

Building New Dreams

Supporting Parents' Adaptation to Their Child With Special Needs

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Raising a child with a congenital anomaly or other chronic medical problem challenges families. Although most families are resilient, depending on families' relative balance of strengths and vulnerabilities, chronic child health conditions can contribute to problems with parenting and family relationships. We believe interventions can broadly promote family well-being by focusing on parental emotional, cognitive, and behavioral adaptation to their child's condition. Parents' adaptation to their child's diagnosis has been found to predict both family well-being and their child's attachment security. After reviewing these and other relevant findings on families with children with chronic medical conditions, the second half of this article describes a parent group intervention designed to promote adaptation among such families. The rationale, goals, and guidelines of this 8-session intervention are provided. Considerations and unanswered questions about implementing the intervention are also discussed. **Key words:** *attachment, group intervention, infants, parental adaptation, social support, special needs*

FOR MOST parents, the birth of their child is a joyous time. However, nearly 4% of parents receive distressing news about their child's health. In fact, about every 3.5 minutes a parent is told that their child has a serious chronic medical illness, health defect, disability, sensory impairment, or mental retardation (March of Dimes, 2000). For these parents, the time of their child's birth may become mixed with stress and despair.

As reviewed in this article, social, emotional, and cognitive variables often pertaining to parents' reactions to their child's condition have consistently been identified as markers of parent and child well-being. We believe that they are more than markers. In our view, they represent social, emotional, cognitive, and behavioral processes that influence family functioning. Consequently, we contend that parents' adaptation to their child's condition can serve as a pivotal focus when intervening to improve parent and child functioning. Following a review of research on parent and child functioning when the child has a chronic medical condition, we present an outline of an intervention designed to promote parent and child well-being by focusing on parental adaptation to their child's condition. We define *adaptation* as an ongoing process whereby parents are able to sensitively read and respond to their child's signals in a manner conducive to healthy development. On the basis of our review of the research, we contend that parental perceptions, thoughts, and emotional reactions to their child's condition are effective avenues for promoting adaptation.

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Work on this article was supported by grants from the March of Dimes, and the National Institute of Mental Health. The authors also express appreciation to Hillary J. Heinze and Lisa Merlo for their helpful comments on prior drafts of the manuscript. We are especially grateful to the families who have helped teach us so much about parenting and providing services to families.

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PARENT AND FAMILY ADAPTATION: STRESS, SUPPORT, AND RESILIENCE

Numerous studies have documented the unique emotional and physical demands that stress and strain parents raising a child with a chronic medical condition or disability (Bruce, Schultz, Smyrniotis, & Schultz, 1994; Florian & Findler, 2001; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992; Wade, Taylor, Drotar, Stancin, & Yeates, 1996; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). In addition to the normal stressors associated with having a new baby, these parents have to cope with many uncertainties about their child's health and prognosis, frequent medical appointments and procedures, and the additional workload of caring for a child with special needs. When coping strategies fall short, these challenges can detract from marital and other family relationships as well as work and careers, thereby creating further tensions within families. Perhaps as many as one third of families are pushed beyond their psychosocial resources, and the stresses of having a child with a birth defect affect parent mental health, family relationships, and child adjustment at a clinically significant level (Barakat & Linney, 1992). For instance, several studies have found increased symptoms of depression and incidence of major depressive disorder among parents of children with medical conditions (Blacher, Lopez, Shapiro, & Fusco, 1997; Breslau & Davis, 1986; McKinney & Peterson, 1987; Speltz, Arnsden, & Clarren, 1990). Families with children who have special needs also experience more marital conflict and are less likely to be able to rely on prior social supports, as friends and family members are often unsure of how to help and may avoid becoming involved altogether (Powers, 1993; Speltz et al., 1990).

Research has shown that higher levels of stress, anxiety, and depression have a negative impact on parenting (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Singer et al., 1993). In samples of children with and

without medical conditions, parental responsiveness has been found to have a positive influence on child development and well-being (Barakat & Linney, 1992; Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000; Endriga, Speltz, Marris, & Jones, 1998; Smith & Pederson, 1988). But, parents of children with special needs have been observed to be less responsive than are parents of children without special needs (Mahoney & Powell, 1988). Parental responsiveness and sensitivity are necessary to promote secure attachment among children with special needs (Atkinson et al., 1999; Clements & Barnett, 2002). Consequently, the stress of having a child with special needs can challenge family functioning in a variety of interrelated processes that appear to influence parental well-being, the spousal relationship, extraspousal supports, and parenting behavior.

Despite these strains, the research literature indicates that having a child with special needs is not primarily a story of "gloom and doom" (Vacca & Feinberg, 2000). The same research that identifies increased stress and symptoms among such parents finds that the majority appears to cope well with these added demands, and remains relatively resilient. Many parents raising children with chronic health conditions and developmental disabilities report high satisfaction and enjoyment of their role. Knowledge of the factors associated with resilience and healthy outcomes has informed intervention programs including our own so that positive adaptation can be encouraged among a larger number of families (Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999). In addition to focusing on parental reactions and perceptions of their child in our intervention, we strive to build and increase the number of family protective factors. For instance, because of their consistent association with positive outcomes in the research literature, we address improving parental access to and perceptions of social support. We chose a group intervention over an individual intervention because of the high potential for the group to improve social aspects of parents' adaptation.

