

## Psichologija praktikai

### AUTISM, INTERVENTIONS AND PARENT TRAINING

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*Worldwide, the prevalence rates of autism are increasing. This review looks at the additional stressors that parenting a child with autism can bring, including psychological distress and mental health difficulties. With the difficulties associated with the autism diagnosis and additional demands on the parents, research has shown that parent training, which helps teach parents new skills, may be advantageous. This review also looks at the most commonly used interventions that parents might avail of in order to acquire new skills, and it examines whether they are based in science, pseudoscience or anti-science. Utilizing best practice from evidence-based research, parents can be successfully trained to teach new skills across a variety of different domains. The advantages and disadvantages of one-on-one training sessions versus group training events, as well as the different components that contribute to each, are discussed. A number of training packages are discussed, including Behavioral Skills Training, video modelling and manualized training packages. We conclude that there is substantial evidence showing that packages with behavioral underpinnings are more effective for children with autism. Autism awareness and education is simply not enough – educate the parents using evidence-based practice to help effectively educate the children.*

**Keywords:** autism, ABA, parent training, evidence-based practice.

Autism Spectrum Disorder (ASD) is a developmental disability that is purported to affect approximately 1 in 160 children worldwide (WHO, 2017). This high prevalence rate has resulted in the Centers for Disease Control and Prevention considering autism as “a public health concern” with 1 in 67 children in the United States being

diagnosed (CDCP, 2016). To receive a diagnosis of ASD, individuals will present with difficulties in social interaction and communication as well as a narrow range of interests and activities that are unique to the individual; many of these activities are carried out repetitively (NHS, 2016). As autism is a spectrum disorder, the difficul-

ties presented by one individual may be completely different from those presented by another individual on the spectrum. Other difficulties that are associated with an autism diagnosis, outside of the key difficulties referenced above, include but are not limited to challenging behavior, cognitive difficulties, learning difficulties and co-morbid conditions, such as attention deficit hyperactivity disorder (ADHD) and epilepsy. An individual with a diagnosis of autism may be able to successfully complete their education, access employment and have relationships with friends and significant others; however, another individual on the autism spectrum may require 24-hour support for the rest of his/her lifespan. This is the main reason why a “one size fits all” approach for intervention would not be warranted.

Although some stress is considered normal when parenting a child (Deater-Deckard & Scarr, 1996) research has demonstrated that those parenting a child with autism are more likely to experience significantly higher levels of parenting stress and psychological distress (Abbeduto et al., 2004; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005); 84% of mothers of children with a developmental disability reported higher levels of stress scores falling within the clinical range (Oelofsen & Richardson, 2006). Studies have compared stressors that the parents of a child diagnosed with autism may experience with the stressors associated with typically developing children (Brobst, Clopton, & Hendrick, 2009) and those diagnosed with Down’s syndrome, intellectual disability, cerebral palsy or cystic fibrosis (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Bouma

& Schweitzer, 1990; Donenberg & Baker, 1993). Invariably, higher levels of stress appear in those families where there was a child with a confirmed diagnosis of autism. The demands that come with parenthood, particularly when parenting a child with a disability, are further exacerbated whenever there is a lack of extended family support networks (Lawton & Sanders, 1994). The substantial consequences of emotional and behavioral difficulties in a child with a developmental disability were a key indicator as to whether parents will seek a residential placement for their child away from the family home (McIntyre, Blacher, & Baker, 2002). However, it has been also noted that more children with an intellectual disability are being raised independently in the family setting and extended community (Taube-Schiff & Serbin, 2006).

The perceived level of social support and general coping styles of parents have also been associated with higher stress levels. Families with more available support tend to report less stress (Factor, Perry, & Freeman, 1990) and those with more productive coping strategies also report less stress (Benson, 2010). Traditional coping strategies have often been escape/avoidance tactics, resulting in higher stress levels, whereas those that are more problem-focused in nature have lower stress level outputs (Hastings & Johnson, 2001). Parents of children who are diagnosed with autism have already higher stress levels (as referenced above), and these traditional coping strategies may be ineffective. Subsequently, four other coping strategies were identified – distraction coping, disengagement coping, engagement coping and cognitive reframing coping

(Benson, 2010). Distraction coping and disengagement coping best fit into the model of escape/avoidance coping mechanisms, e.g., modulating emotions or substance abuse. The other two, engagement coping and cognitive reframing coping, are more applicable to problem-focused theory, e.g., active involvement in addressing the stressor and ‘coming to terms’ with the autism diagnosis positively. Whilst this research is limited, it has been concluded that escape/avoidance, distraction/disengagement strategies had a greater negative impact on parental well-being (Benson, 2014; Hastings et al., 2005). In order to help with coping, the level of social support must also be addressed. Social support can be classified as both formal and informal. Formal social support is that which is provided by a relevant health professional and, whilst it has its merits, some research has concluded that informal social support is actually more important for those parents insofar as it is ‘a more effective stress buster than formal support’ (Boyd, 2002). However, social support was not found to have any impact on the well-being of a cohort of parents in Lebanon (Obeid & Daou, 2015). What is apparent is that parents tend to fall into two categories. Some are reactive, that is, they address the ‘problem’, source information and implement recommendations to help their child. Then there are others – those who effectively ‘bury their heads in the sand’ and view the diagnosis as something that is ‘fixed’ and therefore unchangeable.

