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IX. The science of Applied Behaviour Analysis as the basis for effective autism treatment

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According to recent estimates, 1 in each 59 new-borns will be diagnosed with Autism Spectrum Disorder (ASD) in the USA (Centers for Disease Control and Prevention, 2018). Data in Europe are scarce and indicate that 1 in 159-333 children will receive an ASD diagnosis (European Commission, 2005), with the majority of European countries not availing of direct population data. Interestingly, research in the USA has shown that prevalence may vary significantly between states of the same country with the number of children identified with ASD ranging from 1 in 77 in Arkansas to 1 in 34 in New Jersey (Baio et al., 2018). The lack of population-based rates internationally (Kim et al., 2011), which results in estimated rates rather than real figures, firmly supports the need for further population studies to be conducted.

Individuals diagnosed with ASD share a set of characteristics at varying levels of severity: impairments in social communication skills and the presence of restricted interests and repetitive behaviours (American Psychiatric Association, 2013). As many as 31% of all children with ASD present a co-occurring intellectual disability (Baio et al., 2018), while about 30% are minimally verbal (Tager-Flusberg & Kasari, 2013). When looking at adults with ASD, only 16% of them are in full-time paid employment, with 32% reporting being in some kind of paid employment (The National Autistic Society, 2016). Clearly, the social impact of ASD on the overall health and wellbeing of both people with ASD and their families is enormous.

ASD appear before the age of 3 with many signs being observable from the first year of life and others appearing around the age of two years, including those presented in children who seem to develop typically until approximately the age of two and then regress in previously acquired skills (Maestro et al., 2005; Zwaigenbaum et al., 2005). Research data show that a diagnosis of ASD can be given reliably to 2-year old children (Robins, n.d.) but parents and important others may have observed the first signs and started worrying even before the child’s 1st birthday (Stone, Coonrod, & Ousley, 2000; Zwaigenbaum et al., 2005). Unfortunately, the formal diagnostic process takes several months, with as many as half of all children with developmental delays in the USA not being identified until they reach school age (Glascoe & Marks, 2011). Receiving a late diagnosis poses a great obstacle to accessing early intervention that enables children to reach their full potential (Fein et al., 2013; Howlin, Magiati, & Charman, 2009; Klintwall, Eldevik, & Eikeseth, 2015). Establishing a universal procedure for screening and reaching an early diagnosis would therefore be extremely beneficial. For this, a number of reliable screening and diagnostic tools have been developed, some of these based on caregivers’ reports, others requiring a clinician (Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2008; Gray, Tonge, & Sweeney, 2008).
In the last decades, a wealth of studies employing varying methodologies (i.e., systematic reviews, meta-analyses, randomised controlled trials, and single-subject research designs) have evidenced that behavioural interventions, especially when applied early in life, can lead to optimal outcomes for children with ASD, including significant gains in cognitive ability, social communication and adaptive behaviours (Dawson et al., 2012; Hardan et al., 2015). These behavioural strategies employed by well-trained educators and parents enable individuals with ASD to reach their full potential, promote generalisation of acquired skills and ensure cost effectiveness (Behavior Analysts Certification Board, 2014).

Applied Behaviour Analysis (ABA), the science that studies socially significant human behaviour (Cooper, Heron, & Heward, 2007), constitutes the basis of the most effective interventions for autism to date (Virués-Ortega, 2010), while lack of ABA has been shown to correlate with dependence in adulthood (Howlin et al., 2014). Some of the numerous strategies employed in ABA-based interventions are naturalistic teaching, discrete trial training, functional assessment, the use of pictures for communication, shaping, and chaining, among others. What is common across all ABA-based interventions is that only scientifically validated teaching procedures are used for skills acquisition and the reduction of challenging behaviours, most of which are based on reinforcement; treatment is individualised; decisions are data-driven; and continuous assessment of progress across developmental areas determines ongoing needs and individualised learning goals. Multidisciplinary work and collaboration across stakeholders and settings is of paramount importance (Dillenburger et al., 2014).

From a human rights’ perspective, individuals with a disability including ASD should have the freedom to make their own decisions, fully and effectively participate in society, be respected and accepted, and enjoy equal opportunities (United Nations, 2007). Given the impact of ASD on our society constitutes a pressing need, an ethical response would necessarily involve universal access to evidence-based education that enables individuals to reach their potential. Evidence-based effective education for ASD is synonymous to ABA-based interventions (Keenan et al., 2015).