

Developmental
Perspectives
on Children With
High-Incidence
Disabilities



Edited by

Ronald Gallimore
Lucinda P. Bernheimer
Donald L. MacMillan
Deborah L. Speece

4 Family Life Is More Than Managing Crisis: Broadening the Agenda of Research on Families Adapting to Childhood Disability

**Ronald Gallimore
Lucinda P. Bernheimer
Thomas S. Weisner**
University of California, Los Angeles

This chapter reviews efforts to broaden research on families adapting to childhood disability and delay. First, we briefly review and critique the long-standing emphasis in family research on crisis, stress, coping, and the restoration of emotional well-being. Second, to broaden family research to include capacities other than crisis management, we revisit what Rueben Hill (1949) called the “established routines” of family life and what families do to sustain them. Third, we review contemporary research on families adapting to childhood disability for evidence that sustaining a daily routine of life is a function distinguishable from those attendant to crisis and stress. Finally, we examine the intervention and research implications of the idea that an enduring family project is creation and maintenance of a sustainable daily routine of life.

INTRODUCTION

Recent initiatives underscore a needed expansion of the scope and content of research on families adapting to children with special needs. The 1989 legislation (Amendments to the Individual With Disabilities Education Act, or IDEA), mandating development of individual family service plans (IFSPs), codified the idea that families can be recruited as proactive agents in interventions for

children with disabilities (Harbin, 1993). The wording of the legislation refers to "enhancing the capacity of families to meet the special needs" of their children with handicaps (Gallagher, 1989, p. 388). Among other intentions, this wording encouraged professionals to regard families as partners to be empowered as active co-decision-makers rather than as cases to be managed.

These initiatives resonate with many contemporary social trends and are no longer the subject of debate. However, this is an instance of legislation and policy ahead of science, because many family functions remain largely unexamined. One exception is the capacity to manage the demands, strains, and stresses associated with childhood disability (Beresford, 1994b). Many significant contributions have been made in the study of crisis management, including family systems (Olson, Sprenkle, & Russell, 1979), family stress (McCubbin & Patterson, 1983), Patterson's Family Adjustment and Adaptation Response (FAAR) model extended to health issues (1988), and family life-cycle theory (Turnbull, Summers, & Brotherson, 1986). Many of these contributions owe a debt to Rueben Hill's (1949) classic study of family response to war separations in which he presented the ABCX model (A=stressor event; B=family's crisis-meeting resources; C=family's definition of stressor; C interacts with A and B to produce X (crisis)). The ABCX model was based on yet earlier studies of family adaptation to the Great Depression. Preceding adoption by the disability field, other foci of family stress research included effects of alcoholism and bereavement. Thus, the family model borrowed from sociology framed the rearing of a child with disabilities in terms of the stress and reactions attending crisis or disturbance of the family's homeostasis. Many efforts focused on the impact of initial diagnosis and entry into services rather than on daily life. The appeal and value of crisis-centered family theories is understandable, given the demands of childhood disability. The early emphasis on psychopathological reaction (Farber, 1959; Holt, 1958) reflected long-standing trends in social and behavioral research.

The stress/coping focus had many good effects: It helped justify services for parents dealing with childhood disability, documented that these families needed assistance, and called attention to the need for more funding. However, so exclusive a focus on crises, stress, and psychological reactions also perpetuated the notion "that a family with a child who has a disability is a family with a disability" (Glidden, 1995). Many studies focus on how much stress such families face, what they do about it, and how negative or psychopathological the consequences are. One problem, as Glidden (1995) noted, is the failure to distinguish between *demands* and *stressors*. The failure to maintain this distinction is explicitly contrary to the Lazarus and Folkman (1984) formulation, which insisted that demands are experienced differently in different families and environments, and that high demands do not inevitably produce high stress and therefore higher probabilities of negative reactions. Because *demands* are certainly higher in families dealing with childhood disability, failure to distinguish them from stressors "has tended to perpetuate the perception of maladjustment in families rearing children with developmental disabilities" (Lazarus & Folkman, 1984, p. 483). In addition, much of the

research in the area has been carried out by researchers interested in psychological application and it is understandable that they may have focused on psychopathological problems families face in crisis and how professionals can help. Finally, because of the pathological perspective on families, much of the research has been conducted without reference to general research on families in the social sciences. As a result, families of children with disabilities continued to be viewed by implication or by default (if not explicitly) as different, more prone to pathology, and by implication, less competent (Byrne, Cunningham, & Sloper, 1988).

The past decade has seen a call to broaden research perspectives on families of children with disabilities to include adaptation and adjustment. Although there is a continuing interest in family stresses associated with childhood disabilities, there is also increasing recognition that families of children with problems are faced with the same tasks as are families with typically developing children (Barnett & Boyce, 1995; Byrne et al., 1988; Freedman, Litchfield, & Warfield, 1995; Hodapp & Zigler, 1993; Turnbull et al., 1986). All working parents, for example, struggle to balance values/goals, personal needs, work and home responsibilities, and to find and keep affordable child care, health care, and flexible and supportive environments.

The call to broaden research perspectives beyond crisis response comes from many sources. One of the most compelling is from the families of children with disabilities who in recent years have joined the dialogue and in some cases become partners in the search for new perspectives on family capacities. A recent volume included numerous first-person accounts of coping with childhood disabilities, many of which suggested that families are concerned with more than crises and their management (Turnbull et al., 1993). Indeed, many volumes in the personal account genre suggest families dealing with childhood disabilities do not think their lives and functions can be understood solely in terms of periodic crises breaking long paragraphs of everyday living (e.g. Kaufman, 1988). Some parents of children with disabilities have forcefully objected to researcher and practitioner focus on stress and coping (Vohs, 1993). Some suggest that we ask additional questions: "Professionals kept asking me what my 'needs' were. I didn't know what to say. I finally told them, 'Look, I'm not sure what you're talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help'" (remark made by parent panelist at a 1989 HCEEP conference on Parent-Professional Partnerships, reported in Bernheimer, Gallimore, & Kaufman, 1993, p. 267).

