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ABSTRACT

These three papers report preliminary findings of an early intervention collaboration study on developmentally vulnerable infants and their families in Massachusetts and New Hampshire. Subjects, 190 infants with Down syndrome, motor impairment, or developmental delays of unknown etiology, were recruited from 29 community-based early intervention programs. Each child was evaluated at home, then again after 1 year of service, and at the time of the child's third birthday. The research design also calls for evaluating the child at 6 weeks after preschool entry, and at age 5. The study focuses on: first, the measured effects of distinct aspects of the early caregiving environment on child competence; second, tendencies toward stability in the adaptation of families of children with disabilities; and third, the existence of identifiable subgroups of children and families who demonstrate greater degrees of vulnerability or resilience. The second paper, by Marty Wyngaarden Krauss, specifically addresses stability and adaptation concluding that: (1) mothers in the study did not experience atypical amounts of depression or stress; (2) other sources of stress impact families of children with disabilities; (3) an increased risk for parental stress occurs as behavior problems become manifest; and (4) family cohesiveness and the informal support network serve different functions. The third paper, by Penny Hauser-Cram, focuses on outcomes for the subgroups of children with severe cognitive/psychomotor impairment, children with seizure disorders, and children whose mothers demonstrated large increases in their interactive parenting skills. (DB)

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CONCEPTUAL ISSUES IN THE DEVELOPMENT OF VULNERABLE INFANTS: FINDINGS FROM THE EARLY INTERVENTION COLLABORATIVE STUDY

Paper Symposium

Chair: Jack P. Shonkoff

Presenters: Jack P. Shonkoff
Marty Wyngaarden Krauss
Penny Hauser-Cram

Discussants: Bettye Caldwell
Keith Crnic

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Presented at the 60th Anniversary Meeting of the Society for Research in Child
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CONCEPTUAL ISSUES IN THE DEVELOPMENT OF VULNERABLE INFANTS: FINDINGS FROM THE EARLY INTERVENTION COLLABORATIVE STUDY

The need for an integrated framework to guide the study of developmentally vulnerable infants and their families presents a major challenge to both researchers and policymakers. The Early Intervention Collaborative Study was established in 1985 at the University of Massachusetts Medical School to address this challenge through the pursuit of three interrelated goals:

-- INSERT SLIDE 1 HERE --

(1) to investigate the predictors of vulnerability and resilience and thereby enhance our understanding of variations in the development of young children with disabilities and in the adaptation of their families over time; (2) to contribute to the knowledge base that informs social policy by analyzing the mediating influences of family ecology and early intervention services on selected child and family outcomes; and (3) to generate conceptual models of child development and family adaptation to guide future research on children with special needs.

-- INSERT SLIDE 2 HERE --

The first phase of the study was designed to test hypotheses about the unique contributions of child and family characteristics, and early intervention services, to changes in child competence and family adaptation over the first year of participation in an early intervention program. Phase II was designed to study the durability and stability of these effects and to test hypotheses regarding the predictors and mediators of ongoing child and family development through the preschool years. During the first phase, each child and family was evaluated at home within 6 weeks of their enrollment in an early intervention program (T1) and again after one year of service (T2). The research design for the preschool phase includes three data points: in-home child and family assessments at the time of the child's third birthday (T3), classroom observations and collection of teacher information 6 weeks after the child's preschool entry (T4), and in-home child and family assessments and school-based data collection at age 5 years (T5).

The initial study sample was recruited from 29 community-based early intervention programs in Massachusetts and New Hampshire between November, 1985 and December, 1987. Children and families were enrolled at the time of program referral, based on the child's presenting problem, yielding a sample of 190 infants with Down syndrome (mean age at entry = 3.4 months), motor impairment (mean age at entry = 11.5 months), or developmental delays of uncertain etiology (mean age at entry = 16.0 months), with an overall mean age at study entry of 10.6 months.

-- INSERT SLIDE 3 HERE --

At T3, the study sample of 160 included 51 children with Down syndrome, 72 with motor impairment, and 37 from the original group with developmental delay, reflecting an aggregate retention rate of 84%. The sample was 89% white and 56% male.

-- INSERT SLIDE 4 HERE --

Seventy-six percent of the children had an initial Bayley Mental Developmental Index of 50 or greater and 24% were classified as moderately to severely impaired with an MDI of less than 50 at study entry. In general, the children were quite healthy, although one-quarter had congenital heart defects (primarily among those with Down syndrome) and one-fifth had a seizure disorder (primarily among those with motor impairment).

-- INSERT SLIDE 5 HERE --

Despite their relative racial homogeneity, sample families represent a fair degree of socioeconomic diversity. The mean maternal education level was 13.8 years. Forty-five percent of the mothers completed a high school education or less; 14% had more than 4 years of college. At the time of the T3 data collection, the mean family income was between \$20,000 and \$30,000 per year. Sixteen percent of the sample had an annual income of less than \$10,000; 52% earned more than \$30,000 per year. Eighty percent of

the mothers were married and half were working outside the home at the time of their child's third birthday.

Child and family data were collected during home visits that were conducted independently of the service delivery system. All study findings related to child development and family adaption after the first year of service are described in a recent SRCD monograph. Today's symposium extends the Phase I analyses to include assessments of child and family adaptation through age 3 years.

Three conceptual themes will be addressed. First, that the measured effects of distinct aspects of the early caregiving environment on specific domains of child competence become more pronounced during the preschool period. Second, that there are general tendencies toward stability in the adaptation of families of children with disabilities. And third, that there are identifiable subgroups of children and families who demonstrate greater degrees of vulnerability or resilience in their development. Each of these themes will be presented, followed by a discussion of the implications of our study findings for further research and for the development of public policies for children with developmental disabilities.

