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Advances in Supporting Parents in Interventions for Autism Spectrum Disorder

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INTRODUCTION

Recent data suggest that 1 in every 44 children are diagnosed with autism spectrum disorder (ASD).¹ ASD is a highly heterogeneous neurodevelopmental disorder that presents along a spectrum of differences and challenges in social interaction and communication accompanied by restricted interests and repetitive behaviors.² Research has shown that early intervention is key in improving the lives and wellbeing of autistic individuals and individuals with ASD.^a As such, there is an urgent need for the early identification of ASD to accelerate linkage to early intervention services. Routine ASD screenings can take place in pediatrician offices during 18- and 24-month well-child visits, followed by referral for further evaluation along with concurrent referral to early intervention. Many early interventions include parents and caregivers as a key component of implementation to increase the child's exposure to intervention strategies as well as the child's generalization of skills. Caregiver involvement in intervention can be considered a caregiver-mediated or caregiver training intervention.³ Caregiver-mediated interventions refer to those that focus on teaching parents and caregivers how to target core features of ASD, such as social interaction and communication skills. In contrast, caregiver training interventions refer to those that train caregivers on behavioral techniques for decreasing maladaptive behaviors for children with ASD.³ Largely, this research has focused on the feasibility and acceptability of teaching treatment strategies to caregivers as well as the effectiveness for improving child outcomes. There is an emerging interest in telehealth models for caregiver-implemented interventions as well as caregiver support models for removing barriers to treatment implementation. The focus of this clinical review is to describe recent

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DISCLOSURE

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advances in (1) caregiver-mediated interventions that aim to improve social interaction and communication for children with ASD, (2) caregiver training interventions for reducing challenging behavior, and (3) specific strategies to support caregivers and improve the effectiveness of these interventions.

Supporting Social Interaction and Communication

Social interaction and communication challenges comprise a hallmark feature of ASD. The average age of ASD diagnosis is between 4 and 5 years,⁴ yet communication differences can be observed as early as 9 months in infants later diagnosed with ASD.⁵ Some of the first social-communication skills to emerge in infancy include shared facial-expression and eye gaze, gestures such as showing and giving, and directed vocalizations. Following the onset of first words at around 12 months, additional social-communication skills include coordinating the use of eye contact, gestures, and words as well as combining words to form phrases and sentences. Following the onset of fluent speech and communication, pragmatic language skills, such as conversational turn-taking and context-driven changes in communication style become critical.

Social-communication skills can be supported in infants and children with ASD using naturalistic developmental behavioral interventions (NDBIs). NDBIs are a set of intervention approaches that incorporate the following empirically based components: intervention delivery in natural settings within everyday play- or routine-based contexts, use of activities that are child-preferred and motivating, intervention targets that are informed by developmental science, and intervention strategies based on behavioral principles (eg, antecedent, behavior, consequence).⁶ Examples of such NDBIs include Pivotal Response Treatment,⁷ the Early Start Denver Model,⁸ Early Social Interaction,⁹ JASPER,¹⁰ and ImPACT.¹¹ Caregiver involvement in NDBIs is common practice, but it is especially crucial in the infant and toddler period when play and daily routines are frequently mediated through caregivers.

A surge of interest in caregiver-mediated interventions has occurred over the past decade, and a recent systematic review identified 54 studies of family-mediated interventions that focus on social interaction and communication.¹² The primary goals of these studies were to teach caregivers to implement the intervention with fidelity (ie, deliver the intervention accurately as it was intended) and to improve child skills. To accomplish this, caregivers meet with a trained therapist who teaches the intervention using live modeling, video modeling, role play, and practice with feedback. For example, Project ImPACT¹¹ is a 24-session manualized caregiver-mediated intervention that targets 4 core social-communication skills: social engagement, language, imitation, and play. During each session, a trained therapist meets with the parent and child to discuss the topic of the day, model intervention strategies with the child, observe the parent practice the strategies with the child, and provide in vivo feedback on intervention implementation. The therapist then provides homework assignments to practice the strategies during daily routines at home. Preliminary results suggest that Project ImPACT significantly increases parent adherence to treatment, improves child social and communication skills, and decreases parent stress and depression.¹³ As another example, the parent-mediated JASPER model, is an 8 to

