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The University of
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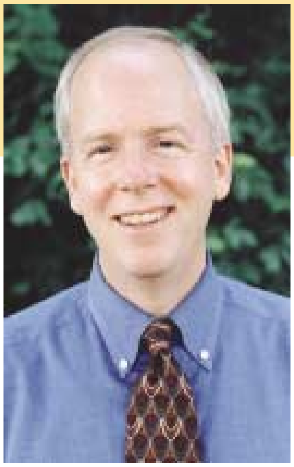
Children with Special Needs

news



Don Bailey
Director of FPG

Bailey appointed W.R. Kenan, Jr. Professor

The Board of Trustees of the University of North Carolina at Chapel Hill approved the appointment of Don Bailey as W.R. Kenan, Jr. Professor effective July 1, 2002. This honor recognizes Don's leadership as a researcher and director of the FPG Child Development Institute during the past ten years.

Bailey Receives AAMR Research award

Don Bailey, director of FPG, received an award for his research on mental retardation from the American Association on Mental Retardation (AAMR) at the association's 126th annual meeting in Orlando, FL.

AAMR presented its annual Research Award to Bailey "for formulations and investigations that have contributed significantly to the body of scientific knowledge in the field of mental retardation."

Unexpected Journey wins Silver Reels award

Unexpected Journey: The Earliest Days, a 24-minute documentary produced by the Partnerships for Inclusion project at FPG, won a Silver Reels award January 12. The Silver Reels regional competition honors video, film and interactive communications from across North and South Carolina.

Produced by Pat Wesley in collaboration with Julie Dixon of Raleigh-based Words and Pictures, the video follows several families through the earliest days of parenting premature infants. *Unexpected Journey* also addresses ways to promote smooth transitions for the family and child as they prepare to leave the hospital and begin their lives together in their communities.

Pat Wesley
Director of Partnerships for Inclusion

To Learn More

Visit the PFI website at www.fpg.unc.edu/~pfi

A New Name, a New Look

The Frank Porter Graham Child Development Center is now the FPG Child Development Institute. Our mission is the same as it was 30 years ago when we were founded… to cultivate and share the knowledge necessary to enhance child development and family well-being. Our modified name, new logo, and tagline (*advancing knowledge, enhancing lives*) are designed to help us communicate our mission more clearly with the consumers of our research, teaching, and outreach efforts.

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NCEDL NEWS

For the development and well

NATIONAL REPORTS indicate that in a given year as many as 5.5 million children are identified as having a disability that interferes with school performance and requires special education services. Some disabilities are obvious at birth, occurring as a result of genetic disorders or birth trauma. Others can emerge later in life as a result of injuries, illness or environmental factors. Whatever the case, there is now widespread agreement that disabilities must be identified as early as possible and the appropriate services provided.

This issue of *Early Developments* highlights some of our current work with children with disabilities. Since our main focus is on the early childhood period, we are especially concerned about promoting earlier identification and improving early intervention and preschool services. Recent reports show that while 11-12% of school-age children are eligible for special education services, less than 2% of children receive early intervention services during the first three years of life and less than 5% during the preschool years. The peak enrollment of children in special education services occurs at age 10. This means that many children's disabilities are not identified until after they enter school and experience failure.

Our commitment to disability-related work goes back to the earliest days of our institute and the involvement of the Kennedy family in mental retardation programs and legislation. It is well known that President John F. Kennedy had a sister with mental retardation. One outgrowth of Kennedy's work was the establishment of a national network of mental retardation research centers. FPG was part of a consortium of organizations at UNC that was funded as one of the original 12 Mental Retardation Research Centers in 1966 and we continue this affiliation today.

Since the 1960s, we have been involved in a wide range of disability-related activities. These include basic research, the development of models for working with children and families, studies of disability policies, and training and technical assistance activities designed to help policy makers and practitioners develop and implement high-quality services. We have also focused much of our efforts on understanding how children with disabilities can be included in programs for children without disabilities. As a part of this work, the child care program at FPG has been a fully inclusive program and the staff have worked hard to model effective inclusionary practices since 1984. Examples of those practices at the FPG child care center are presented in an article in this issue.

being of all children

By Don Bailey, Director of the FPG Child Development Institute

Some of our work focuses on specific disabilities. We have projects involving children with disorders such as vision impairment, autism and spina bifida. This issue features an article on our studies of one particular disorder–fragile X syndrome–and the challenges surrounding early identification and the provision of services. From projects such as this one, we hope to learn about the specific learning needs of children with identifiable conditions, trying to determine the needs that are unique to each disorder in comparison with the needs that are common to almost all children. This work draws heavily on the individual interests of investigators working at the center. Other research, however, is not so focused on a particular disorder, but on children with special needs as a group. From this perspective, the range of disabling conditions and needs is enormous. Our challenge is to discover ways that service systems can respond appropriately to this wide variation in needs and abilities.

Serving young children with special needs is a complicated endeavor. It requires coordinating the medical, educational, public health and mental health communities, and working in partnership with schools, child care programs and families to provide appropriate support for children and families. A comprehensive set of national and state laws and regulations govern these activities, but as expected, the challenges often come in the appropriate implementation of policy.

We try to engage in work that helps us understand how policy affects practice, and how practice can be modified to be consistent with policy. In this issue, we look at one FPG project—the Early Intervention Training Center for Infants and Toddlers Who Have Visual Impairment—and how it is helping colleges and universities prepare personnel to serve children with this disability.

At FPG, we believe strongly in conveying the results of our research not just to fellow academicians, but to a larger audience of policy makers, service providers, and parents, who can put the findings to use right away. In this regard, we are particularly proud of the work of the National Center for Early Development & Learning, whose information dissemination program is featured in this issue.

Our work on disability issues emphasizes our belief that we need to be concerned about the development and well being of *all* children. By focusing part of our effort on disability, we can reinforce the notion that every child needs to be viewed as an individual with his or her unique styles of learning and developmental growth.

