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FOCUS ON EXCEPTIONAL CHILDREN

Family Adjustment and Adaptation With Children With Down Syndrome

Brian H. Abery

Jim and Sally French* were both in their mid-20s when they got married. Sally worked as a teacher, and Jim was employed part-time as an electrical engineer, completing a master's degree with the goal of soon assuming a management-level position with his company. During Jim's school years the couple spent a lot of time dreaming about their life in the future. Well-educated individuals dedicated to their chosen professions, they saw themselves buying a house in the suburbs and starting a family. When Sally became pregnant, both parents-to-be were overjoyed and waited for the birth with great expectations. They planned for Sally to take a year off from work and then for her mother to assume child-care responsibilities. The pregnancy itself was without complications, and, as the due date approached, extended family members telephoned regularly to see what assistance they might offer the young couple.

When Michael was born, at 6 pounds 8 ounces, he appeared to be a healthy little boy. Twelve hours later the attending obstetrician informed Sally and her husband that their son was "severely retarded—a child with Down syndrome." Although Michael had no obvious medical problems, his parents were informed that he would be at high risk for a variety of health complications throughout his life. Professionals suggested on several occasions that the best thing for the family and the child would be to place him in an institution where, according to their physician, "he will get the best care possible." Immediately rejecting this idea, both parents looked to their families for emotional support. Unfortunately, this was not forthcoming, as relatives on both sides of the family seemed to agree that the young couple would not be able to rear a child with a "severe disability" successfully.

Michael's birth set into motion a chain of events that, according to Jim and Sally, "drastically changed our lives." Despite a lack of family support, Sally and Jim were adamant that Michael would be reared at home. Years later the couple seem sure they made the right decision. Jim describes Michael as "a determined young man who knows what he

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*Parent names used in this article are pseudonyms. The circumstances described, however, are factual and quotations are taken from transcriptions of interviews with family members.

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wants out of life and will probably get it." Sally characterizes her son as someone who sets his goals high and is good at creating the support necessary to reach his objectives. Both parents are quick to point out that rearing Michael (and his two younger siblings) has not been without its struggles, but, as Jim states, "the decisions, accommodations, and changes we have made have been well worth it."

Jean Robinson was 36 when she became pregnant with another child. At that time she and her husband, Carl, had three other children ranging in age from 2 to 9 years. Jean chose to remain at home with the children, and Carl held both full- and part-time jobs to make ends meet. Living in a densely populated urban area, both parents longed for a better neighborhood in which to rear their children. This would have to wait until Jean returned to work after the last of the children entered school, however, because, as she put it, "both Carl and I agreed that it was important for the children to be raised by their parents rather than a day-care provider." Jean had a number of complications during pregnancy and spent the last weeks before giving birth on "bed-rest." Luckily for the family, a number of close relatives lived nearby and came over to care for the other children, clean house, and help with meal preparation.

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After an extended delivery, Kathy was born. Almost immediately her parents were aware that something was wrong. The infant experienced respiratory distress and quickly was given oxygen and moved to an intensive-care unit. Fortunately, Kathy's initial medical problems were not as serious as first thought, and within 12 hours she was back in her mother's arms. During one of these periods, Jean reports, she was "still marveling at her child's birth" when one of the attending nurses asked when Carl would be returning to the hospital. When she questioned why, Jean was informed only that her physician had something she wanted to discuss with her and her husband.

Carl described the meeting he and his wife had with their physician as one of the most "gut-wrenching" experiences he had ever encountered. "Our doctor was direct and to the point, explaining that our daughter had Down syndrome, would likely experience some degree of mental retardation, and would need special educational and medical services as she grew up." What made the meeting so difficult, Jean stated, was that she couldn't answer most of their questions at that time—things like how retarded Kathy would be, if she would learn to talk, read, and write, what type of education and medical services she would need. No one at the hospital could (or would) answer these questions for the Robinsons. When they brought Kathy home from the hospital, they knew little about what to expect.

Shortly after completing this past school year, Kathy celebrated her 16th birthday. Despite some of her health difficulties, her mother described her as "just as independent and stubborn as her brothers and sisters when they were that age." During the summer Kathy participates in inclusive recreation programs offered by the local park and is looking forward to returning to school in the fall. Kathy's parents say her persistence and independence has served her well so far in school and in her interactions with peers. Although they indicate that life is going well for Kathy and the family at the present time, they do express concern about what the future holds for their daughter, especially in developing friendships with other young adults.

The Frenches and Robinsons now have had many years of experience rearing children with Down syndrome. For both families the process has been one with both its triumphs and disappointments. Over the course of the years, these families have adjusted their expectations and plans for the future, coped with developmental and unexpected sources of stress, and undergone many transitions, each in their own, individual manner. Members of both families also state emphatically that they have grown as individuals and as families as a result of this experience. Even though each family has followed a somewhat different path in achieving what might be called a "psychologically healthy family environment," the process of coping and growth they experienced has many commonalities.

THE FAMILY SYSTEM

Among the questions parents with children who have Down syndrome ask most often is: How will rearing a child with this disability affect the family? The question can take many more specific forms, including: How will rearing a child with Down syndrome affect the marital relationship, parental relationships with other children, interactions between siblings, affiliations with members of the extended family, friends, and neighbors? How might the family best cope with the stressors that inevitably accompany dealing with educational, health, and social service systems that are something less than "user-friendly"? In what ways can the family support the developing competence of a child with Down syndrome while it provides for the continued physical, cognitive, and emotional needs of the remainder of its members?

These questions have no easy answers. Each individual, with or without a disability, has different capacities and needs, and so does each family. Each family responds to situations such as these in its own unique manner. Some families cope extremely well with rearing a child with Down syndrome. Many do much better than cope; they thrive. Other families, for a variety of reasons, have considerably more difficulty.

The birth of a child with Down syndrome has the *potential* to have many effects upon the family. Conversely, the way in which individual family members and the family as a whole respond to this situation has the capacity to have a profound impact on the child's development. This *bidirectional* process in which the child's behavior affects the family at the same time the family affects the child has begun to be understood only recently. Given that interest in this area has been recent, there is much more we do *not* know about families with children with developmental disabilities than what we do know.[1]

What we know about families with children with disabilities has increased dramatically in the last two decades. Farber was one of the first to note the impact that raising a child with a developmental disability could have on a family, finding a disruption in the "normal family life-cycle."[2] More recent research efforts have found that families of children with developmental disabilities often have added stress,[3] social isolation,[4] more marital discord,[5] more tension among siblings,[6] greater caregiving burdens,[7] and poorer physical and mental health.[8]

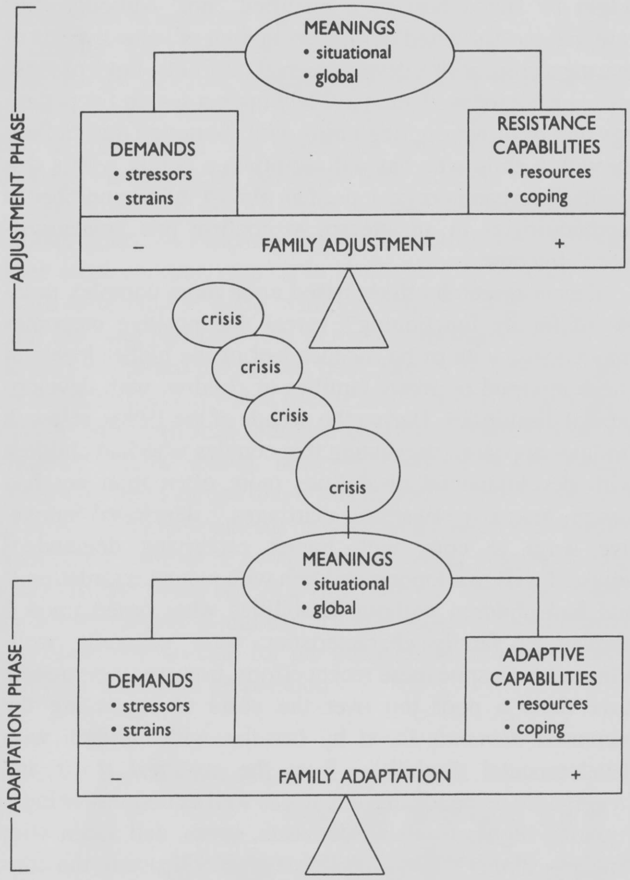
Is the situation really this grim? Are most families with children who have developmental disabilities destined to be more dysfunctional than families without children with disabilities? The answer to this question is not simple but might be stated best as a qualified "no." Although past research has furthered our understanding of some aspects of rearing a child with a developmental disability, most of these efforts have focused almost solely upon a search for pathology and dysfunction. Beginning with the notion that "a family with a child who has a disability is a family with a disability,"[9] researchers have used an almost infinite number of methodologies in an attempt to confirm this "maladjustment" hypothesis.