10-week program that teaches parents strategies for improving the frequency of social communication and play acts.¹⁴ Through didactic instruction, therapist modeling, and practice-with-feedback, parents are taught to identify the current play and communication level of their child, follow their child's interests, and insert opportunities for the child to initiate joint attention and engage in joint play routines. Results across multiple studies demonstrate effectiveness in improving joint engagement with a caregiver, responsiveness to joint attention, and diversity of play skills.^{14,15} Overall, studies on family-mediated interventions for improving social interaction and communication suggest that these teaching strategies are generally effective in improving caregivers' skills in intervention implementation, resulting in improvements in a variety of child social behaviors, including social engagement, communication skills, and reciprocal social interactions.¹² Some studies also report improvements in parent stress, mental health, and parenting confidence following parent-mediated social-communication interventions.^{16,17}

While intervention programs are tailored to the individual skills and motivating activities of each unique child, very little research has been conducted to individualize caregiver-mediated approaches within the unique needs of the caregiver and family context. A recent study showed that parents with high levels of stress before intervention have better outcomes with a lower-intensity intervention, whereas parents with lower stress benefited more from a higher intensity intervention.¹⁸ Parent stress, socioeconomic strain, and autistic traits have also been associated with child outcomes.¹⁹ In general, parents of children with ASD experience heightened levels of stress and mental health challenges²⁰ and caregiver-implemented interventions result in small, but significant improvements in parenting confidence and, to a lesser degree, mental health.¹⁷ Continuing this emerging line of work will be essential in developing effective and highly tailored coaching strategies.

Telehealth models of caregiver-mediated interventions for social communication are also of particular interest to increase access for rural and lower-resourced families. Synchronous, asynchronous, and hybrid models of remote social-communication NDBIs have been explored, demonstrating the feasibility and preliminary effectiveness for teaching caregivers intervention strategies and improving child social-communication skills, including language, eye contact, and social engagement.^{21,22} Some research suggests that telehealth approaches and in-person models result in similar outcomes,¹² while other studies suggest that in-person models are more beneficial.²¹

Interventions for Reducing Challenging Behavior

Challenging behaviors, although not included in the diagnostic criteria for ASD, are common in children and youth with ASD.²³ Current prevalence estimates suggest that 56% to 94% of children with ASD engage in one or more challenging behaviors,^{23,24} including aggression, tantrums, self-injury, and property destruction. Challenging behavior can adversely impact the individual's quality of life as well as that of their family, limit access to typical educational and community settings, and increase parental stress. Thus, challenging behavior is a critical treatment target for many individuals with ASD and an area in which caregivers may need significant support.

Researchers have identified numerous empirically supported interventions to address challenging behavior that is rooted in the field of applied behavior analysis (ABA)²⁵ and an understanding of how events in the environment affect behavior. Specifically, effective intervention begins with identifying the function of challenging behavior, or the conditions under which it is likely to occur. Then, a function-based intervention can be developed with strategies that address the purpose of the behavior.²⁶ Central to this approach is an emphasis on teaching and reinforcing appropriate behaviors to build adaptive skills and to prevent challenging behavior from reoccurring in the future.²⁷

Ample research supports the effectiveness of teaching caregivers of children with ASD to implement interventions for challenging behavior^{28,29} and suggests that practice and feedback are integral aspects of effective training because they improve caregivers' implementation fidelity.³⁰ Unfortunately, the inclusion of practice and feedback in such training can be resource-intensive. Further, therapists who deliver effective caregiver training need specialized knowledge not only about ABA, ASD, and challenging behavior but also about family-centered practice and caregiver coaching.²⁹ Taken together, these factors can result in reduced access to high-quality caregiver training that maximizes both child and family outcomes.

Recently developed intervention models, including Research Units in Behavioral Intervention (RUBI),³¹ Prevent-Teach-Reinforce for Families (PTR),³² and An Individualized Mental Health Intervention for ASD (AIM HI),³³ focus on scaling up and increasing caregiver access to high-quality training on empirically supported interventions for challenging behavior. Critically, each model includes key ingredients of effective training (ie, caregiver practice and feedback). In addition, each model is manualized and thus can be implemented with consistency by therapists without extensive training in ABA or ASD and who practice in existing service systems such as early intervention and community mental health.