Autism is considered a spectrum disorder; therefore, there are differences in how the disorder is presented as well as differences in severity levels. Those with an autism diagnosis ‘may be severely im-

paired or may face only mild challenges’ (Hoogenhout & Malcolm-Smith, 2016), but the severity level of the diagnosis has been suggested as a contributing factor for parental stress and depression (Eisenhower, Baker, & Blacher, 2005; Hastings & Johnson, 2001). Child characteristics (age, autism, severity, child quality of life and problem behavior) were studied to examine their impact on parenting stress levels (McStay et al., 2013). Whilst the child’s age did not suggest higher stress levels in the parents, there was partial support for higher stress levels for those parents who reported a poorer quality of life for their child as well as a more severe diagnosis and more occurrences of problem behavior. This would suggest that parents “may not perceive these factors to be due to their individual parenting styles or parenting skills” – ultimately, not within their control.

The age of a child has also been identified as a possible contributing factor to stress levels for parents (Gray, 2002). However, research findings have been inconsistent. Changes in maternal stress levels were examined in mothers of children of varying ages with a developmental disorder (Orr, Cameron, & Dobson, 1993). Findings suggested that parents of children between 6–12 years old reported significantly higher levels of stress than parents of 2–5 years old and 13–18 years old. Other studies, however, found that parent stress was significantly higher in parents of children within the younger age bracket. A meta-analysis of cross-sectional research identified that rates of depression and anxiety were higher in parents of younger children with a developmental disorder compared with those of older children (Singer, 2006). Based

on this finding, it was hypothesized that older parents adjusted to parenting demands throughout their child's lifespan. However, a strong positive correlation between stress and parenting young adults (15–18 years old) suggested that parents may find it hard to manage a child approaching adulthood (Teehee, Honan, & Hevey, 2008).

To help reduce these reported stress levels, it has been suggested that there may be some advantage in educating these parents to have new skills for addressing the difficult behaviors they often have to manage. For example, Smith, Buch and Gamby (2000) found a decrease in parental stress following parent training, and they also found an increase in parental optimism and parental access to leisure time (Koegel, Schreibman, Britten, Burke, & O'Neill, 1982). Indeed, it has been observed that children with an ASD diagnosis benefit from targeted parent education to help achieve their full potential (National Research Council, 2001; see also Schopler & Reichler, 1971; Neef, 1995; Carr, 1999; Lafasakis & Sturmey, 2007; Seiverling, Williams, Sturmey, & Hart, 2012).

### **Current “Interventions” for Autism:**

With so many interventions available that claim to help individuals with autism, it can be confusing and difficult to sort out those that are based in science from those based in pseudoscience and those based in anti-science (Green, 1996; Freeman, 2007).

Facilitated Communication (FC) is one intervention that has been embraced for use within the autism community (Biklen, 1990). FC is a method that enables individuals with disabilities including ASD,

cerebral palsy and intellectual disabilities to communicate via the means of a ‘facilitator’ – a person who provides pressure to the hand, wrist or arm to help the user overcome physical and emotional problems. They then help ‘guide’ the individual to letters, words or pictures on either a keyboard or a tablet. Following an increase of the use of FC for individuals with autism, the validity of the procedure began to be questioned (Green & Shane, 1993; 1994; Prior & Cummins, 1992). The suggestion was that the champions of FC could not demonstrate, experimentally, that the increase in literacy skills and subsequent prose from the disabled individuals were their words and theirs alone. It was proposed that the increase in skills could, perhaps, be attributed to the facilitator ‘writing’ the words independent of the individual. A study found that when simple questions were asked of the individuals using FC, they could only respond correctly when their facilitator also heard the question (Hudson, Melita, & Arnold, 1993). Subsequently, the American Psychological Association (APA) declared FC as “a controversial and unproved communicative procedure with no scientifically demonstrated support for its efficacy” and that it could be construed as being of an “immediate threat(s) to the individual civil and human rights of the person with autism” being facilitated (APA, 1994). Other organizations followed suit shortly after, denouncing the scientific validity of the procedure, stating that there “are good scientific data showing it to be ineffective” (American Academy of Pediatrics, 1998), and stating that it is “a discredited technique” and its use with individuals with disabilities is “unwarranted and unethical” (ABAI, 1995).

