

The Role of Family-Centered Care in Research Supporting the Social Communication of Children With Autism Spectrum Disorder

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Families and their children with special healthcare needs require effective interventions to address children's needs in the context of daily family interactions. This article offers a unique perspective to understanding the role of family-centered care. It extends beyond expected practice in service delivery to the role of families in the implementation of intervention research, specifically when collaborating with families of children with autism spectrum disorder. Two intervention studies are described involving children with autism spectrum disorder and their families and the application of principles of family-centered care. Elements of family-centered care demonstrated in the intervention research are summarized. Finally, specific challenges are described associated with conducting family-centered intervention research and suggestions are offered to clinical researchers to inform future research endeavors. **Key words:** *autism spectrum disorders, family-centered care, intervention, research*

FAMILY-CENTERED CARE has seen an evolution over the last 30 years in the role of families when planning and implementing services for children with special needs. It recognizes that families can and should be supported in their natural caregiving roles wherein typical patterns of living are promoted and choice in services is an option (Shelton, Jeppson, & Johnson, 1987; Wehman, 1998). A family-centered care philosophy fosters parent participation in all aspects of a child's program, recognizing that the family is a critical consumer whose priorities and decisions should be respected. This philosophy has led to an evolution of the role of service providers as they participate not as sole decision

makers but as members of a team of professionals who collaborate with the family to determine what is in the best interest of a child. Service providers may struggle to achieve the ideals of family-centered care, but evidence from several studies (Beatson, 2006, 2008; Beatson & Prelock, 2002; Dunst, Trivette, & Hamby, 1996; Letourneau & Elliott, 1996; Thies & McAllister, 2001) suggests that when professionals recognize the family as a core team member who can help define the service options, the child's goals are more likely to be achieved.

Historically, several factors have influenced the evolving family role, two of these being legislation and research in early intervention, examining the transactional nature of development, as well as ecological, family, and social support (Wehman, 1998). The legislative changes began with the formation of Head Start and federal funding for model demonstration programs, highlighting innovations in preschool teaching and curriculum development in the mid to late 1960s. Then, the

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Education for All Handicapped Children Act of 1975 affirmed the role of families in designing educational program for their children with special needs. These requirements specified that parents and professionals are responsible for the co-construction of a child's individual education plan. Legislative changes continued with the Handicapped Act Amendments of 1986 and the reauthorization of the Individuals with Disabilities Education Act of 1990, in which services were adjusted to include the family unit, not just the child. Such changes were consistent with values that identifying the goals, needs, and priorities of families best addresses opportunities for change and intervention effectiveness (Wehman, 1998). Furthermore, the emphasis on home and community-based interventions is a consequence of the natural environments provision of the 1997 amendments to Public Law 105-117 (Walsh, Rous, & Lutzer, 2000).

Concurrent with legislative changes, theoretical frameworks and research findings indicated that there are transactions among a child's developmental domains and the family, social, and environmental systems in which the child lives and grows. For example, Wehman (1998) described the influence of family systems theory (McGoldrick & Carter, 1980; Minuchin, 1974), ecological theory (Bronfenbrenner, 1979, 1986), a transactional model of development (Sameroff, 1975), and social support theory (Cohen & Syne, 1985; Dunst, 1985, 1986) in justifying a role for families in early intervention practices. Family systems theory suggests that factors affecting one family member affect all family members. For all these reasons, it makes sense that a team's focus for understanding, planning, promoting, and evaluating change cannot rest with just the child. There are also sources of influence within a child's community and culture, including the settings and social structures within which a child functions. This ecological-theoretical perspective requires professionals to consider the child and the social environment as an integral part of family function (Wehman, 1998). This perspective is expanded to consider a transac-

tional model of development in which the child becomes a product of synergistic interactions, involving current abilities that the child brings to a situation and the experience provided by the child's social and family context. When parents change the way they interact with their child on the basis of what the child has done, a notable transaction has occurred (Wehman, 1998). A final theoretical framework influencing the role of families in early intervention practices is social support theory. This perspective highlights the provision of support that facilitates the well-being, not only of the child, but also of the family and the broader community. Social support takes many forms, but the ultimate goal is the development of adaptive behavior that can be self-sustained so that the family is empowered to address its own needs.

This article offers a unique perspective to understanding the role of family-centered care beyond expected practice in service delivery. That is, it addresses the role of families in the implementation of intervention research, specifically when research entails collaborating with families of children with autism spectrum disorders (ASD). To provide a familiar context for the family role, a brief review of family-centered care in service delivery is presented. This is followed by a discussion of the family role in research. Two intervention studies involving children with ASD and their families are then described in which the principles of family-centered care have been applied. A summary of the elements of family-centered care demonstrated in the intervention research presented is provided. The article ends with a discussion of the challenges to implementing research with family-centered care and suggestions to clinical researchers in their current and future research endeavors.