RUBI is a manualized, 16-week caregiver training program for challenging behavior that has been implemented in both individual³¹ and group formats.³⁴ RUBI includes instruction, discussion, modeling, and role play with feedback; caregivers are assigned homework to complete between sessions. Home visits and booster sessions may also be included in the program. Researchers have found that RUBI produces larger decreases in parent-rated child challenging behavior than parent education when implemented individually with families,³ and that RUBI can be effectively delivered via telehealth to further increase access.³⁵ Preliminary research also suggests that RUBI is feasible for group delivery in a community-based clinic.³⁴

PTR is an intervention model for persistent challenging behavior that incorporates empirically supported strategies and is based on positive behavior support.²⁷ Positive behavior support is an approach to addressing problem behaviors that focuses on improving the target individual's quality of life by increasing their functional and social skills through evidence-based interventions that fit within the natural environment.³⁶ Originally developed for school systems, PTR has been adapted^{29,37} and manualized for use with families.^{32,38} PTR involves a facilitator collaborating with the caregiver to identify the function of

specific challenging behavior and develop an individualized function-based intervention that is tailored to the caregiver's preferences, values, and context. The facilitator teaches the caregiver to implement the intervention using modeling, coaching, and feedback. Researchers have served as facilitators in most studies of PTR with families; however, in a notable exception, Rivard and colleagues³⁹ trained early interventionists to implement PTR with families and reported promising outcomes on parent stress, child challenging behavior, and child-appropriate behavior after the 12-week intervention.

Unlike RUBI and PTR, AIM HI³³ is a therapist training model focused on increasing provider capacity to assist families of children with ASD who engage in challenging behavior. AIM HI is designed to be implemented within ongoing mental health treatment and includes training for therapists in empirically supported interventions for challenging behavior and a manualized protocol to structure sessions with the caregiver and child. Similar to PTR, in AIM HI the therapist and caregiver collaborate to identify the function of the challenging behavior and select function-based intervention strategies. The therapist teaches the caregiver how to implement the intervention strategies during subsequent sessions using modeling, active practice, and feedback. A recent cluster-randomized clinical trial demonstrated significant decreases in the intensity and severity of child challenging behavior⁴⁰ and significant increases in parent-reported competence⁴¹ following AIM HI as compared with routine care (ie, typical therapy in the community mental health clinic).

While these models of supporting caregivers can decrease cost and increase access to high-quality training, caregivers may still experience barriers to participation related to therapist capacity and logistics of attending trainings.⁴² Families of young children with ASD may access funding for behavioral services and supports through a variety of service systems, including Part C Early Intervention, Medicaid, and private insurance. However, it can be difficult for families to navigate these complex systems and even when they do, they may be placed on a wait list for services due to therapist capacity limitations. In addition, researchers have identified racial, ethnic, and socioeconomic disparities in service use by families who have a child with ASD. Clinicians can support families in accessing services by providing information about available services in a culturally responsive way and by focusing on the coordination of care. Making behavioral supports available in the local community can reduce transportation costs and logistical barriers related to travel, and providing child care during parent training may also increase access for underrepresented groups.⁴³

Technology can also be leveraged to reduce some of these barriers. Telehealth can reduce travel time and costs, and it can be as effective as face-to-face training for supporting families in addressing challenging behavior.⁴⁴ Asynchronous support, such as online training programs and apps, can make empirically supported interventions more accessible to families and circumvent shortages in providers who are qualified to train families.⁴² For example, Barton and colleagues⁴⁵ developed the Family Behavior Support App, which prompts caregivers to enter information about their child's challenging behaviors and then uses algorithms to suggest individualized, function-based interventions tailored specifically to the child. The app also includes supplemental training videos to support caregivers' implementation of intervention strategies.

Strategies to Enhance Caregiver Implementation

The aforementioned interventions have strong evidence to support their effectiveness in addressing challenging behaviors and social communication differences in children with ASD. However, the effectiveness of caregiver-implemented interventions depends, in large part, on caregivers' ability to use the skills correctly and consistently in everyday life. This is no small task, given a large amount of time, energy, and expense required to achieve significant child improvements. A recent systematic review found that parent-implemented interventions required parents to participate in training between 2 and 48 hours over periods ranging from 5 weeks to 2 years.⁴⁶ Parents were also asked to devote regular time to implementing the intervention with their child (30 min/d to 20 hours per week).⁴⁶ Caregiver-implemented interventions require caregivers to learn new ways of thinking, acting, and communicating with their child. Changing habitual patterns of caregiver-child interaction requires consistent effort and focused attention without an immediate reward as child behavior change often happens over a period of weeks and months. Therefore, caregiver motivation and social-emotional support are vital to success.