Support from spouses, friends, and family has been found to have a positive effect on healthy adaptation among families (Barakat & Linney, 1992; Crnic et al., 1983; Florian & Findler, 2001; McKinney & Peterson, 1987). For instance, in a study of families of children with Smith-Magenis syndrome, the size of the family's support system was the best predictor of lower stress and fewer family difficulties (Hodapp, Fidler, & Smith, 1998). In families adapting to a child with special needs, a good match between actual and desired spousal support was found to significantly predict positive personal, marital, and parental adaptation (Bristol, Gallagher, & Schopler, 1988). Bristol et al. (1988) found that support from one's spouse was the best predictor of parental quality in a sample of children with and without disabilities. Parental coping and perceptions of control and stress also have been found to buffer or protect parenting sensitivity and well-being from the deleterious influences of stress. For instance, parental coping styles were found to mediate the relation between having a child with congenital anomalies, perceived stress, and parental sensitivity (Atkinson et al., 1995). Parental perceptions of their ability to influence positively child outcomes also have been shown to predict healthy adjustment among parents with a high-risk infant (Affleck, Tennen, & Gershman, 1985).

To summarize, having a child with a congenital anomaly sets into motion a number of chronic and acute stress conditions that detract from parent well-being, the quality of family relationships, and parenting behavior. Psychosocial resources such as perceived control, the ability to utilize social support, and cope with stress appear to be important in helping parents provide the types of parenting behaviors that will support healthy development in their children. Consequently, we focus on bolstering parental perceptions of control, support, and coping to improve parental emotional well-being and behavior. Additional research to further understand effective parental coping and to identify other pro-

tective processes within these families is also warranted.

PARENT AND FAMILY ADAPTATION: GRIEF AND RECOVERY

In addition to the stress associated with the extraphysical demands of raising a child with a chronic condition, parents experience psychological stress and disappointment when their child does not meet their hopes and expectations for a healthy child. From this perspective, many parents go through a process of grieving, although most appear to recover. We believe this *recovery* is the process of updating, rebuilding, and replacing the hopes and expectations they had prior to their child's birth with the realities of their child's actual prognosis. Influenced by theory and research on human attachment, loss, and caregiving (Bonanno & Kaltman, 1999; Bowlby, 1988; Pianta, Marvin, & Morog, 1999), this perspective emphasizes that when a child is born with special needs, parents have to let go of and grieve for their expectations and images of their anticipated or "hoped for" child (Moses, 1988). Developing a representation or schema of their child's actual, in contrast to their wished for, abilities facilitates parents' ability to respond sensitively to their child, thereby promoting a secure relationship with their child.

At various levels of awareness, all potential parents have fantasies about their children and their child's future. These hopes and dreams intensify during pregnancy. Parents imagine the kind of person their child will become, the relationships they will have with him or her, and the pride and joy they will experience as a parent. We view these seemingly narcissistic and self-indulgent daydreams to be a normal part of the attachment process. They prepare parents to form attachments to the helpless and dependent newborn who will soon arrive. They help parents to make the long and difficult self-sacrifice and investment needed to raise children. However, high hopes and expectations may be a liability. They can be crushed when

a child is born with a medical condition or disability.

For many of these parents, a complicated process—similar to bereavement—begins (Emde & Brown, 1978). Some common parental experiences at the outset of this process are listed in Table 1. We believe that many parents and professionals are slow or fail to recognize this process of grieving and adaptation. One of the complications has been identifying for whom the parents are grieving. Physically, their baby is not lost; he or she is right there with them. Instead, these parents are grieving for their hoped for child—the child they were expecting who never arrived (Moses, 1988). Parents have to adjust their expectations and hopes for their child in the face of the substantial uncertainties inherent in their child's medical, motor, intellectual, and social prognosis. Emotionally and cognitively, parents must come to terms with their child's condition.

Pianta, Marvin, and colleagues (Marvin & Pianta, 1996; Pianta et al., 1999; Pianta, Marvin, Britner, & Borowitz, 1996) have examined parental reactions and developed a technique for assessing parents' state of mind regarding their child's diagnosis. On the basis of their responses to a brief, semistructured interview, parents are rated on the degree to which they have resolved their thoughts and feelings about their child's condition. In Pianta and Marvin's scheme, parental resolution is marked by an integration of the facts and realities associated with their child's condition along with emotional reactions to the diagnosis. This integration is present in both their mental images of their child and their relationship with him or her. Indices of resolved and unresolved reactions are presented in Table 2.

Like grief and mourning (Bowlby, 1980), parental reactions to diagnosis are thought to be determined by a complex set of processes related to personality, relationship history, and how one has learned to process information about emotions and relationships. Mothers' resolution of their child's diagnosis has been found to be significantly associated with a variety of measures of parent and family

functioning including maternal mental health, perceived social support, and husbands' ratings of the marital relationship (Sheeran, Marvin, & Pianta, 1997). Notably, lack of maternal resolution of child diagnosis has been shown to be strongly associated with the formation of an insecure attachment in the diagnosed child (Barnett et al., 1999; Marvin & Pianta, 1996; Pianta et al., 1999). From this research, we have hypothesized that parents who are unresolved regarding their child's diagnosis have difficulty responding sensitively to their child. We believe that until parents have achieved a balanced view of their child, they will have difficulty accurately reading their child's signals and providing their child with a secure base from which to explore new relationships, learn to trust others, develop social skills, and feel lovable and efficacious.