ROLE OF FAMILY-CENTERED CARE IN SERVICE DELIVERY

Family-centered models of service delivery are consumer-driven in that the needs of families influence all aspects of service delivery. Dunst et al. suggest, "... families should

play a major role in shaping the direction of resources and supports they receive, and that resources and supports ought to be provided in ways that strengthen the capabilities of families" (1991, p. 124). In earlier child-centered models, families were considered information givers alone, specifically sharing information about their children's developmental history. In family-centered models, families are encouraged to set goals for their children and family. The expectation is that families will be treated with dignity and respect, offered individualized, flexible, and responsive practices, provided intervention and program choices, and connected to needed resources (Dunst, 2002). Thus, professionals are learning to move from a family needs perspective to a family strengths perspective that builds on the family's own resources (Turnbull, Turbiville, & Turnbull, 2000). A strengths-based, family-centered approach considers individuals' strengths (e.g., cognitive, emotional, coping, and physiologic), as well as environmental strengths, in the context of the family's personal and emotional challenges. It provides a framework in which families and individuals with special needs can collaborate with clinicians to set goals and access available resources (both individual and social) that support the desired goals (Russo, 1999).

In addition to supporting family-centered practice principles in intervention planning and implementation, it is also important to consider ecocultural approaches to working with families. Families actively respond to their circumstances and build an environment that gives direction and meaning to their lives (Bernheimer, Gallimore, & Weisner, 1990; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Weisner, 2002), often, with the goal to create a foundation for positive social experiences for their children. Furthermore, it is important to allow families to tell their stories in their own words and share the adjustments they have made to accommodate the daily and routine needs of their children, particularly those with developmental disabilities. Intervention is

more likely to have an impact if it can be integrated into the daily routines of a family or an individual (Bernheimer & Weisner, 2007).

Families are also responsible for several areas of their children's well-being including the development of social communication skills to ensure their children can follow age-appropriate behavioral and social conventions (Prizant & Meyer, 1993). As their children's primary decision makers (Zaner & Bliton, 1991), parents make choices that can have significant effects, not only on their children's daily life experiences, but also ultimately on their development. Families interpret the societal and cultural norms for their children and guide them in knowing what is and is not culturally and socially acceptable (Garcia Coll & Meyer, 1993; Levine, 1977). The family environment also provides several opportunities for children to experience success in their communication and emotional relationships (Sameroff & Fiese, 1990). Because the characteristics of developing relationships and varying situational contexts have profound effects on children's ability to communicate and participate fully in their environment, intervention should be planned for and occur in the family context, reflecting caregiver and child preferences and relevant routines (Prizant & Meyer, 1993). Therefore, it is important to engage families in discussions about the strengths and challenges of their children with the aim of identifying familial priority concerns and expectations regarding development. This is appropriate not just for clinical or educational services, but we propose that it must also be incorporated when designing research to examine intervention effectiveness in meaningful contexts with functional outcomes.

ROLE OF FAMILY-CENTERED CARE IN RESEARCH

The practice of involving the perspective of caregivers and family in identifying a research question, determining a design and a method, implementing and evaluating an

intervention, or disseminating results is a defining characteristic of what has come to be collectively known as “participatory research” (Uding, Sety, & Kieckhefer, 2007). Not surprisingly, research studies characterized as participatory differ in which of these aspects and the degree to which each aspect uses the families’ involvement. As such, Uding et al. viewed participatory research as lying on a continuum and best understood within the context of the unique aims and circumstances surrounding the research.

Traditionally, participatory research has involved important principles of family-centered care in both assessment and intervention practices for children with special needs; yet, there has been relatively little discussion about the role of family-centered care in the implementation of research. Furthermore, there is limited literature describing concrete ways caregivers can be active participants in assessment and intervention (Crais & Calculator, 1998) and even less about ways to promote and engage families in the intervention research that is designed to measure the effectiveness of achieving desired outcomes for their children.

Historically, the family role in the assessment and intervention process has been limited to informing a child’s team about how a child has developed and what challenges require support (Andrews & Andrews, 1990; Crais, 1993). Clinical researchers recognize that caregivers should be a more integral part of their children’s assessment and intervention teams, activities should match their perceptions of what is relevant and meaningful (Crais & Calculator, 1998), and caregiver input can facilitate the assessment and intervention process. Caregivers have been shown to be reliable judges of their children’s development (Bricker & Squires, 1989; Glascoe, McLean, & Stone, 1991) and areas of low and high interest (Crais & Calculator, 1998). Furthermore, the importance of families in the intervention efforts for children with special needs is a principle for most communication intervention activities because it recog-

nizes the interactive nature of communication and the critical contribution caregivers make (Girolametto, 1988; MacDonald & Gillette, 1988; McLean & Snyder-McLean, 1978; Norris & Hoffman, 1990; Wilcox, 1992).

Our research team has been engaged in two intervention studies for children with ASD in which families play a significant role in the planning, implementation, and evaluation of the research. The first was a social stories intervention study (Hutchins & Prelock, 2006, 2008b) and the second was a study of an intervention targeting peer play (Prelock, 2004, 2008). Each of these studies is discussed more specifically in the sections that follow. The elements of family-centered care that were demonstrated in the research studies are highlighted, followed by a discussion of the challenges in implementing family-centered care in research.

