



Research Roundtable Summary

23

**TWENTY-
THIRD**

in a Series of Seminars

on MCHB-funded

Research Projects

The Early Intervention Collaborative Study

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Reaction

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About This Series

The Research Roundtable Series, sponsored by the Maternal and Child Health Bureau (MCHB), disseminates the results of MCHB-funded research to policymakers, researchers, and practitioners in the public and private sectors. The results of these projects influence future service, research, and policy development. The Research Roundtable sessions provide an opportunity for researchers to discuss their findings with policymakers, MCH program directors, service providers, and other health professionals.

The MCHB Research Program is directed by Dr. Gontran Lamberty and administered through the Division of Systems, Education and Analysis, MCHB, Health Resources and Services Administration (HRSA). HRSA is a component of the Public Health Service, U.S. Department of Health and Human Services. The purpose of the MCHB Research Program is to support applied research that shows promise of substantial contribution to the advancement of maternal and child health services.

Introductions

Dr. Rosalind B. Johnson introduced the speakers for the Research Roundtable. Penny Hauser-Cram, Ed.D., is an associate professor of developmental and educational psychology at Boston College. Her major research focus has been the development of children with disabilities and the adaptation of their families. She has also conducted studies on the long-term effects of early education on youth and the effects of family support programs on children growing up in poverty. In addition to writing two books and contributing to many others, she has published articles in various journals, including the *Journal of Pediatrics*, *Developmental and Behavioral Pediatrics*, *Monographs of the Society for Research in Child Development*, and *Child Development*. She received her doctorate from Harvard University, where she was co-chair of the *Harvard Educational Review*.

Rebecca Reid Fewell, Ph.D., is a professor at the University of Miami School of Medicine. She is also the education director of the Mailman Center for Child Development and the director of The Debbie Institute. Dr. Fewell has published extensively in such journals as *Pediatrics* and the *Journal of Developmental and Behavioral Pediatrics*. She has also coauthored books and monographs on children with special needs. Dr. Fewell was the editor of *Topics in Early Childhood Special Education* and has been a guest reviewer for *Developmental Psychology and Child Development*.

Presentation of Research and Relevant Findings

Statement of the Problem

The care of children with persistent health or developmental problems has been a core focus of maternal and child health services since programs for “crippled children” were instituted under the original Title V provisions of the Social Security Act of 1935. This mandate has been intensified by subsequent legislation calling for a commitment to family-centered, community-based, coordinated care for children with special health care needs. Unlike traditional therapeutic services, which focused exclusively on the child, contemporary early intervention (EI) for young children with disabilities (as guided by Part C of the Individuals with Disabilities Act) is designed to enhance the nurturing and growth-promoting capacities of the caregiving environment. The Early Intervention Collaborative Study (EICS) was designed to respond to the growing tension between the heightened demand for comprehensive services and the increasing strain on public resources. To address this problem, our study empirically investigated the extent to which characteristics of children, families, and the caregiving environment at discharge from EI predict children’s functioning and parental well-being during the middle childhood period; the study may thereby help in the estimation of relative service needs.

Research Objectives

The findings of the infant and toddler period of EICS were reported in a monograph published by the Society for Research in Child Development¹ and were discussed at the Fifth Research Roundtable (1993), sponsored by the Maternal and Child Health Bureau. The aim of the most recent phase of EICS has been to determine which factors assessed during the EI period predict the well-being of parents and the positive functioning of children during middle childhood.

Study Design and Methods

This study is a continuation of a longitudinal, nonexperimental, prospective design. Participants entered the study at the time of their enrollment in an EI program in either Massachusetts or New Hampshire. Child and family data have been collected at several times: at entry to early intervention, 1 year later, at age 3 years, at age 5 years, and at age 10 years. The core battery for children has measured cognitive performance, adaptive skills, health, behavior problems, and peer relationships. For families, the core dimensions have included family cohesion, parenting stress, and social support. Data were collected from participating mothers and children during home visits. Mothers were interviewed; mothers and fathers completed questionnaires; and children were assessed by project staff.

