The Nature and Long-Term Implications of Early Developmental Delays:
A Summary of Evidence from Two Longitudinal Studies

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I. HISTORY AND CURRENT STATUS OF THE CATEGORY AND CONCEPT OF DEVELOPMENTAL DELAY

Developmental delay is generally defined as the failure of a child to reach developmental milestones at the expected age (Frist & Palfrey, 1994). Delay rather than disability is commonly used to describe young children who perform poorly on developmental tests or who otherwise display a slower-than-expected rate of development when a more specific diagnosis is absent (Bernheimer & Keogh 1982, 1986). Drillien, Pickering, and Drummond (1988) reported a 10% prevalence rate for developmental delay. A survey of 65 Early Education Programs for Children with Disabilities (EEPCD) indicated that 36% of the children being served were labeled delayed with no specific diagnosis, 21% were considered at risk for developmental delays, and only 3% of the children were labeled with mental retardation (Stayton & Karnes, 1994). As states are now permitted to serve children using relatively broad criteria for defining developmental delay, it is probable that increasing numbers of young children with problems will receive this nonspecific label.

Like developmental disabilities, the term developmental delay came into use over the past two decades as an umbrella category signifying a continuum of problems. In reference to younger children, developmental disabilities and develop-
mental delays are often treated as synonymous and as substitutes for more specific diagnoses. Bernheimer and Keogh (1986) suggest that despite the nonspecific diagnosis, the referential breadth and lack of diagnostic specificity of the term delay signals the need for early interventions with children and families. It also offers clinicians a relatively benign way to describe problem development to parents with less ominous overtones for the future. Because of the substantial variation in children’s development, describing a child as “delayed” offers the possibility of a “catch-up” to age norms and the hope “the child will grow out of it” (First & Palfrey, 1994, p. 478). The long-term implications of early delay are discussed in subsequent sections of this chapter.

One of the puzzling aspects of children exhibiting nonspecific developmental delays is that the etiology is often uncertain or unknown. The delays cannot be attributed with certainty to either biological or environmental factors such as initial biologic insult, chromosomal abnormalities, genetic conditions, to maternal prenatal drug or alcohol usage, or to postnatal neglect or abuse. The number of children with developmental delays of unknown or uncertain etiology has been estimated to be from 50 to 80% of the overall population of persons with retardation (Batshaw & Perret, 1981; Hayden & Beck, 1982). Many of these children display varying delays in language, behavior, social, and cognitive development. In contrast to known diagnostic conditions (e.g., Down syndrome) relatively little information is available to describe long-term outcomes or likely developmental paths. Early identification remains problematic (First & Palfrey, 1994), as before age 3 or 4 it is often difficult to diagnose a wide range of problems including language/speech, behavioral/emotional, learning disabilities, and mild to moderate retardation (Palfrey, Singer, Walker, & Butler, 1987). It is likely that some children identified as developmentally delayed would meet criteria for Pervasive Developmental Disorders (PDD), a medical/psychiatric diagnostic category defining “a group of neuropsychiatric disorders characterized by specific delays and deviations in social, communicative, and cognitive development” (Volkmar, 1991, p. 489). Like developmental delay, the term PDD describes a heterogeneous set of problems (including autism) that are apparent early in a child’s life but that may not receive specific early diagnoses. The ambiguity of these conditions presents troubling problems for families and professionals alike, some children remaining low profile until age 4 or older, with questions being raised only after entrance into preschool or kindergarten.

To address the lack of information about outcomes for children with early developmental delays, in 1977 a research team at UCLA’s Graduate School of Education organized a longitudinal study of a cohort of 44 3- and 4-year-olds with ambiguous, uncertain delays (Project REACH, Keogh & Kopp, 1982). Research in REACH focused on questions of child characteristics, issues of measurement, and features of the broader environment. Not quite 10 years later, a second UCLA longitudinal study (Project CHILD, Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Keogh, Bernheimer, & Guthrie, 1997) replicated the REACH sampling procedure and expanded the scope of investigation to include family adaptations. Drawing on the results of both projects, in this chapter we summarize the results of 15 years of longitudinal study of children exhibiting delayed development in preschool. Our review includes a summary of the characteristics of the two longitudinal samples of children with developmental delays, Projects REACH and CHILD. For both two samples, we summarize the changes over time in the children’s cognitive and developmental status and their social/behavioral competence and problems. For Project CHILD, we summarize the results of our longitudinal analyses of family responses and adaptations to developmental delay. Finally, we offer some observations on our experiences in the conduct of two longitudinal studies.

II. REACH AND CHILD CHILDREN IN THE PRESCHOOL YEARS

Before summarizing the cognitive/developmental characteristics of the children, we note briefly some issues in sample selection. Uncertainties in diagnosing young children with developmental delays pose formidable sampling problems for researchers. Because the term, developmental delay, is a nonspecific diagnosis, we found a range of problems in both REACH and CHILD samples. Delays were often expressed across developmental and behavioral domains or in some cases the delay was focused primarily in one. Furthermore, although all developmental and cognitive testing was done by trained and experienced assessors in the children’s homes, we sometimes questioned the appropriateness of standardized tests and assessment procedures for evaluating the status of young children with problems. We also had occasional concerns about the accuracy of retrospective reports of parents when describing their child’s developmental and health histories. In both the REACH and CHILD projects we used multiple measures and multiple probes over time in our efforts to gather reliable and interpretable data about the children’s development. In this section we describe sampling procedures and provide summary information about the developmental status of our sample children in the initial stages of our studies. These findings provide a picture of the developmental characteristics and early histories of children with delays.