Family roles in a study of social story intervention

The Social Story Intervention Project (Hutchins & Prelock, 2006, 2008a) used comic strip conversations and social stories to teach appropriate social behaviors to twenty-nine 4- to 12-year-old children with ASD. This study combined a multiple baseline single-subject design across behaviors and participants and a group experimental design with a 6-week follow-up assessment. Participants were diagnosed with autistic disorder, Asperger disorder, or pervasive developmental disorder—not otherwise specified (PDD/NOS). Some participants were functionally nonverbal; whereas others were highly verbal. To ensure full benefit in the social story intervention, participants were required to demonstrate an ability to respond to bids for regulating behavior and engage in joint attention initiated by another. With few exceptions (see subsequent discussion), participants were randomly assigned to one of two groups; those receiving an immediate 8-week social story intervention and those receiving 8 weeks of control stories, followed by 8 weeks of social story intervention. Every

aspect of the research involved collaboration with families, from developing treatment targets to data collection procedures.

Two critical components in designing the intervention that involves families are learning about the family's priorities for intervention and developing an intervention plan that is responsive to the children's needs (Hutchins & Prelock, 2006, 2008a). Recognizing and respecting the knowledge families have about their children, parents completed several measures to inform the research team about the children's social skills (e.g., *Social Skills Rating System*; Gresham & Elliot, 1990), language skills (e.g., *CELF-3: Observation Rating Scales*; Semel, Wiig, & Secord, 1996), and theory of mind (e.g., *Perception of Children's Theory of Mind Measure*; Hutchins, Bonazinga, Prelock, & Taylor, 2008). These parent measures were chosen not only because they have been demonstrated to be reliable and valid but also because they are consistent with a family-centered perspective in that they are designed to obtain information that has been accumulated by the informant over time using questions that span a variety of situations and settings (McCauley, 2001).

During a preintervention interview, parents were asked to reflect on and identify social situations in which their children had demonstrated inappropriate behaviors, experienced communication challenges, and failed to understand others' perspectives, which resulted in a recurring interpersonal conflict. This input informed the construction of three social stories for each child with ASD in this study. Gray's (1995, 1998) general guidelines were followed for developing the social stories, with added emphasis on the promotion of perspective-taking skills (Hutchins & Prelock, 2006, 2008a); therefore, a number of perspective sentences (e.g., *My mother likes it when I eat slowly*) and mental state terms (e.g., *want, think, know, happy, sad, mad*) were incorporated. To ensure that the social stories were responsive to the families' reported concerns and considerate of children's receptive and expressive language, all

social stories were reviewed and edited by the families.

Families were also significant contributors to evaluating intervention outcomes. Individualized diaries were developed to obtain each family's daily and general impressions of the specific behaviors targeted in the social stories. Specifically, mothers rated their general and subjective impressions of their children's change in behavior by indicating the degree to which they agreed with a statement (e.g., "Based on my judgments today, Carlos is nice to [his friend, Sam]") on a 10-point Likert-type scale anchored by "strongly disagree" and "strongly agree." Higher values reflected greater confidence that the targeted behaviors had abated. Mothers also reported information on their perception of the impact that intervention was having on them and their families. Testimony was frequently provided concerning the nature, context, and frequency of the targeted social communication behaviors and the families' feelings regarding the intervention (see Hutchins & Prelock, 2008a, for a detailed description using a case vignette).

Baseline diary data were collected on the targeted behaviors over a 2-week period before the social stories were introduced. The interventionists then read the social stories three times a week for approximately 8 weeks in the home of the children with ASD. To maintain consistency in the implementation of the intervention for all participants, additional scaffolding and discussion were not used. Families' perceptions for many of the children indicated decreased inappropriate behaviors and increased perspective-taking skills. The research team collaborated with families to identify intervention goals, determine the appropriateness of the intervention procedures, and evaluate effects of the intervention on the functioning of the child within the family (Hutchins & Prelock, 2006, 2008a). As a result, dynamic, emerging, and contextual aspects of the children's function were revealed. Results of this study are still being analyzed and prepared for publication.

Family roles in a study of peer play intervention

The Peer Play Intervention Project (Prelock, 2001, 2004; Prendeville, Prelock, & Unwin, 2006) targeted the development of joint attention, social interaction, and behavior regulation through play intervention, including children with ASD and peers without disabilities in eleven 4- to 8-year-old dyads. The study design was an ABABA single-subject design with 3- and 6-month follow-ups. Intervention occurred in the homes of the children with ASD and involved familiar toys and routines on the basis of the rationale that verbal and nonverbal attempts were more likely to occur to regulate behavior, to engage in social interaction routines, and/or to establish joint attention with a peer when the environment is familiar and predictable (Prendeville et al., 2006).