Population Description and Sampling Plan

Families were invited to participate in EICS at entry to EI if their child was younger than 24 months and had received a diagnosis of Down syndrome (n = 54), motor impairment (n = 77), or developmental delay of uncertain etiology (n = 59). Independent review of both medical records and developmental assessments confirmed families’ eligibility. A total of 190 families participated in the infant-toddler phase; 179 families completed the age 3 assessment; 161 families completed the age 5 assessment; and 150 families completed the age 10 assessment. The sample is diverse in terms of family income and child functioning. At age 10, 90 percent of participating children are receiving special education services. The mean cognitive composite (on the Stanford-Binet Intelligence Scale) for the sample children at age 10 is 63.0 (standard deviation [SD] = 30.2), and the mean adaptive behavior score (on the Vineland Adaptive Behavior Scales) is 52.3 (SD = 21.8).

Findings

Our data base is extensive, and we have chosen to focus this presentation on four related sets of findings: (1) the effects of the family environment on the development of children with Down syndrome; (2) the relation between the intensity and duration of EI services and family functioning; (3) the identification of which child and family characteristics measured at the termination of EI services (age 3 years) predict the future well-being of mothers, fathers, and children (at age 10 years); and (4) differences in parenting stress between mothers and fathers.

In the first set of analyses, we consider the adaptive behavior of children with Down syndrome ($n = 54$). These findings will be published in the July/August 1999 issue of *Child Development*.² Much has been written about IQ in children with Down syndrome, and a few longitudinal studies have mapped trajectories of IQ. Although these studies are useful in describing patterns of cognitive change, parents and service providers have stressed the importance of understanding adaptive domains of development as well. Furthermore, although some studies on children with Down syndrome present data on the relation between the mother's socioeconomic status and the child's IQ (with mixed findings), few have considered the relation between family processes and changes in children's development.

In our first set of analyses, we used hierarchical linear models to develop trajectories of growth in adaptive behavior. Using these models, we estimated trajectories of growth for each participating child in daily living and in social, communication, and motor skills (termed Level One models). These trajectories were then used as outcomes in Level Two models in which predictors of growth were entered. At Level Two, we tested three predictor variables: (1) the child's Bayley Mental Developmental Index (MDI) at entry to EI; (2) maternal education; and (3) a composite measure of the family environment consisting of mother-child interaction (the Nursing Child Assessment Teaching Scale) and a measure of family cohesion (the FACES II). Although children's initial Bayley scores did not predict growth in any domain, maternal education predicted growth in social skills. We found the family environment to be a significant predictor of growth in three outcomes: daily living, social skills, and communication skills. We found no differences for developmental changes in motor skills. Children from more positive family environments demonstrated more growth in daily living and in social and communication skills during early childhood.

Our second set of analyses also focused on the importance of family functioning. Although a focus on family functioning is now a core part of EI services, in a meta-analysis conducted more than 10 years ago,³ we found that family functioning had not been measured in any study of EI effectiveness. As we began analyzing data collected in EICS (e.g., hours of service received each month for every family from entry to exit from EI), we were interested in learning the extent to which EI services were related to changes in family functioning. Since findings from previous research on early educational interventions had stressed the importance of both the duration and the intensity of services, we divided our sample into two groups: those who had participated in EI 2 years or more, and those who had participated less than 2 years. We found that the groups did not differ significantly in total average hours of service received per month (mean [M] = 9.1, SD = 6.1 for the short duration group; M = 8.3, SD = 4.1 for the long duration group) or the distribution of service hours by type of service (e.g., home visits, child groups). We recognize that 8 to 9 average hours of service per month is a modest number of service hours.

We conducted hierarchical regression analyses separately for the two duration groups to see if hours of EI service predicted changes in family cohesion for each group. Using family cohesion (measured on the Family Environment Scale) as the dependent variable, we entered variables in the following order: child's diagnostic group, mother's education, family cohesion (based on the FACES II) reported at the entry to EI, and hours of EI services. For the short duration group, we found the child's diagnostic group to be the only significant predictor of family cohesion at exit from EI

services. In particular, families whose children had motor impairments reported fewer positive changes in family cohesion than other families. In the long duration group, child's diagnosis did not significantly predict changes in family cohesion. Hours of EI services—above and beyond maternal education and family cohesion at entry to EI—added a small but significant percentage of variance in positive changes in family cohesion at exit from EI. Thus, EI services appear to have improved family cohesion for those participating in the program for at least 2 years.

