

Caregiver-mediated approaches to managing challenging behaviors in children with autism spectrum disorder

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A significant proportion of children with autism spectrum disorder (ASD) are referred to mental health centers due to the presence of challenging behaviors. Because challenging behaviors in children and adolescents with ASD often result from underlying social and communication difficulties and comorbid anxiety, traditional caregiver-mediated behavior intervention techniques developed for children with disruptive behavior disorders may need to be adapted for this population. Behavioral interventions that target communication skills, social skills, anxiety, and sensory responsiveness in children with ASD may be needed. Notably, while best practice necessitates the involvement of caregivers in treating children and adolescents with ASD, few randomized control studies have examined the effectiveness of caregiver-implemented interventions in reducing challenging behaviors. This review summarizes the current literature with regard to caregiver-mediated behavioral interventions for children with ASD, and suggests areas for intervention development and research.

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Introduction

Imagine a 6-year-old boy with autism spectrum disorder (ASD) standing in the middle of the grocery store and screaming. Faced with his behavior and the glances she is receiving from others in the store, his mother tries to interpret his behavior and respond appropriately. Is he screaming because the store is full of people using eye contact and social smiles that he doesn't understand? Is he screaming because he is hungry, sees a cookie, and doesn't know how to ask for something to eat? Is he screaming because this isn't the same grocery store that he usually goes to with his mother? Is he screaming because he is overwhelmed by the bright lights in the store? Or, is he screaming because he was asked to put food in the shopping cart and he doesn't want to do so? In other words, is this behavior problem a result of the social-communication impairments, repetitive behaviors, or sensory interests that characterize individuals with ASD, or is this boy being noncompliant? In this moment, his mother attempts to choose an intervention strategy that fits with the underlying reason for his behavior problem. If his mother believes that he is hungry she might coach him to ask for

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a snack. If his mother believes that he is upset by the change in routine, she might use a visual schedule to show him what to expect in this new location. If her interpretation is accurate, then she is likely to see a decrease in his challenging behavior and have a more successful shopping trip with her son.

Children with ASD are often referred for mental health services to treat behavioral problems. Indeed, Mandell and colleagues¹ reported that 40% of children with ASD are referred for treatment of disruptive behaviors including aggression, noncompliance, and hyperactivity. From the above example, it is clear that: (i) an understanding of the underlying symptoms of ASD is necessary for successful management of challenging behaviors; and (ii) the involvement of caregivers in treating challenging behaviors in children and adolescents with ASD aids in generalization to community settings. Indeed, the involvement of caregivers has been identified as an essential component of a good treatment program.^{2,3} Caregiver involvement in treatment is not new. In fact, the utility of parents as interventionists has spanned over four decades, with Schopler and Reichler⁴ cited as being the first advocates for involving parents as cotherapists in the treatment of behavior problems in children with ASD. Parents are the child's natural teachers, and caregiver-implemented interventions have been documented to promote skill generalization and maintenance while also potentially reducing parental stress and increasing quality of life.^{5,6} The nature of caregiver involvement varies across programs, with some programs focusing on providing education to caregivers about the child's symptoms and other programs focusing on teaching caregivers specific techniques that can be used in the natural environment.⁷ While both approaches have been successful, in order for treatment effects to be maintained, the intervention program needs to be compatible with the family's daily routines.⁸

Traditional caregiver-mediated interventions designed to reduce behavior problems in children without ASD are typically geared toward treating noncompliance.^{9,10} In these interventions, caregivers are taught to facilitate appropriate behavior by using rewards, and to decrease noncompliance by using consequences including ignoring and time out. Little research has been conducted to determine whether these traditional behavior management strategies are effective at treating problem behaviors in children with ASD. Because it is often an underlying symptom of ASD rather than noncompliance that

