



REVIEW

# Parent training for parents of children on the autism spectrum: a review

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## Abstract

Autism is a neurodevelopmental condition with biological, genetic, environmental and developmental causes, which are still not clearly understood. Parents are usually the primary caregivers for their children and the essential link between home and school environments. Often they also take on a coach or therapist role across a variety of interventions, which demands a great amount of time, dedication, energy and financial resources. Increased parent skills allow for continued opportunities for the child to learn in a range of different situations and environments, and parent training is now considered an important component of successful intervention programs. This paper is a review of current research regarding parent training for parents of children on the autism spectrum.

**Keywords:** Autism, Parent training, Parent education programs, Parent stress.

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## Introduction

Autism is a neurodevelopmental condition with biological, genetic, environmental and developmental causes, which are still not clearly understood. Children on the autism spectrum (AS) face challenges that arise from their difficulty in understanding social behavior and interaction, difficulty in understanding and effectively using communication, and difficulty with having reduced flexibility of thought and behavior [1]. One of the most significant aspects of the AS is the clinical heterogeneity and diversity, but most children on the AS present challenges (to a greater or lesser extent) in these areas. Many also experience sensory perceptual differences such as hyper or hyposensitivity, fragmented and distorted perception, delayed perception and sensory overload [2], which impact the way they relate to people and the world around them.

There are a variety of interventional approaches that are currently used for children on the AS, which vary considerably in their theoretical background. A review of these intervention options is beyond the scope of this paper but not all children benefit equally from similar interventions and there is little research as to what variables (child or other) predict response to treatment [3]. In absence of this important information, the choice of early intervention programs by families and clinicians is largely dependent on factors such as availability/proximity of services or cost of interventions rather than on scientific information regarding which intervention will result best, taking into account the individual characteristics of the child and family [3, 4]. The demand for specialized services for children diagnosed on the AS has grown considerably over the past decade and reflects a substantial increase in the estimated prevalence of autism [5]. Service providers are faced with the challenge of providing high quality interventions, at an early stage (as early as possible after the diagnosis), with an intensive nature and over an extended period of time [6]. Where specialized services are offered as a public service, they must also be equitable (available to all children) and accessible. Faced with insufficient resources to meet demands, an increasing number of children (and parents) are placed on waiting lists, and such periods have been linked to high stress levels and psychological distress [6].

Parents of children on the AS experience higher levels of stress when compared to parents of typically developing children [7, 8] and children with other developmental disabilities [9, 10]. Their ability to deal with higher stress levels depends on factors such as their own personal characteristics, the child's characteristics, the family and social support system, their socioeconomic status and the availability of professional help [11]. Parents are usually the primary caregivers for their children and the essential link between home, school and recreational environments. Also, they are often asked to take on a coach or therapist role across a variety of interventions which demands a great amount of time, dedication, energy and financial resources.

There have been reports that high levels of parenting stress can counteract the effectiveness of early teaching interventions in children on the AS [12, 13]. Also, parent depression may contribute to less parental responsiveness during play, which in turn, is associated with decreased child engagement, social interaction, and socio-emotional functioning [14]. Decreased parental responsiveness has also been associated with delay in language development and joint attention [15] and high levels of parenting stress and depression have also been associated with low expectations regarding treatment, which in turn predicted greater obstacles throughout the treatment process, lower attendance, and early termination of therapy [16]. Therefore, parent psychological well-being should be an important part of any intervention approach as parents have a pivotal role on the effectiveness of the intervention and the child's future.

Increased parent skills allows for continued opportunities for the child to learn in a range of different situations and environments, and parent training is now considered an important component of successful intervention programs. This paper is a review of current research regarding parent training for parents of children on the AS. We conducted a non-systematic literature review using databases such as Pubmed, Web of Science and the University of Birmingham database. Keyword searches were performed to retrieve relevant information that has been published in English over the last 15 years. Additional studies cited in reference lists and books in the autism field with relevance to the topic were also included (even if published at an earlier date).

## The importance of parent education programs

Parent education is defined as an educational effort that aims to enhance or facilitate parent behaviors that will influence positive developmental outcomes in their children [17]. The aim is that of teaching skills designed to help parents teach skills to their children, help them emotionally regulate, manage problem behaviors and improve the quality of the parent-child relationship. It differs from psychoeducation, which aims to teach particular knowledge-based content, as opposed to specific skills [17]. In a meta-analysis of general parent education programs to enhance behavior and adjustment in children under seven years of age, Kaminski et al. [18] highlighted that teaching parents specific skills, versus general information alone, was correlated with more positive outcomes. Bearss et al. (2015) compared parent training (specific strategies to manage disruptive behavior) with parent education (information about autism but no behavior management strategies) in parents of children on the AS with disruptive behaviors [19]. The authors found that the parent training program was superior to parent education in reducing disruptive behaviors, both on parent-reported measures and a measure of overall improvement rated by a blinded clinician.

cian. The authors suggested that parents having a greater understanding of the AS and treatment options, acting as an indirect pathway for disruptive behavior improvement, might explain the improvements reported in the parent education group [19].

