Clin Child Fam Psychol Rev (2012) 15:247–277
DOI 10.1007/s10567-012-0119-6

Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation

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Abstract Raising a child with an autism spectrum disorder (ASD) can be an overwhelming experience for parents and families. The pervasive and severe deficits often present in children with ASD are associated with a plethora of difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. In addition to significant financial strain and time pressures, high rates of divorce and lower overall family well-being highlight the burden that having a child with an ASD can place on families. These parent and family effects reciprocally and negatively impact the diagnosed child and can even serve to diminish the positive effects of intervention. However, most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy. It cannot be assumed that even significant improvements in the diagnosed child will ameliorate the parent and family distress already present, especially as the time and expense of intervention can add further family disruption. Thus, a new model of intervention evaluation is proposed, which incorporates these factors and better captures the transactional nature of these relationships.

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Keywords Autism spectrum disorders · Parents · Caregivers · Families · Intervention

Introduction

Autism spectrum disorders (ASD) represent a spectrum of complex, neurological, and developmental disorders characterized by deficits in reciprocal social interaction and communication, along with the presence of restricted, repetitive, and stereotyped interests and behaviors. These deficits manifest in early development and are pervasive in nature, affecting individuals throughout their lifespan. The impairments germane to ASD not only affect the diagnosed individual but also his or her caregivers, family, teachers, and community. The current prevalence rates of ASD are estimated at approximately one in 88 children in the United States (Center for Disease Control and Prevention 2012). The rate of ASD diagnoses in the United States and elsewhere has shown a sharp increase in the past three decades (Lord and Bishop 2010), and much of the research has thus been dedicated to developing better understanding of biological and genetic markers related to the etiology and manifestation of ASD. However, research on interventions designed to help individuals with ASD and their families has been comparatively more limited. Further, intervention literature to date has demonstrated some significant limitations, including small sample sizes, a lack of randomized, controlled trials, and disagreement over appropriate outcome measures (Lord et al. 2005; Odom et al. 2010; Rogers and Vismara 2008; Smith et al. 2007). One additional, notable limitation has been the exclusion of assessing how ASD treatments impact parents and families, who often take on a crucial role in the intervention process. This review will examine how parents and families are affected by having a child with ASD, the role they play in various intervention modalities, the effects these interventions have on caregivers and siblings, and how changes in parents and families reciprocally affect children with ASD. We will propose that it is essential for ASD intervention studies to include parent and family outcomes to fully understand the effectiveness of treatment.

Impact of ASD on Parents and Families

The effects of having a child with an ASD on parents and families are, like the disorder itself, multifaceted and pervasive. Approximately 85 % of individuals with ASD present with cognitive and/or adaptive limitations that limit their ability to live independently, leading to the possibility that they will need some measure of care or assistance from their parents and families for the duration of their lives (Volkmar and Pauls 2003). In Seltzer et al. (2001) longitudinal study of parents of children with developmental disabilities, over 50 % of parents aged 50 or older indicated that they still lived with their child, compared with a rate of 17 % for typically developing children. The lifelong burden often placed on parents and siblings of children with ASD likely exacerbates the difficulties encountered by families of children with ASD, may alter caregivers' perception of parenting, and likely decreases optimism about their own future, as well as the future of their affected child. In addition, the understanding and conceptualization of ASD is rapidly and continuously changing (Rutter 2011). As a result, families of children with ASD are faced with a disorder for which etiology is unclear and optimal treatment is contested. These families are thus often left navigating a complex and ever-changing course, all the while knowing that delays in accessing services could lead to poorer treatment outcomes.

Caregiver and family distress related to ASD typically begins long before a formal diagnosis is provided. Parents of children later diagnosed with an ASD report early concerns regarding differences in social behavior, communication, play, and motor skills within the first 6 months of age, with most parents reporting specific concern about ASD at around 18 months (Bolton et al. 2012; Howlin and Asgharian 1999). However, the actual time parents are informed of an Autistic Disorder diagnosis for their child often comes much later, when the child is approximately 3.1 years of age, with an average of 7.2 years of age for a diagnosis of Asperger Syndrome (Mandell et al. 2005). Parents of children with ASD often express relief following the diagnosis, which can help them better understand their child's difficulties (Midence and O'neill 1999). However, Chamak et al. (2011) reported that approximately 63 % of parents expressed dissatisfaction with the way the diagnosis was announced. The experience of the diagnosis itself likely contributes to the way in which parents make sense of their child's disability, and Shyu et al. (2010) found that the way in which parents explained their child's deficits impacted their personal well-being, their child's functioning, and the treatment methods chosen by the family. Parental understanding and explanation of deficits is likely correlated highly with the way ASD is explained to them by treatment professionals (e.g., Pediatricians or Psychologists). However, no research to date has examined how specific explanatory styles or methods at the time of diagnosis impacted parent and family functioning or coping from that point forward. Evaluating these areas seems particularly important given the broad and ever-changing perspectives within the scientific community on the etiology of ASD and optimal treatment methods for children with ASD (Lord and Bishop 2010).

Raising and supporting a child with an ASD appears to have negative effects on parents and families regardless of the severity of symptomatology or the time since diagnosis (Pottie and Ingram 2008). Ekas et al. (2010) noted that core symptoms, associated symptoms, and behavior problems associated with ASD all contributed significantly to negative maternal well-being, with approximately 12 % of the variance in well-being explained by children's ASD deficits. Given the variability in ASD presentation, it is important to explore specific domains affected by having a child with ASD to gain deeper understanding of what deficits/behaviors contribute to each particular area of impact. In doing so, we can later more thoroughly examine the relationship between interventions for ASD (which vary greatly in objective, form, and level of parent involvement) and the parent and family outcomes of these treatments. Ultimately, better understanding of these relationships will help shape the development of intervention and improve the scope of studies evaluating the outcomes of therapies for ASD.

Effects of ASD on Parents

Parental Self-Efficacy

It appears important to understand caregivers' belief in their own ability to effectively parent their child, or parenting self-efficacy (PSE), regardless of the presence of a disability. In part, this construct may impact actual parenting behaviors, as a review of PSE in parents of typically developing children by Jones and Prinz (2005) suggested that PSE predicts the level of parenting competence. These authors further stated that "parents with higher PSE tend subsequently to demonstrate more effective parenting even in the face of challenging child behavior" (Jones and Prinz 2005, p. 358). The importance of PSE discussed in Jones and Prinz's review warrants consideration of how this construct is affected by having a child with an ASD. If negative effects exist, it is crucial to understand how they impact children with ASD and the services they receive, as well as how they contribute to further difficulties for parents, as PSE has been associated with increased levels of parenting stress in parents of children with disabilities (Giallo et al. 2011). Parenting self-efficacy may be uniquely affected by having a child with ASD for several reasons. Parents with broader autism phenotype (BAP) or sub-threshold characteristics of autism often seen in parents of children with ASD (Losh et al. 2008) may lack confidence in helping their child address difficulties that they also experience (e.g., social anxiety or difficulties with nonverbal communication). Further, the debate over ASD etiology and definition, in conjunction with the plethora of interventions available for ASD, often leaves parents feeling unsure and confused about the optimal course of treatment for their child (Mackintosh et al. 2012). In addition, Sofronoff and Farbotko (2002) noted that the delay in diagnosis (which, with Asperger syndrome, can extend into the teenage years) often means parents of children with ASD have been using ineffective parenting strategies for long periods of time, leaving themselves frustrated and doubtful of their own parenting abilities. Finally, PSE may be uniquely affected in parents of children with ASD due to the child's lack of reciprocal social communication, a hallmark deficit of autism. Parents may feel less able to meet the emotional wants or needs of their children with ASD, who are often unable to fully express such needs due to impairments in both verbal and nonverbal communication.

Sofronoff and Farbotko (2002) emphasized the importance of targeting PSE in parents of children with ASD in their investigation of a parent management training program designed to increase parents' self-efficacy. They found that parents in a 1-day workshop and parents attending individual treatment sessions both reported increased self-efficacy compared with control groups, with significantly greater improvement seen in maternal caregivers (Sofronoff and Farbotko 2002). In addition, Keen et al. (2010) reported that a parent-focused intervention led to greater improvement in PSE relative to a self-directed intervention. These findings suggest that PSE in parents of children with ASD is malleable and amenable to brief, targeted intervention. Sofronoff and Farbotko also found that parents reported fewer child behavior problems post-intervention, suggesting that increases in PSE in parents of children with ASD can have a direct impact on the diagnosed child. Overall, however, there is a paucity of research specifically examining parents of children with ASD with respect to parenting self-efficacy. Some early research (e.g., Gowen et al. 1989, as cited in Hastings and Brown 2002; Haldy and Hanzlik 1990, as cited in Hastings and Brown 2002) suggested that parents of children with developmental delays showed increased parenting competence in comparison with parents of typically developing children, but did not relate competence to perception of efficacy.

In a study of mothers of children with ASD, Kuhn and Carter (2006) found that decreased sense of agency and increased feelings of guilt in parents were both correlated with lower PSE. Parental agency was conceptualized as "the extent to which a mother assumes an active role in her child's development, engages in interactions with her child, and persists in identifying strategies that minimize maladaptive child behaviors and maximize adaptive behaviors" (Kuhn and Carter 2006, p. 565). Kuhn and Carter noted that agency and guilt contributed significantly to diminished PSE beyond other factors such as depression, parenting stress, the amount of time since the child's diagnosis, and whether another child in the family had a disability. It also appears that there are differences between maternal and paternal caregivers of children with ASD with respect to parenting efficacy. Hastings and Brown (2002) found that PSE acted as a mediator for mothers between child misbehavior and maternal anxiety and depression, while for fathers, PSE was found to moderate the relationship between child behavior problems and paternal anxiety. The relationship between parental knowledge about ASD and PSE appears important given the complexity of the disorder, but research in this domain has been limited. Kuhn and Carter (2006) found that autism-related knowledge was not significantly correlated with maternal self-efficacy, though they indicated that limitations in their measure of autism knowledge, along with a homogenous sample, provided insufficient variance to confirm the lack of a relationship between these constructs. These researchers noted a positive association between autism-related knowledge and time since diagnosis, implying that parents continued to improve their own knowledge about ASD following diagnosis. Mackintosh et al. (2012) noted that parents continue relying heavily on the internet for information about their child's disorder. However, it is unclear what effect, if any, enrollment in any type intervention had on parent's knowledge of ASD. Taken in sum, there are many reasons to believe that parents of children with ASD suffer from decreased PSE, though no longitudinal studies to date have confirmed this hypothesis. However, given that increases in PSE through interventions such as that by Sofronoff and Farbotko (2002) seem to positively impact parents and their children with ASD, it seems important to take this variable into account in understanding the overall impact of having a child with ASD on parents and families.

Parenting Stress

One of the most widely examined areas of impact regarding parents of children with ASD is parenting stress, broadly conceptualized as strain, pressure, and tension revolving specifically around the task of parenting (Rao and Beidel 2009). Parents of children with ASD experience higher levels of parenting stress than parents of typically developing children (e.g., Duarte et al. 2005; Hoffman et al. 2009; Rao and Beidel 2009) as well as parents of children with other types of developmental delay or special health care needs (e.g., Estes et al. 2009; Schieve et al. 2007; Schieve et al. 2011). Factors contributing to parenting stress in caregivers of children with ASD include the child's cognitive impairment, externalizing behavior problems and internalized distress, disturbed mood or irritability, functional dependence, hyperactivity, noncompliance, lack of self-care abilities and low adaptive functioning, language deficits, learning disability, imposed limits on family opportunities, need for care across the lifespan, inappropriate eating, toileting, and sexual expression, broad social difficulties, and high likelihood of remaining in the home (Bebko et al. 1987; Brown et al. 2011; Gray 1994; Hall and Graff 2011; Ingersoll and Hambrick 2011; Koegel et al. 1992a, b; Lecavalier et al. 2006; Lee et al. 2008; Little and Clark 2006; Lyons et al. 2010; Tomanik et al. 2004). Though cognitive impairment was once identified as one of the greatest contributors to elevated parenting stress (e.g., Bebko et al. 1987), Davis and Carter (2008) found that cognitive deficits did not contribute uniquely to variance in parenting stress when assessed along with other child characteristics. Further, Rao and Beidel (2009) noted that higher intellectual functioning in "high-functioning" children with ASD did not ameliorate high levels of stress in parents. Davis and Carter (2008) and Tomanik et al. (2004) both suggested that neither deficits in language and communication nor stereotyped behaviors contributed significantly to parenting stress, despite these two categories representing two of the core deficits of ASD. These findings lend support to the notion that the unique combination of emotional, functional, and behavioral problems common in children with ASD, in conjunction with the pervasive and often severe impact of the disorder, affect parents more than the "core symptoms" of autism, per se. Thus, the targets of ASD interventions (i.e., functional difficulties vs. symptoms) may be important to consider when assessing how treatments impact parenting stress.