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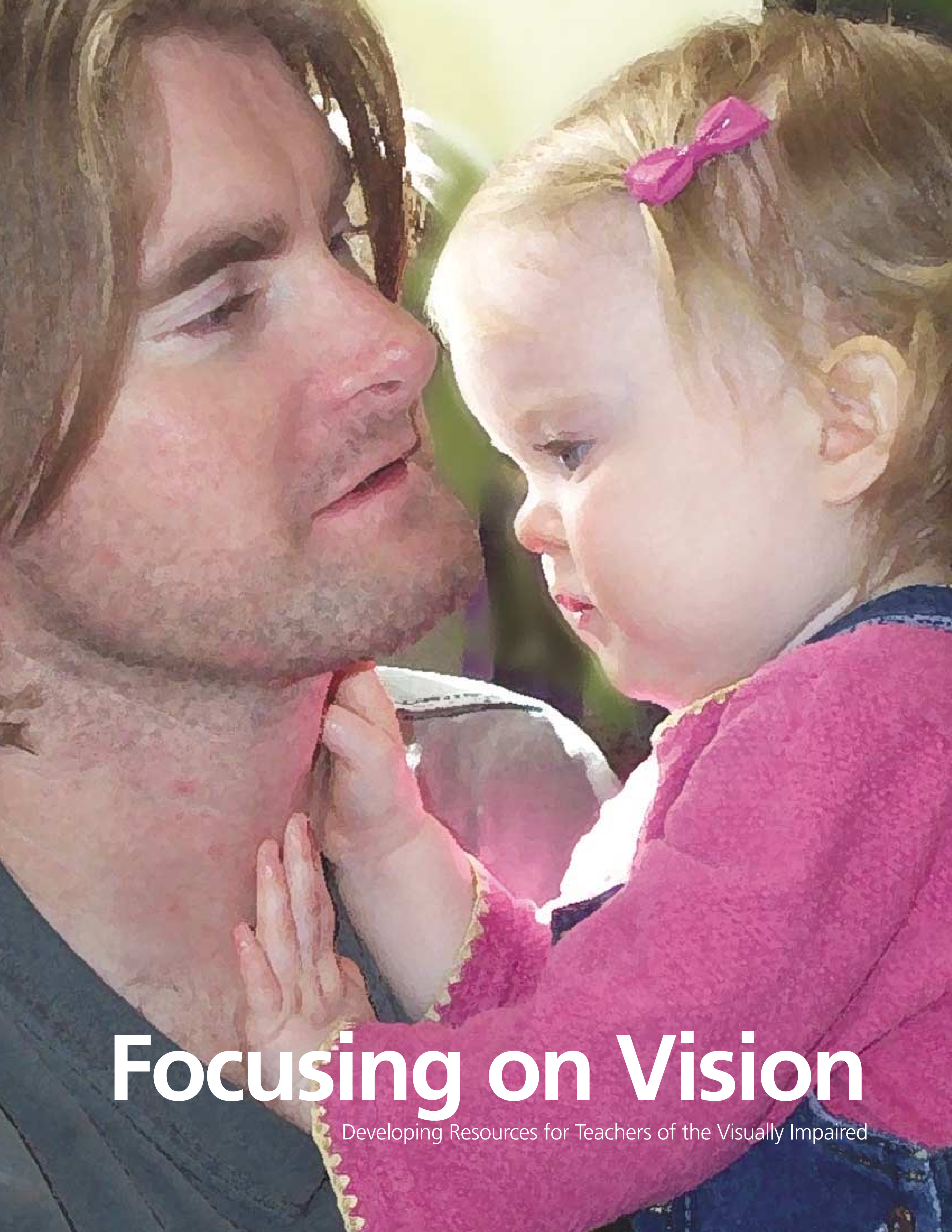

Focusing on Vision

Developing Resources for Teachers of the Visually Impaired

AS A PRESCHOOL DIRECTOR FOR A STATE SCHOOL FOR THE BLIND, a graduate student focusing on visual disabilities, and a researcher at FPG specializing in early childhood visual impairment, Deborah Hatton has seen the problem first hand.

"Early intervention can help infants and toddlers with visual impairments and their families face many of the challenges of growing up without sight," Hatton says. "Yet there is a shortage of teachers and other personnel who are prepared to provide this support."

Preparing additional teachers of children with visual impairments (TVIs) is the responsibility of colleges and universities with programs in this specific field; however, they can be aided in that mission by having access to resources that help prepare personnel to serve infants and toddlers with visual impairments. That is the primary mission of The Early Intervention Training Center for Infants and Toddlers with Visual Impairments, a project directed by Hatton and funded through a five-year grant from the US Office of Special Education.

Researchers estimate there are approximately 20,000 children with visual impairments in the United States in the birth to five age range. In 2000, US colleges and universities turned out only 273 teachers of the visually impaired, 77 instructors in orientation and mobility, and 38 with dual certification (teachers of children with visual impairments and orientation and mobility), and these personnel typically were hired to provide services to children between the ages of 5 and 21 years. That leaves a big gap in time during which children with visual impairments and their families miss out on valuable intervention services.

Visual impairment can affect childhood development in numerous ways. Unable to make visual links with caregivers and with their surroundings, children with little or no sight may face particular challenges in preverbal communication, motor development, and areas of cognitive development such as body, object, spatial, and other basic concepts that are ordinarily acquired incidentally through vision. Parents of infants and toddlers with visual impairments may also become perplexed or depressed when the child fails to respond to eye contact or smiling, or acts in a way that may be interpreted as rejection (examples of such behavior include stilling or freezing at the sound of the parent's voice, lack of facial affect).

At the same time, children with visual impairments can function successfully if they and their families are provided appropriate support. For example, caregivers can vocalize more extensively to provide cues about their whereabouts and the surrounding environment. They can use touching games and sound cues to help infants anticipate certain actions. Caregivers report that support from early interventionists in specific strategies and techniques for teaching their children with limited vision, as well as information about the specific eye condition and prognosis, are most helpful. Yet this kind of support has not been widely available.

Dr. L. Penny Rosenblum, a faculty member from the teacher preparation program in visual impairment at the University of Arizona, is also an investigator on the FPG early intervention project who serves as a liaison to the universities that prepare TVIs.

During the first six months of the project, Hatton focused on developing partnerships with university faculty who prepare teachers of children with visual impairments. Since then, she and her colleagues have been developing a series of multimedia, interactive content modules geared toward a university audience. Video clips show parents of children with visual impairments talking about the supports they need for their young children and give examples of exemplary early intervention practices. Case stories have been developed with activities based on them.

For many years, early intervention did not exist in most areas of the United States for children with visual impairments under the age of 5. We now have approximately 20–30 university programs in the United States that prepare teachers of children who are visually impaired.

Because visual impairment is a low incidence disability, however, these university programs may have relatively small numbers of students, and so the programs are difficult to sustain. Often, faculty members must spend considerable time in grant preparation to keep their programs running, and they may not have time to develop their own materials. We hope to make their job easier by giving them materials they can infuse into existing courses.

The modules will be available in multiple formats. A printed copy with objectives, major points, instructional sequence, overhead transparencies, case stories and activities, recommended readings, and study questions will be available. In addition, a audio-narrated CD of a multimedia program will be available. The CD will be configured so that it can be accessed by screen readers for individuals without vision. "Our mission is not just to get the information out, but to make it easy and interesting to use," Hatton says.

While these resources and materials are primarily for use by faculty, Hatton believes the materials are flexible enough to be used by families, as well as agencies and individuals that work with the visually impaired. The materials should be useful in preparing personnel in the fields of child development, speech/language pathology, occupational science, physical therapy, and medicine.

The project has created an electronic mailing list and a web site (www.fpg.unc.edu/~edin.). These will be used to share information about resources and to secure feedback from practicing professionals and future consumers as materials are developed.

| ed |

Family centered support,
typically provided during home visits,
is the foundation for effective early intervention.

To learn more

Developmental growth curves of preschool children with vision impairments. Hatton, D.D., Bailey, D.B., Burchinal, M.R., Ferrell, K.A. (1997). *Child Development, 68,* 788-806.

Model registry of early childhood visual Impairment: First year results. Hatton, D.D., & Model Registry of Early Childhood Visual Impairment Collaborative Group. (2001). *Journal of Visual Impaiment and Blindness, 95*(7), 418-433.

For more information about this project, please call Project Director Deborah Hatton at 919-966-7186 or email deborah_hatton@unc.edu. **Project web site:** www.fpg.unc.edu/~edin.

Fragile X

It is the most common inherited form of mental retardation, yet it often remains undiagnosed for the first three years of a child's life. It is not curable at the present time, but early identification can lead to educational and therapeutic treatments that can help affected families and children cope with the condition. Fragile X syndrome (FXS) is gradually coming into the limelight and the FPG Child Development Institute is pioneering research defining early development and intervention strategies.

First named in 1969, it was not until 1991 that several international teams of researchers discovered the gene that causes fragile X syndrome and an understanding of the way it is inherited. Fragile X is a single-gene disorder carried on the X chromosome. The disorder can be passed through several generations in a carrier state, with each generation having a higher risk of the gene causing the syndrome itself. An expansion of this gene (FMR1) leads to a lack of production of a protein believed to be essential for normal brain functioning. Both males and females can have the disorder, however, males are usually more severely affected than females. Most will have mental retardation, ranging from mild to severe. Many will experience delays in development, most notably in cognitive and communication skills. Males may develop distinguishing physical features, including large ears, loose joints and muscles, and an elongated face. However, children born with fragile X look and behave normally at birth with the result that few are immediately identified as having the condition.

