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Issues and Theoretical Constructs Regarding Parent Education for Autism Spectrum Disorders

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Abstract Participation of parents of children with autism is commonplace in most comprehensive intervention programs, yet, there is limited research relating to the best practices in this area. This article provides an overview of parent education programs for young children with autism and details data-driven procedures which are associated with improved parent and child outcomes. In addition, we provide a troubleshooting guide based on the literature for professionals regarding a variety of complex issues which may arise during parent education.

Keywords Parent education · Parenting · Parent stress

Introduction

Due to increasing prevalence rates of Autism Spectrum Disorders (ASD) in recent years, there is a strong need for efficient, cost-effective, and Empirically Supported Treatments (ESTs) for this population (Wing and Potter 2002). Moreover, with the average age of diagnosis declining and many children diagnosed prior to the age of three (Chawarska et al. 2008), children may begin intervention at a young age and best practices suggest that parent involvement is essential (NRC 2001) both for more rapid gains and for consistency across the child's waking hours. Additionally, for school-age children and adolescents parent involvement in treatment programming is also highly desirable (Brookman-Frazee et al. 2009). In fact, every comprehensive program identified by the National Research Council (2001) involves some parent component, suggesting its importance in a comprehensive treatment package. While the nature of parent involvement can vary widely across programs, families, and children, the most common form of parental participation is a parent education model, in which parents are taught techniques to work with their child so that intervention can continue in the absence of the professional. Although parent involvement across the age-span is important, this article will focus primarily on parent education programs for young children (e.g., toddlers, preschoolers) with ASD, as these are the most common.

The notion of the utility of parents as interventionists has spanned over four decades (McConachie and Diggle 2007; Schopler and Reichler 1971). Since parents spend more time with their child throughout the day, evenings, and weekends than any service provider, they are able to provide "around the clock" intervention for their child (Koegel et al. 1995, 1996b). Additionally, parent education can address the issue of generalization, given that service providers often only see children in a restricted number of settings, such as a clinic room, while parents are able to provide learning opportunities for their child in many natural settings, such as at home and in the community. Including parents in their child's habilitation process is not only cost-effective, but by increasing the support that a child has throughout the day, it can increase the child's rate of progress (Cordisco et al. 1988; Kaiser et al. 2000; Koegel et al. 1998; Laski et al. 1988; McClannahan et al. 1982; Moes 1995). Research has documented that parents

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have been able to learn strategies to effectively teach their children with autism across a variety of areas, including reducing problem behaviors (Koegel et al. 1992; Lutzker et al. 1998), decreasing restricted and repetitive behaviors (Bahng 2010), improving communication (Anderson and Romanczyk 1999; Koegel et al. 1999, 2002; McGee et al. 1999), improving sleep habits (Reed et al. 2009), increasing joint attention (Kasari et al. 2010; Vismara and Lyons 2007), improving social skills (Sofronoff et al. 2004), and improving self help skills such as toilet training (Kroger and Sorensen 2010).

Moreover, by learning strategies that improve their child's behavior, many parents may experience reductions in some aspects of parental stress. In particular, this is true when parents are able to develop an increased sense of self-efficacy, and when parent education programs are carefully designed to fit naturally into everyday routines (Hastings and Symes 2002; Moes 1995; Koegel et al. 1996a). This notion is highly relevant to parents of children with ASD, as numerous studies suggest significantly high levels of stress in parents of children with autism, exceeding that of parents of children with other developmental disabilities or children with an otherwise poor prognosis (Bitsika and Sharpley 2004; Donenberg and Baker 1993; Sharpley et al. 1997). In fact, there appear to be stress profiles for mothers of children with autism that are both severe and consistent across cultural and geographic areas, maternal age, and the child's functioning level (Koegel et al. 1992a, b) which relate to specific areas of stress around the child's dependency and management, behaviors that may place limits on family opportunity, and behaviors that suggest prolonged life-span care may be required (Davis and Carter 2008). There are also a variety of stressors that are not necessarily specific to the child's behavior, such as limited provision of services at the time of diagnosis, and difficulty understanding the disorder (Keen et al. 2010). Given that parent education programs teach parents of children with autism strategies to manage many of the difficult behaviors which are correlated with poorer parent-psychological outcomes and facilitate understanding of the disorder, several studies have noted decreases in parent stress (Moes 1995; Rickards et al. 2007; Singer et al. 2007; Keen et al. 2010; Solomon et al. 2008; Tonge et al. 2006) and improvements in parent affect (Koegel et al. 1996a) following participation in parent education programs.

