



1 Osborne Road
Brookline, MA 02446

FROM CHALLENGE TO JOY:

Transforming Common Dilemmas for Parents Raising Children with Developmental and Medical Disabilities

Andrew L. Miser and Susan Rosano

Parents with children who have developmental and medical disabilities have in common a number of family dilemmas that they deal with on a day-to-day basis. This article specifically distinguishes eight of these family dilemmas and suggests ideas for dealing with them. First, this paper looks at the nature of each dilemma from the point of view or from the experience of the parents or the family as a whole. Then, the task of the family over time in dealing with each dilemma is examined. Third, different empowering contexts or perspectives are identified that parents can generate to assist them in experiencing a sense of wholeness and well being. Finally, this paper highlights the transformative effect of shifting perspectives when parents are dealing with the family dilemmas of raising a child with special needs.

Parents with children who have developmental and medical disabilities have in common a number of family dilemmas that they deal with on a day-to-day basis. Many parents are comforted when they find out they are not alone in their experience and they gain strength in coping with their unique circumstances when they understand that many of the difficulties they are facing are common to other families with children with disabilities.

The word “dilemma” aptly describes the kind of difficulties that these families tend to encounter every day. A dilemma, defined by Webster’s New World Dictionary, is “a perplexing or awkward situation.” In such circumstances, parents may find it difficult to navigate or to see things clearly. Such circumstances require parents to problem solve, to come to grips with what is going on, and to seek help from other people and professionals. Feeling confused, not knowing what to do or where to turn, feeling sad and being alone are all common experiences for parents with children with developmental disabilities. The word “dilemma” points to the nature of the circumstances with which these families must learn to cope.

This article specifically distinguishes eight of these family dilemmas and suggests ideas for dealing with them. First, this paper looks at the nature of each dilemma from the

point of view or from the experience of the parents or the family as a whole. Then, this paper examines what might be the task of the family over time in dealing with the specific dilemma that they are encountering. Third, different empowering contexts or perspectives are identified that parents can generate to assist them in experiencing a sense of wholeness and well being in dealing with each dilemma.

There is a good deal of research to suggest that one of the adaptive responses that parents make to the birth of a child with a disability is to attribute positive meanings to the circumstances in which they find themselves (Patterson, 1991; Austin & McDermott, 1988; and Antonovsky & Sourani, 1989). Couples will find interpretations to make their situations more manageable, adopt positive attitudes toward their child's disability, shift expectations of what can be done, identify growth and capabilities in their child, or acknowledge the child's contribution to their family as a whole. Over time, such ways of shifting the perspective through which they are viewing their life circumstances can aid significantly in helping couples heal family trauma and foster family well-being (Miser, 2001). This paper highlights the transformative effect of shifting perspectives when parents are dealing with the family dilemmas of raising a child with special needs.

The Dilemma of an Unexpected Future: We don't know where we are headed

Parents who are expecting a baby naturally approach their due date with a great sense of anticipation of the birth of a normal, happy, healthy child. When events go terribly wrong and the mother gives birth to a child with a developmental or serious medical problem, parents end up going home, devastated, in a state of shock, feeling shaken and feeling quite alone with their situation. The impact that the birth of a child with chronic illness, physical disability or developmental disabilities has on the family is well documented in the literature (Patterson, J.M., 1988; Patterson, J.M., 1991)

For new parents who bring a baby with a disability home from the hospital, there is a profound sense that the trajectory of their lives has been altered or shifted in a permanent and unforeseen way. As parents cope with their new reality, they have to continually deal with the central concerns, "What has happened to us?" "What is going on?" "What is going to happen to us and to our child in the future?" and "Where are we headed?" Parents all of a sudden find themselves on a whole different path than the one they had anticipated when they first found out that they were going to have a baby.

From the time parents suspect or learn that their child may have a disability, they may experience a whole host of feelings, ranging from shock to confusion, from despair to anger, from sadness to hopelessness, and from frustration to fear. There may be a profound sense of loss of the future, the dreams and the expectations of having a normally developing child and a typical family life. The parents, who had expected a healthy, typically developing child, must now deal with a very uncertain future, one that has no familiar guideposts.

