

# Mistaking Courage for Denial: Family Resilience After the Birth of a Child with Severe Disabilities

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## Abstract

While the birth of a child with severe disabilities is a challenge for parents, the literature suggests that many families are able to adjust. Coping with stress is related to lifestyle, social interest, and, perhaps most importantly, to courage. The courage parents demonstrate is often confused by professionals who do not understand that parents must both accept their child and push for their child's future. This potential confusion is illustrated by a common research instrument, the Questionnaire on Resources and Stress. Recommendations are made for how professionals can encourage parents in their appraisal of their situation and in addressing the needs they experience.

The birth of a child with disabilities surely qualifies as a stressor for parents and families (Dyson, 1993; Gallagher, Beckman, & Cross, 1983). Families may experience depression, increases in anxiety, lowered self-esteem, frustration, and decreased marital and personal satisfaction (Zeitlin, Williamson, & Rosenblatt, 1987). Trout and Foley (1989) pointed to parental confusion over their reactions to their child, the sense of loss these parents may experience, guilt, informational overload, and impaired family dynamics as natural outcomes from the birth of a child with disabilities. However, while some researchers have suggested that the blow of such a birth may be so overwhelming that parents and families rarely recover, others have demonstrated the capacity of many parents to make healthy adjustments (e.g., Burden & Thomas, 1986).

Here is an email message (used with permission, with name changed) from a mother of a nearly six-month-old child born with CHARGE Syndrome, a disorder involving sensory impairments, balance difficulties, heart defects, and swallowing/feeding problems:

Hi Everyone!

I haven't posted lately cuz I've just been overwhelmed emotionally. How do you guys do it? We've been getting out a bit and the constant reminders of what our life would be like without CHARGE are sending me over the edge. At the park, a friend was feeding her baby as easy as you please. At our local health fair's PT/OT booth, the therapists recognized Jane as different right away. It was nice that they wanted to hold her, etc. cuz no one usually asks to do that, but I hated that they could see her differences so easily. At the EMT booth she had

her first vomiting/mucus/choking episode in public. I actually cried a few tears right there—so frustrated that we couldn't just enjoy this simple thing. I see acquaintances with their daughters who are growing up and doing so much and I wonder what Jane will do. I am so weary of this. How do you go on every day?

I have been avoiding phone calls and insurance stuff and researching more services, etc. cuz I just want us to be normal. Now it's all piled up waiting for me.

I've been so hoping that Jane was going to be "better". When the doctor or therapist says that she's doing great, I want to know by what standards. Doing great for a regular 5 month old, or for a kid who we didn't expect to do anything?

How do you know if you have the right doctors and therapists doing the right things? How do you know if you're doing all the right things and enough of them? I can't possibly do all the "therapies" that have been suggested. Every suggestion will take just a few minutes a few times a day, but that adds up to more than 24 hours, plus there's her regular care and my other kid and my husband and my sanity.

And why, oh why, won't our babies eat???????

Clearly, this email supports the position that having a child with significant disabilities creates enormous stress. Here is an email from the same mother 2.5 years later, written in response to another parent's concerns:

Boy, what you said about wishing that your kid will be "normal" at a certain age sure hit home. I felt exactly the same way when Jane was an infant. We imagined that by kindergarten she'd be a regular kid who just had some trouble walking and stuff. Well, she's almost three and she's sort of "normal" in many ways, but very "different" in other ways. She seems totally normal to me—which means I've adjusted my concept of normal and our family has become accustomed to living with CHARGE. We still have more doctor visits than a typical kid, still have possible surgeries for ear tubes and eye muscle realignments (but nothing major any more). Jane doesn't talk like a typical kid—she uses a combo of sign and speech. But she communicates her messages very well. She has above age-level receptive language skills so she understands everything we say. She's silly and can express her sense of humor. She can walk but still falls more than usual, needs help on curbs and unsteady surfaces, can't quite run, etc. She gets where she needs to go and keeps up with the others, it's just different. It's so hard to explain. Everything she does is "different" but it's not really "abnormal". She's just her. And she's so absolutely cute that everyone who meets her thinks she's a living doll. Our life is not "normal" in the sense that I had hoped it would be (meaning as it was before CHARGE) but it is "normal" in the sense that we still do the same things we did before, we still interact the way we did before, we're used to the new considerations we have (like her being afraid of the air show, etc.) and life is fine. It's not perfect and

there are times when I'm exhausted and frustrated by this CHARGE thing, but for the most part it's ok and we're content.