leads to challenging behaviors in these children, a traditional behavior management approach focused on noncompliance may not be effective. There have been several case studies reporting the effectiveness of using a traditional parent-mediated behavioral intervention, Parent Child Interaction Therapy⁹ (PCIT), to decrease challenging behaviors in children with ASD.¹¹ These studies suggest that PCIT may be effective in reducing challenging behaviors, particularly when used with high-functioning children with ASD and when adaptations are made to target social skills. However, the use of ignoring is not recommended when targeting repetitive and self-stimulatory behaviors as the lack of social attention may actually provide increased opportunity to engage in these behaviors. Solomon and colleagues¹² conducted the only study to date that compared the effectiveness of a traditional caregiver-mediated behavioral intervention (PCIT) in a group of children with ASD and a waitlist control group. They found increased shared positive affect in parent-child dyads but no changes in parent stress or parent report of challenging behaviors compared with the comparison group. They noted the importance of building a parent-child relationship for children with ASD. Thus, caregiver-mediated interventions targeting challenging behaviors for children with ASD have not been consistently found to reduce challenging behaviors and may need to be adapted to meet the specific needs of this population. In a comparison of the caregiver mediated intervention literature for children with ASD and children with disruptive behavior disorders (DBD), Brookman-Frazee and colleagues¹³ reported striking differences in intervention techniques. While 100% of the DBD literature reported targeting parenting strategies and discipline techniques, none of the ASD literature targeted these skills. In contrast, 68% of the ASD literature targeted communication skills while none of the DBD literature targeted communication. Therefore, while mental health professionals may be tempted to treat challenging behaviors in children with ASD using traditional caregiver-mediated behavior intervention techniques, different techniques may be needed. In the present article, we describe current caregiver-based intervention approaches geared toward understanding behavior problems within the context of ASD symptomatology. Further, we review the literature on caregiver-mediated interventions treating the most common causes for behavior problems in this population.

Working with families to understand challenging behaviors

Schopler¹⁴ used an iceberg metaphor to explain behavior problems in children with ASD. When faced with a child's observable challenging behaviors (ie, those visible above the waterline), caregivers are encouraged to use their understanding of ASD to identify possible underlying causes for these behaviors (ie, those hidden below the waterline). This image supports the notion of conducting a functional behavior assessment to identify the communicative function or intent of a challenging behavior. Indeed, a functional behavior assessment has been recognized as a necessary component in designing interventions to understand and to modify behavior in children with autism.^{15,16} In the behavior analytic literature, the reason why children exhibit problem behavior is often described as either to obtain an item, escape a task, or to seek attention. However, in children with ASD the underlying reasons why children may engage in challenging behaviors may be related to autism-specific symptoms. In our example of the boy screaming in the grocery store, the social and sensory demands of the situation may have caused him to want to escape. In contrast, if his screaming was driven by hunger, then his behavior was a form of request. That is, the hidden explanation for his disruptive behavior may be the social, sensory, or communicative demands of the situation. An accurate functional assessment is vital in building effective *and* efficient behavioral supports.¹⁶

When working with families to conduct a functional behavior assessment and develop an intervention plan, Moes and Frea¹⁷ emphasized the importance of considering the family's own environment, values, and beliefs. They suggested that a contextualized behavior support assessment that examines more than just the child's behavior is important in increasing the compatibility between the behavioral intervention and family routines. In this approach, the emphasis is placed on the collaborative parent-professional relationship in developing behavior plans. Moes and Frea¹⁷ found positive outcomes for a contextualized behavior support plan with significant reductions in challenging behavior and an increase in compliance during the contextualized behavior phase. This suggests that developing sustainable plans (eg, compatible with family resources, constraints, beliefs, values, goals, abilities, and needs), may contribute to the generalization and maintenance of treatment gains.

In our own clinical work, we have found that the most frequent communicative functions of challenging behavior include frustration over inability to communicate, difficulties with social interaction, anxiety, and atypical sensory sensitivities. We review the literature in each of these areas with a focus on interventions that include caregiver-mediated approaches.

Behavioral approaches to improving communication skills

Because one of the functions of challenging behavior is communication, it is not surprising that a considerable amount of intervention research has focused on developing successful procedures for improving communication.^{18,19} In addition to improvements in verbalizations, mean length of utterance, and spontaneity of language use, successful communication intervention has been associated with decreases in problem behavior²⁰ and increases in positive affect.²¹ As a result, communication intervention is often a key component in caregiver-mediated behavior intervention programs.^{22,23} The replacement of challenging behaviors with appropriate and increasingly complex communication skills has the potential to have far-reaching implications for academic achievement, social relationship development, and vocational outcomes. If challenging behavior (eg, screaming in the grocery store) is a request (eg, for food), then the most effective interventions are directed at increasing appropriate spontaneous and functional communication. Clinically, this means that the child must learn to request using a system that is compatible with his/her mental age (eg, pictures, sign language, words). Further, the communication must be functional (eg, instead of learning to sign the word "more" it would be more effective for him to learn to sign the word "cookie").

