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early developments Frank Porter Graham Child Development Center

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How early family research led to practical help for professionals and families

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The evolution of research projects to practice is rarely a straight line or a short step. For example, retreats will be held next year in Atlantic Beach, NC to prepare parents of young children to become leaders in a variety of advocacy and advisory roles with early intervention agencies and organizations across the state.

But this new practical resource for North Carolina families with children with disabilities can be traced back to institutes and research that began more than two decades ago at the Frank Porter Graham Child Development Center (FPG) at the University of North Carolina at Chapel Hill.

ONE OF THE EARLIEST SUCH INSTITUTES was the Carolina Institute on Research and Early Education for the Handicapped (CIREEH). “It was one of four similar institutes in the nation funded in the 1970s by the U.S. Bureau of Education, as it was called then, to produce research to help in the educating of children with disabilities,” said Jim Gallagher, CIREEH’s principal investigator and also FPG director at the time.

CIREEH was one of the first large-scale research projects to examine family involvement in programs for preschool children with disabilities. The institute ran for 10 years and among its achievements are:

- research on how families adjust to the birth of a child with disabilities (they cope remarkably well, especially when they receive early help from professionals);
- the development of programs that encourage specialists working with children with disabilities to focus on the family as well as the child;
- the development of dozens of curriculum items for use with children under a year of age with various types of disabilities; and
- the creation of numerous assessment scales.

An example of CIREEH’s legacies is *Family Assessment in Early Intervention* by Don B. Bailey Jr., now FPG director, and Investigator Rune J. Simeonsson. The book, published in 1988, was an outgrowth of the CIREEH’s F.A.M.I.L.I.E.S. Project, a five-year study of families with young handicapped children enrolled in a home-based intervention network in North Carolina.

Bailey said, “It’s a natural evolution, particularly at an institution such as FPG where we have many researchers working together and in collaboration with others. Taking the research of one project and designing a more refined project to answer questions raised by the first project is a natural progression for us. And more often than not, this leads to implications and help for personnel preparation, professionals, and families.”

CIREEH’s beehive of activity also helped spawn a 1989 study by Bailey, Virginia Buisse, Rebecca Edmondson, and Tina M. Smith (all at UNC-Chapel Hill) that examined the perceptions of professionals in four states concerning family-centered services in early intervention. And that led to the development of a scale to determine perceptions of how families are included in an early intervention program or community. The scale was called *FOCAS: Family Orientation of Community and Agency Services*. Later came *Guidelines and Recommended Practices for the Individual Family Service Plan*, published in 1991 by the National Early Childhood Technical Assistance System (NECTAS) and the Association for the Care of Children’s Health.

Family-centered practices

The work of CIREEH also led to one of the larger current projects at FPG: Latino Families of Children with Mental Retardation. “We are looking at how families adapt to a child with mental retardation, focusing on three areas: beliefs about mental retardation, its causes, treatment options, and ultimate expectations for the child with mental retardation; perceived family needs that extend beyond direct

NEILS longitudinal study

The long history of the Frank Porter Graham Center’s research into family involvement in programs for preschool children with disabilities continues to the present: Today, Rune J. Simeonsson and four other FPG investigators are part of a national team conducting the National Early Intervention Longitudinal Study (NEILS)—funded by the Office of Special Education Programs, U.S. Department of Education.

NEILS is a five-year study designed to provide answers to four main questions:

- Who are the children and families receiving early intervention services?
- What early intervention services do participating children and families receive and how are those services delivered?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics and services provided?

More than 3,300 children and their families are being followed from 3 to 5 counties in each of 20 states. Families with children between birth and 31 months of age who are newly entering early intervention are being enrolled in NEILS. Other data presented in the fall of 1999 during a presentation at the National Center for Health Statistics’ National Conference on Health Statistics:

Categories of Conditions, Impairments & Functional Limitations

Speech/communication impairment	41.1%
Prenatal/perinatal abnormalities	19.0%
Motor delay	17.5%
Global delay.....	12.0%
Congenital disorders.....	8.9%
Intellectual/cognitive impairment or delay.....	7.2%
Central nervous system disorder	6.5%
Social/environmental risk	3.9%
Social/behavioral impairment.....	3.7%
Sensory systems	3.3%
Self-help skills	2.6%
Neurologic impairment.....	2.2%
Musculoskeletal disorders.....	2.0%
Illness or chronic disease.....	1.9%
Use of medical devices	1.4%

intervention services for the child; and perceived usefulness of professional and agency services,” said Debra Skinner, project director.

FPG’s early work with families and professionals also helped generate another project—Longitudinal Study of Boys with Fragile X Syndrome and Their Families. Fragile X syndrome is the most

common inherited cause of developmental disability, affecting as many as one in 2,500 people. Since 1993, FPG has been following selected young children with fragile X syndrome and their families in Virginia and the Carolinas.

“A pattern in this kind of research is clear,” said Bailey. “Make sure we have the big picture, collect and analyze good data, postulate and examine outcomes, create and test models of change, and then figure out how to get changes that work to professionals, teachers, and families. We’ve been fortunate at FPG to have this continuity in our research and our researchers.”

Helping parents & families

FPG’s family research has led to another of the center’s newest projects, the Parent Leadership Development Project. Begun in 1999, the Parent Leadership Development Project is working to develop a cadre of parents to fill a variety of advocacy and advisory roles with state and local agencies and organizations.

“Comprehensive, high-quality, individualized early care and intervention for children with disabilities now requires simultaneous attention to child development, community building, professional development, and family involvement,” said Virginia Buisse, co-principal investigator along with Pat Wesley. “Families should be considered essential advisors in public policy, research, personnel preparation, and program development, as well as partners in all aspects of their children’s care and education.”

The Parent Leadership Project is recruiting 72 parents and other family members of children with disabilities interested in devel-

Data from the NEILS longitudinal study

Data are already beginning to flow in from the study. The first round of findings, based on a larger sample, indicate that of 5,667 children entering the early intervention system, 59% were reported to qualify for services because of a documented developmental delay, 28% with a diagnosed condition, and 13% who were eligible because of being at risk for developmental delay.


Neils data collection is being conducted by:

- Telephone interviews with families for information about child and family characteristics, child functioning, and families’ perceptions of services. Families are being interviewed when their child enters early intervention, when their child is three years old, and again when their child is five years old.
- Semiannual reports from service providers on early intervention services provided to NEILS families, included information about children’s transitions out of early intervention.
- One-time survey of service providers about their background, training, and the ways they deliver services.
- One-time survey of teachers about the children’s programs and services being provided when the NEILS children are five years old.

In addition to Simeonsson, other FPG researchers in the study are Don Bailey, Robin McWilliam, Anita Scarborough, and Lynne Kahn.

The NEILS study is being conducted by SRI International, Menlo Park, CA.

oping or improving partnerships with professionals. These parents will receive intensive training, including follow-up activities to develop leadership skills. This cadre will then be linked to institutions of higher learning, and organizations and agencies providing early education, early intervention, and family support services.

Other major offshoots of CIREEH were a project named the Carolina Institute for Research on Infant Personnel Preparation and a series of projects aimed at changing early intervention personnel development systems. These are discussed in an article beginning on page 8. 

If you want to know more

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Recent publications

By researchers at the Frank Porter Graham Child Development Center

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Awareness, use, and satisfaction with services for Latino parents of young children with disabilities

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