

*A Newsletter Dedicated to Promoting the Application of Findings from MCHB-Supported Research to Practice*

## ***Introduction to the First Issue***

**S**afeguarding and improving the health of mothers and children is a demanding national responsibility. It requires significant expenditures, highly trained and dedicated professionals, private and state-supported professional schools to educate new practitioners and update seasoned clinicians, and systems of vital statistics, laboratory results, and hospital data to monitor morbidity and mortality events whenever and wherever they occur. Above all, safeguarding and improving the health of mothers and children require an expanding base of scientific knowledge and the means for scientists and practitioners to draw on this knowledge quickly and accurately.

Our scientific knowledge base expands through the mechanism of research. In some cases, this research generates new knowledge; in others, it validates or rejects existing scientific information. These activities do not  
*(continued on page 2)*

# **The Early Intervention Collaborative Study**

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## **Statement of the Problem**

**T**he 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  
*(continued on page 3)*

## *Introduction to the First Issue* (continued from page 1)

happen overnight, and at the research project level, they often do not produce more than modest gains in knowledge.

Quality research requires more than the application of the scientific method to data collection and the careful monitoring of research in the laboratory or the field. With few exceptions, it is essential that at the planning stage, proposed research be peer reviewed and assessed for originality, importance, and technical quality. Since research proposals involve a significant commitment of national resources, only proposals that can pass this scrutiny should be approved and funded. When completed, the research project should again meet the standards of peer review before the findings are published in professional journals—a prerequisite for acceptance by the scientific community.

After being accepted by the scientific community and incorporated in the knowledge base, research findings need to advance to the application or practice stage. As with formulating and executing research, translating research findings into practice calls for careful planning and hard work. The publication of findings in scientific journals does not automatically lead to clinical applications. Sometimes,

professional inertia may delay the application of new findings; at other times, the potential for clinical application may not be fully realized. This newsletter is intended to raise the level of awareness of the potential application of specific MCH research findings to clinical practice and the administration of programs.

*MCH Research to Practice* thus has two objectives: (1) to foster the application of findings from MCHB-supported research projects to maternal and child health (MCH) practice and (2) to explicate selected concepts in health services delivery that influence the organization and delivery of MCH services. The intended audience is primarily—but not exclusively—the state, county, and city directors of MCH programs and special health care needs programs. Each issue of the newsletter will consist of an article on a completed MCHB-supported research project or a conceptual paper.

The completed projects will be selected from those that have already been presented—or that will be presented—as part of the MCH Research Roundtables. These seminars seek to inform MCHB central-office professionals of the findings of applied research supported by Title V. For the most part, the findings from

these completed research projects have been published in peer-reviewed journals before their presentation as MCH Research Roundtables. The Roundtable presentations are made by the principal investigators of the research, and the discussants are either subject matter experts, clinicians, or administrators.

The conceptual papers will address new or rediscovered concepts of how MCH services can be organized and delivered to optimally influence particular outcomes. Because these concepts make intuitive sense, the health care delivery approaches they advocate skyrocket in popularity before the scientific evidence needed to support their use has been accumulated. Through the various papers explicating these concepts, this research-to-practice newsletter hopes to infuse a healthy dose of skepticism into what is sometimes an uncritical process of acceptance. Some of the conceptual papers will be written by the staff of MCHB's Research Branch or the staff of the National Center for Education in Maternal and Child Health. Others will be commissioned from national experts.

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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 Development<sup>1</sup> 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 database is extensive, and we have chosen to focus this summary 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

# MCH

# Research to Practice

No. 1

September 1999

This newsletter was produced jointly by the Maternal and Child Health Bureau (MCHB) and the National Center for Education in Maternal and Child Health (NCEMCH) under its cooperative agreement MCU-119301. MCHB is a component of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

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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 considered the adaptive behavior of children with Down syndrome ( $n = 54$ ). (These findings will be published in the July/August 1999 issue of *Child Development*.<sup>2</sup>) 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

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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,<sup>3</sup> 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

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*Our second set of analyses also focused on the importance of family functioning.*

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*<sup>4</sup> 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 years.

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.

We found that a high proportion of children (71.6%) reported being lonely at school. At the age 10 inter-

views, 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 work<sup>5</sup> and discuss similarities and differences in mothers' 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 reported 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. ▲

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# Response to Findings from the Early Intervention Collaborative Study

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The analyses 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 researchers' paper, "The Effect of Early Intervention Services on Family Cohesiveness" (under review), the researchers found that for families enrolled for 2 years or longer, higher scores of density of services predicted greater family cohesion. The purpose of the analysis reported in "Family Influences on Adaptive Behavior in Young Children with Down Syndrome" 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 envi-

ronment 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 the child'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 more than 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 was on goals for the child. 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 participation in EI programs.

These investigations raise issues and questions that may shape many facets of future services.

Unfortunately, we know 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 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 continu-

ing to assist families in meeting the special needs of their children, but rather to suggest that the time is ripe to rethink our practices. We may also need to reconceptualize who should be the primary recipient of EI services, what our measurable goals should be, and how we might optimize outcomes. The results of these studies 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. ▲

## Future Issues . . .

A recently completed research project, "Methods to Monitor Perinatal Outcomes in States, Cities and Smaller Geographical Subdivisions," studies a current research-to-practice issue. The project's findings will be presented as an MCH Research Roundtable on September 9, 1999. The Centers for Disease Control and Prevention will broadcast this live to state health departments via audioconference.

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