Parents such as this mother are talking about concerns beyond the emotional costs of daily demands and strains. They are telling researchers what they do to sustain a daily routine of life that—besides being emotionally tolerable—takes account of other realities and interests they have at stake. These parents are telling us to revisit Hill's ABCX model—a foundation of contemporary family research in the disability field—and remember that he defined stress-producing family crises as "disruptions of *established routines*" (Hansen & Johnson, 1979, p. 584, emphasis added). As some parents and researchers

have suggested, the "established routines" of families and how they are created and sustained have been unwisely treated as background to more dramatic phenomena (Hansen, 1993; Weisner, 1984; Whiting & Edwards, 1988). It is not surprising that dramatic responses associated with crisis/stress/coping capture more attention than do established routines. For everyone, including researchers, "Most of our day-to-day behavior in families is routine: We act in a well established manner, and think about our actions—if we think about them at all—only after the fact" (Hansen, 1988, p. 54).

What some researchers have theorized about creating and sustaining a daily routine as an essential family function has direct relevance to IDEA's challenge regarding family capacities (Hansen, 1993; Weisner, 1984, 1998). Knowing what families do in crisis or how they handle emotional costs of dealing with childhood disability are necessary but not sufficient indicators of their functioning. We also need to conceptualize and research how families construct and sustain unremarkable times—the times of family life between episodes of crises and problems, when there is established routine, balance, homeostasis, and equilibrium. There is more to family life than crises that punctuate long passages of living; sustaining an established daily routine is an achievement worthy of respect and scientific inquiry. If family coping in times of stress is an important family capacity, ability to sustain a daily routine of life that is viable all the rest of the time deserves serious study and recognition. It represents a potentially important indicator of family functioning that is not tied to stress and psychopathological theories and models, and is related to many factors in addition to childhood disabilities. This is the central claim of our chapter. What are the implications of this claim for theory, research, and policy?

A FAMILY PROJECT: CONSTRUCTING A SUSTAINABLE DAILY ROUTINE

All families must construct and maintain a daily routine, but not all daily routines are possible. A sustainable family routine is a compromise among the constraints we must live with, the values we hold, and the characteristics of individual family members. We do not arbitrarily choose when to go to work or shop or cook dinner; it is not irrelevant to deeply held values that families schedule meals so that parents and children are usually present; we do not participate in carpools to get children to special activities or services because we like the incidental social interactions involved in organizing them. Sustaining routines to reconcile many competing factors is an enduring family project, not just an occasional mobilization of coping strategies in response to stress.

Daily routines evolve over time and are neither static, rigid, arbitrary, optimized, nor entirely voluntary. Although routines change, they are not easily altered because the sustainability of the routine is the product of so many trade-offs. Some changes are a consequence of crisis and stress, but many are the reorganizing and fine-tuning of daily and weekly schedules that are familiar to every family. Sustainability rests in part on how congruent a family's routine is with the numerous factors that it must accommodate. When a family

describes its daily routine much more is involved than may be manifest in brief narratives. Like everyday concepts, *patterns* of everyday life are experience-near, transparent, and taken for granted as the way things are and must be. As Geertz (1984) noted, "People use experience-near concepts spontaneously, unselfconsciously ... they do not, except fleetingly and on occasion, recognize that there are any concepts at all. That is what experience-near means—that ideas and the realities they inform are naturally and indissolubly bound up together. What else could you call a hippopotamus? Of course the gods are powerful, why else would we fear them" (p. 125).

Of course, many pieces of our routines are the way they are; how could they be otherwise? Naturally, we do not mention the redundant constraints and multiple purposes our routines reflect. They are both ordinary and transparent, and do not make as good a conversation topic as do more dramatic episodes of our lives. The established routine and its constraints are the ground on which the figure of dramatic events occur. The relative lack of attention to routines is evidence for their power in everyday life, a power so pervasive that it goes without saying. What factors influence the shape and sustainability of the family daily routine?

Factors Affecting Sustainability

Ecological Features. The features of the ecological niche in which a family lives are a powerful constraint on what routines can be sustained. One of the most powerful features, as Whiting and Edwards (1988) documented, is the means by which the family's living is earned. In many parts of the world, daily routines are shaped by how far mothers must travel to fetch water or harvest their subsistence crops. In many societies, the 40-hour work week and the length of the daily commute ripple through a family and child's day, forcing compromises and choices that may be necessary but not always desirable. Whatever else must be accommodated by the family's routine, subsistence activities—whether in wage jobs or otherwise—have influence that places them first among equals. In addition to earning a living, in some environments, health or safety factors greatly influence family routines (e.g., in neighborhoods where children must be protected from violence, racial discrimination, and other urban ills). Transportation and communication required for work or other health, safety, and support requirements are also important features shaping routines. According to cross cultural research, another major factor affecting the organization of a family's routine is the number and complexity of domestic chores, including child care (Whiting & Edwards, 1988; Wishart, Bidder, & Gray, 1981). The reciprocal costs as well as benefits of social support networks also shape routines in many niches (Beresford, 1994b; Kazak & Wilcox, 1984; Trute & Hauch, 1988b; Waisbren, 1980).