Recent research efforts based upon more complex models of family functioning[10] reveal that positive outcomes may coexist with or be independent of the higher levels of stress reported by many families of children with developmental disabilities. During the decade of the 1980s, research findings appeared suggesting that couples who had children with developmental disabilities more often than not had strong, mutually rewarding marriages,[11] developed innovative ways to cope with higher caregiving demands,[12] adjusted well to adopting children with mental retardation,[13] and had children without disabilities who, based upon a number of family characteristics, were generally well-adjusted.[14] Despite these recent efforts, however, researchers have done a poor job over the years of separating the increased *demands* faced by families with children with developmental disabilities from the *potential stress* and *strain* these demands may create, as well as unquestioningly equating higher levels of demands, stress, and strain with "maladjustment."[15] As a result, despite evidence to the contrary, the notion persists that most families with children with disabilities are not well-adjusted.

REARING A CHILD WITH DOWN SYNDROME: UNDERSTANDING THE PROCESS

An overview of the research literature as well as personal experience suggests that, though some families do have difficulty rearing a child with a developmental disability, many families take it in stride, adjusting over time, adapting to higher demands, and growing as individuals and families along the way. How might one best understand this complicated process of adjustment, adaptation, and coping?

Patterson and her colleagues[16] developed what they refer to as the *Family Adjustment and Adaptation Response (FAAR) Model* (see Figure 1). This model suggests that when an infant with a disability joins a family, a two-phase process of *adjustment* and *adaptation* occurs over time. During the adjustment phase the family and its members make immediate short-term changes to cope effectively with the additional demands of rearing a child with a disability. If a family is to not only survive but also thrive and grow, long-term changes also have to be made over the course of the



From "Families Experiencing Stress: The Family Adjustment and Adaptation Response Model," by J. M. Patterson, in *Family Systems Medicine* 5 (1988): 202–237. Used by permission.

FIGURE 1
Family Adjustment and Adaptation Response (FAAR) Model

child's and family's life cycles. These adaptations are in response to the family's attempts to meet the demands it faces from both expected (developmental) and unexpected stressors and strains.

DEMANDS, STRESSORS, AND STRAINS

One of the important distinctions Patterson and her colleagues made is between demands placed on the family, the stressors and strains the family endures, and the experience of stress. It is inconceivable that rearing a child with Down syndrome, or any disability for that matter, will not create additional demands on a family. The external environment acting on the individual often creates a demand, sometimes called a potential stressor. The demands change over time. Some demands result from what are referred to as "normative" sources, the expected transitions and changes over the course of the individual and family life cycle. Expected events that place demands on the family include a child's initial entry into school and the transition from childhood to adolescence. A second set of demands are "non-normative." They are unexpected, as in a divorce or the sudden death of a spouse. For the family of a child with Down syndrome, non-normative demands might include extensive participation in early intervention programming, daily or weekly physical therapy, or the need to meet with professionals (teachers, school psychologists) regularly to ensure that the child is receiving adequate services.

The normative and non-normative demands of a family with a child with Down syndrome potentially can create stressors and strains. A *stressor* is a demand or event that has an impact on the family because it produces changes in the family system.[17] This change may be in any one or more of a number of areas including family boundaries and goals, patterns of family interaction, the quality of relationships, the number or type of roles one must fill, and the values of individuals within the family. Family *stress* is defined as a state that arises from an actual or perceived imbalance between the demands placed on a family and the family's capability to meet these demands. If a family does not have the capacity to respond to additional demands or can do so only by making significant changes, one or more family members may experience stress. *Strain* refers to the actual negative effect on the person or persons as a result of the stress.[18] It is an unpleasant state that most persons seek to avoid or at least minimize. Although all individuals endure some amount of stress and strain, if experienced over a lengthy period, this can lead to both individual and family needs not being met effectively.

Upon the birth of their children with Down syndrome, the French and the Robinson families were faced with a number of demands above and beyond those of most new parents. Both the French and Robinson children, for example, required physical therapy for some time. This requirement placed a demand upon the two families. As pointed out by Glidden, however, the stress caused by the same demand can be different for different families.[19] Because Jim French was working part-time and had some flexibility in his class scheduling, the demand of taking their son for physical therapy could be spread across both parents. Sharing this responsibility, Sally and Jim were able to minimize stress from this demand, and they experienced little strain. The Robinson family, on the other hand, had to deal with the same demand in a different way. Carl was employed full-time and was not able to share the responsibility for taking his daughter to physical therapy with his wife. The stress and subsequent strain this situation created for the family was quite high at first because Jean not only had to take her daughter with Down syndrome to the therapy sessions but also had to bring along her second youngest child. Only when Jean was able to arrange for day-care for Kathy's older siblings was the strain reduced to a manageable level.

To understand a family's response to rearing a child with Down syndrome, one must consider not only the demands of stressors and strains placed on individuals within the family but also the demands placed on the family unit as a whole. These demands stem from the child as well as the community's response to the child. All of these systems can be viewed as a source of both demands and capabilities. Take, for example, the French family. Upon the birth of Michael, their son with Down syndrome, Sally and Jim French had to respond to caregiving demands that did not exist before his birth. Michael was the French's first child, so they did not have the luxury of previous practice as parents. They had to respond to the demands typical of all infants and also had to attend to the special needs of their child associated with his disability.

The caregiving demands placed on parents of children with Down syndrome obviously are different for each parent and child and are determined by the characteristics of both the parents as well as the child. Some parents who need eight hours of sleep a night often find it difficult to remain alert. Others can get by on five hours of sleep each night. Like their parents, each child with Down syndrome is also a unique *individual.* Some are extremely active, others mellow. Some may quickly develop regular schedules for eating, sleeping, and other biological functions, and others may not.

The birth of a child with Down syndrome also creates a set of demands on the *family,* because mothers, fathers, and siblings often have to redefine their roles within the system. Before the birth of their daughter Kathy, Jean Robinson undertook most of the child-care responsibilities within the Robinson family. Shorty after Kathy's birth, however, Jean experienced what most family psychologists would term "role overload." As Jean reported, "It became impossible for me to continue to do everything associated with raising the family by myself. It affected not only my relationship with the children but with Carl as well." Carl Robinson, who prior to Kathy's birth worked both full- and part-time jobs to help make ends meet, also felt the strain and observed it in his other children. Over time the Robinsons redefined their roles as parents. Carl quit his part-time job and took over more of the child-care responsibilities, and Jean eventually obtained employment outside of the home.