Characteristics of Children at T₃ (n = 160)

	%	n
Down Syndrome	32	51
Motor Impairment	45	72
Developmental Delay	23	37
Male	56	89
Female	44	71

Severity of Cognitive Impairment T₁ (n = 160)

Bayley MDI	%
< 50	23.8
≥ 50	76.2

Characteristics of Mothers at T₃ (n = 160)

Maternal Education	Mean = 13.8 yrs.
Family Income	Mean = \$20,000 - \$30,000
Married	80%
Employed	50%

STABILITY AND CHANGE IN THE ADAPTATION OF FAMILIES
OF CHILDREN WITH DISABILITIES

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Paper presented at the 1993 Society for Research in Child
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Retardation, Heller School, Brandeis University.

STABILITY AND CHANGE IN THE ADAPTATION OF FAMILIES
OF CHILDREN WITH DISABILITIES

One goal of our study has been to understand the extent to which patterns of parental adaptation are characterized by stability or change during the early childhood period. We have also focused on understanding factors that contribute to or buffer parents from adaptational difficulties. Parental stress has been used as an indicator of adaptation in research and clinical settings for decades. We have tracked parental stress for our sample of families, using the Parenting Stress Index. This measure is a fairly commonly used instrument among families with and without atypically developing children. It yields scores for two broad domains, namely parenting stress, defined as the stress associated with personal impacts of being a parent, and child-related stress, defined as stress associated with the child's temperamental and behavioral characteristics.

Issue 1: Stability and Change in Parental Adaptation

We now have collected PSI data from 115 families over three measurement points--upon entry into EI (Time 1), one year later (T2), and around the child's graduation from EI at age 3 (T3). (SLIDE 1). As shown on the first slide, the average scores for parenting stress have not changed significantly over these three measurement periods. At T1, the average score was 118; at T2, it was 119; and at T3 it was 121. Further, as shown on SLIDE 2, the average scores for child-related stress are also fairly stable over these three measurement periods. At T1, the average score was 100;

at T2, it was 103; and at T3, it was 105. Thus, we conclude that stability in maternal adaptation is more common than dramatic change during the early childhood period-- at least as far as parenting and child-related stress are concerned.

It is also useful, however, to examine specific aspects of parenting stress. For today's discussion, I'll focus on two indicators of how the mothers, as individuals and as parents, are doing. These indicators are: (1) maternal depression and (2) stress associated with a sense of competence as a parent. The reasoning is as follows. There is a great deal of research that investigates the effect of maternal well-being on the social, emotional, and cognitive development of children with disabilities. There is also a growing interest in the factors that contribute to the well-being of mothers who have experienced the dramatic event of being a parent for a child with substantial disabilities.

The two outcomes selected for today's session were chosen because they represent salient issues for mothers. Specifically, there is a great deal of literature which suggests that depressive feelings plague mothers (in particular) of children with developmental problems. Relatedly, one of the major challenges facing mothers of children with disabilities is to develop a sense of competence as a parent. Feeling comfortable with one's parenting instincts is a developmental task for most parents; for parents of children with disabilities, there are few guidelines that can reassure them that their instincts and parenting strategies are correct or effective. After three years of

parenting, and after a presumably significant experience as a recipient of early intervention services, stress related to feelings of incompetence as a parent should be a succinct marker of parental well-being. As one would expect, scores on these two outcomes were statistically correlated ($r=.65$, $p<.001$). However, we have found important differences in the factors affecting depression and sense of incompetence.

I should note that the mean scores for both depression [$x=19.7$ for EICS sample vs. 20.4 for stand. sample] and stress related to parenting competence [$x=28.7$ for EICS sample vs 29.2 for stand. sample] are comparable to the mean scores for the standardization sample of the PSI. That is to say, as a group, the mothers in this sample were no more stressed by feelings of depression or incompetence as parents than mothers of comparably aged children without disabilities. There is, however, variability in the measured amount of stress among mothers, so our focus is on factors associated with more or less parenting stress among mothers of three year old children with disabilities.

Issue 2: Factors Affecting Parental Adaptation

For today's session, we have focused on the role of 5 specific factors: (1) family income, (2) significant negative life events that are not (presumably) related to the child, (3) the perceived helpfulness of the support received by the mother, (4) the extent to which the mother views her family as a cohesive, supportive unit, and (5) the level of the child's behavior problems. As Jack has just described, we have found that child behavior problems are

affected by the level of family cohesion. Thus, the analyses on parenting stress enable us to extend our focus on the interrelationships among different domains of family life and the children within the families as they affect parenting well-being.

Thus, these five factors reflect our interest in understanding the effects of normative stressors--such as differences in income and negative life events, the effects of different spheres of support--such as from natural support networks and the family's emotional climate, and the effects of what may be emerging as a significant characteristic for some children with disabilities--namely behavior problems that are manifest around the age of 3 years.

As Jack noted earlier, there is considerable variability in the financial resources of the families used in these analyses. Let me also say a word about negative life events. We examined the incidence of 11 negative events during the year prior to the child's third birthday. As shown on SLIDE 3, nearly half (47%) of the sample had experienced at least one negative event. The most common were related to financial issues (such as decreases in income or going into debt) or to experiencing a death in the family. Other types of events--such as legal problems, separation or divorce--were experienced by almost 10% of the sample.

Our measure of helpfulness of social support is based on the sum of the ratings of helpfulness, using a 5 point scale, for 16 potential sources of support [$x=10.1$ sources of support]. On average, mothers rated their sources of support as between

moderately and quite helpful.

Our measure of family cohesiveness was derived from the Family Environment Scale, a 90 item self-administered instrument that measures 10 dimensions of the family environment [\bar{x} =7.4 for cohesion subscale].