Often, parents report that they feel "robbed" of the experience of the joy and happiness that accompanies the birth of a healthy child. Understandably, there may be much anxiety about their child's development, health, and future outcome. It becomes very difficult to deal with the feelings of not knowing what each day will bring and with the unpredictable life circumstances. There is daily concern and uncertainty about their family's future and their adjustment to living with their child who has a disability. There is often a desperate need to make sense of and find reasons for what happened. Some parents have reported feeling as though God has punished them in some way. Others attempt to find blame or assign responsibility to medical practitioners. It is natural for parents of children with developmental disabilities to seek an answer to the fundamental question, "Why did this happen to us?"

Over time, the parents' task is to understand, cope with, and accept the reality of the situation in which they find themselves. Parents are required to continually learn to deal with challenging circumstances, with difficult emotions and unanticipated experiences. Feelings of sadness and loss, confusion and uncertainty, and resentment and regret are common. The feeling of having been victimized by forces outside their families and the overwhelming reality of coping with the day-to-day challenges are typical for parents.

The parents of a child with a developmental and medical disability want to know that they have a future, a future of many hopes, dreams and possibilities. It is important that family support personnel work with the family in generating a context or perspective that the family can enjoy a future of possibility that is filled with hope, happiness, and joy. It is empowering for parents to know that what they feel at any given time is a normal and typical reaction to very challenging life experiences. It is also empowering to create a context with the parents that they can and will cope effectively with the challenges of raising their child successfully and be able to have a wonderful and joyful family experience.

The Dilemma of Uncertainty: There is something wrong

Parents report that there is often the experience of a lot of confusion and uncertainty about just what is "wrong" with the child's health or development. Parents often have to live for a long period of time with this sense of uncertainty. In addition, at the time of the birth of their child, parents often experience little support from the medical establishment in how to deal with all the ramifications of having to live and cope with their newborn child. Parents report that medical personnel can be insensitive to their needs and to what they are experiencing at the time of their child's birth and weeks thereafter. Parents report that they find themselves having to learn all kinds of medical information for which they are unprepared. Some parents feel they have to push their doctors for information so that they can understand what is going on. The central concerns focus on the questions, "What is wrong with our child?" "Will our child live a happy healthy life?" "Is it possible to right the wrong that has happened to our child, to our family and to our lives?"

Other parents are reluctant to push the medical personnel out of fear of what they might discover. Parents report that they experience anguish over having to take their child to get all the medical tests involved in the diagnostic procedures. Repeated visits to the doctor's office or hospital can recreate earlier painful experiences where they found out what was "wrong" with their child in the first place (seizures, cerebral palsy, blindness, mental retardation, feeding problems, etc.). Over time, parents may start to feel that the medical experts always know what is best for their child and to distrust their own experience.

The quality of the relationship that medical personnel have with the parents of a child with a developmental or medical disability has a great impact on the family's adjustment to the birth of their child (Patterson, 1991). The task of the parents over time is to develop a safe and supportive relationship with medical personnel who can help them understand what is going on medically and developmentally with their child. Parents need to be able to deal effectively with not knowing the answers to their questions and their own feelings of inadequacy around their child's developmental and medical issues. They need to be supported in trusting their experience of what their child needs and what they as a family need. Research has found that parents who are able to build collaborative relationships with their child's medical team have much improved family adaptation (Patterson, 1991).

Parents want to be able to trust themselves and to know that they are good and capable parents. Understanding and dealing with their child's medical and developmental issues are vitally important to the parents' sense of confidence. Parents have reported having file cabinets and bookshelves full of their child's medical records and developmental information in an attempt to stay on top of all the concerns they have with their child. The mother often is the primary custodian of all the documents and charged with the responsibility of following up on all the medical appointments. For parents, underneath all of this activity is a fundamental desire to be good parents who are taking good care of their child. The constant state of medical uncertainty often, however, undermines their feelings of competence and confidence in themselves.