At a third level, rearing a child with a developmental disability has the potential to create demands (from stressors and strains) at the *community* level. Both the French and the Robinson families have spent considerable time attending meetings related to the education and health care needs of their children. These families estimated that, over the course of their children's lives, they spent an average of 30–50 hours per year participating in meetings to ensure that their children were receiving quality services and necessary supports. Although one might expect the level of community demands to lessen as children mature, families often indicate that these demands decrease only slightly and may even increase as their children move into adulthood.[20]

SHORT- AND LONG-TERM DEMANDS

Over time a family attempts to balance short- and long-term demands with its capabilities for meeting these demands.[21] The short-term outcome of this balancing effort is termed adjustment, and the long-term outcome is referred to as adaptation. When a family adapts to rearing a child with Down syndrome, it is able to effectively meet the child's needs as an individual as well as its needs as a family.

The demands associated with rearing a family in general and a child with a disability in particular (and the stressors and strains associated with them) change continually. If they are not resolved, demands may pile up, placing the family and child at risk for poor outcomes. This notion of a pileup of demands suggests that families of children with developmental disabilities may be especially vulnerable during periods of major developmental changes.

FAMILY CAPACITIES

How does a family adjust and adapt to rearing a child with Down syndrome? Why are some families successful while others struggle? Although these may seem like simple questions to answer, we do not yet fully understand all of the complex processes involved in families' adapting and coping. Two decades of research in this area, however, have provided enough information for professionals to begin to understand the process. A number of factors associated with families' success in adapting to rearing a child with Down syndrome or any other disability have been identified. These factors, called family capacities, include the following:

- The *meanings* the family and its individual members attribute to the demands of the situation and their capability to meet these demands
- The *resources* the family has available or is able to acquire
- The *coping behaviors* the family uses in an attempt to achieve a balance between demands and resources

Family meanings. The way family members think about what is happening to them as a group and as individuals has a powerful effect on their success in adjusting and adapting to potentially stressful events of all types,[22] including rearing a child with Down syndrome.[23] This involves the way in which a family defines and perceives the demands associated with the disability as well as its capabilities for coping effectively with these demands. The ability to develop positive, adaptive beliefs and meanings increases the probability of a proactive approach to life, not only for the family but on the part of individual family members as well, including children with disabilities.

Finding meaning in what many may call negative events has been viewed as a way in which families can restore some order and purpose in life, especially during times of great stress and strain.[24] The belief systems that families develop to deal with demands have been found to be global, influencing how a family responds to multiple situations, as well as specific as related to particular situations and demands.[25]

Like other characteristics, the meaning a family attaches to having a child with a disability is subject to change over time. For some families the initial meaning is quite negative but becomes more positive as family members adjust and adapt to the child. If, on the other hand, demands build up to a point where family members no longer have the resources to deal with them, an initially positive or neutral meaning may become more negative. During the first months of their son's life, Sally and Jim French experienced this change in the meaning they attached to having a child with Down syndrome. Jim stated:

> When we first realized that our child had Down syndrome, we were both kind of numb. I don't think either of us saw the situation as anything less than a catastrophe. I had nightmares of my career going up in smoke. Sally quickly realized that she could not go back to teaching after only one year off because finding child care would be impossible. The reactions of our families to the birth of Michael didn't help either. Everyone kept encouraging us to place him for adoption or institutionalize him, even our physician. One strategy they used was to attempt to convince us how difficult ... no, how impossible it would be to successfully raise our child. It got to the point where I think we both began to believe that this was a situation we could not possibly endure.

Over time the Frenches were able to meet other families that had children with Down syndrome. As they talked to these parents, they reported that a change seemed to take place. Sally described the change and what it meant to the family:

> We talked to parents who were members of a support group. They all had horror stories to tell about how professionals and family members told them to institutionalize their children. More important, they all had positive things to say about how their families had grown and coped with the difficulties. Most of these people identified some point in their family's life where they as parents came to see their child as a gift ... as a person with capabilities and capacities just like any other child. From that point on, it seemed like things got much easier for them. That's not to say that these families didn't make sacrifices along the way. At least at this point, though, they saw the concessions as worth it.

How might the meaning a family and its members attach to having a child with a disability affect the child and the family? Viewing one's child as "less than normal," "sick," or "less capable" may have a number of effects upon interactions between parents and children. This negative meaning has been associated with more dependency on parents, lower levels of competence, and poorer developmental outcomes for the child.[26] Attributing positive or neutral meanings and attitudes to children with disabilities ("Our child is just like other children," "Our child has drawn us together as a family") is a protective factor for families, helping them manage the situation while minimizing stress and strain.[27] The meaning a family and its members attach to a child's disability influences not only the family's ability to adapt but the child's as well. The meaning a child comes to attach to his or her disability, in turn, likely will affect the family's adaptation.

An example may illustrate this point. If a family comes to view the birth of a child with Down syndrome as having meaning or a "good thing," the family is less likely to develop resentment toward the child and more likely to provide the loving, nurturing environment that will facilitate the child's growth and development. This positive family atmosphere increases the likelihood that the child will develop the skills, attitudes, and values that enhance the probability of later independence, autonomy, and a high quality of life. These are all factors that can lessen the demands, stressors, and strains within a family.

The reader may wonder how parents could consider the birth of a child with Down syndrome a "good thing." Certainly most parents do not wish for the birth of a child with a disability. The *frame of reference* within which the family determines the subjective meaning of an event, however, may lead to a view of the birth as a negative and stressful occurrence or something that is neutral or even positive.[28] Consider the meaning of Down syndrome to the following parent, whose frame of reference is children the same age as her son who are average to above average in verbal, academic, and other abilities:

> It was extremely hard for us to not see Thomas's birth as a catastrophe. His sister, who is only a year older, has always been an extremely bright child. She talked at 14 months, learned to read at age 3, and is now in her school district's gifted program. Every time we look at Thomas, we can't

> help but see that he's falling further and further behind his sister and other children his age, and there is really nothing we can do about it.

It would be extremely hard for this parent to see the child's disability in a positive light. Contrast this situation with that of Jean Robinson, Kathy's mother, who has a distinctly different frame of reference:

> My sister is a nurse in a pediatric intensive care unit. I guess that helped Carl and me a lot because, before Kathy's birth, we had heard all sorts of stories of children born with severe, multiple disabilities, kids with degenerative diseases, children with leukemia and other forms of cancer whose parents knew they would probably never grow to be adults. That kind of helped us put it all into perspective. We know Kathy has a disability. I don't want to minimize that. But when you look at the whole picture, both she and the family were quite blessed. After some early physical problems she's been pretty healthy all these years, was able to take part in an early education program, learned to read, and is now thinking about a career. I guess we were the lucky ones.

Using a different frame of reference, Jean Robinson views her daughter and the family as fortunate. The meaning the Robinson family attached to Kathy's birth and her disability is one of the factors that allowed them to feel empowered and take a decidedly proactive approach to meeting Kathy's education and health-care needs. Viewing Kathy's disability as a challenge rather than a catastrophe, her family was able to take proactive stances and avoid major crises. This has proved especially valuable during major transitions or changes because the family was prepared for these eventualities.

Perceiving the demands associated with rearing a child with a disability as "something we can beat" makes a family (other things being equal) more likely to attempt to find, use, and, when necessary, develop the resources required to rear the child effectively and at the same time meet the needs of other family members. Negative meanings, in contrast, increase the probability that parents and other family members will neglect to seek out resources, such as parent and advocacy organizations, that can provide extensive support and lessen demands. Attaching neutral or positive meanings to the situation also increases the probability that a family will achieve a balance between meeting demands and accepting limits to capabilities through strategies such as lowering expectations to reasonable levels.[29] Jean Robinson related how unattainable expectations at first hindered her family's attempts to cope with Kathy's disability and the positive changes after more realistic expectations were developed:

> Carl and I, like most parents, often got caught up in trying to be the perfect father and mother. Because Kathy has often had physical problems, there were a lot of exercises and activities that her physical therapists wanted us to do with her at home daily. This was fine when the other children were young and weren't involved in a lot of other activities. We could spend the necessary time with Kathy, and the other kids often took part, too. As they got older, though, we began to feel the crunch—school meetings, basketball practice, church functions, choir. The demands on our time as parents quickly built up. We didn't want to deny Kathy's brother and sister the chance to take part in activities their friends were. On the other hand, we felt like "bad parents" when we forgot or didn't have time to work with Kathy.
>
> Things really got out of hand until Carl and I called Kathy's therapist and then had a family meeting with the kids. It turned out that missing a couple of days a week of Kathy's exercises wasn't really going to do any harm. Then we sat down with the kids and informed them that, while we really wanted them to have the chance to do all they wanted, there had to be some limitations. We asked each of them to choose two after-school activities they were really interested in and wanted to pursue. We agreed to support them in those areas—drive them to practice, pick them up after school, and so on. If they wanted to do more, they understood that they needed to figure out ways to do them on their own or with the help of friends.