We also examined an important child-related stress--namely, the extent of child behavior problems, as measured by the externalizing score on the Child Behavior Checklist. While there was a broad range in the T-scores on this subscale [from 28 to 73], only one child had a T-score above 70, the cut-off indicating clinically significant levels of behavior problems. I should note that in preliminary analyses, we examined the relation between the severity of the child's psychomotor disability, as measured by the Bayley Scales or the McCarthy Scales, and found no significant relation between the severity of impairment and parenting stress.

In order to examine the effect of these 5 factors on maternal depression and sense of incompetence, we conducted hierarchical regression analyses. SLIDE 4 presents the results for the analysis of maternal depression as measured around the time of the child's third birthday. Overall, 31% of the variance in maternal depression scores was explained by the five variables used in the analysis. The largest single contributor to the explained variance was family cohesion, which added 11% unique variance, after the influence of family income, negative life events and satisfaction with support were taken into account. However, even after these

well-acknowledged sources of stress were accounted for, child behavior problems accounted for an additional 8% of the variance in maternal depression.

With respect to sense of competence (SLIDE 5), 35% of the variance was explained by the 5 variables. Interestingly, all five variables added significantly to the explained variance. The largest incremental increase, however, was attributable to the influence of child behavior problems, which added 11% unique variance after all the other sources of stress were entered into the equation.

Conclusions

Let me summarize what we perceive to be the important findings from these analyses. First, it is becoming increasingly untenable to assert that most or even many families of children with disabilities are at high risk for negative or pathological outcomes. Our results indicate that, in general, mothers were not experiencing parental depression or stress associated with their parenting skills at levels that are atypical of mothers of children without disabilities. Granted, pockets of negatively affected mothers exist, and we have found elsewhere that percentage may increase as the children age. However, the long dominant image of most mothers falling apart and remaining emotionally fragile does not seem substantiated.

Second, for families of young children with disabilities, there are many other sources of stress besides the child with a disability. It is easy to define a family by the most visible

"problem" it has and to forget that these families also experience disruptive changes in family income, stress on the job, deaths of family members, etc. For most families of young children, this stage of the family life cycle is marked by change, not stability, in life circumstances. Parental careers are being developed, changes in family finances can occur precipitously, new members are being born, etc. Our models of family adaptation need to be cognizant of the multiple and varied changes and stressors that most families in this stage of life experience.

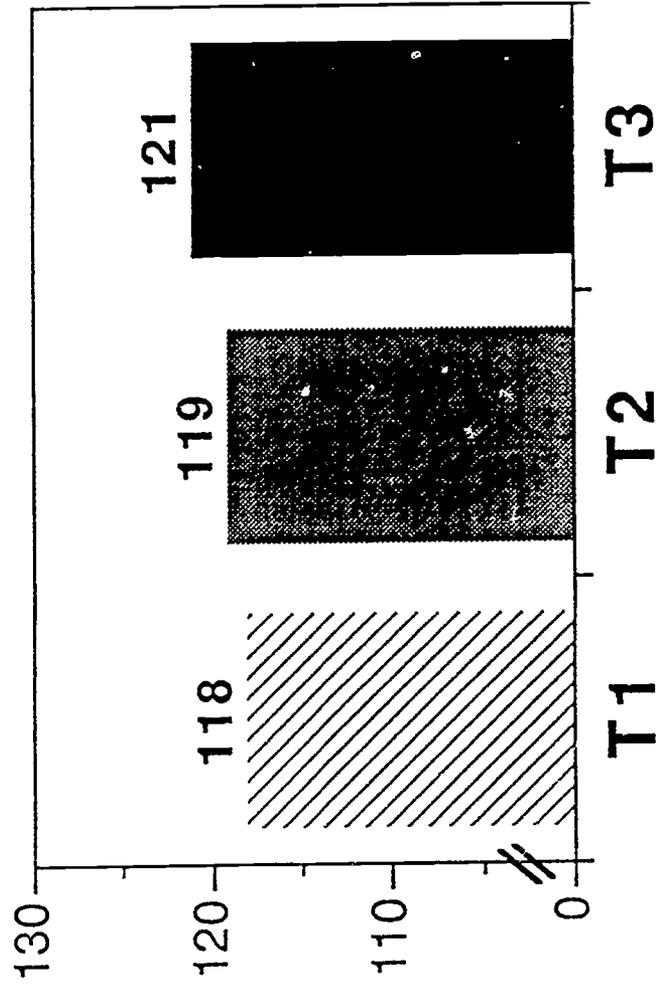
Third, as behavior problems in young children become manifest, there is an increased risk of greater stress for mothers. Interestingly, the severity of the child's cognitive impairments is not a factor in parenting stress. Rather, children with more intense behavior problems, even among a sample which doesn't manifest clinically significant levels of behavior problems, present increasing difficulties for their mothers.

Fourth, while both the family environment and feelings of being supported by one's informal network are consistent predictors of maternal well-being, there were subtle differences in the role that each sphere of support exerted. Depression in mothers was much more strongly predicted by the cohesiveness of the family environment than by their satisfaction with social support. For maternal stress associated with feelings of parenting competence, every factor examined contributed significantly to the explained variance. It appears that perceiving one's family as cohesive provides a critical zone of safety for mothers. Too often the

needs of the child may seem the most important issue--to parents and to service providers. It is clear from these analyses that sustaining and enhancing high quality family environments should be a priority.