There have been a number of behaviorally based communication intervention approaches designed to increase requesting skills, particularly focused on toddler and preschool aged children with ASD. Traditional applied behavior analysis approaches (eg, discrete trial training),²⁴ have been criticized for teaching prompt dependence (eg, the screaming boy in the grocery store would wait for a prompt before using his learned verbal skills to say "cookie"), and for limited generalizability across contexts (eg, he may learn to say "cookie" only in the grocery store). Thus, there has been an increased emphasis on naturalistic or child-directed behavioral

intervention approaches.²⁵ These more naturalistic behavior interventions include incidental teaching,²⁶ enhanced milieu teaching,²² and pivotal response training²⁷ to teach requesting and other communication skills. While there are differences among the approaches, naturalistic behavior models share common characteristics, including child choice (eg, teaching communication skills that fit with the child's interests; eg, the boy in the grocery store would learn "cookie" as a first word), intervention in natural contexts (eg, learning to communicate during family routines such as eating dinner), and the use of intrinsically related rewards (eg, the child would receive a cookie along with social praise). Results have indicated that, compared with the traditional structured models, interventions that are less structured and more child-focused result not only in faster learning by children with ASD,^{20,27} but also result in children displaying higher levels of affect²¹ and engaging in less avoidant and disruptive behavior.^{20,28}

As our ability to accurately diagnose autism in the first few years of life has improved, there has been an increased demand for intervention approaches that integrate developmental and behavioral approaches to target social communication skills in toddlers and preschool-aged children with ASD. Kasari's JASPER (joint attention, symbolic play, emotion regulation) program resulted in increased expressive language skills with continued gains 1 year post study completion.²⁹ This combined developmental and naturalistic behavioral approach was more effective than a more traditional applied behavioral intervention preschool program. Similarly, the Early Start Denver Model³⁰ incorporates behavioral and developmental strategies and has been associated with increased cognitive development and adaptive behavior. While not directly targeting requesting behavior, the focus on facilitating early social communication skills is designed to increase spontaneous communication skills and decrease challenging behaviors.

Most of these naturalistic interventions include a caregiver education/training component. The caregiver has an advantage as s/he can optimize learning moments throughout naturally occurring opportunities during daily activities within the home and community. This may be more successful than instruction occurring only during specified times, which may burden the family by requiring extra time and effort.³¹ Thus, naturalistic approaches are ideally suited for caregivers.^{7,32} Recently, a large community-based study found improvements for

up to 1 year in children's expressive and receptive communication and decreases in problem behavior with parents who learned how to implement pivotal response treatment.³³ Similarly, Minjarez and colleagues³² found significant increases in children's functional spontaneous speech for parents who participated in a communication intervention training where feedback was delivered based on the videotapes they brought in. However, more research is needed to determine whether caregiver-mediated interventions that combine developmental and behavioral approaches are effective at decreasing challenging behaviors.³⁴

Behavioral approach to improving social skills

Clinically, we often see behavior problems in children with ASD who are overwhelmed by social situations (eg, the child in a crowded grocery store) or who want to engage in social interactions but do not have appropriate initiation skills (eg, a preschool girl whose only way of initiating social interaction with siblings and peers is to pull their hair). While the boy in the grocery store may need to learn to request a break, the girl wanting to interact with her peers may need to learn a more appropriate way of initiating social interactions. Indeed, Bauminger and colleagues³⁵ reported that children and adolescents with high-functioning ASD may be interested in interacting with peers but do not have the knowledge about how to interact appropriately. In their study, children and adolescents with high-functioning ASD initiated and responded to peers about half as often as age- and IQ-matched children and adolescents with typical development. However, this decreased rate of social interactions may not be an indicator of a lack of interest in social interaction, as children and adolescents with ASD reported higher levels of loneliness than their peers with typical development.