This finding requires certain caveats. First, it relies on maternal report of family cohesion. Second, we used different (but significantly correlated) measures of cohesion at the two data collection points. More importantly, we suspect that quality of service is a critical unmeasured variable. Finally, we cannot answer the question, is EI family-focused or family-friendly? Nevertheless, when we asked the parents of 10-year-olds to reflect on their experiences in EI, many reported that although EI services focused on their child with special needs, the services respected the needs of the family as a whole. One mother commented:

EI is great, they are positive and helpful. I just couldn't wait for [my home visitor] to come to our house once a week. After she was gone for 2 days, I just couldn't wait to see her again. I asked her a lot of questions. . . . I realized after that, that EI was sensitive to the family's needs . . . they were good to all the kids [in our family].

Does family cohesion matter for the long-term well-being of parents and children? To address this question, our third set of analyses assesses the extent to which we can predict parent and child well-being during middle childhood from characteristics of children and families as they leave EI. If we can make such predictions, we will be better able to identify those children and families who may benefit from additional intervention.

The data we have presented here are based on preliminary analyses, which we intend to explore more fully. We developed a series of hierarchical regression equations to identify the significant predictors of parents' stress (reported independently by mothers and fathers using the Parenting Stress index), children's peer acceptance (based on the Pictorial Scale of Perceived Competence), and children's loneliness (reported by children using the Loneliness Scale) at age 10. We entered three sets of independent variables: (1) family factors (first maternal education, followed by family cohesion); (2) child developmental characteristics (cognitive performance, adaptive behavior, and cognitive composite as a block); and (3) child behavior problems (as rated by the mother). Much happens to children and families during the 7 years between ages 3 and 10, but our findings display a consistent pattern. For mothers, our results are similar to those reported for findings to age 5 years, which were recently published in the *Journal of Developmental and Behavioral Pediatrics*.⁴ Mothers and fathers who viewed their families as more cohesive at exit from EI also reported less parenting stress at age 10. For mothers (but not for fathers), fewer children's behavior problems (based on the Child Behavior Checklist) also predicted less parenting stress at age 10.

For child outcomes (e.g., measures of social well-being), family cohesion at exit from EI significantly predicted level of peer acceptance and loneliness. Children from more cohesive families reported significantly higher levels of peer acceptance and lower levels of loneliness at age 10 years.

We found that a high proportion of children (71.6%) reported being lonely at school. At the age 10 interviews, parents also expressed concerns about their children's loneliness and social relationships. For example:

She plays with a lot of kids but she doesn't have a best friend. She's not invited to kids' birthdays or to other kids' houses. . . . She has just not had a good friend at school.

I'm concerned that he doesn't have a lot of friends. I would like it if he could go to friends' houses and sleep over and eat dinner and all that stuff.

In the final set of analyses, we will build on some of our previous work⁵ and discuss similarities and differences in mother's and fathers' experiences in raising a child with a disability. We have measures of parenting stress, based on the Parenting Stress Index, over multiple time points. Both mothers and fathers reported significantly increasing levels of parenting stress during the early to middle childhood period. Although the overall level of parenting stress is similar for mothers and fathers (but consistently higher for fathers), two areas of stress differ significantly: (1) From entry to EI through middle childhood, fathers reported significantly higher levels of parenting stress related to their attachment to their child, and (2) beginning in early childhood, fathers reported higher levels of stress associated with their own social isolation. Fathers have reported to us that they are often left out of neighborhood sporting events that revolve around children's teams and that services (such as EI, school, and medical services) tend to focus more on mothers. As one father said in a discussion of EI:

They are neglecting dads . . . come on, let's say it the way it is.

In summary, these findings point to areas of strength and of vulnerability within families. Like all children, children with disabilities live in multiple systems, and the family system in particular appears to be central in nurturing their development. EI services, when of sufficient duration and intensity, appear to be related to positive changes in family cohesion. Higher family cohesion at the termination of EI, in turn, predicts lower levels of parenting stress for both mothers and fathers 7 years later. Families who report being more cohesive at the termination of EI also have children who report higher levels of peer acceptance and lower levels of loneliness at age 10 years.

Along with areas of family strength, however, we note two areas of vulnerability that deserve careful examination. Fathers have an important but neglected story to tell and appear to be vulnerable to stress related to attachment to their child and to their own social isolation. And finally, children in this sample report high levels of loneliness during the middle childhood years. We plan to explore these critical areas during the next phase of this study, when we visit children and families during middle adolescence. At that time, we also will focus on many of the concerns parents have alerted us to, such as children's behavior problems, sexuality, safety, friendships, and management of medical issues. We hope to continue to delineate areas of resilience and strength, as well as points of vulnerability, in ways that will be useful to the community of parents, service providers, and ultimately, the children themselves.

