

# The effects of early autism intervention on parents and family adaptive functioning

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**Abstract:** This review describes the effects of intervention for young children with autism spectrum disorder (ASD) on parents. Like all children, children with ASD bring both negative and positive experiences for parents and families-from increased resource needs, to higher levels of parenting-related stress, to positive personal growth for family members. It is increasingly recognized that, although children with ASD are the primary targets of early ASD intervention, ASD intervention also impacts parents. From the time emerging developmental concerns begin to be identified, through the process of obtaining a diagnosis and initiating services, parents play a central role in addressing the needs of young children with ASD, including implementing and supporting early intervention. Parents experience the impact of intervention directly, through interaction with providers within the health care and educational systems. Parents also experience indirect impacts of ASD intervention due to accelerated developmental progress of children who are benefitting from services and when children make slower progress than expected or have challenging behaviors. Parental stress and psychological well-being are legitimate targets of intervention and compelling research objectives, needing no additional justification. However, parents are also the major contributors to family adaptive functioning—the activities families employ to support positive outcomes for children with ASD (e.g., family-orchestrated child experiences, parent-child interaction, child health and safety functions; Guralnick, 1997). A parent's ability to carry out adaptive functions is, in part, related to their levels of stress and psychological well-being. Thus, there is a transactional process in which parents are both impacted by and have an impact on ASD interventions for their child. Evaluating the effect of ASD intervention on parents is needed to develop new strategies for helping parents and children with ASD reach their full potential. This review will provide an overview of research on the impact of early ASD intervention on parents. Evidence regarding the impact of three types of intervention (i.e., early intensive behavioral intervention, parent-implemented intervention, and programs directly targeting parent stress) on parent well-being and family adaptive functioning will be reviewed. Potential moderators of the impact of ASD intervention on parents and family adaptive functioning will be discussed. We conclude that research on the impact of ASD intervention on parents of young children with ASD is a promising avenue for improving the lives of children with ASD and their families.

**Keywords:** Autism; parenting; early intervention; stress; family

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Interventions for young children with autism spectrum disorder (ASD) can lead to meaningful developmental gains in cognitive ability, communication skills, and reduced ASD symptoms (1-4). The primary goal of ASD intervention is improving child outcomes, but child-focused ASD interventions also impact parents. The experience of parenting a young child with ASD can vary widely and includes both negative and positive aspects, ranging from increased resource needs, to higher levels of parentingrelated stress, to positive personal growth for family members. There is a transactional relationship between parent well-being and child intervention outcomes, with each mutually influencing the other (5). Research and innovation is needed to develop ASD interventions that support parental well-being and improve family functioning. We argue that parent outcomes should be considered alongside child outcomes in trials of ASD interventions, both as predictors of intervention success and as targets of intervention in their own right. The goal of this review is to examine research evidence related to the impact of childfocused ASD intervention on parents of young children with ASD.

The current landscape for early intervention services in the United States includes early intensive behavioral (EIBI), parent-implemented, and publicly-funded interventions. Currently, therapist-delivered, comprehensive, high-intensity EIBIs that incorporate naturalistic and developmental principles are considered the most efficacious approaches for improving outcomes for young children with ASD. These approaches are delivered by trained therapists for a significant number of hours per week using naturalistic developmental and behavioral principles (NDBI) to systematically reach developmental goals (6,7). However, barriers, such as lack of trained providers, high expense, and poor coverage through private and state insurance programs, impede access for many children and families. To overcome these barriers, less expensive parent-implemented interventions have been a focus of innovation and research. Parent-implement interventions can address a range of parenting strategies and child outcomes (8) or be targeted to improve single, specific behaviors or symptoms (9). However, when implemented outside of comprehensive intervention programs, parent-implemented approaches have rarely demonstrated efficacy with regard to addressing the major developmental needs of children with ASD, despite improving proximal outcomes such as parent-child interaction patterns or joint attention (10). An additional avenue for intervention can be found through publiclyfunded services (often referred to as early intervention) which are free and available to all qualified children with disabilities through birth-to-three centers in the United States. Best practice in the field of early intervention involves parents and practitioners working collaboratively to develop child treatment goals and to ensure parents have the skills to implement aspects of intervention at home (11,12). Common to all these approaches is the integral role of parents in establishing treatment goals, practicing skills outside of intervention, and (in a few cases) taking on the primary role of intervention provider. Therefore, the mental health and readiness of the parent is likely to be critical to the success of such interventions.