A variety of skill-based intervention programs have been developed to teach social skills to children with ASD. While early intervention programs have focused on relationship-based approaches that combine behavioral and developmental techniques,^{29,30,36} approaches for older children and adolescents have focused on skill building. These skill-building programs have taught social scripts to teach specific nonverbal and verbal behavior for specific situations, social stories to teach social norms and expectations, role plays to provide opportunities for practice, and self-monitoring through

videotapes and checklists to increase self-awareness.^{37,38} Remarkably, few of the skill-building intervention programs have included caregivers as cotherapists, or even included a caregiver education component. In a review of 66 studies published in peer-reviewed journals between 2001-2008 targeting social skills, Reichow and Volkmar³⁸ reported that parent training was only measured as a main intervention variable in four studies, all targeted at improving social skills in preschool children. Thus, while best practices consider parent and family involvement as an essential element of intervention programs for children with autism,³ very few studies targeting social skills have included parents beyond the toddler and early childhood years. The inclusion of caregivers is particularly important when social skills difficulties lead to challenging behaviors in the home and community settings. Indeed, Kasari and Lawton³⁹ cautioned that current social skills intervention approaches using behavioral principles seem to train children to produce specific operationalized behaviors rather than facilitating learning and generalization of the behavior across contexts. They caution that many current interventions may teach “form” but not “function.”

Notably, two recent social skills intervention programs have incorporated parents into the intervention.^{40,41} Both studies utilized a group intervention approach to teach specific social skills. Frankel and colleagues taught conversation skills, peer entry, handling teasing, practicing good sportsmanship, and good host behaviors using Children’s Friendship Training. In concurrent sessions, parents were taught how to facilitate the use of these skills at home by arranging for supervised “play dates.” Compared with a delayed treatment control group, parents of children in the intervention group reported that their children showed increased social skills and other appropriate play date behaviors. Further, the children in the intervention group self-reported increased popularity and decreased loneliness compared with those who did not receive the intervention. In a study of the Skillstreaming approach, Lopata and colleagues targeted social skills, emotion recognition, and understanding of metaphoric language. Parents received a concurrent educational session focused on understanding symptoms of ASD and techniques for generalization of skills learned in the child intervention group. Compared with a delayed treatment control group, the intervention group showed increased parent-reported social skills. Further, children in the intervention group showed increases on

standardized measures of emotion recognition and non-literal language interpretation. Both studies are encouraging and suggest that caregiver-mediated social skills interventions may be more successful at increasing flexibility and generalization of skills to the community setting than traditional social skills intervention programs.

Cognitive behavioral interventions for anxiety

Many children with autism experience clinical significant levels of anxiety, with 11% to 84% of children and adolescents with ASD reported to have a diagnosable comorbid anxiety disorder.⁴² Anxiety symptoms are varied and can include behavioral outbursts (yelling, aggression), repetitive behaviors (asking repetitive questions, reciting television quotes, pacing), withdrawal, and refusal to engage in activities. These anxiety symptoms are often debilitating for the family and the child with ASD. For example, we saw a child in the clinic with an irrational fear of “black top” surfaces, which led to temper tantrums when he was asked to leave the car to walk across a store parking lot. The most common anxiety symptoms in children and adolescents with ASD are compulsive/ritualistic behavior and irrational fears and beliefs. Leyfer and colleagues⁴³ reported that 44% of the children and adolescents with ASD in their study experienced specific phobias and 37% experienced symptoms consistent with obsessive-compulsive disorder.

There is a growing literature on the use of adapted cognitive behavioral treatment (CBT) techniques to treat fears and irrational beliefs in ASD.⁴⁴⁻⁴⁸ Using CBT, children with ASD have been taught to identify their own anxiety, rate their anxiety levels, replace irrational thoughts with rational thoughts, and use progressive muscle relaxation routines (see Klinger and Williams³⁷ for a review). Several recent randomized control studies have been conducted examining the efficacy of CBT for treating anxiety in children with ASD.^{45,46,48,49} All of these studies showed significant reductions in anxiety. Approximately 58% to 64% of children who completed the CBT treatments no longer met diagnostic criteria for an anxiety disorder, compared with 0% to 9% of children in waitlist control groups. Further, several studies reported that these reductions were maintained 3 months after the intervention was completed.^{48,49} While most of these interventions do not include caregivers, Reaven and colleagues⁴⁶ Face Your Fears program