This is an example of family resilience. The parents have learned to cope with having a child with disabilities and to develop a life they would describe as "normal."

### **What We Know About Parental Stress and Coping**

Several reviews have examined parent and family stress and coping with the birth of a child with disabilities. Murphy (1982) noted some agreement that the experience was profound, affecting marital relationships, child rearing, and siblings. The self-concept of parents is affected, and parents may react to the event with feelings such as anger, guilt, ambivalence, and sorrow. However, Murphy cited the dearth of controlled studies, the lumping of different disabilities together, and the failure to take into account the dynamic aspects of raising a child as problems with the literature. She concluded, "Most researchers have dwelled on the problems and deficits instead of the strengths of the families who have adjusted" (p. 81).

Yau and Li-Tsang (1999) noted that many researchers in the past 20 years have examined these families from a deficit model. Researchers have neglected evidence for successful family functioning. More recent studies "indicate that families of children with disability, including those whose disabilities are severe, often believe their lives have been enriched by their children's presence" (p. 39). Yau and Li-Tsang identified five factors that seem to enhance family adjustment: personal resources, strong marital relationship, positive characteristics of the disabled child, participation in parent support groups, and access to a small, but intense, social support network.

Scorgie, Wilgosh, and McDonald (1998) reviewed 25 studies published from 1988 to 1995. They found four categories of variables that facilitate family coping. Family characteristics such as socioeconomic standing and family composition were inconclusive. Other variables like family cohesion, hardiness, problem-solving skills, and roles and responsibilities seem to be important. Parent variables such as the quality of the marital relationship, maternal locus of control, positive paternal appraisal, and finding time were all important. The literature is conflicting on child variables such as severity of disability and child's age. However, there is some agreement that children with a more positive temperament promote adjustment. Finally, external variables like stigmatizing social attitudes, a poor social support network, and difficulties with professionals were all related to adjustment. The authors suggested professionals consider focusing on those variables that can be changed in preference to those that cannot.

### **A Model of Coping with Stressful Events**

Orr, Cameron, and Day (1991) applied Hill's ABCX model of stress to families of children with disabilities. A is the event, B represents the use of coping resources, C is the perception of the event, and X is the outcome. Using path analysis, they found that for families with children who were developmentally delayed, the actual order was ACBX. In other words, the perception of the event, or its appraisal, is the first step in coping with an event like the birth of a child with disabilities, followed by an analysis of resources.

From the Adlerian perspective, differences in reaction to events are attributable to differences in lifestyle. Lifestyle can be conceptualized as the organization of each individual's understandings of his or her world, his or her ideas and schemata (Manaster & Corsini, 1982). These provide the foundation for the person's appraisal of events.

According to Zeitlin et al. (1987), the appraisal of events (C in the model) is based on beliefs, values, and expectations that have developed over time, certainly lifestyle characteristics. Park and Folkman (1997) elaborated on the function of meaning in this appraisal. They conceptualized two levels of meaning, global and situational. "Global meaning encompasses a person's enduring beliefs and valued goals" (p. 116). They discussed three beliefs that contribute to global meaning, beliefs about the world, about the self, and about the self in the world. These clearly comprise a definition of lifestyle.

The second step (B) in the model is decision making about resources. When a person is faced with an event and perceives it as a threat, his or her response is to consider his or her resources for coping. While lifestyle affects the appraisal of an event, the response a person makes to his or her appraisal will be influenced by his or her social interest. This central Adlerian concept is difficult to define, but it refers to a sense that one belongs and feels closely tied to one's communities (Manaster & Corsini, 1982). Humans are social beings, and they have always found their strength in community. Crandall (1978) examined the interaction between stress and social interest, concluding that physical stressors do affect social interest, but that social interest may also provide "courage and psychological strength" (p. 46) in facing difficult situations.