Given the central role that parents play in early ASD intervention, gaining an understanding of the parentlevel barriers (e.g., stress, psychological functioning) and facilitators (e.g., self-efficacy and resilience) of intervention success is a critical research goal. There is substantial evidence that parents of children with ASD experience higher stress than parents of children with typical development or developmental disabilities (13-20). Psychological distress, an individual's experience of negative feelings or emotions, is also increased in parents of children with ASD. For example, compared to parents of children with typical development, parents of children with ASD reported higher levels of anxiety (21) and depression (17,21,22). Parents of children with ASD may also experience more distress than parents of children with other developmental disabilities; one study found that approximately one-third of mothers of children with ASD report clinical levels of depressive symptoms a significantly higher proportion compared to mothers of children with Fragile X (18.2%) or Down syndrome (10.3%) (13). Elevated levels of parenting-related stress and psychological distress in parents of young children with ASD have the potential to disrupt family function and may also impact the effectiveness of early interventions. Osborne et al. (23) reported that children receiving high levels of intervention showed less improvement when their parents had high levels of stress.

If parent stress can negatively impact intervention outcomes, positive parent characteristics or experiences also have potential to improve them. Less research has investigated parent-related facilitators of intervention success, despite some evidence that positive parent expectations are associated with improved child outcomes (24). An even broader construct that goes beyond the functioning of an individual parent is family adaptive functioning; an

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extension of the concept of adaptive functioning for an individual (i.e., the ability of an individual to carry out ageappropriate skills needed to function in daily life, such as dressing, eating, following rules, avoiding accidents, and making friends). The developmental systems (DS) model (25,26) describes family adaptive functioning as the ability of a family to carry out specific functions that can improve child outcomes. The three components of family adaptive functioning are parent-child interaction (e.g., verbal commenting on child play, responsiveness to child initiations, positive physical play), family-orchestrated child experiences (e.g., holiday celebrations, meal time, leisure activities), and child health and safety functions (e.g., medical care, regular sleep patterns, monitoring child whereabouts). Consistent with the DS model, personal characteristics of parents, such as parenting-related stress, efficacy, and psychological function can be conceptualized as having the potential to detract or support family adaptive function. Indeed, in most cases, parents are the single-most important contributors to family adaptive functioning.

The tasks involved in parenting a young child with ASD demand a higher level of family adaptive functioning than what is required for parenting typically-developing children. Parents of children with ASD are involved in identifying developmental difficulties, arranging developmental testing and diagnostic evaluations with specialists, and joining with an interdisciplinary team to implement early intervention (27). Parents who are highly stressed, overwhelmed, or under-resourced may be less likely to initiate intervention for their children, or be less able to fully engage in the learning process that early ASD intervention requires of parents (28). In contrast, parents who are well-supported and ready to learn and adapt will likely experience the best outcomes. The potential for early autism intervention to better support parents has only begun to be understood, but growing evidence—presented in the following sections—suggests that positive impacts of intervention on parent and family functioning could further improve child outcomes.

# **ASD** intervention for young children: impact on parents

### Early intensive behavioral intervention (EIBI)

Research has demonstrated that EIBI can lead to improved outcomes for children with ASD, but a less well-understood set of findings suggests that parents may also benefit from their child's participation in EIBI. Studies using a multiple baseline design provided initial evidence of a positive effect for many parents, including increased parental knowledge, skills, and performance (29-31).

We are not aware of any randomized controlled trials that evaluate the secondary effect of child-focused comprehensive EIBI on parents. However, in a communitybased intervention sample of 65 families with preschoolage children with ASD from the United Kingdom, more intervention hours were associated with a greater improvement in parent stress. Interestingly, when parents reported lower levels of parenting stress, higher intensity intervention was associated with improved intervention outcomes for children in the domains of intellectual and educational functioning. Children demonstrated fewer gains when parents reported higher levels of parenting stress (23). Mothers reported lower depression scores when their children were receiving more EIBI hours; however, when these mothers provided more EIBI hours themselves, they reported higher levels of personal strain (32). These data suggest that the intensity of the intervention and delivery mode (i.e., provider or parent-delivered) may moderate the impact on parent stress and family adaptive functioning.