For one mother, the medical diagnosis of her son consumed much of her time (Cantoni, 2001). As she embraced and accepted that special needs were not only part of her son's life, but also part of her life, she found she could "give herself permission" to be a "Mom" and make time for being with her child. She reported that rather than attending to mountains of paperwork, she found time to play, to sing, to read and to cuddle with her child, bringing her child and herself happiness. This activity restored her feelings of goodness and adequacy as a mother.

To assist parents in coping with medical uncertainty, family support personnel can focus on creating an empowering perspective that both the husband and the wife are good and capable parents who can trust their experience and competence in caring for their child. It is all right not to know everything right away and it does not mean that they are not "capable" or "good." Also, when parents are able to recognize and experience their unconditional love of their child, they are able to experience their child as whole and as having special gifts. Rather than the presence of the disability being a reminder of their incompetence or of what is "wrong" with their child, their unconditional love fosters feelings of acceptance, contribution and empathy. This experience can have a healing effect and can assist parents to be able to find balance when they feel uncertain and overwhelmed.

The Dilemma of Being Understood: We have to explain everything all the time

Another dilemma that many parents report is finding that they have to continually explain to family and friends about their child's disability and their situation. Parents find that often their family and friends do not fully understand what they are going through on a daily basis. They also report that they find it burdensome having to deal with or to accept the feelings or the attitudes of other people, even friends and family members. It can be very tiresome to cope with the concerns and the questions of the extended family on a regular basis. Because of this ambivalence, parents may inadvertently send mixed messages to friends and family. They want others to understand what is going on in their life but they do not want to have to explain all the time. As a result, they end up pushing others, even the people they love, away.

Over time, parents must learn to cope with the concerns of the extended family and to figure out how to include their family and friends in what they are going through on their terms. Although it is not uncommon for extended family members to be "worried" about how the parents are dealing with their situation and how their child is developing, parents often report that they get few calls from family members offering the kinds of logistical support that could free up time and make a real difference for them. Such possible support includes babysitting, going on errands, and/or assisting with some of the daily household chores. Family support personnel can encourage parents in making clear and simple requests to friends and family for specific concrete help. This enables

the parents to include concerned family members and friends in contributing to their lives and to get the assistance they need.

It is helpful for most parents to recognize or to be reminded that friends and family love them, care about them, and want to contribute to their family but may not know how. When the relationships with friends and family members become strained or difficult, it is helpful to sort out what kinds of specific help those friends and family members can give. It is important for the parents to see how they can remain in charge of what they need and make requests accordingly. This helps the parents establish clear family boundaries while at the same time including friends and family positively in their lives.

Family support personnel can contribute to these parents by helping to develop their network of support, professionally and socially. Early intervention professionals can provide technical and medical expertise, while specific friends and family members can provide emotional support. Still other people are better able to provide hands-on logistical support. Creating clear expectations and roles for the family's network of support can help to establish healthy family boundaries, which play a key role in family resilience (Patterson, 1991). It is also important to encourage parents to know that it is acceptable not to have to explain to everybody what is going on. In other words, it is all right to be private and to decide when to share their experiences and with whom.

Being understood and having one's experience validated is critical to the mental health of parents with developmental disabilities. Early intervention specialists have often found that, in addition to their specific medical role (e.g., physical therapy, occupational therapy, speech therapy, etc.), they become sounding boards and key listeners for the parents, particularly for mothers who are faced with the challenges of raising a child with a developmental or medical disability (Palmer, 2001). These professionals not only model healthy attitudes about raising a child with disability, but they can understand the unique dilemmas such parents are facing.