THE ADAPTATION PROCESS

Although researchers and clinicians use the terms *resolution* and *acceptance*, we have chosen to emphasize the term *adaptation* when we work directly with parents. Our reason is that the words *resolution* and *acceptance* both suggest an end point, whereas *adaptation* assumes an ongoing process. Others in the field have argued that there is no final stage of absolute parental acceptance (Blacher, 1984; Featherstone, 1980; Powers, 1993). Rather, some grief and contradictory emotions are likely to persist or reappear. Although the connotation of the term *resolution* may be misleading, those using these terms agree that there is no end point to this process. Pianta and Marvin's classification system assumes that there are elements of lack of resolution present in all interviews. To the extent that the balance is tipped toward resolution, the interview is classified as Resolved. While we view the concepts of resolution and adaptation as compatible, we use the term adaptation for group sessions with parents.

The processes by which parents adapt to or come to terms with their reactions to their child's diagnosis are not yet understood. There is some controversy about the validity

Table 1. Common parental reactions to news of child disability

- Feeling devastated, overwhelmed, and traumatized by the news
- Shock, denial, numbness, and disbelief
- Feelings of crisis and confusion when attempting to cope with news of their child's diagnosis
- Sense of loss for the "hoped for child"
- Experience grief reactions similar to those experienced by individuals who lose someone through death
- Expectations and hopes for the future are challenged or destroyed
- Feelings of guilt, responsibility, and shame
- Strong anger directed toward the medical staff and professionals involved with child
- Wondering whether things would be better off if the child dies
- Decreased self-esteem and efficacy as parents' senses of themselves as providers and protectors are severely challenged
- Marital and other family relationships become severely strained
- Family routines are disrupted

of a grief model for parents of children with special needs (Vacca & Fienberg, 2000). Some of this controversy may be the result of a misunderstanding regarding the meaning of phrases such as grief, resolution, and adaptation. We do not view grief as an obvious, overt phenomenon that is pathological and synonymous with distress and negative affect. Theoretically, we view grief adaptation to be a normal cognitive and emotional process. Cognitively, parents must come to understand the meanings and implications of the diagnosis for themselves and their child. They must accurately process information about their child and their child's condition. Emotionally, parents must experience, accept, and express feelings of disappointment, sadness, grief, anger, and guilt that understandably may accompany the news that their child has a serious disability. Additionally, distressed parents must move past intense negative feelings to experience the pleasures, rewards, joys, and connection with their actual child. This does not mean that they will not feel distress about their child's condition, but that those feelings will not be as strong or preoccupying as they were initially. Many if not most parents who have a child with special needs will and do achieve resolution on their own and perhaps relatively quickly. We do not see it as a universal issue for all families. Signs

that parents are having problems adapting to their child with special needs assume a variety of forms. One pattern includes parents who remain preoccupied with negative reactions associated with their child's diagnosis. These parents' intense, raw affect suggests that they received the news recently, when in reality years have passed. A second pattern characterizes parents who deny any negative feelings or disappointment regarding their child's diagnosis. These parents appear to idealize their child and their role as caregiver. They may be identifiable by their extremely positive scores on measures of stress and stress-related symptoms (Barnett et al., 1999). Other parents may combine these patterns or fluctuate between them.

In our research with parents who have children with mild-to-moderate impairment, we found approximately half of parents were classified as unresolved in their reactions to their diagnosis 2 or more years after learning of their child's diagnosis (Barnett et al., 1999). Time since learning of child's diagnosis has not been found to predict parents' resolution status regarding their reactions to their child's diagnosis (Barnett et al., 1999; Pianta et al., 1996). Even when we reinterviewed parents more than a year and a half after their initial interviews, nearly half remained or had become unresolved (Clements et al., 2001).

Table 2. Signs of resolution and lack of resolution from Pianta and Marvin’s reaction (Pianta & Marvin, 1992) to Diagnosis Classification System

Evidence of resolution	Signs of lack of resolution
<ul style="list-style-type: none"> ● Acknowledgment of emotional difficulty of learning of the diagnosis ● Recognition of change in reactions since learning of the diagnosis ● Suspension of search for an existential reason for child’s condition ● Acknowledgment of the need to move on in their life ● Accurate representation of child’s abilities 	<ul style="list-style-type: none"> ● Denial of emotional impact of diagnosis ● Cognitive distortions related to child’s diagnosis or abilities ● Confusion and mental disorganization (contradicting oneself; loss of memory) ● Active search for existential reason for child’s condition ● Disoriented or stuck in the past ● Boundary violations (attempts to draw interviewer into collusion against medical personnel)

Consequently, time in and of itself does not appear to be sufficient for parents to resolve their reactions or adapt to their child. Through longitudinal research on parents who participate in our intervention, we hope to show that processing their reactions with other parents in a therapeutic setting can improve parents’ adaptation to their child. These findings would provide compelling evidence that interventions are useful in promoting parent and child adjustment

within families raising a child with special needs.