Zeitlin et al. (1987) described the second step in coping with the stress of having a child with disabilities as an analysis of resources, both internal and external. The former include personal beliefs and values, coping behavior patterns, and physical and psychological status, while the latter include support systems and material resources. These resources, both internal and external, would be influenced by social interest, that is, people with higher levels of social interest would have different beliefs, coping patterns, and psychological status than those with lower social interest, and they would be

more likely to avail themselves of support systems. Manaster and Corsini (1982) pointed out that in Individual Psychology, social interest is often equated with mental health and thereby associated with coping and psychological status. Tolsdorf (1976) introduced the construct of network orientation, "a set of expectations or beliefs that it is inadvisable, impossible, useless, or potentially dangerous to draw on network resources" (p. 413). These beliefs suggest a sense of alienation from others, which Manaster and Corsini noted as the opposite side of social interest.

Social interest influences the individual's developing approaches to the life tasks of love, work, and friends, which are all sources of resource support. The life tasks can be challenging given the birth of a child with severe disabilities. There is considerable evidence that this event can have profound effects on the marital relationship (Murphy, 1982; Seligman, 1985). These effects can be due to feelings of blame and guilt, the pressures of time and activities needed to raise the child, and different styles of coping (due to different lifestyles and degrees of social interest). Partners who are able to cooperate with one another in the raising of their child will have greater success in coping with stress than those who cannot (Yau & Li-Tsang, 1999).

The event can also affect work. The demands of raising a child with a disability may require one of the parents to give up work or a career. Parents may need considerable flexibility at work to find time to attend to emergencies with their child. The need to maintain insurance may require one parent to remain in a job where he or she is unhappy. Work at home may also be affected. Parents who stay at home find additional demands on their time beyond what they might expect with a child who does not have disabilities. The birth of a child with disabilities may require parents to redefine their work lives, and their success depends on social interest.

The friendship life task can be affected several ways. First, families may have to curtail their social life to devote more time to their child. Second, as in other cases of family crisis, family members will discover which of their friends can actually be counted on to provide support. Some parents withdraw after such an event, while others reach out to find support. In either case, it is common for friendship networks to become smaller (Berger & Fowlkes, 1980; Kazak & Marvin, 1984). In 1991 I defined the work life task as "an inclination and a readiness to participate with others that emerges from an interest in and a concern for others and leads naturally to being a part of the community" (p. 478). I noted the literature that shows a relationship between family functioning and the nature of its social support network. Social support helps individuals in crisis and provides a buffer against the impact of events (Cohen & Wills, 1985). Thus those parents who have developed the friendship life task should have more social support resources available to them than those who have not.

Running through all the life tasks is a theme of cooperation. The ability to cooperate with one's spouse, with the demands of work, and with friends assists in making resources available for coping with stressful situations. Adler said that courage is one side of cooperation (Ansbacher & Ansbacher, 1956, p. 437). In fact, courage is seen by Adler as the result of *social interest* and *activity*, although only activity that fosters cooperation. In other words, individuals who have enough confidence in themselves and their abilities to contribute and cooperate demonstrate courage. Because no individual is perfect and because everyone experiences feelings of inferiority, to have this sense of confidence and ability to participate actively and cooperatively with others takes a great deal of courage. Courage is embedded in encouragement and discouragement. The former increases confidence and cooperative action; the latter reduces it.

### **Courage in the World of Disability**

The world of disability is all about what a person cannot do, *dis*-abilities. If all humans experience feelings of inferiority, these are certainly present with disabilities. Dating back to Adler's early work on organ inferiority, Adlerian theorists have looked at compensation and over-compensation as basic responses to felt inferiority. There is certainly much evidence that some people with disabilities are able to rise above them and make huge contributions. But the problem is not just for the person with disabilities. It is also for the parents and other family members of a child with disabilities. Table 1 is a partial list of the ways disability can be discouraging for parents.