The importance of training parents as intervention providers was first emphasized by Lovaas after noting that following intensive treatment, children whose parents were trained on the intervention continued to improve, as opposed to children who returned to an institutional setting and lost the previously acquired skills [20]. Parent training is now considered as an important component of successful intervention programs for children on the AS, although large scale randomized trials are still scarce and comparisons across studies are complicated due to differences in the theoretical basis of interventions, and the outcome measurement tools that are used. Reviews on interventions for parents of children on the AS focus on two different aspects: the use of models that focus on training parents to intervene with their children themselves, or models that aim to provide information and coaching to help parents complement professional services [6]. Training parents to work with their children allows intervention to begin early with the aim that parent-interaction strategies help enhance the child's earliest social relationships [21]. By supporting the child in establishing shared interest and learning the power of imitation, parents act in a 'synchronous' way with the child's focus and intentions, and language and communication are enhanced [21-23]. Increased parent skills also allow for continued opportunities for the child to learn in a range of different situations and environments.

### Different types of parent education programs

In terms of parent education programs for parents of children on the AS, many teaching approaches exist and programs differ in mode of treatment delivery, therapeutic components provided and targeted recipients [17, 24, 25]. Most parent education programs tend to address core symptom areas of the AS (such as communication and social interaction) or problem behavior although programs can address more specific aspects such as sleep, toilet training and feeding [17]. Also, parents can be taught skills that relate to managing their own emotions, cognitions and behaviors and programs that include these counseling components (or focus on counseling aspects entirely) have also been considered to be useful for parents of children on the AS [17].

According to Bearss et al. (2015) [25] parent-mediated interventions are programs designed to actively engage the parent in promoting skill acquisition or behavior change in the child. These programs focus on *technique* and the parent is the agent of change while the child is the *direct* beneficiary of treatment. Parent-mediated interventions can focus on the treatment of the core features of ASD or on maladaptive behaviors, and can be further divided

into *primary* or *complementary* interventions [25]. While primary programs actively engage parents to facilitate the child's acquisition of specific skills or the reduction of maladaptive behaviors, *complementary* programs primarily or initially involve the child working with a therapist, that is, they are therapist-led interventions. Parental coaching is then used to teach parents the principles and specific techniques and encourage application of them during everyday activities [25]. Examples of complementary programs include the Early Start Denver Model (ESDM) [26] for children aged 12 to 48 months and the Developmental, Individual-Difference, Relationship-based (DIR)/Floortime™ model [27, 28].

Several other programs have been designed with the aim of giving parents practical guidance in how to interact more successfully with their child and some have been modified to specifically help parents of children with disabilities or on the AS. Examples of such programs are 'The Portage' program [29]), which has recently been modified for children on the AS by the National Portage Association, the 'EarlyBird' program [30], which was developed by the National Autistic Society for parents of newly diagnosed preschool children on the AS, the 'Stepping Stones Triple P - Positive Parenting Program' for parents of pre-adolescent children with a disability [31, 32] and the 'Incredible Years Autism and Language Delay program—IY-ASLD' [33, 34]. Other programs also exist which draw on a number of interventions but lack a specific name [35].

As to the format of the intervention, a common approach is parent training that is conducted in one-on-one sessions with the parent and child [17, 35]. This approach has the advantage that the intervention can be tailored to the child's specific needs, enables practice with feedback and the generalization of skills in those sessions can take place where needed [36]. However, group parent education programs [32, 37, 38], combined group and individual programs [39] and teaching parents to train other service providers [40] are formats which can benefit large numbers of families. Studies have shown that group-based parent programs can be effective in reducing behavioral problems in children on the AS [32], improving dysfunctional parenting styles [32], increasing parents' ability to facilitate the child's development of communication skills and increasing vocabulary [41]. Group programs provide major advantages in terms of cost-effectiveness and may also have additional benefits in terms of social support and stress reduction [42]. Further, the group model provides the opportunity for parents to learn from other parents and the group can simultaneously function as a social support group [38]. Also, with advances in technology, the use of self-directed technological training programs [43] or web-based programs [44] has also become a promising approach [17].