With respect to parent gender, mothers of children with ASD appear to suffer from increased levels of parenting stress compared with fathers (Davis and Carter 2008; Herring et al. 2006; Little 2002; Sharpley et al. 1997; Tehee et al. 2009) and were found to perceive higher levels of stress for other individual family members and for their family as a whole (Little 2002). Bebko et al. (1987) noted interaction effects between parent gender and child age, with mothers of older children with ASD showing lower stress levels, while father's stress remained consistent throughout childhood. These researchers suggested that this decrease in stress might represent a relationship between parenting stress and the "acceptance" of ASD deficits, at least in maternal caregivers. Hastings (2003) indicated that maternal stress was related not only to child difficulties but also paternal mental health (i.e., the mental health of the other caregiver), while fathers' stress did not appear to be directly affected by maternal mental health. However, Tehee et al. (2009) found that mothers of children with ASD demonstrated increased levels of parental involvement compared with fathers. The amount of parental involvement exhibited by caregivers was correlated with parenting stress, and it has been proposed that parenting involvement may partially or fully mediate the relationship between parent gender and stress (Tehee et al. 2009). These findings suggest a need for more detailed understanding of how parents divide care responsibilities for their children with ASD and how this division of caretaker tasks affects parent mental health. Mothers and fathers may also differ in terms what child characteristics contribute most to their parenting stress, with respect to both etiology and severity (Davis and Carter 2008). Davis and Carter (2008) found that child emotional dysregulation contributed significantly to maternal stress, while fathers were impacted by their child's maladaptive externalizing behaviors. Deficits in social relatedness contributed significantly to both maternal and paternal stress (Davis and Carter 2008).

Though the extent to which any particular construct contributes to parenting stress likely changes over the course of the child's development, Lecavalier et al. (2006) found that, overall, stress levels in parents of children with ASD are stable over time. Several researchers have found parenting stress to be significantly impacted by the type of coping strategies utilized and the extent of social support received by parents (Lee et al. 2008; Lyons et al. 2010; Pottie and Ingram 2008; Tehee et al. 2009; Weiss 2002). Parenting stress seems to also be affected by parental dysphoria and by whether parents put off or give up life plans and/or become isolated from family and friends (Wolf et al. 1989). Further, there appears to be a relationship between parenting stress and BAP (Ingersoll and Hambrick 2011). Ingersoll and Hambrick (2011) found that parents expressing BAP were more likely to use poor coping strategies and less likely to use more adaptive techniques for coping with stress and also received decreased social support. Importantly, the use of maladaptive coping was found to partially mediate the relationship between parent BAP and parenting stress. Further, Ingersoll and Hambrick found that social support partially mediated the relationship between child symptom severity and parenting stress. A recent increase in both genetic and psychological testing for BAP will help to better understand how ASD-related parent characteristics impact their ability, either positively or negatively, to raise a child with autism. Parents with BAP could identify with their child's difficulties more easily, or conversely, struggle to help their child overcome certain deficits that are also areas of personal weakness.

Parent Mental and Physical Health

Along with effects on parenting self-efficacy and stress, raising a child with an ASD appears to contribute to a general decrease in parental well-being and increase in mental health concerns (Ekas et al. 2010). Researchers have identified elevated levels of parent mental health problems, particularly depression and anxiety, in comparison with both parents of typically developing children and parents of children with other developmental disabilities (Benson and Karlof 2009; Carter et al. 2009; Gau et al. 2011; Kelly et al. 2008; Olsson and Hwang 2001; Sawyer et al. 2010). Singer (2006) employed planned comparison techniques in a meta-analysis of studies assessing depression in maternal caregivers of children with and without developmental disabilities and found significantly higher effect sizes for parents of children with ASD than other groups assessed (i.e., parents of children with other types of developmental concerns). Further, Davis and Carter's (2008) assessment of maternal and paternal caregivers of 54 children with ASD suggested 33 % of mothers and 17 % of fathers were in the clinical range for depression, with 6 % of both groups reporting clinically significant anxiety symptoms, while Davis and Carter found that between 28 and 42 % of mothers of children with ASD attained depression scores in the clinical range even in a sample of educated mothers without significant socioeconomic challenges. The mental health effects of having a child with ASD may not be limited to depression and anxiety, as a large study by Gau et al. (2011) indicated that, compared with parents of children without developmental concerns, parents of children with ASD in Taiwan demonstrated increased obsession-compulsion, interpersonal sensitivity, hostility, schizoid traits, paranoia, and schizophrenia. Though these results were correlational and have not been replicated universally, they highlight important concerns regarding the overall mental health status of the parents of children with ASD. Researchers have also found that mothers of children with ASD experience higher levels of overall distress and reported lower quality of life than mothers of children with intellectual disability (ID) without autism (Mugno et al. 2007; Olsson and Hwang 2001), as well as those with children with Cerebral Palsy and a typically functioning control group (Mugno et al. 2007). Results of a survey of 219 parents of children with ASD by Sharpley et al. (1997) found that just under 30 % of these parents were experiencing moderate to severe levels of anxiety while just under 20 % were experiencing clinically significant levels of depression. Further, 80 % of these parents reported sometimes feeling "stretched beyond their limits" (Sharpley et al. 1997, p. 3). Parents of children with ASD reported that dealing with child behavior problems was the greatest contributor to feelings of anxiety and depression, while both family support and PSE contributed to more positive parent mental health (Sharpley et al. 1997).

Similar to parenting stress, gender differences have emerged among parents in terms of mental health concerns. Olsson and Hwang (2001) noted that both mothers of children with ASD and those with another developmental disability experienced significantly greater distress than fathers of children with ASD, whose depression scores fell in the "normal" range compared with the general population. In a study of married couples that had a child with an ASD, Hastings (2003) reported that mothers experienced higher anxiety levels than fathers. However, in contrast to most other studies, Hastings (2003) indicated that mothers expressed similar levels of depression as fathers. Hastings also suggested that mothers were more affected by the health and functioning of their child and spouse than were fathers. However, it has also been noted (Olsson and Hwang 2001) that single mothers of children with ASD experienced more distress than those living with a partner. This relationship was not explained by socioeconomic status (which was not associated with distress), suggesting that the presence of paternal (or other) caregivers impacts the relationship between raising a child with ASD and maternal depression.

As with parenting stress, the mental health effects of parenting a child with an ASD are largely contingent on specific parent and child characteristics. In a longitudinal study ranging from toddler age to early childhood, Carter et al. (2009) found depressive symptoms in mothers of children with ASD to be stable over time. However, these researchers noted individual variability based on parental anxiety, efficacy, coping style, and social support and cited child behavior problems and competencies as contributing to elevated levels of depression. Benson (2006) found a relationship between parental depression and child symptom severity as well as between depression and stress proliferation, defined as "the tendency of stressors to engender additional stressors in other life domains" (Benson 2006, p. 685). Similarly, Herring et al. (2006) suggested that children with ASD's behavioral and emotional functioning contributed more to parent mental health problems than the child's specific diagnosis or gender. Further, it may be important to understand how parental personality contributes to parental distress, as Yamada et al. (2007) found that maternal emotional distress was correlated with mothers' own neuroticism and agreeableness. This finding further suggests that caregivers' personality characteristics are important to consider in understanding the impact of children with ASD on parent mental health. A recent study by Meltzer (2011) also noted that, in addition to child behavior problems, sleep quality of both children and fathers predicted maternal depressive symptoms in families of children with ASD.

Parents of children with ASD also reported higher levels of fatigue (Smith et al. 2010a, b) and greater physical health impairment than parents of both typically developing children and children with ID (Allik et al. 2006; Mugno et al. 2007). Though the mechanism for physical health impact is not entirely understood, it is likely that the high levels of demands placed on parents of children with ASD take a toll in terms of both physiological and mental fatigue. Gender differences again emerged in the domain of physical health, as mothers of children with an ASD reported worse physical health (in conjunction with decreased psychological well-being) than fathers (Allik et al. 2006). However, the directionality of both physical and psychological symptom differences between parents of children with ASD and those of typically developing children is unclear. Prenatal environmental and genetic factors (Larsson et al. 2004), parental psychopathology (Larsson et al. 2004), and substance use or abuse (Miles et al. 2003) have all been identified as risk factors for having a child with an ASD and are also correlated with an increase in physical health concerns. Thus, it could be that the relationship between having a child with ASD and increased physical health concerns is explained by a third variable such as substance use or harmful environmental exposure. Future research in this domain should elaborate on the primacy of physical health symptoms, as well as the association between impaired physical health and the lack of self-care by parents due to limitations in time and financial resources.

Parent–Child Relationship

One domain in which parents of children with ASD appear to maintain relatively healthy functioning is the quality of their relationship with their child. Montes and Halterman (2007) reported that, despite increased stress levels and diminished quality of communication, mothers of children with ASD reported higher levels of relationship closeness with their child compared with mothers in the general United States population. Further, mothers of children with ASD did not differ from mothers of typically developing children on a measure of emotional closeness with their children (Hoffman et al. 2009). Hoffman and colleagues' finding, which was derived from the "Attachment" subscale of the Parenting Stress Index (PSI), was in contrast to significant differences found between mothers of children with ASD and mothers of typically developing children on all other PSI subscales, in which parents of children with ASD reported higher levels of stress. For both "ASD" and "typically developing" groups, it was suggested that higher levels of problem behavior contributed to decreased closeness. For parents of children with ASD, attachment was also negatively impact by severity of ASD symptoms. Though ASD-specific symptoms appeared to contribute to less variance in attachment than behavioral problems when assessed via a hierarchical multiple regression (Hoffman et al. 2009), the typology of behavior problems exhibited by children with ASD is still often unique in their pervasiveness, co-occurrence, and severity.

Hoffman et al. (2009) hypothesized that the diagnosis of ASD itself may actually serve as a protective factor in the parent–child relationship, in that parents view the child as less responsible for his or her behavior. In support of this theory, Montes and Halterman (2007) found that parents of children with ASD were less likely to be angry with their child, despite reporting that they were bothered by their child's behavior. Additionally, Whittingham et al. (2008) found that parents of children with ASD attributed most of their child's misbehavior to ASD symptoms, rather than their child's personality or temperament. However, Hoffman et al. also noted that parents might blame themselves, rather than their child, for any misbehavior, which in turn could contribute to decreased parenting efficacy and well-being. Further, Gau et al. (2011) suggested caution in interpreting high levels of parent–child relationship closeness (or family cohesion) as inherently positive, noting that it could represent enmeshed, or overly close, dyadic relationships between one or both parents and the child with an ASD, which could have a negative effect on siblings and/or the family as a whole. Baker et al. (2011) found that mother–child relationship quality was not predictive of change in maternal symptoms of depression or child behavior problems, but did not explore concepts such as self-efficacy or parenting stress. More thorough understanding of parent adaptability, relationship cohesion, and dyadic relationship satisfaction is needed to understand the interplay between these constructs.

Parenting behaviors of caregivers of young children with ASD also appear to be comparable to those of parents with typically developing children. Siller and Sigman (2002) found that caregivers of children with ASD did not differ from parents of children with other developmental delays or typically developing children in their ability to synchronize both verbal and nonverbal behavior with their child's attention and activity. Siller and Sigman noted that maintaining synchronization is a more difficult task when playing with children with ASD, who often provide less overt social cues as to their interest. The ability to synchronize with children with ASD appears important, as children of parents with higher ratings of synchronization showed increased communication skills over long-term (1, 10, and 16 year) follow-up. However, when using a measure of parent responsiveness and affect (The Maternal Behavior Rating Scale), Kim and Mahoney (2004) found that mothers of children with developmental disabilities did not perform as well as parents of typically developing children, suggesting that emotional responsiveness may be more affected than behavioral responsiveness in parents of children with ASD. The lack of affective reciprocity from children with ASD may be more harmful for parents than cognitive or behavioral limitations, and more detailed understanding of this distinction appears important.

Two factors that may moderate the relationship between child emotional response and parenting practices are parental attitude and emotional control within the scope of their interactions with their child. Mindful parenting practices, emphasizing a "clear, calm mind that is focused on the present moment" (Singh et al. 2006, p. 170) have been found to decrease aggressive behavior, noncompliance, and self-injury in children with ASD and are also associated with increased maternal satisfaction with parenting skill and child interaction. Gender differences in the parent–child relationship in autism have been identified. Hartley et al. (2011) found that mothers reported closer relationships with both adolescent and adult children with ASD than fathers, despite similar self-reported levels of parenting burden. They also noted that fathers' parenting experiences were impacted more by specific child characteristics, including child age (fathers reported an improved relationship from adolescence to adulthood) and the amount of time the child spent in the home (improved paternal relationships were associated with decreased child time in the home).