A. Project REACH

In the initial research 69 children between the ages of 18 and 42 months were studied over a 3-year period. The children had been recruited from pediatricians, early intervention programs, regional centers, and preschools. All children evidenced suspect or known delays in major developmental domains. Although the
concept of developmental delay is represented across the continuum of infancy through preschool, it was apparent that the patterns of abilities and disabilities and the expression of problems varied relative to age such that the infant/toddler and preschoolers comprised discrete groups, the infants demonstrating more serious problems. Reports of the infant studies may be found in Krakow and Kopp (1982) and in Kopp, Krakow, and Johnson (1983). The findings reported here are based on study of the preschool children. The mean chronological age (CA) of the 44 preschool children (29 boys and 15 girls) was 33.8 months, \( SD = 3.7 \), range 25 to 42 months. Mean development quotient (DQ) was 74.9, \( SD = 16.8 \), range 50–85. Twenty-two children were firstborns, 16 second borns, and 15 were only children. Age of parents when the study child was born was 26 (4.4) years for mothers, and 29 (4.7) years for fathers. All children were Caucasian and in English-speaking families. Mean maternal and paternal education levels were 13.4 years and 14.5 years, respectively. Occupations of parents ranged from unskilled to professional, with 83% of the fathers holding skilled, managerial, or professional positions. All but five children were enrolled in intervention programs, and many were receiving additional speech, physical, or occupational therapy. Health histories of the children suggested a high number of complications. The mean birthweight was 6.4 (\( SD = 2.0 \)) pounds, range 1.4–11.7 pounds. Twenty-three percent of the sample were preterm, and 59% were reported to have health problems in the first month of life. Forty-five percent did not leave the hospital with their mothers, 32% were hospitalized, and 27% had some kind of surgery prior to entering the REACH study.

At the time of entry into the study the children were assessed with standard developmental and language tests (the Gesell, Sequenced Inventory of Communication Development, Bayley, and the McCarthy where appropriate); all testing was done by trained and experienced assessors in the children’s homes. The Caldwell Preschool Home Inventory was administered at the same time, and parents were asked to complete the short form (Keogh, Pullis, & Cadwell, 1979) of the Thomas and Chess Parent Temperament Questionnaire. Children were reassessed five times at 6-month intervals based on time of entry, and parents were asked to update information at the same time points. REACH children were assessed twice in the elementary school years and again as adolescents. These findings are reported in a subsequent section.

B. Project CHILD

Project CHILD used similar sampling procedures to those in REACH, thus providing reasonable comparability of samples. Children had been identified by pediatricians, teachers, early interventionists, and/or regional center professionals as having mild to moderate nonspecific developmental delays. A total of 313 children were reviewed for possible entry into the CHILD cohort and 103 were entered into the sample with parental consent. About 5% of the 313 children met our sampling criteria but were not studied, primarily because parents declined to participate. The final CHILD sample consisted of 103 children in 102 families. In all cases, the etiology and prognosis were unknown or uncertain. Children were excluded from the sample if they were known to have chromosomal abnormalities and/or genetic conditions associated with mental retardation, or if the delays were associated with either known prenatal drug or alcohol usage, or with postnatal neglect or abuse. The children were all Euro-American from English-speaking, primarily middle class families. Sixty-two percent of the mothers and 49.5% of the fathers had some college education; 80.4% of the fathers held skilled, managerial, or professional positions. Only two children received no formal services at entry and over one-third of the children were receiving three or more services or therapies. As with the REACH sample, many children had health problems in the first 3 years of life: 28% of the sample were preterm, 39% had some kind of surgery, and 47% were hospitalized at least once prior to entering the study. At entry, the mean CA was 41.8 months (\( SD = 6.2 \); range 32 to 55). The mean Gesell DQ was 72.3 (\( SD = 16.0 \); range 38 to 117). All but 18 of the children had DQs below 90, and all 103 had significant delays in one or more areas (motor, speech, or cognition). Fifty-eight percent of the children were boys.

The initial data collection at age 3 included the Gesell, the short form of the Stanford-Binet, the Communication and Daily Living Subscales of the Vineland, the Caldwell HOME, and the short form of the Parent Temperament Questionnaire (Keogh et al., 1979). Teachers also completed a teacher version of the Temperament Questionnaire (Keogh, Pullis, & Cadwell, 1982) as well as a project-developed questionnaire about the child’s problems and competencies in the program setting. Concurrent with the child testing, parents were interviewed at length about the daily lives of their family when raising a child with delays. Fieldworkers gathered parents’ reports of behavior, medical, and communication “hassle,” with hassles defined as the extent of the child’s impact on the daily routine of family life. Based on the interviews fieldworkers also made ratings of family accommodations or adaptations made in response to the child with delays. Accommodations were defined as the family’s functional responses or adjustments (Gallimore et al., 1989; Bernheimer & Keogh, 1995) and included actions taken, avoided, or delayed in order to create and sustain an everyday routine of life.

C. Cognitive and Developmental Status in the Preschool Years: Summary Findings

For the REACH sample, results of the developmental testing over time (5 time points) confirmed the reality of the delays recognized early on. Means and standard deviations for the Gesell DQ from time points 1 to 5 were 74 (16.9), 73 (16.90), 72 (17.7), 69 (15.5), and 67 (17). Examination of the correlations between test scores across time points, regardless of specific test, also confirmed the sta-
bility of developmental rate for the REACH preschool sample as a whole. Correlation between the Bayley mental age (MA) from time 1 to time 4 was .93; the r for the Gesell DQ from time 1 to 4 was .94. Relationships among scores from the different tests within time periods were also strong and consistently significant. At assessment time 2 for REACH, the Gesell language scores correlated .81 and .76 with the SICD expressive and receptive subscales; at time 5 both the SICD scales were significantly associated with the Gesell language and personal-social scales, values of r .60 and .93. Also to be noted were the significant correlations among subtests within any assessment measure. At time 1 the strength of association among the five subtests of the Gesell ranged from .67 to .81. Finally, there were moderate and generally significant relationships between the REACH children's CAs and their performance on the developmental tests. At time 1 the correlations between CA and Bayley MA was .38; the comparable value of r for CA and the Gesell developmental age (DA) was .56.

Turning to the CHILD sample, at entry, the mean Gesell DQ was 72.3 (SD = 16.0); the mean Binet IQ was 70.6 (SD = 13.8); means for the Vineland Daily Living and Communication Subscales were 71.8 (SD = 11.2) and 72.5 (SD = 10.5), respectively. Over 50% of the CHILD parents reported problems in speech, language, learning, physical, and behavioral areas. The mean number of problems reported by parents was 4.4, with a range from 0–8; number of problems was moderately associated with the developmental test scores (range of r = -.24 to -.48). As with the REACH sample, CHILD parents struggled to make sense of the ambiguity of their children's diagnoses and prognoses. It was not uncommon for children to have more than one diagnosis or label, and at entry 90% of the parents reported multiple, sometimes conflicting diagnoses. The most common diagnoses at age 3, reported by 50% of parents or more, were developmental delays and language/communication problems. Other labels/diagnoses, in descending order of frequency, included cerebral palsy, mental retardation, normal development, visual impairment, hearing impairment, and attention deficit disorder (ADD)/hyperactivity. CHILD parents' expectations regarding the future reflected their confusion: 53.4% predicted that their children would catch up and participate in regular education programs when they entered school, whereas 46.6% felt it was likely their child would retain a marginal status and require continuing special education services.