Reactor Response

The studies presented were designed to determine how factors assessed during the earlier EICS investigation predict the well-being of parents and positive functioning of children during middle childhood. In the study "The Effect of Early Intervention Services on Family Cohesiveness," researchers found that for families enrolled for 2 years or longer, scores of higher density predicted greater family cohesion. The purpose of the paper "Family Influences on Adaptive Behavior in Young Children with Down Syndrome"² was to determine how family environment predicted differences in the developmental trajectories of adaptive behavior in young children with Down syndrome. Using hierarchical linear modeling to estimate the parameters of growth, researchers found that at age 5 years, measures of family environment at program entry predicted growth in three areas of adaptive development (communication, daily living, and socialization) above and beyond the growth predicted by maternal education and children's mental development indices taken at a mean age of 3 months. Taken together, these findings have important implications for future programs, research, and policy.

These studies call for a reflection on the purpose and expectations of P.L.99-457 (Part H/C) when it was added to the Individuals with Disabilities Education Act over a decade ago. In many ways, Part H reconceptualized the roles of intervention specialists and parents: intervention staff were

to assist and support family members as they nurtured and enhanced their child's development. Individualized Family Service Plans included family goals, but the overwhelming focus of these plans were child goals. The anticipated outcome was that the child's competence in areas of developmental needs would be enhanced.

The outcomes of these studies support the family-focused aspects of services of Part H. That is, the family is the key, and families with healthy environments (cohesion and mother-child interactions) have children with enhanced adaptive growth. In addition, greater cohesion was found in families with longer and more intense program participation.

These investigations raise issues and questions that may shape many facets of future services. Unfortunately, we know very little about the content of the services rendered. We do not know whether the cohesion trait was a resource or strength contributed entirely by families independently of service exposure. In terms of practice, these findings suggest that program staff may want to focus their efforts on strategies that strengthen home environments, at least in terms of cohesion and mother-child interaction. Likewise, the case can be made for beginning programs during the early months of the child's life. Administrators may need to reconsider staff qualifications. Specialists in child development and special instruction may not be qualified to focus efforts on family cohesion. If family cohesion and well-being are to become the primary focus of early intervention services, then it may be appropriate for other agencies to take a more active role in EI services. The raising of these issues is not intended to downplay the importance of helping families become stronger emotionally or of continuing to assist families in meeting the special needs of their children. Rather, these study outcomes suggest that the time is ripe to rethink our practices. We may also need to reconceptualize who should be the primary recipient of early intervention services, what our measurable goals should be, and how we might optimize outcomes. The study results are a clarion call to other agencies, such as health, mental health, social and human services: their roles are critical—perhaps more so than education's—in achieving positive outcomes for children and families during the early years.

Discussion

The discussion focused on several areas, including the stress level of fathers, the social development of the children, and who the primary recipient of EI services should be. Several participants commented on the finding that the fathers are more stressed than the mothers. All participants were interested in the findings suggesting that the children, even those who attend inclusive schools, feel lonely and isolated from their peers. In addition, there was an in-depth discussion of what type of families EI services should target and how intense the services should be. It was concluded that more research is needed to examine the fathers, the social development of the children, and who should be the primary recipient of early intervention services.

References

1. Shonkoff JP, Hauser-Cram P, Krauss MW, Upshur CC. 1992. Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development* 57(6):v-vi, 1-153, Serial No. 230.
2. Hauser-Cram P, Warfield ME, Krauss MW, Shonkoff JP, Upshur CC, Sayer A. 1999. Family influences on adaptive behavior in young children with Down syndrome. *Child Development* July/August.
3. Shonkoff JP, Hauser-Cram P. 1987. Early intervention for disabled infants and their families—a quantitative analysis. *Pediatrics* 80:650-658.

4. Warfield ME, Krauss MW, Hauser-Cram P, Upshur, CC, Shonkoff JP. 1999. Adaptation during early childhood among mothers of children with disabilities. *Journal of Developmental and Behavioral Pediatrics* 20(1):9–16.
5. Krauss MW. 1992. Child-related and parenting-stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation* 97:393–404.

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