

## Psichologija praktikai

# WHEN POLICY DECISIONS FOR AUTISM TREATMENT IN EUROPE ARE HIJACKED BY A CATEGORY MISTAKE

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*Behavior analysts have an important role to play in the management of autism spectrum disorders (ASDs). While empirical support for interventions that are based on behavior analysis is extensive, this is not the case for many other kinds of interventions. This has resulted in significant differences in public policy and recommendations in different parts of the world, most notably between Europe and North America. In this paper, we outline some of the reasons for this disparity.*

**Keywords:** *Autism, ABA, RCTs, evidence-based practice, eclecticism, category mistake.*

The diagnosis of Autism Spectrum Disorders (ASD) is based on the criteria set in the 5<sup>th</sup> Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) that identify deficits in the following areas: social communication and interaction, and restrictive repetitive patterns of behavior (Autism Speaks, 2016). According to Normand (2008), autism treatment “happens to be one of the largest single areas of application for behavior analysts” (p. 42). The focus of this paper is to explore some of the issues that affect policy decisions regarding the uptake of Applied Behavior Analysis (ABA) by statutory authorities.

ABA is the applied branch of the science of Behavior Analysis with the methods employed used to increase and maintain

socially important behaviors and decrease maladaptive behaviors (Cooper, Heron, & Heward, 2013; Myers & Johnson, 2007). Within the behavioral tradition, behavior is viewed as a natural phenomenon in its own right and is investigated by the methods of natural science (Chance, 2014). The word “behavior,” though, as used by behavior analysts, is something entirely different from the everyday understanding of this term.

*For a behaviour analyst, the term behaviour covers the cascade of changes that simultaneously encapsulates two differing phenomenological perspectives, what others see of the changes in the person [over time] and at the same time the world as viewed by the person [being observed]. [...] The everyday*

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*understanding of the word “behaviour” does not capture the sophistication of this perspective and herein lies the source of much misunderstanding (Keenan, 2016, p. 6).*

With this view of behavior, the scientific goal is to establish functional relations between independent variables (i.e., physical and social environmental contingencies) and dependent variables (i.e., the behavior under investigation). Data collection is usually done on a continuous basis because it is the changes in behaviour over time that are of interest. These data provide the basis for determining the likelihood that a particular behavior will occur under specific circumstances (Chance, 2014; Bailey & Burch, 2006). The behavior-analytic view of human development emphasizes the person’s interaction with his or her environment with information on genetic and learning histories considered essential for understanding and changing behavior.

Lovaas (1987) was the first large scale peer-reviewed study published on the treatment of young children with autism using Early Intensive Behavioral Intervention (EIBI), with dramatic improvements shown in IQ, language and adaptive skills. A long-term follow-up study by McEachin, Smith, & Lovaas (1993) showed that improvements had endured into adolescence; IQ scores were maintained, children continuing in mainstream education, and scores on adaptive behavior far exceeding those of the control group. Critics point to methodological limitations in the Lovaas (1987) study, such as the lack of random selection and assignment; however, they ignore the subsequent body of research that have replicated and corrected the limitations of the original study (refer to McEachin

et al., 1993; Smith, Eikeseth, Klevstrand, & Lovaas, 1997; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Sallows & Graupner, 2005).

Criticism that is levelled at the field of ABA more generally concerns its use of single-case research studies as a basis for concluding that treatment based on ABA is effective (Smith, 2013). Some have argued that it is difficult to compare outcomes with other techniques as single-case studies compare results, not with control subjects (inter-subject comparison) but with the person’s own behavior before, during and after an intervention (intra-subject comparison) (Goodall, 1972). This kind of research methodology has in-built strategies for establishing the extent to which functional relations are evident between the behavior under investigation and purported independent variables, including the replication of effects. Significantly, though, this is precisely the goal of any intervention that is tailored toward the needs of the individual with autism. In fact, the strategies adopted in single-case research are examples of the scientific method that come under the umbrella of evidence-based practice (Keenan & Dillenburger, 2011).