What is Parent Education?

Parent education is defined as an educational effort that attempts to enhance or facilitate parent behaviors that will influence positive developmental outcomes in their children (Nixon 2002; Smith et al. 2002). The primary focus of parent education programs in general is that of teaching discrete skills that are designed to aid parents in managing problem behavior, teaching skills to their child, and improving the quality of the parent–child relationship (Brookman-Frazee, et al. 2009; Green et al. 2010; Kaminski et al. 2008; Lundahl et al. 2006). Parent education differs from psychoeducation, which is typically designed to teach parents particular knowledge-based content (e.g., what is autism?) as opposed to skill-based (e.g., how to implement a treatment for autism). Broadly overviewed, research to date in the field of parent education suggests that parent education programs have a positive effect in the amelioration of symptoms in children and families. Influenced by the seminal work of Hanf (1969), Forehand and McMahon (1981), and Patterson (1982), behaviorally-based parent education programs are well-established, empirically supported treatments for a variety of childhood problems (Herschell et al. 2002; Kazdin and Weisz 2003).

In terms of parent education programs for ASD, many teaching formats exist and differ in amount of intervention, mode of treatment delivery, therapeutic components provided, and targeted recipients (Marcus et al. 2005). While most parent education programs tend to address core symptoms of ASD (e.g., communication, social interaction) or problem behavior (e.g., noncompliance, aggression), other programs address more specific issues (e.g., sleep, toileting, feeding), although the techniques utilized are often quite similar regardless of the target behaviors. It is important to note that parent education is one form of service delivery within a larger comprehensive program (NRC 2001), but it is not recommended as the only service in a child's program. One widely adopted format is in vivo parent education conducted individually with the parent, child, and parent educator once to twice a week over many months (e.g., Dawson et al. 2010; Koegel and Schreibman 1996; Mahoney 2004).

However, due to the significant needs and growing numbers of children with ASD, new service delivery models are emerging as a way to reach a larger number of families. These formats include group parent education programs (Openden 2005; McIntyre 2008; Minjarez et al. in press; Whittingham et al. 2009), combined group and individual programs (Ingersoll and Dvortcsak 2010), and teaching parents to train other service providers (Symon 2005). Advances in technology have also played a role in the development of parent education interventions. With the increasing availability of video equipment and DVDs, the use of self-directed technological training programs (Nefdt et al. 2010) or web-based programs (Vismara et al. 2009) have become a promising parent education approach. This method may help decrease the number of families

who are unable to receive treatment due to remote location or other transportation obstacles.

Parent education programs may also take on slightly modified formats, whereby the skills parents are taught may relate to managing their own emotions, cognitions, and behavior. Parent education programs that include these types of counseling components or focus on counseling aspects entirely have also been proposed to be useful for parents of children with autism. For example, Bitsika and Sharpley (1999, 2000) indicate that parents found some utility in groups that focused on social support and behavioral stress management skills. Specifically, in groups in which parents of children with autism were taught specific cognitive-behavioral skills for stress management procedures, the parent participants reported significant increases in their ability to cope with parenting stress, and reductions in guilt, negative thoughts and attributions, as well as symptoms of depression (Blackledge and Hayes 2006; Hastings and Beck 2004; Nixon and Singer 1993).

