



Research Roundtable Summary



FIFTH

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Research Projects

Early Intervention: Child Development and Family Adaptation

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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 Maternal and Child Health Research Program is directed by Dr. Gontran Lamberty and administered through the Division of Systems, Education and Analysis, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA). HRSA is a component of the Public Health Service (PHS), part of the U.S. Department of Health and Human Services (DHHS). The purpose of the research program is to support applied research relating to maternal and child health services that shows promise of making a substantial contribution toward advancing those services.

Introduction

Woodie Kessel, M.D., Director, Division of Systems, Education and Analysis, MCHB, introduced the speakers, Jack P. Shonkoff, M.D., and Penny Hauser-Cram, Ed.D., who presented selected findings from their MCHB-funded project, The Early Intervention Collaborative Study: Phases I and II (MCJ-250533 and MCJ-250583). At the time of the presentation, Dr. Shonkoff was professor of pediatrics and chief of the Division of Developmental and Behavioral Pediatrics at the University of Massachusetts Medical School. Dr. Hauser-Cram is associate professor in the Department of Counseling, Developmental Psychology, and Research Methods at Boston College School of Education. Reaction was provided by Janet DiPietro, Ph.D., assistant professor in the Department of Maternal and Child Health at The Johns Hopkins University School of Hygiene and Public Health.

Presentation

Overview. The Early Intervention Collaborative Study, initiated in 1985, was a nonexperimental study that involved independent, longitudinal data collection from a cohort of children and families participating in community-based early intervention programs in Massachusetts and New Hampshire. The project began with three goals: (1) Understand the predictors of relative

vulnerability and resilience among children and families in intervention programs, (2) investigate the mediating influences of the family environment and the impact of early intervention services on specific child and family outcomes, and (3) generate an integrated, conceptual model of child development and family adaptation to guide future research and policies on children with special health needs.

Study Design and Methods. As a two-phase, nonexperimental, longitudinal study, this research involved independent data collection from a cohort of 190 children and their families recruited from 29 community-based early intervention programs in Massachusetts and New Hampshire. The first phase examined the contributions of child and family characteristics and early intervention services to changes in child competence and family adaptation over the first year of program participation. The second phase examined the early predictors, durability, and stability of individual differences in child and family development over the early childhood period.

The study population comprised three target groups: (1) Children with Down syndrome; (2) children with motor impairments, defined as abnormality in muscle tone with atypical motor development, with or without problems in other areas; and (3) children with developmental delays of uncertain etiology in at least two areas of development. The mean age at entrance into the study was 10.5 months.

Demographics of the Sample Population. The demographics of the sample reflected that of the families participating in the Massachusetts and New Hampshire early intervention service systems at the time. The mean maternal education level was 13.8 years; 9 percent had not graduated from high school and 14 percent had completed more than 4 years of college. The median family income was \$20,000–25,000. In the sample population, 80 percent of the children were from two-parent households. Because the sample was ethnically homogenous (88 percent white), conclusions drawn from the study cannot necessarily be used to make generalizations across ethnic groups. However, having an ethnically homogeneous sample provided the researchers with an opportunity to examine differences related to maternal education and family income without ethnic diversity as a confounding variable.

Rationale for Study Design. For ethical and practical reasons, the study did not follow a controlled, randomized trial design. The ethical considerations of withholding treatment for the duration of the longitudinal study precluded using a control group that would receive no treatment. Additionally, the legally mandated individualization of services that may change over time, based on child and family circumstances, presented a limitation to design. The analytic approach chosen did not attempt to understand the difference between families who receive early intervention services and those who do not; rather, the researchers sought to document services that families receive and to investigate variables that explain why some children and families do better than others.

Data Collection. Data were initially collected at two time points. Baseline data were obtained through a home visit involving a child and family assessment within 6 weeks of initial referral to the early intervention program, at time one (T1). The second family and child assessment occurred 12 months later at time two (T2), concluding the first phase of the study.

In the second phase of the study, data were collected at three time points. Time three (T3) involved a home-based assessment of the family and child at age 3 years, when the children in the sample were leaving early intervention. School-based data were collected 6 weeks after preschool entry, at time four (T4). And, school-based data were collected and the child and family were assessed within 1 month of the child's fifth birthday, at time five (T5).

Service Experience. The greatest portion of early intervention service hours consisted of home visits, followed by center-based, child-group services, and then a fairly equal distribution of center-based individual services, parent-child groups, and parent groups. Information on the number of

hours of service used in each category was collected monthly from each case manager in each service program. Families received an average of 3 hours of home visiting per month, with a standard deviation of 1.9 hours and a range from almost 0 to 9.5 hours. Because of the range of hours of services received and the lack of information on service content variability, Dr. Shonkoff emphasized the importance of being conservative about inferences regarding the relationship between services and outcomes.

The service data indicated one variable that consistently predicted differences in intensity of service—the severity of the child’s cognitive impairment. In addition, it was found that more severely impaired children demonstrated less developmental change. Thus, children with more severe cognitive impairment received greater intensity of service and had slower developmental growth. This confounding of service intensity and severity of disability needs to be addressed in efforts to evaluate early interventions.