Several aspects of the Peer Play Intervention Project involved roles for the family as a collaborator with the researcher and/or as an interventionist. In the preintervention process, families completed a *caregiver questionnaire* (Wetherby & Prizant, 2002) to ascertain the nature of their children's communication, play skills, and interaction patterns with others. Parents also completed the *MacArthur Communicative Development Inventories* (Fenson et al., 1993) to contribute to assessment of their children's basic communicative levels. These documents were reviewed prior to completion of the study to address the families' questions and observations regarding their children's language function.

The research team interviewed the families using *The Family Inventory of Play Behaviors* (Prendeville & Grasha, 2000). This tool uses an ethnographic interview format to allow families to engage in and expand on a discussion of their children's play preferences and interactive styles, beginning with a dialogue about the children's typical play experiences and requesting examples of the children's preferred play. Families were invited to tell the story of whom their children played with and how they played together, the kinds of things their children played with and

how they used them, what their children did when they played, how long their children typically played, what the families thought their children felt when they played, what made their children excited or happy when they played, and what bothered their children when someone played with them (Prelock, 2001; Prendeville et al., 2006). Interventionists used this information to modify their interactions during the play sessions in the homes of the children with ASD. For example, the play activities and materials families reported as particularly motivating for their children were used to facilitate play within the dyad. Furthermore, families' descriptions of what made their children happy or uncomfortable or what they might be thinking during their play were considered when interventionists employed cues to support behavior regulation (e.g., "Ethan wants to play with race cars and you want to play a video game, what should we do?"), social interaction (e.g., "I like the way you are playing together and taking turns"), and joint attention (e.g., "The pirate is looking for the buried treasure. Where do you think he should look?"). A complete list of intervention cues has been discussed in Prendeville et al. (2006).

The focus of the Peer Play Intervention Project was on developing a peer partnership; therefore, careful consideration was given to match the peer with ASD with a peer without disabilities. Families made the final decision on their children's peer partner. Children with ASD ranged in age from 4 to 7 years and were previously diagnosed with PDD/autism or PDD/NOS, as described in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (American Psychiatric Association, 2000). The children with ASD were required to demonstrate, at a minimum, an ability to respond to bids for regulating behavior, engage in social routines, and establish joint attention (Prizant & Wetherby, 1989).

Peer partners without disabilities were similar in age and had some familiarity with the children with ASD. They were selected by the parents of the children with ASD in collaboration with the research team on the basis of

several factors, including an interest the typical peer might have shown toward the child with ASD or an interest the child with ASD might have shown toward the peer; the parents' comfort with a particular peer's ability to initiate and sustain interaction with their child who had less flexible and responsive play; and the availability and commitment of the peer play family to commit to weekly play dates for up to 15 weeks.

Three baseline sessions (weekly for 30 min each) occurred prior to intervention to observe and analyze the peers' interaction observed by the parent and the interventionist but without adult support. As the baseline sessions were often difficult for families to watch because most of the children had limited success in their peer interactions without adult support, the research team spent time debriefing with families after each session, talking about their experience, listening to their concerns, and reframing ways these concerns would be addressed in the intervention cues that were established for the intervention sessions. Ten 30-min weekly intervention sessions with interventionist support then occurred. After the fifth intervention session, the intervention was withdrawn for one session to assess engagement and communicative behaviors without adult support. The remaining five intervention sessions followed and were designed to decrease adult support as the children became more independent and successful in their interactions.

Families were provided with a listing of the intervention cues that would be used throughout the course of the intervention sessions and were invited to watch the intervention as appropriate without engaging but with the intent of asking questions at the end of a session to talk about what they observed, what might motivate their children to participate, and to offer ideas the interventionist might consider in the implementation of the cues. Comments were reviewed with the research team to determine how these might be included in the Peer Play Intervention Project without compromising the fidelity of the intervention. The research team collaborated with families in

the discussion of what suggestions or comments could or could not be folded into the intervention plan for their children. Throughout the intervention, families were asked to document any changes in the peer interactions of their child with ASD or observations of play when engaging with siblings or other children not part of the intervention project. Families were not asked, however, to implement the intervention cues outside what the interventionists provided during the weekly sessions.

Postintervention follow-up occurred after the 10th session, again to assess engagement between the child with ASD and the typical peer without adult support. A second interview using *The Family Play Inventory* was carried out and the format previously described to gather information regarding the families' assessment of the development of their children's play and play preferences was used. Families were given videotaped copies of the baseline and intervention sessions, as well as a listing of the intervention cues used, and were encouraged to continue the play dates with the trained typical peer, as well as other peers, and implement intervention cues as appropriate. The children were seen at 3 and 6 months postintervention where possible, and families were asked again to participate in an interview to tell the story of the evolution of their children's play with peers.