Individualized Parent Education Programs

A common approach in the field is to provide parent education in one-on-one sessions with the parent and child. According to Kaiser and Hancock (2003) this strategy can be advantageous as this intervention strategy can be tailored to the child's needs, provides an emphasis on "practice with feedback," and individual sessions can take place where needed (e.g., home, community settings) to aid in the generalization of skills. A common approach to teaching parents specific strategies in individual parent education is to combine (1) didactic instruction and/or review of written materials, (2) modeling or demonstrating new procedures, and (3) in vivo practice with immediate feedback (Gillette and LeBlanc 2007; Ingersoll and Dvortcsak 2006; Schreibman and Koegel 2005). As described by Gillett and LeBlanc, in many programs, a parent's preliminary practice opportunities are with someone other than their own child and they are later transitioned to working directly with their child after successful practice. Several programs also use video feedback (Green et al. 2010) and video examples to teach (Johnson et al. 2007) during individual sessions. Additionally, in Parent Child Interaction Therapy (PCIT) for ASD, the therapist provides feedback from behind a one-way mirror using a "bug in the ear" microphone while the parent works with their child (Masse et al. 2007; Solomon et al. 2008). A recent meta-analysis of parent education components found that having parents practice their new skills in session was associated with larger effects than other programs without these components, regardless of other program content or delivery (Kaminski et al. 2008). Similarly, Ingersoll and Dvortcsak (2006) suggested the emphasis should be placed on having parents practice skills rather than on spending more time modeling the procedures. This is an important point for the parent educator, as it can often be more challenging and require a more skillful approach to not take the lead in a session. In addition to practicing the skills in the session, teaching parents to reduce negative communication (e.g., criticism, sarcasm), demonstrating enthusiasm, and showing parents how to let the child take the lead on the play activities also were components of parent education programs with successful outcomes for parenting behaviors and skills (Kaminski et al. 2008).

As noted above, parents can be effective agents of change, but providing a continuous therapeutic environment for their child can be exhausting and difficult if families are required to sit down and teach their children with specialized materials (Koegel et al. 1996a). However, professionals can develop strategies for the family to use in their daily routines to reduce stress and facilitate parental use of treatment strategies by utilizing naturalistic treatment approaches (e.g., Koegel et al. 2003; McGee et al. 1999; Rogers and Dawson 2010; Wetherby and Woods 2006; Yoder and Stone 2006). For example, if a target behavior is expanding vocabulary, parents can provide opportunities to teach language if the child is hungry and wants a snack. Within such a context, the parent can give the child a choice of snack items, model the label of the item the child chooses, have the child repeat the target label, and then provide the item as a natural reinforcer. This naturalistic approach takes very little extra time from a parent's schedule, but when applied systematically, can provide the child with a multitude of teaching opportunities throughout the day. Many such teaching opportunities can be implemented in contexts such as getting into the car, play activities, pausing the television during the child's favorite cartoon, and so on. A naturalistic approach is easy to individualize to fit within a family's routine, and research suggests that these types of teaching trials can result in faster child gains, lower levels of disruptive and avoidance behavior, and lower levels of parental stress when compared to a more structured drill practice program (Koegel et al. 1992).

Group and Distance Programs

Although group parent training paradigms are widely researched and implemented for many childhood disorders, there are comparatively few empirical studies addressing the notion of group parent training for children with ASD. However, group programs provide major advantages in terms of cost-effectiveness, and also may have additional benefits for parents in terms of social support and stress

reduction (Singer et al. 2007). While group programs may provide information relevant to individualized programming, children are often not present at these groups, providing a unique opportunity for more formalized didactics. For example, some group programs have parents bring in videotapes of working with their child, and feedback is provided to the parent within a group context based on the videos (e.g., Minjarez et al. in press; Openden 2005). As Minjarez and colleagues note, the group model provides opportunities for parents to learn from other group members as well as by their own tapes, potentially enhancing parent learning, and the group can simultaneously function as a social support group for the participants. At present, there is little research to suggest best practices specific to group training for parents of children with ASD, however, it is recommended that practitioners consult resources regarding group therapy and training for other types of childhood disorders (e.g., The Incredible Years, Webster-Stratton 1992; Triple P programs, Sanders 1999) for additional guidance. In fact, researchers have begun to make modifications to these programs to incorporate the needs of families of children with autism. Specifically, Whittingham et al. (2009) have adapted the parenting program, Triple P, to Stepping Stones Triple P and similarly, McIntyre (2008) adapted the Incredible Years Parenting Program. These adapted programs provide emerging evidence for the use of such treatment models for parents of children with autism, as parents reported improvements in their child's behaviors and showed improvements in their own parenting behaviors from participating in these programs.