Parent outcomes and stress levels may also differ depending on the stage of the intervention: prior to starting, in the midst of, or after it ends. Further, a recent online survey of 570 parents of children with ASD revealed intriguing correlations between parent stress and phase of intervention (i.e., not yet tried, active, completed, abandoned) (33). Specifically, parent stress was higher when children were actively engaged in intervention or had abandoned intervention than when the child had not vet tried intervention or had completed intervention. Because this was a cross-sectional, non-randomized study, interpreting these relationships is difficult. Increased parent stress when children are actively engaged in intervention may be a sign of healthy adaptive functioning or of interventions overwhelming a family's coping resources. Lower stress in the "untried" and "completed" groups could be related to general low motivation, denial, or, alternatively, to a child who is doing very well and doesn't need intervention.

In summary, although EIBI is considered the most efficacious approach to intervention for young children with ASD, the impact on parents is not yet well understood. EIBI requires a great deal of parental time and resources and has the potential to support or detract from family adaptive functioning and parent well-being. The literature to date suggests many interesting hypotheses that require testing,

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especially utilizing randomized and controlled trials, to better understand the secondary effects of EIBI on parents.

# Parent-implemented and targeted interventions

The secondary effects of parent-implemented intervention have been studied more extensively than EIBI, and the evidence suggests that this approach may have positive effects on parents. A seminal study of 28 mothers of preschool children with ASD participated in a psychoeducational parent training program or a no-treatment control (34). The treatment consisted of parents and therapists working together to develop an early intervention program using behavior modification and educational techniques for the parents to deliver in the home. Mothers in the treatment group showed decreases in depressive symptoms over time. This was not a randomized trial, as mothers could choose whether or not to participate in the psychoeducational program, but it provided early evidence of secondary positive effects on parents. Recently, a non-randomized pre-post design study in Japan found that Hizen Parenting Skills Training, in which parents of children with ASD were taught to take data on behavior and use structured teaching and reinforcement, was associated with increased coping and decreased depression and anxiety (35).

We evaluated the secondary effect of a parent-implemented intervention based on the Early Start Denver Model on parent stress and sense of competence (P-ESDM) (36). The P-ESDM is a manualized intervention that provides parents with information, modelling, and direct coaching to implement strategies from the ESDM model to improve outcomes across a comprehensive range of core developmental skills (e.g., communication, socialization, adaptive functioning) with their young child with ASD (37). Participants were part of a multisite, randomized trial comparing P-ESDM (n=49) with community intervention (n=49) for children 12 to 24 months of age. The P-ESDM group reported no increase in parenting stress, whereas the Community group experienced an increase over the same 3-month period. Parental sense of competence did not differ between groups. This suggests that a parent-coaching intervention teaching parents to more effectively interact with and teach their young child with ASD may have had a secondary, positive effect on parents and helped to maintain parental adjustment in the time period soon after an ASD diagnosis.

Parent-implemented intervention studies have generally reported positive effects on parents (38). However, it is also notable that most studies report a mix of positive and null findings, particularly with regard to parent stress. A study of the effects of the Social ABCs for toddlers found parent-reported gains in self-efficacy but not a decrease in parent stress (39). Developmental Reciprocity Treatment conducted for 12 weeks with parents of preschoolers with ASD resulted in improved parent empowerment and social quality of life but did not affect parent stress (40). A non-randomized community effectiveness trial, Project ImPACT, implemented 12 weeks of parent training sessions using NDBI for ASD in children from 18 months to 8 years of age compared to community intervention as usual. No effect on parent stress or depression was found. However, baseline parent stress was negatively correlated with child social skills from baseline to 12 weeks (41). Mothers with young children with ASD and typical development who participated in an early intervention inclusion program utilizing Pivotal Response Training for at least 6 months showed reductions in stress on the Child Domain but not on the Parent Domain on the Parenting Stress Index (42). The Child Domain consists of parent ratings of child behavior and is difficult to interpret as a measure of parents stress per se. It is important to note that all studies to date have utilized parent self-report of stress, quality of life, psychological functioning, and related constructs. Parent in these studies were not blinded to intervention group assignment, and thus, these self-reports may be subject to positive bias. However, unless a study were to incorporate psychophysiological measures of stress, which have their own strengths and weaknesses, it would be challenging to escape this methodological challenge.