Parents may feel different, singled out, and ill prepared to cope with the demands they confront. Like the person with disabilities, the parents need to find ways to compensate for these feelings. This comes from finding the courage to be imperfect and letting their child be imperfect.

The parents of a child with disabilities are confronted with what could be called the "courageous paradox." On the one hand, they need to be realistic about their child and to be able to feel genuinely that if their child never improves, never progresses, never becomes that healthy human being they want their child to be, that this is okay. This is not resignation: This is real acceptance. Parents of healthy children may believe they do this, but they can have a reasonable expectation that their child will grow up and be a well functioning human being. Parents of a child with disabilities experience much less certainty, and so acceptance can take enormous courage.

On the other hand, parents of a child with disabilities should never give up the hope that their child will exceed all expectations and make tremendous progress. This is not based on fantasy, but on hope. If the parents give up

**Table 1**

## Sources of Discouragement for Parents of a Child with Disabilities

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- Parents may feel inadequate to deal with the medical and educational needs of their child.
  - Parents may feel they failed in not producing a healthy baby.
  - Parents may feel embarrassed by the notice they and their child receive from others.
  - Parents may feel they must rely on what professionals say, because parents are not experts.
  - Parents may find the barriers that exist in the environment, such as steps, curbs, small entrances, etc., make them feel second class.
  - Parents may have difficulty putting in as much time at work as other employees, due to their child's needs, and so feel they do not measure up.
  - Although entitled to special treatment such as a handicapped parking space, some parents may avoid this because it singles them out as different.
  - Parents may feel concerned that their child creates a huge medical insurance problem for group coverage, as they use a disproportionate amount.
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hope, their child's future is much less certain. When parents are able to maintain both of these positions at the same time, they are demonstrating what Adler meant by courage based on both social interest and activity. By accepting their child as worthwhile and able to contribute even with no change, they are showing social interest. By never giving up hope for their child's potential, parents are led to action. Parents with courage will seek out services for their child and push medical and educational institutions to provide what the parents believe their child requires.

Professionals often misunderstand the behavior of courageous parents. The first email from the parent quoted earlier might cause a professional to conclude reasonably that she needs help. Her second email might cause a professional to conclude she is being naïve and is due for some disappointment. Ignored is the possibility she is being honest and realistic and developing courage. Courage is not denial. The unhappy and apparently discouraged parent may in fact be so, or he or she may be past denial and starting to struggle with the development of courage. The extent to which the parent becomes courageous will depend on lifestyle, social interest, and the amount of encouragement he or she receives from others, particularly his or her social support system and professionals.

### **An Example from the Research**

The Questionnaire on Resources and Stress (QRS; Holroyd, 1974) is a 285-item instrument (of which 222 items are scored) designed to measure stress in families of children with disabilities. All questions are answered true or false. Friedrich, Greenberg, and Crnic (1983) developed a 52-item short form that correlated .997 with the original and had a coefficient alpha of .93.

I (2000) administered the Friedrich et al. (1983) short form of the QRS in an interview format to 27 parents of preschool children with disabilities. In listening to the answers given, I realized that the responses were influenced by the overall level of courage and that in some cases parents who were very encouraged about their child were receiving scores that reflected more stress. Some of the questions that were particularly troublesome are shown in Table 2.

Consider question #2 regarding family members' doing without. Answering "true" to this item increases the stress score for the family, perhaps because these parents might be pessimistic or overly involved with their child. Answering "false" to the item is intended to mean there is less stress, but it could also be an indication that a very stressed parent is in denial. Considering the question from the concept of courage, a parent who has courage may answer "true" because it is a matter of fact, and not because it is stressful or "false" because of courageous efforts to make sure all family members are attended to.