There is little research, however, regarding how to conduct parent education sessions. In general, collabora-

tive or partnership models are recommended and these refer to the parent educator and parent working alongside to develop treatment goals [45]. When parent educators used a partnership approach, and made more collaborative rather than directive statements to parents regarding treatment recommendations, improvements were found in parent stress and confidence, as well as child improvement [46]. In such an approach, the parent is provided with an opportunity for input and it also allows a certain degree of program individualization to fit the family's values, goals, preferences, routines and traditions [17]. The same authors showed positive effects of strength-based statements during parent education sessions regarding child behavior, namely, improvements in parent affect which in turn led to parents making more positive statements regarding the child [17]. A recent meta-analysis of parent education components found that practicing new skills during sessions was associated with larger effects when compared to programs without these components, regardless of program content or format of delivery [18]. Other authors have also suggested that more emphasis should be placed on parents practicing new skills rather than spending more time modelling the skills [47]. Further, teaching parents to reduce negative communication (such as criticism or sarcasm), demonstrate enthusiasm and let the child take the lead during play are components which have also been associated with successful outcomes [18].

Parent educators require important prerequisite skills namely, mastery and conceptual understanding of intervention procedures, responsive and collaborative teaching style, fluency in presentation, providing immediate feedback (after a parent demonstrates a skill as opposed to the end of the session) and the ability to individualize the intervention program and evaluate progress [36]. Further, parent educators should use concrete and positive examples and be able to provide feedback based on observed parent and child behaviors (as opposed to hypothetical situations), at the appropriate time while being specific [36]. Other authors recommend inviting formal and informal feedback from parents and building rapport by acknowledging parental feelings and listening to parents' concerns [17]. Another important aspect is that of the types of program materials used in program delivery. In the review by Schultz et al. (2011) [35], program materials found in studies were divided into three categories: curriculum, manual or neither. The authors found that only 10% of the parent education programs reported using a curriculum and only 43% used some type of training manual or provided a manual with information to parents. The majority of studies (47%) did not report using a curriculum or training manual to teach skills to parents making it difficult to know if the interventions were implemented consistently and accurately [35]. Further, without detailed protocols for implementing parent education programs, researchers cannot efficiently identify the key variables associated with effective programs for parents of children on the AS [48].

## How do parent education programs benefit children and parents?

Research to date suggests that parent education programs have a positive effect on both children and families. Parent education provides increased knowledge and insight into the individual child, enables the incorporation of therapy into the child's own environment and facilitates the generalization of learned skills [36, 49]. It also improves social behavior and communication skills [50-52] and parents' knowledge and skills in managing behavior [32]. Studies on the effects of such programs have also reported a decrease in parent stress and increase in parental confidence and quality of life [53]. Further, improved responsiveness and emotional regulation, reduced levels of stress and depression, overall improved mental and physical health, and greater parenting self-efficacy have also been described as benefits of parent training programs [49, 54]. In a review by Brookman-Frazee et al. (2006) comparing parent education programs for parents of children on the AS and parent education programs for parents of children with disruptive behaviors, all programs were found to have positive outcomes for children and parents [55].

A review by Schultz et al. (2011) on parent education programs for parents of children on the AS concluded that most education programs targeted either behavioral or communicative techniques; the majority of parents included in the studies were mothers (only 23% of studies included fathers); the majority of education programs used a one-on-one training approach (13% used a group approach combined with one-on-one approach); there was an 87% increase in parent skills (use of intervention techniques and behavioral strategies) and 83% improvement in targeted skills for children (such as spontaneous speech, appropriate behavior, play behaviors and social skills) [35]. The same review concluded that 13% of studies reported a decrease in parent stress as a result of the education program while 13% reported a decrease in child challenges (aggression, disruptive behavior and non-compliance). Positive outcomes were reported regardless of whether the parent program was one-on-one or a combined group and one-on-one format and, in general, programs had positive outcomes regardless of frequency or duration. However, other studies have found inconclusive results or inconsistent results across studies.

In a review of randomized controlled trials (RCT) of early intervention for children on the AS, Oono et al. (2013) assessed the effectiveness of parent-mediated early interventions in terms of benefits for both children and parents [21]. The review included 17 studies from six countries but not all studies could be compared directly or combined in meta-analyses due to differences in the theoretical basis regarding interventions, duration and intensity of interventions, and the outcome measurement tools that were used. Therefore, only data from subsets of 10 studies, that evaluated interventions to enhance parent interaction style

and facilitate children's communication, were included in meta-analyses. Overall, the authors did not find statistical evidence of gains from parent-mediated approaches in most of the primary outcomes assessed (namely expressive language and social initiation and parenting stress) with results being largely inconclusive and inconsistent across studies. However, they did find strong and statistically significant evidence for positive change in patterns of parent-child interactions and some evidence suggestive of improvements in child language comprehension. Further, they found evidence suggesting a reduction in the severity of the children's autism characteristics.