The meaning a family attaches to rearing a child with Down syndrome also relates to the extent to which specific family meanings are associated with a sense of control and empowerment among family members. A belief that one has some control over life events has been found to be related closely to adjustment and adaptation to stressful events[30] including rearing a child with Down syndrome.[31] Why might this be the case?

Determining the educational and health-care services children with disabilities need is not an exact art. Professionals within education and human services fields often have to guess as to the type and level of services that will facilitate a child's development. As a result, the services provided to these children and their families often do not meet their needs fully. Given the nature of service systems through which children with disabilities receive their education and care, families often have to advocate for additional services they believe are necessary for their children's optimal development. The meaning a family attaches to having a child with Down syndrome is likely to have a profound effect on the extent to which a family experiences a sense of control and empowerment and is able to advocate effectively for their child.

Perceiving themselves as in control of their lives, Sally and Jim French have taken a decidedly proactive stance in advocating for services for their son, Michael. Be it health care, educational, vocational, or other services, the Frenches have, according to Sally, "done whatever was necessary to make sure that Michael gets the services and supports he needs." Provided with these services, Michael has had the opportunity to develop skills and abilities that many children and young adults with developmental disabilities never have the chance to acquire. These capabilities have enabled him to reach levels of independence and self-sufficiency that neither his family nor the professionals with whom they work originally thought possible.

Family resources. Family resources consist of the psychological, social, interpersonal, and material characteristics of: (a) individual family members (personal resources), (b) the family unit (informal resources), and (c) the community (formal resources).[32] When available, these can be called upon to reduce stress, solve problems, and facilitate parents' balancing the demands of rearing a child who has a disability with their capacities (see Table 1). Resources at each of these levels are of two general types. The first is *existing resources,* already in place and available to a family and its members before the birth of a baby with Down syndrome and with the potential to minimize the impact of a potential source of stress. Existing resources might include a strong marital relationship, financial stability, and the health of family members.

The second type of resources are *new resources* the family and its members develop in response to new or additional demands associated with rearing a child with a disability. These might include making friends with other families with children with disabilities who can provide a source of support, joining a parent support group, and finding a child-care provider experienced in working with children who have disabilities. Because the demands and strains of rearing a child with Down syndrome (or any child, for that matter) tend to build up over time and vary with the child's stage of development, families must develop new resources continually that will help them meet current and future demands.

The extent to which families have access to and can use specific resources effectively varies depending upon a number of factors. Even so, examining resources that have

TABLE 1
Levels and Types of Resources

Resource Level	Type of Resource	Potential Resource Use
Individual	1. Physical health	1. Better physical stamina necessary to meet increased caregiving needs.
	2. Psychological health	2. Ability to cope with frustration, intense caregiving, etc.
	3. Level of education	3. More knowledge of disability and service system; financial stability.
	4. Spiritual beliefs	4. Ability to derive positive meaning from birth of child with disability; sense of empowerment.
	5. Problem-solving skills	5. Capacity to solve problems/remove barriers necessary to ensure provision of appropriate services; ability to minimize or effectively deal with conflict.
	6. Self-esteem/self-confidence	6. More persistence; greater likelihood of proactive approach to dealing with child-related issues; enhanced quality of caregiving; higher levels of marital and family satisfaction.
Family	1. Family interaction style	1. Higher levels of family and marital satisfaction; better able to provide intrafamilial support; greater capacity to develop and maintain informal and formal support network; enhanced ability to provide support and nurturance to family members while fostering autonomy; ability to adapt to change.
	2. Marital relationship	2. High levels of spousal support; agreement on roles, rules, and responsibilities; shared caregiving.
	3. Informal support network	3. Provision of emotional, informational, instrumental, and companionship support.
Community	1. Formal support network	1. Provision of emotional, informational, and instrumental support; training/education; furnishing of physical support/services; introduction to individuals who may become part of informal support network.

been helpful to many families that have raised children with disabilities may be instructive.

1. *Personal resources/supports.* Resources at the individual level include, but are not limited to, the individual's physical and psychological health, level of education, intensity of spiritual/religious beliefs, problem-solving skills, and sense of self-esteem and self-confidence.[33] One's *physical* and *psychological health* is essential if a parent is to adjust and adapt to the demands of an infant or child with a disability. Increased demands, such as spending more time in direct caregiving or attending ongoing meetings with health-care providers and school personnel, are potential sources of physical and psychological stress and strain that can lead to anxiety, feelings of incompetence, and depression. As Jean Robinson related:

> It wasn't until Kathy was 5½ years old that she slept through the night without needing some sort of care. Adding up all the sleep I lost over that period of time, it's amazing that I wasn't sick more often. If you add the time demands, frustration, and anxiety Carl and I had from meeting almost weekly with at least one of the many professionals who provided services to Kathy, it's amazing that at least one of us didn't have a breakdown.

The *level of education* of family members also has been found to predict adjustment and adaptation to the stressors associated with rearing a child with a disability. Typically, the higher one's educational level the greater a family's financial resources, the more influence one has with professionals, and the more skills one has in negotiating the service delivery system. Level of education also has been associated with parental understanding of the disability affecting a child, setting appropriate and realistic expectations for the child and others, and participating in support groups. All of these factors have the potential to reduce stress and strain.

The intensity of one's *spiritual and religious beliefs* has been associated with less stress in families who have children with developmental disabilities.[34] At this point, however, we do not know how these beliefs help families adjust and adapt to having a child with a disability. Maybe a spiritual belief system allows one to give meaning to the birth of a child with a developmental disability. Or these beliefs may allow family members to adopt a positive, empowered outlook on life. Religious beliefs also may promote adaptation by providing family members with an additional network of friends who can provide social, informational, and material support. A combination of these factors seems to have aided the Robinson family in developing a set of positive meanings regarding their daughter's Down syndrome. Carl Robinson said:

> Our church has helped us in many way in dealing with Kathy's disability. I think it was at least partially our belief that there is a reason and a meaning to everything that helped us put things into the proper perspective after Kathy was born. It was also through our church that Kathy was able to develop some friendships with children her own age when she was younger. Although many of these friends are no longer around, I know Kathy still remembers them and considers them an important part of her life. And friends that our family made through its activities with the church have been extremely helpful in helping us care for Kathy when we needed a respite.

Rearing a child with or without a disability, a parent faces many obstacles. The parents of children with developmental disabilities often face more demands as they attempt to navigate a complex social and human services system that includes regular interactions with physicians, nurses, physical therapists, occupational therapists, special and general education teachers, psychologists, and a host of other professionals. Parents' *problem-solving skills and style* may either facilitate or hinder their ability to work with professionals, family members, and others within the community to create an optimal environment in which their child can develop. A preference for and skill in active problem solving rather than self-blame or denial have been associated with psychological health in the general population[35] and with lower levels of distress in parents of children with developmental disabilities.[36]

Both Jim and Sally French have displayed this active style of problem solving throughout their interactions with representatives from the various systems that provide their son with services. For example, after being frustrated with the quality of transition services provided to their son, these parents enlisted the aid of a local parent advocacy organization in an attempt to improve Michael's vocational training. After several meetings with an advocate from this organization, the Frenches met with educational and administrative staff from their son's school. Their level of preparation was so thorough that, according to Sally French, "we obtained the changes in Michael's program that we wanted, and our advocate asked us if we wanted to serve as volunteer advocates for the parent organization."