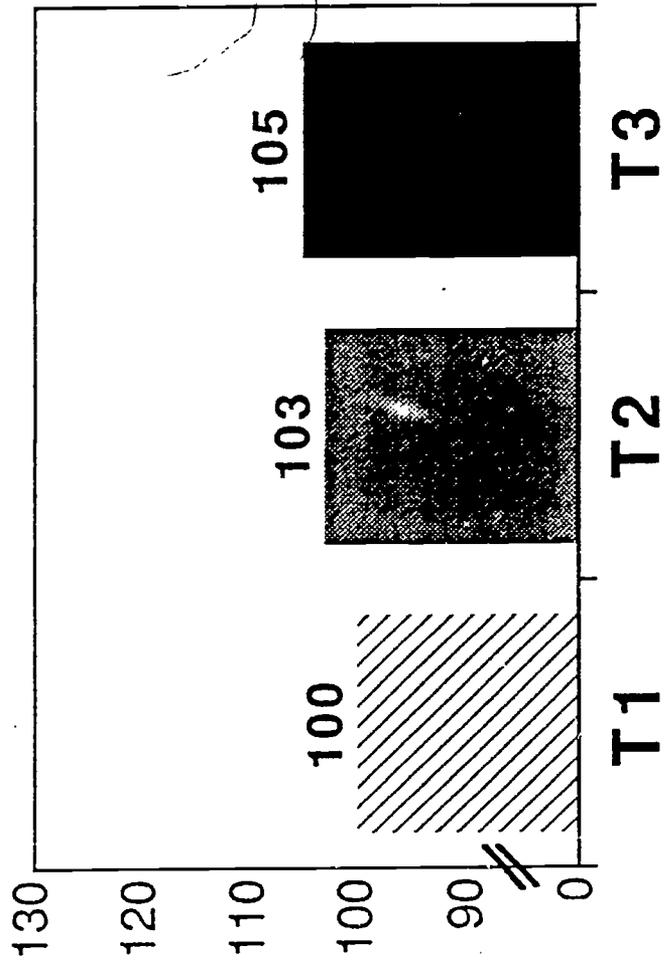
SLIDE 1

Parenting Stress Scores (n = 115)



SLIDE 2

Child-Related Stress (n = 115)



SLIDE 3

Life Events

*47% experienced
at least one event*

Decrease in income	18 %
Went into debt	17 %
Death in the family	14 %
Legal problems	9 %
Other relative moved in	9 %
Separation	9 %
Divorce	5 %
Alcohol / Drug	5 %

Regression Analysis of Maternal Depression

	R ² Change	Beta
Income	.03	.036
Life Events	.06**	.138
Helpfulness of support	.02	-.038
Family cohesion	.11***	-.300**
Child behavior problems	.08***	.325***
TOTAL R ²	.31	

** p < .01

*** p < .001

Regression Analysis of Stress Related to Sense of Competence

	R ² Change	Beta
Income	.08**	-.085
Life Events	.05*	.092
Helpfulness of support	.05*	-.152
Family cohesion	.06**	-.194*
Child behavior problems	.11***	.371***
TOTAL R ²	.35	

* p < .05

** p < .01

*** p < .001

VULNERABILITY AND RESILIENCE IN CHILDREN WITH
DISABILITIES AND THEIR FAMILIES

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Development Meeting, New Orleans, LA, March 27.

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VULNERABILITY AND RESILIENCE IN CHILDREN WITH DISABILITIES AND THEIR FAMILIES

One of the important tasks in pursuing longitudinal research is to identify unusual subgroups--that is, children or families who change either more or less than we expect-- and to understand more fully what has contributed to those changes. On a pragmatic level, by identifying subgroups of vulnerable or resilient children early in their development, we may be able to provide more appropriate and targeted intervention services. On a theoretical level, by understanding the development of children in specified subgroups, we may be able to develop new conceptual models that make sense not only for mean development of the average child but also for children with diverse developmental trajectories.

During the first phase of this study (when children were infants or young toddlers) we identified several subgroups of children and families whose development differed significantly from that predicted based on traditional predictors, such as type of disability or family socioeconomic status. I'd like to discuss our findings at age three years for three of these groups with you today. The three groups are: (SLIDE 1)

1. Children with severe cognitive/psychomotor impairment
2. Children with seizure disorders
3. Children whose mothers demonstrated large increases in their interactive parenting skills

The first two groups are children who are not progressing as well as predicted, whereas the third group is composed of children who are exceeding predictions in terms of their development.

Although it may not seem surprising that children with severe cognitive impairment and children with seizure disorders are progressing only slowly in terms of their development, it is instructive to understand the way that development diverges for these two vulnerable groups.

(SLIDE 2) First, a note about the way these slides are presented. In order to visually compare the performance of each subgroup on a range of outcomes, the outcomes were standardized, and the bar charts were developed based on the standardized scores. For each outcome the subgroup is represented by the bar on the left, the rest of the sample by the bar on the right. The bars in violet represent significant differences. The actual mean scores for the nonstandardized measure is presented above each bar.

A total of 38 children for whom we have data at age 3 years had Bayley scores of less than 50 at entry to this study. [This group included 3 children with Down syndrome, 27 children with motor impairment, and 8 children with developmental delay; 8 of the children had been premature; the group is almost equally divided in terms of gender (20 males, 18 females).] Compared to our sample as a whole, even controlling for their initial status scores, we found these children to demonstrate less progress in certain areas of development. At age 3 their cognitive scores remain very low, their mental age (based on either the Bayley Scales or the McCarthy Scales) at 36 months averages 13.8 months, their adaptive behavior (based on the Vineland Scales of Adaptive Behavior) averages 14 months. Their level of play (based on an adaptation of the Belsky-Most Scale) has not reached a level of even preliminary pretense

Interestingly, however, they do not differ from other children in the EICS sample in terms of their interactive skills with mothers (based on the Nursing Child Assessment Teaching Scale) (NCATS). (SLIDE 3) Their parents adaptive behaviors differ from those of other families in only one important way: mothers are reporting higher levels of stress relating to their child (based on the child domain of the Parenting Stress Index). Multivariate analysis of variance conducted on the subscales indicated that the "acceptability" subscale contributed the most to this finding; that is, mothers expressed high levels of stress about their child's acceptability. This subscale contains items, such as "My child looks a little different than I expected and it bothers me sometimes" and "My child doesn't do as much as I expected." On other parent outcomes this subgroup does not differ from other families in the study.