Effects of ASD on Family System

Marital Impact

The impact of having a child with an ASD extends beyond caregivers to the entire family system. The increase in parenting stress, conflict, and child behavior problems contributes to a higher rate of divorce for parents of children with ASD than in families of children with typically developing children (Brobst et al. 2009; Freedman et al. 2012; Hartley et al. 2010). Hartley et al. (2010) found divorce rates of families with children with ASD to be almost twice as high as in families with typically developing children, which they noted is similar to effects seen in families of children with attention-deficit/hyperactivity disorder (ADHD). Hartley et al. also noted an extended period of risk for divorce for parents of children with ASD, which persisted beyond early childhood into the child's early adulthood. This extended risk period is likely due to the continued parenting stress and unique demands placed on parents of adolescents and young adults with ASD, including the high likelihood that they will remain in the home. Kelly et al. (2008) noted that family conflict was predictive of ASD symptomatology and found that negative family relationships influenced ASD symptom manifestation more than positive family interactions. These findings suggest that, despite lower levels of social awareness, children of ASD may pick up on and are negatively affected by parent conflict. Even for parents who remain married, having a child with an ASD is associated with decreased marital satisfaction compared with married parents of typically developing children (Brobst et al. 2009; Gau et al. 2011). Contributing to decreased marital satisfaction in parents of children with ASD are lower dyadic consensus, or agreement between parents, and lower levels of positive affective expression compared with parents of typically developing children (Gau et al. 2011). In a recent study, Hartley et al. (2011) suggested that marital satisfaction significantly impacts the parenting experience of parents of children with ASD, especially for fathers (who were also more affected by their child's symptom severity. Marital satisfaction also appears to impact the sibling relationships of children with ASD (Rivers and Stoneman 2003), demonstrating ways in which the deficits of ASD can reverberate throughout the family system.

Sibling Impact

The impact of having a sibling with an ASD has been subject to even less investigation than that of having a child with autism. Most typically developing siblings report positive relationships with their sibling with an ASD (Rivers and Stoneman 2003), despite potentially dealing with decreased parental attention as well as their siblings' poor communication skills, limited social interaction and reciprocity, and embarrassing or difficult public behavior. These children may in some way benefit from being able to be a teacher or social mediator for their sibling with an ASD (Rivers and Stoneman 2003). However, the initially close sibling relationship appears to deteriorate over time, as typically developing children were more likely to report close relationships when their sibling with an ASD was younger. Parents of children with ASD were somewhat less positive about the sibling relationship between the unaffected child and child with an ASD than the sibling themselves (Rivers and Stoneman 2003). Further, parents have been found to overestimate the extent to which their unaffected children understand the impact of their sibling's disorder on the family, and as a result it has been suggested that siblings may internalize blame for family difficulties (Glasberg 2000).

Family Resources and Quality of Life

In addition to the emotional burden of caring for a child with an ASD, families typically face a multitude of practical demands. These demands include continuous time pressures, significant financial burden, the need to provide support and accommodations for their child's education, greater investment in healthcare and greater delays in accessing medical care, increased necessity for vigilant parenting, constant self- and child-advocacy, fewer opportunities to work, and often the presence of one or more therapists in the home (Lord and Bishop 2010; Morrison et al. 2009; Pakenham et al. 2005; Woodgate et al. 2008). Lord and Bishop (2010) cited recent estimates of economic impact on families of raising a child with an ASD at approximately three to five million dollars more than a typically developing child, a figure that increases significantly when the child with an ASD also has a severe cognitive impairment. Even when federal or state programs are in place to mitigate the financial burden on families, the effects on time for either work or leisure for parents and families are significant. The high level of financial commitment often included in raising a child with ASD is particularly concerning given Gabriels et al. (2001) finding that low SES served as a significant predictor of treatment outcome for children diagnosed with an ASD. Mothers of adolescents with ASD were found to devote more time to providing childcare and completing household work and less time participating in leisure activities than mothers of typically developing children (Smith et al. 2010a, b). As a result of this strain, mothers of children with developmental disabilities work approximately 8 fewer weeks per year than mothers of children with other mental health difficulties (Seltzer et al. 2001). The inability to work increases financial stressors on families and may also diminish parents' resources for both social and emotional support.

Family quality of life (QOL) is a commonly used measure of the negative impact of physical or mental illness and/or disability on the family system. Families of children diagnosed with autism were found to have greater overall negative QOL effects than those of children with ADD/ADHD (Lee et al. 2008) or healthy children (Khanna et al. 2011; Lee et al. 2008; Mugno et al. 2007; Sivberg 2002). For fathers, the best predictor of overall life satisfaction was absolute (i.e., total) parenting burden, while for mothers, relative parenting burden (i.e., burden compared with that of fathers) appeared to be more important (Milgram and Atzil 1988). Maternal caregivers' QOL is also impacted by their own history of chronic disease, as well as maternal religiosity (Shu 2009). While the demands of raising a child with an ASD are significant, parents do report a variety of positive experiences (Bayat, 2007; Phelps et al. 2009). The most prevalent joys reported by parents of children with ASD included individual personality traits of their child, observing their child being happy, and watching them mature and succeed (Little and Clark 2006).

Factors Impacting Parent Stress and Health

Coping styles

Overall, having a child with an ASD can clearly be a difficult experience for parents and families, and it is important to identify the development of coping strategies and use of social support by families raising a child with an ASD, as both have been shown to be associated with positive adjustment in the individual caregiver (Dunn et al. 2001; Pottie and Ingram 2008; Sivberg 2002), as well as the family unit (Higgins et al. 2005). Parents of children with ASD have been found to use a variety of adaptive coping strategies simultaneously, including the use of community services, support from friends and family, information seeking, and individual methods of stress management (Gray 1994; Rodrigue et al. 1990). However, Rodrigue et al. (1990) also noted that parents of children with ASD frequently utilize maladaptive coping strategies, particularly self-blame. Contextual factors likely impact which strategies are beneficial for each family (Lyons et al. 2010), indicating the need for better understanding of variables that impact the success of various coping mechanisms. While the variability in each child and family makes definitive understanding difficult, Pottie and Ingram (2008) utilized multi-level modeling with a large sample of parents with children with ASD to identify coping strategies associated with both positive and negative mood. They found five coping styles that predicted higher levels of positive mood, including "Problem Focused, Social Support, Positive Reframing, Emotional Regulation, and Compromise Coping," (p. 861) while noting that four coping styles ("Escape, Blaming, Withdrawal, and Helplessness" (p. 861) were associated with decreased positive mood. With regards to negative mood, these researchers identified "Distraction" and "Emotion-Regulation" coping as decreasing levels of negative mood while "Problem-Focused, Blaming, Worrying, and Withdrawal coping" were associated with increased levels of negative mood. Parents' appropriate expression and control of emotional experience, the extent to which parents sought social support, and the amount of time spent worrying about negative aspects of their stressors all moderated the extent to which stress impacted daily parental mood (Pottie and Ingram 2008).

The ability of parents of children with ASD to make meaning out of their parenting experience also has been shown to improve their ability to cope in an adaptive manner (Pakenham et al. 2005). As noted earlier, meaning-making may be in part related to the experience of the diagnosis as well as to cultural and religious variables. While the process by which families make meaning of an ASD diagnosis is not well understood, Weiss et al. (2012) found that parents' psychological acceptance of their child's diagnosis served as a partial mediator between problematic child behaviors and parent mental health problems. Psychological and psychiatric interventions have also been shown to benefit parents of children with ASD (Gray 1994), and many of the coping strategies identified above could be associated with involvement in individual or family therapy. Unfortunately, the financial and time constraints of raising a child with an ASD likely serve as a barrier for parents to accessing mental health services, despite the increased need for such services (Lord and Bishop 2010). While no current research has compared parents of children with ASD to other parents with regards to seeking mental health services, mothers of children with ASD reported higher levels of antidepressant use and involvement in therapy than fathers, indicating greater maternal use of these resources to help cope with their own difficulties (Little 2002). Taken together, this research suggests that better understanding of why parents choose to pursue treatment, or not, would benefit professionals working with caregivers and families of children with ASD.

Social Support

Although individual coping strategies and characteristics such as hardiness are important for parents and families of children with ASD, the enormous demands associated with raising a child with a disability also necessitate continued support from external sources (Bromley et al. 2004; Khanna et al. 2011; Weiss 2002). Daily received social support has been identified as a predictor of daily parental mood for parents of children with ASD (Pottie et al. 2009). Social support for these parents has been shown to be associated with decreased psychological distress (Bromley et al. 2004), reduced feelings of depression, improved overall mood, and decreased parenting stress (Ekas et al. 2010), as well as increased parenting efficacy (Weiss 2002). Ekas et al. (2010) also demonstrated that support from within the family was associated with increased levels of optimism, while both family and friend support was correlated with positive maternal well-being. Parents of children with ASD appear to benefit from both emotional and instrumental support as demonstrated by associations with increased levels of positive mood, while emotional support is also associated with decreased negative mood (Pottie et al. 2009). However, persistent parenting stress, which is common in parents of children with an ASD, is associated with lowered perceptions of social support (Quittner et al. 1990). Therefore, it is likely that parents of children with ASD may not be fully aware of and/or utilize the resources available to them. Further, Bromley et al. (2004) noted that being a single parent was associated with decreased levels of support, which is particularly troubling given the high rate of divorce in families of children with ASD (Hartley et al. 2010).

In addition, social withdrawal of parents due to their own characteristics (e.g., BAP) or those of their child (e.g., social aversion or sensory-related behaviors) may decrease the social contact these parents have (Schaaf et al. 2011; Sivberg 2002). Social withdrawal has been identified as a maladaptive coping strategy (Pottie and Ingram 2008) that may serve to alleviate parental anxiety but has negative long-term outcomes for parents and their children with ASD. However, parents of children with ASD are dealing with a unique set of challenges, and as a result the emotional support and understanding needed may be difficult to obtain from families with typically developing children. Thus, more formal social support groups are often a helpful resource for parents. There is a paucity of research examining such groups, though two-thirds of parents of children with ASD surveyed indicated that they had participated or were participating in a support group related to their child's ASD (Mandell and Salzer 2007). Families who did participate in support groups were found to be mostly well-educated, middle-income families and were more likely to have children who were older, male, and had problems related to sleep, language, and/or self-injury.

Transactional Effects

The significant stress placed on parents and families often contributes to and exacerbates difficulties in children with ASD. Baker et al. (2011) found that family adaptability influenced both maternal depression and child behavior problems in ASD and noted that their findings supported the idea that "children with autism…likely respond to their family environment in addition to acting upon it" (Baker et al. p. 605). Though the relationship between child and parent functioning appears bidirectional, it does appear that parenting stress can even diminish or eliminate the positive outcomes of intervention for young children with ASD (Osborne et al. 2008). Further, a recent study by Mandell et al. (2011) suggested that increased spending on parental respite care decreased hospitalizations for children with ASD who were enrolled in Medicaid, while the same was not found for increased use of child therapeutic services. This finding highlights the importance of parental well-being in maintaining appropriate child behavior. Indeed, high parenting stress can lead to increased externalizing behavior problems over time in children with ASD (Baker et al. 2003; Lecavalier et al. 2006), which in turn places heightened stress on parents, siblings, and the family as a whole. Conduct problems, disruptive and/or rule-breaking behavior, and restricted or isolated behaviors associated with autism were all found to contribute to stress in parents and teachers of children with ASD (Lecavalier et al. 2006), but this transactional or "mutually escalating effect" (Baker et al. p. 227) was not identified in teachers. This contrast suggests a relationship between the maladaptive behaviors of children with ASD and caregiver stress that is unique to the parent–child relationship. Along with parenting stress, other mental health and social impairments in parents also directly impact the functioning of children with ASD. Specifically, symptoms of depression (e.g., fatigue, anhedonia, etc.) in parents may contribute to deficits in parental responsiveness and synchronization with their child during play, which are associated with decreased child engagement, social interaction, and socio-emotional functioning (Kim and Mahoney 2004; Mahoney and Perales 2003). Furthermore, decreased parental responsiveness is associated with delays in language development and joint attention (Ruble et al. 2008; Siller and Sigman 2002).