In addition to being strikingly similar in terms of their developmental status at entry, the REACH and CHILD cohorts shared other characteristics when the children were 3, in spite of being recruited 10 years apart. Examples included the mean age of parents' first concern that there was a problem (9.1 months for both samples); and mean age of diagnosis by a professional (12.7 months for REACH, 13.7 months for CHILD). The CHILD sample entered intervention earlier than did the REACH sample (20.3 months vs. 25.3 months), a predictable difference given the passage of PI 99-457 in 1986.

D. Generalizations from REACH and CHILD Preschool Studies

A number of generalizations emerged from the findings during the preschool years. Not surprisingly, children who are delayed at age 2–3 had a high probability of being delayed at age 4–5. The cognitive/developmental scores underscored the stability of the delays, even when CA was taken into account. The magnitude of the correlations among the various tests lent support to their reliability in assessing young children with delays. In addition to strong agreement between different tests, there were significant relationships among the various subscales within tests suggesting that the scales may in fact tap one broad ability factor (Bernheimer & Keogh, 1982, 1986). Although they have labels that have meaning on a construct level (e.g., fine motor, adaptive, personal/social), the tests may measure a global aptitude. This may be especially so for children with developmental delays, as the various ability domains may not be well differentiated early on, as shown in the significant correlations among subtest scores. When patterns of change scores for individual children were examined it was clear that the children who made the most overall gain during the 3 years of the REACH study had change scores on the language subscales which exceeded the corresponding change in CA (e.g., 31-months gain in a 24-month period).

Although it was clear that there was real stability of cognitive/developmental level over time based on group data, our findings also showed that predictions about individual children must be made with caution, especially on the basis of findings from a single test session. Within our samples a few children made rapid progress while others maintained a stable pace and still others declined in developmental level. The reasons for these differences in patterns were unclear, but provided direction to many of the follow-up efforts that were the focus in Project CHILD. For detailed information regarding the range and distribution in developmental patterns, see Bernheimer and Keogh (1988).

E. Stability of Cognitive Development over Time

The stability of cognitive status of children with developmental disabilities has been confirmed by a number of different investigators (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). REACH correlation coefficients between DQ and IQ at different time points ranging from .74 to .81 were reported by Bernheimer and Keogh (1988). These findings are consistent with those reported by Goodman (1977); Stavrou (1990); Truscott, Narrett, and Smith (1994); and Vanderveer and Schweid (1974) in studies focused on children with identified diagnoses such as Down syndrome or other genetic conditions. The questions of stability of cognitive development over time may be less certain when the etiology of the delay is unknown or uncertain, as was the case with the children in our studies. In this sec-
tion we focus primarily on the results of the CHILD studies in which children’s
cognitive status was assessed when the children were ages 3, 7, and 11 years chronologically.

Results of the cognitive tests by age are shown in Table I for the CHILD sample
and for boys and girls separately. These analyses were based on children (N = 82)
for whom we had complete data over time. Correlations between cognitive
scores over time are also shown in Table I for the total group and for boys and girls
separately. The magnitude of the associations suggest that early signs of delay signal
the probability of continuing delays.

Scores for the CHILD group as a whole decreased over time, but examination
of individual growth curves suggested that there were differences in the amount
and direction of change. Between ages 3 and 11 years the majority of children (61%) had cognitive scores with ± 1 SD, some (33%) decreased by more than 1
SD, and only five children (6%) increased by 1 SD or more. Use of a random coefficient technique identified differences in rates of decline (Keogh et al., 1997). Variations in scores documented stable declines in DQ/IQ (estimated means slope = −1.52 IQ points per year, Z = −4.03, p = .001) for boys and for girls. Tests of possible child and family covariates of change (e.g., number of child problems,
DQ, temperament, family socioeconomic status and family accommodation) confirmed that only the children’s entering DQ and their temperaments were significantly associated with rate of decline. The relationship between temperament and

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**TABLE I**

Means and Standard Deviations of Developmental/Cognitive Scores at Three Time Points for Total Group, Boys and Girls

<table>
<thead>
<tr>
<th>Child age</th>
<th>Age 3</th>
<th>Age 7</th>
<th>Age 11</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>DQ/IQ</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total = 82</td>
<td>72.22</td>
<td>(15.34)</td>
<td>69.60</td>
</tr>
<tr>
<td>Boys = 45</td>
<td>72.85</td>
<td>(14.06)</td>
<td>68.46</td>
</tr>
<tr>
<td>Girls = 37</td>
<td>71.46</td>
<td>(16.94)</td>
<td>70.99</td>
</tr>
</tbody>
</table>

Stability coefficients for developmental/cognitive scores over three time points

<table>
<thead>
<tr>
<th>r ages 3–6</th>
<th>r ages 3–11</th>
<th>r ages 6–11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total = 82</td>
<td>.76***</td>
<td>.74***</td>
</tr>
<tr>
<td>Boys = 45</td>
<td>.74***</td>
<td>.67***</td>
</tr>
<tr>
<td>Girls = 37</td>
<td>.77***</td>
<td>.81***</td>
</tr>
</tbody>
</table>

***p < .001; **p < .01

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EARLY DEVELOPMENTAL DELAYS: LONG-TERM IMPLICATIONS

DQ was nonsignificant. Of particular interest was the counterintuitive finding that
it was difficult temperament rather than easy temperament that was associated with
a slower decline in cognitive scores. We speculate that difficult children with delays may elicit more interaction and attention from other family members than do delayed children with easy temperaments, thus providing the difficult children with more opportunities for stimulation. Consistent with this interpretation were the findings of significant relationships between parents’ views of behavioral hassle and children’s temperaments at age 3. Values of r were −.35 and .29 for hassle scores and easy and difficult temperaments, respectively. This interpretation is also consistent with the findings of Maziea, Cote, Boutin, Bernier, and Thivierge (1987) in Canada, and with morbidity studies in Africa by DeVries (1984). The findings raise interesting questions about the possible influence of experience on the cognitive development of children with delays.