The *self-confidence* and *self-esteem* of family members, especially parents, are crucial to family adjustment and adaptation.[37] People differ dramatically in their estimates of their ability to deal successfully with new situations. Some individuals believe they can easily handle anything. Others are much more conservative with respect to their levels of self-confidence. Individuals who truly believe they have the skills and experience to adapt to demanding situations will be more proactive and persist in the face of adversity.[38] Past experiences in coping successfully also result in parents' developing positive attitudes about their ability to cope with an infant with a disability. Moderate to high levels of self-confidence, therefore, may help parents avoid crisis situations and take effective action when they inevitably do arise.

Self-esteem in most individuals varies over time. Success tends to build self-esteem, and failure may diminish it. The initial reaction of many parents to the birth of a child with a disability is a sense of failure. If parents have a difficult time caring for the child, their levels of self-esteem may decrease further. This is likely to have a direct, negative impact not only on the quality of care a child receives but on marital satisfaction as well. Establishing realistic expectations, avoiding blame of self or others for difficulties, and utilizing formal and informal supports are strategies that have been found to maintain levels of self-esteem and self-confidence.

2. *Family resources/informal supports.* Informal supports are resources available to the family that are interpersonal and derive from family members' interactions with each other and with individuals they know personally. These resources include the family's predominant style of interaction, the marital relationship, and the family's social support network including relationships with extended family members and affiliations with intimate friends, acquaintances, and neighbors.

Over the past three decades a considerable amount of research has been conducted in an attempt to determine how families adjust and adapt to rearing children with disabilities. In recent years these studies have expanded to include investigations of the extent to which *family interaction* affects the development of children with disabilities. Although much remains to be learned in this area, what we do know is that the style of family interaction has a major impact on the ease and extent of family adjustment and adaptation, parenting competence, and child outcomes. Aspects of family interaction and their relation to rearing a child with a developmental disability that have been studied include family levels of cohesion and adaptability, family structure, sharing of affect, extent of support available, role and task assignments, and many other variables.

One of the most important findings of this research is that families display a wide variety of styles of interaction. A series of studies of families with children who have varying degrees of mental retardation[39] revealed five distinct styles of family interaction, which the researchers described as

1. cohesive–harmonious,
2. control oriented–somewhat nonharmonious,
3. low disclosure–nonharmonious,
4. child oriented–expressive, and
5. disadvantaged–low morale.

Although the severity of a child's disability was found to have an impact on family adjustment, it was not associated with a variety of measures of marital adjustment.

Family interaction research directly relevant to the adjustment and adaptation of families with children who have Down syndrome also has been conducted in recent years. Using the *circumplex model of family interaction,*[40] Abery[41] compared sixty-five families with children with Down syndrome ranging in age from 5 to 18 to a comparison group of families of children without disabilities. This research program considered two basic aspects of family interaction: family cohesion and family adaptability.

Family cohesion refers to the extent to which family members are connected emotionally with each other. It ranges on a continuum from enmeshment, or extreme connectedness, characterized by overidentification with the family, to disengagement, or extreme separateness, characterized by extremely low levels of connectedness and the lack of a "sense of family."[42] Continued functioning at either of these extremes is viewed as dysfunctional. Moderate or balanced levels of cohesion (connected or separated) are viewed as more functional as the family strikes a balance between togetherness and separateness, allowing its members to deal more effectively with stressors and developmental change.

Family adaptability is defined as the family's ability to change its power structure, role relationships, and relationship rules in response to developmental and situational changes.[43] Families are viewed as being on a continuum of adaptability ranging from rigid (extremely low levels) to chaotic (extremely high levels). Rigid families are characterized by authoritarian leaders, stereotyped roles, and rigid, strictly enforced rules. Chaotic families, at the other extreme, have little to no leadership, dramatic role shifts and reversals, and loosely, arbitrarily enforced rules. Moderate or balanced levels of adaptability (flexible or structured) are more functional to families. Moderate adaptability allows for a sense of stability and at the same time provides room for change. Rules, roles, and the family's power structure are flexible but not constantly changing.

Overall, I found that families of children with Down syndrome displayed moderate levels of both cohesion (connected or separated) and adaptability (structured or flexible) and seemed satisfied with their current styles of interaction. Although no differences were found in the levels of adaptability between families with children with Down syndrome and the comparison group (families with children without disabilities), families of children with Down syndrome were more cohesive than the comparison group. Equally important, families with children with Down syndrome who were moderate in cohesion and adaptability showed more positive communication styles, reported lower levels of stress, were more satisfied with their marital relationships, had lower rates of divorce, and had children whose teachers rated them as having higher levels of social, academic, and behavioral competence than families who displayed extreme levels of cohesion and adaptability.[44] Similar findings have since been reported in a number of studies of families with children with other types of disabilities.[45]

The styles of family interactions of the French and Robinson families provide excellent examples of the way in which different patterns of interaction may facilitate the adaptation of individual families. The French family functioned in a flexibly separated manner (moderate cohesion; moderate adaptability). Given the ages of their children (18, 16, and 14), this style of family functioning allowed enough independence and autonomy for the children and at the same time provided a sense of connectedness that encouraged each person to feel that, if he or she needed support, it would quickly be provided. Jim French reported:

> Although I think our family is close, we are probably not as close as we used to be. I mean, as the children have gotten older, they have spent more and more time with their friends. That's something Sally and I think they are entitled to and would never dream of telling them that "family comes first." What we have been able to do as the kids have grown up, though, is set aside a little bit of time each day and week when we do something together. During the weekday it's usually nothing more than making sure we eat dinner together as a family. It may seem like this is a pretty simple thing, but I think it gives us a sense of being connected and an opportunity to know what's going on in each others' lives.

The levels of adaptability characteristics of the French family (flexible) allowed Jim, Sally, and their young adult children to strike a balance with respect to family rules, roles, and leadership so all family members were able to take part in decision making, had well-defined roles, and understood the basic rules under which the family functioned. Family leadership, roles, and rules, however, were open to change and were adapted quite frequently as the family deemed necessary. Extensive interviews with family members suggested that this style of interaction was meeting the needs of all members effectively.

The Robinson family functioned in a structurally connected manner (moderate adaptability; moderate cohesion). The rules, roles, and power structure of the family clearly were not as flexible as those of the Frenches. Nevertheless, there was a good deal of give and take between Jean and Carl, as well as between parents and children. Jean said:

> Because of the time-consuming nature of many of Kathy's needs, things in our family have to be somewhat structured if we are going to get done what needs to be done. But we've always been big on family meetings, and as the kids have gotten older, it's been necessary to provide a lot more give and take.

The Robinsons also were considerably more cohesive than the French family, and all members reported strong feelings of closeness. Family activities played a big part in the lives of Jean, Carl, and their children. Both parents and the children reported engaging in many activities together as a family each week. Some of these activities revolved around an individual's participation in recreation/leisure activities (for example, the whole family attending one of the children's baseball games and then going out to eat afterward). Other activities were based on the interests and commitments of the entire family, such as their participation in church-related events. What is obvious from interacting with the Robinsons is that parents and children are extremely close and supportive of each other without anyone having to give up his or her individuality.