The reciprocating, negative impact of ASD deficits on parents, families, and children with ASD also has been found to limit participation in community activities, which often serve as a source of social learning and improve the quality of life of these children (Lam et al. 2010). Again, both psychological (i.e., stress, depression, and anxiety) and practical (i.e., financial, temporal) concerns often faced by parents of children with ASD may contribute to a decrease in participation. Regardless of the reason(s), researchers have demonstrated that children with ASD are less likely to attend religious services, more likely to miss school, and less likely to participate in organized activities than children with ADHD or typically developing children (Lee et al. 2008). Lam et al. (2010) found that willingness to participate in community activities was associated with parents' perception of the difficulty of this participation, the importance of participating, and the emotional experience during such activities. In all of these domains, parents of children with ASD are negatively affected. Participation in community activities is likely made more difficult by the special needs often encountered by children with disabilities, and perceived importance is often impacted by the child's relative disinterest in social engagement. As a result, negative emotional experiences for parents in these situations may lead them to avoid future social engagements. In theory, this would reduce parental anxiety and negatively reinforce a lack of participation in community activities (Benson et al. 2011). This trajectory would be unfortunate, given that Orsmond et al. (2007) noted that increased maternal participation in social activities predicted child social and recreational participation. Overall, it seems imperative for families of children with ASD to access resources in order to cope with the many demands they face. However, the very stressors that contribute to this need often appear to hold parents and families back from utilizing these means of support.

Summary and Critique

The immense impact of having a child with an ASD is evident in both the severity and breadth of parent and family domains that appear to be affected. Parents of children with ASD consistently demonstrate decreased belief in their ability to parent their child effectively, increased parenting stress, and higher levels of mental health concerns than parents of both typically developing children as well as children with other impairments such ADHD or intellectual disability. Further, having a child with an ASD is associated with decreased family quality of life along with an increase in marital and sibling relationship problems. Many of these findings have been corroborated over time (as evidenced by the multitude of studies reviewed earlier) as well as across divergent cultures (e.g., Kheir et al. 2012; Moh and Magiati 2012; Pakenham et al. 2005; Sivberg 2002; Wang et al. 2011) Though it has been notably limited to date, longitudinal research (e.g., Benson and Karlof 2009; Carter et al. 2009) suggests a relationship between ASD-related child deficits and parent and family distress that appears to be transactional and bidirectional in nature (Baker et al. 2003; Lecavalier et al. 2006; Osborne et al. 2008; Singer 2006). In support of this hypothesis, Rezendes and Scarpa (2011) found that parenting stress mediated the relationship between child behavior problems and decreased PSE, while decreased PSE partially mediated the relationship between parenting stress and increases in depression and anxiety. While some of the impact of having a child with an ASD may be mitigated by the use of adaptive coping skills as well as utilization of social support, raising a child with ASD often puts temporal, financial, and practical limitations on the ability of parents to employ such strategies.

However, it is important to note that significant challenges exist within empirical attempts to understand the impact of having a child, or multiple children, with ASD on parents and families as well as attempts to clarify the direction of the relationship between child deficits and parent and family functioning. Methodological limitations include wide variations in the understanding and conceptualization of ASD and the heterogeneity in presentation from each child (Rutter 2011). A lack of longitudinal research concerning parents and families, logistical complexity regarding the number of variables included, limited use of reporters other than parents or caregivers, and type of methodology and statistical analyses used also contribute to difficulty in making causal connections and establishing more definitive trajectories related to parental and child well-being. Most notably, the broad use of cross-sectional research conducted with parents and families of children with ASD fails to capture the dynamic processes that occur over time as the deficits of each particular child and the parenting and family response take effect on each other. Greater use of longitudinal work such as Benson and Karlof's (2009) investigation of anger, stress, and depression in parents of children with ASD or Baker et al.'s (2011) examination of adaptability, behavior problems, and maternal depression in families of adolescents with ASD could further understanding of causal and cyclical factors within this relationship. Furthermore, no research was found in which parents of typically developing children interacted with children with ASD, or in which parents of children with ASD interacted with typically developing children (either their own or others). Despite inherent limitations in this methodology, such investigation may improve understanding of how parents' interactions styles change as a result of having a child with an ASD and how children with ASD could perhaps alter their interactions when interacting with an adult not faced with the burdens noted above. If conducted longitudinally, it would also offer insight into how these parent–child interactions change over time. In some instances, longitudinal investigation may even provide evidence of optimal or adaptive levels of parent and family distress (e.g., heightened anxiety leading to increased motivation to seek treatment or social support).

In addition, the differing and ever-changing conceptualization of ASD and associated subtypes (i.e., Autistic Disorder vs. Asperger Syndrome vs. PDD-NOS) impairs comprehensive understanding of parent and family factors. Comparison of results across studies is complicated by differences in age range, symptom severity, and diagnostic category assessed. Autism spectrum disorders demonstrate tremendous variability in presentation, particularly across subtypes, yet no research to date identifies differences between parents and families of children with each diagnosis. Even within each subtype, there are likely differences in child symptomatology that drastically alter effects on parents and families. For example, children and adolescents with Asperger Syndrome are often grouped colloquially as being either "Shy and Withdrawn" or "Active but Odd" (e.g., Mackintosh and Dissanayake 2006). The way in which these different manifestations of Asperger Syndrome present not only may have contrasting impact on parenting stress and mental health (in this instance, the former would likely be more subject to depressive symptoms while the later may face more embarrassment or anxiety due to externalizing child behaviors), but also on the way in which parent and family characteristics reciprocally affect the child. Better distinction of subtypes within this research could help mental health professionals provide better assistance to parents tailored in association with the needs of the individual child. Proposed changes in the DSM-V, including the elimination of subtypes (which will be subsumed under the broader "autism spectrum disorder"), a reduction to two symptom domains, and use of severity ratings for both (American Psychiatric Association 2010), may help increase the specificity of diagnosis and research, better capture individual differences in children with ASD, and as a result expand our understanding of parents and families. However, it is also possible that the change in diagnostic status, terminology, and "labels" may vastly alter how parents and families understand and are affected by their child's diagnosis.

Another related difficulty encountered when studying parents and families of children with ASD concerns the complexity of statistical analyses used, specifically with respect to the inclusion or exclusion of interdependent variables such as family functioning, marital distress, siblings and parent–child relationships, parenting efficacy and stress, and parent mental health, in conjunction with related mediators and moderators such as child behavior problems, coping methods, etc. Thorough investigation of each of these variables often requires a specific focus, with between-group comparisons identifying how parents and families of children with ASD are different from others, and within-group correlational and regression analyses used to understand child-level factors related to/contributing to parent and family concerns. However, advanced statistical techniques such as multilevel modeling (MLM; e.g., Pottie and Ingram 2008; Smith et al. 2010a, b), structural equation modeling (SEM; e.g., Ekas et al. 2010), and path analysis (e.g., Ingersoll and Hambrick 2011) have only recently been utilized to develop a broader understanding of how these constructs interrelate and advance the certainty with which causal connections can be drawn. These approaches, in conjunction with an increase in longitudinal investigation, have the added benefit of moving away from using child characteristics as predictor variables and parenting/family functioning as outcome measures. Rather, intricate modeling techniques help capture the complex and dynamic factors within families that impact the development of children with ASD.

In addition, the majority of current research assessing the effect of ASD on parents has utilized parent rating scales, and occasionally self-report measures, to understand child functioning and behavior problems. Behavioral and observational ratings of children with ASD among children, parents, and teachers have been found to be similar with respect to domains of difficulty but vary significantly in terms of the reported severity (Bebko et al. 1987; Johnson et al. 2009; Knott et al. 2006; Murray et al. 2009). Clearly, parent ratings of child functioning could easily be confounded by parenting self-efficacy and competency, parenting stress, and parent mental health. It is likely difficult for a parent feeling defeated by the difficulties or raising a child with ASD to provide an objective assessment of their child's abilities and limitations. Further, many difficulties or areas of impairment in ASD may be "context bound" (Murray et al. p. 113) and thus be more reliably rated by informants in a specific environment (e.g., teachers observing social behavior at school). In addition, Dritschel et al. (2010) noted that even high-functioning individuals with ASD may lack the appropriate insight to provide sufficiently valid assessment of their own social functioning. Therefore, ratings from multiple informants should be incorporated whenever possible to comprehensively understand the child with ASD's functioning—not only in different domains but according to observers with differing levels of emotional salience and duration of involvement in the child's life. The use of a broad range of informants seems particularly imperative when evaluating intervention effects. Kazdin and Weisz (1998) noted that caregiver perception of child functioning and adjustment was influenced by mental health, family relationships, and outside support. Thus, parents burdened or overwhelmed by the effort involved in treatment may be unable to recognize positive changes in their child; or conversely, the time and money spent throughout treatment may bias parent report in a positive direction, lest they feel that these efforts went to waste. Ultimately, Kalyva (2010) suggested that self-report, teacher report, and mother and father report all varied widely enough to recommend utilizing multiple informants whenever possible.

Finally, research on parents, siblings, and families of children with ASD is complicated by practical considerations, such as the limited time and resources parents of children with ASD have to devote to research studies, complexity in finding appropriate comparison groups (i.e., other developmental disabilities, other childhood disorders, and/or typically developing children), and limitations in the information that can be accurately obtained from children with ASD given their deficits in communication and social interaction. Furthermore, the possibility of baseline biological, neurological, and psychological differences in parents and siblings of children with ASD (such as BAP) have not been completely delineated and may confound current findings in this area. Recent interest in parents and families of children with ASD has coincided with three other phenomena: Expanded research into etiological, particularly genetic factors, associated with ASD; an increased rate of diagnosis, which has led to a shortage of trained professionals available for treatment; and the development of several therapeutic modalities that incorporate parents and siblings in an attempt to develop more naturalistic opportunities for children with ASD to learn. The multitudes of parent and family factors reviewed above are thus imperative to understand as caregivers and siblings become active agents within therapy.

ASD Interventions and Parent Involvement

A wide variety of interventions are available for children and adolescents with ASD, though the high variability in treatment options can be confusing for families. Mackintosh et al. (2012) noted that parents of young children with ASD have their children in an average of seven different interventions at one time, likely contributing to the strain on time and finances for these families. In their review of the challenges faced by those research ASD interventions, Lord et al. (2005) suggested that the high level of treatment variability is due in part to the heterogeneity of the disorders itself. There is also wide variation in empirical support among treatments, and debate continues over what criteria should be used to consider treatments "evidence based" (Rogers and Vismara 2008). In their review of comprehensive treatment models for ASD, Odom et al. (2010) found that evidence of treatment efficacy was very limited for ASD interventions, suggesting a need for improved analysis of intervention outcome across therapeutic modalities. Further, the heterogeneity of ASD often leads to differential response to treatments (Sherer and Schreibman 2005), suggesting a need for improved matching of children and treatment based on individual and family factors. However, a priori analysis to identify the optimal treatment fit for each individual child would be both complex and time-intensive, especially if relevant caregiver and family factors were considered.

Parent Involvement and Pre-Treatment Functioning

Parents are included either directly or indirectly in the majority of ASD therapies: a review of early interventions for children with ASD indicated that 52 % of these services actively supported the parent–child relationship, while 59 % involved parents in the delivery of the intervention (Schertz et al. 2010). However, the subtle distinctions between interventions with parent-as-therapist, parent-with-therapist, parent training, etc. are often unclear. Even the same general therapeutic modality (such as those described below) may include very different levels of parent and family involvement, depending on the provider and individuals involved in treatment. Though the intensity, form, and function of parental involvement in ASD intervention varies greatly (Granger et al. 2012), caregiver participation in treatment appears imperative. Current research suggests several benefits of parent involvement in ASD intervention, whether directly (i.e., providing the therapy themselves or with the help of a trainer) or indirectly (i.e., minor involvement in the evaluation or treatment process and/or learning intervention strategies to utilize in the home). Among many benefits, parental involvement in intervention for children with ASD provides increased insight into the individual child (Kaiser and Hancock 2003; Koenig et al. 2009; McConachie and Diggle 2007), readily incorporates therapy into the child's own environment (Kaiser and Hancock 2003; Krasny et al. 2003; Leef 2005; Schreiber 2010), and helps facilitate greater generalization of skills learned in treatment (Krasny et al. 2003; Matson et al. 2009; Rocha et al. 2007; Schreiber 2010; White et al. 2007). Inclusion of parents and other family members in the intervention process also seems to benefit the family system as a whole, with improvements seen in the marital, parent–child, and sibling relationships (Dunlap 1999; Rogers 2000; Schertz and Odom 2007; Schreiber 2010; Stoddart 1999). Parent involvement also helps diminish both the time and financial strain involved with most interventions (Lord and Bishop 2010; Matson et al. 2009).