Despite the doubts cast on the efficacy of FC, it is still very much prominent when it comes to “helping” individuals with disabilities. It has since been rebranded as the “rapid prompting method” (Halo-Soma, 2016), or “supported typing” and repackaged as an augmentative and alternative communication (AAC) system (Syracuse University, 2016), perhaps to deflect from the lack of scientific evidence on what it purports to do. In fact, a recent review of autism communication interventions explicitly excluded FC from its evaluation due to the very nature of the program (Brignell et al., 2016).

Another intervention that has been used for helping individuals with autism is a sensory-based intervention called Sensory-Integration Therapy (SIT). SIT was originally developed to place focus on the neurological processing of sensory information (Ayres, 1963) and is one of the most prevalent when working with children with various developmental and learning disabilities. Reports in the literature suggest that the range of children with sensory processing disorders (difficulties in response regulation and high levels of self-stimulatory behavior) is between 42% and 88% (Baranek, 2002). It is not surprising, therefore, that 82% of occupational therapists report that SIT was “always” used when working with children on the autism spectrum (Watling, Deitz, Kanney, & McLaughlin, 1999). Proponents of sensory-integration as an intervention for autism believe that individuals diagnosed with ASD may be either hyper- or hyposensitive to sensory input (Cook, 1990), which has an impact on their sensory systems. Therefore, an intervention based on a “sensory diet” is introduced that helps in the areas of under- or overstimulation (Alhage-Kientz, 1996).

The Son-Rise Program, known in the United Kingdom as the Option Method, is another common program utilized for individuals with an autism spectrum disorder. The home of the Son-Rise Program, the “Autism Treatment\* Center of America,” state on their website that the program “teaches a specific and comprehensive system of treatment and education <...> to help families and caregivers enable their children to dramatically improve in all areas of learning, development, communication and skill acquisition” (Autism Treatment Center of America, 2016). It does so by offering “highly effective educational techniques” in a “one-on-one, home-based, child-centered program.” The program itself is extremely time-intensive, with parents implementing the child’s program for the majority of the day (Powell & Jordan, 1993). Parents attend a one-week training course and, following that, attend advanced group training courses with ongoing support provided by telephone or video conferencing. However, a study of parents in the UK utilizing the Son-Rise Program found that most did not receive feedback or support on program implementation, and that over half of the respondents had reported that they did not avail of the ongoing training programs (Williams, 2006). Yet, 52% of these parents found the program very effective. The majority of the research on the effectiveness of the Son-Rise Program is based

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\* The term *treatment* within the context of discussions on autism is contentious. The term is often associated with medical interventions. We prefer the term *intervention* because it does align with a medical perspective but is more in line with the educational expectations of attempts to help children acquire skills that benefit them, insofar as new skills give them more choices in life.

on anecdotal evidence from parents who have taken part in the program with their child. Even the Autism Treatment Center of America acknowledge that “to date there is very little published research on the Son-Rise Program” (Autism Treatment Center of America, 2016).

A program known as the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), devised by Schopler and Reichler (Autism Speaks, 2016), has generated considerable interest both in empirical research and service demand. Following a survey of 552 parents of children with autism across the world, 30% reported that they still used or had used the TEACCH program (Green et al., 2006), and that TEACCH is frequently used as a special education program in many schools (Hess, Morrier, Heflin, & Ivey, 2008). Unlike other educational interventions, the TEACCH program was developed specifically for children with autism through an understanding of the core deficits of the diagnosis.

A “structured teaching” method underpins the methodological framework of TEACCH, which includes an assortment of teaching principles and strategies based on the learning types of an individual diagnosed with autism, including strengths in visual processing and difficulties in social communication, attention and executive function (Autism Speaks, 2016). It has been suggested that the TEACCH program builds on the behavioral models of education. This is done by placing emphasis on structure to teach new behaviors, targeting and teaching new skills, defining conditions where behaviors should occur and the consequences of behaviours through a shaping procedure (Mesibov, 1997). The literature supports the

efficacy of TEACCH in different settings and when implementing for different durations (Welterlin, Turner-Brown, Harris, Mesibov, & Delmolino, 2012). Results also demonstrate improvements in children’s independent work skills as well as improvements in parental ability to structure the environment and prompt during teaching. Improvements have also been reported in both communication and social skills as well as decreases in inappropriate behaviors (Mesibov, 1997).

