Child and Family Outcomes Over Time: A Longitudinal Perspective on Developmental Delays

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BACKGROUND AND INTRODUCTION

This chapter is focused on outcomes for children with developmental delays and their families. Children with developmental delays identified in the preschool years present unique problems, as they often do not fit the usual diagnostic categories. The delays may be expressed as generalized slowness in reaching expected milestones, or by delays in specific areas, such as language or motor skills. Despite uncertainties about etiology and diagnosis, and the heterogeneity of problems identified by the term, there is increasing support for the category as a justification for providing early services for young children and families (Bernheimer, Keogh, & Coote, 1993; McLean, Smith, McCormick, Shakel, & McEvoy, 1991). It is clear, too, that families of children with developmental delays, as well as the children themselves, may benefit from services and support. Indeed, parents with children who have nonspecific delays face particular and sometimes excessive demands, including coping with the ambiguities and uncertainties of the children’s conditions and futures.

Based on our work in Project CHILD, a 10-year longitudinal study of young children with developmental delays and their families, we argue that both children and families must be considered as meaningful units of analysis when assessing outcomes. We suggest further that outcomes for both children and families must be differentiated to address a range of conditions and problems and that time and setting effects must be taken into account.
our approach we have relied on theory and findings from different disciplines and professional perspectives, including the burgeoning research about risk and resilience, which has identified a number of child, family, and contextual conditions associated with different developmental outcomes for children (see Masten, Best, & Garmezy, 1990; Pianta, Egeland, & Sroufe, 1990; Rutter, 1990; Werner & Smith, 1989, 1992). Understandably, the focus in most developmental studies has been on the characteristics of children, and the literature on risk provides a solid basis for defining child outcomes. Less is known about the range of outcomes for families. While proximal and distal family characteristics have been investigated as contributors to children’s development (Baldwin, Baldwin, & Cole, 1990; Caldwell & Bradley, 1994), family status and adaptive conditions have seldom been studied as outcomes themselves. How families function in response to a child with problems is critical to our understanding of developmental delay over time and, thus, deserves to be a major component in the study of outcomes.

Reactive-Stress Models of Family Adjustment

Historically, family adjustment to children with delays has been considered within a reactive, mental health model. A large literature suggests that families with children with developmental problems experience high levels of stress and family disruption (Boyce & Barnett, 1993; Hampson, Hulgar, Beavers, & Beavers, 1988; Longo & Bond, 1984; Minnes, 1988). Researchers have described the negative impact of a disabled child on the family, citing higher than expected rates of maternal depression (Carr, 1988; Trute, 1995), marital problems (Gabel, McDowell, & Cerreto, 1983) and sibling problems (Gath, 1973). A common generalization is that a problem child equates to a problem family.

A smaller, but growing, body of work questions this model of expected impairment (Boyce & Barnett, 1993), as well as the association between increased parental stress and family maladjustment or dysfunction (Dyson, 1991; Glidden, 1993; Hanson & Hanline, 1990; Sloper, Knussen, Turner, & Cunningham, 1991). In an effort to capture the variation among families of children with disabilities, researchers have turned their attention to more positive aspects of family life. For example, a number of investigators have examined social support networks that help sustain families by alleviating some of the demands involved in meeting the daily needs of children with disabilities (Dunst, Trivette, & Cross, 1986), and/or by providing general support that has positive psychological benefits for parents (Beresford, 1994; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). With the exception of findings relating to stress, however, the specific effects of a delayed child on family functioning are seldom delineated, obscuring the interactions over time between child outcomes and family outcomes.

13. A LONGITUDINAL PERSPECTIVE ON DEVELOPMENTAL DELAYS

Without dismissing the added demands and potential stresses that a child with developmental problems poses for parents and siblings, we suggest that the stress model is inadequate for understanding family functioning and the effects on children. Baldwin et al. (1990) pointed out that “... proximal and distal risk variables differ from one another in the degree to which they directly impinge upon the child” (p. 257). In their study of stress-resistant families and children, they emphasized that distal variables (e.g., social class) are mediated by proximal variables that reflect a wide range of individual differences. The challenge is to identify the functional influences represented by proximal variables that operate within families. Thus, we propose an approach to the study of families and children with disabilities that emphasizes the adjustments and adaptations that make up the daily routines of family life.