Question #6 is somewhat similar. Being realistic about the fact that all children have limitations in the kind of work they can do results in a higher stress score for the parents. Parents who have the courage to be imperfect may allow their children to be imperfect without experiencing stress about it. A parent who answers "false" may be in denial, but he or she may also have the courage to work actively for his or her child's future and seek to remove possible obstacles in the way of the child's work options.

The problem with Question #7 is that it presumes the child will live his or her life in an institution, and the only issue is one of acceptance. Several of the respondents said, "Well, my child will not live in an institution, and so the answer is 'false.'" That meant they scored as more stressed on the scale. Parents with courage may actively work against institutionalization for their child. Does a response of "false" mean the parent cannot accept his or her child's condition, or does it mean that he or she refuses to be resigned to only one possible outcome and has the courage to seek others? Could it be, in fact, that the parent who answers "true" is more stressed because of having given up?

Question #13 makes the assumption the child will never get any better. The issue is whether or not this bothers the parent. If it does, the parent is presumed to be more stressed. But how should a parent respond if he or she does not believe the child will always be this way? This is exactly the



**Table 2**  
 Problematic Items from Short Form of the Questionnaire on  
 Resources and Stress

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- T* 2. Other members of the family have to do without things because of \_\_\_\_\_.
- T* 6. \_\_\_\_\_ is limited in the kind of work he/she can do to make a living.
- F* 7. I have accepted the fact that \_\_\_\_\_ might have to live out his/her life in some special setting (e.g., institution or group home).
- T* 13. It bothers me that \_\_\_\_\_ will always be this way.
- F* 18. The family does as many things together now as we ever did.
- T* 22. \_\_\_\_\_ doesn't do as much as he/she should be able to do.
- T* 28. I am disappointed that \_\_\_\_\_ does not lead a normal life.
- T* 32. I worry about what will be done with \_\_\_\_\_ when he/she gets older.
- F* 38. \_\_\_\_\_ can ride a bus.

Source: Friedrich, Greenberg, & Crnic, 1983.

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courageous paradox described above. Parents need to be able to accept their child as he or she is even if the child is always going to be that way, and so might answer "false." At the same time, parents need the courage to work to achieve progress in their child's life, and so might answer "true." So a courageous parent would have to answer "both."

Question #18 implies the family does as much now or does less than it did before. Several parents said that they actually do more now because they are more conscious of the importance of family and family activities. So they answered "false" to the question and were scored as higher in stress. In fact, they were more encouraged.

Question #22 implies there is a standard of what a child should be able to do. Some parents replied by comparing their child to a normative standard and answered "true." Other parents compared their child to himself or herself and said "false" because they believed their child did as much as he or she could do. Either response could be courageous.

Question #28 seems to presume a child with disabilities does not lead a normal life. Think about the mother in the quotes above and her difficulty in defining "normal." The parent of a normal child who answered "false" because he or she is not disappointed in his or her child is then agreeing that he or she does not lead a normal life. An encouraged parent is stumped as to how to answer. To say "false" means they agree their child does not have a normal life, but to say "true" means they are disappointed.

Question #32 was a problem for parents whose child had a short life expectancy. But the question is also a challenge for those with the courage to seek a better future. They might answer "true" but be under less stress than those with less courage.

Finally, on question #38 some parents immediately said "of course not" without showing much discomfort about it. Other parents said "certainly" and then explained that they would have to provide assistance. Courageous parents could answer either way.

The major problem with these items is the presumption that a parent who is realistic about his or her situation is therefore under a great deal of stress. It ignores the possibility of the parent having less stress because of encouragement. It also ignores the model of stress that says the outcome of the experience depends on lifestyle and social interest. A parent who perceives the event as having potentially positive meaning and who is able to identify resources to support their child and family will be under less stress, even while answering the questions realistically.

Yet a great deal of the literature on stress in families of children with disabilities is based on the QRS and similar scales (Minnes & Nachshen, 1997; Sexton, Burrell, Thompson, & Sharpton, 1992). Of the 25 studies reviewed by Scorgie et al. (1998), 10 used a version of the QRS. Professionals may conclude from such studies that these parents are inevitably strained and in need of remedial treatment (Glidden, 1993). Such treatment aimed at addressing primary deficits may, in fact, increase feelings of inadequacy and discouragement in families who are trying to develop the courage to raise this child.