Oono et al. (2013) found that only three RCT studies tested a combination of parent-mediated interventions with other locally available services, suggesting that this might be the preferred pattern for local autism treatment provision so that the burden on parents is shared. However, there is sufficient evidence of the effectiveness of parent-mediated interventions in the treatment of young children on the AS and there is a need for service providers to pay more attention to models and approaches that facilitate parent participation as part of available therapies [21]. The review by Oono et al. was unable to answer questions such as which parent interventions should be recommended or which children and parents will benefit most from a particular intervention. This is due to the fact that available evidence reports on variability in interventions including length, intensity, content and delivery; lack of direct comparisons between interventions; variability in recruitment; and how characteristics of children and parents are described across studies, all of which make generalizations difficult [21].

Rivard et al. (2017) evaluated a parental training and coaching program for the parents of children who had recently been diagnosed on the AS and placed on a waiting list for early behavioral intervention. The program consisted of five intensive group sessions followed by individual, at-home coaching (one hour a week for 12 months). Overall, parents reported that the program improved their psychological well-being and parenting skills and enhanced their child and the family's quality of life. Many parents also reported benefits in the child's daily living, language, communication, emotional management and social interaction skills. However, parent stress scores increased during the program. The authors suggest that increased knowledge or awareness of the child's condition or a focus on systematic interventions for the child might induce greater stress on parents. However, another possibility could be that this increase was unrelated to participation in the program, as many children were enrolled in day care at the same time [6].

### Barriers to parent education programs

Despite the evidence that parent-mediated interventions have benefits for both parent and child, research has demonstrated that parent-mediated interventions are underutilized in community settings, with less than 25% of

parents using this intervention approach with their child on the AS [56]. Several barriers or obstacles to the dissemination of parent-mediated interventions have been pointed out and include factors such as shortage of trained professionals, limited financial resources and transportation, lack of child care, geographical isolation, long waiting lists and extensive time commitments [56], which can be even more pronounced for low-income families. In fact, parents of children on the AS from low socioeconomic backgrounds are more likely to refer that these parent mediated interventions are an unmet need [57]. Additional potential barriers that require evaluation are situational and family stressors (such as marital discord or low socio-economic status), mood and anxiety disorders and parent stress. While some studies have reported that as many as 30% of parents do not benefit from parent education programs due to clinically significant stress levels [17], others have reported that families with higher stress levels showed greater parent improvement when treatment delivery in a specialist nursery program was augmented with individualized sessions at home [58]. Programs may also require further individualization to meet specific needs of the family to ensure adequate comprehension and implementation of the training technique [17], for example, the use of video feedback for parents who have difficulty in acquiring techniques with only in vivo feedback or the use of different teaching approaches when working with fathers as opposed to mothers [17]. Finally, given the influence of family culture on caregiver knowledge, acceptance and utilization of intervention [59, 60] the family's cultural background should be considered in order for interventions to be successful. For example, in a pilot study in Latino mothers, the intervention was culturally adapted and delivered by a Latino mother of a child with autism (or similar developmental disability), using weekly home visits over 16 weeks (two modules of eight weeks) [61]. The authors found significant improvements in maternal knowledge regarding autism, in understanding of the child's strengths and needs and also significant improvement in the child's language impairment [61].

### Conclusion

Research to date suggests that parent education programs have a positive effect on both children and families. Parent education provides increased knowledge and insight into the individual child, enables the incorporation of therapy into the child's own environment and facilitates the generalization of learned skills [36, 49]. It also improves social behavior and communication skills [50-52] and parents' knowledge and skills in managing behavior [32]. Further, it can decrease parent stress, increase parental confidence and quality of life [53] and overall improve the psychological well-being of parents.

Children on the AS face challenges which have a profound impact on parents and other family members. Ser-

vices ought to continually assess the needs of the child and family and offer support that matches the family's requirements, which may change over time. Parents need to be considered as active participants of any intervention program, working closely with health and educational professionals. Parents have unique knowledge and experience of their own child and, if better equipped and supported, in their ability to help their child, will become better advocates for their child's needs. Further, parents are usually the primary caregivers for their children and will accompany them into adolescence and adulthood. Parent training should therefore be a part of any intervention program and so far has proved to benefit both parents and children on the AS.

Future research in this field requires studies with larger samples sizes and fewer methodological weaknesses so that results can be more easily generalized. Also, a better understanding of possible moderators and mediators of effects and outcome measures is needed [21]. Studies should include detailed information regarding program components to facilitate replication and enhance outcomes for parents and children on the AS [35].

#### Abbreviations

AS: Autism spectrum; DIR: Developmental, Individual-Difference, Relationship-based; ESDM: Early Start Denver Model; RCT: Randomized controlled trials

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#### Competing interests

The authors declare that there are no conflicts of interests.

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