The most popular way for addressing autism with the most robust scientific evidence to support its efficacy is Applied Behavior Analysis (ABA), the applied branch of the science of behavior analysis. It focuses on improving language deficits, imitation skills, self-help and independence, pre-academics and social skills (Sturme & Fitzer, 2007). All programs designed to develop these skills are tailored to meet the needs of each individual using known principles of learning. Skills are broken into discrete components and are initially taught on a one-on-one basis either in a home or school setting (with planned generalization), using technologies and principles such as discrete trial teaching, shaping, reinforcement, chaining, prompting and prompt fading as well as extinction (Duker, Didden, & Sigafoos, 2004, cited in Peters-Scheffer, Didden, Korzilius, & Sturme, 2011).

Over the past 40 years, there has been a large body of literature published that has shown behavior analytic technologies to be effective in reducing problem behavior and increasing appropriate skills within a number of different areas, which are not autism-specific. The evidence for behavioural-based interventions have come to the forefront of autism literature with

a review on outcome studies recognizing Intensive Behavioral Intervention (IBI) as the most effective intervention for autism (Smith, 2009). The research has shown that statistically, there is a significant relationship between ABA-based interventions and children considered to have achieved “optimal outcomes” – those children who no longer meet the criterion to be diagnosed as ASD as well as attaining normal levels of cognitive function (Orinstein et al., 2014) or the achievement of “normative functioning, defined by standard psychological methods and practical outcomes” (Healy, O’Connor, Leader, & Kenny, 2008). The American Academy of Paediatrics has recommended that children displaying traits associated with autism be screened from 18 months in a bid to aid early intervention efforts. Early Intensive Behavioral Intervention (EIBI) (i.e., the delivery of ABA intervention at an early age) is the only intervention for autism that has been endorsed by the Surgeon General of the United States (United States Surgeon General, 1998). It has been identified as being effective when compared with those with no intervention controls or with eclectic/autism specific special education interventions (Eikeseth, 2009; Rogers & Vismara, 2008). Independent review panels consistently agree that EIBI/ABA is effective and that the research literature “meets high standards of scientific evidence” (Larsson, 2013). It has been estimated that the annual cost to the UK for autism is £32 billion in specific interventions, lost earnings, care and support for both children and adults with the diagnosis (Buescher, Ciadav, Knapp, & Mandell, 2014), so investing in EIBI could potentially lead to long-term savings in both social and financial costs.

## **Parent Training**

Training teachers and staff in various institutions has been a defining feature of behavioral intervention since its inception (Kazdin, 1997). The next logical step would be to train parents in how to implement behavior change programs. Schopler and Reichler (1971) highlighted the importance of parental involvement in any part of a program for children with autism. The importance of parental involvement in educating children with disabilities has been well-documented (Neef, 1995; Lafasakis & Sturmey, 2007; Seiverling et al., 2012), with parent training being the most common intervention used to address behavioral problems in children (Carr, 1999). Children with a diagnosis of an autism spectrum disorder and associated difficulties (aside from those within the triad of impairments), such as cognitive impairments and difficulties learning from their natural environment, benefit from targeted parent education to help achieve their full potential (National Research Council, 2001). The very nature of the autism diagnosis, with associated challenging behaviors for some individuals, would suggest that the need for parent training is significant. Therefore, parental training interventions should be addressed as an option to facilitate service demand deficits. Parent-led behavioral interventions for young children with ASD have many advantages. Rather than relying on waiting lists to access services, parents are able to implement programs earlier, thereby providing early intervention. Disseminations of the appropriate intervention through training programs are more cost-effective to facilitate (Wetherby et al., 2014). Other benefits that have been

attributed to effective parent training include an increase in family satisfaction and the reduced chance of the child being placed in a residential setting (Harrold, Lutzker, Campbell, & Touchette, 1992). Conversely, despite the evidence that shows the benefits of parent-led interventions, data suggest that some EIBI programs do not receive either the frequency or quality of supervision that has been specified in programs with the best child outcomes (Mudford, Martin, Eikeseth, & Bibby, 2001), resulting in lesser overall gains than clinic-based programs.

Parent training refers to “educative interventions with parents that aim to help them cope better with the problems they experience with their children” (Callias, 1994, cited in O’Reilly, 1995, p. 63). Parents are the primary caregiver, thus playing a critical role in teaching and managing problem behavior exhibited by individuals with autism and other disabilities. This can help reduce the cost of therapy and promote generalization (Matson, Mahan, & Matson, 2009) as well as a potentially high level of reinforcement for parents when implementing programs that result in positive behavior change (McClannahan, Krantz, & McGee, 1982).