To date, we have yet to identify parent factors that predict whether they successfully adapt to their child. We did find that type of child’s impairment predicted lack of resolution. Specifically, we found parents were more likely to be classified as resolved if their child had a correctable condition such as cleft lip, where surgery could repair the majority of the disfigurement. Parents were more likely to be

Table 3. Challenges to adapting to child diagnoses

<p>Distress</p> <ul style="list-style-type: none"> ● Parents are likely to re-experience grief at each new developmental stage and milestone that their child fails to achieve ● Preoccupation with guilt, anger, and unanswerable questions about blame <p>Uncertainty</p> <ul style="list-style-type: none"> ● Implications of the diagnosis are unknown ● During early months child may not appear different from others and can briefly or permanently appear developmentally advanced in some areas <p>Avoidance</p> <ul style="list-style-type: none"> ● Parental denial and suppression of negative feelings about their child ● Family and friends may be reluctant to acknowledge the disappointment and sadness of the news, and be overly optimistic or focus only on the positive <p>Isolation</p> <ul style="list-style-type: none"> ● Members of the medical community may appear insensitive, emotionally distant, and not reach out and connect with parents ● Family and friends may withdraw from parents or parents may push them away

classified as unresolved if their child had a diagnosis that did not have a medical remedy such as limb deficiencies and cerebral palsy (Barnett et al., 1999). However, child condition made only a tiny contribution to parental adaptation. Several processes that we hypothesize may interfere with parents achieving resolution are listed in Table 3. We believe the unfolding nature of parents' knowledge of their child's prognosis to be one of the biggest challenges to parental adaptation. Specifically, a parent may understand that the child has serious motor impairments and will not walk. However, it may be years before they actually experience the emotions. For example, they may not fully realize their grief until they see their child not walking when his or her peers are, or their child not running and playing tag, when other children are. At each new developmental phase, the parent is likely to experience new emotions related to the child's condition. This developmental unfolding appears to be particularly stressful for parents. They may begin to master their thoughts and feelings, only to have them reawakened over and over. For these reasons, one of the goals of our intervention is to help parents understand the ongoing challenges of raising a child with special needs and to develop the confidence and tools needed to adapt not only in the present, but to anticipate future change and to adapt accordingly.

A GROUP INTERVENTION PROGRAM FOR PARENTS OF TODDLERS AND PRESCHOOLERS WITH SPECIAL NEEDS

Because many families report finding it significantly challenging to raise a child with special needs, and because these children are at risk for adjustment problems, we have developed an empirically informed intervention that can improve parent and child well-being. Our group intervention is geared toward parents who have a toddler or a preschooler with special needs. The group was designed for parents of children with Down syndrome, cerebral palsy, epilepsy, spina bifida, hydrocephalus, mental retardation, and related dis-

orders. It can be adapted to address other conditions. The primary focus is the parent or family psychosocial adaptation to their child rather than working directly with their child *per se*.

Currently, we are offering groups to parents who have known of their child's diagnosis for at least 6 months. We believe that parents should be past the period of initial shock or what Miller (1994) refers to as "surviving" and to have had a chance to learn first hand about their child's condition and some of its implications. Both the literature and parents in our groups suggested that several months are needed to process the medical information on their own or with trusted loved ones, before they are ready to discuss these matters in a group setting with mental health professionals and other parents. We decided not to offer the group to parents of newborns, in part so that they had more time to process the diagnostic information, and because many of the developmental manifestations of their baby's special needs may not be evident until they are older. In contrast, toddlers and preschoolers share a number of developmental issues pertaining to early autonomy and the initial developmental milestones of locomotion and communication (Erickson & Kurziemer, 1999).

At the same time, there may be some parents who are more open to change during the initial period of shock and distress. Perhaps the opportunity to engage parents becomes time-limited as some quickly reject their child, placing him or her in the care of a relative or foster parent. An intervention by Pelchat et al. (1999) provided individual counseling by nurses, starting in the hospital and continuing at home soon after the child's birth. Pelchat and colleagues' intervention was based in systems theory. It also had a broad focus that included an effort "To help the parent gain a realistic understanding of the situation and to help them grieve their dream of a perfect child" (p. 468). Those parents who completed the intervention demonstrated significant improvements in their adjustment and social support compared with

comparison parents, even when parents were reassessed a year after the intervention. Consequently, identifying when optimally to offer interventions is an open and important question.

Our intervention is grounded both in the stress, support, and coping as well as in the grief and adaptation research reviewed in the initial sections of this article. We also conducted focus groups with parents to gather their input and reactions to our research and ideas for intervention prior to ever conducting an intervention group. The result was an 8-session program that is conducted with small groups consisting of approximately 2 to 4 families. Both mothers and fathers are strongly encouraged to attend. We recommend keeping the number of group participants in any given session to no more than 4 or 5 parents. Parents often have a lot to share with the group, and when more than 5 attend all parents do not have much of an opportunity to participate. Meetings are held weekly and last for 90 minutes. Opportunities to attend a missed session are provided. The groups are jointly led. Preferably at least 1 therapist is a master's level mental health professional, and at least 1 of the group leaders is a parent who has an older child with special needs. We recommend recruiting and training such a parent to serve as a group leader. Graduates of the group may be appropriate future group cofacilitators.