A Proactive Approach to Family Functioning

Our thinking is consistent with contemporary views that treat families as proactive agents, not hapless victims of implacable social and economic forces. Families do not merely have an ecology and a routine of daily life. Rather, they actively create their family ecology and routines, taking into account many pressures including the particular needs and demands of a child with problems. Through their management of everyday life families can affect the impact of their ecocultural circumstances on children’s activities and development. To do so, they use whatever resources they have to arrange their daily lives, a process guided by their values and limited by ecological and other constraints, including economic considerations. From a mix of constraints, resources, and values, families attempt to construct a sustainable everyday routine (Weisner, Matheson, Bernheimer, & Gallimore, 1994). In our model, the adjustments families make to sustain the daily routine are called accommodations (Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

Accommodation is defined as a family’s functional responses or adaptations to the demands of daily life with a child with delays. Family accommodation is presumed to occur in response to both serious concerns and mundane problems of daily life, and does not require individual or family stress to be activated. There is no presumption that accommodation is intentional, that families are conscious of their activities, or that they see themselves as dramatically different or special. We emphasize that this approach to family functioning is not limited to families with children with developmental problems. All families construct daily routines, some of which appear to be orderly, and others somewhat haphazard or even chaotic. The daily routine captures the common stuff of family life, and is an expression of how families organize their lives, of what is done and what is not done (Bernheimer & Keogh, 1995). The content of the daily routine reflects the nature of the accommodations made in order to ensure some continuity of
everyday family life and reflects both the cultural code and the family code as proposed by Sameroff (1994).

Every accommodation is presumed to have costs as well as benefits to each individual in the family, and to the family as a whole. To illustrate, intense and daily language therapy may improve a delayed child's speech, but may intrude on parents' time with siblings. Such an accommodation could be judged positive for the child, but both positive and negative for the parents or siblings. Developing and maintaining a workable daily routine of family life depends on parents making accommodations to sometimes-competing pressures, such as getting a child to inconveniently located or scheduled services when both parents work fulltime, distributing care of a child who requires constant monitoring, or balancing needs of a child with behavior problems against religious or social obligations. Accommodation is not assumed to be positive or negative in its effects on the family or child because the valence of an accommodation must be determined by its correlation with other variables. The goodness of accommodations depends on long-term outcomes for parents and siblings, as well as for children with delays.

In our work about family accommodations to childhood disability we have documented accommodations in ten different ecological and cultural domains, including those pertaining to health and safety, family subsistence, domestic chores, and social and emotional relationships. The accommodation domains are listed in Table 13.1. (More detailed descriptions of these domains may be found in Gallimore, Weisner, Berneheimer, Nihira, & Guthrie, 1993; Weisner, 1984.) As example of an accommodation, to incorporate a long commute to a special-needs program into a family routine, a mother might cut her paid work to part time but strike a deal with her employer to maintain a valued career path. The father might arrange to leave his job early to pick up a sibling from day care. Each of these functional tradeoffs and adjustments represents a family accommodation to childhood disability (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996).

The accommodations identified in our work in Project CHILD are consistent with findings from other researchers who have studied families' functional responses to children with problems. Based on their work with physically disabled children and their families, Sloper and Turner (1993) 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; and psychological resources such as personality, control orientation and problem-solving, and help-seeking skills and strategies. In a comprehensive review of relevant literature, Beresford (1994) identified socioecological coping resources, which included social support, support from spouse, support from extended family and formal agencies, marital status, socioeconomic circumstances, and the family environment.