There are numerous terms to describe parent training within the literature: “parent education” (Schultz, Schmidt, & Stichter, 2011), “in-home training” (Seung, Ashwell, Elder, & Valcante, 2006), “parent implemented” (Ingersoll & Gergans, 2006), “parent-mediated” (Wainer & Ingersoll, 2013) and “parent-assisted training” (Frankel et al., 2010). The objective of all parent training is to provide parents with information, teach them new skills and supplement

or augment current parenting strategies (Brookman-Frazer, Stahmer, Baker-Ericzen, & Tsai, 2006). If these objectives are met, there is the potential for improvement in long-term child outcomes (Simpson, 2001).

The advantage of parent training is that it is comprehensive, has the ability to target multiple functions and is adaptable to the needs of the parent, the behavior problems they are managing and/or the skill deficits of each child. Yet, Bearss, Burrell, Stewart and Scahill (2015) suggested that parent training involves “a variety of treatments that may or may not share common features” (p. 2). They suggest that this may be because the complexity of ASD and associated skill deficits lead to a myriad of interventions that are inconsistent in what they purport to offer. Ultimately, though, parent training refers to “educative interventions with parents that aim to help them cope better with the problems they experience with their children” (Callias, 1994, cited in O’Reilly, 1995, p. 63).

The benefits of parent training have been acknowledged as an essential component of successful interventions for children with an autism diagnosis (National Research Council, 2001). In fact, the momentum for parental involvement in educating their children on the spectrum has been growing and has evolved to “generate positive child and family outcomes” (Gavidia-Payne & Hudson, 2002, p. 42). Research has focused on interventions (in relation to challenging behavior) that are “proactive, positive and strengthen both parents’ and children’s skills in natural settings” (Gavidia-Payne & Hudson, 2002, p. 32). Other research has indicated that parents can be effective

implementers of behavioral, social and communication programs for their children (Koegel et al., 1996). A central point in the evidence-based intervention literature is the importance of training parents in skill development across a variety of skills domains, such as feeding programs (Sharp, Burrell, & Jaquees, 2013), social skills (Mandelberg et al., 2013), joint attention (Rocha, Shcreibman, & Stahmer, 2007) and sleeping (Reed et al., 2016).

Other benefits for parent-led behavioral interventions, apart from being able to implement programs regardless of waiting lists, also include their cost effectiveness, family satisfaction and the reduced chances of a child being placed in a residential setting (Lutzker, 1993; Wetherby et al., 2014). By training parents specifically in a number of strategies to help increase appropriate behaviors and teach new skills, there is an increased probability of the generalization of these skills to new settings and skills (Koegal et al., 1982). Training parents to implement behavior interventions also makes sense in simple practical terms, because they can implement programs outside of the “traditional” teaching times – such as holidays – therefore providing children with multiple teaching opportunities in many different situations that might not happen in a clinic or school setting. Parents, then, should be placed in a more central role in their child’s education, as they have more opportunities to teach new skills on an ongoing daily basis (Mahoney & Wiggers, 2007). As children learn within the context of their family setting, it makes sense that intervention techniques are transferable across all settings which the child and family frequent (Dunst et al., 2001).

Knowing how to transfer knowledge and skills from professionals to parents is “essential if evidence-based parent-implemented interventions are to be successfully delivered in community settings” (Stahmer et al., 2016, p. 3). Indeed, there are data to suggest that some Early Intensive Behavioral Intervention (EIBI) programs do not receive either the frequency or quality of supervision that has been specified in programs with the best child outcomes (Mudford et al., 2001), resulting in lesser intervention gains than clinic-based programs. Fortunately, some studies have shown that parents can be trained to implement programs to a high degree of fidelity within 5–24 hours of training over 2–12 weeks (Vismara, Colombi, & Rogers, 2009; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010).

Overall, there appears to be an overwhelming consensus that parental involvement can have huge benefits to an individual with an autism spectrum disorder. Yet, as with any intervention, there are potential shortcomings, and the professionals involved with the families need to be pragmatic about their expectations. A randomized control design assessing the differences in general parent training versus training in intensive Applied Behavior Analysis (ABA) found better outcomes for intensive intervention (Smith, Groen, & Wynn, 2000). However, the same study found that child outcomes in the parent training group (while statistically less successful on some measures) were clinically comparable.