A total of 30 children were reported by physicians during Phase One of this study to have some form of seizure disorder. The bulk of these children were motor impaired (19). [3 children had Down syndrome, 8 children were developmentally delayed; 9 of the children in this subgroup had been premature, and the subgroups consists of almost equal numbers of males (17) and females (13).] These children did not differ from other children in this study on child development indices at entry to the study (i.e., during infancy). (SLIDE 4) In terms of child outcomes, this subgroup is significantly lower than other sample members on mental age, adaptive behavior, and spontaneous play. This pattern of delay is

similar to that seen in the prior subgroup--children with severe cognitive impairment. One point is noticeably different, however. This subgroup is significantly poorer than other sample children in their interactive skills with their mothers. (This was not found for children with severe cognitive impairment.) (SLIDE 5) In addition, mothers of children with seizure disorders differ from other mothers in their interactive behaviors with their child. Although it is impossible to know the extent to which the development of children with seizures is compromised primarily by CNS dysfunction or proportionately more by medication effects, these results indicate that dyadic mother-child interaction is a particularly vulnerable area for children with seizure disorders. Since this same vulnerability does not exist for children who are extremely impaired cognitively, and since we had no indication of poor maternal interactive skills in this subgroup at earlier data collection points, we believe these results indicate an effect of seizures on mother-child interaction over time.

The third subgroup is composed of the 20 children whose mothers demonstrated large increases in their interactive skills during the first year of the study. Specifically, these mothers increased by more than one standard deviation on the two growth-promoting subscales (cognitive growth and social-emotional growth) of the NCATS. Examples of items are: "the parent uses verbal description and modeling simultaneously in teaching any part of the task," and "the parent praises the child's effort at least once during the episode." Neither the mothers in this subgroup nor their

children differed significantly from the rest of the EICS sample in terms of demographic variables. [Children were almost equally divided into the three types of disability groups, 4 children had been premature, and about two thirds of the children (13) were male.]

(SLIDE 6) Analyses of child outcomes at age 3 revealed that these children had significantly higher cognitive performance and adaptive behavior. MANOVA tests indicated that the communication subscale on the Vineland contributed to the overall significant difference in adaptive skills. (SLIDE 7) Analyses of the parent outcomes indicated that these parents reported having significantly lower levels of stress related to their child than did other sample members.

Conclusions

There are several important points to be gleaned from these analyses. First, although children with severe cognitive impairment differed from the rest of the sample during infancy, the children with seizure disorders and the children of mothers with large interactive gains did not differ from other children developmentally at study entry. Observed differences emerged during assessments performed after one year of early intervention and were more pronounced during the age 3 assessment. Second, we have a paucity of research on the developmental progress of children with seizure disorders. These results highlight the importance of further understanding the needs of children and

families in this particular subgroup. Third, parents of these three subgroups did not differ on demographic indices from other parents. This suggests that demographic differences per se would not be a useful characteristic on which to base predictions of the development of children with seizures or severe cognitive impairments. Finally, the salience of dyadic interaction between mothers and children with disabilities is underscored by the results of the vulnerable subgroup of children with seizure disorders and the resilient group of children whose mothers improved in interactive skills.

Characteristics of Mothers at T₃ (n = 160)

Maternal Education	Mean = 13.8 yrs.
Family Income	Mean = \$20,000 - \$30,000
Married	80%
Employed	50%

Characteristics of Children at T₃ (n = 160)

	%	n
Down Syndrome	32	51
Motor Impairment	45	72
Developmental Delay	23	37
Male	56	89
Female	44	71

Severity of Cognitive Impairment T₁ (n = 160)