The relationship between parent involvement in intervention and enhanced child outcomes is likely moderated by the general well-being of parents and families, who serve as the "gatekeepers to their children's access to services" (Mackintosh et al. 2012, p. 58). In a review of general child therapy, Nock and Kazdin (2001) found that high levels of parenting stress and depression were associated with low expectations for treatment, which in turn predicted greater barriers throughout the treatment process, lower treatment attendance, and premature termination of therapy. Socioeconomic disadvantage was also found to contribute to lower expectancy for therapy (Nock and Kazdin 2001), a concern given the high financial stress typically encountered by families of children with ASD. Motivation before treatment and expectations/adherence throughout treatment likely determine whether parent involvement is beneficial, and ultimately, whether the treatment is effective for the child as well as whether it results in positive changes in the child's parents and family (Hastings and Johnson 2001). Brooks-Gunn et al. (2000) noted that increased family involvement in treatment planning and implementation often leads to more "buy in" and engagement from families. Lord et al. (2005) noted that it is "impossible to separate the effects of hope, enthusiasm, and confidence…from specific aspects of the treatment" (Lord et al. 2005, p. 700). Further, parent treatment expectations are likely tied to the type of treatment they pursue (Grindle et al. 2009), such that parents seeking behavioral treatment desire changes in functional behavior while parents utilizing relationship-focused interventions care more about the development of appropriate social relationships. Grindle et al. (2009) noted that treatment providers also play a large role in establishing expectations, with some suggesting the possibility of a complete return to "normal functioning" (Grindle et al. p. 53) and others providing more cautious prognosis. The former extreme may initially help increase parent expectation but ultimately lead to disappointment in overall progress, while the latter may decrease motivation at the outset of intervention and could also lead to diminished follow-through post-treatment. Mackintosh et al. (2012) reported that caregivers' relationship with treatment professionals served as an important factor in assessing parental perception of interventions, with 22 % of parents surveyed reporting difficulties in this relationship and many expressing a high frustration at the frequent turnover of therapists.

Overall, there is a great deal of literature suggesting that parental treatment expectations and involvement are associated with long-term outcomes of children with disabilities (Ivey 2004), including adolescents with ASD (Field and Hoffman 1999). Field and Hoffman (1999) suggested that parental modeling of advocacy and adaptation serves as an important link through which children themselves learn self-determination skills that foster improved treatment. Treatment motivation and expectations are likely directly impacted by factors such as parenting stress and efficacy and parent mental health. Ivey (2004) noted an important difference between "outcome expectancy," or knowledge that certain behaviors will lead to certain outcomes, and "efficacy expectations," which includes the belief that one can carry out those actions. Interventions for ASD may help a parent become more cognitively aware of the responsibilities they must undertake to help their child, but these same treatments may not address their lack of belief in themselves to carry out these tasks. Further, parental depression resulting from having a child with ASD may lead to a decrease in motivation or optimism, which is associated with both child self-perception as well as actual achievement (Ivey 2004). Finally, high levels of caregiver anxiety may lead to over-protective parenting, which Powers (2000, as cited in Ivey 2004) noted can limit the development of independent skills in children. Caregivers of children with ASD may also face decreased efficacy expectations as a result of their own deficits associated with

BAP. For example, parents who themselves struggle developing close social relationships may lack confidence in their ability to help their child do the same. Conversely, the chance for parents to review skills ostensibly presented to them for their child's benefit (e.g., within a social skills group) may actually increase parent motivation and adherence to treatment.

Parent Involvement in Early Intervention

Applied Behavioral Analysis

Behavioral interventions are the most widely available, funded, and utilized form of therapy for children with ASD. Overall, when parents are taught behavioral treatment skills and implement them directly (i.e., without regular involvement of a professional therapist), there is evidence that they are able to employ behavioral procedures correctly (Smith et al. 2000). A review of parent-managed behavioral treatment outcomes from Bibby et al. (2002) suggested that children do make significant progress in parent-directed programs, though improvements across most domains were reportedly less than those seen in children enrolled in an intervention delivered by a professional. The most common and well-validated behavioral intervention approaches include discrete trial (DT; Lovaas et al. 1973; Lovaas 1987; Lovaas and Smith 2003; Smith and Lovaas 1998) and Pivotal Response Training (PRT; Koegel et al. 1992a, b, 1996, 1999a, b; Koegel and Frea 1993).

Discrete trial techniques are broadly incorporated in applied behavioral analysis (ABA) therapy, which emphasizes behavior modification through changes in environmental antecedents and consequences, most often through the use of positive reinforcement techniques. Parents reported feeling more "involved and satisfied" with ABA compared with other forms of therapy (Regehr and Feldman 2009), which the authors suggested was associated with their belief that the intervention was effective for their children. With respect to parent involvement, Lovaas and Smith (2003) recommended that parents be involved in intervention meetings and also suggested that parents work alongside the therapist for approximately five hours per week. In doing so, these researchers indicated that parents could provide feedback to the therapist, and vice versa. Even in the early development of DT, Lovaas et al. (1973) suggested that parent involvement and continuation of therapy techniques was a key factor in maintaining gains made in DT behavior therapy.

Pivotal Response Treatment

Pivotal response treatment (PRT), a behavioral intervention that focuses on a select group of "pivotal" areas of development proposed to be necessary for children with ASD to develop a broader range of skills, has received support as an evidence-based treatment for children with ASD (Kazdin and Weisz 2003). Rogers and Vismara (2008) noted that limitations in use of standardized outcome measures, longitudinal design, and comparison groups or treatment models prohibit PRT from meeting criteria as a well-established treatment (Chambless et al. 1996) but did report that current literature does place PRT in Chambless and colleagues' categorization of a probably efficacious intervention. Researchers support parents' abilities to implement PRT (Coolican et al. 2010; Smith et al. 2010a, b), and Minjarez et al. (2011) suggested that parents could be instructed on PRT techniques in a group format, which would help serve more families at a lower cost to community providers.

Relationship and Developmentally Based

Relationship and developmentally focused approaches constitute another widely available intervention format for children with ASD. These interventions typically emphasize the facilitation of social emotional bonds in children with ASD, particularly with their caregivers, and often include more direct parental involvement than behavioral interventions. These approaches are typically individualized based on the child's developmental level, rather than focusing on chronological age. Specific modalities include developmental, individual differences, relationship-focused (DIR, or Floortime) techniques (Greenspan and Wieder 1997; Greenspan and Wieder 1999) and associated interventions such as The Play and Language for Autistic Youngsters (PLAY) Project (Solomon et al. 2007). Developmental, individual differences, relationship-focused treatments often include a professional consultation or clinician who provides initial assessment and treatment while helping parents develop their own program at home. This approach is "child-led" and allows the child to choose activities for therapy. Another primary developmental approach is relationship-development intervention (RDI; Gutstein et al. 2007; Gutstein and Whitney 2002). Relationship-development intervention is parent and therapist-led, though like DIR is designed to be interactive and supportive of joint engagement between the caregiver and child. To date, neither DIR nor RDI has received sufficient empirical support in large-scale trials to be considered empirically validated treatments for ASD.

Other Early Interventions

The Early-Start Denver Model (ESDM; Vismara and Rogers 2008; Rogers and Vismara 2008) is an intensive, early intervention for ASD that combines aspects of ABA with relationship-based and developmental approaches. The ESDM approach has shown promise in development of cognitive, adaptive, and language-based skills in toddlers with ASD (Warren et al. 2011). This treatment involves both trained therapists and parents, who can be provided with parent training along with semi-monthly meetings with the primary therapist. Parents are asked to use ESDM strategies during routine activities and also help guide objectives throughout therapy, and parental use of techniques likely contributed significantly to children's success with the program (Dawson et al. 2010; Vismara and Rogers 2008). Parents learning ESDM techniques were found to have acquired proficient skill by the fifth to sixth hour of working with their child (Vismara et al. 2009). Parental involvement in intervention is common in other early interventions as well, including those with an emphasis on parent–child communication (Green et al. 2010), joint engagement (Kasari et al. 2010), and joint attention (Schertz and Odom 2007), all of which have demonstrated child improvement in the specific domains targeted in treatment.

Parent Training

Though parents are almost always indirectly "trained" in the intervention strategies used in the early intervention approaches such as those described above, there is a growing body of research examining explicit parent training programs for parents of children with ASD. Direct parent training often implies that parents of children with ASD are presented with a variety of parenting skills and strategies, but which otherwise involve little or no direct communication between a professional therapist and child in day-to-day treatment. The recent emphasis on parent training comes in part from the success of behavioral management parent training programs for childhood disruptive behavior disorders such as ADHD and ODD (The MTA Cooperative Group 1999). Direct parent training methods for parents of children with ASD have shown evidence of success in the extent to which parents learn appropriate intervention techniques, and following parent training, there is evidence of increased parent knowledge regarding ASD (McConachie and Diggle 2007). Parent training outcomes also include decreases in parent mental health concerns, enhanced parental understanding of their child's difficulties, improved parent–child interaction, and improvement on child outcomes on measures of social behavior and communication ability (Matson et al. 2009; McConachie and Diggle 2007).

Specific parenting training programs demonstrating success for parents of children with developmental disabilities and/or ASD (success defined in terms of child gains) include a targeted joint attention intervention (Drew et al. 2002), the Autism Spectrum Conditions—Enhancing Nurture and Development (ASCEND) parent training program (Pillay et al. 2011), the Triple P Positive Parenting Program (Whittingham et al. 2009), the Incredible Years Parent Training program adapted for children with developmental disabilities (McIntyre 2008), a parent training component added to the early childhood special education (ECSE) curriculum (Ingersoll and Dvortcsak 2006), and a parent training model for parents of children with ASD introduced in the People's Republic of China (Wang 2008). Furthermore, a group-based family training program for young children with ASD (Group Intensive Family Training (GIFT) demonstrated improvement in children's cognitive and adaptive functioning (Anan et al. 2008). Finally, Solomon et al. (2008) reviewed use of Parent–Child Interaction Therapy (PCIT) for families of children with ASD, noting improvements in child adaptability and shared affect in parent–child dyads. The efficacy of parent training programs for children with ASD has not been universal, however, as Oosterling et al. (2010) reported limited effects on language development, overall clinical improvement, or parent skill change resulting from the addition of the Focus parent training program to a "care-as-usual" control.

Comprehensive understanding of the benefits of parent training programs is complicated by variance in both therapeutic approach and measurement of outcome. Specific recommendations for such programs include use of individual sessions along with workshop or group approaches (Ingersoll and Dvortcsak 2006; Sofronoff et al. 2004), emphasis on parental knowledge along with skill (Pillay et al. 2011), and inclusion of overall family support (Anan et al. 2008; McIntyre 2008). Child progress following parent training is also difficult to ascertain given the possibility that improved parent understanding of their child following treatment changed their interpretation or tolerance of their child's behavior. Furthermore, though much of the current research suggests that parent training programs can be effective for young children with ASD, there is a dearth of literature reviewing similar programs for adolescents (Reichow and Volkmar 2010).

Parent Involvement in Interventions for Older Children and Adolescents

As children with ASD develop, the targets of the intervention change concurrently, and the majority of interventions for adolescents with ASD focus on deficits in social impairment. There are a plethora of social skills interventions available for teenagers with ASD, but differences in methodology, inconsistency in the conceptual definition of "social skills," insufficient development of manualized treatments, and a lack of common outcome measures have limited the development and empirical support of such programs (Matson et al. 2007; White et al. 2007). Reviews of the many social skill interventions developed for children with ASD (Matson et al. 2007; Rao et al. 2008; Schreiber 2010; White et al. 2007) highlight the significant variation in approaches utilized, which Schreiber (2010) broke down into: Social Stories, Manualized Instructional Programs, Non-manualized Training and Support Groups, Cognitive Behavioral Therapy, Parent or Family Mediated, Peer Mediated, and Activity Based. Even within each of these categories, parental involvement in specific programs was wide-ranging. Many of the interventions utilized parents only to provide pre- and post-assessment of their child's social abilities, while others garnered only therapy satisfaction ratings from parents. Some individual and small-group interventions incorporated parents into the development or modification of the curriculum itself, while others included concurrent parent sessions (Schreiber 2010). Many of the programs reviewed were based on the school, a naturalistic setting where "practice" opportunities with peers are plentiful, but which often included very little parental involvement and instead rely on teacher support (Sansosti 2010), thus further separating caregivers from the intervention process.