Parent training and the parent implementations of programs can require a substantial amount of time and energy; therefore, considerations of other factors

that may have impact on the family need to be addressed. These issues include time demands, particularly if there are younger children in the home (Matson et al., 2009), and the ability to accurately and consistently implement programs (Mudford et al., 2001). However, the adherence to programs in community-based ABA programs, where parents are the main therapists, has been found to be sporadic and with inconsistent applications of program recommendations or no implementations of intervention at all (anecdotal evidence). Attendance at a training event will not necessarily guarantee the implementation of training at home. Therefore, it would be prudent to begin by not only focusing on the variables impacting the child's behavior but also on those variables that impact the parent's behavior (Stocco & Thompson, 2015). Allen and Warzak (2000) state that medical literature looks at adherence as a result of subject variables, e.g., subject demographics, the perception of illness and the benefits of treatment rather than "adherence behavior as a function of its consequences" (Allen & Warzak, 2000, p. 374). They proposed the use of a functional assessment to determine the contingencies that could strengthen or weaken adherence to a behavioral intervention. The contingencies which they identified as having an impact include:

- "Treatment" effectiveness as a prerequisite for success;
- Establishing operations;
- Failure to establish intermediate outcomes as reinforcers;
- Failure to disestablish competing social approval as a reinforcer;
- Stimulus generalization;

- Trained insufficient exemplars;
- Trained a narrow range of setting stimuli;
- Weak rule following;
- Response acquisition;
- Consequent events.

Accordingly, the design of any parent training program should take these contingencies into consideration to maximize the chances of success for both parents and children.

### **One-on-One Parent Training Versus Group Events**

There are currently a range of strategies that are used to implement a parent training program. Two of the most utilised are "one-on-one sessions," where parents practice skills demonstrated by the therapist and "group-sessions," where a similar peer group accesses the training. Each strategy has its own advantages and disadvantages. Cunningham et al. (2008) suggest that one-on-one training (that which is conducted individually with both the parent and the child, led by a professional up to twice a week for a number of months) is the preferred choice by many parents. During one-on-one training sessions, parents are provided with access to a service that is tailored to the individual needs of their family. Other advantages include the possibility that a parent may disclose more to the practitioner in the absence of an audience, and that there is also a reduced risk of a lack of individual participation. Individual training may also afford greater accountability, as a lack of participation can be addressed much quicker than in group sessions (Piper, 2011). Whilst topics and principles covered within a session are constant, it is the unique

application of these to parent-specific issues that give them merit. One-on-one training, however, can be costly when compared to group training.

The one-on-one parent training models have the most empirical evidence to support their use (Ingersoll & Dvortcsak, 2006). One such study is that of Alpert and Kaiser (1992), wherein the scholars taught six parents to successfully implement a natural language program with their children who had language impairments. There were three specific elements to this training – clinic-based training, home training and a generalization training session. Results demonstrated that these parents were able to successfully implement the training program to increase language, and the effects were generalized to other settings and maintained over time. Another study using one-on-one training sessions compared the effectiveness of individual parent training with a parent education training event (Bears et al., 2015). The individual parent training sessions were far superior to the education sessions in overall behavior improvement. Another study compared the effects of group training sessions on increasing communication skills with one-on-one training sessions (Wetherby et al., 2014). Both groups resulted in skill increases, but one-on-one training resulted in substantially more gains across all skills. This type of individualized training enables the behavior analyst to teach parents specific skills that are based on the unique needs of their child. The programs are tailored precisely to take into consideration all of the other demands that the family life entails; thereby, the expectations of programs are reduced and systematically increased as program imple-

mentation continues and skill acquisition rates increase. However, it may take time to specifically train each of the components to a certain level of mastery in order to maintain the program's integrity (Cook, Subramaniam, Poe, & St. Peter, 2015).

Group parent training events have been used successfully in community-based ABA programs. These types of events, according to Brightman, Baker, Clark and Ambrose (1982), require at least half the professional time per family compared to one-on-one sessions. These types of events would therefore be more time-efficient for agencies and service delivery providers than one-on-one sessions. Providing a group parent training session is, therefore, more cost-effective in reducing the overall cost of the intervention on a per-client basis (Cunningham et al., 1995). A comprehensive review by Furlong et al. (2012) concluded that parent training programs delivered in group settings are effective and cost-effective for “improving child conduct problems, parental mental health and parenting skills.” However, they recommended that more studies assess the long-term effectiveness of such programs as gains have been noted to be short-lived. One study aimed to increase positive social interactions in families of adolescents with behavior problems (Serna, Schumaker, Sherman, & Sheldon, 1991). Results showed that interactions within the parent group and the adolescent group increased in the group sessions, but generalization did not occur in non-trained settings. This would suggest that consideration must be given to the identification of contingencies that will ensure the generalization of new skills to non-trained environments.