One of the most important factors in successful adjustment and adaptation to rearing a child with a disability is *marital status and satisfaction.* Single-parent status has been found to be one of the most powerful factors associated with stress and strain in families with children with disabilities.[46] The satisfaction, or lack thereof, that mates derive from their marriage, and reports of marital distress, have been linked to parental stress levels, parental functioning, and feelings of parenting competence.[47]

The importance of a supportive spouse as a resource in parenting a child with a disability should be obvious. Increased parenting demands require that a couple be flexible and reach consensus on the sharing of roles, workloads, and responsibilities. A spouse also is a prime source of a social support. Given the extra demands and difficulties in caring for a child with Down syndrome, the quantity and quality of spousal support not surprisingly is associated with stress and with child outcomes. *Emotional support*—a measure of affection, respect, and satisfaction with the marital relationship—and *cognitive support*—an indication of agreement with respect to child care—are related to mother's and father's parenting competence.[48] Sally French related the importance of this type of support:

> When we brought Michael home from the hospital, we had no idea what to do. I mean, he was our first child. We were new parents. During the early years we were just feeling our way, never really sure if we were handling things correctly. Without the support I got from Jim and he received from me, I think we both would have had a hard time meeting Michael's needs. As I think back to when Michael was young, that was the time we each needed support the most. Neither of us was confident in what we were doing. Jim constantly reminded me that I was a good parent and that things would get better as we learned about Michael's style and needs. It was also important that Jim wanted to be involved in parenting and that we were able to agree on our parenting responsibilities. Without Jim's willingness to be involved, it would have been impossible.

Our *social networks* consist of people with whom we have regular contact and perceive as important.[49] Not only are individuals connected socially and emotionally with each person within their network, but to a greater or lesser extent each person within the network is linked with (has contact with, or knows of) others within the network. Informal social networks include extended family members, intimate friends, neighbors, and acquaintances. Interaction with people within one's social network can promote adjustment and adaptation in families with children with Down syndrome in a variety of ways, the most important being *emotional, instrumental, informational,* and *companionship support* (see Table 2).

The role of social support in helping families cope with the effects of potentially stressful life events and in promoting psychological adjustment is well-established.[50] Some researchers have speculated that it serves as a buffer between the family and upsetting events so the family has fewer adjustments to make.[51] Others believe it aids families in adjusting more quickly to changes brought about by life events.[52] Regardless of the specific processes involved, the research is quite clear: Families with children with developmental disabilities are much better able to adjust and adapt when a significant amount of support is available from their social networks.

What types of support are most effective in enhancing a family's adaptation? The answer to this question depends on the characteristics of the family, its individual members, and its situation. Young parents who have had little experience in rearing children and lack confidence in their abilities may profit most from emotional support. If a family moves to a new community and has little knowledge of the existing service system, informational support may best promote adjustment and adaptation. A child with many health-care and physical needs that require family members to spend a lot of time transporting the child to doctors and therapists might be supported best through instrumental support in the form of transportation. Parents who have spent considerable time advocating for their child with various agencies within the service system may welcome companionship as the most needed and effective form of support.

Although each family must decide for itself the types of support that are most needed, available, and likely to promote adaptation, recent research evidence indicates clearly that support from members of one's informal social network are likely to enhance a wide variety of individual and family capacities. Mothers who have weekly contact with friends, for example, are involved more actively with their infants[53] and have children who are more securely attached.[54] Child-related assistance (instrumental or informational support), which could take the form of a friend providing child care, cooking a meal for a family, or assisting with transportation, is a form of support related to family adaptation and is valued most highly by mothers of children with disabilities, who tend to shoulder the largest share of responsibility for child care.[55] Jean and Carl Robinson related their experience with their informal support network:

> *Jean:* Without the help of aunts, uncles, cousins, friends, neighbors, and people we knew from church, raising Kathy would have been a lot more difficult. We were reluctant at first to maintain contacts with these people immediately after Kathy's birth, but it quickly became clear that we weren't going to be able to go this on our own. I think it was our families that first became involved. My sister is a nurse,

TABLE 2
Types and Functions of Social Support

Type of Support	Function	Example
Emotional	1. Reaffirms self-worth 2. Assures individual that he or she is loved and valued	1. Reinforces a spouse's competence as a parent 2. Tells a child that he or she is loved
Instrumental	1. Directly provides concrete assistance/tangible support necessary to solve problems	1. Gives financial aid 2. Provides material resources (use of car, etc.) 3. Supplies needed services
Informational	1. Gives advice 2. Bestows guidance	1. Makes suggestions as to how to deal with a personal problem 2. Refers the person to someone who has resources necessary to help solve a problem
Companionship	1. Serves as supportive person with whom to share activities	1. Plays a game with a friend (tennis, cards, etc.) 2. Accompanies a friend to a movie or out to dinner

> so she was able to get us a lot of information on Down syndrome that we read and then gave to the extended family. We all learned a lot about the disability and Kathy together. That seemed to calm some of their fears about helping out with Kathy. You know, they quickly found out that she was a lot more like other babies than different from them. Once this happened, things got better. People started calling to ask if they could help out—with the other kids and with Kathy. The support we got was with a lot of different things—having someone to talk to when we were battling the school over Kathy's program, having someone to take care of the kids, including Kathy, when Carl and I needed some time to ourselves, having people available to take the other children places we could not because we were tied up with meetings or therapy sessions.
>
> *Carl:* When Kathy was a baby, Jean's sister and her husband would come over at least a couple of times a week. At first it was usually to do stuff with the other kids, to give us a break. But soon they felt comfortable enough with Kathy so we were able to spend some individual time with the other children. When Kathy got older and started school, Jean decided to go back to work. Well, I don't need to tell you how hard it is to get day-care for a child with a disability. Fortunately, one of our neighbors ran a family day-care. Jean maintained contact with her all through Kathy's infancy, and soon Joyce [the neighbor] got to know Kathy quite well. When Jean returned to work all we had to do was ask, and Kathy had a great day-care situation. That's not to say everything was easy. It was hard work getting people to accept Kathy. Jean and I had to work hard on it with our family, with our friends, and with others. I think it was our belief that if people really took the time to get to know her they would come to love her as much as we did that helped us get through the early part.

How can a family ensure that it will have the adequate support available from its informal support network? One of the most crucial factors is that a family not allow itself to be cut off from others after a child with a disability arrives. Often families of children with developmental disabilities are socially isolated, with smaller friendship networks.[56] The reasons for this isolation vary with the family but have been found to include high levels of emotional and physical exhaustion on the parents' part, parental avoidance of social contacts because of the stigma associated with having a child with a disability, friends' and relatives' avoiding the family because of their uneasiness in handling the situation,[57] and extreme levels of cohesiveness the family adopts as a way to cope with the demands of having a child with special needs.

Although it may be difficult, families can avoid most, if not all, of the scenarios described above. For example, by carefully negotiating role responsibilities within the family, with each spouse providing the other with adequate support, parents can minimize the possibility that one of them will have to shoulder all of the demands and strains associated with rearing a child with a disability. By accepting the disability, learning about it, and educating extended family, friends, and neighbors, families can dispel many of the myths and misconceptions about children with disabilities. This has the side benefit of alleviating the anxiety that many people feel with respect to social interactions with the child or family members.

In attempting to adjust to a child with a disability, one of the most potentially damaging responses a family can make is to develop extreme levels of cohesiveness (closeness) to the point where family members find themselves cut off from the outside world. Even though "standing together as a family" and "taking care of our own problems" may be laudable in some situations, families who are able to adapt to rearing children who have Down syndrome effectively maintain moderate, not extreme, levels of cohesion and adaptability.[58] This allows the family as a whole and its members to maintain and build outside contacts that may serve as valuable sources of support over the long run. Jim French related how difficult, but eventually rewarding, this process can be:

> After Michael's birth Sally and I wanted to crawl into a hole. We were embarrassed to a certain extent to have a child with Down syndrome. It didn't help matters that neither of our families was that supportive and initially encouraged us to place Michael in an institution. I guess it got to the point where it became an "us against the world" thing. We withdrew at first, thinking that the only way to handle this situation was to do it by ourselves. As a result, we found ourselves in danger of losing our connections with family and friends. I think it remained pretty much that way for the first several years of Michael's life. When we decided this wasn't the way to go and we weren't meeting each others' needs or Michael's, it was a long process of rebuilding friendships and connections with family. We've been working on this for some time now—hey, Michael's now an adult—and we lost some good friends because of our initial reactions.