Cognitive/developmental scores were also examined relative to possible etiologic conditions of the children (Keogh & Bernheimer, 1995). Review of records of 102 CHILD children identified 28 who had signs of perinatal or immediate postnatal stress (e.g., low birthweight, anoxia, or other medical conditions); 41 had no histories of pre- or perinatal trauma or stress. There were no differences in mean values for DQ or IQ between the groups at ages 3 and 7, but the patterns of associations between early developmental scores and outcomes varied by subgroup. The most robust correlations between early measures and subsequent outcomes (r = .80) were in the group composed of the children with unknown etiologies; the comparable value of r was .47 for the group with known perinatal stress. The relationships between early measures and outcome was particularly strong for girls with disabilities of unknown etiology. For this subgroup of girls significant relationships were found between developmental measures at both ages 3 and 7 and behavioral characteristics at 9 or 10. For example, correlations between the Gesell DQ at age 3 and subsequent Vineland communication and daily living skills were −.58 and −.64, respectively. The correlation between the age 3 DQ and number of problems reported by parents at age 9 were −.55. Similarly, the early DQ was also significantly associated with teachers’ views of competencies and problems. In contrast to the findings for the girls whose disabilities were of unknown etiology, there were few significant associations for girls with identified pre- or perinatal stress, findings similar to those for boys. We have no powerful explanation for the gender-by-etiolo gy findings. However, a reasonable inference about etiology without regard to gender is Kopp’s theory (Keogh & Kopp, 1982) that the children of unknown etiology experienced trauma in the early gestational months, leading to pervasive delays in many domains, whereas perinatal stress occurred when the infants were more mature and thus more resilient.

Results of the REACH and CHILD studies of delayed children were strikingly similar, despite the 10 years between the projects, a period which has seen changes in policies, services, and attitudes. Findings from both REACH and CHILD were
consistent in documenting the stability of cognitive development across ages 3–11 years. Stability was related to etiology (unknown vs. suspect) and gender; the strongest associations between early delays and subsequent problems were for girls with delays of unknown etiology. Declines in cognitive scores were associated with early developmental status and children’s temperament. For both samples, the findings document long-term and continuing cognitive limitations when delays are evident in the preschool years. They also underscore the need to consider different areas of outcomes—cognitive/academic, personal/social, and behavioral. A consistent finding from work to date is that personal/social competencies and the number and expression of problem behaviors of children and youth with developmental delays are related to, but not highly correlated, with cognitive status. That is, the problem behaviors cannot be “explained” on the basis of IQ. Rather they are associated with other characteristics of the children and families and are, in part at least, age related. These findings led us to broaden our study of the children with delays to take into account a range of personal/social and behavioral and educational outcomes.

III. COMPETENCE AND PROBLEMS OF CHILDREN WITH DELAYS

Our studies of competence and problems of children with delays was guided in part by the model proposed by Masten, Garnezy, and their colleagues at the University of Minnesota (Masten, Best, & Garnezy, 1990) and by the work of Werner and Smith (1982, 1992) in their research in Hawaii. We also were influenced by the literature defining the major developmental tasks of the middle years of childhood and adolescence (Erikson, 1959; Havighurst, 1972). There is considerable evidence suggesting gender and age differences in normal developmental patterns through these time periods, but less is known about the developmental paths of children with nonspecific delays. Having documented the stability of cognitive development over time, we focused on progress and outcomes in two related areas: education/schooling; personal/social and behavioral competence and problems. In the following sections we summarize findings from both REACH and CHILD projects.

A. Schooling and Educational Achievement

We consider first the school placements of children in both REACH and CHILD cohorts as they entered and proceeded through elementary school. The majority of the children moved directly into special education placements, a finding consistent with the earlier work of Edgar, McNulty, Gaetz, and Maddox (1984), Edgar, Heglelund, and Fischer (1988), and Walker et al. (1988). We note that much of the earlier work on placement was done before the movement toward inclusion was well established, and when separate classes were the placement of choice. Consistent with earlier REACH findings, however, examination of the placements of 87 CHILD children at ages 9–10 in elementary school indicated that 78% were in separate special education classes full- or part-time, and only 22% were placed in regular education (Keogh, Coots, & Bernheimer, 1995). CHILD children in special education programs were served in categories of learning handicaps (25%); severe handicaps (30%); visual, physical, or communication handicaps (23%); or other. For most children, integration was limited to recesses, lunch periods, and assemblies; only one child at age 9–10 was integrated academically for more than half a day. Follow-up of the CHILD children when they were age 11 documented that 50% remained in separate full-day special education classes, and 21% were based in separate classes but also spent time in regular or mainstreamed classes. Similarly, 50% of the REACH sample were in separate special education programs in middle and high school, and another 30% continued to receive special help on a part-time basis (Bernheimer & Keogh, 1996).

There were significant differences across CHILD elementary school placement groups in cognitive scores. IQ means and SDs for the regular education, learning handicapped, severely handicapped, and other groups were 87 (15.86), 75.90 (12.79), 52.94 (14.43), and 66.06 (13.32), respectively. Similar differences were found for communication test scores and daily living competence scores, and on teachers’ ratings of children’s educational problems, suggesting that placements reflected individual differences in children’s cognitive status. Examination of the placement groups in terms of the children’s characteristics in preschool or at entrance to elementary school showed clearly that the severity of problems predicted the need for subsequent special services.

B. Personal and Social Competence and Problems

In contrast to direct testing of cognitive level, children’s competencies and behavior problems are defined and assessed primarily through the reports of others, usually parents and teachers. Thus, both competencies and problems reflect the observers’ perceptions as well as possible situational or setting effects (Keogh & Bernheimer, 1998). In an effort to take into account both observer and situational effects, where possible we assessed our children’s competencies and problems drawing on the views of both parents and of teachers.