The way in which parent coaching is delivered may be an important consideration. In a study using a repeated reversal design with three families with 2-year-old children with ASD, clinician-directed parent training was compared to parent-clinician partnership parent training (43). Both groups were taught using Pivotal Response Training. In the partnership condition, the clinician asked for parental input, provided choices about target behaviors, and followed the parent's lead where possible. In the clinician-directed condition, the clinician chose activities and target behaviors without asking for parent input. Mothers showed decreased stress and increased confidence during parent-clinician partnership periods but not during clinician-directed periods.

Parent training programs to improve a targeted problem behavior in children with ASD, in contrast to the comprehensive parent coaching programs described above, provide parents with focused education and skills Pediatric Medicine, 2019 Page 5 of 14

specifically designed to decrease problem behavior. The first randomized trial of which we are aware to evaluate the impact of this type of program on parents compared a parent education and behavior management intervention to a parent education and counseling control for parents of children with ASD (44). Recently diagnosed children (age 2.5 to 5 years) were randomized to a parent education/ behavior management intervention or control. The active intervention included rehearsals, modeling, and homework tasks on topics such as education about ASD and available services, behavior modification techniques, skill training, and stress management for parents. The control group also received educational information but no skills training or homework assignments. Parents in both groups improved in overall mental health post-intervention and at a 6-month follow-up. The active intervention group showed a greater reduction in anxiety, insomnia, somatic symptoms, and family dysfunction at follow-up, suggesting that learning and practicing specific behavior management strategies may be important for reducing parent stress.

A recent review and meta-analysis evaluated the secondary effects of behavioral parent training to improve problem behaviors in children with ASD on parent stress and efficacy (45). Seven trials were identified that included parent stress outcomes and five trials were identified that included parenting efficacy outcomes. The meta-analysis demonstrated a small effect of parent intervention on parenting stress and no significant effect of interventions on parenting efficacy. However, when an outlying trial was removed, a significant effect on parenting efficacy was found.

The evidence from EIBI and parent-implemented interventions suggests that parents experience positive impacts from participation. However, the results are mixed and there is a need for larger, randomized trials to evaluate the secondary impact of EIBI on parents. Participation in EIBI and parent-implemented interventions demands a great deal of time, energy and resources from families. It is not always clear that parent stress decreases in families involved in early autism intervention (42). One study reported a linear relationship between mothers' personal strain and increased number of hours spent delivering early intervention to their children (32). Nonetheless, consistent with early intervention policies and best practices, efforts to involve parents in early intervention have been increasing (46-48). Thus, it is important to understand the impact of parent-delivered intervention on parents in order to develop approaches that support optimal outcomes for parents as

well as children.

# Interventions directly targeting parent stress

The significant investment of time, energy, and resources required to parent a child with ASD, including participating in interventions, has led researchers and clinicians to test the effectiveness of interventions that directly aim to reduce parenting stress and limit negative emotional, social, and health outcomes for parents. Da Paz and Wallander (49) conducted a narrative review on single- (e.g., relaxation training, positive psychology) and multi-modality [e.g., acceptance and commitment therapy (ACT), family systems therapy] interventions targeting caregiver mental health in parents of children with ASD. Results revealed medium to large effects on parenting stress, depression and anxiety; however, authors note homogeneity of samples, overall small sample sizes, and limited follow-up data beyond three months post-intervention. Similarly, Frantz, Hansen, and Machalicek (50) conducted a systematic review of interventions targeting parental well-being in parents of children with ASD. Results revealed medium effect sizes for behaviorally-based interventions and large effects for psychoeducation and mindfulness-based interventions. Both reviews noted positive findings for group and individual interventions; however, there were not enough studies to fully compare effects across delivery mode.

An increasing number of mindful parenting programs have recently been adapted for parents of children with ASD. Cachia, Anderson and Moore (51) conducted the first systematic review of mindfulness-based interventions for parents of children with ASD, demonstrating support for long-term stress reduction, increases in psychological well-being, and decreased child problem behavior. Studies using ACT training for parents of children with ASD demonstrated improvements in parent psychological flexibility and experiential avoidance, psychological symptoms such as depression, and physiological responding in the presence of aversive stimuli (52,53). Researchers have also begun to explore cultural adaptations of mindfulness-based interventions in Latinx and Thai populations (54,55) as well as family-centered treatment for Iranian parents (56).