### **Facilitating Family Resilience**

As noted above, Scorgie et al. (1998) suggested that "professionals can help parents to discover their own strengths and existing resources to meet family needs; that is, professionals can help parents discover what 'works' for them" (p. 39). To facilitate greater family resilience, professionals need only encourage parents to build on their own strengths. From the lifestyle framework, one would work with assets instead of mistakes. But while it is difficult to address lifestyle and social interest directly, professionals can provide encouragement. Dreikurs (1967) stated encouragement "is a means to restore that patient's faith in himself, the realization of his strength and ability and the belief in his own dignity and worth" (p. 13).

Within the model of stress, there are several ways for professionals to provide encouragement. In step one of the model, the individual appraises the meaning of the situation, influenced by his or her lifestyle. Lazarus and Folkman (1984) listed several situational factors that may also influence this

appraisal. One is novelty. For most parents, the birth of a child with disabilities is a novel situation, not having happened to them before or to any of their friends and relations. They may have no background to prepare themselves for understanding their situation. A professional can encourage parents to examine what they do know and to focus on experiences they have had that can reduce novelty. Novelty can also be exciting, creating opportunities for learning, and developing new skills and understanding. Professionals can encourage parents to approach novelty with less fear and more confidence that this is something they can master.

Another factor is predictability. Predictable shock is less aversive than unpredictable. A professional can encourage parents to investigate information that makes their life more predictable. Professionals can help parents to have faith in their ability to respond well when the unpredictable happens.

A third factor is event uncertainty. This means living without knowing if a particular event will occur. For example, a cancer in remission may or may not come back. A child with a disability may or may not learn to walk, to talk; may or may not go into puberty, be employable, be independent. A professional can encourage parents to mark carefully what events do take place. With most babies, learning to hold up their head is only briefly noted. With other babies this can be a big event, coming after months or even years of waiting. Professionals who model enthusiastic appreciation for such events are very encouraging.

Imminence is another factor. People like to prepare for events, although too much time can increase stress. Parents might have a hard time dealing with the announcement that their child must have surgery immediately, but having surgery postponed for weeks would also be stressful. Professionals can encourage parents to focus on the present, and what they can do now. Parents do best when they have faith in their ability to cope when the event hits. Professionals can also be role models for patient waiting, if that is needed.

A fifth factor is temporal uncertainty. This occurs where an event is going to happen, but one does not know when. Parents who seem to be ignoring "the inevitable" might be labeled as in denial. However, professionals should be certain it is not simply a courageous focus on the present. To help parents with temporal uncertainty, professionals may encourage parents to progress toward an event by focusing on markers, as well as to encourage the parents' faith in themselves to be prepared when the event occurs.

Ambiguity is a sixth factor. Human beings like structure and will make meaning out of ambiguous situations. Parents want answers, and there are many questions: Which medical procedure should be used, what kind of speech system would be best, is a segregated or an inclusive educational program most appropriate? There may be a tendency to push professionals for the "right" answers. Professionals can encourage parents to choose the right answers for themselves, with the understanding there may be no absolute right answer or

any way to find one. Parents can be supported in having made the best decisions they can given what is known. Of course, professionals can also encourage parents to investigate all available information.

The final factor identified by Lazarus and Folkman (1984) is timing in the life cycle. This is an issue for people who find life events occur "off time." For example, a couple become new parents at age 50. If they project into the future, they may still be dealing with diapers and dependency long after their friends are coping with empty nest. These parents may need considerable encouragement to find the positive meanings in their situation.

To summarize, parents will appraise the birth of a child with severe disabilities based on their lifestyles. Professionals can encourage these parents by using their lifestyle assets and by helping them to find faith in themselves to deal with the uncertainties within the situations that confront them.