With the understanding of fragile X as a genetic disorder, the scientific community has pursued two main lines of inquiry. One seeks to understand the molecular consequences of the condition with the hope of some day developing targeted pharmacological treatments and gene therapy. The second line, pioneered by FPG, seeks to understand the developmental, behavioral, and functional aspects of fragile X.

FPG is the first and only group defining the early development of fragile X,

In 1993, FPG received the first grant to describe the early development of children with fragile X. Prior to this, research had been done only on older children and adults with the syndrome. Interviewing 41 mothers of young boys with fragile X, FPG researchers learned that fragile X was typically not diagnosed until children had reached a mean age of 35 months. For the most children, a parent, usually the mother, first became concerned about the child. The parent most often noticed a delay in meeting expected developmental milestones. They may have noticed other problems, including speech delays, health problems, and lack of eye contact or attentiveness. Pediatricians or other physicians whom the parents consulted often downplayed their concerns, especially if the child was under 18 months, suggesting that the child was simply late in developing.

The study clearly showed that society is slow to identify children with fragile X. As a result, parents of these children become unnecessarily frustrated with their own parenting skills and with their children, whose delayed development they do not understand. Parents may also become disenchanted with medical professionals who fail to recognize the condition. Children and families miss two-to-three years of support from an early intervention system that is in place and available for services; families fail to get important information on genetic risk which might have affected their decisions about bearing subsequent children.

Since this first grant was awarded, an interdisciplinary team of researchers at FPG and other UNC schools have conducted a series of studies on early development. Principal researchers include Don Bailey, Deborah Hatton, Jane Roberts, Joanne Roberts, Penny Mirrett, and Jennifer Schaaf. These studies have led to more than 20 publications and wide recognition of FPG as the primary research center studying FXS during the early childhood years. Currently, FPG is conducting seven studies on fragile X. These include a study on the neuropsychological functioning of fragile X children in late elementary and middle school; a study of the life functions of the same group, including where these children go to school, what their interactions are with other children, and what opportunities they have to participate with other children; completion of a pilot project looking at early identification issues for children at 9, 12, and 18 months of age; two studies on language development and hearing for children with fragile X; a study observing parent/child interactions of families with children with fragile X; and a grant from the Ronald McDonald House Charities to set up a web site for parents and practitioners distilling crucial information about fragile X and addressing issues in the field. The latter grant is consistent with FPG's mission of linking research with outreach.

What is the significance of fragile X research at Frank Porter Graham? "FPG Child Development Institute

and developing an understanding of its consequences for families.

is the first and only group defining the early development of fragile X, and developing an understanding of its consequences for families," says Don Bailey, director of FPG and principal investigator of the initial study. "Our immediate goal is to learn enough about fragile X syndrome so that we can help improve early identification and design appropriate early intervention strategies.

"Our studies of fragile X could also provide a prototype for how society will deal with other genetic disorders," Bailey continues. "With the advances in the Human Genome Project, we will soon be able to identify a whole host of disorders whose origin can be traced to the mutation of specific genes, some of which are inherited and passed down from generation to generation. This capability will raise a number of challenging questions, including whom we should screen, what disorders we should screen for, and what to do when disorders are discovered. By focusing on fragile X, we can answer questions broadly related to other disorders."

Several critical questions remain unanswered with respect to fragile X itself. Though estimates of 1:4000 males have been made, the true incidence of the syndrome is unknown. Likewise, factors such as ethnicity have not been studied, and more needs to be learned about infant development to help pediatricians do a better job of identifying the disorder. Toward this end, FPG has applied for a grant to plan a very large study in which researchers would screen approximately one million children to determine the incidence rate and what the behavior and development of affected children looks like in the first year, and to test different models for early intervention.

"FPG provides a great context for studying this and other disabilities," Bailey says. "We have an interest in covering the waterfront from understanding the basic phenomenon to understanding the ramifications for society." | ed |

To learn more

FMRP and early development in fragile X syndrome. Bailey, D.B., Hatton, D.D., Tassone, F., Skinner, M., & Taylor, A.K (2001). *American Journal on Mental Retardation, 106*, 16-27.

Overview: Fragile X syndrome. Bailey, D.B., & Nelson, D. (1995). *Mental Retardation and Developmental Disabilities Research Reviews: Fragile X Syndrome, 1*(4), 237.

Family experiences and factors associated with diagnosis of fragile X syndrome. Bailey, D.B., Skinner, D., Hatton, D., & Roberts, J. (2000). *Journal of Developmental and Behavioral Pediatrics, 21*(5), 315-321.

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recent publications

Child care quality and children's engagement. Raspa, M.J., McWilliam, R.A., & Ridley, S.M. (2001). *Early Education and Development, 12,* 209-224.

Discerning the dialogical self: A theoretical and methodological examination of a Nepali adolescent's narrative. Skinner, D., & Valsiner, J. (2001). *Forum: Qualitative Social Research, 2*(3). Available at: <http://www.qualitative-research.net/fqs-texte/3-01/3-01skinneretal-e.htm>.

Early interventionists' perspectives on professional comfort as consultants. Wesley, P.W., Buysse, V., & Skinner, D. (2001). *Journal of Early Intervention, 24*(2), 112-128.

Evaluating parent involvement and family support in early intervention and preschool programs: Three levels of accountability. Bailey, D.B., (2001). *Journal of Early Intervention, 24*, 1-14.

FMRP and early development in fragile X syndrome. Bailey, D.B., Hatton, D.D., Tassone, F., Skinner, M., & Taylor, A.K. (2001). *American Journal on Mental Retardation*, 106, 16-27.

Fragile X syndrome and autism. Hatton, D.D., & Bailey, D.B. (2001). In L. Marcus, E. Schopler, C. Shulman, & N. Yirmiya (Eds.), *The research basis of autism intervention outcome*, (pp. 75-89). New York: Kluwer Academic/Plenum Publishers.

Identifying infants and toddlers with fragile X syndrome: Issues and recommendations. Bailey, D.B., Roberts, J.E., Mirrett, P., & Hatton, D.D. (2001). *Infants and Young Children, 14*(1), 24-33.

Implementing early intervention policy: Are we making the grade? Harbin, G.L. (2001). *Journal of Early Intervention, 24*(2), 103-105.

Model registry of early childhood visual impairment: First year results. Hatton, D.D., & Model Registry of Early Childhood Visual Impairment Collaborative Group. (2001). *Journal of Visual Impairment and Blindness, 95*(7), 418-433.

Models of acculturation and health behavior among Latino immigrants to the U.S. Arcia, E., Skinner, M., Bailey, D., & Correa, V. (2001). *Social Science and Medicine, 53*, 41-53.

North Carolina Preschool Services for Children with Disabilities: A Profile of Local Education Agency Programs and Practices. Mengel, P., Payne, B., Trohanis, P., & Baars, K. (2001). Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance System.

Parent Leadership Development: Building Strong Voices for Children (Facilitator Guide). Parent Leadership Development Project. (2002). Chapel Hill: The University of North Carolina, FPG Child Development Institute.

Parent Leadership Development: Building Strong Voices for Children (Participant Notebook). Parent Leadership Development Project. (2002). Chapel Hill: The University of North Carolina, FPG Child Development Institute.

Putting the child back into child care quality assessment. Ridley, S.M., & McWilliam, R.A. (2001). *Young Children, 56*(4), 92-93.

Removing Barriers to Health Clubs and Fitness Facilities. North Carolina Office on Disability and Health. (2001). Chapel Hill: The University of North Carolina, FPG Child Development Institute.