Palmer (2001) reported that parents often find it easier to talk to visiting professionals, rather than other family and friends because these professionals listened with greater empathy and acceptance. She articulated an important role of visiting professionals to help bridge the gap of understanding that many parents feel is missing with the people in their lives whom they love the most. In addition, early intervention professionals can promote parent groups and help connect different parents dealing with similar issues. Finally, for the families with very overwhelming challenges, marriage and family therapy is being increasingly recognized as a vital discipline in helping parents to understand and cope with the challenges of raising a child with a disability (Malone, Manders, Stewart, 1997; Miser, 2001)

The Dilemma of Balance: We have increased demands on our family

Another common dilemma for parents is that they find much of their attention is focused on the child with a disability. The husband and the wife have little time for their marital relationship and not enough time to spend with their other children. There is often a sense that things are out of balance. Patterson (1991) describes a familiar family pattern where one parent, particularly the mother, will become overly involved with the child who has the disability, excluding the other parent. As a result, "the executive functioning of the parental/marital dyad needed for optimal functioning is disrupted" (Patterson, 1991).

The routines around the child with a disability put stress and demands on the entire family. As a result, the husband and wife tend to focus less on the health and well being

of their marital relationship as there is often the perception that there is no time for them to be together. And when they are together, much of their communication is around their children. Many parents report that, because numerous household activities have to be planned on a daily basis, there is much less spontaneity and many more demands on the executive relationship of the family.

Over time, the task of the family system is to balance the needs of the disabled child, the other children, the marital couple and the family as a whole. Patterson (1991) found that in families where there was greater resilience, the marital or parental subsystem is able to maintain its generational boundary. The marital couple is nurtured by a sense of mutual respect and support and is able to bring greater partnership to the challenges facing them. As a result, the health and well being of the entire family is enhanced.

It is vital to support couples in adopting the perspective that their marital relationship is as important as every relationship in their family. Often, this is a perspective that is continually challenged because of the increased demands of the parental role in raising a child with the disability. Parents have reported that the single most difficult task for them is finding a babysitter whom they can trust and who has the confidence and competence in taking care of their children so that they can go out for the evening. Finding time to go out to a movie or to dinner, for many couples, is seen as next to impossible. It is not uncommon for older siblings, especially girls, to be expected to play a key role in babysitting or in the day-to-day operations of the household.

Parents of a child with a disability also find that they give less of their time to their other children. Parents may feel guilty about not spending more time with their other children and/or they may blame themselves if the other children are having adjustment difficulties in dealing with the stresses in the family. It is crucial that family support personnel assist parents in finding a balance in attending to the needs of the child with a disability, the needs of the other children and the needs of their own marital relationship. This is crucial to family health and well being.

The Dilemma of Normalcy: We are not a “typical” family

Some parents find that they often feel that other parents with typically developing children will not understand what they are going through and feel as though they do not have a “normal” family. The sense of normality for many of these parents is linked to what they had expected in relationship to some standard or picture of how family life with a baby “would” have been. With the birth of a disabled child, all sense of “normality” is abandoned. Parents can feel very alone or isolated in their difficult situation when speaking to other parents. They can feel as though other parents who have not gone through similar circumstances cannot identify with or understand what they are going through. Parents can feel as though they do not have a normal day-to-day existence or any hope that they ever will. Patterson (1991) found that families that coped well with difficult circumstances were families who could maintain normalcy in their routines and in their family identity. In such cases, the family was able to incorporate the child’s disability within the organization of the family’s needs without it becoming the centerpiece of the family attention.

Having a child with a disability can leave parents feeling left out or not included the mainstream of community life. To the degree that families are able to participate in community and school activities and see themselves as able to take advantage of opportunities in their community, their sense of being different or “not normal” is lessened (Grimaldi, 2001). When couples feel that they have choice and control over how they live their life, they can feel as if they are contributing members of the

community. One mother reported that she came to the understanding that every family (in the community) is unique which allowed her to see and accept the special gifts of her own family (Cantoni, 2001)

Parents, over time, need to have the experience of belonging to the community. In parent groups, parents feel comforted in being connected to other families who have been through similar situations. It is important to support parents in recognizing that they are a “normal” or typical family dealing with extraordinary circumstances. Their family is of the community, not apart from it. By feeling included in the mainstream of the community, parents can begin to feel they have greater control over important aspects of their life.