Many of the social skills programs that do include higher levels of parental involvement appear promising. These interventions include the Junior Detective Training Program (Beaumont and Sofronoff 2008), the Program for the Education and Enrichment of Relationship Skills (PEERS; Laugeson et al. 2009), a parent-delivered cognitive behavioral social skills program (Gutstein et al. 2007), and a behavior skills training approach delivered by the family (Stewart et al. 2007). When parents are involved in social skills treatment, however, Schreiber (2010) noted that the extent of their inclusion (and associated expectancy effects) may bias post-treatment assessment of their child's social functioning, which is made more problematic by the lack of validated outcome measures available for social skill development (White et al. 2007). However, Rao et al. (2008) noted that one of the primary challenges for social skill groups is to help children with ASD generalize the skills learned, which may be more difficult without the incorporation of parents (and even siblings) into therapy (e.g., through the use of homework assignments such as get-togethers, which often necessitate parental supervision). Parent involvement is also variable in other interventions available for older children and adolescents with ASD. These include cognitive-behavior therapy (CBT) with (White et al. 2010) and without (Wood et al. 2009) parent involvement, theory of mind training with monthly adjunctive parent training sessions (Begeer et al. 2011) and without parent involvement (Ozonoff and Miller 1995), and a social adjustment enhancement curriculum that included a parent educational component (Solomon et al. 2004).

The TEACCH Program

Though more comprehensive in scope than most interventions, the TEACCH (Treatment and Education of Autistic and related Communications handicapped Children) program (Schopler and Reichler 1981) is notable for its systemic approach and inclusion of parents in treatment of children with ASD. Developed by Schopler and Reicher at the University of North Carolina, TEACCH emphasizes individual differences and strengths, structure and visual learning, a focus on psychoeducation across systems, and a high level of collaboration with parents and families (Schopler et al. 1982). Schopler et al. (1982) stated that parents should be involved in both the assessment and implementation of a teaching program for children with ASD, with parents often included as co-therapists as part of the TEACCH curriculum. Schopler et al. (1982) found significant improvement in mothers' teaching skills across all nine domains of assessment included (e.g., teaching pace, child compliance) and noted a positive association between involvement in the program and parent perception of TEACCH as "extremely helpful" (p. 265). Further, researchers investigating TEACCH indicated that parents found the program helpful in managing the difficult behaviors of children with ASD and was found to improve parents' "ability to manage, understand, and teach them" (Schopler et al. 1982, p. 266) In a recent review of treatments for ASD, the TEACCH program met criteria as an evidence-based comprehensive treatment model for children with ASD (Odom et al. 2010).

Parent and Family Outcomes of Intervention

Very few studies of ASD interventions have assessed parent outcomes following intervention. Research into parent training programs has been the most prevalent to date and suggests that parents benefit from this type of intervention in a variety of ways, including an increase in ASD-related knowledge and therapeutic skill (McConachie and Diggle 2007), improved responsiveness and emotional regulation (Whittingham et al. 2009), reduced levels of stress, depression, and overall improved mental and physical health (McConachie and Diggle 2007; Roberts and Pickering 2010; Solomon et al. 2004; Tonge et al. 2006), and greater parenting self-efficacy (Leef 2005; Sofronoff and Farbotko, 2002; Whittingham et al. 2009). These outcomes are promising, but not universal, as Drew et al. (2002) did not find differences in parenting stress compared with a control group following a pilot trial of a parent training intervention. However, it is clear that for the most part, parents benefit from interventions for ASD in which they are taught skills to help them deal with their child's particular challenges. These benefits appear to hold true even when parent training programs are adjunctive to primary programs for children (e.g., Solomon et al.'s (2004) social skills program with added parent training). These findings suggest that the psychoeducation and skill building for parents are important components to include in therapies developed for children with ASD. Leef (2005) cited Dr. Leon Sloman's "cycle of success" regarding parents' involvement in social skills intervention, stating that:

"Parents are an essential part of this cycle, since they are the link with the child's home and school environments and can help their child become more socially competent. If parents feel supported, educated, and more confident about their abilities to cope with their AS child, their interactions with their child will improve. To truly impact the child's emotional and social needs, parents must be integrated into the therapeutic process" (Leef 2005, p. 14).

Clearly, there are distinct benefits for both parents and children when parents receive training in various forms of ASD intervention. However, research is significantly more limited with respect to parent outcomes of interventions in which they are not the direct targets of the program. As early, intensive, and behavioral interventions are the most commonly available, the limited research on parent outcomes has primarily been within the scope of this therapy modality. Some studies have found decreases in parenting stress following early, behavioral interventions (e.g., Smith et al. 2000), to the point of being comparable to parents of typically developing children (Hastings and Johnson 2001.) However, little follow-up has been done to help understand what factors, including specific domains of child improvement, contribute to the reduction in stress. Grindle et al. (2009) conducted interviews with a large sample of parents whose children were enrolled in early intensive behavioral intervention (EIBI) and found overall positive views of such programs despite many associated challenges. Eighty-six percent of maternal caregivers and 67 % of fathers endorsed practical benefits for parents resulting from EIBI, including increased support in the home and greater amounts of free time. The parent–child relationship was found to improve for 100 % of parents, while approximately half of mothers and 60 % of fathers reported improved relationships among siblings. Parents also reported positive emotional experiences as their child made improvements, and though findings were mixed, stress levels decreased for approximately 30 % of parents. To understand the trajectory of parenting stress throughout EIBI, Remington et al. (2007) examined parent functioning at three different time points during the course of therapy. These researchers suggested that parents did not suffer adverse mental effects despite the intensity of early intervention; however, most domains appeared stable and there were no significant decreases found in parental stress or anxiety during or following intervention. Unfortunately, significant limitations exist in much of this research. Remington et al.'s (2007) evaluation of early behavioral intervention was not a randomized controlled trial, did not include a manualized treatment, and had a marginal sample size (Intervention group $n = 23$, comparison group $n = 21$); while Grindle et al. (2009) used descriptive, exploratory techniques that need to be more rigorously tested and need to include more precise quantitative measurement.

Koegel et al. (2003) suggested that the PRT evaluation should include measures of parent fidelity to treatment along with assessment of parent–child interactions, parenting stress, affect, mental health and further suggested future research into "parent empowerment" (Koegel et al. 2003, p. 350). Schreibman et al. (1991, as cited in Koegel et al. 2003) identified increases in parental positive affect in parents trained in PRT compared with those focusing on individual target behaviors (ITB) and parents were also found to increase requests for the vocalization from their child following treatment (Laski et al. 1988; as cited in Koegel et al. 2003). Koegel et al. (1996; as cited in Koegel et al. 2003) found that PRT led to more positive parent–child interactions in comparison with ITB treatment.

Research into other interventions such as ESDM (Vismara et al. 2009) and DIR principles (Solomon et al. 2008) has suggested that parents can effectively learn and apply therapeutic techniques and furthermore that this leads to improved social interactions between children and caregivers. However, these and other approaches lack research demonstrating the effects of this involvement on parenting stress, efficacy, mental health, and overall family functioning. Grindle et al. (2009) suggested that many parent and family difficulties associated with intervention for ASD are reduced or eliminated with higher levels of parental involvement, but there is currently a lack of large scale, randomized studies to fully support this assertion.

Summary and Critique

The vast array of interventions for ASD is as wide as the presentation of the disorder itself (Lord et al. 2005). Comparison of treatments can be difficult, as families typically choose which type of intervention to use for their child, leading to baseline differences in the type of families enrolled in different programs. Further, families often enroll their children in multiple intervention programs simultaneously (Mackintosh et al. 2012) making studies of effectiveness difficult at a practical level. The choice of intervention may be affected by family's cultural beliefs regarding ASD and medical treatment, and socioeconomic status may determine the availability of certain therapies by affecting ability to pay privately, enroll in insurance programs covering treatment, or even to travel to areas where treatment is available. The state or country in which the family lives can also affect the number of treatment options as well as which treatments are covered by federally or state-funded programs. Moreover, the limited number of randomized efficacy trails has made empirical validation of treatments difficult (Lord et al. 2005; Smith et al. 2007). This debate is further complicated by the time and intensity recommended for ASD treatments, which is significantly greater than what is required for most other childhood disorders, complicating the practical ability to measure change throughout treatment (Lord and Bishop 2010). Lord and Bishop (2010), in a policy review regarding autism research and treatment, noted that parents often resort to diet and medication treatment programs not proven effective by research because they are "more straightforward" (Lord and Bishop 2010, p. 11) than many of the evidence-based approaches.

The heterogeneity of ASD presentation and lack of agreement on appropriate outcome measures contribute to the difficulty in establishing practices that can be considered evidence based (Lord et al. 2005; Smith et al. 2007). Outcomes may be tied to full recovery from autism (e.g., Lovaas 1987), but as the disorder is considered to be pervasive in nature, most treatments instead focus on building skills to counter core ASD impairments. These treatments also frequently target improvement in neuropsychological, cognitive, and/or adaptive functioning, along with other treatment-specific goals, such as language and joint attention development in younger children and social skills in higher-functioning children and adolescents. The practical logistics of measuring some of these outcomes is a significant limitation. For example, research on joint attention often requires tedious and subjective coding of child and caregiver behaviors, which includes inferring whether behavior is social or instrumental in nature. To conduct this type of research in an appropriately large sample of children with ASD would require an overwhelming amount of time and funding. Further, Kasari and Lawton (2010) noted that while most ASD treatments are behavioral, the disorder itself is a neurobiological disorder, suggesting the need for greater use of complex neuroimaging techniques to understand actual "changes" at the neural level. Lord and Bishop (2010) and Rogers and Vismara (2008) noted the importance of evaluating the long-term maintenance and generalization of treatment progress, which would be enhanced with higher-quality outcome studies. It cannot always be assumed that children or adolescents with ASD are able to translate a specific change seen in treatment (e.g., the naming of a specific object on a flash card) to broader or more useful situations (e.g., requesting the object by name). Furthermore, even larger changes made in treatment may not be sustained over the course of development, and there are insufficient longitudinal treatment outcome studies published in order to understand which interventions lead to the best overall trajectory for children with ASD (Lord and Bishop 2010). The lack of sufficient research is particularly alarming when considering the heterogeneity of symptoms common in ASD, suggesting that one modality of treatment is unlikely to work for all children with ASD.

The result of the aforementioned research complexity is increased empirical support for treatments that lend themselves to less complex and more quantitative outcome measures, and perhaps those that are less individualized (Lord and Bishop 2010; Lord et al. 2005). Complex, comprehensive measures of outcomes, including the well-being of parents and families, are often not available or feasible when evaluating ASD interventions. However, comprehensive assessment of parent outcomes in therapy for children and adolescents is necessary to fully understand process variables contributing to therapeutic effects (Hoagwood 2005), as well as factors that affect long-term efficacy of treatment (Kazdin and Weisz 1998). Parents inevitably play a role in child therapy, whether direct or indirect, supportive or dismissive, involved or disengaged in nature. This role only increases after formal or professional therapy is completed, which often happens at a relatively young age. Understanding how the therapeutic process impacts the parents themselves is important in order to fully understand the comprehensive impact of different therapy modalities.

Kazdin and Weisz (1998) noted that at the most basic level, contextual family factors can impact attendance to and participation in treatment. It is entirely possible that treatments deemed "effective" for children and adolescents put so much strain on the parents and family that even the child's gains are not maintained over time or that parents withdraw their child from treatment if they do not believe they can withstand the negative impact on their own mental health. Sawyer et al. (2010) noted that time pressures (but not actual time spent engaged in caretaking) were associated with increased maternal mental health problems and suggested that interventions in the home may increase time pressure, thus diminishing caregiver well-being. In addition, the increase in family conflict, divorce, and other collateral damage on the family no doubt affects the extent to which children with ASD benefit from treatment. Furthermore, improved understanding of parent mental health throughout and following treatment could help shed light on whether parent functioning impacts the ability of caregivers to detect positive changes in their children.

Evaluating parent and family outcomes will also help identify barriers to family involvement in both community and professional services. Researchers have found that parental cognitions related to difficulty and importance of participation in activities (Lam et al. 2010), parenting stress (Osborne et al. 2008), parent mental health, and improved parent child interactions (McConachie and Diggle 2007; Schertz et al. 2010) all contributed to parenting behaviors as well as immediate and long-term outcomes for children with ASD. However, these factors have not been comprehensively evaluated in the context of treatment effects. It has long been assumed that any intervention that improves child functioning must therefore improve parental health and diminish difficulties associated with having a child with an ASD. However, the intensive nature of ASD therapies likely takes its toll on families regardless of how such treatments ameliorate symptoms and reduce functional impairment. Osborne et al. (2008) noted that the time-intensive nature of ASD treatments is beneficial for the affected child but found that fewer gains were made when parenting stress levels were high, particularly in more time intensive treatments. Koegel et al. (2003) noted that: “Parent and family variables are also important to assess because our research suggests that parents are not likely to use the techniques if the interventions are too burdensome, require one-on-one time to be set aside for teaching, increase stress, or do not fit with a particular family’s values” (Koegel et al. 2003, p. 349). Clearly, the evaluation of therapy outcomes cannot take place in a vacuum: Lord and Bishop (2010) suggested that any clinically, socially, or statistically significant gains made by children throughout treatment must be balanced against “secondary and possible negative effects” (Lord and Bishop 2010, p. 13) of treatment, including effects on the family. Most treatments for ASD are time-consuming, expensive, and demand high levels of parent and family flexibility. Therefore, contextual outcomes, including the well-being of parents and families, must be evaluated. Lord et al. (2005) noted that models of developmental psychology highlight the importance of understanding “higher level organizational factors,” (Lord et al. p. 697) such as family systems, which affect both short- and long-term treatment outcomes. Unfortunately, this has not been the case in most intervention research, and methodological limitations (e.g., low subject numbers and a lack of randomized, controlled trials) exist in the few studies that have included such outcomes.