Sally French, Michael's mother, also recounted what happened:

> While I'm sort of embarrassed to admit it, I think one of the main reasons why we came out of the shell we had built for ourselves was because of the birth of Michael's brother and sister. It was only then that we started making connections with family and friends again. Our earlier withdrawal made it quite difficult. Talking to one of the friends we had "remade" one day, I was startled to learn that our putting up a wall led them to think that Michael and other children with Down syndrome must be awful because we didn't want our family and friends around to see him. I think our behavior just added to the many misconceptions that people had about Michael and about Down syndrome in general. With no social life or support, we became a "Down syndrome family." Just about everything we did focused on Michael.
>
> Unfortunately, it wasn't until later that we realized this wasn't the best for him. He had us, and we loved him dearly, but he had no one else. His grandparents didn't visit much. Our brothers and sisters, all of whom had their own children,

> rarely came over, and that meant Michael lost a chance to play with kids his own age. If I had one piece of advice for families, it would be to make sure that in your own coping you're not locking out people who love and care about you. They can be an incredible source of support.

Although developing and using informal social networks for support can greatly enhance a family's ability to cope with a child with a disability, there are several caveats. First, though social networks have the potential to be a source of support, they also may be a source of conflict or criticism.[59] Sally and Jim French found this out shortly after Michael was born, when family members encouraged them, at times quite forcefully, to place their son in an institution. Although this was a common piece of advice to parents of children with Down syndrome at that time, it created friction between the couple and the extended families. Criticism of parenting styles, disciplinary techniques, the way parents handle the school situation (for example, inclusion versus segregated programming) can all provide fodder for critical remarks by extended family and friends. Relying heavily on one's informal network, with the resulting increase in contact this brings, makes some conflict and criticism inevitable.

Research over the past decade also has shown that some forms of social networks are more beneficial to families than other types of relationships are:

1. Families should strive to develop networks in which they have one or a few intimate friends or relationships with whom they have daily or semi-daily contact. These types of networks seem to be more helpful than those in which an individual has many acquaintances, none of whom is particularly close.[60]
2. It is better if the individuals within one's support network serve multiple needs or are capable of providing a variety of types of support. Each individual's ability to provide many types of support protects the family from losing its sole source of support in a given area if one individual within the network is unavailable for some reason.[61]
3. To maintain a support network over time, one must contribute to the network oneself. Reciprocating with those who have provided support in the past will help ensure that they will continue to do so in the future. Interestingly, it is better if all individuals within the network do not know each other. This eliminates the chance of losing all contributors to the network if problems arise between individual members.[62]

3. *Formal support networks.* The formal support network consists of professionals, community organizations, and agencies the family uses. Even though a network of caring, understanding professionals can be vital to promoting family adjustment and adaptation, no universally available or comprehensive sets of community services exist to promote family and child adaptation and growth throughout the developmental period.[63] In most states, services available to families vary from city to city and county to county. Some take an approach in which a family deals with one professional for all of its needs. In others a family may find itself working with close to a dozen professionals and organizations. Though the latter approach may provide for specialized services, its potential to create more demands and strain on the family might offset the support it offers. Actually, recent studies have found that many families feel alienated from formal support services[64] and turn to a formal network only when they have been unsuccessful in their attempts to obtain support from family and friends.[65]

Does this mean that trying to build a formal support system will be unproductive? Fortunately, the picture is not quite that dismal. Community services and organizations can be a crucial factor in how well a family adapts to having a child with a disability. In some situations people contacted initially through community organizations and services eventually become part of the family's informal support network. This type of relationship occurs quite frequently in situations in which parents of children with disabilities staff the organization. Within many areas, county ARCs (Associations for Retarded Citizens) provide this type of opportunity.

A number of metropolitan centers have organizations geared toward providing support to parents and families of children with specific disabilities such as Down syndrome. How can participating in such an organization be helpful? While rearing their son Michael, Jim and Sally French relied heavily on this type of support. Sally relayed their experience as follows:

> It was extremely important for us to be able to get to know parents of other children with disabilities, especially Down syndrome. The parent organizations we joined made this possible. As new parents, we had no idea what to expect with Michael. While the professionals we dealt with were competent, and family and friends provided some support, they hadn't been through what we'd been through. They didn't understand why we were asking some of the questions we were asking. It was through joining a number of parent-oriented groups that we were able to connect with people who really understood us, could give us an idea as to what to expect from Michael, what to expect from professionals, and what to expect from ourselves. Sometimes it was important just to have someone available to talk to about your frustrations—someone you knew could empathize because they had probably been through it themselves.

Professionals and the organizations to which they belong also can extend support for families. Though some parents, often with good reason, come to view teachers and the school as their adversary, developing close ties with several individuals within the educational and health-care service systems can help families avoid crises and adapt effectively to having a child with a developmental disability. Think of the differences in the potential sources of support available to the following two families.

When the Johnsons' daughter, Katie, began first grade 3 years ago, her mother waited with her at the bus stop and put her on the bus when it arrived. When she returned home from school at 3 o'clock, her mother was at the bus stop to pick her up. Following the first day of school, Katie's parents met with their daughter's teacher individually during the evening and had periodic contact with this teacher over the course of the school year at parent-teacher conferences.

Contrast this situation to that of Tyler Smith. One week before Tyler began kindergarten, his parents contacted the school and asked for a tour of the facilities. When the school agreed, the Smiths decided they would spend as much time as possible during the tour getting to know *all* of the people with whom their son would be interacting. In addition to meeting Tyler's teacher, they introduced themselves to the school's principal, the school secretary, several paraprofessionals who would be working with their son, cafeteria staff, and the school custodian. Further, they picked up a list of all of the children who would be Tyler's classmates and the names of their parents. The first day of school, Tyler's mother made a point to strike up a conversation with her son's bus driver. When the Smiths attended the school's first-grade orientation, they made it a point of getting to know the parents of his classmates as well. During a relatively short time the Smith family was able to establish connections or links to a relatively large number of people who would be providing services to their son, as well as to other parents. This rich network of connections continued to build over the course of the school year. When things were not going well for Tyler, his parents could rely on a host of people for information and support. If one individual wasn't available, others were.

The situation was quite different for the Johnsons and their daughter. They established only a single source of contact between school and family. When problems arose, the parents had only their daughter's teacher from whom to gain information, ideas, or other forms of support. When Katie's teacher left school in January on a pregnancy leave, the one connection they had established disappeared.

Just as it serves families well to establish a rich, interconnected network of family and friends upon whom they can depend for support, it is also important to develop a similar type of formal support network. In either case the resources available to the family are richer and more varied, and they do not rely upon a single individual who may not always be available or capable of providing the type of support a family needs. Families should note, however, that they could become too dependent upon community organizations or services as providers of support. Some families have been found to rely on community organizations and services so extensively that they jeopardize close relationships with family and friends.[66]

FAMILY COPING

Family coping refers to the *responses* or *behaviors* that family members use to try to achieve a balance between the demands on the family and the resources it has available. Coping efforts aid in family adjustment and adaptation in a number of ways including the following:

1. Reducing demands
2. Increasing resources
3. Maintaining and allocating resources
4. Managing unresolved tensions
5. Altering meanings

Although resources suggest potential avenues through which a family may enhance adaptation, *coping refers to what the family does.*

Reducing demands. The demands on family members differ in a variety of ways. The simplest strategy to reduce demands on any single person is to redistribute them. Family members first might search for individuals within the family who are not overburdened and assign them additional roles. Fathers, for example, who traditionally have not taken as active a role in childrearing or maintaining the family home may be asked to assume more of these responsibilities. Older siblings also may be asked to help out with general household tasks. If all family members are overburdened already, support may be obtained by going outside the family, using the informal support network.