In an early study as part of Project REACH when the children were age 6 (Keogh, Bernheimer, Haney, & Daly, 1989), parents were asked to complete a measure of personal care competencies (Alpern & Boll, 1972) and of behavior problems (Achenbach, 1981). Results confirmed that as a group the children exhibited lower personal competency scores and higher behavior problem scores than expected from either mental or CA norms. There were no statistically signif-
significant differences in behavior problem scores by gender, although the number of problems reported was greater for boys than girls. Importantly, the correlations between the behavior problem scores and the children’s IQ or mental ages (MA) were not statistically significant. Further study of the REACH children at ages 7, 8, and 9 years of age (Keogh, Ratekin, & Bernheimer, 1992), using ratings from both parents and teachers, confirmed the higher than normal rates of behavior problems at home and at school. The relationships between scores for rater groups became stronger as the children grew older (r for intensity at CA 7 = .38, r at CA 9 = .55).

Salient problems for both parents and teachers focused on immaturity, clumsiness, impulsivity, and inattention, characteristics which appeared to represent the “core” problems evident at home and at school. Not surprisingly, teachers also emphasized problems related to learning and classroom behavior, while parents were more concerned with personal and social interactions.

In a survey of the REACH sample at adolescence (CA mean = 18.2 years), parents were asked to describe their child’s living arrangements, employment, education, health, social life, and problems. The majority of the adolescents were living at home, were autonomous in self-help skills, and were still in special education programs. Few were employed, even on a part-time basis. Of particular interest was the finding that almost half of the high-frequency behavior problems identified by parents when the children were age 6 were still considered problems by parents when their children were age 17–18. Specific problems included acts too young (73%), speech problems (57%), stubborn (67%), likes to be alone (53%), and can’t concentrate (43%).

Detailed examination of the personal and social and behavioral competencies of the children with delays was carried out with the CHILD sample when the children were 11 years of age (Keogh & Bernheimer, 1998). Data were collected from both teachers and mothers using the Teacher–Child Rating Scale (T-CARS; Hightower, Spinell, & Lotyczewski, 1988) and Hightower et al. (1986) and a Parent–Child Rating Scale adaptation of the T-CARS (Juvonen, Keogh, Ratekin, & Bernheimer, 1992; Juvonen, Keogh, & Bernheimer, 1992). Both scales tap competence factors of Frustration Tolerance, Assertive Social Skills, Task Orientation, and Peer Social Skills, and three clusters of behavior problems: Acting out, Shy/Anxious, and Learning. Mothers and teachers also completed a checklist assessing children’s status in areas of independence, conduct, social skills, and health. In general there were few differences between mothers’ and teachers’ ratings of competencies and problems, although teachers rated children higher (better) than did their mothers on the global checklist items. For both mothers and teachers, personal social competencies and behavior problems at age 11 were associated with difficult temperament and DQ in the preschool years. For mothers, difficult temperament at age 3 was associated with acting out, frustration tolerance (negative correlation), and assertive social skills. For teachers, difficult temperament at age 3 was associated with assertive social skills. For both mothers and teachers, DQ at age 3 was associated with assertive social skills and task orientation. Not surprisingly, DQ was also associated negatively with learning problems for teachers.

The findings confirmed that the children had persistent problems in behavior and learning, but that there were differences related to home or school setting. High-frequency behaviors identified by teachers included difficulty in following directions, failure to complete assignments, inattention to task, messy work, and the like. Home-specific behavior problems included loud, disobedient, argues a lot, brags and boasts, bites fingernails, jealous, and temper tantrums (Keogh et al., 1992). The range of r between mothers’ and teachers’ ratings was .18–.57 for the full sample, .19–.57 for boys, .07–.71 for girls. Correlations between the children’s cognitive scores and the behavior ratings were for the most part nonsignificant, but were greater for mothers than for teachers, a rather surprising finding. There was also stronger agreement between rater groups in externalizing than internalizing problems. The findings confirmed that children with cognitive delays have higher than normative expectations in behavior problems and are less competent in personal social areas both at home and at school, as compared with the scores reported by Hightower et al. (1986).

Taken as a whole, our findings are consistent with prior literature on cognitive and personal/social outcomes for children with developmental delays, suggesting that early signs of developmental problems are reasonable predictors of subsequent problem status. 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. We emphasize that cognitive level did not explain variations in personal/social competencies, and that cognitive status did not necessarily predict personal social competence. Further, 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 at different time points and in different settings using a variety of techniques. 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. We also emphasize the importance of considering context when evaluating children’s personal and behavioral problems.

IV. FAMILY RESPONSES TO CHILDREN WITH DEVELOPMENTAL DELAYS

A major purpose for undertaking Project CHILD was to expand the scope of REACH’s investigations of early developmental delays to family responses to rearing such children. Project REACH had documented that many families were
actively engaged in proactive strategies that were not well represented in a research literature focused mainly on stress and psychopathology. In 1983, for example, a lead article in the American Journal of Mental Deficiency concluded no theory presently "exists through which one can develop an empirical understanding of families of retarded children. Rather, investigators have seemed to rally around the concept of anticipated pathology in these families" (Crcnic, Friedrich, & Greenberg, 1983, p. 126). Our goal in CHILD was to document and understand the functional nature of family adaptations to children with developmental problems.

In CHILD we augmented standard procedures and measures with a more exploratory, open-ended approach that might discover new categories of family response to developmental delay. Project CHILD families were visited either at home or at a location of their choice by an experienced fieldworker who conducted a 2-3-h semistructured interview with the principal caretaker (mothers, with few exceptions). These interviews were conducted three times, at child ages 3, 7, and 11. Parents were asked to talk about their experiences with the child with delays, the family's daily routines, and how their child affected everyday life. This interview approach was designed to provide each family the opportunity to "tell their story" in accord with evidence that adults organize and recall personal experiences and knowledge in narrative form (Bruner, 1989; Coles, 1989).

To insure uniform coverage of topics, interviewers were provided open-ended questions and topics to be covered. In addition, they were trained to use probes to ensure that equivalent material was obtained for all families on all key topics. The same protocol was followed in the interviews at 3, 7, and 11. For the interviews when the children were 7 and 11 some topics no longer relevant were deleted and new topics were added as appropriate. All interviews were audio recorded, and later transcribed for more systematic analysis. Parents were in general enthusiastic for the "story" interview approach, and many commented that they felt for the first time someone had been willing to listen to their account of their child's disabilities and related issues. Using materials from the "story-interview" we explored several lines of investigation, including the three summarized here: ambiguity of child status and parental expectations, family adaptations to developmental delay, and family outcomes.