Resource Guide: Selected Early Childhood/Early Intervention Training Materials (10th ed.). Catlett, C., & Winton, P.J. (2001). Chapel Hill: The University of North Carolina, FPG Child Development Center.

Resources within reason: Supporting inclusive programs and practices within communities. Catlett, C., Winton, P., & Dennis, B. (2001). *Young Exceptional Children, 4*(4), 27.

Resources within reason: Resources that increase awareness about inclusion in diverse environments. Catlett, C., & Winton, P.J. (2001). *Young Exceptional Children, 4*(2), 29.

Section 619 Profile (10th ed.). deFosset, S. (Ed.). (2001). Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance System.

Seizures in infants and young children: An exploratory study of family experiences and needs for information and support. Aytch, L.S., Hammond, R., & White, C. (2001). *Journal of Neuroscience Nursing, 33*(5), 278-285.

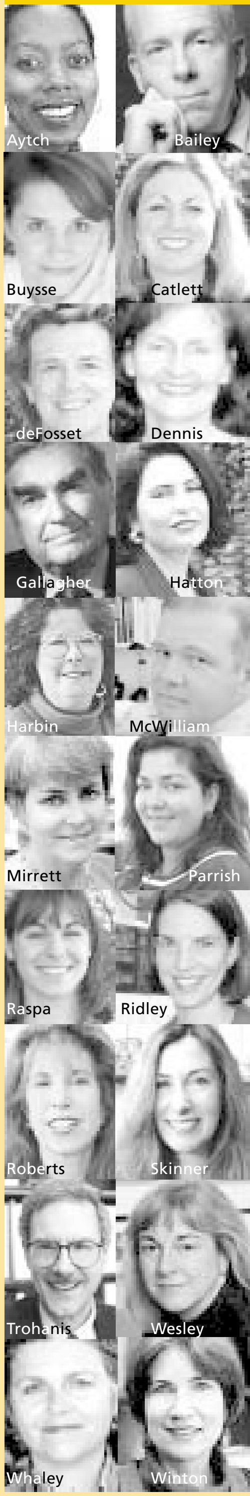
Smooth Moves to Kindergarten. Wesley, P.W. (2001). Chapel Hill, NC: Chapel Hill Training Outreach Press.

The evolution of transition policy for young children with special needs and their families: Past, present, and future. Rosenkoetter, S.E., Whaley, K.T., Hains, A.H., & Pierce, L. (2001). *Topics in Early Childhood Special Education, 21*(1), 3-15.

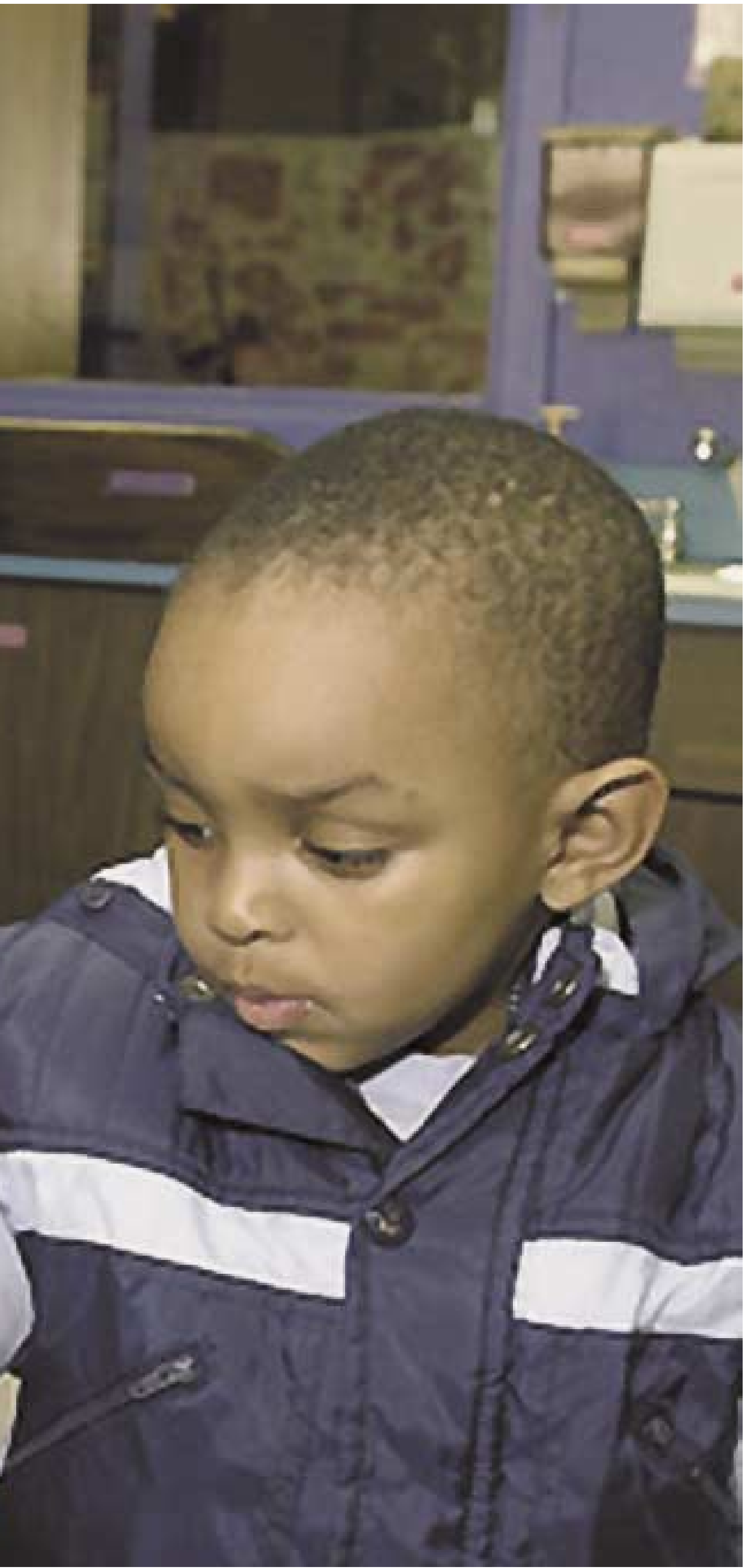
The role of religion in the lives of Latino families of young children with developmental delays. Skinner, D., Correa, V., Skinner, M., & Bailey, D. (2001). *American Journal on Mental Retardation, 106*, 297-313.

Toward a definition of quality inclusion: Perspectives of parents and practitioners. Buysse, V., Skinner, D., & Grant, S. (2001). *Journal of Early Intervention, 24*(2), 146-161.

Walking the Walk: A Guide to Diversity Resources for Trainers. Catlett, C., Winton, P.J., Parrish, R.N., & White, C. (2001). Chapel Hill: The University of North Carolina, FPG Child Development Center.



A Model of Inclusion



With the 1975 passage of the Education of Handicapped Children Act, and its reauthorization in 1990 and 1997 as the Individuals with Disabilities Education Act (IDEA), Congress called on states to embark on a bold effort to incorporate children with disabilities into the mainstream of education. That effort has met with mixed results nationwide, but at the FPG child care center, inclusion of children with disabilities has been the norm since 1984. Results of that effort suggest that inclusion can be beneficial for both children with disabilities and those who are typically developing.

Housed in the first two floors of FPG, the child care program serves 80 children ranging in age from 6 weeks to 5 years old. It is a full day program, operating from 7:30 AM to 5:30 PM and open year round. Approximately 30% of the children within each age group have an identified disability, with slightly more children with disabilities enrolled in preschool classrooms than in the infant-toddler groups. A diverse range of types and severity of disabilities are represented, including Down syndrome, cerebral palsy, other specific syndromes, children who are medically fragile, and autism.