Values and Goals. Just as not all routines are possible, not all are acceptable even if possible. To be sustainable, a daily routine must not only be congruent with competing ecological factors, it must also be meaningful enough to

the family that it is honored and defended (Weisner, Beizer, & Stolze, 1991). Thus, parents with strong familistic values will have difficulty sustaining a routine that is driven primarily by the demands of their high-pressure careers. Families of children with disabilities may find it easier to sustain a hectic schedule of transporting the child to a variety of community activities if they have strong "normalization" values. Parents who believe that all children, delayed or not, move through different, largely unrelated "stages" in life each of which is unique and special, may be less likely to sustain a routine directed at long term outcomes reached far in the future. Such cultural goals and moral values for child development and parenting play important roles in how daily routines are lived out in a community, by providing the end points, the purposes for parenting and development, as well as the appropriate scripts for how to achieve those goals (Harkness, Super, & New, 1996). In spite of the importance of parental goals, values, and moral commitments, little empirical work exists on the role played by values and goals in families with special needs children. Studies of meaningfulness have focused largely on religious values, which contribute to sustainability in two ways: by serving as a means of interpreting and giving meaning to the disability (Weisner et al., 1991), and by providing a system of support to help cope with the day-to-day realities of raising a child with problems (Fewell, 1986). It should be noted that religious beliefs can lead to negative as well as positive interpretations of parents' circumstances. For example, parents may evaluate their family circumstances as either punishment or reward, extensions of God's will, or lessons from God (Haworth, Hill, & Glidden, 1996). Religious belief systems are generally regarded as having a positive impact, however, because they provide a valuable interpretive framework (Haworth et al., 1996) and, by implication, contribute to a more sustainable daily routine.

Personal Characteristics. Characteristics of family members are another factor that must be accommodated by the daily routine. For our purposes in this chapter, a good but not only example is the impact of a child's disabilities on the daily routine. Whereas earlier investigators suggested that the impact of the disability varies according to child diagnosis or cognitive level (Cummings, 1976; Holroyd & McArthur, 1976), more contemporary work confirms that it is the burden of care that matters to families (Byrne et al., 1988; McDonald, Couchonnal, & Early, 1996; Quine & Pahl, 1985). Thus, a child with limited independent living skills has the potential to cause more disruption (e.g., major financial expenditures associated with altering the home environment), daily hassles (e.g., complications in daily transportation), and disability-related problems (e.g., finding suitable leisure activities for the child) than does a child with better skills (Wallander, Pitt, & Mellins, 1990). Families adapting to disability often describe in substantial detail the measures they take to accommodate perceived child characteristics in order to sustain a routine (Gallimore, Weisner, Kaufman, & Bernheimer, 1989). Hence, one of the challenges of parents is to create and sustain a routine that balances the inevitably competing

and varied competencies and personal characteristics of family members as well as care of the child with disabilities.

A Sustainable Daily Routine and Other Family Projects

Sustaining a routine over the long haul and managing time-limited crises may be distinguishable projects, but they are always connected in experience. Some changes are initiated by crisis or emotional discomfort, but not all changes in the daily routine (or perhaps even most), are provoked by what is stressful or discomforting. Some are driven by strongly held beliefs about the way life should be lived. For example, Weisner et al. (1991) compared religious and nonreligious families regarding their adaptations to a child with early developmental delays. Although results were mixed for the impact of religion, there was some evidence that religious convictions mobilized noncrisis-related daily routine adjustments that were partly related to incorporating a child with delays into family life.

In other cases, a period of crisis may initiate a long rebuilding of the routine to restore sustainability in response to new circumstances. For example, Gallimore et al. (1989) presented a case of a family who bought a new home, in part to reduce stress on the family caring for two children, one with delays. Purchasing the house required the mother to take employment to pay the mortgage, which led to many other changes (including domestic role arrangements and increased access to child services) that the mother's paycheck also provided. In other cases, changes in the routine are made as small, unnoticed adjustments so mundane and ordinary that only through extended interviewing or observation would they be detected—because the families themselves do not encode them as important adaptations. Examples include a subtle change in dinner schedules, the quiet giving up of career goals by some mothers, or increases in child care by fathers that go unremarked.

As personal experience and stress research suggest (Beresford, 1994a), no family routine is sustainable if it takes too great a toll on any single individual. The disability literature is filled with accounts, for example, of mothers taken to the breaking point trying to sustain a routine that might optimize developmental gains for a child with disabilities (Featherstone, 1981; Kaufman, 1988; Park, 1982). No matter how much is gained in a child's development and safety, in domains of family functioning, or the instantiation of values into everyday life, if the emotional or social costs are too great a routine cannot be sustained.

However, in many instances the emotional and psychological well-being of parents and children are only one set of costs that families take into account. Gallimore et al. (1989) used case studies to illustrate how sustaining a daily routine depends on balancing multiple factors, including emotional well-being. For most of the 93 families followed over more than 10 years, emotional costs were not the pre-eminent factor driving parents' choices and efforts—the sustainability of their daily routine was often the focus of their efforts

(Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Keogh, Bernheimer, Gallimore, & Weisner, in press; Weisner, Matheson, Coots, & Gallimore, 1997). The parents recognized that no matter how tired or stressed they individually or jointly felt at some time, life had to go on, and that often the best way to "feel better" and restore family harmony was a sustainable routine. Although it might not be perfect or optimized for every individual, it was "good enough" and, most important, it could be maintained over the long term. Many spoke of how they would "like it to be," but quickly added that what they were sustaining was as close as they were likely to get to their ideal—give or take a few adjustments here and there.

The daily routine project is often superordinate to emotional well-being, in part because individuals in a family are in conflict over resources, material and otherwise (Weisner, 1984). This is a familiar tension "expressed in the aged Hobbesian problem of a rational order of free individuals: If all pursue their own rational interests, how can order be maintained" (Hansen, 1993, p. 75). If each did, then the sustainability of a family's routine would be put at too great a risk by self-interest.