Bayley MDI	%
< 50	23.8
≥ 50	76.2

Subgroups Identified in Phase I Analyses

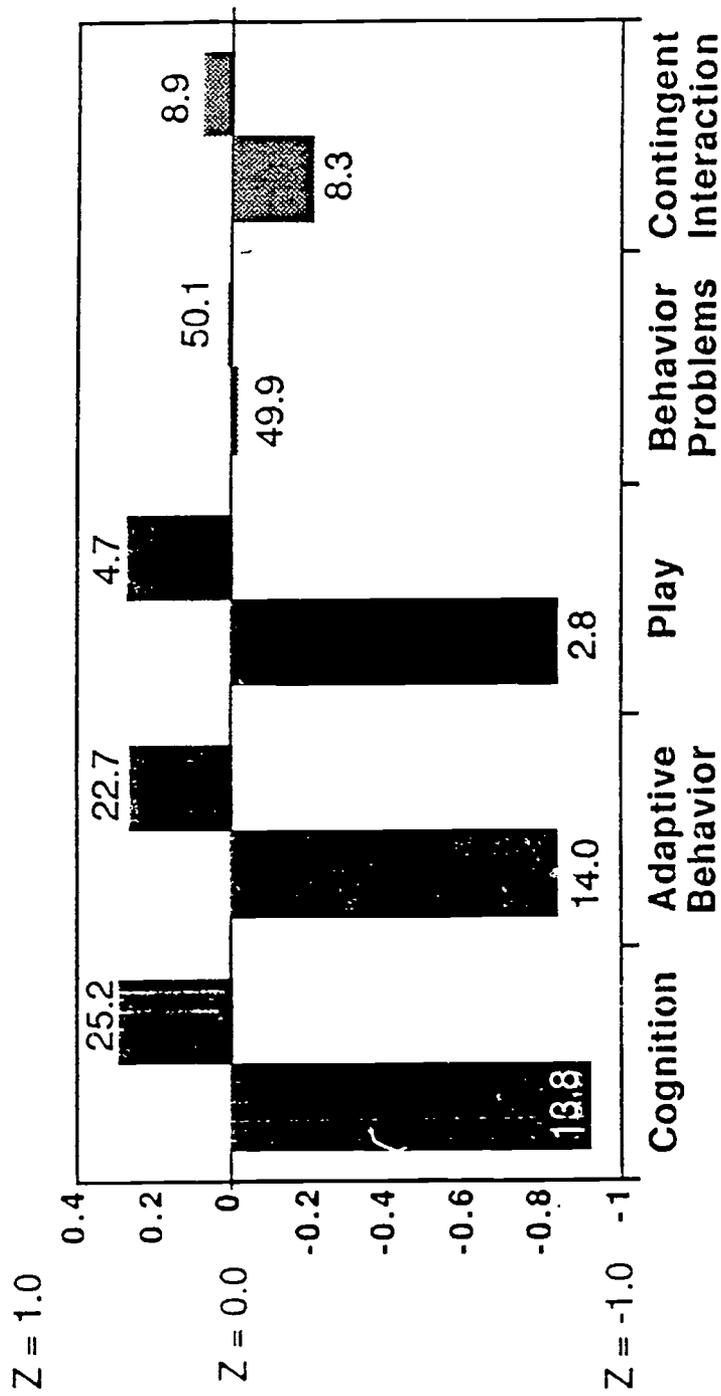
Vulnerable Groups

- Children with severe cognitive impairment
- Children with seizure disorders

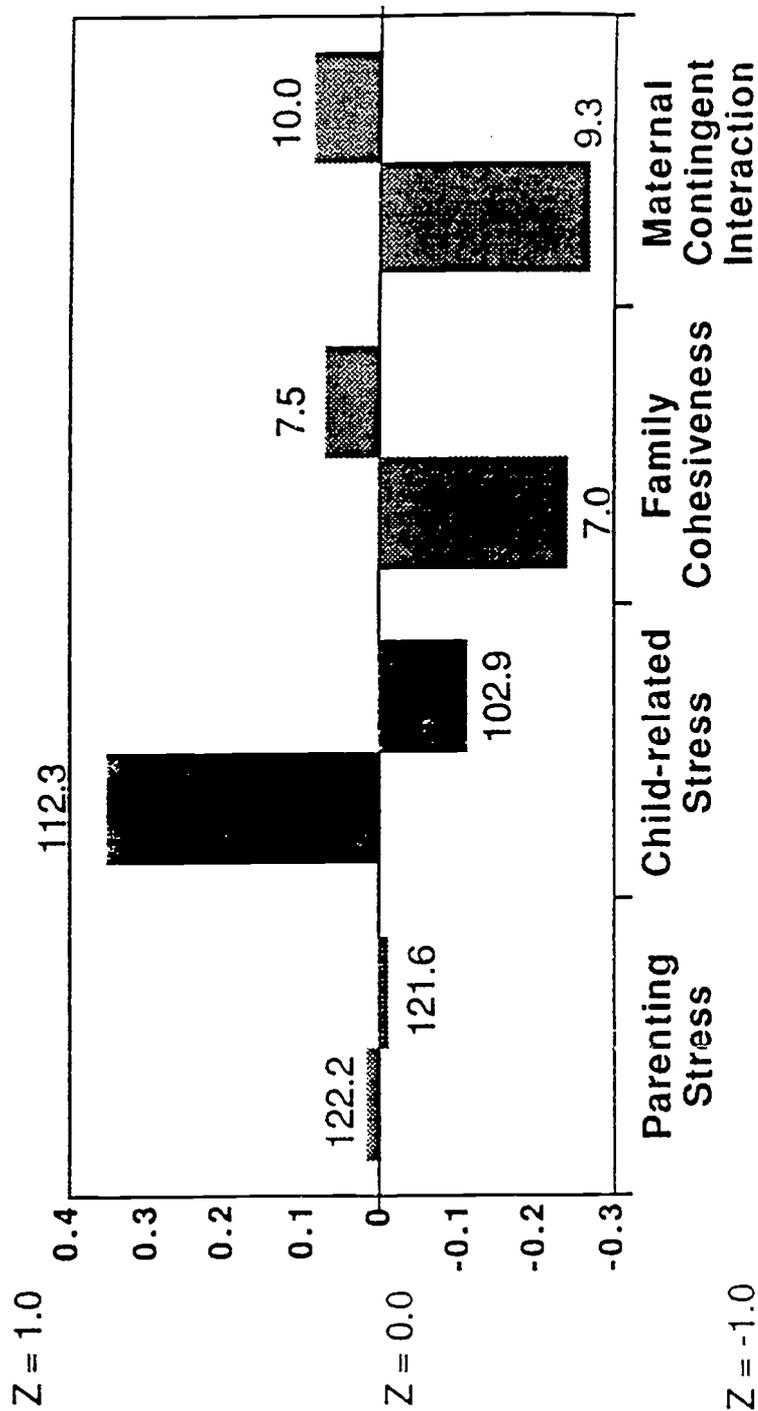
Resilient Group

- Children whose mothers demonstrated substantial increase in their interactive skills