One consistent finding emerged in relationships between services and outcomes: Families who received more of the services in groups (i.e., with other families) perceived the size and the helpfulness of their support networks to be increasing more so than did families who received more of the services at home.

Findings from Phase II: Changes in Children and Families

Family Outcomes. The three dimensions of family adaptation examined in the study were (1) parenting stress, (2) effects of the child’s disability on family functions, and (3) social support. Dr. Hauser-Cram’s presentation focused on the first of these dimensions, especially parenting stress reported by the mother.

The Parenting Stress Index was used as a measure of parenting stress and relied on two domains: Stress related to the parenting role, and stress related to the child. Data collected at T1 through T3 revealed little change in either domain. On average, there was a stable, normal amount of parenting stress, well within the means reported for parents raising children who are developing typically. One-fifth of the mothers, however, did show evidence of significant stress. Thus, in the sample population, four out of five families who had a child with a disability did not report more parenting stress during the first 3 years of the child’s life than did families of children without a disability.

Since the investigators found no significant changes during these earlier times, Dr. Hauser-Cram stated that the team decided to examine more discrete dimensions of maternal well-being, such as depression and sense of competence as a parent. Both are important predictors of later child development. Although most of the study sample scored well within the normal limits for these dimensions, some subgroups scored beyond the clinical cutoff, especially at T3.

To consider possible correlates of these areas of stress for mothers, five predictors of maternal depression and sense of competence were examined: (1) Family income, (2) significant negative life events, (3) helpfulness of support, (4) family cohesion, and (5) child behavior problems. Through regression analysis, Dr. Shonkoff and Dr. Hauser-Cram determined that family cohesion was a significant buffer for maternal depression, and that adverse life events and child behavior were the most significant variables that contributed to a diminished sense of competence. Thus, lower levels of family cohesion, child behavior problems, and other (adverse) life events appear to be key markers of vulnerable families.

Child Outcomes. Traditionally, research on early intervention has used IQ to measure child outcomes. However, Dr. Hauser-Cram and Dr. Shonkoff pointed out that a child’s IQ alone serves as an inadequate measure, and that many other dimensions of child development may be more adequate in accounting for growth, change, development, and environmental impact. The researchers

developed a construct for child adaptation consisting of four dimensions: (1) Psychomotor/cognitive skills or abilities, (2) adaptive skills, (3) independent play, and (4) social behavior.

Another key element of the study examined the impact of the caregiving environment on several domains of child adaptation. During the first phase of the study, very few relationships between the two were found. However, since children were between the ages of 1 and 2 years during the first phase, many were still quite young developmentally. At this age, a child's development may still be constrained by biology and neurology, leaving little room for environmental effects on standard cognitive psychomotor scores. These children are not unlike those who are developing typically, and the researchers hypothesized that the effects of the caregiving environment would become more pronounced as the sample moved beyond the sensory-motor period.

To examine this hypothesis, three features of the caregiving environment were described and evaluated with respect to child outcomes: (1) Mother-child interaction (the most proximal measure of the caregiving environment), (2) child-oriented quality of the home, and (3) family cohesion (the most distal). Mother-child interaction and the measure of the home environment both correlated significantly with child cognitive abilities and adaptive skills at age 3 years; family cohesion, on the other hand, did not. For independent play, mother-child interaction was the most significant predictor, the home was less significant, and family cohesion was not significant. But, with child behavior problems, the reverse was found: Mother-child interaction was not a significant predictor, but family cohesion was highly related.

In summary, the most distal predictor, family cohesion, predicted behavior problems; the most proximal measure, mother-child interaction, predicted child skills; and the medial measure, the home environment, influenced both.

Dr. Hauser-Cram hopes that this model, examining three levels of the caregiving environment, will be testable among other groups of children as well. Traditionally, children with disabilities have been treated as learning and behaving in an entirely different way from other children. However, as this study shows and as service providers are beginning to realize, this may not be true. Thus, there is a need to think about the relevance of some of the principles of learning and development that apply to all children.

Conclusions. Dr. Shonkoff concluded by summarizing four findings. First, the data make a strong case for focusing on selected aspects of the caregiving environment as they influence the development of young children with special health needs. Although environment had little impact on short-term change in children with disabilities when they were very young, environment showed a stronger influence and became a significant predictor of adaptation as the children grew older. This finding reinforces the importance of focusing on the caregiving environment as a point of intervention.

Second, the data illustrate the importance of the differential potential of children. Although the severity of the child's disability was the most powerful predictor of change, relationships can still be found between child outcomes and the caregiving environment.

Third, the data underscore the importance of recognizing the different adaptive capacities of families. Only one-fifth of the sample gave evidence of maladaptation, revealing that families who have children with disabilities are resilient in their adjustment.

Finally, the data strongly support the importance of individualized services. A one-size-fits-all approach to intervention is simply not adequate.

In summary, the outcomes of child competence and parent well-being measured at the termination of early intervention services can be predicted in part by the characteristics of the children and families at enrollment. Beyond these influences, early intervention services have an effect at three levels of the caregiving environment, which have differing effects on different aspects

of child competence. Similarly, parent well-being is influenced in part by characteristics that the families themselves bring to the situation, such as the buffering effect of their social supports or the effect of other (adverse) events in their lives.

