledge the child's need to engage in his preferred activity!

Conclusion

With so many parents of profoundly autistic children now championing ABA while others try to stop all ABA, it is clear that something is amiss. As can happen in any profession, some people have been on the receiving end of malpractice. In medical practice, some people have even been murdered by their doctors (Gunn, 2010) and of course, the actions of such people must be restricted, but not at the expense of the entire discipline of medicine. The same has not been the case with ABA. It seems that some malpractice has led to the condemnation of the whole science.

In the midst of the struggle for equality, one very important point should not be overlooked. There is a strategy often fostered by an establishment in many walks of life called "divide et impera" [divide and conquer], an approach that Julius Cesar used successfully 22 centuries ago (Razzetti, 2018). While autistic self-advocates and behavior analysts are at logger heads, the establishment does not need to change and can continue to discriminate unhindered. This paper is a call from behavior analysts to autistic self-advocates to heed Milton's (2018) call for the full appreciation the double empathy problem and join together against the real nemesis of autistic people, societal and political discrimination, inertia, and indolence.

Competing Interests

Authors are Irish doctoral-level behavior analysts and identify as somewhere on the spectrum of human

diversity. They have no financial or non-financial interests that are directly or indirectly related to the work submitted for publication. No funding was received for research reported here.

Author Contributions

Authors contributed equally to the paper.

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