incorporated a parent component into their treatment protocol. Parents received education about anxiety symptoms and the relation between behavioral outbursts and anxiety. Parents were taught to identify their child's anxiety symptoms and to create graded exposure hierarchies to help their child "face" his/her fears. Parents became their child's "coach" throughout the CBT intervention and were able to continue using the strategies outside of group. Clinically, we have found that the involvement of caregivers in a CBT program provided a way for caregivers to understand the underlying reason for misbehavior. For example, we worked with a child whose fear of failure prevented him from completing his homework. Once his mother understood the underlying reason for his refusal to complete homework, they were able to work together to reduce his fear and help him become more successful at completing his homework without any outbursts. To date, there is no data on whether the incorporation of caregivers as coaches increases the effectiveness of CBT interventions for children with ASD compared with programs that only include children in the intervention protocol.

In addition to irrational fears and beliefs, ritualistic and compulsive behaviors are often indicators of anxiety in children with ASD. Because of difficulties with flexible thinking, students with ASD may prefer routines and become anxious when routines are altered. Children with ASD may exhibit anxiety by becoming disruptive when there is a deviation from the typical family routine (eg, when grandparents visit or when a vacation is scheduled). The use of a visual schedule can help to significantly reduce a child's anxiety and in turn, reduce the behavioral symptoms that accompany a new situation.⁵⁰ Using this preventive approach, caregivers are encouraged to use a daily schedule that lists the activities planned for each day. Schedules can include objects, pictures, or written words depending on each child's developmental levels. Rather than causing children to become more inflexible, a daily schedule provides an opportunity to indicate when a change is planned to reduce anxiety.⁵¹

Behavioral challenges as a result of sensory sensitivities

Sensory sensitivities are often identified as an underlying cause for challenging behaviors. For example, the child that screams in the grocery store may be bothered

by the fluorescent lights or by the loudness in the store. Indeed, Reese, Richman, Zarcone, and Zarcone⁵² reported that attempts to escape uncomfortable sensory situations explained disruptive behavior in 14% of the children with ASD in their sample. Clinically, atypical sensory processing has been attributed to three overlapping dimensions—hyperresponsiveness, hyporesponsiveness, and sensory seeking. However, little research has supported these dimensions. Recently, Brock and colleagues⁵³ identified sensory hyporesponsiveness in preschool-aged children with ASD. Despite the fact that it is commonly recognized that challenging behaviors are often exacerbated by atypical sensory processing in children with ASD, very little intervention research has been conducted in this area. Lang and colleagues⁵⁴ conducted a review of all research on sensory integration therapy (SIT). Only three of 25 studies included in the review considered SIT to be an effective therapy based on post-treatment measures. In contrast, 14 of the studies saw no improvement in children with ASD who had received SIT. Thus, to date the most effective approaches for decreasing behavior problems due to sensory sensitivities may be aimed at reducing the anxiety that usually arises as a result of these sensitivities.

Other considerations for utilizing caregiver-mediated behavioral interventions

It is important to consider family social and cultural factors that may impact the successful use of caregiver-mediated approaches. The requirements of an intervention approach often conflict with the caregiver's other time demands including workplace, siblings, spouse, and extended family. Further family cultural values must be considered, as any attempt to modify the caregiver's behavior without attending to cultural factors may be ineffective.⁷

Further, the chronicity of ASD and its impact of caregiver stress should be considered. Because behavior problems often arise from the underlying symptoms of ASD, caregivers are likely to face a lifetime of behavior management challenges. Thus, it is important to consider the impact of long-term caregiver stress on effective intervention implementation.¹² Indeed, raising a child with ASD is associated with higher levels of caregiver stress and psychological distress than raising a child with typical development or a child with another developmental disability.⁵⁵ Weiss and colleagues⁵⁵ reported that