The Dilemma of Personal Space: We have no privacy

Many parents feel that, while they are very grateful for the assistance they receive at home through programs like the Birth to Three Early Intervention Program, they do not have any personal privacy in their home. When so many professionals (medical, educational, speech therapy, physical therapy, etc.) are involved in their child's health and development and come into their home repeatedly over time, parents can feel a loss of boundaries around their family and a lack of personal space. They end up having a sense of a loss of personal freedom, personal privacy, and choice.

The early intervention model suggests intervening early in the child's life can make a significant difference in later development. Because many parents feel that there is a vital window of time when intervention is crucial, they may adopt the view that, when they are not engaged in some sort of therapy with their child, they are guilty of “not doing enough.” Parents, particularly mothers feel compelled to learn all the therapies “in order to” help her child. When a mother is compelled to attend every therapy session, she may feel that she has no choice but to be a therapist, a teacher as well as a mother at all times. A mother may question, “When do I just get to be a mother?”

It is the task of the parents over time to feel that they can take control of the planning and the decisions concerning when their child's medical and educational support. Parents need to be reminded that they are the executives in the home and in the family system. Parents need to feel they have choice over the support (who, what, when, where, etc.) their child is receiving and the role that they are going to play. They should be able to negotiate all of this with their child's early intervention support team. Being able to have greater control over the family's boundaries and personal space is vital to the sense of the family's health and well being (Patterson, 1991; Miser, 1991).

An empowering perspective for parents to embrace is that they have choice in the matter of what is best for their child, family and their lives. For instance, family support personnel should assist parents in being in charge of the consultation they receive through the various local, state and federal organizations. Professionals who actively respect the family's boundaries foster not only the parent's collaboration with medical and support personnel, but also the parent's ability to identify family needs and make requests to fulfill them. Helping parents to have a sense of choice over the services their family is receiving can help them maintain a strong sense of family cohesion and balance and protect a sense of privacy. Developing communication competence, maintaining family cohesion, maintaining family boundaries, and having collaborative relationships with all developmental and medical support staff are key indicators of family health and resilience (Patterson, 1991).

The Dilemma of Comparison: Our child is not like other children

A very difficult dilemma that parents deal with is their tendency to compare the growth and development of their child with a disability with typically developing children. Parents report that they experience a great deal of unhappiness and suffering when they compare the development or the health of their child with that of other children. The differences in developmental milestones and abilities between their child with a disability and a normally developing child can remind them of the loss of having a typically developing child or of having the future they had once envisioned.

Often, parents can find it difficult being around children who are typically developing. One father reported that he disliked going to the playground or the park with his son because he would see other children of the same age and be reminded of the impact of the disability on his son's life. He found himself comparing the capabilities of his son with those of the other children in the park. When parents find themselves in the "world of comparison," they re-experience the hurt and the pain of loss. Parents who catch themselves and stop comparing their child with typically developing children will find themselves better equipped to deal emotionally with their child's health and development (Grimaldi, 2001).

There are many personal stories of parents in the literature highlighting the healing power of accepting their child as they are (Klein & Schive, 2001). Parents who stop comparing their children with other children find that they are better able to accept their child's developmental milestones and growth and to embrace their child's gifts (Grimaldi, 2001). When parents are able to be aware of the impact of comparing their child with other children and avoid such behavior, they are better able to restore a sense of family well being. Parents can be redirected to comparing the development of their child at one point in time with their child's development at an earlier point in time and to acknowledge their child's developmental progress. Parents learn to appreciate the small steps and can look forward to future growth.

It is healing when parents step into the perspective that their child, like every child, is unique and special in every way. When parents are able to see their child's unique abilities and special gifts, they are able to experience unconditional love for their child and the joy this child brings to their family.