Several family models subsume the problem of self-interest conflict among individuals within a superordinate family-level process. Systems theory, for example, is based on the hypothesis that there are two central processes of family life: adaptability (communication and role flexibility) and cohesion (emotional bonding of individuals in family; Olson et al., 1979). Such family-level processes help mediate the conflictive potential of self-interest and its disruptive impact. However, to restore smooth function or to sustain it, Olson (1986) also argued that the family must preserve a *familiar sense of order and maintain balance between inevitable interpersonal conflicts* (emphasis added). This comes very close to saying that in addition to mediating conflict that arises among members, strengthening family bonds, and restoring emotional harmony, the family has a superordinate, and enduring project—constructing a *sustainable* daily life in which personal and interfamilial relations can be nurtured and mended. Constructing an emotionally and physically tolerable daily routine that accommodates everyone's needs and concerns, yet is sustainable given their ecological circumstances, is one way to preserve a sense of order and balance individual conflicts.

The theory and definition of adaptation itself leads us to consider ongoing systematic demands, rather than focusing on perturbations of the family's homeostasis. Adaptation is the *diminishing* responsiveness to repeated and continued stimulation (Helson, 1964), not continuous high responsiveness. Its functions are homeostasis and regulation of information. Adaptations enhance the relative ability to survive in a particular niche. Excessive focus on the immediate response to change due to stress, then, misses the deeper activity of adaptation, which is the routinization and balance of the person or family within the everyday routine and environment, not the dramatic changes. But what is the evidence that constructing a sustainable routine is a distinguishable, enduring project for families adapting to childhood disability?

CONTEMPORARY FAMILY LITERATURE: LOCATING THE DAILY ROUTINE

In this section, we review selected literature for evidence that sustaining the daily routine is a family project distinguishable from coping with stress, a project that is described, implicitly or explicitly, by researchers, practitioners, and parents. The review is not confined to the mental retardation and developmental disabilities (MR/DD) field; we have also included publications from psychology, pediatrics, nursing, social welfare, and social work in addition to those from mental retardation. In some of this literature, the daily routine project and the family efforts to sustain it are relegated to the background by the focus on a stress model, or by an emphasis on individual coping. In other literature, the daily routine project is itself the focus, and sustaining it is an end in itself, not just a means of reducing stress or increasing individual well-being. We begin by examining two models of family functioning in households of children with disabilities, both of which refer to periods of balance, homeostasis, or stability: Patterson's FAAR model (Family Adjustment and Adaptation Response) and Turnbull et al.'s (1986) application of family life-cycle theory to disability.

Patterson (Patterson, 1988, 1991, 1995a, 1995b) recognized that crises and their management do not represent a full accounting of adaptation to childhood disability. Whereas a model of stress and coping underlies the FAAR, Patterson focuses on adaptation and adjustment, following Hill's (1949) definition of crises as "disruptions of *established routines*." The FAAR model is constructed around three domains: sources of stress, mediators of stress, and outcomes of stress:

The sources of stress are termed *demands*, and can emerge from individual members, the family unit, or from the community. The mediators of stress are called *capabilities*, and also found in any of these systems. The family attempts to maintain balanced functioning by using capabilities (resources and coping behaviors) to meet demands (stressors, strains, and daily hassles). The meanings the family attributes to their situation (demands and capabilities) are a critical factor in achieving balanced functioning. ... The outcome of the family's efforts to achieve balanced functioning is called *family adjustment* or *family adaptation*. ... Good outcomes are reflected in (1) positive physical and mental health of individual members, (2) optimal role functioning of individual members, and (3) maintenance of a family unit that can accomplish its life cycle tasks. (Patterson, 1995a, p. 50)

One does not have to look any further to recognize that the task of constructing a sustainable routine is central if not featured in Patterson's conception. Family and community-level demands and capabilities are compatible with ecological *resources* and *constraints*; a positive outcome requires a *balance* between demands and capabilities. Family *meanings* serve as facilitators or inhibitors of balanced functioning. Like the sustainable daily routine de-

scribed earlier in this chapter, Patterson's definition of *adjustment* constitutes relatively stable periods during which only minor changes are made in response to the daily demands of life. Patterson comments that during *adjustment* periods the organization of day-to-day family life incorporates the child's disability, but the disability does not become a focal point around which all else revolves (Patterson, 1991). Said differently, the daily routine is not solely child-driven. There is a balance between the needs of the child, the needs of other family members, and, by implication, all the other factors that must be accommodated to achieve a sustainable routine. In the FAAR model, the organization of day-to-day family life is not an end in itself, however. Of greater importance is the positive physical and emotional health of *individual* family members, and the optimal role functioning of *individual* members. Good outcomes are recognized at the level of the individual. At the family-level, the daily routine functions to accomplish its life cycle tasks.

Turnbull et al. (1986) also addressed life-cycle tasks. Applying family life-cycle theory to disability, they noted that families with mentally retarded members must adapt to chronic demands as well as life-cycle transitions. Although these transitions occasion change, discontinuity, and stress, within developmental stages routines are established that contribute to stability—until the next stress-producing transition. An extensive list of "chronic" family functions that Turnbull et al. assembled (generating income, health care and maintenance, food purchasing and preparation, to name a few) is distinguished as much by its applicability to everyday periods of stability and ordinariness as its relevance at times of transition, disruption, and crisis. These "chronic" functions that contribute to stability are not featured as targets of investigation themselves, but instead are viewed as "products or outcomes of family interaction, because they represent the results of interaction in terms of the ability to meet the individual needs of the family members" (Turnbull et al., 1986, p. 51).

Like the Patterson and Turnbull et al. contributions, many studies we reviewed come close but never explicitly explore routine sustainability as a distinguishable family function. Several investigators referenced family efforts to sustain their daily routine in studies of individual and family responses to the stress of parenting a child with disabilities. As example, Bradley, Parette, and VanBierenviet (1995) identified additions to family routines in homes with technology-dependent children: daily battery charging and cleaning, keeping a protected space clean for the ventilation system, and dealing with size/portability of the equipment when transporting the child.