Through the work of Archie Cochrane in the 1970s, the concept of evidence-based medicine was developed and in 1992, the UK government funded an international collaboration of 11 500 researchers with the purpose of facilitating systematic reviews of Randomised Control Trials (RCTs) to the healthcare field (Belsey, 2009). This led to bodies such as the National Institute for Health and Clinical Excellence (NICE), and other Welsh and Scottish Medical groups, informing the National Health Service (NHS)

about which treatments should be made available to the UK public (Belsey, 2009). Within the UK context, the government, research advisors and health authorities view RCTs as the gold standard in determining whether or not an intervention should be recommended. Within the parameters of RCTs, in the guidelines for the management of children with autism (NG170; NICE, 2013), NICE concluded that it could find no evidence to support the use of ABA and therefore did not recommend ABA for children with autism. By contrast, in the US, 46 states have introduced new laws to ensure that ABA is available to parents of children with autism. This means that on 46 separate occasions, it was concluded there *was* sufficient evidence for the effectiveness of ABA to warrant the creation of new legislation. It appears, then, that exclusive reliance on RCTs in this context has created serious anomalies in conclusions drawn about ABA. The stark difference in these conclusions exposes a number of issues when different research methodologies (RCTs vs. single-case studies) are used to inform policy. In fact, RCTs have been criticised heavily in relation to their value when assessing the effectiveness of ABA (Keenan, 2016).

By far, the biggest issue concerns the view that ABA is merely a treatment for autism. This is a classic category mistake because a scientific discipline (applied behavior analysis) has been relegated to the category of an intervention (Chiesa, 2005). If ABA was indeed an intervention on a par with a drug, for example, then the use of a RCT might be appropriate. However, because ABA is a scientific discipline, it makes as much sense to use RCTs to assess the effectiveness of ABA as it does to use

RCTs to assess the effectiveness of Physics, Biology or Chemistry. RCTs have other limitations in relation to their use when assessing ABA because even if ABA were to be an intervention, there are so many versions of its application, since the needs of each individual are so different that data obtained would be from an assortment of methods and not from a single entity, like a drug. Keenan (2016) drew attention to another issue by stating that “single case research designs pioneered by behaviour analysts are generally ignored by mainstream educators and researchers [...] who focus instead on group designs [...] where the individual is sacrificed on the altar of group statistics” (p. 8).

According to Dillenburger (2011), there are two directions that governments around the world have adopted in relation to autism interventions. Most of North America, where training in ABA is widely available, has adopted ABA-based treatments, whereas an eclectic approach to treatment is implemented by most European countries. In Europe, where access to training in ABA is severely limited, there is no legislation requiring statutory services, such as providers of health care, social care and education, to implement ABA-related services (Keenan, Dillenburger, Moderato, & Rottgers, 2010). Statutory bodies in Germany, for example, with responsibility for treating children with autism, provide an average of two hours per week of eclectic interventions (Keenan et al., 2010) despite the advice of an expert committee on autism recommending a minimum of 25 hours per week (National Research Council, 2001). Furthermore, studies comparing intensive ABA programs to equally intensive eclectic approaches demonstrate

that ABA programs are significantly more effective (Myers & Johnson, 2007).

Another European jurisdiction that has had difficulty establishing ABA-based services for ASD is Northern Ireland. In 1997, a parent-based charity was established to provide ABA-based services to children diagnosed with ASD despite the strong opposition from government sources (Keenan, 2004; Keenan et al., 2010). Similar circumstances arose in the Republic of Ireland, where thirteen ABA schools were founded by parents with the government later forcing these schools to adopt an eclectic approach (Keenan et al., 2010; McCormack, 2012). The large-scale failure of governments in Europe to endorse ABA-based services for ASD demonstrates that non-facilitative and obstructive public policy often compromises adequate services and prevents children and families from receiving appropriate services to treat autism (Cuvo & Vallelunga, 2007).

In comparison to Europe, the U.S. Department of Health and Human Services concluded that a nearly 50-year history of research supported the efficacy of ABA for children with autism (Surgeon General, 1999). This research evidence led the New York State Department of Health to recommend that ABA interventions be incorporated into all programs for young children with autism (for a full list of National and State legislation in support of ABA-based services in the US, see Hagopian, Hardesty, & Gregory, 2014). A review by US and British paediatricians in the well-regarded medical journal *The Lancet* found that programs based on the principles of applied behavior analysis were the most well-researched training programs avail-

able (Keenan, 2016). If further evidence was needed from the paediatric community, the American Academy of Pediatrics (2007) published a report stating that the “effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research” (Myers & Johnson, 2007, p. 1164).

How can we pass judgement if claims for autism therapies are scientifically robust? According to Normand (2008), “to be sceptical is to judge the validity of a claim based on objective empirical evidence” (p. 42). Proponents of pseudoscientific approaches to ASD turn their back on objective evidence in favor of anecdotes and testimonials, mostly from parents and professionals (Normand, 2008). Anecdotes can be used to support all kinds of practices, yet they are the least reliable sources of information and cannot qualify as hard evidence (Chance, 2014). Claims that account for the effective treatment of children with autism are many and varied; two examples include mega-vitamin regimens and facilitated communication (Normand, 2008). Do these claims stand up to scientific scrutiny? Talking with parents whose children had favorable results or discuss this with professionals who have vested interests in the abovementioned therapies, one might be convinced of their effectiveness. The claim that mega-vitamin regimens produce improvements relies almost entirely on parental reports, are seen as poor sources of evidence that lack objectivity and cannot be independently verified (Normand, 2008). Take the example of facilitated communication, which was shown as a breakthrough treatment for helping children and teenagers with autism who had communication difficulties, yet

there was an absence of data and evidence to support this procedure (Bailey & Burch, 2006). Indeed, the American Psychological Association (APA) issued a resolution in 1994, stating that there was no scientific support for facilitated communication, as study after study had shown its ineffectiveness as a therapy for autism as well as the dangerous potential it had in yielding misleading results (APA, 2016).