# Moderators of the relationship between ASD intervention and parent outcomes

We have reviewed evidence that child-focused ASD interventions (EIBI, parent-implemented, and targeted) can

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have positive secondary effects on parents, and parent-targeted interventions can reduce stress and psychological distress. In this final section, we will discuss potential moderators of the impact of ASD intervention on parents in three categories—family, environmental, and parent characteristics.

### Family characteristics

#### Resources

Indicators of family resources—such as income and number of children with a disability in the home—may moderate the relationship between ASD intervention and parent/family adaptive functioning in ASD. For example, lower household income predicted higher reported levels of maternal depressive symptoms (22), whereas higher household income predicted lower parenting-related stress (57). Mothers who had one child with ASD and another child with a disability (ASD, ADHD, learning disability, or other psychiatric condition) reported higher levels of depressive and anxiety symptoms and poorer family cohesion and adaptability compared to mothers with just one child on the autism spectrum (22). Pickard and Ingersoll (58) found that parent knowledge of ASD service options partially mediated the relationship between parent socioeconomic status and ASD service use. Parents with lower socioeconomic status reported more structural barriers to accessing services, such as lack of information, parent work schedule and transportation. The parent-professional partnership has also been shown to mediate the relationship between parent education and access to services (59).

# Child characteristics

Parents face unique challenges related to characteristics of children with ASD. Unlike some other developmental disabilities, ASD impairs social relatedness, which may have a unique effect on parent stress. Many children with ASD also exhibit unusual language and communication patterns, such as stereotyped speech or language delays, and odd and ritualistic behaviors. Sleep problems affect up to 80% of children with ASD, a rate 2-3 times higher than typically-developing children. Parent sleep can be negatively affected by child sleep disturbances and associated with decreased parent quality of life (60). Problem behaviors, such as irritability, hyperactivity, and self-injury, have consistently emerged as an important child-related source of parental distress for parents of children with ASD (61-65). We investigated the relationship between behavior problems, adaptive functioning, and parent stress and psychological function

in two cohorts; preschool-aged children with ASD (18) and toddlers with ASD (66). Parents in both age groups show increased parenting-related stress as related to child problem behaviors but not in relation to decreased daily living skills.

Intellectual disability is a child characteristic that does not consistently appear to be associated with parenting stress and psychological function (67,68). Although a common assumption is that increased intellectual disability is associated with increased parent stress, some research indicates that having a cognitively lower functioning child with developmental disabilities is actually associated with lower parental distress (69). Similarly, whereas some studies find better child adaptive function is associated with maternal well-being (70,71) others find no association with adaptive skills (18,62,72).

# Spousal relationships

Positive spousal relationships may buffer the additional demands of parenting a young child with ASD; in contrast, challenging spousal relationships may exacerbate parent stress. Some studies suggest parents with a child with ASD report lower levels of marital happiness and marital intimacy compared to parents of typically-developing children or children with Down syndrome (73-77). Divorce among parents of children with ASD has been estimated to be up to 50% greater than parents of children with other developmental disabilities or typical development (78,79). However, this is not consistently reported, and some studies have found divorce and marital adjustment to be within the normal range (80-82). Decreased marital adjustment in parents of children with ASD is associated with increased parenting stress and increased child behaviour problems, suggesting a complex transactional relationship between these factors (73,83,84). Typically-developing children exposed to marital conflict may be vulnerable to behavioral, social, and emotional disturbances (85). If this holds true for children with ASD, then families with increased marital conflict may also be characterized by increased problem behaviour and parent stress, which would be important to consider when implementing intervention programs.

# Environmental characteristics

### Stressful life events

The occurrence of major life events such as the birth or death of a family member may impact family adaptive functioning by increasing stress levels in parents of children with ASD, which in turn may disrupt parenting practices Pediatric Medicine, 2019 Page 7 of 14

and parent-child interaction. Over time, increased exposure to stressful life events is likely to have an impact on parents. For example, one study following families of children with ASD across a 10-year period found that stressful family life events were associated with increased maternal anxiety, and higher depressive symptoms for younger mothers in the sample (86). The number of negative life events parents reported in the weeks prior to beginning a randomized trial of parent-delivered ESDM-based early intervention was a significant predictor of parenting stress and sense of competence across both the experimental (P-ESDM) and community intervention groups (36). However, families of children with ASD may not experience a higher quantity of stressful life events, as reported by one study of stressful events during pregnancy in families with an older child with autism vs. a typically-developing older child (87).