Leyser (1994) conducted a 4-year follow-up interview study of families of children with disabilities and found that significantly fewer mothers in Year 5 than in Year 1 reported that the child had a negative impact on family life. At the same time, there were no differences in mothers' perceptions of the time needed to care for the child, or in perceptions of child behavior problems. In discussing the decreased negative impact, Leyser implicated three factors that have a direct impact on the daily routine's sustainability: subsistence, domestic workload, and support. Fewer mothers at follow-up reported financial hardships, more fathers were in better-paying jobs, and more mothers were in the

work force. Regarding workload and support, more mothers reported weekly and daily contact with grandparents, who provided "help with daily routines, preparation of meals, and respite care" (Leyser, 1994, p. 383). The latter results suggest that focusing on the daily routine project would provide a more satisfying lens through which to examine changes during the 4 years that Leyser et al. followed these families. Additional glimpses of the daily routine project in studies of family stress may be found in Hornby and Seligman (1991); Quine and Pahl (1985); Sloper, Knussen, Turner, and Cunningham (1991); Tunali and Power (1993); and Wallander et al. (1990).

In other studies of positive parent outcomes, a sustainable daily routine can be identified as a background goal. Examples of positive outcomes include satisfaction (Byrne et al., 1988; Sloper & Turner, 1993), improved mental health (Beresford, 1994a; Quine & Pahl, 1985), and positive adaptation (Trute & Hauch, 1988a). In these studies, there is reference to a balance between resources and constraints and values, (e. g. mother and father roles in domestic and childcare task; Trute & Hauch, 1988b), or amount of time a mother has for herself and participation of other family members in household tasks (Byrne et al., 1988). In their study, McDonald et al. (1996) recorded parents' views of major pleasant events in the past year. Glimpses of daily routine concerns were visible in some reports: "C's behavior improved at home. I was able to remain in the car while he went into the local store and made purchases appropriately" (McDonald et al., 1996, p. 506).

Like this quotation from McDonald et al., in the literature cited thus far the daily routine project is treated implicitly and either obscured by the stress model or confounded with improving individual well-being (usually the mother's). In a comprehensive review on coping in families of children with disabilities, Beresford (1994b) examined research findings using the process model of coping (Lazarus & Folkman, 1984) as a theoretical ground. In this model, Beresford made a distinction between two kinds of coping resources: personal and socioecological. A close look at Beresford's description of socioecological resources reveals evidence of families working to sustain their routines (e.g., the marital relationship, social network, functional resources, and economic circumstances). However, in the studies reviewed these socioecological resources were evaluated for their instrumental contributions to coping with stress and restoring well-being.

The literature reviewed by Beresford extended also to the means by which families achieve a sustainable daily routine. For example, Quine and Pahl (1985) reported that many of the mothers of severely handicapped children in their interview study were sleep deprived because their children woke frequently at night. They noted that some mothers found the only solution was to sleep with the child so as to be able to attend to his or her needs without disturbing other family members. The implication is that as costly as this solution was to the mother, it was more costly to have the entire family's sleep disturbed. In a later study Quine and Pahl (1991) found a significant correlation between financial resources and lower maternal stress. Beresford's comment on this finding seems to acknowledge the impact of making a daily routine

more sustainable, although the implications are filtered through focus on stress-induced emotional costs: "Money can buy practical resources such as child-minding, laundry equipment, and cleaning services, thus relieving parents of certain care and household tasks" (p. 189). That the routine might be made more sustainable was not noted as an explicit end in itself.

In summarizing an ethnographic study by Bregman (1980), Beresford clearly implicated sustainability of the daily routine as a family outcome worthy of consideration. The data were obtained by Bregman, who spent several days with each of six families whose child had a progressive neuromuscular disease. Beresford (1994b) described this study as a "fascinating, and perhaps unique" (p. 192) account of coping strategies:

First, the families adopted a "take each day as it comes" philosophy and focused on the present. This was reflected in the ways their lives were organized. Daily activities were planned and completed. The children experienced interesting and exciting activities while they were still able to enjoy them. The families avoided pre-empting a need, preferring to deal with it when it actually arose. Second, parents aimed to maintain a lifestyle that was as normal as possible. Various strategies were used to attain this goal, including modifying clothing so the child could dress him or herself, and ensuring the child maintained social contacts with healthy children. ... Third, the parents sought to minimize their family's vulnerability by reducing the risk of crises. This was done by keeping well informed, seeking out the best options for the child's health care and education, trouble-shooting, and monitoring the standard of services. Finally, Bregman noted that an important aspect of parental coping was to maintain and develop coping resources. Parents developed and capitalized their personal strengths. They believed they were caring for their children well and acknowledged their successes. Coping with the emotional strains of care included recreation and releasing emotions by crying. In addition, the parents drew on informal and formal support networks, including financial, emotional, and practical support. (Beresford, 1994b, pp. 192-193)

In Bregman's work, the treatment of the daily routine project is more explicit. There are references to meaningfulness, in the parents' goal of maintaining a normal lifestyle, and in the parents' beliefs that they were providing quality care to their children. We can also see evidence of congruence, in terms of the parents planning activities that their ill children could still enjoy, while using recreation and support to meet their own needs. Although Bregman's study is explicitly concerned with coping strategies, the focus on adaptation at the family level revealed snapshots of their everyday life. She brought explicitly into focus not only the central importance to families of constructing sustainable routines, but also some of the actions they took to sustain them.