We have settled upon an 8-session program. Prior programs have been effective when they were relatively short in duration, such as 5 to 8 sessions for 1 to 2 hours at a time (Moxley-Haegert & Serbin, 1983; Nixon, 1993; Pelchat et al., 1999; Sandler, Coren, & Thurman, 1983; Singer et al., 1993; Singer, Irwin, & Howkins, 1988). In our focus groups, parents emphasized the importance of brevity. We do not believe 8 weeks is sufficient to make and see big changes in family functioning. Eight sessions do not provide adequate time to explore in depth any of the larger issues addressed in the group. However, 8 sessions do appear to be enough time to initiate a process within the parent that will help him or her move for-

ward toward healthier adaptation. We hope research will answer the question of whether booster sessions are needed to help maintain well-being over the course of each family's development (Hauser-Cram et al., 2001).

Overarching goals of our parent group intervention

- I. Facilitate parental adaptation by identifying and validating the range of feelings, identifying parental strengths, and increasing parents' supports and coping as they work to build new dreams for their child.
- II. Encourage mutual support and sharing of information among group members.
- III. Increase perceptions of support available and received as well as quality of important relationships, including the spousal relationship.
- IV. Improve skills at seeking information, support, and resources regarding child medical diagnoses and services for children and families.
- V. Promote parenting sensitivity and effective parenting skills.

Session 1: Getting to know each other

The goal of the first session is to create a comfortable, friendly, and trusting atmosphere in which participants can begin to listen and share. Group facilitators introduce themselves, the purpose of the group, and describe their relevant background and experience. Parents are then invited to introduce themselves and encouraged to share something about themselves, their families, and their child with special needs. During this session, parents are asked to think about previous group experiences, and to discuss the elements that make valuable contributions to parent groups. We expect a third or more have participated in some type of support group for parents. Typically, parents' prior group experiences were loosely structured, single-session meetings. Learning from these prior group experiences facilitates parents connecting with and benefiting from the proposed

8-session intervention. Participants develop guidelines for group participation and are encouraged to express expectations of what they hope to gain from the group sessions. Parents are informed that they may opt to pass on group activities that they are not comfortable with or prepared to deal with, but they are encouraged to revisit these activities when they are ready.

The basic goals of the program are introduced and discussed. Group facilitators clarify what the group can and cannot reasonably offer to the participants. Appropriate referrals and references will be provided in instances where requested services and information are beyond the capacity of the group. Sections of Nancy Miller's book *Nobody's Perfect* (Miller, 1994) are read aloud, illustrating the range of reactions and feelings that parents experience surrounding their child's diagnosis. Miller (1994) also uses the term adaptation to describe the process that a parent experiences after receiving a diagnosis of the child's condition. Her work has had a significant influence on our thinking. As a heuristic, Miller views the process of parental adaptation as a progression from "surviving" to "searching" to "settling in" to "separating." She does not view these as discrete stages, but rather as overlapping and spiraling components with parents returning to earlier phases as new parenting and emotional challenges are encountered.

One of the challenges of group work is that parents' experience and reactions are quite varied so that each parent will be in a different psychological place with regard to the child. Miller's idea of 4 phases of adaptation helps parents to develop a mental map of the adaptation process, specifically, where they are in this process, and most important, that they can attain more adaptive responses to parenting and relating to their child. In Miller's framework (Miller, 1994), the surviving stage involves parental coping with the life-changing nature of the experiences and feelings associated with the diagnosis of a child with a disability. Suggestions for parents in this stage include normalizing varied

parental feelings, expressing those feelings, using support networks, and finding time for oneself. The searching stage involves the search for reasons, for information about the diagnosis, for understanding about how this will affect one's life, and for treatment and/or services. While searching can lead to empowerment, it can also be frustrating. Searching is necessary for parental adaptation; however, it never ends. During the settling in stage, the parents achieve a sense of balance and predictability in their thoughts and feelings about their child. This stage has several elements related to Marvin and Pianta's concept of diagnosis resolution (Marvin & Pianta, 1996) such as shifting priorities, arriving at more realistic expectations, focusing on the present, and moving on with life. The last stage described by Miller—separation—becomes a larger issue as the child becomes more independent and spends increasing time away from home. In this stage, parents are faced with letting go of some of their helping and protecting behaviors, and trusting their child's abilities to care for themselves. Miller's work (Miller, 1994) is helpful to parents because it acknowledges the flexibility and continuity within the adaptation process.

Session 2: Getting to know our questions

The goals of this session are to help parents clarify questions they have about their children and their relationship with them and to understand their own approach to working with professionals and acquiring information, resources, and services. Parents are asked to discuss how they learned of their child's diagnosis, what they learned about it, what information is missing, what concepts are unclear, and what problem-solving strategies are needed to gain resources/information. Parents learn about identifying and posing key questions to health, medical, and school service providers. Sections are read aloud of *Do You Hear What I Hear? Parents and Professionals Working Together for Children With Special Needs* by Janice Fialka and Karen Mikus (Fialka & Mikus, 1999). The book includes discussions of the differences in

perspective between parents and professionals in schools and clinics. Effective strategies for working with professionals to obtain and organize information are detailed and explored. Parents are asked to keep a journal of words and/or pictures chronicling their experiences rearing a child with a disability or medical condition. Including journal entries of emotional reactions and questions is emphasized. Although journal entries will not typically be shared with the group (unless parents wish to do so), parents are informed that keeping a journal can be a helpful and safe way of expressing their thoughts and feelings surrounding having a child with a disability. As an alternative to writing in a journal, parents may choose to speak out loud to a photo of their child, saying things they feel but do not say to their child. Research on expressing emotions verbally support that these processes promote well-being (Pennebaker, 1990; Smyth, 1998).