A second strategy to reduce demands involves prioritizing and then eliminating activities and roles that have low-level priority. A family, for instance, might ask its members to prioritize outside activities and limit participation to two activities a week. The Robinson family found this tactic necessary to reduce the demands on parent time as a result of the children's leisure and recreation pursuits.

Increasing, maintaining, and reallocating resources. In its coping efforts, the family has to work to ensure that it is utilizing the maximum amount of resources available and is expending them in the areas in which they are most needed. This type of coping is essential for two reasons. *First,* over the course of a child's development, resources will be exhausted if they are not replenished continually. A family, therefore, needs to build continually upon the resources it has available, and be aware of and able to access new forms of support when old forms are exhausted.

Second, the demands of having a child with Down syndrome are not constant over time.[67] The skills needed to adapt to an infant with a developmental disability are different from those for an older child. Sally and Jim French first joined a group specifically for parents of children with Down syndrome. While providing them with various types of support over an extended time, members of this group did not have the expertise necessary for helping the Frenches make some dramatic changes in their son's transition program when he was in high school. At that time the French family drew on the support of an organization founded specifically to provide assistance to parents in education advocacy. Without developing this new resource, the French family, in all likelihood, would have had an extremely hard time promoting the educational changes they thought necessary for their son and would have experienced a great deal of additional strain.

Managing unresolved tensions. Managing unresolved tensions among family members and between the family and others within the community assures that frustrations, disagreements, and other sources of conflict do not pile up over time to a point at which individuals begin to behave in a dysfunctional manner. Two resources the family can use toward successful conflict resolution are (a) maintaining a positive, open style of communication so family members have sufficient opportunities to voice their concerns; and (b) fostering a moderate degree of adaptability. The Robinson family developed its own strategy to minimize conflict between family members. Jean Robinson said:

> At least once a week we had a family meeting. Anyone in the family could call one as long as everyone could attend. At first it was usually Carl or myself directing things. As the kids got older, they took more and more of a role. The meetings had two purposes. One was to air our gripes—things we were upset about or didn't like. The other part of these meetings was used to brainstorm, to try to figure out ways to deal with the situations that came up. As I look back, I can't say that everyone always left these meetings with perfect solutions to their problems, because in most cases there was a lot of compromise involved. I think the kids would admit, though, that the family tried its hardest to deal with everyone's complaints as best it could.

Altering family meanings. As indicated earlier in this chapter, the meaning a family attaches to having a child with Down syndrome is likely to have a dramatic effect on its ability to adjust and adapt to the child. Just as the demands associated with rearing a child with Down syndrome change over time, so can the meanings attached to this situation. Families who at first think the birth of a child with a developmental disability is catastrophic may come to believe over time that they have some control over the child's development and his or her impact on the family. The belief that one has control over life events has been linked closely to success in coping with potentially stressful situations.[68] A change in the family's belief system or the meaning it attaches to having a child with Down syndrome will be influenced, of course, by many things including the child's characteristics, the family's resources, and the extent to which the family has been successful in coping previously.

This brings us back to the question most families ask: What is the best way to adjust and adapt to a child with a developmental disability such as Down syndrome? This question has no easy answers, for there is no single, best way to cope with having a child with Down syndrome. The coping behaviors that work best for a family depend on a number of factors including the characteristics of the child, the family, and the community.

For some families the most effective way is through extensive use of an informal support system. This has been the primary source of support for the Robinsons. Of course, they were part of what has been called a "kinship-based help-exchange network."[69] As part of a closely knit group of parents, grandparents, more distant relatives, and family friends, the Robinsons had many sources of informal support available to them. To maintain this support, however, the family had to reciprocate with kin. Carl Robinson's profession was in the building trades. He and the family therefore were able to establish reciprocity with kin through Carl's providing significant amounts of free labor when family members decided to remodel or improve their homes. He also was called often to do emergency fix-up work during his free time, such as to install a new water heater when an old one had broken. The Robinson family, while fortunate to have extensive resources upon which it could draw, nevertheless paid a price for the support it received.

Unlike the Robinsons, Jim and Sally French and their family have not made as much use of their kin network in adapting to having a child with Down syndrome. Part of this difference may stem from the fact that, because Jim's family is not from the area of the county in which the Frenches have been living, the family's kin network is limited to Sally's relatives. For this and probably other reasons, the Frenches have relied extensively on a more formal support network. Sally's job as a teacher equipped her well to network with fellow educators and other professionals. Through one of these contacts the French family first became involved in their county ARC and later an organization for parents of children with Down syndrome. Over the years some of the boundaries between the family's informal and formal support network have disappeared. Individuals who once knew the Frenches on a professional or an organizational basis now are considered friends.

A LOOK BACK AND AHEAD

Much remains to be learned in the realm of family adjustment and adaptation to the presence of a child with Down syndrome. What is known at this point is that no single, "best" way can be recommended for all families to adapt. Just as each child with Down syndrome is an individual and has unique characteristics that set him or her apart from others, so, too, are the families of children with Down syndrome.

The French and Robinson families were both highly successful in adjusting and adapting to children with Down syndrome. One of the reasons is that each developed a style of adaptation that fit the characteristics of the family and its members. Looking at these two families, they obviously differ in many ways. The Robinsons are an African American family living in an urban setting. Carl Robinson works in one of the skilled trades, and his wife, Jean, recently has returned to out-of-home work. Kathy, their daughter with Down syndrome, was the last born of their four children, and both parents were in their 30s at the time of her birth. The Robinsons are a reasonably cohesive family that functions in a structured manner. In adapting to rearing Kathy, the family made great use of an informal kin network to obtain necessary supports and relied upon formal sources of support only when informal bases were not available or sufficient.

The French family, on the other hand, is Caucasian and lives in the suburbs. Jim French is an engineer. His wife, Sally, a teacher, went back to work shortly after their youngest child started school. At the time of Michael's birth, both Jim and Sally were in their early to mid-twenties. The Frenches as a family are flexible and considerably less close-knit than the Robinsons. Although family members obviously care about each other, on any given day the parents and children are likely to be independently "doing their own thing." Leadership and the roles family members play are fluid, with parents and children alike assuming a variety of roles and taking turns in positions of leadership based upon the specific issues at hand. In adapting to rearing a child with Down syndrome, the Frenches, for a variety of reasons, made extensive use of their formal support network and relied little, especially during their son's early years, on support from the extended family.

Despite their differences, the ways in which the French and the Robinson families adapted to rearing children with Down syndrome have much in common. The meanings these families attached to having a child with a disability were neutral or positive. They saw it as a challenge rather than as a catastrophe from which they could not recover. Both families worked hard at developing and maintaining the resources necessary to cope effectively with the demands and strains of rearing a child with Down syndrome. They also showed similarities in their communication styles, which were quite positive and open. Despite some differences in their interaction styles, both families adopted styles that allowed for flexibility and resulted in family members' feeling a sense of caring, love, and support while not having to give up their individuality.

Are the French and Robinson families unusual? Although each family is unique, the adaptation of these two families is not unusual. In the only study available to date that specifically studied the adjustment and adaptation abilities of families with children with Down syndrome, the majority were found to be functioning in a healthy manner with moderate degrees of cohesion and adaptability, had low rates of divorce, reported average to higher than average degrees of marital satisfaction, and had developed what they perceived to be adequate sources of support.[70] These results indicate that neither the French nor the Robinson family was unique but, rather, representative of many families of children with Down syndrome who over time are able to cope, adjust, and adapt successfully.

This isn't to minimize the challenges faced by families with children with Down syndrome. All will encounter many difficulties over the course of a child's and family's development. What these results do suggest is that the potential to meet the challenge is there and, with hard work and a willingness to learn and grow, adaptation is within the grasp of most families.

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