Group-based parent training events are typically delivered using interactive and collaborative teaching. Facilitators introduce key behavioral principles that can be utilized in many ways to improve the parenting skills of those attending. Parents then practice the skill they have just been taught and receive corrective feedback and reinforcement on accurate skill rehearsal. Key elements that help create effective parent-training programs are those that include learning how to use positive parenting skills (reinforcement and alternatives to the use of an aversive), learning to observe behaviors, modelling, rehearsal, peer support, discussion and homework assignments (Furlong et al., 2012). The number of parent support groups established in N. Ireland and in the UK more generally (AutismNI, 2016; NAS, 2016) suggests that peer support from another parent experiencing similar difficulties is beneficial. This “shared experience” can prove invaluable in behavioral parent training, particularly group events. The additional element of peer support may increase participation in the training as well as cultivate friendships with other individuals who understand the autism diagnosis and help “normalise” the experiences of those attending (Cox, Vinogradov, & Yalom, 2008). However, a study that compared individual home training with group training events showed that those children whose parents received individualized home support made the greatest gains (Wetherby et al., 2014).

### **Specific Strategies for Training Parents**

In view of the overwhelming amount of evidence, it is easy to see why parents of

children with an autism spectrum disorder should be given access to training. However, published research demonstrates that there are many different issues concerned with ways to teach, what to teach and how to teach. One of the seven dimensions of Applied Behavior Analysis is being “effective” (Baer, Wolf, & Risley, 1968): “if the application of behavioral techniques does not produce large enough effects for practical value, then application has failed” (p. 96). What is vital, then, regardless of which technique is used for parent training, is that training should be “effective” in order to be relevant. Behavioral Skills Training (BST) is a training/teaching package that consists of a number of methods that, when used together, result in an effective education for individuals. It is defined by Ward-Horner and Sturmey (2012) as “an effective training package that consists of instructions, modelling, rehearsal, and feedback” (p. 75). A verbal or written instruction can be used for the instruction component of BST. The goal is to ensure that the participant understands how to competently complete the skill or the behavior of interest. The next step – modelling – is when the skill is demonstrated and followed by rehearsal, during which the opportunity to practice is given. This role-play element will help the learner practice what they observed during the instruction and modelling components in a safe, controlled manner. Feedback is the last component of the BST package, where, following the previous steps, corrective feedback is provided by the trainer. BST has been shown to be effective in training parents how to implement behavioral-based interventions, such as food selectivity (Seiv-erling et al., 2012). This study demonstrated

that parents could successfully implement a feeding program but also that the parents reported the modelling component to be the most helpful. BST was successfully used to teach three special education teachers how to implement a discrete trial teaching procedure with a child with ASD (Sarokoff & Sturmey, 2004). Following BST, there were significant gains in the teachers' percentage of correct discrete-trial responses. BST has also been successful for teaching an adult with autism to converse with a peer – successes that were maintained over time (Kornacki, Ringdahl, Sjostrom, & Nuernberger, 2013). Parents in Saudi Arabia were also successfully taught how to implement a discrete-trial procedure with their children using BST; results showed that there was a generalization of this skill to non-taught examples, long-term maintenance and improvements in child behaviors (Eid et al., 2017). BST has been demonstrated as being an effective way to teach parents, teachers and individuals with developmental disabilities how to successfully teach, maintain and generalize new skills. For parents, the modelling and rehearsal components enable them to observe and practice a skill that will help them in the absence of a professional.

As technology has developed, so too have the ways that parent training packages are presented. One such development is the addition of video modelling as a training component. Video modelling is a visual teaching method where individuals watch someone engage in a skill on a DVD or video and then go and practice or imitate that observed skill. The Incredible Years© is a program that has evaluated the use of videos to deliver parent training programs. The program focuses on “strengthening

parenting competencies and fostering parent involvement in children’s school experiences, to promote children’s academic, social and emotional skills and reduce conduct problems” (The Incredible Years, 2017). The videos depict parent-child interactions to foster a discussion of behavior management principles in a group training environment. Other studies have shown that incorporating video modelling into parent training events is superior to those on a waiting list for services (Webster-Stratton, & Hammond, 1997). A video modelling intervention was used in 2012 by Kahn (as cited in Majszak, 2015) to increase positive parenting statements to their children with autism. There was only a slight improvement in parental behavior but a decrease in child problem behaviors as reported by the parents, which could suggest that the strategy is not effective as a stand-alone intervention. Video modelling has also been used to teach individuals with an autism diagnosis road safety skills (PEAT, 2018b) and navigation through an airport (PEAT, 2018c). These resources were filmed from the perspective of a child with a voiceover detailing the situation within each video. “Autism in the air” embraced the use of video models alongside a practical application of these skills in conjunction with a local airport (Ruddy et al., 2015). Children and their families were able to engage in the skills that had been learned through the video models in the actual setting of an airport (The Irish News, 2016). These examples demonstrate how developments allow for newer technologies to train both parents and children.