The association between stressful life events and poor parental outcomes may be moderated by social support and coping style (88). A daily diary study of parents of children with ASD across 12 weeks found that daily parenting stress predicted lower levels of positive mood, on average, but this relationship was moderated by coping strategies (89). Similarly, Weiss and colleagues (90) found that family hardiness (i.e., sense of control over life events and active coping orientation) partially mediated the relationship between stressful life events and family distress. Prior exposure to negative life events may also impact parental ability to cope with the daily stress of parenting a child with ASD. One study measuring waking cortisol found that mothers who had experienced more negative life events showed an abnormally blunted cortisol response to daily stressors (91). These findings suggest that each family's unique set of risk and resilience factors will shape the extent of the impact of stressful life events (ASD-related or otherwise) on their family adaptive functioning.

#### Social support

Social support has repeatedly been shown to correspond with outcomes for parents of children with ASD. Parents who endorse lower levels of social support report increased stress (92) and higher rates of depression and anxiety (93,94), as well as decreased quality of life (95-97). Smith, Greenberg, and Seltzer (98) showed that social support predicted parent well-being above and beyond child problem behavior. A complex transactional relationship between increased broader autism phenotype characteristics in parents, lower social support and higher rates of depression and stress has been reported (99). Social support

was also shown to mediate the relationship between child symptom severity and parenting stress and depression (99).

Social support can derive from multiple sources, each of which may contribute to parent outcomes (100). Many caregivers seek social support online, and parents view the internet as a source of emotional and informational support (101,102). Ekas, Lickenbrock and Whitman (94) compared various sources of social support (i.e., from partner, family, and friends) for mothers of children with ASD and showed that optimism was positively related to all sources. Increased network size has been shown to correspond with increased perceived support (95) and psychological wellbeing in mothers of adolescents and adults with ASD (98). Furthermore, both positive and negative support from these networks directly influenced caregiver outcomes.

Understanding the effects of quantity, quality, and valence of social support will be important for optimizing parent outcomes. Cultural norms should also be considered (103). For example, certain cultures may discourage parents from seeking support due to negative collective beliefs about children with developmental disabilities (104,105). However, several studies have reported similar benefits of social support across cultures. Lin *et al.* (106) compared mothers of children with ASD in the US and Taiwan, finding that the two groups did not differ significantly in their reported level of social support. These results suggest that while cultural norms may encourage parents in some countries to seek social support more than others, the protective effects of social support may have universally beneficial effects.

#### Parent characteristics

The central role of parents in early autism intervention means that identifying parent-related facilitators and barriers to intervention may be just as important as understanding family and child characteristics that moderate intervention success.

# Dispositional optimism and expectations for intervention

A number of studies have reported that dispositional optimism in parents confers resilience to parenting-related stress. Optimism is considered to be a key resilience factor in predicting maternal adaptation to pediatric illness (107). Optimism has also been associated with less distress and greater resiliency in working mothers who do not have children with disabilities (108). Greenberg and colleagues (109) investigated the role of dispositional

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optimism in mothers of adults with Down syndrome, schizophrenia and ASD. They found that optimism was related to better mental and physical health across all groups and mediated the relationship between the quality of the mother/child relationship and maternal well-being. Optimism also appears to be closely related to other resilience factors such as social support. Some authors have shown that higher social support is associated with increased optimism (96), and others describe the relationship in the opposite direction—increased optimism leading to greater social support (107,110). In reality, this relationship is likely to be bidirectional: parents who feel more supported may be more hopeful for the future, and parents who are more optimistic may have an easier time enlisting and benefitting from help provided by social support networks. Indeed, optimism's association with employing effective coping strategies may help explain its role as a resilience factor for parents of children with ASD (111,112).