The Peer Play Intervention Project had three major goals for which the data are still being analyzed, but preliminary results are described here. The first goal was to enhance the engagement that occurred between the children with ASD and their typical peer during play interactions. Videotape analysis showed that dyads increased the time engaged in play with their typical peers over the course of the intervention (Prelock, 2004, 2008). The second goal was to nurture the relationship between the children with ASD and their typical peers so that it might extend beyond the intervention. Qualitative data were gathered to measure this outcome for the 11 dyads participating. For one dyad, the family described that the two children became good friends and spent time with each other each week

even 6 months after intervention. For another dyad, both the children and their mothers became friends. Parents of six other dyads reported improved peer connections for their children with ASD beyond those with the trained typical peers (Prelock, 2008). A final goal was to empower families with strategies they could use during play dates not only with trained peers but also with untrained peers. Face-to-face interviews following intervention and again during the follow-up phase (i.e., 3 and 6 months later) were used to gather information about families' use of the intervention cues, changes they observed in their children's interaction with peers, and opportunities they created for continued play dates. Data from these interviews indicated that the peer play experience fostered the ability of families to identify what constituted socially competent peers who would be the most appropriate play partners for their children and use strategies modeled to scaffold interactions between their children and their peers. Parents were an integral part of the study. Not only did they provide contextual information (e.g., their children's play interests, cues to which their children most likely responded) during the baseline phase that informed the intervention but they also created play opportunities following intervention that facilitated their children's continued interactions with their peers, expanding play and communication opportunities with new peers (Prelock, 2008; Prendeville et al., 2006).

Elements of family-centered care incorporated in this research

Eight key elements of family-centered care (Shelton & Stepanek 1995) were incorporated in these two research projects:

- First, as the *constant* in the participants' lives, the research team recognized the importance of hearing the families' voices beyond the informed consent to participate in the research. We worked with families to both design and implement the interventions, expecting that they would be more likely to continue the

interventions if they helped construct them and observed any benefits for their children.

- Second, *family-professional collaboration* characterized our approach in deciding how to design the intervention (e.g., co-construction of the social stories and family selection of the peer partners), where to implement the intervention (i.e., in the home of the child with ASD), how to evaluate the intervention (e.g., families completed dairies indicating behavior change and provided feedback on the materials used), and how to sustain any noted intervention effects (e.g., continue reading social stories or support peer play dates following completion of the intervention phases).
- Third, we exchanged *information* about the reported value of social story and peer play intervention, sharing the strengths and the weaknesses of both interventions, the need to examine the potential benefits in natural settings (e.g., home), and the reality that these interventions may or may not be effective for an individual child.
- Fourth, we worked hard to *honor diversity, strengths, and individuality within and across families* with the development of unique stories for each child, using the families' words in the development of social stories and including the toys of the child with ASD in the peer play intervention.
- Fifth, recognizing that families have *different ways of coping and responding to the challenges their children present*, we included their words to direct the desired behaviors in the social stories study and responded to their concerns and frustrations in their children's lack of response to peers in the baseline sessions by decreasing the number of baselines during the peer play intervention.
- Sixth, we encouraged *family-to-family support and networking* by sharing available resources in the community to connect with other parents who had children

with ASD and trainings related to social stories and peer mediation.

- Seventh, to consider a *flexible, accessible, and comprehensive* intervention research plan, we developed a schedule that was sensitive to the families' needs while recognizing feasibility for the interventionists, rescheduling when family events came up, adjusting a social story to meet the more immediate needs of the family, adjusting the number of baseline sessions in peer play when children with ASD showed no response to a typical peer and spent their time in another room away from their peer for two consecutive sessions.
- Finally, we attempted to *appreciate families as families and children as children* by designing an intervention protocol that did not compromise the children's current intervention program, capitalized on the concerns families had regarding specific behavior requiring intervention and the desire for their child to have a friend. We responded to the emotions of mothers who were having a difficult day by staying to talk with them after the formal research protocol and to the desire of the children who wanted to share an experience by staying to play a desired game.

Intervention that considers the family perspective is more likely to have pervasive results on the family system, affecting not only the child with autism but also all members of the family (Boettcher, Koegel, McNeerney, & Koegel, 2003). Similar to prior family-centered studies (Hobson, Chidambi, Lee, & Meyer, 2006; Rocha, Schreibman, & Stahmer, 2007; Schertz & Odom, 2007), parents were included as prominent contributors to the intervention for both the peer play and the social stories interventions. In the peer play study, families selected the typical peer to participate in the intervention with their children. They also participated in the initial and ongoing assessment of their children's function, completing the *MacArthur Communication Development Inventories* to as-

sess early receptive and expressive language planning and engaging in interviews describing their children's play prior to the intervention, upon its completion, and at 3 and 6 months following the interventions. Parents' roles in the social stories intervention were extended to their development of the social stories that served as the intervention targets for their children in collaboration with the researchers. As in the peer play study, these parents also provided initial and ongoing assessment of their children's functioning through the collection of data via daily diaries.