Distance learning also addresses the issue of cost-effectiveness, and additionally, aids a service-need discrepancy created by the fact that the dissemination of ESTs has not grown along with the disorder (Brookman-Frazee, et al. 2009; Croen et al. 2002; Symon 2001). For example, Nefdt et al. (2010) conducted a randomized controlled trial to examine the effectiveness of a self-directed DVD and treatment manual to teach Pivotal Response Treatment (PRT) techniques to parents of toddlers and preschoolers with autism. The study suggested that parents were able to improve their interactions with their children and learn to implement effective strategies to encourage child communication after observing only a brief 2-h long DVD. In addition, researchers have also demonstrated promising findings regarding a program to deliver parent education via an internet conferencing program (Vismara et al. 2009). Furthermore, there are a number of websites that offer a variety of services to parents and professionals regarding training and program management (e.g., Rethink Autism, www.rethinkautism.com). Although additional research is needed to determine the efficacy of these interventions, as technology continues to advance, parent educators may begin use this treatment modality more regularly.

Parent Education Procedures

Therapeutic Approaches

Although parent-education plays in integral role in the vast majority of intervention programs for children with autism, relatively few studies provide guidelines for *how* to conduct parent education sessions (Mahoney et al. 1999). In general, collaborative or partnership models in which the interventionist and parent work together to develop treatment goals are emphasized (Turnbull and Turnbull 2000). In particular, Brookman-Frazee (2004) found that when interventionists used a partnership approach, defined as making more collaborative rather than directive statements to parents about treatment recommendations, improvements in parent stress and confidence were found, in addition to child improvement. Specifically, during the traditional parent education sessions, the parent educator may make suggestions to the parent, such as "It looks like Sammy likes playing with the ball. Why don't you practice verbs by having him ask you to *throw* or *kick*, or *roll* him the ball." In contrast, during the partnership approach, the clinician may say "It looks like Sammy likes playing with the ball. What types of activities *do you think* that he would like to do so that we could work on verbs?" In the partnership model, not only is the parent provided with an opportunity for input, but it allows some individualization of the program to fit the family's values, goals, preference, routines, and traditions, which researchers in the field of disabilities have noted as important (Dunst et al. 1994; Turnbull and Turnbull 1990). This work suggests that, in addition to participating in goal-setting, including the parent in the decision-making process, regarding how and what to work on during weekly intervention sessions, may be beneficial for both child and parent progress.

Other research similarly suggests that a strength-based approach also may increase hope, thereby facilitating the development of the working relationship. According to Cosden et al. (2006), the promotion of positive personal and family characteristics is particularly important given the stress and uncertainty associated with ASD (Koegel et al. 2003, 1996a; Moes 1995). This is consistent with early literature showing that parents of children with autism who coordinated with professionals to develop their child's strengths during parent education programs were less likely to institutionalize their child in adolescence (Schopler and Mesibov 1995). Durand (2001) identified another variable, parental optimism, as important in parent education. For example, Kessler (2004) examined the effects of implementing an optimism component in parent education for disruptive behavior for parents of children with autism. Optimism was "taught" through individual, cognitive-behaviorally oriented therapy sessions wherein

the parent and interventionist discussed the child's behavior and the parent's reactions to the behavior as part of a parent education program. For example, parents were asked to share their thoughts and beliefs regarding their child's disruptive behavior (e.g., "I can't do anything to improve tantrums") and taught more adaptive responses (e.g., "Even though tantrums are difficult, I do have some skills to address them"). Preliminary data indicated that those who participated in the optimism training were more likely to complete parent education programs (for a complete practitioner guide, see Durand and Hieneman 2008).

In addition, Steiner (in press) demonstrated the positive effects of interventionists who made strength-based statements regarding child behavior during parent education sessions. That is, if a target behavior for the child was attention, the parent educator could note, "It's hard to get Suzy to focus. She moves quickly from toy to toy. Let's help her focus by (provides strategy)." On the other hand, using a strength-based approach, the parent educator could conceptualize Suzy's behavior in a positive light by saying, "It seems like Suzy is interested in a lot of different toys. Let's help her focus on one toy by (provides strategy)." When the parent educator used strength-based statements, improvements in parent affect were noted, and in turn, parents made more positive statements regarding their child. These preliminary studies suggest that there are explicit and implicit ways in which professionals can approach parent education to facilitate positive adaptation for families of children with ASD.