Considered in the context of ASD intervention, dispositional optimism may moderate outcomes by influencing parent expectations about the effectiveness of intervention. Parent expectations of what they hope to achieve through intervention range widely, from specific incremental goals (e.g., eat a broader range of foods) to more general and vague goals (e.g., achieve "normal") (113,114). Parents consider perceived efficacy of interventions when making decisions about which interventions to pursue (115). Once enrolled in interventions, expectations may influence both child and parent outcomes. For example, in a placebo-controlled trial of intranasal oxytocin treatment, parents who believed that their child received active treatment vs. placebo reported greater improvements in their child's symptoms (24). Beliefs or expectations of positive outcomes for children with ASD or developmental delays have been also associated with lower parent stress (116,117). Taken together, these findings suggest that parental optimism and expectations for improvement through intervention may directly influence parental health and well-being, with potential carryover effects to improved child outcomes.

#### Coping strategies

In an effort to respond to the stressors associated with parenting a child with ASD, parents employ a variety of coping strategies. Applying Lazarus and Folkman's stress and coping theory (118) to families of children with ASD, researchers have generally found that parents who use higher rates of problem-solving coping strategies and lower rates of emotion-focused coping strategies have improved

outcomes (13,22,119). Furthermore, the use of coping strategies may moderate the relationship between stressors and psychological distress (119). However, some argue that this classification system may be an oversimplification and call for research to consider the unique context posed to families of children with ASD as well as cultural considerations (120-122). Hastings and colleagues (120) and Benson (121) completed factor analyses within samples of parents and mothers of children with ASD and showed evidence for four main coping dimensions. Benson (122) also examined the longitudinal effects of four coping strategies (i.e., engagement, disengagement, distraction, and cognitive reframing) on maternal outcomes. Increased use of engagement strategies (e.g., problem-focused coping) corresponded to reduced distress; increased cognitive reframing and engagement strategies led to increased parent efficacy; and engagement, disengagement, and distraction strategies were linked to increased stress.

Exploring coping strategies used by parents in different cultures yields important considerations for future research. Within their review of Asian families of children with intellectual and developmental disorders, Ghosh and Magana (104) call for the inclusion of appraisals when studying different coping mechanisms used by parents in different cultures. For example, in China, active avoidance may be an effective strategy given the negative cultural implications of having a child with a disability and help the parent "save face" (123). Similarly, in an Arabic sample of parents of school-age children with ASD, researchers found that social support and escape avoidance moderated the relationship between parenting stress and quality of life, such that more avoidance and social support led to higher quality of life (124). Several researchers have adopted the strategy of analyzing qualitative interview responses to better understand the variation of coping strategies across ethnic groups [e.g., Taiwanese families (125); firstgeneration Southeast Asian-American families (126)].

# **Conclusions**

A variety of factors contribute directly and indirectly to family adaptive functioning, but parents are typically the most important contributor. Parents of children with ASD consistently report elevated levels of parenting-related stress and psychological distress, even when compared with parents of children with other types of developmental disabilities. From a resiliency standpoint, parents of children with ASD also often endorse positive psychological

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functioning and effective coping strategies. Confronting new challenges and achieving incremental victories are characteristic of the parenting experience in families of children with disabilities. When designing empirical studies and interventions for children with ASD, it remains critically important to consider the potential threats and supports to family adaptive functioning, including socioeconomic status, spousal relations, availability of social support, coping strategies, and specific child characteristics.

Research on the relationship between parent factors (e.g., parenting-related stress) and child-focused interventions (e.g., EIBI, parent training) is still in the early stages, and presents a number of challenges given the transactional nature of the relationship between child behaviour, response to intervention, and parent and family adaptive functioning. More work is needed to understand the characteristics of intervention approaches that support family adaptive functioning (e.g., intensity, delivery mode) and the factors that result in parents becoming effective advocates for their children (28). However, the existing literature already suggests potential intervention targets (e.g., child problem behavior, parent expectations) and intervention approaches (e.g., parent-clinician partnership) that may improve family adaptive functioning. Interventions that directly target parent well-being also have the potential to improve outcomes when delivered alongside child-focused interventions. Taken together, there is strong evidence that a child's treatment can have positive impacts on parents. Continued research and clinical innovation is needed to ensure that EIBI and parent-implemented interventions are optimally designed to improve family adaptive functioning and lead to better outcomes for children with ASD and their families.

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#### **Footnote**

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

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