A. Ambiguity of Child Status and Parental Expectations

Except for the most profound handicapping conditions, young children with developmental disabilities or delays often present a highly ambiguous diagnostic and prognostic picture. As Bernheimer and Keogh (1986) noted, even though parents and professionals usually recognize that "something is wrong" by the first or second year of life, it may take several months or years to identify autism, cerebral palsy, and visual, hearing, or speech disorders. Even Down syndrome which may be less ambiguous to diagnose has an uncertain prognosis, with the degree of retardation ranging from mild to severe. For parents of children with delays of uncertain or unknown etiology and prognosis, case materials suggest a substantial impact of the ambiguity of children's status.

Ambiguity of child status is a potentially significant factor for parents since it puts in doubt what might be realistic expectations for their child's development. This effect has raised concern given the correlational evidence that parents' developmental expectations are associated with outcomes for all children with and without developmental delays (Duran & Weller, 1992; Entwistle & Hayduk, 1981; Hunt & Paraskevopoulos, 1980). Such findings reinforce the idea that parents' expectations can create a "self-fulfilling prophecy" (Merton, 1948) that may determine or at least affect the level of functioning a child ultimately achieves. Extended to parents of children with delays and disabilities, the assumption that parents' expectations for their children may create self-fulfilling prophecies has raised concerns about possible inaccurate expectations due to ambiguity of the child's status. Some have suggested that parents may underestimate their children with delays, and do not challenge them enough (Schneider & Gearhart, 1988). Others have suggested the opposite effect, that parents may overestimate their children's future development, and thus not adequately prepare children to cope if their disabilities persist into adulthood (Zettlin & Turner, 1984).

However, strong claims that parents' expectations have causal effects on children's development are undercut in many studies by the limitations of correlational and cross-sectional designs. In most cases, it is equally plausible to propose an opposite direction of influence between parents and children (Bell, 1968). Parents may adjust their expectations over time as a child's abilities and functioning level become more apparent. This may be especially true of parents with children with developmental delays of unknown etiology whose future developmental status is frequently ambiguous early on, but becomes more certain in subsequent years (Bernheimer & Keogh, 1982). Indeed, parents generally get more accurate in their estimations of children's abilities as children mature (Anton & Dindia, 1984; Jensen & Kogan, 1962), and adjust their developmental goals for children over time in response to children's abilities (Clare, 1998).

When their children were preschoolers, a majority of REACH and CHILD parents initially expressed strong hopes of a "catch-up" to age norms. Except for about 8% of the children in both cohorts who did "catch up," this was not the case. To explore the impact "not catching up" had on the parents and their children, Clare et al. (1998) used data from the CHILD cohort to examine relationships between parents' developmental expectations and child characteristics for children at ages 3, 7, and 11. At each of these age periods, part of the "story interview" described above was devoted to a conversation about parents' "developmental expectations" using parents' personal semantic frames. Using interview materials, parents were...
reliably assigned to one of four categories: (1) Parents who thought that their children would definitely be permanently handicapped or "mentally retarded" as adults; (2) parents who were certain about their children's future functioning and handicapping conditions; (3) those who believed that their children would be only marginally handicapped (i.e., that the handicap would be present in some form, but not salient); and (4) parents who believed that their children would outgrow their developmental delays (i.e., "catch-up") and have no residual handicaps.

Clare et al. (1998) found that parents' developmental expectations were moderately stable over time, but tending to decline as children matured. As hypothesized, parents' developmental expectations were associated with children's characteristics at age 3 and, over time, became increasingly correlated with cognitive functioning, daily living competence, child hassle, and total number of child problems. The results of regression analyses generally supported the hypothesis that early child characteristics, but not early parent expectations, were the best predictors of parents' developmental expectations and child outcomes at child age 11. The one exception was the children's daily living competence, which was predicted by a combination of early parent expectations and children's Gesell DQ scores. Path analysis revealed a transactional relationship between parents' expectations and children's daily living competence. Although parents may not be completely accurate in assessment of 3-year-olds, over time they adjust their expectations in response to children's developmental status and functioning.

The CHILD case materials indicated that the ambiguity of diagnosis is early on a source of great concern to most families, but in time some parents began to discount its importance. By the time children were 11 or older, most families were more focused on finding programs that fit the needs at hand. Although they still were concerned with the long-term, many had come to recognize and accept that they may never know why their child was delayed in development. Almost all had also come to terms with the recognition that the delays would continue, despite the fact that the diagnoses became more specific and changed over time. As an example, at age 3, the most frequent diagnoses were language or communication disorder (65%); developmental delay (58%); cerebral palsy (33%); and mental retardation (30%). By age 11, 7% were identified with language/communication disorders; 15% with developmental delay; 23% with cerebral palsy; and 19% with mental retardation. Other diagnoses reported at age 11 included ADD/hyperactivity (22%), learning disabilities (13%), and other neurological conditions (11%).

B. Family Adaptation to Developmental Delay

One purpose of Project CHILD was to explore alternatives to the historic focus of researchers on stress and coping (Beresford, 1994). The stress and coping focus had many good effects: it helped justify services for parents dealing with childhood disability, documented that these families needed assistance, and called at-
daily routine captures the common "stuff" of family life and is an expression of how families organize their lives, 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 upon parents' time with other 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 full-time, distributing care of a child who requires constant monitoring, 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, as 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 on 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 II. The cross-cultural evidence of the universality of most of these domains can be found in 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 keep on 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 trade-offs and adjustments represents a family accommodation to childhood disability (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996).