Bregman's work suggested that one capacity of families worthy of investigation is their efforts to incorporate a child with disabilities into the families' routines. Such efforts would have to take account not only the child's needs and

the emotional well-being of parents, but all the other factors that affect routine sustainability. In a longitudinal study that inquired directly about family effort to construct sustainable routines, these efforts were defined as *accommodations* (Gallimore et al., 1989; Gallimore, Goldenberg, & Weisner, 1993; Gallimore, Weisner, Guthrie, Bernheimer, & Nihira, 1993; Keogh et al., *in press*; Weisner et al., 1997). In this study, family accommodations were presumed to occur in response to both serious concerns and mundane problems of daily life.

Using an ecocultural model as a framework (Weisner, 1984), in-depth interviews gave parents an extended opportunity to describe their daily routines and what they did to achieve sustainability, including the kind and intensity of accommodations made in response to the child with delays. Asking parents directly produced a wealth of reports about efforts made to sustain their daily routines. Using a rating system checked for reliability by independent, blind coders, each family was assessed for number and intensity of accommodations made at three child ages. From preschool to late childhood, 93 families reported a substantial, statistically significant increase in the number of accommodations made: 749, 891, and 1,388 at ages 3, 7, and 11, respectively. Ratings of intensity, or how much effort families put into their accommodations on the other hand, showed little change over the same period (Gallimore et al., 1996). Accommodations were reported by parents in 10 different ecological and cultural domains, including those pertaining to health and safety, family subsistence, domestic chores, and social and emotional relationships. Most of the accommodations reported have parallels in Beresford's (1994a) "socio-ecological coping resources" of social support, support from spouse, extended family, and formal agencies, marital status, and socio-economic circumstances. In addition, they were similar in many respects with those reported by other researchers, for example Sloper and Turner's (1993) study of physically disabled children and their families. Sloper and Turner suggested that parent resources and coping strategies include material resources, employment, housing, social and family resources, social networks and support systems, family environment, and marital relationship; as well as psychological resources such as personality, control orientation and problem-solving and help-seeking skills and strategies. Although many of these coping resources no doubt serve to secure or restore emotional well-being, they are also plausibly used to sustain a daily routine.

Although much remains to be explored, available literature (and every reader's own everyday experience) provides some support for our contention that sustaining a daily routine is a major family function. Often treated as given, once featured it is relatively easy to find hints and hard signs in the research literature that it is a family function distinguishable from crisis response and management functions. It is a candidate for the broadened agenda that the research community has been challenged to develop, an agenda that includes the positive as well as the psychopathological forms of family adaptation to developmental disabilities. How the sustainable routine project might

aid intervention planning, and what more we need to learn about it are the subjects of the next section.

INTERVENTION AND RESEARCH IMPLICATIONS

Intervention Issues

Legislated changes and increased awareness of the importance of families in the lives of children with disabilities have had a significant impact on clinical practice (Bailey & Simeonsson, 1988; Guralnick, 1989; Krauss & Jacobs, 1990). The change in emphasis from child to family is epitomized in the shift from Individual Education Programs (IEPs) to Individual Family Service Plans (IFSPs). Desired outcomes of intervention programs, once conceptualized solely in terms of child characteristics, now include parent empowerment (Dunst, Trivette, & Deal, 1988; Johnson, McGonigle, & Kaufmann, 1989), and parent satisfaction (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; McWilliam et al., 1995). The traditional interpretation that a child with problems means a family with problems has received serious and healthy challenge (Dyson, 1993; Glidden, 1993; Innocenti, Huh, & Boyce, 1992; Mahoney, O'Sullivan, & Robinson, 1992; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). From these and other sources, professionals are now urged to recognize and build on family capacities in order to design interventions that will best meet the needs of the child in the context of the family.

Not surprisingly, the shift to family-focused intervention has encountered some difficulties. Many IFSP plans fail to be fully implemented or sustained by parents (Meyer & Bailey, 1993). Clinicians frequently complain that parents do not follow through on what seem to be well-thought-out intervention plans. Bernheimer and Keogh (1995) observed that the gap between professional advice and parental practice is common and gives pause—why aren't well-designed plans always implemented and sustained? One possibility is suggested in preceding sections of this chapter—family-focused interventions may not always be consistent with, and embedded in, the everyday routines of family life. This possibility is clearly indicated in recent literature emphasizing the importance to parents of professionals who “consider unique family environments and routines” (Brotherson & Goldstein, 1992, p. 519; see also Affleck & Tennen, 1993; Bosch, 1996; Herman, Marcenko, & Hazel, 1996).

There is also some indication that attention to a family's daily routine increases the likelihood that more precise treatment plans will be developed. Reflecting on the lack of an empirical rationale for services to children with severe disabilities, Quine and Pahl (1985) described these services as a “mixture of expediency, idealism, and consumer demand” (p. 501). They advocated translating detailed research about the everyday challenges faced by parents into services, noting that such an approach is important in terms of deciding what services should be provided, and which families should be given priority if services are limited.

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The issue then becomes the most effective (and least intrusive) way to identify problems with and challenges to intervention plans. Byrne et al. (1988) stressed the importance of not simply asking parents if there are problems and accepting their replies at face value. Rather, parents should be given time to think about how things really are, and should be asked specific questions in order to help them do this. The aim is “not to discover a problem come what may, but to obtain a valid picture” (p. 53). When parents describe their daily lives, they are providing professionals with a picture of something that implicates intervention planning. Assessments that precede intervention planning must address a wide range of characteristics describing family functioning, including what the daily routine represents and what it reflects.