The second step in the coping with stress model is to identify and access resources for support, which depends to a great extent on developed social interest. Like lifestyle, it is difficult to address social interest directly. However, professionals can facilitate greater family resilience by encouraging parents to find resources that address their needs. Bailey and Simeonsson (1988) developed a Family Needs Survey which categorizes the needs of parents of children with disabilities into six areas: information, support, help explaining to others, accessing community services, financial assistance, and family functioning. By the manner in which they work with parents to address these needs, professionals can be particularly encouraging, but also discouraging.

In two studies (Hartshorne, 1993, 2000), parents rated information as their most important need. Some professionals might be tempted to respond by simply providing as much information as possible, but doing so can be overwhelming and discouraging. Parents can be supported in developing the skills to locate and access information for themselves. This means they might become familiar with medical sections of libraries and medical resources on the Internet and that they might correspond with other parents who have similar situations to find out what they did. A parent on the listserv for CHARGE Syndrome reported recently that one of her child's physicians had told her to stop looking for information on the Internet and get off the listserv and to listen just to him. (This parent dropped him as a physician.) This is not encouragement. While parents may not have the background to understand all the information or to sort out accurate from inaccurate information, encouraging professionals can support their learning to do this and finding resources for their other needs. In this process, parents develop faith in their own abilities to identify resources for themselves.

Parents of children with disabilities frequently link together by various means, a powerful one today being the Internet. Parent networking may

become formalized through support groups or listservs or may remain informal. Often these networks are accessed when parents are making decisions concerning services for their child and need information about the quality and options available. Parents may contact the network for emotional support from others who understand the fear, anguish, and hope they experience or for information about members' experiences with the situations they face. Parents might contact the network for sources of funding to supplement insurance or for locating equipment, such as suction machines, monitors, or wheelchairs, that may be needed. Such support need not be restricted to nonprofessional members, but can benefit from professional input. Professionals who wish to be encouraging of parents in linking with resources might consider joining the social support network of those parents.

First, professionals should seek to enter the network by making themselves available both emotionally and instrumentally to parents. This means being available to parents, even giving out home phone numbers, and taking calls from panicked parents late at night. In fact, it implies breaking down some of the professional-client distance that conventional wisdom (read "medical model") has for so long supported. It means interacting with parents as equals who share in a concern for the well-being of a child. Second, professionals should work to strengthen the network by encouraging the active participation of other professionals and by encouraging members to organize more formalized support groups/systems when not present. Third, professionals need to affirm continually the central position of parents in the provision of services. To paraphrase Dreikurs, this means supporting the parents' faith in themselves and the realization of their strength and ability and belief in their dignity and worth.

### **Summary and Conclusions**

Turnbull (1988) emphasized that raising a child with disabilities is a long-term, or marathon, activity. "The real issue for families . . . is to be able to remain intact as a family *over time*, meet the developmental needs of the child *over time*, and develop the kinds of relationships that remain resilient and vital *over time*" (p. 263). She suggested eight skills that families need to develop in order to finish the marathon well. These include the ability to meet basic needs, to know one's self and one's family, to love one's child unconditionally, to establish relationships, to experience and benefit from emotions, to take charge and make things happen for one's child, to anticipate the future and learn transition planning, and to establish balance in one's life. Clearly, these skills describe courageous parents. Family resilience is facilitated when professionals encourage by their actions and attitudes.

Here is a more recent email from Jane's mother illustrating the family resilience she has experienced as she "runs her marathon" with courage:

Jane is just turning 3, and although she's not "normal", she is delightful and wonderful and amazing and fun and competent. . . . I never thought I'd be this content this soon. I thought the overwhelming, distraught feelings you are having now would last forever. Everyone on the list told me it would get better. I didn't know how they could be right, but they were.

I remember going to the CHARGE conference in Houston. When I walked into the reception area and saw all those wonderful families and competent, intelligent, successful parents, I felt so relieved. I hadn't realized it, but I must have felt that I was flawed in some way. When I got back up to my room, I cried as I told my mom how wonderful it was to see those great families and know that my family could still be whole and that I could still be worthwhile.

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