



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, an 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 Impairment 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.