Therapist Skills and Strategies

Another area often ignored, albeit a key area of importance, is the specific skills and strategies employed by parent educators (Brookman-Frazee et al. 2009). Kaiser and Hancock (2003) highlight important prerequisite skills of parent educators and suggest that programs should explicitly teach clinicians these skills. The suggested skills are as follows: mastery and conceptual understanding of intervention procedures, responsive and collaborative teaching style (discussed above), fluency in presentation, providing immediate feedback (e.g., providing feedback immediately after a parent demonstrates a skill, as opposed to the end of the session), and ability to individualize the intervention program and evaluate progress. Furthermore, the authors suggest some key strategies parent educators should implement. For example, *using concrete and positive examples* is strongly recommended, that is, it is suggested that clinicians provide feedback based on observed parent and child behaviors (as opposed to hypothetical situations) and focus on identifying instances in which parents correctly demonstrate a skill while also providing corrective feedback at times. In addition, it is helpful to provide *specific feedback* to parents. In particular, if a parent properly implements a strategy, rather than commenting, "That was really nice," it can be more facilitative to reply, "That was really nice how you waited for Nicholas to make eye contact before you gave him what he wanted. That is a nice example of contingent reinforcement."

Brookman-Frazee et al. (2009) also recommend inviting formal and informal feedback from parents. By letting parents know that they are the experts on their own child, and that you as a parent educator are open to suggestions, you can help to create an environment in which parents feel comfortable providing feedback, either through conversation during sessions, progress meetings, or anonymous questionnaires. Other important skills helpful for building relationships with parents include building rapport by acknowledging parental feelings (e.g., guilt, frustration) and listening to parents' concerns. While the parent educator's primary goal is typically teaching skills, it is important for the parent educator to acknowledge the myriad of other issues parents may have regarding raising their child. Moreover, it is particularly important, and sometimes difficult, to avoid creating an alliance with one parent when working with both parties from a dual-parent household (Ingersoll and Dvortcsak 2006). For example, it is recommended that a parent educator attempt to redirect a parent or facilitate a discussion with both parents when one parent asks the parent educator, "Don't you think my spouse is too easy on Andrew?" These types of issues quickly bring an additional level of complexity to parent education sessions, far beyond that of introducing skills to parents to teach their children.

Therapist Role and Professional Boundaries

Given the complexity of issues that can arise during parent education, it is often helpful for the parent educator to have expertise not only in the treatment of ASD, but also general adult psychotherapy, family-systems therapy, and marital therapy, as these skills can be an asset when family dynamics are complicated. However, that being said, while the parent educator can ideally draw on a breadth of therapeutic skills, it is important to also be mindful of professional boundaries. As a parent educator, it is easy to be drawn into marital and familial conflict, and issues related to parental anxiety and depression (Doherty 1995). In most programs, the parent educator's explicit role is to teach parents skills to address their child's behavior, not to provide broader counseling services to address familial and personal issues. We recommend that the parent educator be clear in their role with the family and make appropriate referrals when necessary.

Parent Education Obstacles: Troubleshooting

Prior to implementing a parent education program as part of a child's comprehensive service plan, some considerations need to be taken into account. For example, Kaiser and Hancock (2003) recommend consulting with the family to ensure they have enough time and energy to devote to the program. Other areas to investigate are the potential barriers, such as situational and familial stressors (e.g., marital discord, low socio-economic status) and mood related issues (e.g., anxiety, depression). Despite evidence supporting the inclusion of parents in intervention programs, (Forehand and Kotchick 2002a) some parents may need additional support in order to acquire the new teaching strategies (Corcoran 2000; Singer 1993). Although research suggests that parent education programs are effective at reducing stress levels other studies have also documented that as many as 30% parents do not benefit from parent education programs due to clinically significant levels of stress (Robbins et al. 1991; Singer 2002; Stern 2000; Webster-Stratton and Reid 2003). In fact, Osborne et al. (2008) demonstrated that a match between the program and parental stress is important, as a more intensive program (in terms of hours of child-directed services) for highly stressed parents may only further increase parental stress and can potentially impede child progress compared to less intensive programs (e.g., a program with less hours of child-related programming). In addition, the setting of a parent education program can also be a factor, as Rickards et al. (2007) found that families with higher stress displayed greater parent improvement when treatment delivery in a specialist nursery program was augmented with individualized sessions at home. Thus, as a parent educator designing a child's program, it is important to bear in mind the family's life stressors and time available to devote to parent education sessions. Depending on the family's needs and ability to benefit from parent education, the parent educator can alter the setting or reduce or extend the proportion of the overall program involving parent education components—some parents prefer to be part of every intervention session, while for others, more infrequent participation is preferable.