Caregiver stress and interventions

A high level of chronic stress can impede intervention implementation because it reduces a caregiver's ability to learn new concepts and skills, regulate their emotions, and stay "tuned-in" to their child.^{47,48} Therefore, clinicians are encouraged to assess caregivers' current level of stress and anticipate the potential impact of any proposed intervention. Introducing a new ASD parenting intervention was found to decrease parent stress in some studies and increase stress in other studies.⁴⁹ On the one hand, parents gain confidence and parenting efficacy as they receive guidance and learn new skills for helping their child grow. On the other hand, they are learning a number of complex strategies and shifting time and energy away from other family members and responsibilities.⁴⁹ Some parents may also experience stress and frustration if the new parenting skills are inconsistent with their parenting style or cultural beliefs about parent-child relationships.⁵⁰

One strategy researchers are using to address parent and caregiver stress is combining caregiver-implemented interventions with stress-reduction interventions. Andrews and colleagues⁵¹ combined Acceptance and Commitment Therapy (ACT) with the RUBI program in an online format and found promising results for parent implementation and child challenging behaviors. ACT is a mindfulness and values-based intervention that reduces parent stress by promoting psychological flexibility and value-consistent action.⁵² Weitlauf and colleagues combined Mindfulness-Based Stress Reduction (MBSR) with the parent-implemented Early Start Denver Model (P-ESDM) and found lower parental distress and greater parent mindfulness when compared with parents receiving P-ESDM alone.⁵³ Hence, evidence to date suggests that adding stress reduction training to parent-mediated ASD interventions successfully reduces stress among parents of children with ASD. It is not yet clear whether such programs improve parenting skill implementation, or whether they can be feasibly delivered in diverse community settings.

Reducing intervention burden

Perception of treatment burden is a predictor of treatment adherence for caregivers of children with ASD.⁵⁴ As such, a number of strategies have emerged to reduce the burden of interventions on caregivers and families. Online and telehealth delivery strategies have been developed for several caregiver-implemented interventions for ASD. By leveraging technology, these programs reduce travel time, allow for more flexible scheduling, and reduce the family disruptions that can result from clinic-based and home-based interventions. Perhaps more importantly, they provide access to evidence-based parenting strategies in communities whereby none exist. One systematic review identified several technology-assisted parent-mediated interventions that use diverse delivery formats including: DVD's (animated children's shows and parent training), app-based games and programs, self-paced computer courses with videos and self-quizzes, weekly virtual coaching with a trained clinician, and augmented reality glasses providing real-time emotion feedback to the child.⁵⁵ The researchers concluded that these interventions are feasible to deliver and acceptable to parents, but that their effectiveness as standalone interventions has not yet been adequately demonstrated.⁵⁵ Other strategies for reducing burden include providing childcare and respite care to assist with other caregiving responsibilities, offering flexible appointment times including nights and weekends, and helping parents strengthen their informal support networks with people who can provide emotional and practical support (eg, other parents of children with ASD, extended family, neighbors, friends, church).

One of the most powerful and often overlooked sources of support for parents is other family members. Most caregiver-mediated interventions are conducted with the primary caregiver alone.⁴⁹ This places additional responsibility on the primary caregiver to educate and obtain buy-in from other caregiving adults and child siblings. Additionally, the effectiveness of the intervention can be dampened if family members, particularly coparents, undermine intervention strategies when they are with the child. Conversely, coparent support and coordination are associated with increased parenting efficacy and reduced stress among parents of children with ASD.⁵⁶ For these reasons, clinicians are encouraged to educate all family members about the purpose and process of the intervention and why it will work. Including family members in the intervention process whenever possible reduces the burden on the primary caregiver to be the "champion" of the intervention. Research has shown that including other caregivers and siblings during intervention delivery improves parent-child, sibling, and marital relationships.

DISCUSSION

Best care practices for children with ASD involve caregivers in intervention implementation (for a summary, Table 1). Interventions that adopt naturalistic, developmental, and behavioral approaches are effective for improving some of the hallmark features of ASD—social interaction and communication. Studies of caregiver-mediated NDBIs have proven their effectiveness while also identifying barriers to treatment implementation, including caregiver strain, stress, and mental health challenges.

Challenging behavior can be a significant stressor for individuals with ASD, caregivers, and the family system. Behavioral strategies that start with identifying the function of the challenging behavior are extremely effective but can require a high degree of expertise and detailed data collection. Caregiver training programs can teach caregivers how to identify functions of behavior and select specific treatment strategies that reduce challenging behaviors. Research shows that caregiver training can be effectively delivered at differing intensities in a variety of settings (eg, home, clinic, community). Access to such training is expanding with technology-based synchronous and asynchronous programs and phone-based apps.