The Dilemma of Empowerment: We are feeling victimized by the circumstances

Over the long term, parents can come to feel they have been victimized by circumstances that were out of their control. They can feel they have experienced a grave injustice and that life has not been fair to them. Parents might come to feel that much of their distress has been "caused" by the circumstances of having to raise a child with a disability.

Their anger and sense of victimization can get projected onto medical personnel, educational personnel or insurance companies. Someone "should" take responsibility for what has happened. In an attempt to balance the scales or to right the wrong that has befallen them, parents can feel that the people "in power" or "in control" owe them or their child services. By law, parents of children with developmental and medical disabilities are entitled to developmental, medical and educational services. This very sense of entitlement, however, while, on the one hand, fosters feelings of being in control over one's own life, can, on the other hand, inadvertently reinforce a sense of one's victimization.

One of the most difficult tasks that parents must face is to learn to accept what has happened in their lives. This kind of acceptance requires parents not to find blame or find fault, but to embrace their experiences of sadness, anger, and loss and to learn that their emotions are normal given their circumstances. Parents who are able to embrace their experience of life and to avoid making the circumstances of their lives the “reason” for how they are feeling find themselves better able to feel in control and to avoid feeling victimized. By not justifying how they are feeling, which can leave them with a sense of powerlessness, parents are able to deal more effectively with their circumstances.

Far from being passive or taking no action, this kind of acceptance frees parents to take responsibility and to create positive meanings or empowering life perspectives that lead to successful family adaptation (Patterson, 1991). Rather than dealing with life as it should have been, parents are able to deal with their lives as they are. They are able to adopt perspectives that will give them power in dealing with difficult circumstances, freedom in taking committed action and hope for their future.

When parents can experience what they are feeling and allow their life circumstance to be what they are, they can come to deal more effectively and powerfully with life’s dilemmas. This can provide them with a sense of freedom and choice in their lives and of empowerment in their day-to-day circumstances. When couples are able to accept and embrace their lives as they are, they are able to actively live as full participants in their lives and dream new dreams for their future (Klein & Schive, 1991).

Summary

Parents with children who have special needs have in common a number of family dilemmas that they deal with on a day-to-day basis. This paper has distinguished eight of these common family dilemmas, examined their potential impact on the family, looked at the family’s task over time, and delineated different empowering perspectives that parents can generate to assist them in experiencing a sense of wholeness and well-being. Throughout the paper, the transformative effect of shifting one’s context when dealing with difficult circumstances is stressed.

Patterson (1991) has found that resilient parents of children with disabilities are able to find positive meanings in life’s most difficult circumstances and are able to restore a sense of family cohesion and well being. There are a number of powerful perspectives that parents can adopt when raising a child with a developmental and medical disability. These include the following:

- What each family member feels is a normal response to difficult circumstances.
- Nothing is inherently “wrong” with themselves, with their children, or with life itself.
- Medical personnel are committed to their child’s medical well being and want to form a collaborative relationship with them.
- The couple are good and capable parents who can trust themselves and their competence in caring for their child.
- It is normal not to know everything right away.
- Friends and family love their family, care about them and want to make sure that they are all right.
- Friends and family members want to contribute but may not know how.
- The health of the marital relationship is vital to the well being of the family as a whole.
- It is all right not to have to explain to everybody what is going on in the family.

- Early intervention professionals understand the dilemmas the parents are facing.
- Couples have a “normal” family that is continually dealing with extraordinary circumstances.
- Parents have choice in the matter of what is best for their child, their family and their lives.
- The child with a disability, like every child, is unique and special in every way and the parents’ love for their child is unconditional.
- The family as a whole can and will enjoy a future of possibility that is filled with hope, happiness, and joy.

Resilient families tend to be naturally able to generate such empowering perspectives. Medical personnel and early intervention specialists can also model and create these perspectives with the parents of children with developmental and medical disabilities. With the ability to invent new ways of looking at their circumstances, parents can have new hope, create new futures and design happy and fulfilled family lives. These parents, as a result, have powerful access to transforming their experience of the daily dilemmas associated with raising children with disabilities from challenge and burden to resilience and joy.

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