The program is accredited by the National Association for the Education of Young Children and has a five-star North Carolina license—the highest quality rating in the state. Teachers at FPG tend to be more educated than is typical of child care providers in the community, with most having a four-year degree, and many having a North Carolina Birth-to-Kindergarten teaching license, according to P.J. McWilliam, who directs the center.

"A more educated staff and lower child-to-adult ratios leads to more engaging and developmentally-appropriate activities going on in the classrooms," McWilliam says. "Teachers' interactions with children tend to be more positive, aimed at facilitating social-emotional development rather than merely controlling undesirable behavior."

Children with disabilities participate in all classroom activities, at whatever level of ability they are capable, and provided with whatever level of assistance they may need. “Sometimes a child’s participation requires an extra hand, special materials, a piece of adapted equipment, or just plain old creative thinking on the part of a teacher or specialist,” McWilliam says.

While they may hold degrees and licenses, few teachers enter the program with extensive experience in working with children with disabilities. “A lot is learned on the job,” McWilliam adds.

Although a team of specialists supports each child’s developmental progress and inclusion, children at FPG are not pulled out of their classrooms for therapy. Instead, specialists share their expertise through consultation with teachers and, less frequently, through direct intervention within the context of classroom routines. These routines include morning circle, meal times, outdoor play, pretend play, storybook reading, and field trips.

The role of specialists and the purpose of therapy are to enable each child to participate in the regular early childhood curriculum and to support his or her membership in the group. “The fact that children stay with the same group of buddies for at least their first three years of enrollment at FPG helps,” McWilliam says.

Team approach

FPG’s approach to special services relies heavily on teaming. The program is fortunate to have an on-site special services staff, which consists of a service coordinator (special educator), a speech-language pathologist, an occupational therapist, a physical therapist, and a behavior analyst.

“Although some of our specialists only work part-time for the program, the *consistency* in who works with the children and teachers makes a big difference,” McWilliam says. “Regular and effective communication among members of the special services staff and, perhaps more importantly, between the special services staff and the classroom teachers is critical. Stolen moments during a specialist’s visit to the classroom, a chance encounter in the teacher’s lounge, or a few words shared out on the play yard allow for informal communication and intervention updates with teachers.”

Additional time, however, is required for more in-depth communications about children’s progress and needs. The special services staff tries to meet more formally with each teacher at least every other week for an hour or so to discuss the children. In addition, formal individualized education plan (IEP) meetings and individualized family service plan (IFSP) meetings are scheduled for each child, along with meetings to review and update these plans.

Partnership with parents

Child care center staff emphasize that effective parent-teacher partnerships are a key factor in meeting the needs of children with special needs, as well as those of children who are typically developing. The cornerstone of these partnerships is honest and ongoing communication. This can take many forms, from informal chatter at the beginning or end of the day to more formal parent-teacher conferences. Short notes about the child’s day that are stuck in a diaper bag or cubby, as well as e-mail messages or evening phone calls are other good communication techniques. “The more open, honest, and frequent the communication, the more effective the partnership will be between parent and teacher,” McWilliam says. “The same holds true for relationships between specialists and parents.

In fact, parents of children at FPG actually *lead* the team in identifying appropriate goals and priorities for intervention with their child. Over the past year, the program has adopted a routines-based approach to intervention planning whereby the skills and behaviors that children need to be successful in their daily routines are the focus of the intervention plan. This has helped to insure that parents’ values and priorities are clearly communicated to the team and that parents actually direct the design of interventions for both home and classroom.”

Parents of children with special needs are also encouraged to be involved in classroom activities in the same ways as parents of typically developing children. This may mean joining the class during morning circle time, going on a field trip, volunteering in the classroom, attending classroom potluck dinners, or attending FPG's parent advisory board. These parents, like all other parents in the program, are free to choose the type and level of involvement that they find meaningful and that fits into their busy schedules.

A touch of magic

Research suggests that parents of children with special needs and those who are typically developing have concerns as to whether the benefits of an inclusive classroom setting outweigh the drawbacks. The experience at the FPG child care center, as well as wider research in the field, suggests that benefits do outweigh the drawbacks.

"There have been times," admits McWilliam, "when I've wondered what the children with more severe disabilities get out of being in our program...whether it really matters to them that they are in a setting with typically developing peers. Again, there are a few moments here and there that make me realize that the answer is yes."

"Research has shown that in high-quality child care settings, there are clear benefits from inclusion," says Don Bailey, director of the FPG Child Development Institute. "First, children with disabilities and those without do play together. Second, children with special needs engage in more social behavior in inclusive settings than they do in segregated settings. Third, there are no negative consequences for typically developing children placed in inclusive settings. To the contrary, these children develop an appreciation for the differences."

McWilliam admits that even in programs like FPG's, where resources are more plentiful than others, inclusion isn't always easy, nor is it inexpensive. But witnessing the benefits makes the effort worthwhile.

"There's a little boy named Jake in one of our two-year-old rooms who has severe and multiple disabilities," McWilliam says. "He has been in our program, and with the same group of children, since he was an infant. Despite the fact that Jake can't do many of the things that the other children in the classroom can, it is clear from watching and listening to the other children that they consider him a true member of their group. They always notice when he's out sick and they insist upon his name being included in any conversations about the group. They have always approached him readily to play with the adaptive toys on the tray of his wheelchair or special seat and they encourage Jake to activate them, too—after they've had their turn first, of course!"

"One day last week," continues McWilliam, "I was in this same classroom and noticed Jake lying on the floor under a cross bar with toys suspended from it. Another 2-year-old, Demarcus, had joined him under the crossbar and was lying cheek to cheek with Jake, trying to tuck a doll blanket under both of their chins. Demarcus wasn't doing this for adult attention," explains McWilliam, "His affection for Jake seems quite sincere. It's heartwarming to witness."

"There have been times," admits McWilliam, "when I've wondered what the children with more severe disabilities get out of being in our program … whether it really matters to them that they are in a setting with typically developing peers. Again, there are a few moments here and there that make me realize that the answer is yes."

"One day Jake wasn't feeling well," says McWilliam, "so I offered to take him for a walk around the halls in his stroller. As I rounded a corner, his buddy Demarcus burst through the front door, saw Jake in his stroller, and immediately started talking to him. Jake's crying stopped almost immediately and he started to coo. It seemed clear to me that Jake recognized the sound of his friend's voice, that it comforted him in some way, and that he appreciated and benefited from their relationship—albeit in his own manner."

"We all benefit from inclusion," McWilliam adds. "But some of the most important benefits have nothing to do with IQ scores or later school achievement. Perhaps some day, these less clearly measurable outcomes will be understood to be of greater value."

| ed |

Cost, Quality and Outcomes of Preschool Inclusion

For two decades FPG has been conducting research on inclusion. One of our newest research projects on inclusion at FPG, funded by the US Department of Education, is examining widely used ways to implement preschool inclusion: community-based itinerant services, Head Start centers and public school classrooms.

Project Director Virginia Buysse, a scientist at FPG, explained, "Across these three organization models, we'll be looking at the relationships among program costs, program quality and outcomes for preschool-age children with disabilities and their families."

Buysse and her team will collect information from nine North Carolina programs, involving 90 children and families. Sam Odom, principal investigator at Indiana University, will gather the same information on preschool programs in Indiana.

The outcomes will be documented through developmental measures and assessments of friendship formation and peer relations. The programs' quality will be measured through an environmental rating scale, an ecobehaviorial observation tool, and an assessment of the quality of inclusion.

Virginia Buysse, Project Director

Buysse said the costs per child will be assessed through methods developed by the Center for Special Education Finance in Palo Alto, CA, and statistical tests will examine the relationship between program quality and outcomes as well as differential costs between higher- and lower-quality programs.