The development of treatments or programs for ASD without sound empirical support can lead to inconsequential and even harmful practices (Metz, Mulick, & Butter, 2005). In extreme cases, some therapies have caused deaths of children with autism (Bailey & Burch, 2006). For the parents of an autistic child, the main concern lies in accessing effective treatment in an area where there are so many fake and unscientific treatments available (Normand, 2008; Bailey & Burch, 2006; Freeman, 2007).

Parents, teachers and other professionals often attribute the behavior of children with autism to explanatory fictions to explain behavior. Such “mentalistic” explanations seek to explain behavior by referring to “a fictitious attribute residing within the individual and often credited with causality for the behavioral repertoire” (Mason, Davis, & Andrews, 2016, p. 63). A child may be diagnosed with ASD because they display problematic behaviors, which are then said to be caused by the child’s autism (Mason et al., 2016). In fact, the more parents attribute challenging behaviors to the child and not the environmental history, the more likely they are to dismiss behavior analytic interventions (Reimers, Wacker, Derby, & Cooper, 1995). The majority of caregivers use

mentalistic explanations, with up to 100% of the descriptions of problem behaviors accounted for by mentalistic explanations (Mason et al., 2016). Mentalistic notions run counter to how behavior analysts work with children with autism and their families. In addition, cognitive theories often perpetuate mentalistic notions and explanations of behavior (Moore, 2010), which results in further obstacles for ABA being accepted.

Even though autism treatment is the single largest area of application for behavior analysts (Normand, 2008), it is important that behavioral science is not pigeonholed as being one therapy or treatment. In fact, the science of behavior analysis has applications to a wide range of populations and settings. The Cambridge Centre for Behavioral Studies (2016) showcases applications that include behavioral solutions for aging, brain and spinal cord injury, addiction treatment, health and safety, sustainable environments, behavioral neuroscience, psychopharmacology, animal behavior ranging from domesticated pets to farm and zoo animals, teaching and educational practice and many more applications that are too exhaustive to list here.

To conclude, in this paper, we have pointed to some of the main obstacles in Europe for accepting the evidence base of ABA in the treatment of autism. However, there is an obligation on behavior analysts to engage in discourse with professionals and laypeople to correct the misinformation that exists regarding their scientific field. A parent, teacher, government minister, academic or layperson who is seeking information or forming an opinion about ABA in relation to autism needs to consult reliable sources of information, such as peer-reviewed jour-

nals, and not rely on anecdotes. Effective therapies and technologies have been developed by ABA professionals that are poorly understood or undermined by those who lack appropriate training in behavior analysis. There is disagreement between behavior analysts and other researchers, practitioners and professionals about the methodology and efficacy of studies relating to autism. ABA is the applied branch of the science of behavior analysis and it is inappropriate to make recommendations about a scientific field that are based solely on RCTs.

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Cuvo and Vallelunga (2007) suggest that parents, professionals and service providers can exert pressure on government and state agencies to influence social policy for the appropriate services for children with autism and their families. They propose lobbying for funding of university training programs that would help to hire staff faculty members, create appropriate curriculum and develop financial aid to attract students. From a European perspective, this advice is paramount, and we have a lot to learn from the North American experience.

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## KAI NETEISINGA INFORMACIJA LEMIA POLITINIUS SPRENDIMUS DĖLAUTIZMO GYDYMO

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S a n t r a u k a

Elgesio analizė yra svarbi, kalbant apie autizmo spektro sutrikimo intervencijas. Elgesio analize pagrįstos intervencijos turi didelį empirinį pagrindimą, tačiau apie daugelį kitų intervencijų rūšių to pasakyti negalima. Tai lėmė didelius politinių sprendimų ir

rekomendacijų skirtumus skirtingose pasaulio dalyse, ypač tarp Europos ir šiaurės Amerikos. Straipsnyje analizuojamos kai kurios šių skirtumų priežastys.

*Pagrindiniai žodžiai:* autizmas, elgesio analizė, įrodymais grįsta praktika, eklektiškumas, kategorijos.

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