Policy Implications. Dr. Shonkoff stated four challenges from a policy perspective that emerge from the data. First, social policy must consider multiple dimensions of competence in children and adaptation in families. Second, it must be realized that early intervention is not a panacea. For children with more severe disabilities, intervention does not eliminate the effects of those disabilities but shifts the curve in favor of better adaptation in the long run. And, for mild disabilities, it could shift the curve enough that the child would not require any special services later. Third, there is need to rethink the basis for equity in this field. Not everybody needs the same services. An equitable early intervention system would be one in which people received different amounts and different kinds of services based on their resources and needs. Finally, advocacy and science must be combined to determine the best way to use available resources to accomplish specific goals for children and families.

Reaction

Dr. DiPietro complimented the researchers' shift toward emphasizing the transactional nature of the child, the family, and the intervention services they receive, and the multifaceted way that child competence is assessed. The standard IQ, Dr. DiPietro reiterated, is not an endpoint for looking at child outcomes.

Dr. DiPietro noted that a particular strength of the research was in studying the effect of actual services provided in the current delivery system. However, the tradeoff is the limitation on the conclusions that can be drawn without having a control group or random assignment.

Despite this limitation on study design, Dr. DiPietro commended the study's reference to psychomotor behavior and development (rather than intelligence) as the indices measured by the Bayley Scales of Infant Development. The study revealed two interesting issues: Children with disabilities, in the first few years, develop very much as those without disabilities; and the severity of psychomotor disabilities (rather than the specific condition) is the more important way to characterize children in terms of belonging within vulnerable or resilient subgroups.

Dr. DiPietro commented that the data seem to suggest that existing intervention services do not directly affect child development during the first few years of life and that this is in concordance with other studies, although there may be other familial effects. She urged those working in the field always to include an evaluative component when designing intervention services, in order to provide evidence about what works and what does not. Poorly designed or nonexistent evaluation components can fuel skepticism about claims of beneficial effects, while well-designed evaluations can provide clear support for efficacious programs.

Finally, the most valuable applied aspects noted by Dr. DiPietro were the descriptions of the characteristics of children and families, the types of services they need, and the types of services that may be useful with reference to their psychosocial functioning. She commented that, until now, very little was known about the characteristics that early intervention services are trying to reach.

Conclusion

Addressing the issue of whether the study demonstrated the efficacy of early intervention, Dr. Shonkoff agreed with Dr. DiPietro that, because of the limitations of their nonexperimental study design and the marked variety of service experiences, the study did not answer the question one way or the other. He asserted, however, that demonstrating that aspects of the caregiving environment

explain differences in outcome is of greater importance and is a strong argument for focusing interventions on that domain.

In response to a participant's question about measures of father-child interaction and why the discussion had not included fathers, Dr. Shonkoff replied that the data on fathers and the data on mothers were highly correlated, so most of the discussion concerning the mothers could also be applied to the fathers. However, one difference between the mothers and the fathers was found in the area of stress: The mothers experienced stress in the parenting domain, while the fathers reported more stress around their feelings of attachment to their child and their perceptions of the child's temperament. For the mothers, their informal support system was an important buffer for dealing with stress, whereas, for the fathers, family cohesion was the buffer. For all of the family variables, data were collected on both mothers and fathers. Mother-child interaction was the only measure with maternal data alone; fathers were not included in the analyses of this measure because the fathers who were primary caregivers comprised a very small group.

Dr. Kessel posed the following as a final question to the presenters and the reactor: "What would you say if you were called to testify before Congress about the value of early intervention, the value of the family, and the individual need to respond?"

In response, Dr. Hauser-Cram reflected that one area of early intervention that needs more thought is the issue of parent support groups. Though often beneficial, these groups are not always well received by families at the beginning, and attempting to impose them on families may be risky. Thus, it is important to reconsider some of the early intervention services in terms of what can be imposed and what can be made available. Dr. Hauser-Cram also noted the data indicate that certain areas of the home environment seem to be very important to later development in children and should receive further attention.

Dr. DiPietro replied that she would favor child-centered programs that remain at a high intensity throughout the child's developmental course.

Dr. Shonkoff concluded by addressing the issue of cost and allocation of resources. As stated earlier, the data support the fact that children with biologically based disabilities develop in a way that is not very different from that of children without such disabilities. He observed that it does not make sense to have two separate systems of intervention, one for children with biologically based disabilities and another for those who are at risk because of environmental circumstances.

With regard to the cost of services for severely impaired vs. mildly impaired children, Dr. Shonkoff stated that a service system for more severely impaired children can improve their adaptive abilities, but these children will always need costly services. On the other hand, children in the milder range of disability or those at risk are considered the group that cannot afford to be served because they number too many; yet these children actually comprise the group for which significant financial savings are most likely in the long run. Dr. Shonkoff stated that the key issue involves the danger of providing too many services for some, not enough for others, or the wrong kinds of services for specific subgroups.

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