Both studies also responded to the importance of natural learning environments, consistent with the principle that *where* something happens is just as important as *what* happens (Dunst, Trivette, Humphries, Raab, & Roper, 2001). There are three dimensions of the natural environment that should be considered in practice: setting, activity, and practitioner. The setting dimension considers the importance of the learning context, indicating that interventions should help the child participate in socially and culturally familiar and meaningful activities (Kolb, 1984). Considering the value of the natural environment, the setting for both research studies was the home.

The activity dimension suggests that adults follow the children's lead because children determine who or what influences the interaction focus and outcome (Roper & Dunst, 2003). In the peer play study, following the lead of the children with ASD and their peer partners in the context of their play was the primary technique of the intervention, consistent with the expectation that the children's interests were most likely to be facilitative of opportunities for joint attention and social interaction. In the social story study, the children's behavior and interests dictated the content of the stories. The interventionists guided the children through the stories, but their ideas and thoughts were responded to and considered, particularly in their development of the comic strip conversations, which preceded the perspective-taking social stories.

In the practitioner dimension, the primary consideration is the extent to which clinicians are present during natural learning opportunities. Although the presence of the interventionists was important to both research studies, the peer play study design required that the interventionists decrease their mediating behaviors over the course of the intervention to provide opportunities for both children to use the modeled peer interaction strategies. In the social stories study, the parents responded positively to their children's demonstration of the targeted social story behaviors during the course of the intervention. In both studies, the families were given artifacts to facilitate their continued use of the intervention. In the peer play study, families were given a list of the intervention cues at the initiation of the intervention and copies of the videotapes of the peer play intervention following completion of the study. In the social story study, families were given the social stories to continue to read to their children at the end of the intervention phase and provided daily dairies to continue their data collection to document desired changes in behavior during a 6-week follow-up phase.

Roper and Dunst (2003) suggested that clinicians attend to all three dimensions of the natural learning environment when designing and implementing interventions. The ultimate goal is to ensure children's ability to participate in daily activities that can foster their communication and social learning. We propose that this goal should be a primary consideration for intervention research targeting family-centered practices as well.

Gathering information about the children with ASD and their families, as well as the motivations, behaviors, and desires of both, was a critical component of both research projects. Winton proposed that the purpose for gathering and understanding family information is "to ensure that intervention efforts are guided by family priorities and that interventions build on family resources" (1996, p. 32). Recognizing the importance of understanding what families hope to accomplish for their children with ASD and what they might

need from clinicians guided our discussion of the intervention research design and implementation plan. Knowing that a lot of energy is expended in managing daily life activities and changes in both expected (arrival home from school to start the intervention) and unexpected routines (getting sick on a day of the intervention research), critical events in the lives of families that may be expected or unexpected were discussed so that the research team would have some insight about families' preferences for dealing with particular events and what coping strategies they use to manage these events. This was an important dialogue in both studies because it tempered our reactions to why parents attended to some aspects of intervention (e.g., contacting the mother of the typical peer in the peer play study to discuss that the child with ASD was having a difficult day) but not others (e.g., completing daily dairies on the targeted behaviors in the social stories study). We learned the importance of being "receptive to each family's unique and constantly changing situation and the definition families bring to these situations based on cultural heritage, values and beliefs" (Winton, 1996, p. 44).

Dunst and Trivette suggested that family-centered care is "a special case of effective helpgiving" that fosters empowerment in those who are asking for "professional advice and expertise" (1996, p. 334). A major component of empowerment is the opportunity for "participatory experiences" and involvement in activities that enhance existing skills and foster the potential for learning something new. The social stories and peer play research provided several opportunities for families to enhance their understanding of their children's social communication and play. First, we listened to the families' concerns for their children's social communication and peer interaction challenges. Second, we collaborated with families to construct the three individualized social stories designed for each child and to select the typical peer models for the weekly peer play intervention sessions. Next, we made honest and sincere efforts to implement our

research design and procedures with fidelity and social validity while adjusting to individual family events that were unexpected and not under our control. Finally, we provided families with the information they needed to make informed choices about the types of social stories that would be created and why, as well as what peers might make appropriate play partners for their children. In both research projects, families worked with us to make final decisions about all stories and peer partners. We built on the families' strengths of knowing what works and what does not work for their children as they guided us through the content of the social stories and the activities most likely to motivate their children in play.

Laird (1995) proposed that clinical work in social work focus on how people have interpreted or made sense of their experiences and the effects these interpretations have had on their lives. Because reality is mediated through language and conversation, interactions with families can help create a changing narrative and possibly a changing reality in how families or parents tell their stories now as compared with before an intervention or conversation about their experiences. Clinical work in speech-language pathology also provides an opportunity for clinicians to use conversations with families to mediate the families' understanding of experiences with their children with ASD and the effects of their children's communication and social interaction on family life. Our social stories research used this narrative structure to examine the families' values and knowledge about events and how they interpreted these events. Family members' voices guided the development of the three social stories used to support the desired behavior of their children. Through early conversations in preintervention assessment and social story development, we learned what the challenges were, the realities for each families life, and how to capture this in the language of short stories that would highlight the desired behaviors while providing insights about what children might be thinking or feeling about challenging social events.