From preschool to late childhood, 93 families reported a statistically significant increase in the number of accommodations made: 749, 891, and 1,388 at child 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. 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 significant forms of family adaptation to childhood disability continue into early and late childhood and are not simply a function of an early stage of parental grieving and adjustment or a feature of specific developmental periods. Accommodation continues because sustaining a daily routine is an enduring fam-

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<td>Services: Availability of services; eligibility for services; sources of transportation; amount of parent involvement required</td>
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<td>Home/neighborhood safety and convenience: Safety and accessibility of play area; alterations in home (installation of locks, fences related to safety concerns); choice of particular neighborhood</td>
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<td>Domestic workload: Amount of work which needs to be done; persons available to do it; amount of time spent by different family members</td>
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<td>Child care tasks: complexity of child care tasks; presence of extraordinary child care demands (medical problems, behavior problems); number and availability of caregivers</td>
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<td>Child peer groups: Child's playgroups (children with disabilities versus typically developing children); amount of parent supervision needed; role of siblings as playmates</td>
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<td>Marital roles: Amount of shared decision making regarding child with delay; degree to which child care and household tasks are shared</td>
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<td>Instrumental/emotional support: Availability and use of formal (church, parent groups) and informal (friends, relatives) sources of support; costs of using support</td>
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<tr>
<td>Parent information: Reliance on professional versus nonprofessional sources of information; amount of time and effort spent accessing information</td>
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aFrom Bernheimer & Keogh, 1995. (Copyright 1995 by PRO-ED. Reprinted by permission.)

Family project, not a transient stage in family life or child development (Gallimore et al., in press; Weisner, 1998).

The accommodations identified 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, marital relationship; 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 "socio-ecological coping resources," which included social support, support from spouse, extended family, and formal agencies, marital status, socioeconomic circumstances, and the family environment. These categories are consistent with the domains of accommodations reported by the CHILD families.

1. HOW DO FAMILY ACCOMMODATIONS RELATE TO CHILD CHARACTERISTICS?

To examine this, Keogh, Bernheimer, Garnier, and Gallimore (1998) used path analytic techniques to compare the fit of child-driven and transactional models. In
these analyses children’s status in cognitive, personal social, behavior competencies and problems, and “hassel” domains were assessed at ages 3, 7, and 11. Family accommodations and adjustments to the children were collected at the same time points. Results of path analytic techniques indicated that the longitudinal relationships between children’s cognitive and daily living competencies and family accommodations were best explained by a child-driven model. The direction of effects for both intensity and types of accommodation activities was from child to family. Children’s hassle levels were both child-driven and transactional, suggesting that family accommodations influenced children’s behavioral characteristics, and that child characteristics in turn influenced accommodations. Thus, for cognitive and daily living competencies, family accommodations are an important response to the child, and there is no reason to think that one or the other type of family accommodation produces a better outcome for the child. For behavior characteristics the relationships are both more interesting and more complex with accommodations having an effect on behavior, and subsequently the behavior affecting accommodations—a dynamic pattern of adaptation from child ages 3 to 11. The two hypothesized path models representing child-driven and transactional models are shown in Figure 1.

At all child ages, the frequency and intensity of family accommodations were not strongly tied to the family status variables such as SES or mothers’ education. Rather, they were most consistently associated with child characteristics that directly impact the daily routine. Families who reported more accommodations were adapting to high “hassel” children who had many behavioral and emotional 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 wreaking serious destruction. His mother commented when he was age 3: “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.

2. CLINICAL IMPLICATIONS OF FAMILY ACCOMMODATION

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.

Perhaps as much or more than strategies for coping with stress, family accommodations to sustain their daily routine should be factored into planning interventions. Since the inception of Part H of IDEA (currently referred to as Part C in the Amendments to the Individuals with Disabilities Education Act), the focus in early intervention has shifted from child-centered to family-centered care (Bernheimer & Keogh, 1995). The Individualized Family Service Plan (IFSP), developed by professionals in collaboration with families, identifies family as well as

FIG. 1. Two theoretical models of parent accommodation activities and child characteristics, child age 3 to 11 years. The transactional model specifies a reciprocal direction of effects between child characteristics to parent accommodation activities. The child-driven model specifies a one direction of effects from child characteristics to parent accommodation activities. The cross-domain paths from ages 3 to 7 and ages 7 to 11 are indicated by a dashed line (———) for the transactional model and a solid line for the child-driven model (--------).
child strengths and needs, and identifies priorities for intervention. Given dynamic contexts into which interventions are to be inserted, it is not surprising the shift to IFSP sometimes encounter difficulties. Many IFSP plans fail to be fully implemented or be sustained by parents (Meyer & Bailey, 1993). Clinicians frequently complain that parents do not follow through on what seems 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? Family-focused interventions may not always be consistent with accommodations families are already making and thus are not well “fitted” into 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, Marenko, & Hazel, 1996).

Does knowledge about accommodations being made to sustain a daily routine insure 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 and accommodations which 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) (Bernheimer & Keogh, 1995; Gallimore et al., in press). Yet making “a sensitive examination of the . . . context . . . that receives an intervention” (Gallimore et al., 1993, p. 553) should help practitioners understand what needs to happen in order for an intervention to be implemented and maintained. It should also prevent practitioners from introducing additional stress to a multiply challenged family by adding to their adaptive burden.

C. Family Outcomes

With a few exceptions, by child age 13 Project CHILD families are doing relatively well. Like all families, there are ups and downs, but 10+ years of case materials suggest that about 90% of the Project CHILD families are managing “good enough” if not as well as they’d like (Weisner, Matheson, Coots, & Gallimore, 1997). Except for a troubled few, the families included those with stable daily routines, those who were vulnerable but resilient, and those who were described as “hanging on” (Weisner et al., 1997). Some of the variations in accommodation among families in these different circumstances were predictably related to income, availability of instrumental support, and other resources. These variations aside, whatever their circumstances families were actively making accommodations to incorporate the child with delays into their daily routine.

An important point, however, is that contrary to some literature on families adapting to early childhood delay, Weisner et al. (1997) found no indication that Project CHILD families were suffering from exceptionally high levels of stress, emotional problems, or family difficulties. Most of the major problems were not related specifically to children’s developmental delays: Death of a grandparent, spouse or a child, loss of a job, or housing, and other such major events loomed larger than childhood delays in most cases. We do not mean to minimize the stresses, strains, and problems the families have faced. Indeed, some families have carried and some still carry great burdens, but the overall impression is that these families are not that much different from others and we are wise to heed Glidden’s challenge of the assumption that a child disability inevitably means the family itself has a disability (Glidden, 1993, p. 426). That is certainly not true of 90%+ of the families in the CHILD and REACH cohorts.