Finding, Adapting, and Creating “Slots” for Intervention in the Daily Routine

Where is that fifteen minutes [to carry out the intervention plan] going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Because there is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that is added, one has to be taken away. (Featherstone, 1981, p. 78)

As Featherstone suggested, finding a place in a family's routine for something new, such as changes that might be involved in an intervention, nearly always requires trade-offs. Whether the child comes to a center or clinic for treatment, or the professional visits the home, the family's daily routine must accommodate the intervention. To get to services, the child must be transported by somebody, usually a parent who may have to adjust and alter his or her schedule. A schedule alteration may require the assistance of others, such as a neighbor or relative who will supervise the other siblings in the family, or an employer who agrees to flexible work hours. The family that implements a plan at home must make parallel accommodations. Some time, place, and person must be found in the daily routine to do the treatment that has been planned. Said differently, there must be a “slot” in the daily routine to which the intervention can be “fitted.”

If all that is involved is finding a slot, then little more is entailed than a common sense appraisal of whether an intervention can be carried out by the family. But if a slot has to be adapted or created, in many instances the daily routine must be more thoroughly examined to determine what the family is already trying to do. Despite its ordinary and mundane nature, the daily routine of family life is an arena in which parents seek and in fact have some control. Many families use what control they have over their routine to achieve the kind of daily life they desire within the constraints under which they live. Thus, the sustainable daily routine that a clinician sees or has described by the parents is fitted not only to material factors such as income and work hours, but also to

the values and goals of the family. Changing that routine or adapting it to accommodate an intervention may be far more difficult, and have more rippling effects than might at first seem likely. Consider this case reported by Bernheimer, Gallimore, and Weisner (1990):

Todd was one of four children. His parents ran a mom and pop grocery store, and placed a high premium on quality family time, although it was difficult getting everyone together. One daily period of togetherness was the dinner hour. Because Todd was very withdrawn socially, the intervenor felt the dinner hour would be an excellent opportunity for intensive family input for Todd. The parents were initially enthusiastic, because the intended outcome—a more socially appropriate Todd—would enhance the quality of “family time.” The unintended outcome was quite different, however. In addition to being socially withdrawn, Todd was very disruptive; throwing his food on the floor, leaving his seat and running around the table in circles. Thus “family time” became chaotic and stressful. The parents designed a new intervention: Todd was fed early, and during dinner, he was seated in front of the television to watch tapes of “Sesame Street,” an activity he would stay with for a good half hour. The family dinner was salvaged as “quality time” for the other members of the family, while Todd was engaged in an age-appropriate activity [REACH, Case 401]. (p. 229)

Neither the clinicians nor parents fully realized when they designed this intervention that the daily routine followed by the family was not only fitted to work schedules, but to strongly held values. Their evolved, multiply determined routine balanced many considerations, so that attempts to change it tampered with considerations that the parents did not always fully appreciate were at stake. The intervention could not be continued as planned because it threatened the sustainability of their routine that, in the end, they wished to defend.

Does knowledge about the daily routine ensure that professional interventions will be successfully implemented in all families? Clearly, no, some families faced with overwhelming external pressures will always challenge the professionals who plan interventions. The daily routine in these families is likely to be composed of activities that seem unrelated to the child (e.g., keeping up with the rent, making food stamps stretch until the end of the month, coping with substance abuse). Yet making “a sensitive examination of the ... context ... that receives an intervention” (Gallimore, Goldenberg, & Weisner, 1993, p. 553) should help practitioners understand what needs to happen in order for an intervention to be implemented. It should also prevent practitioners from introducing additional stress to a multiply challenged family.

Currently, there is no consensus about how best to assess the family context that receives an intervention. Although assessment of the daily routine represents a promising approach conceptually, a long operational road lies ahead in terms of developing procedures that complement existing measures of stress and coping. Time use and diary measures, or time allocation methods, are available, but have not been used for this purpose to our knowledge,

and may be too clock-based and difficult for parents to complete (Gross, 1984; Juster & Stafford, 1985). Global ratings of daily routine sustainability have been reliably obtained (Weisner et al., 1997) as have ratings of family accommodations (Gallimore et al., 1989, 1993, 1996). However, these ratings have so far been used only in research, and remain unexamined as tools of intervention assessment.

Examining a family's efforts to shape their daily routines offers a window into one form of functional instrumentality that resonates with legislative calls to “strengthen family capacity.” However, “enhancing the capacity of families to meet the special needs” of their children (Gallagher, 1989, p. 388) by attending to the daily routine requires clinicians to recognize that families are already doing something. It requires listening more closely to parents' accounts and concerns, and what they do to sustain their routines. Listening means probing and understanding the complex balancing of ecological constraints, values, and individual characteristics that are encoded into the accommodations that sustain the family's daily routine. By knowing the accommodations a family makes, and the many factors that are balanced by them, parents and clinicians can jointly construct “successful interventions...that can be woven back into the daily routine. They are the threads that provide professionals with the tools to reinforce, rather than fray, the fabric of everyday life” (Bernheimer & Keogh, 1995, p. 430).

Implications for Research

In the past several years, a growing chorus of investigators have noted that there are families of children with disabilities who are managing very well (Bernheimer & Keogh, 1995; Byrne et al., 1988; Hanson & Hanline, 1990; Keogh et al., in press; Trivette, Dunst, Deal, Hammer, & Probst, 1990). As the shift to family-focused interventions has challenged practitioners to chart new territories, so has the shift to family adaptation and adjustment challenged researchers to ask new questions. Increasing numbers of investigators have replaced the question “How sick are these families?” with the question “How healthy are these families?” Family outcomes of stress, marital discord, maladjustment, and malaise are being replaced by outcomes of adaptation, satisfaction, marital harmony, and positive adjustment.

Ironically, this second generation of research is plagued by many of the same issues that were identified for the preceding one. Summers (1988) observed that positive family outcomes are defined as generally as are negative family outcomes. Broad constructs are used (e.g., acceptance, adjustment, adaptation), and various investigators define these constructs differently. The benefit of a focus on family strengths rather than pathologies is clear; but the continued focus on responses to stress due to the child with disabilities, even if now focused on the positive end of the continuum of family responses, has many of the same problems as the earlier work.