the relationship between child behavior problems and parent mental health is mediated by psychological acceptance. That is, those parents who were able to accept the challenges of living with a child with ASD showed fewer negative mental health consequences. They argued that caregiver-mediated interventions need to focus on positive coping strategies in addition to the problem focused strategies discussed in this article. Furthermore, researchers have suggested the importance of individualizing treatment by matching the intensity of the intervention to the caregivers' stress level.⁵⁶ Another consideration for caregiver-mediated intervention programs is how the program content is presented and taught to the caregivers. In a meta-analytic review of program components associated with parent training effectiveness for children with externalizing disorders, Kaminski and colleagues⁵⁷ found that larger effect sizes were associated with programs that required parents to practice the skills during therapy sessions, focused on parenting consistency, and focused on increasing positive parent-child interactions. Conversely, smaller effect sizes were associated with programs focused on problem-solving techniques and promotion of cognitive, academic, and social skills. Further research is needed to identify the specific program elements that are associated with larger effects in caregiver-mediated behavioral interventions for children with ASD. Finally, while the focus of this article has been on treating underlying behavioral causes (communication frustrations, social skills difficulties, anxiety, sensory sensitivities) of challenging behaviors, it is important that caregivers and clinicians also consider possible underlying medical complications including gastrointestinal

difficulties, sleep disorders, and seizures that often co-occur with ASD.^{58,59}

Summary

A significant proportion of children with ASD are referred to mental health centers due to the presence of challenging behaviors. An understanding of the underlying symptoms of ASD is essential in managing behavior problems in this population and the involvement of caregivers in treatment is critical to long-term success. While behavioral intervention approaches have been used extensively to improve the social, communication, and anxiety symptoms that often accompany ASD, few randomized control studies have been conducted. In a review of the 68 behavior intervention articles published in 2008 to 2009, Kasari and Lawton⁴¹ reported that 63% of the studies used case study or single-subject design approaches, 16% used a group design other than randomized control, and 21% of the studies used randomized control trials (ie, 14 of 68 studies). Thus, while the literature on the effectiveness of behavioral intervention is growing,²⁵ there continues to be a need for randomized, controlled studies. Further, while the importance of working with caregivers has been emphasized for the past four decades, more research is needed about the effectiveness of caregiver-implemented interventions and the techniques that are most effective at supporting caregivers use of strategies in the natural environment including family beliefs and culture. □

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Propuestas de los cuidadores para el manejo de conductas desafiantes en niños con trastornos del espectro autista.

Una proporción importante de niños con trastorno del espectro autista (TEA) son referidos a centros de salud mental debido a la presencia de conductas desafiantes. Dado que las conductas desafiantes en niños y adolescentes con TEA se producen a menudo por dificultades sociales y de comunicación, y ansiedad comórbida subyacentes, las técnicas de intervención conductual tradicionales a cargo de los cuidadores y desarrolladas para niños con trastornos conductuales disruptivos pueden necesitar de una adaptación para esta población. A la vez, en los niños con TEA pueden ser necesarias las intervenciones conductuales que apunten a herramientas comunicacionales y sociales, ansiedad y sensibilidad sensorial. Es destacable que, a pesar de que la mejor práctica requiere del compromiso de los cuidadores en el tratamiento de niños y adolescentes con TEA, pocos estudios controlados y randomizados han examinado la eficacia de las intervenciones implementadas por los cuidadores para la reducción de las conductas desafiantes. Esta revisión resume la literatura actual relacionada con las intervenciones conductuales de los cuidadores para niños con TEA y sugiere áreas para el desarrollo de intervenciones e investigación.

Démarche des soignants pour prendre en charge les comportements difficiles des enfants ayant des troubles du spectre autistique

Une proportion significative d'enfants présentant des troubles du spectre autistique (TSA) est adressée à des centres de santé mentale du fait de comportements difficiles. Les techniques comportementales habituelles des soignants destinées aux enfants présentant des troubles comportementaux perturbateurs doivent être adaptées aux comportements des enfants et des adolescents souffrant de TSA, qui proviennent souvent de difficultés sociales et de communication ainsi que d'une anxiété comorbide sous-jacente. Il serait en revanche utile de recourir à des techniques comportementales centrées sur les capacités de communication, les capacités sociales, l'anxiété et la réactivité sensorielle des enfants présentant des TSA. Cependant, alors que les meilleures pratiques nécessitent l'implication des soignants pour traiter les enfants et les adolescents atteints de TSA, seulement quelques études contrôlées randomisées ont analysé l'efficacité des techniques développées par les soignants afin de diminuer les comportements difficiles. Cet article résume la littérature actuelle en ce qui concerne les interventions comportementales des soignants pour les enfants présentant des TSA et donne des pistes pour la recherche et le développement de ces techniques.

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