In sum, very little is known about how the many differences in intervention, including form and function of parent involvement, affect caregivers, siblings, and families. The result is an incomplete picture of the effects of intervention, whether positive or negative. In particular, better understanding of the impact of ASD intervention on parents and families should theoretically help understand factors contributing to long-term maintenance of treatment gains and aid in assessing readiness of caregivers to “take over” the day-to-day care of their child. Given the high likelihood that parents and/or siblings’ involvement in the diagnosed child’s life will last into adulthood, understanding these factors seem particularly important with the ASD population.

Parent and Family Outcome Measures

There are a variety of well-validated measures of parent and family functioning that could be incorporated into the evaluation of ASD treatments, and many of these instruments have already been used to assess how having a child with ASD impacts caregivers and the family system.

Parenting Efficacy

Jones and Prinz (2005) cited a variety of parent self-report and child-report measures in their review of parenting self-efficacy, with the Parenting Sense of Competence (PSOC; Johnston and Mash 1989) being the most frequently used. The PSOC parenting efficacy subscale consists of 7 items assessing agreement to statements such as “I meet my own personal expectations for expertise in caring for my child” (Johnston and Mash 1989, p. 171) and has demonstrated good internal consistency and divergent construct validity (Johnston and Mash 1989). Kuhn and Carter utilized the Maternal Efficacy Scale (Teti and Gelfland 1991, as cited in Kuhn and Carter, 2006) in their assessment of PSE in the relation to parenting cognitions in mothers of children with ASD, while Benson and Kersh (2011) utilized the parent efficacy subscale of the Family Empowerment Scale (Koren et al. 1992, as cited in Benson and Kersh 2011). Additionally, Sofronoff and Farbotko (2002) developed their own measure specific to their study of parent management training for parents of children with Asperger Syndrome, a 15-item instrument referred to as the “Parental self-efficacy in the management of Asperger Syndrome” questionnaire. This measure included a listing of problematic behaviors commonly seen in adolescents with Asperger Syndrome and assessed whether these behaviors had occurred recently, and if so, parents’ confidence in managing each behavior.

Parenting Stress

Perhaps the most commonly used measure of parenting stress throughout both ASD and other literature is the PSI (Abidin 1995), while the associated Stress Index for Parents of Adolescents (SIPA; Sheras et al. 1998) is commonly used with parents of teenagers. Studies using the PSI full or short form (e.g., Davis and Carter 2008; Hoffman et al. 2009; Ingersoll and Hambrick 2011; Rao and Beidel 2009) suggest strong internal consistency and validity in use with the ASD population, while Ozonoff et al. (2005) identified the SIPA as a psychometrically sound measure for use with parents of adolescents with ASD. Lecavalier et al. (2006) noted that, when utilizing the PSI Short Form (PSI-SF) with parents of children with ASD, 57.7 % of these parents scored in the clinically significant range compared with the normative sample for the measure. To further clinical utility of the PSI-SF for parents of children with ASD, Zaidman-Zait et al. (2011) conducted an exploratory factor analysis to develop a unique factor structure for the use with the autism population. Other measures used in assessing stress in parents of children with ASD include the Questionnaire on Resource and Stress (Konstantareas et al. 1992, as cited in Estes et al. 2009) and the Aggravation in Parenting Scale (Schieve et al. 2007). Recently, Silva and Schalock (2012) published data validating psychometric properties of an ASD-specific measure of parenting stress, the Autism Parenting Stress Index (APSI). The ASPI has the added benefit of delineating parenting stress related to core deficits, behavioral symptoms, and co-morbid physical symptoms in children with ASD.

Parent Mental Health

While mental health is a more expansive and amorphous construct, researchers across a multitude of studies have utilized measures assessing parental well-being in caregivers of children with ASD. Broad measures of parent mental health used with this population include the Psychological Well-Being Scale (PWB; Ryff and Keyes, 1995, as cited in Ekas et al. 2010), the World Health Organization's Quality of Life Measure (WHOQOL-100 or WHOQOL-BREF, as cited in Mugno et al. 2007), the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994, as cited in Rao and Beidel, 2009), and the General Health Questionnaire (GHQ; Goldberg and Williams, 1998, as cited in Herring et al. 2006). More specifically, the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) has been utilized by several researchers (Benson and Karlof, 2009; Carter et al. 2009; Sawyer et al. 2010) to assess levels of depression in parents of children with ASD. Researchers have also assessed the level of anxiety experienced by parents of children with ASD using the Beck Anxiety Inventory (Beck et al. 1988, as cited in Davis and Carter, 2008) and the Zung Self-Rating Anxiety Scale (Zung, 1971; as cited in Sharpley et al. 1997).

Parent–Child Relationship

Numerous measures have been developed to assess the parent–child relationship, including the Parent–Child Relationship Inventory (PCRI; Gerard 1994) and Parenting Relationship Questionnaire (PRQ; Kamphaus and Reynolds 2006). Osborne et al. (2008) found strong internal reliability and test–retest reliability when utilizing the PCRI with parents of children with ASD, while no studies were found which employed the PRQ with parent–child with ASD dyads. Whittingham et al. (2008) designed the Parental Attribution Questionnaire specifically for their investigation of parental attributions in parents of children with ASD, while Hartley et al. (2011) assessed parent and child closeness using the Positive Affect Index (Bengtson and Schrader, 1982, as cited in Hartley et al. 2011). In other studies, subscales of larger questionnaires have been utilized. Montes and Halterman (2007) used items from the Parental Attitudes about Childrearing scale from the National Survey of Children's Health, while Hoffman et al. (2009) utilized the "Attachment" subscale of the PSI.

Family Functioning

The more holistic impact of ASD on families has also been investigated using a variety of measures, including the Family Environment Scale (Moos and Moos 1986, as cited in Rao and Beidel 2009), Family Assessment Device—General Functioning Scale (Epstein et al. 1983, as cited in Herring et al. 2006), and the Family Stress and Coping Questionnaire (Minnes and Nachshen 2003, as cited in Tehee et al. 2009). Importantly, these measures could serve to understand not only the impact of treatment on family functioning but also included items that would provide information as to the type of coping skills and social supports utilized by the family. Additionally, the CHAOS (Matheny et al. 1995) is a 15-item, parent-report measure assessing environmental chaos in the home that may be useful in understanding overall levels of family disruption. Marital and relationship satisfaction has also been examined in families of children with ASD using the Marital Satisfaction Questionnaire for Older Persons (MSQFOP; Haynes et al. 1992 as cited in Hartley et al. 2011) and the Respect Toward Partner Scale (Hendrick and Hendrick 2002, as cited in Brobst et al. 2009). Finally, Rivers and Stoneman (2003) explored sibling relationships between typically developing children and their sibling with ASD utilizing the Sibling Inventory of Behavior (SIB; Schaeffer and Edgerton 1981, as cited in Rivers and Stoneman 2003) and the Sibling Relationship Scale (McHale and Gamble 1989, as cited in Rivers and Stoneman 2003); while Rao and Beidel (2009) utilized the Piers-Harris Self-Concept Scale, Second Edition (Piers-Harris 2; Piers and Herzberg 2002, as cited in Rao and Beidel) to assess the overall functioning of siblings of children with ASD.

Other Report Measures

Similar to the limitation noted earlier in assessing child outcomes, one notable shortcoming in the assessment of parent and family functioning is the lack of use of other-report measures. While report on internal states such as stress and self-efficacy clearly lends itself to self-report measures, these reports may be biased by social desirability or expectancy effects following treatment. As a result, it may be beneficial to incorporate ratings of parent and family functioning from teachers, treatment providers, or other individuals with sufficient knowledge of the family whenever possible. Further, utilizing reports of spouses, children (including the affected child) should provide a more comprehensive picture of relationship quality, family functioning, and parent–child interaction. Finally, as is common across the social sciences, most studies assessing caregivers of children with ASD to this point have focused on the experience of mothers. As research reviewed above suggested significant differences between maternal and paternal caregivers in terms of the impact of having a child with ASD, it is recommended that all primary caregivers be included in assessment of parent and family outcome whenever possible.

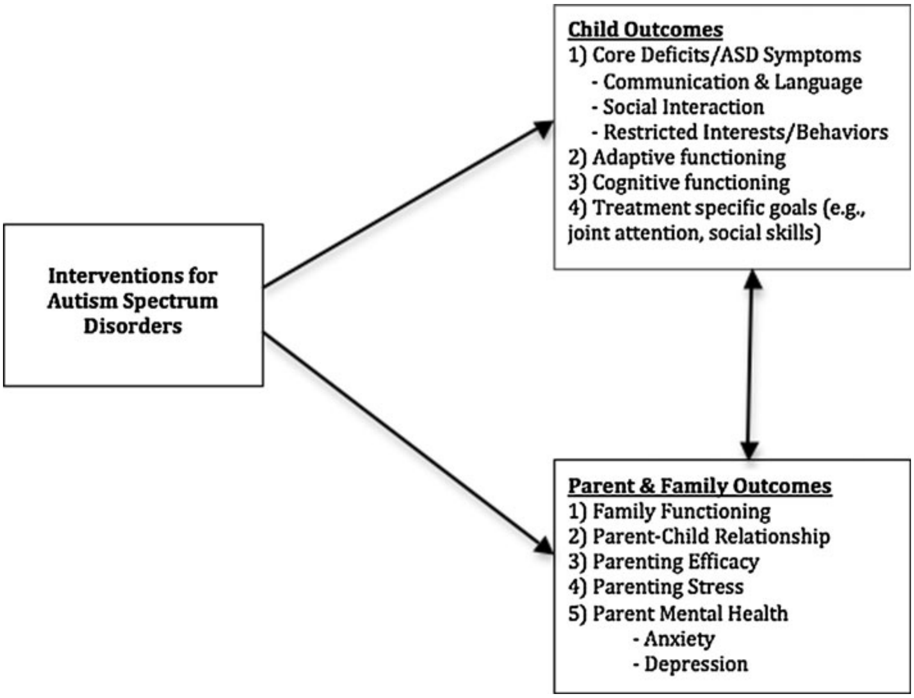
Conclusions and Integration: A New Model for ASD Treatment Evaluation

In consideration of the research reviewed to this point, it is suggested that: (1) ASD deficits are severe, pervasive, variable, and dynamic; (2) These deficits are associated with numerous difficulties in parents and families of children with ASD in domains such parenting self-efficacy, parenting stress, parents' mental and physical health, marital, sibling, and family relationships, and overall family well-being; (3) The impact of ASD on caregivers, siblings, and the family system likely has a reciprocal negative effect on children with ASD, creating a negative feedback cycle that could ultimately mitigate positive effects of intervention; (4) There are a wide range of interventions available for children and adolescents with ASD, with varying intensity, form, and function of parent and family involvement, which appears to be a critical component of effective therapy; (5) Evaluation of ASD therapies is often limited to assessment of the child, without consideration of the treatment's impact on parents and families, regardless of the extent of their involvement.

In a review of the difficulties associated with evaluating psychosocial interventions for ASD, Lord et al. (2005) included the following recommendation: "Modification of existing measures and creation of new measures of outcome in autism should be a high priority in order to document the goals for and effects of treatment. Areas of special interest include measures of parent–child interaction, family satisfaction, negative effects of treatment, and semi-structured observations or probes for targeted areas of change identified by parents or teacher of individuals with autism" (Lord et al. 2005, p. 705). Later, Meirsschaut et al. (2010) noted that intervention outcomes would be enhanced by consideration of parent mental health as well as improved understanding of how parenting cognitions (e.g., self-efficacy) can impact the intervention process. These recommendations echo previous suggestions for child therapy research by Kazdin and Weisz (1998), who noted that parent factors such as stress, mental health, and marital quality significantly influence the nature of childhood impairment and response to intervention and thus are important factors to consider when assessing the empirical support behind child and adolescent treatments. However, comprehensive evaluation of parent outcomes remains extremely limited in the ASD intervention research. Studies that have included assessment of parent outcomes have typically either assessed parent-training interventions or are significantly limited in other aspects (e.g., sample size, lack of randomization among groups). Furthermore, no existing studies have evaluated parent outcomes and child outcomes concurrently and interdependently in order to formulate a comprehensive understanding of how changes in parent and child functioning throughout and following treatment affect one another.