### TABLE 13.1
Accommodation Domains and Examples

<table>
<thead>
<tr>
<th>Domain</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Family Subsistence</td>
<td>Hours worked; flexibility of work schedule; adequacy of financial resources; amount of coverage provided by medical insurance</td>
</tr>
<tr>
<td>Services</td>
<td>Availability of services; eligibility for services; sources of transportation; amount of parent involvement required</td>
</tr>
<tr>
<td>Home/Neighborhood Safety and Convenience</td>
<td>Safety and accessibility of play area; alterations in home (installation of locks, fences related to safety concerns); choice of particular neighborhood</td>
</tr>
<tr>
<td>Domestic Workload</td>
<td>Amount of work which needs to be done; persons available to do it; amount of time spent by different family members</td>
</tr>
<tr>
<td>Child Care Tasks</td>
<td>Complexity of child care tasks; presence of extraordinary child care demands (medical problems, behavior problems); number and availability of caregivers</td>
</tr>
<tr>
<td>Child Peer Groups</td>
<td>Child's play groups (children with disabilities vs. typically developing children); amount of parent supervision needed; role of siblings as playmates</td>
</tr>
<tr>
<td>Marital Roles</td>
<td>Amount of shared decision making regarding child with delays; degree to which child care and household tasks are shared</td>
</tr>
<tr>
<td>Instrumental/Emotional Support</td>
<td>Availability and use of formal (church, parent groups) and informal (friends, relatives) sources of support; costs of using support</td>
</tr>
<tr>
<td>Father/Spouse Role</td>
<td>Amount of involvement with child with delays; amount of emotional support provided</td>
</tr>
<tr>
<td>Parent Information</td>
<td>Reliance on professional vs. nonprofessional sources of information; amount of time and effort spent accessing information</td>
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Thus, there is increasing consensus that a range of phenomena must be considered in assessing and understanding the proactive role of families in the lives of children with developmental problems. One such phenomenon is the set of functional accommodations and adjustments needed to sustain everyday family life. We argue that researching and assessing these accommodations contributes to planning and implementing interventions which are appropriate and sustainable, as well as increases theoretical understanding of the developmental paths of children and families. We illustrate this with selected findings from Project CHILD. In this chapter we will describe outcomes for children and families when the children were 11 years of age. We recognize that outcome is a relative marker because outcomes may be defined at different times and operationalized in a variety of ways.
In this chapter we consider outcomes when the children with delays were nearing the transition from childhood to adolescence.

FINDINGS FROM PROJECT CHILD

As part of Project CHILD we have followed a group of 103 children with nonspecific delays from age 3 to age 11, documenting both child characteristics and family adaptations over time. Children were assessed with standard developmental and cognitive measures at modal ages 3, 7, and 11; parents and teachers provided ratings of social, behavioral, and personal competencies and problems at comparable time intervals. Using an ecocultural model as a framework (Weisner, 1984), in-depth interviews with parents provided detailed information about family status over time, including the kind and intensity of accommodations and adjustments made in response to the child with delays.

Outcomes for Children

The children in our study were identified in their preschool years by pediatricians, teachers, regional center professionals, and parents, or combinations of these groups, as having mild to moderate nonspecific developmental delays. The children were all Euro-American from English-speaking, primarily middle-class families. Children with indications of profound retardation, sensory impairments, or those with known etiologies (e.g., genetic syndromes, maternal drug or alcohol abuse) were not included. The children presented puzzling and ambiguous pictures, and their problems frequently did not match the criteria for established diagnostic categories; treatment implications were often unclear. The developmental profiles based on standard assessment techniques were often uneven, and the children's behavior was inconsistent. Yet, in the preschool years, both parents and professionals recognized that something was amiss, and that the children's behavior and development were not right.

The research literature about developmental delays suggests consistently that early signs of delay are associated with subsequent cognitive status, and cognitive level is clearly an outcome of importance. Correlation coefficients between DQ and IQ at different times ranging from .74 to .81 have been reported by investigators from various research groups (Bernheimer & Keogh, 1988; Goodman, 1977; Stavrou, 1990; Truscott, Narrett, & Smith, 1994; VanderVeer & Schweid, 1974). Based on group data, there is also evidence that children with delays have more behavioral, social, and educational problems than do their normally developing peers (Keogh, Bernheimer, Haney, & Daley, 1989; Thompson, 1986). Importantly, however, there is evidence of considerable within-group variability or change in the status of individual children over time, some children improving in cognitive status, others showing decline over time (Stavrou, 1990; Truscott et al., 1994). Furthermore, there are wide differences in social or behavioral competencies and problems, differences that may, in part at least, be related to context or setting, and to the nature, timing, and intensity of interventions. These findings have implications for both research and clinical practice, and for the assessment of outcomes.