Session 3: Getting to know our dreams

The goal of this session is to elicit, validate, and support parents' past and current dreams for their children. To facilitate this goal, the group views portions of the videotape *Lost dreams and growth: Parents' concerns* by Ken Moses (Moses, 1988). Moses is a mental health professional who has a son with special needs. In the video, he discusses his experience as a parent of a child with special needs, and parents of children who have special needs respond to Moses' experiences and questions. Group facilitators invite the parents to respond to particular stories, feelings, dreams, and questions from the tape that either match or differ from their own experiences. As a homework assignment, parents are asked to write a letter to, or draw a picture of their hoped for child. Although their letters and pictures are not shared with their child, they are asked to reflect on the hopes and dreams they had for their child before learning of their child's medical diagnosis.

Sessions 4 and 5: Giving ourselves time

The goals of these sessions are to help parents accept their reactions to their child,

develop realistic expectations of themselves, and identify the challenges that lie ahead. Understandably, many parents try to deny or avoid their negative reactions to their child and their child's condition. They may feel pressure to "get over" it. They may feel a lack of empathy from others. We believe efforts to avoid, minimize, or hurry negative feelings interferes with the adaptation process. Consequently, we work to normalize parents' reactions and distress, encouraging them to explore rather than avoid these feelings. The facilitator reviews the stages included in the book *Nobody's Perfect: surviving, searching, settling in, and separating*. As previously mentioned, the "stages" in the process of adapting to a disability diagnosis are not necessarily sequential, often overlap, repeat, and do not imply closure or completion. We help parents to realize that adaptation is a lifelong process and to identify important emotional milestones that accompany their struggle to build new dreams for their child. Catalysts for movement from one stage to another as well as stage overlap and repetition are discussed. The book is also used to help parents identify their strengths and abilities and to learn additional ways to handle difficult times. Parents are invited to share the ways that they have worked through or handled the challenges of each stage. Chapter 7 of Miller's book, entitled "Taking care of you," is used to emphasize the importance of parents attending to their own needs.

Session 6: Slowly rebuilding new dreams

The goal of this session is to encourage parents to take new steps in adapting to their child. In this session, parents reflect on their journey up to this point, and they identify their strengths. They consider what their families have done well and the benefits of those experiences. Participants share stories of hope and progress. In the context of reminders of the unfolding nature of their child's development and personality, parents begin to explore new dreams for their child and for themselves as parents. Parents are asked to participate in an art activity in which the instructions are to create 2

pictures/symbols: the first depicting their surroundings and their mood immediately after learning of their child's disability and the second depicting their current mood and surroundings. Parents are then asked to reflect on what has changed since they first learned of their child's disability.

Session 7: Relating to others

The goal of this session is to provide information to boost coping strategies and improve the parents' relationships with family and friends. This session addresses concerns regarding the impact of the child's special needs on the parent and on spousal, sibling, and extended family relationships. Stress, conflict resolution, prioritizing, and other common challenges to relationships within the family are considered. Different ways of responding to and coping with stress are described. Particular attention is given to improving communication and reducing stress in the relationships between mothers and fathers. We encourage mothers and fathers to attend, but in many cases this is not possible. We encourage a group dialogue about step-parents and situations where parents are and are not living together. To clarify differences in how mothers and fathers respond to having a child with a medical condition or disability, group members are asked to read excerpts from Donald Meyer's book *Uncommon Fathers: Reflections on Raising a Child With a Disability* (Meyer, 1995). Group members offer examples and suggestions for meeting various challenges so that they can maintain satisfying, mutually supportive relationships with family members.

Session 8: Relating to my child

The goal of this session is to encourage and reinforce sensitive parenting and to acknowledge the formal ending of the group curriculum. In this session, the significance of parental behavior and emotional reactions to the child's developing sense of trust and security are explored. Group leaders discuss how physical closeness and touch communicate comfort and security to children. Parents are encouraged to learn their child's unique

ways of communicating. The group discusses recognition and acceptance of their children's temperamental styles. Parental strategies for behavior management that promote healthy development and a trusting secure parent-child relationship are described and modeled. To help acknowledge the ending of the formal curriculum, parents are asked to develop a list of ideas, feelings, beliefs, and experiences they want to remember from their participation in the group. In effect, we encourage them to write a note to themselves that they can take out and read at some point in the future when they might be stressed or discouraged about their role as parents. We also ask participants to share their reactions about the group such as what worked, why it was helpful, what more is needed, and what they plan to do next. At the end, they also are given the opportunity to provide anonymous written feedback to the group leaders.