"We expect to offer information that can be used to guide families, teachers and local program administrators in selecting appropriate placements and designing quality improvements of inclusion preschool programs," she said. Findings will be available in 2004. | ed |

Connecting Research Findings to Classroom Practices

Children with special needs in child care, including those enrolled in the FPG Child Care Program, receive specialized services such as physical therapy, special education, occupational therapy, and speech-language pathology. FPG has a history of conducting research on specialized services and has a current project demonstrating recommended practices in this area.


Robin McWilliam, Project Director

For 10 years, Robin McWilliam has been examining and demonstrating the efficacy of different methods of providing specialized services. This work has included a national survey of disability specialists and therapists; studies with individual children and groups of children; and focus groups with parents, service providers, and administrators.

McWilliam summarized the most important findings from these studies in this way: “Specialized services need to be provided in classrooms, in collaboration with the classroom staff, so the staff can carry out the interventions throughout the day. All the worthwhile intervention occurs between specialists’ visits. Integrated therapy and integrated special education are more effective than pulling children out for these services.”

The key dimensions of inclusion, based on research, demonstrated at the FPG Child Care Program are—how to use routines-based assessment—how to integrate therapy and special education, and—how to use embedded interventions. McWilliam says, “All three of these dimensions are designed to maximize the amount and effectiveness of intervention for children with disabilities.”

The FPG Child Care Program employs integrated therapy with the assistance of another FPG project, Individualizing Inclusion in Child Care. This federally funded model demonstration project has helped the staff organize the demonstration aspect of their inclusionary practices. Integrated therapy is achieved through collaboration, especially between teachers and specialists. Specialists provide therapies in the classroom, weaving interventions into classroom activities and consulting with teachers. “Because the specialists are in the classroom and see what the child is able to do, they develop feasible strategies with the teachers so that intervention occurs even when the specialists are not present,” says Stacy Scott, coordinator of the Individualizing Inclusion in Child Care Project. “If you go into one of the classrooms to observe, you’ll see that in just about every classroom routine, at least one, and often several, of a child’s intervention goals is being addressed by a teacher.” | ed |

To learn more

Rethinking Pull-Out Services in Early Intervention: A Professional Resource.
McWilliam, R.A. (Ed.). (1996). Baltimore, MD: Paul H. Brookes.

Integration of therapy and consultative special education: A continuum in early intervention. McWilliam, R.A. (1995). *Infants and Young Children* 7(4), 29-38.

Integrating therapies into the classroom. Scott, S.M., McWilliam, R.A., & Mayhew, L. (1999). *Young Exceptional Children*, 2(3), 15-24.

For more information about the Individualizing Inclusion project, please contact Project Coordinator Stacy Scott at 919-966-5943 or email Stacy_Scott@unc.edu.
Project web site: www.fpg.unc.edu/~inclusion.

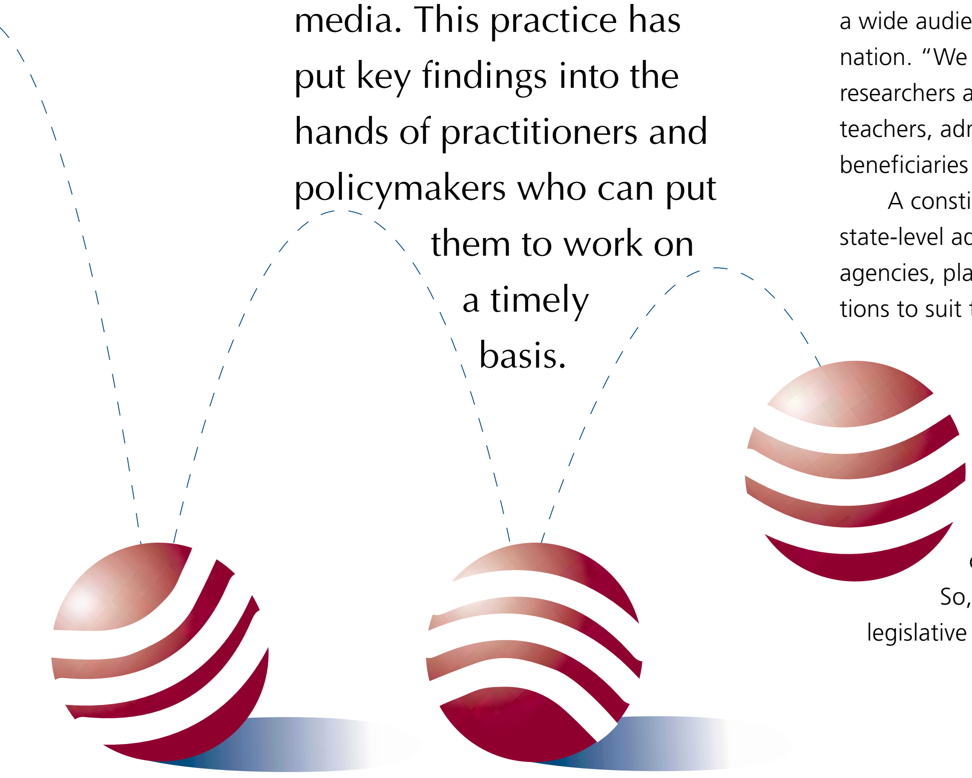
For more information about the FPG Child Care Program, contact Dr. P.J. McWilliam at (919) 966-5098 or email mcwillpj@mail.fpg.unc.edu.

NCEDL

Committed to Sharing

1997 5 YEARS 2002

Academic institutions are not generally noted either for the widespread use of their scholarly articles or their ability to disseminate findings quickly. The National Center for Early Development & Learning (NCEDL) has broken that mold by sharing findings of their research on early childhood development through a diverse array of media. This practice has put key findings into the hands of practitioners and policymakers who can put them to work on a timely basis.



Comprised of a consortium of researchers at the University of California at Los Angeles, the University of Virginia, and the University of North Carolina, NCEDL is one of 12 centers funded under the US Department of Education's Office of Educational Research and Development. It is the only center devoted to research in early childhood development. Since its inception in 1996, NCEDL has sponsored dozens of studies whose findings expand the understanding of early childhood education and development. However, getting those findings out to the broad and amorphous target audience that works with or formulates policies for young children has been a major challenge.

NCEDL has approached this task by developing a comprehensive dissemination infrastructure for a diverse array of publications. The bedrock of NCEDL's publications are peer-reviewed articles on research conducted by the center, articles that are ultimately published in scholarly journals. These form a solid scientific base for other materials—press releases, technical briefs, brochures—that put key information into more readable and timely formats usable to a wider audience.

"In our original grant, the US Department of Education made a point of stressing that the results of our research need to reach a wide audience," says Pam Winton, who directs center dissemination. "We were not satisfied to communicate only with fellow researchers and academics. We sought to find ways to reach the teachers, administrators, parents, and policymakers who are the beneficiaries of our research."

A constituent advisory board, comprised of parents, teachers, state-level administrators, and childhood resource and referral agencies, played a key role in helping NCEDL shape the publications to suit the various audiences.

"At one point, we planned to release a technical report on child care quality with the intention of reaching an audience of administrators and policy makers," Winton says. "Our advisory board told us that the legislators needed something they could 'hold in one hand and read while they were talking on the phone and eating lunch at the same time.' So, we ended up preparing a four-page brief for the legislative staff and a one-page fact sheet for legislators."