Data gathered when the children were age 11 included information from individually administered measures and tests and from parents' and teachers' responses to standardized and Project-developed scales. We tapped a range of developmental and behavioral domains derived in part from the school competence model proposed and tested by Masten, Garmezy, and their colleagues at the University of Minnesota (Masten et al., 1990). Domains assessed included: Health and Physical Growth; Independence-Autonomy; Cognition-Education; Conduct-Behavior; and Social Adjustment. Our findings confirmed that as a group the children continued to evidence cognitive delay. DQ-IQ means and standard deviations were 72.22 (15.34) at entry age 3, and 66.13 (20.37) at follow-up. Examination of within-group variations in cognitive scores over time indicated that almost 40% of the children changed at least one standard deviation from ages 3 to 11; the direction of change was predominantly one of decline. A random coefficient regression technique identified stable differences in rate of cognitive decline over the 8-year period (Keogh, Bernheimer, & Guthrie, 1997). Girls with delays of unknown etiology had the most stable cognitive scores, boys with evidence of perinatal stress had the least stable scores (Keogh & Bernheimer, 1995). Consistent with the cognitive findings, the majority of our children required special education services in elementary school (Keogh, Coots, & Bernheimer, 1995).

Adults' ratings of children's social-behavioral problems and competencies at age 11 confirmed that the children as a group had higher rates of problems when compared to normative expectations, based on nondelayed peers (Keogh & Bernheimer, 1996). However, at age 11 the strength of agreement between parents' and teachers' ratings varied according to the domain assessed. Where significant differences occurred, teachers tended to rate the children more favorably than did their parents. There were few differences in parents' ratings of boys and girls. On the majority of measures teachers rated boys as having higher problem scores and lower competence scores than girls. Parents' ratings were more highly correlated with children's cognitive scores for girls than for boys, but teachers' ratings of children's conduct were significantly associated with IQ for both.

As a whole, our findings are consistent with earlier literature about cognitive and personal-social outcomes for children with developmental delays,
suggesting that early signs of developmental problems are reasonable predictors of subsequent problem status. We emphasize, however, that examination of patterns over time confirmed considerable variation among individual children in the degree and rate of cognitive change, and in their social-behavioral problems and competencies. Cognitive status did not necessarily predict personal social competence, and problems in one personal domain did not always generalize to problems in general. There were differences related to time, setting, and observers, suggesting the need to assess outcomes in different settings using a variety of techniques and at different times. Based on our findings, we underscore the importance of including a range of child attributes when assessing outcomes for children, especially when outcome data are used as the basis for placement and intervention decisions or for evaluating intervention effects.

Outcomes for Families

We proposed earlier in this chapter that families proactively accommodate to the needs of their members, including, but not limited to, a child with disabilities, and that these accommodations are reflected in the daily routine of the family. We suggest further that what families do to sustain the daily routine will often be only loosely coupled with outcomes for individual children, as families do not devote all their resources and activities to a single family member. Rather, a sustainable daily routine deals with intra- and extrafamilial interactions necessary for balancing available attention to, and investment in, individuals and to the family as a whole. Family members are in many ways in competition for emotional, social, and material resources, and a child with delays requires a balancing of that child’s needs with the needs of others. This is not qualitatively different from the task facing all families. The nature and effectiveness of the balance between individual and family provides a way to consider family outcomes.

In this chapter we discuss two outcomes for families based on selected findings from Project CHILD. Both focus on accommodations, that is, on what families do in adapting to their child with delays, and on what these adaptations mean to them. Specifically, we consider the kind and number of accommodations families made over time, and the sustainability of the resulting daily routines. The findings reported here are based on data gathered when the children with delays were chronologically ages 3, 7, and 11.

Accommodations Over Time. 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 accommoda-

dations, on the other hand, showed little change over the same period. The discrepancy between increased frequency and stable effort suggested that by late childhood families were spreading their adaptive efforts and energies across more domains (Gallimore et al., 1996). The findings are consistent with the expectation that some forms of family adaptation to childhood disability continue into early and late childhood and are not simply an early stage of grieving and adjustment. Accommodation continues because sustaining a daily routine is an enduring family project, not a transient stage in family life or child development (Weisner et al., 1994).