In the Peer Play Intervention Project, the conversation that occurred typically centered around the challenge of seeing a child struggle to make a social connection with another child. The research team discussed the impact of the social impairment in autism with families and what that might look like in a play date with a peer. We used the dialogue to talk about the nuances of making peer connections and the context for developing peer friendships. Our discussion then led us to describe the intervention cues that were designed to adjust the social experiences of both the child with and without autism. Because the family provides the most salient context for understanding and changing individually defined problems, the research team recognized that the family system must be considered within its sociocultural context if the intervention is to have any lasting effects.

Laird (1995) also suggested that when new stories are told or are co-created with families, the perception of an event or a behavior as a problem can be dissolved. In both research projects, parents co-constructed stories with the research team that changed the narrative of how they perceived their children's problems; it was no longer what the children did or did not do, it was how the children were thinking and responding to events that challenged him. Involvement in our intervention studies provided an opportunity for families to think in new ways about their children's social communication needs and potential.

Challenges in implementing family-centered care in research

Any discussion of the role of family in intervention research on family-centered care would be incomplete without consideration of the potential challenges and tensions that may arise when the principles of family-centered care are at cross-purposes with standards for evaluating research designs. The nature of such challenges and tensions varies as a function of the purpose, design, and method of study. Although case studies, correlational studies, and qualitative research are

not immune to difficulties, literature has documented the successful implementation of these approaches in the context of family-centered care intervention (e.g., Hutchins & Prelock, 2006; Prendeville et al., 2006; Uding et al., 2007). Experimental research in the conduct of family-centered intervention poses additional challenges because of its emphasis on the preservation of experimental control. The intervention studies described in this article employed both qualitative and quantitative methodologies associated with both correlational and experimental designs. The complicated nature of our methods and designs posed difficulties in our efforts to conduct research that implemented the principles of family-centered care while meeting the standards of experimental rigor. The lessons learned over the course of the studies can be instructive in guiding future research.

A major source of challenge in our research involved what Uding et al. described as “unpredictability . . . due both to involved parents’ family life and to the inherent complexities of research” (2007, p. 316). Certainly, families with children with ASD and other healthcare needs have complex, sometimes unpredictable, and frequently changing life circumstances that can complicate their participation in research, especially when that participation requires the implementation of fixed procedures. For example, the recruitment of parents as the primary source of data collection in the social story study was fitting because parents and families know their children best and are positioned most appropriately to judge whether any changes associated with intervention are observable in everyday family contexts.

On the other hand, such procedures introduced a major threat to internal validity because parents could not be blinded to what was taking place in their own homes, especially when they were an important part of the process of individualizing the intervention. It is important to identify the likely bias or placebo effects that may occur when families are aware of the intervention their children are receiving and/or are asked to provide

responses that evaluate the effects of a particular intervention. As family-centered practitioners, we want and value the input of families, yet we recognize that response demands, and gathering data from families who have a stake in intervention and are not blind to the outcome can be a problem. Opportunities for bias should be identified when interpreting intervention results and considered in defining how families contribute to intervention research protocols.

To address some of the concerns associated with families being aware of and invested in an intervention while providing input on effects, triangulation of data among raters and methods could be used. For example, data on effects would be gathered not only from families but also from school personnel or other more objective observers. In addition, methods used to gather information about intervention effects might include subjective informant measures (such as daily diary data) and more objective performance measures (e.g., reliably coded observations, results from standardized tests). When triangulation among evaluators and methods for assessing intervention effects occurs, there is stronger evidence for true effects. Researchers might also examine the replication of effects and response patterns across participants to support outcome reports.

Despite the efforts of the intervention and research team to discuss, gather, and otherwise support the completion of longitudinal (in this case, daily diary) data, the desired level of parental attention to data recording was sometimes difficult to sustain, leading to occurrences of missing data. For example, in the social story study, three families were dropped from the study owing to scheduling conflicts. Approximately 30% of the daily diary data from another four families were not completed, returned, or scorable. In addition, the first two participants served as pilots for refining intervention procedures, so their data were not included in the final analyses. Therefore, data from only 20 of the original 29 participants could be used. Consistent with the ethical dictates of research and

important principles of family-centered care, the intervention was continued for those families who did not return or complete the daily diary data, as well as the pilot participants. Thus, not only were valuable resources sometimes expended in interventions that proved fruitless from a data collection perspective, but also the concern over the systematic effects of attrition introduced the potential to complicate the interpretation of the remaining data. It could be that parents quit collecting data because they were discouraged owing to lack of improvement, but without the data, that is only conjecture. For the peer play intervention, fewer data were lost because videotaped analysis was used to assess targeted outcomes, although scheduling conflicts affected the length of intervention and available data to be analyzed for 2 of the 11 dyads. One dyad completed 8 of 10 intervention sessions and a second dyad completed 9 of the 10 sessions. Scheduling most often affected the timing of the 3- and 6-month follow-ups for the peer play study.