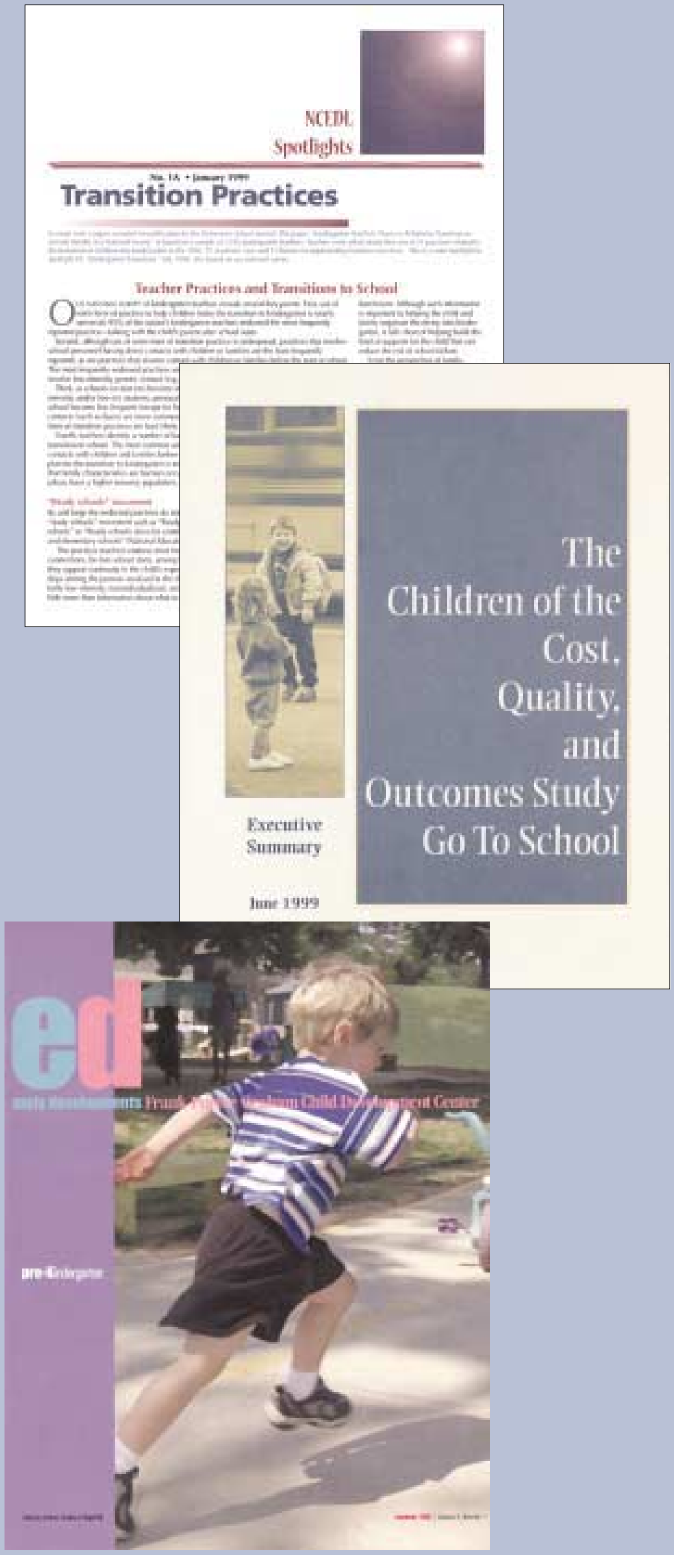
NCEDL has disseminated more than 425,000 copies of major products during its first five years.

To gain the widest audience for their research findings, NCEDL focuses on disseminating the information in ways that are easy for other organizations to customize and redistribute. Press releases are written following a "Swiss cheese" approach, whereby "holes" are left in the stories in which local publications can insert their own information. *Spotlights*, the center's one-page summaries of research findings and events, is disseminated to publishers of statewide, regional, and national newsletters, who are then encouraged to reproduce it in their own publications. NCEDL publishes an electronic newsletter (*Enews*) that is sent to various listservs, through which it is redistributed it to other audiences. NCEDL also hosts a web site, **www.ncedl.org**, on which summaries of all NCEDL activities and projects are posted and available for download.

The versatility of NCEDL's information dissemination capabilities was demonstrated in the activities around the center's 1999 Cost, Quality, and Child Outcomes study. This study provided solid evidence that such factors as child-staff ratios, teacher qualifications, and staff training at child care centers affect children's sociability, language and cognitive development, and self-control. While the researchers prepared and submitted scholarly articles, they also developed a media plan to roll out key findings in advance. They wrote press releases and held a press conference in Washington, DC. A technical report, reviewed and approved by outside experts, was posted on the web site and made available in print. A *Spotlight* was prepared and sent out to interested organizations, as well as being posted on the web. An *Enews* report went out through *Enews* list and listervs.

NCEDL's web site has been particularly effective as an information dissemination tool. Along with summaries of NCEDL studies and activities, the web site also contains lists of related publications, issues of *Early Developments* (available for download), lists of experts and funding sources, and links to related sites. The web site averages over 1,000 hits per month, with users including students, parents, program administrators, teachers and policymakers. Usage has grown over time and peaks around key events, such as press conferences.

A large number of NCEDL's products are directly disseminated by center researchers and staff through presentations, meetings, electronic distribution, and mailings to individuals. NCEDL has also published a number of books summarizing



NCEDL Spotlights

Transition Practices

Teacher Practices and Transitions to School

Executive Summary

The Children of the Cost, Quality, and Outcomes Study Go To School

June 1999

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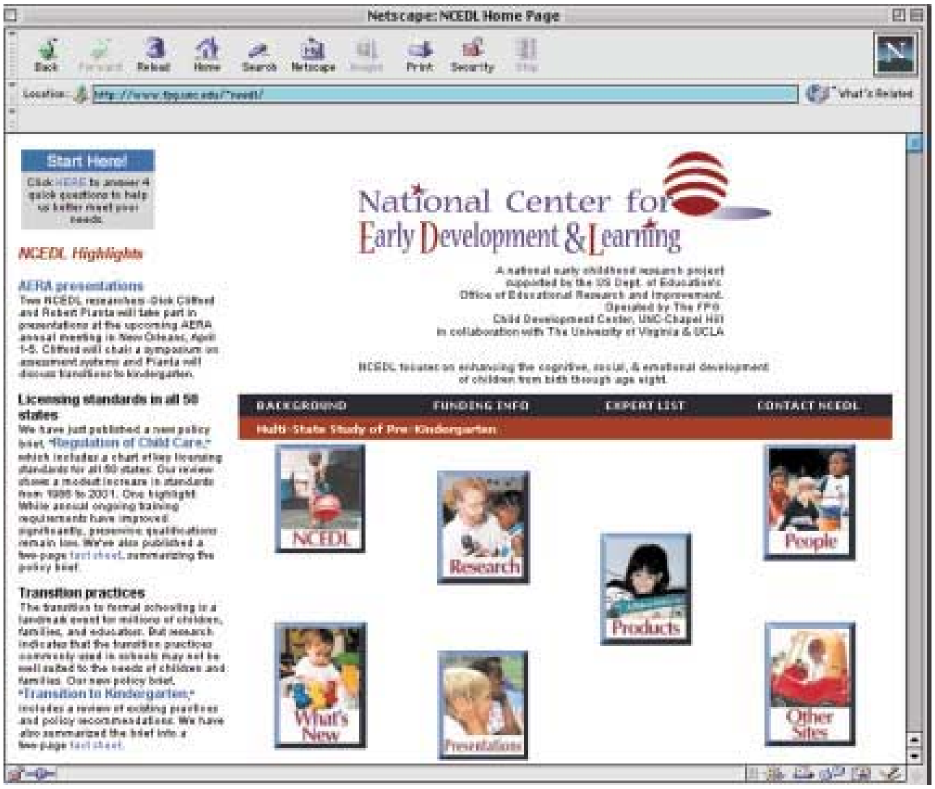
The web site averages over 1,000 hits/month, with users including students, parents, program administrators, teachers and policymakers.