At all three child ages assessed, the frequency and intensity of family accommodations were not strongly tied to the usual family markers such as socioeconomic status (SES) or mothers’ education. Rather, they were related to the characteristics of the children that most directly impacted the daily routine. Families who reported more accommodations were adapting to high-hassle children who had many problems and relatively poor everyday competencies. For example, one family’s accommodations were related primarily to the behavior of an extremely difficult child who required constant monitoring because he was capable of injuring himself or of wreaking serious destruction. His mother commented when he was 3 years old, “Our house is set up around Michael. We still have a gate in here and there’s a smaller area for him and he can function better, and it isn’t that he’s ever been destructive, it’s just that he can’t control himself.” By late childhood, although he was still a high-hassle child, the deadbolts and gates required at age 3 were no longer needed. Parents reported he was now capable of many more things—he was more competent but also more troublesome. For example, he became so competent at using a computer the family bought for him that he managed to purchase a car through the internet. His family still needed to monitor closely his activities, but the nature of their accommodations had changed—less intense, more varied.

Michael and his family illustrate the generalization that different accommodations emerge in response to children’s changing developmental competencies and problems. Our findings concur with the literature describing changing parental concerns over time (Dyson, 1993; Orr, Cameron, Dyson, & Day, 1993), and underscore the importance of designing interventions that are sensitive to family changes in response to developmental transitions. For example, the restructuring of child-family relationships in adolescence for normally developing children is well documented in the developmental literature. It seems likely that the influence of children’s characteristics on family accommodations will be especially strong as children with delays enter adolescence and new issues of autonomy and independence become salient. Thus, the indices of family outcome will vary as a function of children’s developmental age.
Sustainability. Based on our assumption that a family’s sense of well-being depends in part on the sustainability of its daily routine, all Project CHILD families were grouped on sustainability of the daily routines constructed between child ages 3 and 7. Sustainable routines were ones that could be kept going day to day or quickly put back on an even keel using existing resources, such as family income, child services, social support, and psychological resources. Unsustainable routines were buffeted by constant changes and serious problems, sapped material and parental energy and time resources, or were incongruent with some fundamental value or goal of one or both parents. In general, the more sustainable a family's daily routine, the greater the sense of well-being parents reported.

Project CHILD fieldworkers familiar with the cases conducted extensive case reviews. During these reviews the fieldworkers were blind to conventional measures of child and family status. The case reviews produced a high degree of convergence on five exclusive classifications, each representing different degrees of sustainability: (a) Multiply Troubled, (b) Vulnerable but Struggling, (c) Improving, Increasingly Resilient, (d) Active but Less Satisfied, and (e) Satisfied, Stable. (See Weisner et al., 1994, for detailed description of methods and findings.) The Multiply Troubled families (n = 8) were illustrative of low sustainability and low sense of well-being. As an example, during one year, the T family was harassed by a neighbor involved in criminal activities, Mr. T was laid off, Mrs. T had severe emotional problems, and the 12-year-old sister was involved in frequent fights at school. There was little energy left over for Jimmy, the child with delays, who had severe behavior problems and required constant supervision. Life in Multiply Troubled families, as evidenced in the T family, was frequently chaotic, and the daily routine was driven by problems in several areas of living: paying the rent, finding or maintaining employment, marital situation, and child behavior.

Vulnerable but Struggling (n = 15) and Improving-Increasingly Resilient (n = 22) families reflected marginal sustainability and a moderate sense of well-being. Like the Multiply Troubled families, Vulnerable but Struggling families struggled with long-standing problems, often of the same ones encountered by the Multiply Troubled. However, Vulnerable but Struggling families did not appear to be as overwhelmed as their more troubled counterparts. They somehow managed to sustain their everyday routine, often with a single resource such as strong religiosity, or a high-energy, positive, proactive parent. The Improving-Increasingly Resilient (n = 22) families were similar to the Vulnerable but Struggling group, with the exception that they perceived decreasing adaptive problems as their child grew older, and their daily routines changed accordingly.