MECHANISMS OF CHANGE

The efficacy of our group intervention to improve parent well-being, parenting sensitivity, and child attachment security and socio-emotional adjustment has not yet been tested. We are beginning efforts to evaluate its utility empirically. We believe the intervention will be proven effective because it targets and changes parental adaptation to their child. As depicted in Fig 1, we see adaptation to the child with special needs as pivotal to promoting parent and child well-being. From an attachment perspective, *grieving* is a process whereby people update and adapt their psychological attachment to the lost individual. When the child's well-being is threatened, strong emotions of attachment, love, and protection, as well as anger and sadness, are released. Parents have to update their perception of their child and open themselves to integrating their thoughts and emotions. As they adapt their images of their children—giving up aspects of the hoped for child that cannot be realized—they experience the intense negative emotions of loss that can interfere with their ability to care for their youngster. We believe that failures in acknowledging and

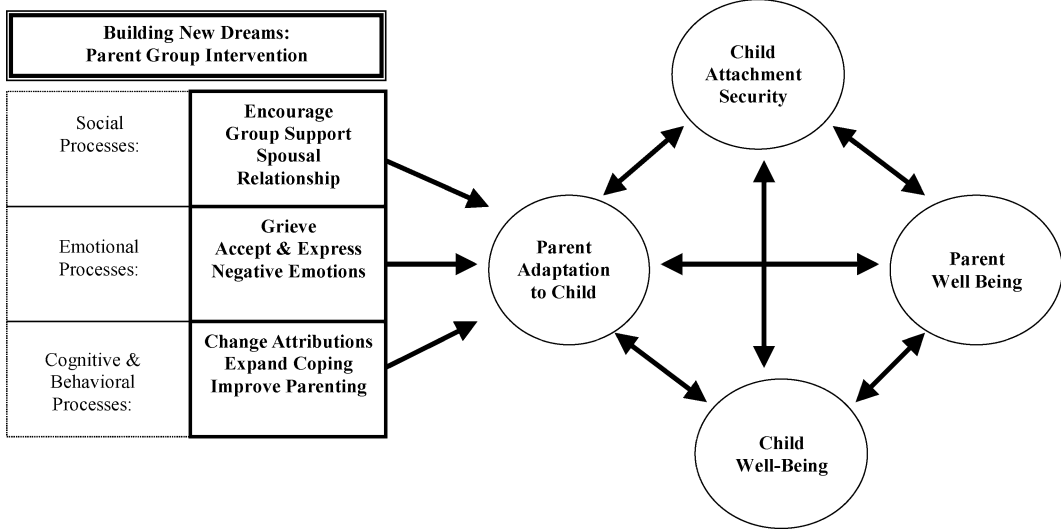


Fig 1. Conceptual model of intervention mechanisms of change.

letting go of the hoped for child contributes to insensitive caregiving, because it interferes with parent’s ability to accurately read and respond to the child’s actual needs and signals.

We believe social, emotional, cognitive, and behavioral processes promote positive adaptation. Consequently, our intervention is designed to target factors in each of these domains. Figure 1 also depicts the multifaceted approach of the intervention. Social factors addressed include improving social support and the spousal relationship. On the basis of the established importance of social support for families whose child has a disability or medical condition, many types of parent support groups have been developed (Davison, Pennebaker, & Dickerson, 2000; Harbin, McWilliam, & Gallagher, 2000; Slentz, Walker, & Bricker, 1989; Santelli, Turnbull, Lerner, & Marquis, 1993). In general, such groups have been successful in increasing parental self-appraisal and competency. Boukydis (1994) found that parents of children with disabilities feel that other parents with similar circumstances would be best able to provide them emotional support. Marital counseling also has been found to have beneficial effects for parents whose child has a medical condition (Hawkins, Singer, & Nixon, 1993). We encourage both parents to

attend our group sessions, and provide support to this relationship in the form of coping and communication strategies.

Emotional factors also are important in promoting parental adaptation. The proposed intervention emphasizes expressing negative emotions and finding adaptive ways of coping with these feelings. Among health professionals, there is increasing recognition of the role emotional expression plays in maintaining physical and mental health (Kelley, Lumley, & Leisen, 1997). Using a grief framework, several have made suggestions for interventions to target emotional expression (Ellis, 1989; Klass, 1988; Powers, 1993). Social Support also has been found to be a significant factor in grief resolution as sharing one’s feelings has been found to increase the likelihood of resolving the bereavement (Rando, 1985; Schut, Stroebe, van den Bout, & Terheggen, 2001). Lehman, Ellard, and Wortman (1986) found that the most helpful emotional supports for those who have experienced a loss include contact with those who have experienced similar losses and the opportunity to vent feelings. Culberg (1971) found that women who suppressed their feelings about having a stillbirth had prolonged psychological problems relative to women who expressed their feelings. In our

intervention, group leaders emphasize that grief is a normal reaction to having a child with a disability or illness. Further, parents are told that grieving the loss of the imagined child does not mean they do not love their actual child (Ellis, 1989). These parents may wish the disability did not exist, but they still experience joy as a parent and pride in their child. Also, parents are informed that some feelings of grief may always persist. They are prepared for feelings of grief that emerge as a result of environmental triggers such as contact with another child who is the same age as their own but who is more advanced developmentally (Bruce et al., 1994; Klass, 1988; Powers, 1993).