V. GENERALIZATIONS AND OBSERVATIONS FROM TWO LONGITUDINAL STUDIES

Our work in REACH and CHILD has documented that early signs of developmental delays signal the likelihood of continuing cognitive delays. We have also identified a broad range of developmental and personal/social outcomes for children with delays and their families, and we have shown that children’s status and family status are only loosely linked. Said directly, a child with problems does not necessarily mean a family with problems. Just as outcomes for children cannot be assumed to be an index of the outcomes for families, family outcomes do not necessarily provide information about child status. Successful outcomes for families may not be the optimal outcomes for a single family member. Similarly, intense parental focus on a single family member may be disruptive to the family as a whole. In addition, from preschool to late childhood we watched the proactive and positive adaptations families made to children with delays, our observations challenging the mental health model of family pathology. We acknowledge that the generalizations from our findings are tempered by the selective nature of our samples, but we argue that the functional accommodations comprising family life are not limited to families of children with delays, but rather are inherent in every culture (Weisner, 1998). While there may be differences in specifics, the kinds of adaptive problems faced by families with children with delays occur in all families with children (Keogh, Bernheimer, Gallimore, & Weisner, 1998).

The theoretical as well as the practical issue has to do with the nature of family–child relationships and the effects on children’s development (Caldwell & Bradley, 1994; Sameroff, 1994). The accommodations by families are driven by the children’s cognitive status, but personal/social outcomes for children are, in part at least, a function of transactions between families and children. The findings of limited influence of family practices on the cognitive development of chil-
dren with delays does not negate the importance of family environments. It does underscore the need to expand the scope and content of research on families' adaptations to children with special needs and draws attention to the need to consider a range of child outcomes.

What are appropriate goals for children with developmental delays? What should be emphasized in early intervention? What child outcomes should be considered in program evaluation? These questions have both clinical and research implications, and the answers are not certain. Our findings confirm the stability of early cognitive delays, but underscore the variability among children in social/behavioral outcomes. This raises questions of the emphasis and content of intervention programs, including the possibility that the focus should be on personal/social and behavioral competencies, rather than on cognitive change. This is not to suggest that enhancing cognitive development should be ignored, but rather that personal/social characteristics and behavior may deserve to be the central focus of interventions.

An emphasis on personal/social competencies of children with delays also has implications for assessment and diagnosis. The emphasis on cognitive/language delays has produced a number of well-designed and well-tested measures for identification and diagnostic purposes (Bailey & Wolery, 1989). There are fewer differentiated and reliable approaches for assessing children's social, affective, and behavioral status (Harbin, Gallagher, & Terry, 1991). Thus, diagnosticians and clinicians who work with young children with delays often must rely on observation and on adults' reports, data sources that may contain threats to validity and reliability (Keogh & Bernheimer, 1998). Similarly, there are few well-developed systems for describing families and for determining family outcomes. A consequence is to rely on summarizing demographic markers (e.g., SES, parents level of education) to describe families. Yet our findings document wide variations in the functioning of families within demographically defined family groups. Income level does not determine how families function. This, of course, implies the need for clinicians and researchers to get beyond demographics to the functional level of family life.

From a policy perspective, our findings of cognitive stability, and of continuing need for special education services through school, may seem discouraging. However, we argue that these findings should not be construed as indicating a "failure" of early intervention. We underscore the variability in personal social outcomes, and note that these outcomes were unrelated to cognitive status. Another interpretation of the placement findings is that the children were appropriately identified early on (e.g., that the delays signaled long-term problems that required ongoing educational intervention). We find it encouraging that the term, developmental delay, although still not a precise diagnostic category, now provides opportunities for intervention from birth to 8 years of age. We also find encouraging the fact that the majority of our families are doing well. The divorce rate in both samples is well below the average for the state. In addition, while few children have "caught up," most of our families have been able to construct and maintain a daily routine of life that balances the needs of the child with those of other family members.

Finally, from a research perspective we underscore the benefits and the problems in conducting longitudinal studies. Our experience in both REACH and CHILD has increased our sensitivity to and understanding of methodological pitfalls and ethical considerations. Like other longitudinal researchers (Bergman & Magnusson, 1990; Egeland, 1991; Nesselroade & Reese, 1973; Nunnally, 1973; Werner & Smith, 1982, 1992), we faced questions of sampling criteria, of the validity, reliability, and appropriateness of measures and assessment techniques in different developmental periods, of possible effects of repeated testing, and of investigator bias in interpretation of interview data. We also were aware of possible cohort effects, given the policy and legislative changes affecting services in the 10 years between studies. A serious problem had to do with the use of standardized tests with children with significant developmental delays, as many of the usual measures have heavy language demands, and the majority of children in both studies were delayed in language development. We also note the practical and analytic problems of dealing with increasingly large data sets over time, at the same time recognizing that there were additional or different data that should have been collected. The "why didn't we" question appeared and reappeared with some regularity.

In addition to methodological issues, over time we became aware of the changing nature of researcher-parent relationships, and of the impact of our research on parents and families (Keogh & Bernheimer, 1998). In initiating both of our studies, we made it explicitly clear that these were research efforts, not interventions. Yet over the years it was apparent that the lines between research and interventions were increasingly blurred. Although we provided only occasional referrals or referral information, something unfolded over the years that we did not anticipate. Despite our continuing efforts to define our work as research, over time more and more parents viewed us as advocates, resources, and friends. One mother in the REACH study said that the project was the most effective intervention she and her child had experienced. We interpreted this as evidence of the importance of stable and ongoing professional-parent relationships, the significance of letting parents tell their stories, and the value of listening to them.

We also became aware of the impact of our research on the families themselves. For example, our policy was to test the children in their homes, encouraging parents to be present, on the assumption that the setting would "demystify" the assessment process. Over time we found that fewer and fewer parents participated in the assessment, as for many this documented the discrepancies between their child's status and "normal" expectancies. The repeated testings appeared to have little effect on the children, but became increasingly painful for parents. Closely related, we were concerned about negative feedback to parents, given the possible
effects on their expectations for their children’s futures. Similar questions arose in regard to information given to teachers and other professionals.

We conclude with the observation that our research in these two projects has changed our views and enhanced our understanding of children with developmental problems and their families. We have been impressed with the range of personal and social outcomes of the children, with the resilience and commitment of the families, and with the positive adaptations and accommodations they have made. As we came to know these children and their families we were increasingly aware of the effects of being good listeners, rather than dispensers of information or advice. Despite the many problems and pitfalls in longitudinal research, we are convinced that it was the continuing research effort over time that allowed us to understand the course of development for both children and families.

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