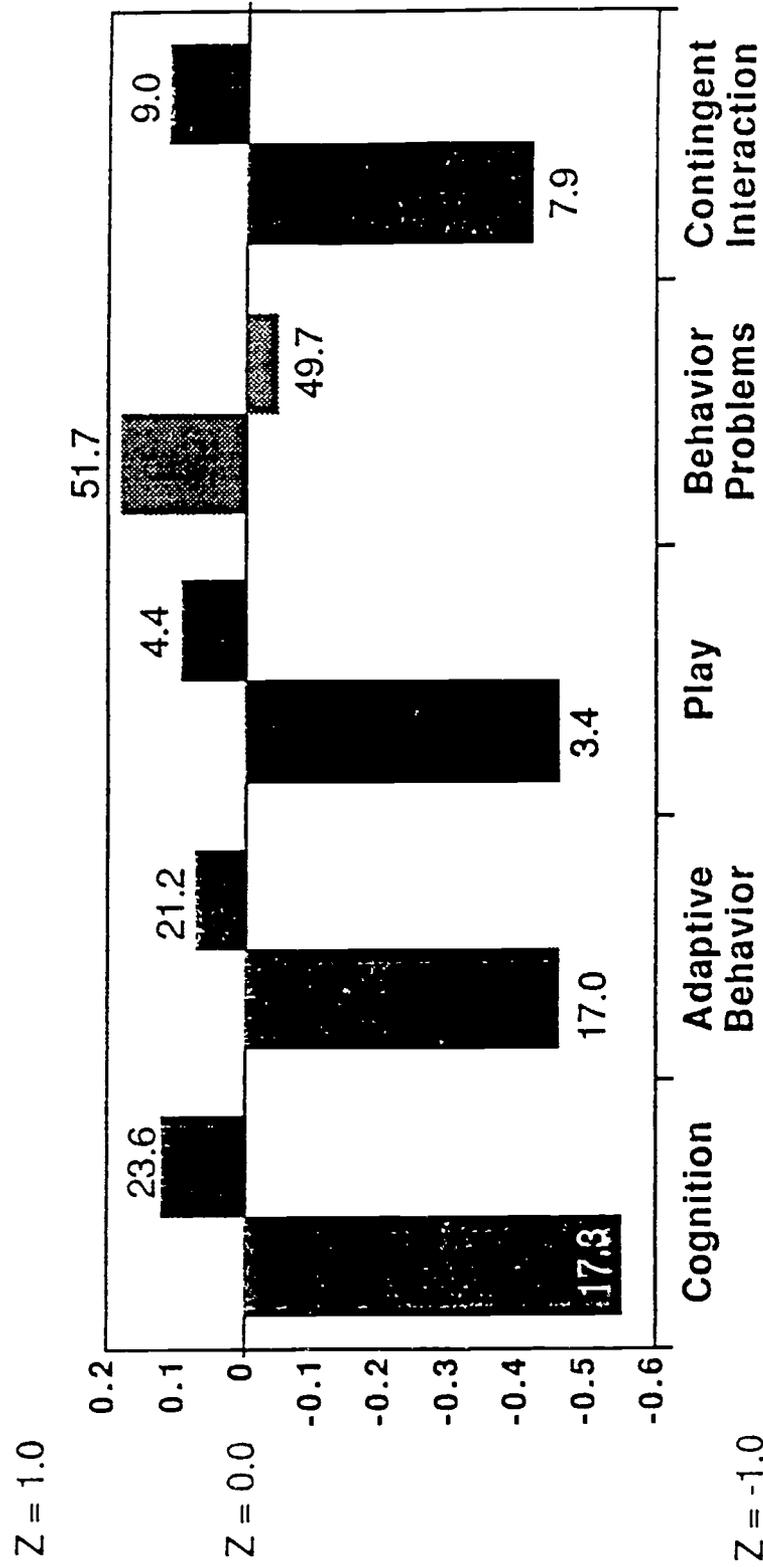
Child Competence at T₃ for Children With and Without Severe Cognitive Impairment



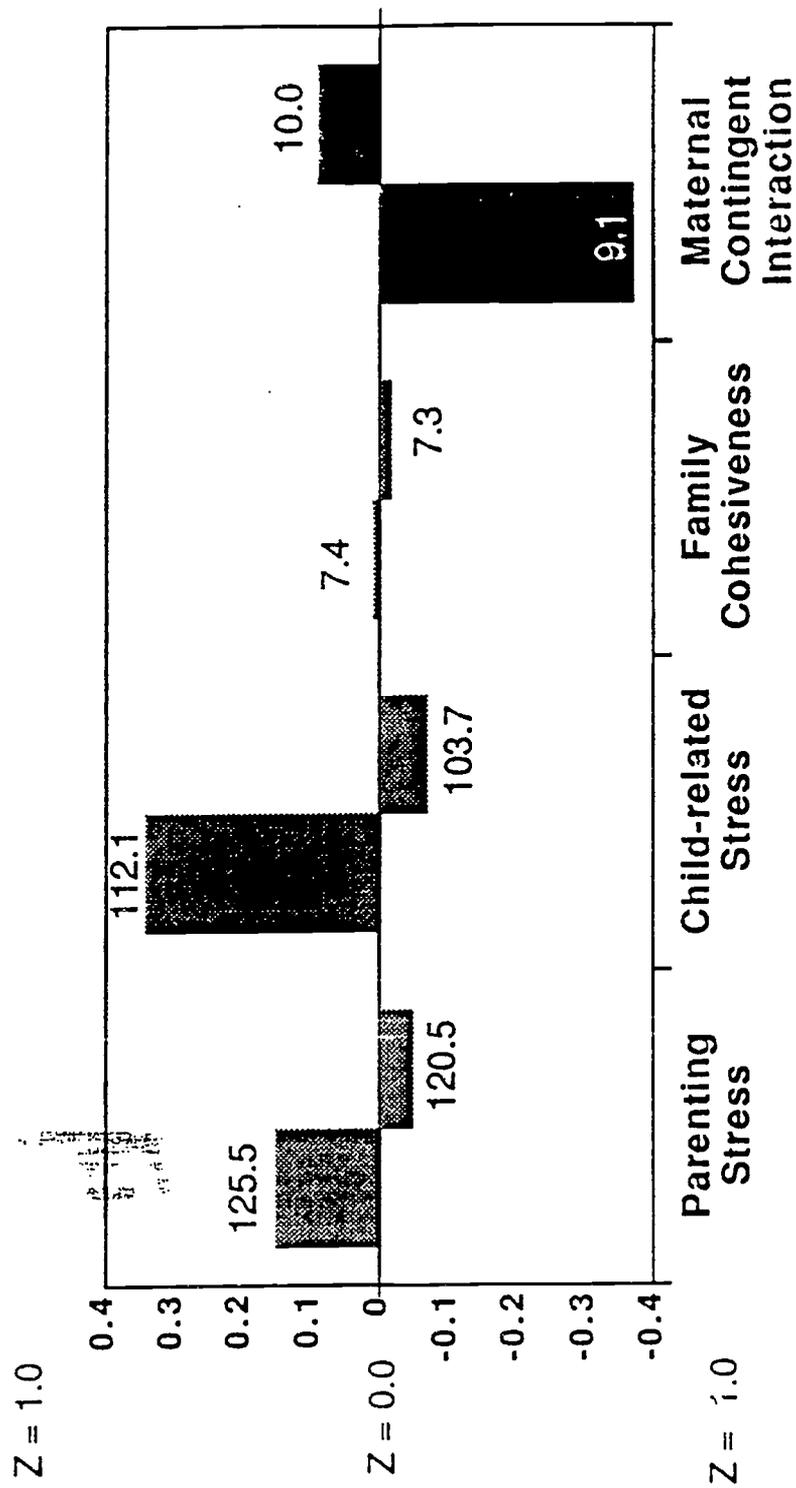
Parent Adaptation at T₃ for Children With and Without Severe Cognitive Impairment