We emphasize the parent-child attachment relationship because it is influenced by and promotes or mirrors parent and child social and emotional well-being (see Fig 1). Children with secure attachments have more sensitive and healthy parents and demonstrate better social and emotional adjustment within and beyond their attachment relationship than do their insecure counterparts (Anan & Barnett, 1999; De Wolff & van IJzendoorn, 1997; Schneider, Atkinson, & Tardif, 2001). Several parent interventions have been developed and shown to be effective at increasing child attachment security (van IJzendoorn, Juffer, & Duyvesteyn, 1995). There is also evidence that these parent interventions are effective in promoting child adjustment by increasing attachment security (van den Boom, 1995).

Cognitive and behavioral factors also play essential roles in parental adaptation, and therefore are addressed in our parent groups. We stress knowledge about child development, sensitive parenting, and enhanced coping strategies. We also emphasize attending to and shaping parental attributions about their child and his or her condition. Other strategies include providing clear information about disabilities, legal and financial matters (eg, insurance, funding sources), as well as local and national parent organizations (Connolly & Sheridan, 1996). In addition, we recommend giving parents clear information about the importance of sensitivity to chil-

dren's signals and providing videotaped modeling of sensitive parenting. Interventions to enhance parenting skills and the competency of parents of children with disabilities have led to improvements in child and parent functioning as well as in parent-child interactions (Mahoney & Powell, 1988; Moxley-Haegert & Serbin, 1983; Pelchat et al., 1999; Sandler et al., 1983; Slater, 1986). For example, an intervention program called Support and Education for Families (SAEF) was developed to address the concern of elevated parental depression among parents whose child has a medical condition (Singer et al., 1988, 1993). SAEF offered the parent several types of interventions, some of which included parent-to-parent support groups, instruction in coping skills, and behavioral parent training. Overall, the SAEF program led to reductions in depression. The behavioral training class, in particular, led to increases in positive parent-child interactions and fewer undesirable child behaviors (Singer et al., 1988, 1993).

At this point in time, we do not believe any of the aforementioned domains (ie, social, emotional, cognitive, and behavioral) addressed in our intervention is of greater importance. Each of these ingredients makes a unique and important contribution toward healthy adaptation. We believe focusing on any one of these processes in exclusion of the others would be a mistake and would decrease the effectiveness of our intervention. Interventions that have focused solely in one domain, such as emotion disclosure, are not likely to be as effective as those that address the social integration of emotion and cognition (Schut et al., 2001). Moreover, we do not see processes in these domains to be mutually exclusive. Rather, we see social, emotional, cognitive, and behavioral processes operating synergistically to promote parental adaptation. For instance, in groups, members can help to validate the feelings and emotions of other members, establishing the universality of grief (Humphrey & Zimpfer, 1996; Summers, Behr, & Turnbull, 1989). Group members can also pool and share information with one another. By sharing their

experiences, parents can become more aware of their thoughts and feelings and realize that not all their thoughts are realistic or accurate (eg, that a parent is responsible for his or her child's disability) (Klass, 1988). Group members make comparisons, recognize, and benefit from other members' knowledge and coping strategies. Accordingly, they learn strategies for managing and expressing their grief. As noted by Humphrey and Zimpfer (1996), "A group has the potential to become a therapeutic community, offering opportunities for support, self-exploration, insight, behavior change, and the development of new socializing techniques." (p. 90). Not only do social, emotional, cognitive, and behavioral processes amplify one another positively, it is impossible to separate them in an intervention. Therefore, we try to emphasize all of these processes, rather than emphasize any one in particular.

PARENT READINESS TO CHANGE

At the outset, parents must see the groups as supportive and helpful if they are going to be open to participating. We believe that there are individual differences in what components of the intervention will appeal to each parent. For some parents, social support is a key entry point toward adaptation, while for others expressing distress is crucial. For most parents, more than one of these processes will work to move them toward seeking help and improving their adaptation. By emphasizing several processes, we believe we can appeal to a larger pool of families, keep participants engaged, and ultimately promote lasting improvements. For some parents this brief intervention may be sufficient. For oth-

ers, it may create the desire and potential to benefit from future intervention.

There are both pluses and minuses to the group approach. The group context has the advantage of providing services to multiple families simultaneously. Groups combine the wisdom of their members. However, some parents may not wish or feel ready to share with others. Prior research on a support group for mothers of high-risk infants found positive effects only for mothers who had high need for support at the outset (Affleck, Tennen, Rowe, Roscher, & Walker, 1989). It is possible that some parents may even have a negative effect on other group members by modeling maladaptive and dysfunctional reactions and adaptations to their child. As a result, it is important for group leaders to interview and get to know all potential group members prior to the first session. We do not believe that all parents are equally ready to participate positively in the group. Therefore, group leaders must be alert and ready to help some parents find individualized interventions, or work with them until they are ready for a group experience.

We believe achieving healthy adaptation is central to parents developing a satisfying attachment with their child. Ideally, parents increasingly are able to learn to love, appreciate, and attach to their child. As the child develops a secure attachment, the parent and child are able to build new, more realistic dreams together. We believe that parental adaptation is facilitated through social, emotional, cognitive, and behavioral processes. In our evaluation research we are examining whether parents' reactions to their child's diagnosis and child attachment security mediate the relation between program participation and parent, family, and child well-being.

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