Despite significant progress in caregiver-implemented interventions, substantial barriers to implementation remain. These include parenting stress and strain, caregiver mental health challenges, and accessibility, particularly in rural and lower-resourced communities. In recognition of these barriers, studies that focus on supporting caregivers, independent from child-focused interventions, are emerging. Direct integration of caregiver support strategies into intervention programs is a promising avenue for improving the overall well-being of families affected by ASD.⁴⁹

SUMMARY

Caregivers have become integral to intervention programs for infants and children with ASD and a range of evidence-based, caregiver-implemented interventions have been developed to reduce challenging behaviors and improve social communication. Interventions vary in complexity, mode of delivery, time commitment, and amount of family involvement. While caregivers should not be the sole source of intervention for children with ASD, their ability to incorporate treatment strategies throughout daily routines and activities can enhance developmental outcomes, reduce challenging behavior, and improve their sense of competence and efficacy.

Barriers to treatment implementation exist for caregivers, especially those who are lower resourced and experience high levels of stress and strain. Research on optimal ways to support caregivers is still emerging, but promising strategies include telehealth modes of delivery, coparenting support, and mindfulness-based stress reduction programs. Thus, physicians should consider a family's resources, availability, motivation, and level of stress to recommend interventions in which families are most likely to succeed.

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KEY POINTS

- Parents and caregivers should be involved in intervention programs for children with autism spectrum disorder (ASD) to improve developmental outcomes and reduce caregiver stress and strain.
- Caregiver-mediated interventions that use naturalistic, developmental, and behavioral approaches are effective for improving social and communication outcomes in infants and children with ASD.
- Strategies for reducing challenging behavior in children with ASD can be effectively taught to caregivers in clinic-, home-, and community-based settings.
- Individualized strategies that support caregivers of children with ASD can reduce burden, strain, and stress, resulting in increased caregiver wellbeing and improved child outcomes.

CLINICS CARE POINTS

- Naturalistic, developmental, and behavioral interventions are among the most empirically validated, caregiver-mediated treatments for improving social-communication skills in infants and children with ASD.
- Caregiver training models that use principles of ABA and focus on the development of function-based interventions are effective for reducing challenging behaviors in children with ASD.
- Caregivers of young children with ASD may access training and supports through Part C Early Intervention, Early Childhood Special Education, or ABA therapy funded by Medicaid or private insurance.
- Caregiver-implemented interventions are generally effective for improving parenting confidence, enhancing self-efficacy, and reducing caregiving stress and strain.
- Emerging research suggests that telehealth approaches to caregiver-implemented interventions are effective, but in-person models may be more beneficial for some.
- Strategies for supporting caregivers of children with ASD can include mindfulness-based stress reduction programs, tailored interventions for unique family contexts, and matching intervention approaches and dosage to parent stress levels and available resources.

Table 1

Features of autism spectrum disorder and associated caregiver-implemented intervention strategies

Features of Autism Spectrum Disorder in Childhood	Caregiver-Implemented Intervention Strategies	Intervention Examples
<i>Social Communication and Interaction</i>	<i>Naturalistic Developmental Behavioral Intervention Strategies for Supporting Social Communication</i>	<i>Teaching Social Communication</i>
Reduced verbal and nonverbal communication of interests, emotions, or affect Limited initiation of social interactions Limited understanding of gestures and body language Difficulty playing with others Reduced or atypical response to social engagement initiated by others	Follow the child's interests and provide opportunities to communicate within natural interactions Reinforce good attempts to communicate Provide opportunities for child to engage in joint play routines	During bath time, if the child reaches for the bubble bath, the caregiver can create an opportunity for the child to request "bubbles." When the child says a good approximation for "bubbles," the caregiver provides natural reinforcement by giving the child bubbles.
<i>Restricted Interests and Repetitive Behaviors</i>	<i>Function-Based Behavioral Interventions for Reducing Challenging Behavior</i>	<i>Reducing Challenging Behavior</i>
Reduced flexibility with routines and distress in response to small changes Hyper-fixation on certain objects or interests Restricted patterns of play (eg, lining up objects) accompanied by distress to outside interference Hyper- or hyporeactivity to sensory stimuli	Use functional behavior assessment to determine the function (or cause) of the challenging behavior Prevention or antecedent strategies include modifying the environment or increasing the predictability of a routine. Instructional strategies include teaching replacement behaviors and improving adaptive behavior skills Consequence strategies include differentially reinforcing adaptive behaviors	For a child who has difficulty transitioning between activities, a caregiver can use a visual schedule and visual timer to increase predictability and prepare for transitions. For a child who demonstrates challenging behavior when wanting an activity to stop, a caregiver can teach appropriate communication (eg, an approximation of "I need a break"), prompt for this communication at the onset or right before the challenging behavior, and reinforce attempts to communicate by providing a break.

Note: Features of ASD based on diagnostic criteria from the DSM-5¹.