To balance additional threats to internal validity, and in efforts to be responsive to the principles of family-centered care, modifications to our intervention and data collection procedures were sometimes necessary. This often involved accommodating families' ever-changing schedules, leading to either fewer baseline and intervention sessions than originally planned in the peer play study or data collection procedures that were not perfectly standardized across participants in the social story study. These factors also introduced some degree of noise into the data. In a similar vein, there were times when families became concerned about new behavioral challenges that emerged after the intervention phase of study began. In situations such as these, we worked with families to flesh out the nature of their new concerns and constructed new intervention procedures to address each. However, as negotiated with families, the implementation of any new intervention procedures was delayed until the conclusion of the study to preserve the fidelity of our research. This demonstrates one way that

the value framework of family-centered care in research can be reconciled with the sometimes competing priorities of researchers. Although requiring greater effort and resources on the part of the research team, our commitment to respond sensitively to the dynamic nature of the challenges faced by families with children with ASD was beneficial to our relationship with families, and we believed it could be achieved without sacrificing scientific rigor.

Critically important from an ethical and family-centered perspective was the need on four occasions (for about 20% of the participants) to assign a family in the social story study to a condition in which the intervention would be implemented immediately, as opposed to random assignment in which a wait-intervention group would be an option. From the beginning of our collaborative relationships, it became clear that a few families with children with ASD were either unable to participate in the wait control condition owing to scheduling or struggling with particularly difficult or potentially dangerous behaviors and situations. Despite the rarity of these occurrences, the degree to which there was differential treatment on such bases sacrificed randomness to group assignment. Of course, conventional randomized designs often fall short of idealized standards owing to concerns of ethics and feasibility, which has led other researchers to make suggestions for overcoming or minimizing these problems (e.g., Lesik, 2006). Researchers have also pointed out that strictly random assignment could introduce unanticipated threats to internal validity by failing to consider treatment preferences and participants' knowledge and appraisal of treatment options (Corrigan & Salzer, 2003), and such a practice is particularly inconsistent with family-centered care.

We attempted to attenuate these difficulties while responding to the needs of families by implementing a quasi-random assignment procedure. Using this approach, the four families who articulated an urgent need or would be unable to participate in the wait-control owing to scheduling difficulties were assigned

to an immediate intervention group (vs. the wait-control group) and all remaining families were assigned on a random basis. Because this procedure was needed only rarely, we retained a high degree of confidence that the tendency of our experimental group to tilt toward children with ASD with the most severe problems was minimal. To examine this empirically, comparisons between groups on a number of dimensions (e.g., ratings of autism severity, measures of verbal ability) were conducted to ensure that the two groups were distribution matched prior to intervention efforts (Hutchins & Prelock, 2008b). Although researchers have argued that quasi-random procedures produce acceptable approximations to results obtained from randomized experiments (e.g., Shadish & Ragsdale, 1996), there is certainly ample room for disagreement regarding the degree to which the contamination of a random assignment mechanism will threaten claims surrounding internal validity. For this reason, procedural adjustments should be documented to provide consumers sufficient information when evaluating the contribution and limitations of our research. This, we did.

CONCLUSIONS

Clinicians and clinical researchers who embark on the journey of family-centered care for children with ASD are pursuing a unique opportunity to truly engage with families in a richly satisfying manner (Prelock & Beaton, 2006). This requires a level of self-awareness and a willingness to openly engage in dialogue centered on values, beliefs, and the contextual nature of knowledge (Kalyanpur & Harry, 1999; Like, Steiner, & Rubel, 1996; Prelock & Beaton, 2006). Child outcomes are enhanced when families are empowered through meaningful inclusion in their children's program development and implementation (Beaton &

Prelock, 2002; Dunst et al., 1996; Letourneau & Elliott, 1996; Thies & McAllister, 2001), as well as designing and implementing intervention research (Turnbull, Friesen, & Ramirez, 1998; Uding et al., 2007). Open and sustained communication with families participating in both research studies reported in this article was critical. When this dialogue was not ongoing, miscommunication and misinterpretations occurred. Knowing when the questions being asked or the story being told was beyond the capacity and primary goals of the research projects, weekly research meetings helped define what was in the realm of institutionally reviewed and approved human subjects protocols and what required outside referral and support. The guiding principle for the research team was what must be considered from a family-centered perspective, even if that meant data loss and participant attrition as the immediate family priority took precedence. When true collaboration is happening, the implications for families and their children with ASD are extraordinary. When families, clinicians, and researchers bridge the cultures among them, children are the benefactors.

In closing, we encourage professionals working with families and their children with ASD to recognize that efforts to support family-centered intervention need not be viewed as insurmountable obstacles to rigorous scientific research. Indeed, strategies to limit and assess the effects of a quasi-random assignment procedure as well as triangulation among raters and methods can be employed to achieve high levels of confidence. Considering the tremendous potential benefits of family-centered research (to the researcher, the family, and the child), this approach has the potential to enhance our understanding and ability to respond effectively to the needs of families and their children with ASD.

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