Therefore, a model for the evaluation of interventions for ASD is proposed (Fig. 1). This model is intended to be prescriptive in nature, encouraging those engaging in the ASD intervention outcome research to include parent and family assessment measures such as those described earlier. The proposed model includes two primary domains, which have been demonstrated by research to be interrelated. Both domains include multiple subcategories that can and should be modified based on the scale and scope of the study, though the model does not elaborate further on the notably complex, dynamic interaction among constructs. Ultimately, it is recommended that the two primary domains (parent and family outcomes and child outcomes) be consistently evaluated both as outcome measures of interventions and in context of their relationship with one another. The model is transactional, considering both the direct impact of intervention on the family, parent, and

Fig. 1 Proposed model of treatment evaluation



child and taking into account how changes in each of these domains affect one another and, reciprocally, the intervention process itself. This model of treatment evaluation thus follows but redistributes the five dimension model of treatment outcome evaluation proposed by Hoagwood et al. (1996), which included symptoms and diagnosis, functioning, consumer perspectives, environments, and system (SFCES model). In consideration of the SFCES framework, the proposed model assesses at the symptoms and functioning of both child and parent, the overall functioning of the family and the family environmental chaos, and the systemic interactions present among the child, siblings, and caregivers. The redistribution of variables into two primary domains helps clarify the transactional nature of the relationship between childhood ASD deficits and parent and family distress, while still capturing the "dynamic and interactional interplay between the child and his or her environments over time" (Hoagwood et al. 1996, p. 1061). From a theoretical standpoint, this model also incorporates the transactional nature of early development described by Sameroff and Fiese (2000), who noted that complex and interactive processes contribute to the development, maintenance, and transformation of childhood developmental concerns. Further, it borrows from the ecological model of human development proposed by Bronfenbrenner (1979, 1986) as well as family systems theory (e.g., Minuchin and Fishman 1981) in supposing that a change in any dimension of the family has impact on other individuals and relationships.

Understanding therapy outcome, therefore, necessitates understanding the direct impact on the family as a whole—the parents, child, and siblings—as well as the impact on interrelationships. Ultimately, data amalgamated from studies using this model may be used to develop and test nuanced models describing the interplay among child, parent, and family variables, which in turn will help facilitate more improved understanding of "effective ingredients" (Kazdin and Weisz 1998, p. 30) of therapy. At this time, however, simply knowing more about how various ASD treatments impact parents and families is of primary necessity. The proposed model should not only be applied to modalities of intervention with direct parent and family involvement. In fact, many therapy models incorporating caregivers, such as parent training models, have included some evaluation of parental outcomes as they are the direct receiver of treatment in these instances. The greatest "gap" in current ASD intervention research is within therapeutic contexts that do not directly involve, but no doubt affect, parent and family functioning. This omission has resulted in incomplete understanding of therapeutic impact as well as factors contributing to long-term maintenance or sustained growth following treatment.

The two primary domains in the proposed model include (A) Parent and family outcomes, which should include assessment of family functioning and well-being, the parent–child relationship, parenting efficacy and sense of competency, parenting stress, parent mental health (specifically, anxiety, and depression), and any other factors deemed appropriate for a particular intervention; and (B) Child outcomes, which should include evaluation of core deficits and ASD symptoms, adaptive functioning, cognitive functioning, and any treatment-specific goal or targets (e.g., behavioral problems, joint attention, social skills, repetitive behaviors, etc.). It is imperative that examination of therapies for ASD address both of the primary domains, as to omit measurement of changes in either sphere is to ignore the context in which children develop and in which ASD interventions are delivered, applied, and/or maintained. The subcategories included in this model appear important based on an extensive review of current ASD literature, which suggested that these domains are often impacted by having a child with ASD and/or that improvement in these domains appears beneficial to the development and therapeutic success for children with autism. Further, we believe the domains included have a greater likelihood of changing as a result of intervention than other, potentially more static constructs such as treatment motivation. The proposed model includes a broad assessment that looks at individual as well as relationship-based variables, encompasses cognitive (e.g., parenting efficacy), behavioral (e.g., the parent–child relationship), and emotional (e.g., parenting stress) processes, and provides an understanding of overall parent and family functioning. While other relevant variables can and should be incorporated in each domain as deemed appropriate for any specific intervention, a balance between comprehensiveness and parsimony must be considered. As noted earlier, both parent and family outcomes as well as child outcomes should be assessed by multiple informants. Assessment of the child should include self-report when possible, along with reports of both maternal and paternal caregivers, teachers, and other primary caregivers. In addition, parent and family outcomes will be most valuable if they include information from all involved caregivers and siblings. When possible, reports of parents should also be completed by their spouse, the affected child, therapists, or other treatment providers. Ultimately, use of this model has broad implications for clinicians and researchers seeking better understanding of the factors affecting ASD intervention processes and outcomes.

Therapy is a dynamic process, and the proposed model should be incorporated in measuring parent and family variables before therapy is initiated, throughout treatment, immediately after intervention, and beyond (i.e., with long-term follow-up evaluations). Assessment of parent and family factors before treatment will help providers develop a better understanding of both strengths and barriers in the child's family environment (Krauss 2000; Meirsschaut et al. 2010). Identifying areas of general or relative weakness within the family system would allow for more focused attempts to provide support in these domains. Rather than accepting factors such as low treatment motivation as an inherent therapeutic barrier, specific characteristics of parents and families that may be contributing to such roadblocks can be addressed. For example, if parents report low parenting efficacy prior to treatment, enhanced efforts could be made to offer psychoeducation to caregivers as well as support and reinforce positive parenting techniques that are demonstrated or reported over the course of therapy. If it is not possible to incorporate parent and family support into existing treatment techniques, referrals for appropriate, empirically supported treatments could be made. In some cases, these recommendations may even need to be addressed prior to beginning therapy. While this may slightly delay the onset of treatment, this seems preferable to allowing parent or family factors to ultimately reduce the effectiveness of intervention (e.g., Osborne et al. 2008). Caregiver and family strengths that are identified prior to treatment can also be capitalized upon to enhance the effectiveness of therapy as well as address more problematic domains. For example, if a parent identifies high levels of parenting stress, but also reports strong relationships between the diagnosed child and a typically developing sibling, therapists could work to identify how this dynamic could help reduce parenting stress (e.g., the typically developing sibling helping her brother or sister with homework).

As pre-treatment factors are identified and addressed, it also seems important to continue monitoring how these issues change over time. In the previous example, clinicians would want to ensure that the sibling relationship did not begin to deteriorate as a result of the changes made. Further, continued assessment through treatment may be helpful in addressing unexpected setbacks in treatment as well as unpredicted problems for parents and families that otherwise may be unnoticed. This may be especially true in with this population, given that children with ASD are less likely to freely offer information about themselves or their families. These factors could change as a direct result of therapy, as parents are faced with the time and financial burden of treatment and are often asked to take on new parenting tasks. For example, the Program for the Education and Enrichment of Relational Skills (PEERS; Laugeson and Frankel 2010), a social skills group for adolescents with ASD, begins with teaching basic skills but soon asks parents to facilitate regular "get-togethers" for their teen. If and when these get-togethers do not occur, it would be helpful for treatment providers to identify specific factors that were impeding completion of this therapeutic "assignment." In addition, factors ostensibly unrelated to therapy (e.g., the loss of a job) could have a significant and negative impact on parents and families, and thus, limit the benefits of intervention. However, without regular assessment of caregiver and family variables, clinicians may be unaware of significant events or changes that are affecting treatment.

Finally, parent and family factors should be measured near the conclusion of treatment and should be considered an indicator of the overall benefits of therapy, along with measures of child outcome. This model would this help clinicians determine whether parents and families had benefitted from treatment, particularly within domains that appeared to be negatively impacted at the outset of treatment. Further, this assessment could serve as a marker of family readiness to utilize techniques suggested during treatment and/or ability to continue finding appropriate support and intervention for their child. Ultimately, the incorporation of this treatment model provides the clinician with a way to assess the overall functioning of the parent and family from the beginning of treatment to any point in the future. It the child has regular scheduled follow-up visits following the completion of an intervention, or if the family returns to treatment citing a plateau or drop-off in gains that had been made, prior assessment of parent and family variables will help the clinician to more quickly troubleshoot the situation, understand factors that are likely impeding continued progress, and make changes or referrals as appropriate.

The benefits of incorporating this model for the evaluation of ASD therapies extend beyond clinical purposes to the controversial and complex field of therapy outcome research. Longitudinal analysis incorporating this model will improve understanding of the relationship among the domains included and give insight into primacy or causal relationship among deficits. Currently, most of the literature on parent and family factors impacted by ASD involves studies assessing one factor in a cross-sectional design. Additionally, very few studies sought to explore the relationship between parent and family deficits and child symptomology or behavior. These limitations have limited the comprehensive understanding of how the family is impacted by having a child with ASD. Most importantly, the lack of long-term studies has limited the extent to which researchers can link having a child with ASD to specific impairment in caregivers or families. As noted earlier, there is a great deal of evidence supporting this hypothesis, but more longitudinal research will provide a greater evidence base from which to operate and clarify the relationships among the variables discussed in this paper. Further, there is a dearth of research assessing interrelationships among constructs across the whole family. How does maternal parenting stress interact with paternal parenting efficacy, or vice versa? Further, how do unique combinations of parenting or family factors impact the affected child? There are innumerable “combinations” of factors to consider, but recent studies that have assessed at least two factors simultaneously (e.g., Benson and Karlof 2009; Pakenham et al. 2005; Rao and Beidel 2009; Smith et al. 2010a, b) have provided a great deal of practical and important information regarding the ways in which parent, family, and child characteristics interact.

Further, use of this model will provide greater insight into the effectiveness of ASD treatments. Longitudinal research throughout treatment may help develop better understanding of the components of treatment that are most meaningful or beneficial to parents and families, which is an important factor in understanding therapeutic benefit (Kazdin and Weisz 1998). The intensive nature of most ASD interventions suggests a need for better understanding of the components of treatment driving change. Thus, this model will facilitate enhanced understanding what aspects of intervention help the child by gaining insight into environmental changes that occur throughout therapy. In addition, incorporating parent and family factors into assessment of ASD intervention should help to understand what factors promote continued child gains throughout and following treatment. Importantly, this may be different depending on the modality of therapy. For example, children in ABA may benefit most from a decrease in family chaos, as the highly structured nature of this intervention often necessitates having predictable routines, rewards, and consequences. Conversely, children in more relationship-based intervention may be more affected by changes in the parent–child relationship or changes in parental emotional functioning, as this type of treatment emphasizes the parent–child interaction as a way of facilitating greater socio-emotional understanding in the child with ASD. These examples are purely speculative, but suggest the ways in which intervention research would benefit from greater understanding of the parent and family variables that are so often omnipresent in the child’s environment. One of the major advantages of psychosocial interventions is the impact that they can have long after therapy has concluded. However, long-term treatment follow-up research is often limited by incomplete understanding of what has helped the child maintain gains, or conversely, what has contributed to a plateau or loss of therapeutic benefit. Kazdin and Weisz (1998) recommended enhanced understanding of how changes are maintained in assessment treatment outcomes. Incorporation of parent and family factors into therapy outcome research will help fill the void that often exists between the end of treatment and the time of scheduled follow-ups, giving context to the environment that the child with ASD has been in since therapy concluded.

The proposed treatment evaluation model can be incorporated within a variety of methodologies, but would be best utilized in longitudinal intervention research with assessments taking place before, during, and immediately after therapy as well as at any long-term follow-ups. In addition to assessing for statistical significance and effect size, these domains could be evaluated with respect to clinically meaningful change (Jacobson and Truax 1991) to help fully understand the practical benefits of interventions to parents and families. Further, the variables recommended in this model should be assessed for both main and interaction effects in order to best capture and understand the complex and interdependent relationship among the constructs. Finally, additional variables can and should be added if appropriate. If similar outcome measures are utilized, this would eventually allow for more comprehensive comparison among ASD treatments, giving families a better understanding of each particular intervention's risks and benefits. The complexity of analyzing all of these domains concurrently and over time is great, but the risk of not doing so when evaluating the effectiveness of ASD interventions far outweighs the enormity of the task required.

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