Active but Less Satisfied (n = 18) and Satisfied-Stable (n = 29) families reflected the highest sustainability. Families considered Active but Less Satisfied adapted actively and fairly effectively over time, yet displayed an underlying attitude of dissatisfaction regarding characteristics surrounding the child with delays, for example, school placement and services, diagnosis or prognosis, or child's behavior problems. These parents often wondered if they were doing enough. Their routine was sustainable, however, and they had a moderate sense of well-being. In contrast, Satisfied-Stable families had an underlying attitude of satisfaction or contentment regarding their child's situation, their ongoing family adaptation, and the way the child's needs fit into the daily routine of the entire family. As an example, Mrs. O was a single mother of three who lived in a rural area with an acre of land and many animals. She considered it a perfect environment for raising children, and particularly appropriate for raising Megan, the child with delays. There were several families who lived near with children around the same age as the O children. Megan was included in all their activities. Mrs. O loved watching Megan run free with the neighborhood children, who seemed impervious to Megan's delays. In addition, she enjoyed a close relationship with the other parents.

The O family was representative of the Satisfied-Stable group because Mrs. O expressed a general sense of well-being and because her daily routine was very sustainable, largely because of the community support. In other Satisfied-Stable families the child had shown significant progress and was currently receiving minimal special education or other services. In other cases in which the child was high hassle or low functioning, the family had made significant accommodations and had created a smooth, workable routine.

When the children reached age 7, the family groups did not differ according to children's IQ, verbal and linguistic competence, or in the total number of child problems as perceived by the parents. This no-difference finding supported the notion of a loosely coupled relationship between family adaptation and the children's abilities, suggesting that there is no simple, direct pathway from child status to family adaptation status. Not surprisingly, the child characteristics that differentiated the groups were those likely to influence family adaptation, a finding congruent with an ecoligological model of family accommodation. Children in the Vulnerable but Struggling families were rated as having the highest hassle, or impact on the daily routine, whereas children in the Satisfied-Stable group had the lowest hassle ratings.

Importantly, the five family classifications were not simply proxies for SES (i.e., level of parental education, marital status, household composition such as single parents vs. couples), although there were differences in how such families were distributed across the groups. The Multiply Troubled group reported the lowest income, as well as the lowest level of parental education. The Less Satisfied group had the highest income, significantly higher than that for the Stable-Satisfied group. There were also significant differences among the groups in accommodation activity. The Less Satisfied families evidenced the most activity with regard to accessing services; the Multiply Troubled group reported the highest childcare workload.
When the children reached age 11, the families were again interviewed about their daily routines and accommodations. This provided a second opportunity to classify the families in terms of the sustainability of their daily routines. On the average, 40% of the families were placed in the same group both times. Two-thirds of the families remained in the same or moved into an adjacent group (e.g., Less Satisfied to Stable-Satisfied or to Vulnerable). The one outlying group was Multiply Troubled—only 1 of the original 7 families was troubled both times. Overall, this suggests a mix of stability and change in well-being over time. Family life, with and without a child with delays, is subject to change over time. These fluctuations work both ways. Families with many problems can, in time, be in a better place, and as our analysis indicated, some doing well now may not be so well fixed later.

The five family groups continued to be differentiated by income, with the Multiply Troubled families reporting the lowest income and the Less Satisfied the highest income. Children with the highest hassle ratings were in the Vulnerable and Multiply Troubled family groups, and children with the lowest hassle ratings were in the Satisfied-Stable group. In contrast to age-7 findings, at age 11 the total number of child problems also differentiated the groups, the children with the most problems were in the Multiply Troubled and Active-Less Satisfied groups. It was the latter group that showed the most accommodation activity across a broad range of dimensions, while the Multiply Troubled group showed the least. Importantly, at both ages family groups were not differentiated by children's cognitive-developmental test scores, but were associated with children's characteristics, which had a direct impact on sustaining the family's daily routine. Clearly, family activities and environments are important to children's well-being. However, the functional connections are complex and often uncertain, suggesting caution in drawing inferences about good or not-so-good families based on the characteristics of the children.