Manualized training packages have also been used in parent training packages utilizing a structured curriculum to introduce

parents to various training tools to help their children with ASD. Training manuals are important when designing a formal training program. They help ensure that there is consistency in the presentation of the training packages and that all materials required, following the training event, are available in one place. Butter (2007) used a manualized training package to reduce non-compliant behavior and increase adaptive behaviors in children with Pervasive Developmental Disorders (PDD). Parental satisfaction and adherence to the program were excellent and there were parent-reported reductions in non-compliance (39%) and increases in daily living skills (19%). Additionally, vignettes of behavior, as well as role-play, were used to help augment the manual training package. Simple Steps (Simple Steps, 2018) is an innovative multimedia teaching platform that focuses on teaching the science of ABA to parents rather than offering a manualized training package. The platform teaches the application of key behavioral principles to parents, professionals and students across the world with the aid of animations, video models and an accompanying textbook. This multimedia tutorial comprises an eight-step program that teaches users how to collect data on observable behaviors, aids in understanding behavioral functions and helps in understanding how to increase/teach new skills or behaviors and how to decrease inappropriate behaviors. It is available in nine European languages with the Czech translation supported and sponsored by the biggest state-owned insurance company (PEAT, 2018a). This training package can be utilized for both one-on-one training sessions or within group-session events.

Another example of incorporating the use of animation and manualized learning for training parents is a tutorial titled “Challenging Behaviour” (Keenan, Gallagher, Booth, Dillenburger, & Moxon, 2016). This online platform enables parents to understand how challenging behaviors can continue throughout the lifespan of the individual with specific needs if not managed correctly. Through the use of animations, difficult concepts are presented to the viewer/reader, allowing for exemplars to be introduced, which may help reduce the frequency and/or duration of behavior problems.

The amount of parent training, particularly in the field of ASD, is growing, yet there appears to be a myriad of different packages proposing different claims, making it difficult to distinguish the effective from the non-effective. However, the consensus appears to be that parents can develop new skills and understandings with training events based on behavioral underpinnings, which “result in more effective treatment for their children” (Matson et al., 2009, p. 872).

As the prevalence rates for diagnosing autism spectrum disorders continue to increase, it would make sense that parents and those individuals with autism are offered interventions that can help target skill deficits and reduce the negative impact autism has on the individual’s quality of life as well as that of families as a whole. Since autism is diagnosed through behavioral observations and caregiver reports, it stands to reason that the intervention used to help would be behavioral in nature. The most popular way with the most robust scientific evidence to support its efficacy is Applied Behavior Analysis, a practical

application of the principles of the science of behavior analysis.

In conclusion, the parents of children with autism spectrum disorders are dealing, at times, with highly stressful situations, and providing them with a level of empowerment through parent training has established that the involvement of parents as the facilitators of interventions can have positive outcomes for individuals on the autism spectrum. It is essential that this

training has a good, substantial science base to help augment any claims. Training practices should address the needs of the parents and have an element of being tailored to target specific family requirements. The research also shows that training practices that are behavioral in nature will result in substantial benefits for the wider family circle. The bottom line is that education on autism awareness alone does not have the same far-reaching consequences.

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## AUTIZMAS, INTERVENCIJOS IR TĖVŲ MOKYMAS

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### S a n t r a u k a

Visame pasaulyje daugėja sergančiųjų autizmu. Šiame straipsnyje analizuojama, kokius papildomus stresorius, tokius kaip psichologinis distresas ar psichikos sveikatos problemos, sukelia vaiko, sergančio autizmu, auginimas. Tyrimai rodo, kad dėl problemų, kurias sukelia autizmo diagnozė ir papildomi reikalavimai tėvams, gali būti naudingos intervencijos, skirtos mokyti juos naujų įgūdžių. Šis straipsnis apžvelgia dažniausiai taikomas intervencijas, kurios gali būti pasitelktos, siekiant tėvams suteikti naujų įgūdžių, ir analizuoja, ar jos grįstos mokslu, pseudomokslu ar antimokslu. Taikant

geriausius metodus, grįstus moksliniais įrodymais, tėvai gali būti sėkmingai apmokyti įvairių skirtingų sričių įgūdžių. Straipsnyje aptariami ir grupinio bei individualaus mokymo, taip pat jų komponentų plusai ir minusai. Be to, aptariami įvairūs mokymo metodai, tokie kaip elgesio įgūdžių mokymas, vaizdo modeliavimas, instrukcijomis grįsti metodai. Galima daryti išvadą, kad tyrimai rodo, jog metodai, turintys ir elgesio komponentą, yra efektyviausi. Autizmo įsišąmoninimo ir švietimo tiesiog nepakanka – siekiant padėti tėvams ugdyti vaikus, reikia mokyti tėvus įrodymais grįstais metodais.

*Įteikta 2017-05-08*