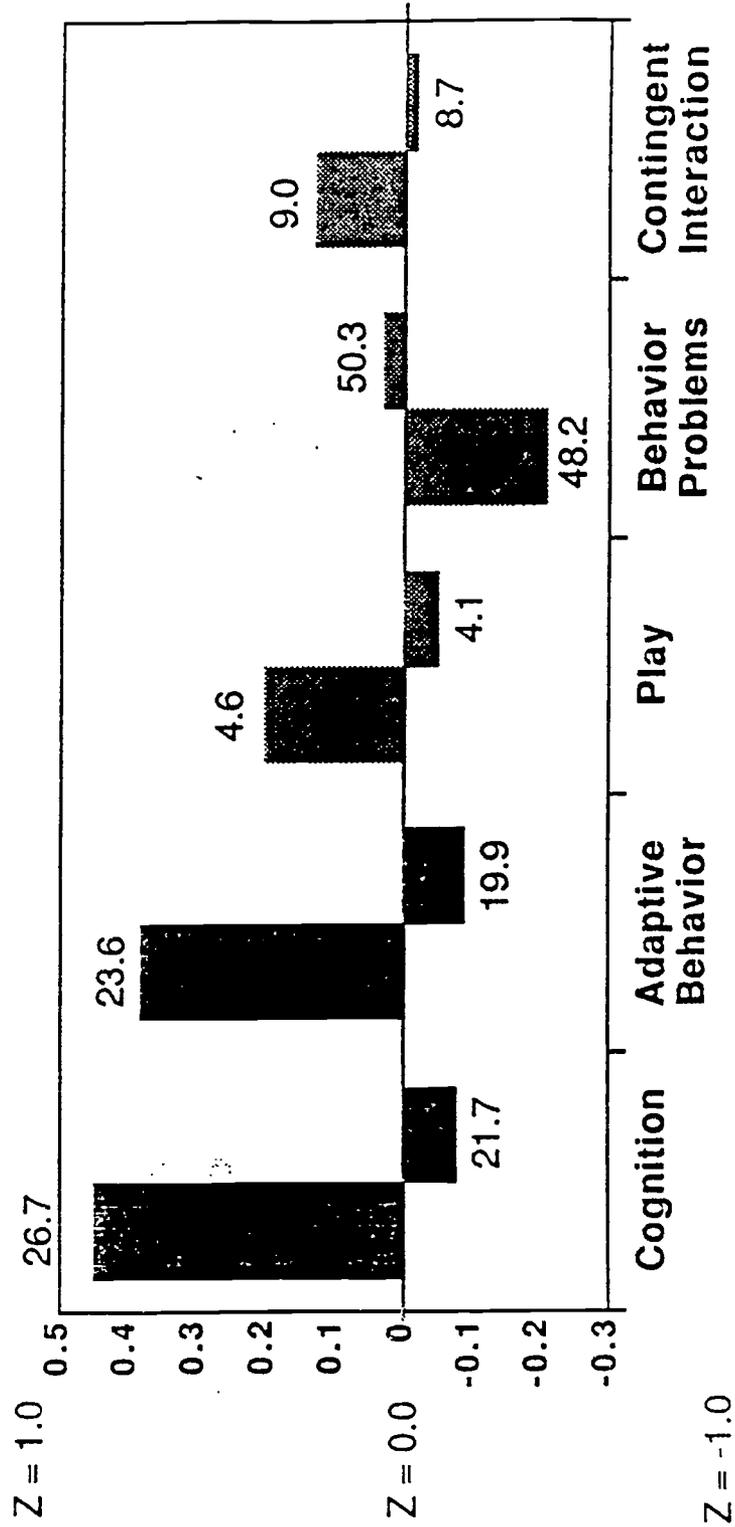
Child Competence at T₃ for Children With and Without Seizure Disorders



Parent Adaptation at T₃ for Children With and Without Seizure Disorders



Child Competence at T₃ for Children of Mothers With and Without Large Interactive Gains



Parent Adaptation at T₃ for Children of Mothers With and Without Large Interactive Gains