We recognize the potential problems and limitations in using this classification scheme as a tool for assessing family outcomes. The scheme has not been validated outside of our sample of families with children with delays, and the turnover of families across the five categories could be due to factors other than family adaptations to the children with delays. However, the five family groups allow us to view family status from the point of view of adaptation over time. They are not intended to be a rigid typology, but rather to provide assistance in understanding family responses to children with delays (Weismann et al., 1994). An essential aspect of our model is the recognition that families can and will change over time and across developmental periods. Thus, we underscore the need to be wary of family outcome measures that assume the status of a stable trait.

As we know from personal experience, family life is not a smooth, linear march toward a happy ending. The ups and downs most families experience somehow have to be captured in our assessments. We should not be surprised that over an 8-year period these families varied in their satisfaction with everyday life as well as with the nature and extent of the accommodations they made. Whether the lack of stability is due to the methods of classification or to reality, the case materials make clear that the families strongly perceived their lives as varying over time. Parents' own views of their circumstances reflected their uncertainty about the outcomes of their accommodation efforts, their changing understanding of their children's conditions, and the effects of being buffeted by other crises in their lives. However, considering both the number and nature of accommodations over time and the finding that the majority of parents were generally satisfied with their family status, our findings challenge the notion that children's problems are inexorably associated with family problems, and that family reactions are best described by a reactive stress model.

DISCUSSION AND IMPLICATIONS

We have addressed outcomes for families and children and have proposed that both must be systematically assessed if we are to understand the long-term implications of developmental problems. Our work has documented a broad range of outcomes for children with delays and their families. We acknowledge that generalizations from our findings are limited by the selective nature of our sample, but we argue that the functional accommodations comprising family life are inherent in every culture and every group. The kinds of adaptive problems faced by families with children with delays also occur in families without delayed children. To date we have focused on the impact of children's characteristics on family adaptations, showing that children's attributes and problems are but one contributor to the nature of family organization and functioning. We have also shown that children's outcomes and family outcomes are only loosely linked, such that a child with problems does not necessarily imply a problem family.

An important background issue in the study of outcomes for children and families has to do with definition. There are serious questions about what constitute appropriate goals for children with developmental delays, about the emphases and content of early intervention efforts, and about the content of program evaluations. Our findings confirm that early nonspecific delays signal the likelihood of continuing cognitive limitations, but underscore the variability in child status in social-behavioral areas. A comprehensive picture of a child with delays requires consideration of both problems and competencies in different domains and in different settings. This indicates the need for differentiated analyses of child attributes across a range of cognitive and personal-social areas and has implications for assessment, intervention, and evaluation of intervention effects. Because cognitive-language delays are
salient characteristics in the identification of young children with developmental problems, the emphasis in assessment has logically focused on these domains, and a number of well-designed and well-tested measures are available for identification and diagnostic purposes (Bailey & Wolery, 1989). There are fewer comprehensive and well-documented approaches to assessing young children's social, affective, and behavioral competencies and problems. This limitation complicates comprehensive description of children's status in the early years. Clinicians working with young delayed children must often rely on observational data and adult reports when assessing those domains, information sources that are subject to a number of threats to validity and reliability (Keogh & Bernheimer, 1996). We emphasize, too, that children with delays, like other children, develop and change, thus mandating the need for continuity of assessment measures and data over time.

How to assess young children's social, behavioral, and affective functioning is a research topic with important practical applications. Consider the need to develop interventions that are sensitive to individual variations in children's abilities and needs. Consider the need to provide reliable evidence of intervention effects in order to ensure continuity of support for programs. The increasing emphasis on accountability requires that intervenors demonstrate the efficacy of their practices, thus underscoring the need for assessment techniques that provide solid data documenting child status across a range of attributes. Few would challenge the generalization that early intervention is positive. Still uncertain is what outcomes should be emphasized and how to document program effects in those domains.

Similarly, what is a good outcome for a family with a delayed child? Are family stability and peace of mind more important than intensive intervention with a delayed child? How are the needs of a single family member balanced against the needs of the family as a whole? We cannot assume that successful family outcomes necessarily lead to the best or most optimal outcomes for any single family member. Rather, for a family as a unit to have a good outcome it must sustain all members in a daily routine of life that creates and supports resilient responses to threat and challenge (Lancaster & Lancaster, 1983). As noted by Minuchin (1985), there are periods in family life when the child is not the stimulus for change but must share in the need to reorganize the system, either because external events or other members have rocked the established routine. Certainly, families with a child who has disabilities face added demands and stresses, but we argue that a reactive stress model does not capture the kind of functional adjustments and balances that families make. Thus, level of stress is a limited index of family outcome. In our view, more powerful outcome indicators are found in the functional accommodations families make in response to a child with disabilities.