Programs may also benefit from further individualization to meet the specific needs of the family to ensure adequate comprehension and implementation of the training techniques. For example, different approaches may need to be used when working with fathers as opposed to mothers. Although the role of fathers in the treatment of autism has been neglected in the literature, some evidence has suggested that fathers may be more directive, respond less consistently, and interact with their children differently compared to mothers (Elder and Goodman 1996). As such, differences in parental behaviors should be considered when providing training (Elder et al. 2003).

In addition, specific teaching strategies may be advantageous for parents that do not learn procedures as readily. The use of video feedback can also be helpful to identify problem areas to parents (Openden 2005) who have difficulty acquiring the procedures with only in vivo feedback. Additionally, some parents may benefit from a self-monitoring program to meet treatment fidelity (Tran 2007). Specifically, after a brief interval of the parent implementing the treatment techniques with his or her child (e.g., 1 min), the parent educator directed the parent to evaluate his or her adequate or inadequate use of a given treatment strategy. Incorporating the self-management technique showed promising results in terms of parent fidelity to treatment procedures, parent affect, and child responding (Tran 2007).

Furthermore, a much needed area of research is to examine the family's broader social and environmental influences that may influence parenting practices, attitudes, and values (Forehand and Kotchick 2002a). Typically, research on parent training in autism does not *directly* address culture and ethnic characteristics, and sensitivity to these factors are necessary and essential given that they may facilitate or hinder the success of parent education (Forehand and Kotchnick 1996, 2002b). Because parenting practices within a particular culture are influenced by cultural values, heritage, and history (Harkness and Super 1995), the family's understanding of the world and direct behavioral expression is a reflection of their values. Thus, attempting to modify the parent's behavior without attending to cultural factors is meaningless (Harkness and Super 1995). Forehand and Kotchick (2002b) have discussed this need and made some suggestions for practitioners to consider while working with diverse families (e.g., increase awareness of cultural attitudes related to parenting, modify interventions to match family values, recognize within ethnic group variability can be as large as between group variability). Other researchers in the field of disabilities have also noted the importance of cultural characteristics and have recommended that family support should be individualized to fit the family's values, goals, preference, routines and traditions (Bernheimer et al. 1990; Dunst et al. 1994; Turnbull and Turnbull 1990). For example, while a partnership approach is generally recommended (see above), for some cultural groups or specific parents, the parent educator is expected to take a much more directive role, and a partnership approach may cause frustration and parents may feel less confident in the parent educator's abilities (Sze and Koegel 2006).

Finally, because parent educators work so closely with families and frequently deliver services in the home environment, it is often difficult to avoid the topic of siblings. Given that prevalence of ASD in siblings of children with autism is estimated to be about 20-fold higher than the

general population (Zwaigenbaum et al. 2009) and there is even a higher likelihood that they will exhibit some type of language, cognitive, or social disability (Zwaigenbaum et al. 2007), parent educators are often faced with the task of advising parents who have concern regarding the younger sibling of their child with autism. While this concern may take the form of more generalized anxiety regarding development (McMahon et al. 2007; Gengoux et al. 2010), for many parents concerns reported at 12-months of age are strongly related to an ultimate ASD diagnosis (Ozonoff et al. 2009) and parents may fear regression in the second year of life following apparently normal development. In these instances, it is important to maintain professional boundaries (see above), as the role of the parent educator is typically not to make diagnostic predictions regarding siblings, and a referral for an evaluation is recommended. While diagnosis in the first year of life is challenging (Rogers 2009), an evaluation is recommended to assess for the early presence of ASD symptomology and to identify any delays in development that may warrant early intervention services.

Conclusion

Although parent education is a ubiquitous component of comprehensive programs for children with ASD, the most effective ways to conduct these sessions in terms of parent and child outcomes is not yet clearly delineated. With advancing technology and an increasing service-need discrepancy, new formats for parent education are emerging over traditional individual in-vivo sessions. Further recognition of the importance of clinician skills and the therapeutic approach in child and parent outcomes will likely lead to additional recommendations for ideally tailoring a parent education program in terms of format, approach, and teaching strategies for a wide variety of presenting concerns, children, and families.

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