A second issue noted by Summers is the need to consider multiple impacts of a child with disabilities on the family. She noted that even a “clean” stress

(or adaptation) measure will not provide a comprehensive picture of the impact of a disability on families. A family might be adapting through the use of one coping strategy or another, but also failing to accomplish some essential task. Perhaps there is very little parental time available for siblings or, perhaps, family life revolves around the child with problems to the extent that parents have little time for their own relationship. Summers advocates developing measures that define several domains of family functioning and evaluating the degree to which each family member feels his or her needs are being met in each area.

A third issue is related to the question being asked with increasing frequency: "Why is it that some families appear to be doing better than others?" Although several investigators have measured the relation between factors such as child characteristics, perceptions of family life, or family structure variables and the well-being of family members, few have examined the processes through which these factors may influence family functioning (Harris & McHale, 1989; Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992; Reddon, McDonald, & Kysela, 1992). For example, a mother's education is often strongly correlated with her children's cognitive development, although many studies leave unexamined the mediating mechanisms between the static and developmental variables.

In our view, research on the daily routine and associated family functions responds to these three issues. First, a new positive outcome can be defined and operationalized as a sustainable daily routine that measures the effective fit among resources, goals, and competing individual interests in the family's social ecology. In presenting this point of view, Weisner et al. (1997) argued that assessing routine sustainability opens new lines of investigation that complement the historic focus on crisis and stress. By not confounding family and individual outcomes, this approach does not assume that successful family outcomes necessarily converge with best or optimal outcomes for any single individual. Rather, this approach explicitly defines a "good family outcome" as one that sustains all members in a routine that creates and supports resilient responses to threat and challenge (Lancaster & Lancaster, 1983).

Second, the issue of multiple impacts is addressed by the fact that family accommodations that maintain a daily routine are distributed across 10 different ecological and cultural domains (Gallimore et al., 1989; Weisner, 1984). Thus, it is possible to identify multiple domains affected by a child with disabilities and thereby obtain a more differentiated assessment of child impact on family functioning. At the same time, the pattern of family accommodations illuminates the processes through which child characteristics or family structure influence family functioning. Support for this notion is found in the work of Boyce, Jensen, James, and Peacock (1983), whose research with families of children with respiratory illnesses demonstrated that family routines constitute an important moderator in the general relationship between stress and illness. They concluded that "family routines appear to be both a rich source of information about an individual family and a sensitive indicator of similarities and differences among families" (p. 194). Thus, it might be possible to identify

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characteristic patterns of accommodation that differentiate families adapting to distinctly different kinds of disabilities—a prediction that depends on a parallel impact on the daily routine.

The third point concerns the relationship between child characteristics and family functioning. A main impetus for the shift to family-focused interventions was the acknowledgment of families as a context for early child development. It seems ironic, then, that the bulk of family research casts child characteristics (e.g., IQ, specific diagnosis, severity of the disability) as independent variables, and family status or functioning (e.g., stress level or marital satisfaction) as dependent variables. When the research question concerns the impact of the family on the child, measures of family stress and satisfaction and other characteristics are not sufficient: We need to identify how those relatively global characteristics affect the everyday routine of development-sensitive activities that influence the child. For example, Baldwin, Baldwin, and Cole's (1990) study of stress-resistant families and children showed that "proximal and distal risk variables differ from one another in the degree to which they directly impinge on the child" (pp. 257), and, we would add, on the family. A major mediator of impingement, according to cross-cultural studies, is the way families organize children's daily lives, who they are with, what they are doing, and the meaning attributed to it by those involved (Weisner, *in press*).

Final Thoughts on Broadening the Research Agenda

Although well-being is often thought of as a psychological state, there is a sociocultural parallel: competence and engagement in established daily routines and activities (Weisner, 1984; Weisner et al., 1997). Well-being is enhanced through participation in sustainable routines, in addition to whatever enhanced well-being comes from specific kinds of interactions, work roles of parents, stimulation in the home, and so forth. A sociocentric conception of well-being is better fitted to the everyday achievement of families in creating a routine, than are individualistic, psychological conceptions of happiness or coping skills. There is robust evidence that sustaining a daily routine is an enduring and valued project for families in all cultures—a project with major impact on child development in addition to well-being (Weisner, 1984; Weisner et al., 1997). Broadening the research agenda to focus on this sociocultural family project is one way to meet the challenge to enhance the adaptive capacity of families of children with handicaps (Gallagher, 1989).

Finally, some research approaches make implicit assumptions about what constitutes "good or better" families and family life. Some of these assumptions are as unexamined as the ones held in our culture about the ideal family of two parents and a few children living in separate households with distanced kin relations. Sometime in the past, unacknowledged cultural models shaped investigations, so that variations in family structure and lifestyle were defined as deviations (Keogh et al., *in press*). Happily, the growing appreciation of diversity in our society has raised awareness that families come in varying forms, sizes, and styles. In disability research, there has been a parallel challenging of implicit

assumptions: Many now question whether managing crises and coping with stress are the only useful lens for studying families rearing children with disabilities, just as many question the overemphasis on decontextualized cognitive and verbal assessments as the central outcome for assessing individual child competencies. Parents, policymakers, practitioners, and researchers have begun to insist that other family matters be added to the investigative agenda. Vohs, a single parent of a child with developmental disabilities, voiced this insistence as well as anyone: "To me, [coping] has always connoted a sense of putting up with, or enduring, an undesirable situation. I personally decided many years ago that the possibility of a life gauged against a standard of coping as the highest value did not inspire me" (Vohs, 1993, p. 51).

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