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NCEDL Highlights

AERA presentations
Two NCEDL researchers -Dick Clifford and Robert Pianta will take part in presentations at the upcoming AERA annual meeting in New Orleans, April 1-5. Clifford will chair a symposium on assessment systems and Pianta will discuss transitions to kindergarten.

Licensing standards in all 50 states
We have just published a new policy brief, "Regulation of Child Care," which includes a chart of key licensing standards for all 50 states. Our review shows a modest increase in standards from 1986 to 2001. One highlight: While annual ongoing training requirements have improved significantly, preservice qualifications remain low. We've also published a two-page fact sheet, summarizing the policy brief.

Transition practices
The transition to formal schooling is a landmark event for millions of children, families, and educators. But research indicates that the transition practices commonly used in schools may not be well suited to the needs of children and families. Our new policy brief, "Transition to Kindergarten," includes a review of existing practices and policy recommendations. We have also summarized the brief into a two-page fact sheet.

National Center for Early Development & Learning

A national early childhood research project supported by the US Dept. of Education's Office of Educational Research and Improvement. Operated by The FPG Child Development Center, UNC-Chapel Hill in collaboration with The University of Virginia & UCLA

NCEDL focuses on enhancing the cognitive, social, & emotional development of children from birth through age eight.

presentations in major conferences synthesizing research on early childhood issues. Collectively, this information is making a difference according to policymakers.

"We have made progress toward full-day kindergarten in Indiana because we've been able to hold up the research that says children need stimulating early childhood environments to do well in school," says Jayma Ferguson, Early Childhood Specialist for the Indiana Department of Education. "We don't have the time or the money to do the research ourselves. That is why what NCEDL is doing is so important. They have responded by putting together the products we need."

Altogether, NCEDL has disseminated more than 425,000 copies of major products during its first five years. Winton credits this success to the center's partnerships with other groups and its development of the web site. "Approximately 32% of our products were disseminated as a result of collaboration with other centers, agencies, or groups," she says. "Another 33% were downloaded from the web site. Thus, 65% of our product dissemination was quite cost effective and reached audiences that we would not have been able to had we relied solely on traditional methods."

Winton credits Loyd Little, NCEDL's communication specialist who has decades of experience as a working journalist. "Loyd understands the media and how to work with them," Winton says. "His contributions to the effort have been critical. At FPG we pride ourselves on our interdisciplinary work. Adding journalism to our mix of staff has yielded great benefits." | NCEDL |

Assessing Early Intervention

Early intervention, the system of services providing support to infants and toddlers with disabilities and their families, has long been a focus of research at FPG. Much of this work has centered on enhancing the quality of intervention policy and practice. In the most recent (1997) reauthorization of the Individuals with Disabilities Act, the federal government directed states to implement strategies to assess **quality** of services, in addition to monitoring for compliance with regulations. To address this need, researchers at FPG are working to develop and refine an instrument which they hope will become a widely-accepted measure for assessing early intervention programs nationwide.

Drawing upon well-established rating scales of child care environmental quality (e.g., ECERS-R, ITERS) developed by FPG researchers, the Early Intervention Services Assessment Scale (EISAS) defines high-quality practices across the broad spectrum of early intervention services. Principal investigator Lynette Aytch says a major challenge has been developing a tool that can effectively evaluate a complex system of services, people, and settings.

"We spent a lot of time looking at what the literature says about quality early intervention practice and combined this with a lot of dialogue with parents, service providers, program administrators, and other researchers," Aytch says. "This led to the design of an instrument that we believe reflects early intervention program quality."

To test the actual utility of EISAS in the "real world" of early intervention programs, researchers conducted a field study involving 29 early intervention programs across 8 states.


Lynette Aytch
Principal Investigator

"In this study, we were able to collect EISAS data from 155 early intervention staff and 450 parents of children served by these programs," Aytch says. "We are now in the process on analyzing and reporting our findings."

Preliminary findings from the field suggest that overall, the EISAS has good content validity. That is, the content of the instrument adequately represents the range of intervention services and quality practices. However, the field study also indicates that program self-assessment has significant limitations.

"Our findings suggest that programs tended to rate themselves as high, despite data which suggest that the programs varied widely in quality," Aytch says.

Researchers are currently refining the instrument and will conduct more studies with early intervention programs across the country.

| NCEDL |

To learn more

Defining and assessing quality in early intervention programs for infants and toddlers with disabilities and their families: Challenges and unresolved issues. Aytch, L.S., Cryer, D., Bailey, D.B., & Selz, L. (1999). *Early Education and Development, 10* (1), 7-23.


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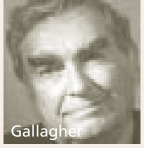
Gallagher


Pianta


Winton

NCEDL recent publications

Caregiver training and classroom quality in child care centers. Burchinal, M.R., Cryer, D., Clifford, R.M., & Howes, C. (2002). *Journal of Applied Developmental Sciences, 6*, 2-11.

Early teacher-child relationships and the trajectory of children's school outcomes through eighth grade. Hamre, B., & Pianta, R. (2001). *Child Development, 71*(2), 625-638.

Education for Four-year-olds: State Initiatives. Supplement to Technical Report #2 (California & Ohio). Gallagher, J.J., Clayton, J.R., & Heinemeier, S.E. (2002). Chapel Hill: The University of North Carolina, FPG Child Development Institute, NCEDL.

Implications of a developmental systems model for preventing and treating behavioral disturbances in children and adolescents. Pianta, R. (2001). In J. Hughes, A. La ,Greca, & J. Conoley (Eds.), *Handbook of psychological services to children and adolescents,* (pp. 23-41). New York: Oxford University Press.

Overt and covert dimensions of antisocial behavior in early childhood. Willoughby, M., Kupersmidt, J., & Bryant, D. (2001). *Journal of Abnormal Child Psychology, 29*, 177-187.

Predicting children's competence in the early school years: A meta-analytic review. La Paro, K., & Pianta, R. (2001). *Review of Educational Research, 70*(4), 443-484.

Preparing the workforce: Early childhood teacher preparation at 2- and 4- year institutions of higher education. Early, D.M., & Winton, P.J. (2001.). *Early Childhood Research Quarterly, 16*, 285-306

Regulation of Child Care. Early Childhood Research–Policy Briefs & Fact Sheet. Azer, S., Morgan, G., Clifford, R.M., & Crawford, G.M. (2002). Chapel Hill: The University of North Carolina, FPG Child Development Center, NCEDL.

Teachers' perceptions of their relationships with students: Effects of child age, gender, and ethnicity of teachers and children. Saft, E., & Pianta, R. (2001). *School Psychology Quarterly, 16*(2), 125-141.

Teacher ratings of behavior among African American and Caucasian children during the first two years of school. Sbarra, D., & Pianta, R. (2001). *Psychology in the Schools, 38*(3), 229-238.

The home environments of children in the United States. Part 1: Variations by age, ethnicity, and poverty status. Bradley, R.H., Corwyn, R.F., McAdoo, H.P., & Garcia Coll, C. (2001). *Child Development, 72*, 1844-1867.

The home environments of children in the United States. Part 2: Relations with behavioral development through age 13. Bradley, R.H., Corwyn, R.F., Burchinal, M., McAdoo, H.P., & Garcia Coll, C. (2001). *Child Development, 72*, 1868-1886.

Transition to Kindergarten. Early Childhood Research–Policy Briefs & Fact Sheet. Pianta, R., & Cox, M. (2002). Chapel Hill: The University of North Carolina, FPG Child Development Center, NCEDL.

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