A major question for researchers and clinicians who work with children with delays has to do with the nature of family–child relationships and the effects on both children's development and family environment (Caldwell & Bradley, 1994; Sameroff, 1994). If we assume that child and family outcomes are only loosely coupled, it follows that the outcomes for children cannot be assumed to be an index of the outcomes for families. The loose coupling assumption contrasts with some research and clinical perspectives that expect specific child outcomes to be strongly correlated with specific family environments (e.g., Caldwell & Bradley, 1984; Moos & Moos, 1986). Our view is that child outcomes are connected to family outcomes to the extent that the child can successfully participate in a sustainable, meaningful, and satisfying routine of family life. Thus, limited cognitive and communicative functions of children that do not disrupt the daily routine will not relate to family accommodations. High hassle levels, severe behavior problems, or other child characteristics will relate to family outcomes to the extent that they affect parents' efforts to sustain a routine. To date, our analyses have focused on the impact of child characteristics on family functioning. We are currently examining relationships between family practices and children's cognitive and personal-social development.

Some final points about research and clinical interventions with families deserve note. To date, much of the work on child and family outcomes has been driven by the search for effective intervention and treatment programs. Comparative evaluations of alternative programs inevitably have led to some implicit assumptions about good or better families. Many of these assumptions are as unexamined as the ones held in our culture about the ideal family, both now and historically. They are based on sociologically conditioned beliefs about the ideal family and about desirable developmental goals for children. In the middle decades of this century, for example, the cultural ideal of family life was defined as a working man, a homemaking woman, and their few children living in an isolated household buffered from the world at large by intimacy, romantic love, privacy, and comfort (Skolnick, 1993). Researchers are no more immune than their fellow citizens to these deep cultural models of how things ought to be. Underlying many studies of child and family outcomes lurks some version of this ideal model of the two-parent, small family. Thus, researchers have often fallen victim to the ideal, treating variations in family functioning as deviations, and defining deviations as pathology or dysfunction. This relates to the problems of defining family outcomes in terms of comfortable structural categories, such as divorce rate or marital harmony, rather than in terms of the satisfaction, sustainability, and meaningfulness of daily life.

Another deep but unexamined assumption in many discussions of outcomes is the American preoccupation with achievement—of differentiating self by ladder increments between how one is now and what one will be in some better future. Yet, in family life there is much of importance that does not easily fit into this conception. What families do every day does not and should not be expected to predict or cause some specific outcome for children.
Scarr (1985) argued that the construction of causal inferences from the web of parent–child correlations is fraught with logical and scientific problems. Her view infers the need for caution in defining outcomes for children based on specific family practices.

This does not negate the importance of family environments in children’s lives. From a cross-cultural perspective it is clear that the ecocultural context and the family environment are major influences that shape children’s development (Weisner, 1996). Recent developments in the disability field have underscored the need to expand the scope and content of research about 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 (IFSP), 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, according to Gallagher (1989), to “enhancing the capacity of families to meet the special needs” of their children with handicaps (p. 388). Put in these terms, family proactivity, or capacity to meet the needs of their children, is a vital indicator of family outcome. We propose that this capacity is best shown in the family’s daily routine, and that understanding the organization of this routine provides direction for planning and implementing appropriate and workable interventions that enhance the probability of positive adaptations both for children and their families.

Generations of women and men have discovered, so history teaches, that constructing and sustaining a rhythm of daily life is a key to survival. We have operationalized this rhythm as the daily routine. Using the functional indicators of family adaptation—meaningfulness, congruence, and sustainability of the daily routine—we are impressed with the positive and proactive adjustments most families have made to ensure that their children, including their children with developmental problems, are able to function within cohesive and positive units. For the most part our children and their families are doing remarkably well.

REFERENCES


13. A LONGITUDINAL PERSPECTIVE ON DEVELOPMENTAL DELAYS


