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early developments Frank Porter Graham Child Development Center

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Family-Centered Research & Practices

From the Director's Office: The Big Picture

Why Do They Do That?

Focus on Families

I Don't Want to Talk About It!

Putting Parents in the Picture

NCEDL News

FOCUS ON FAMILIES

In many FPG projects cultural diversity is expanding early education and intervention practices

GETTING A BETTER UNDERSTANDING of how Latino families view and use services for young children with disabilities is but one of a number of studies at FPG involving the center's commitment to increasing our knowledge of families. For example, one study is studying family literacy programs, while another is looking at how researchers can better ensure that families understand what "consent" means when helping researchers. Transition considerations for families with fragile X children are being examined, and several research instruments concerning families are being translated into Spanish.

Updates on these projects

Regarding services, findings indicate that only 39% of 200 Latino parents of young children with disabilities were "mostly" or "very satisfied" with services for their children. This finding was lower than found in several previous studies.

Don Bailey, one of the study investigators, said that an interesting inverse relationship was found between satisfaction and awareness as well as use of services. For both mothers and fathers, greater awareness and use of services was associated with greater dissatisfaction. A potential explanation is that those who actively seek out and use services have higher

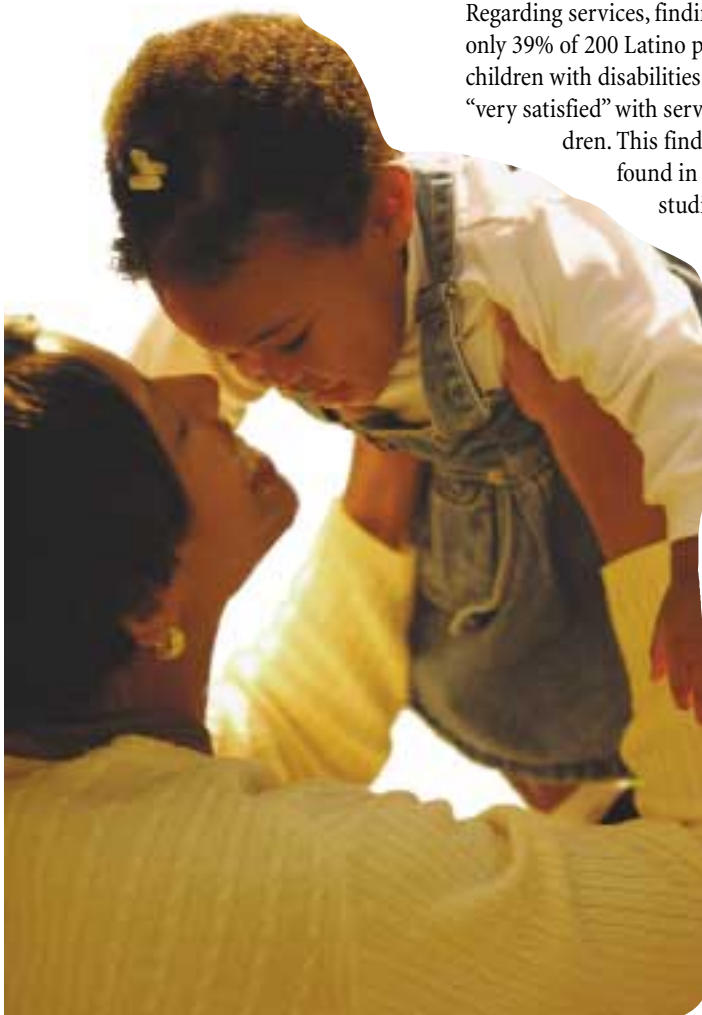
expectations for the service system and thus are likely to be less satisfied than those who have lower expectations.

OTHER FINDINGS

- Mothers (but not fathers) of children with more severe delays and older children reported less satisfaction with services. The fact that this relationship was not found for fathers likely reflects the greater awareness and use of services by mothers and the fathers' frequent allocation of decision making with respect to services to the mother.
- Dissatisfaction is more likely to occur when the program characteristics do not match the needs of the family, as in the case where a Spanish-speaking family does not have access to materials in Spanish or a translator, or when service providers are perceived to be non-accepting or unwilling to be helpful.
- Researchers found very little pursuit of alternative treatments, such as the use of folk medicines or practices that seem exotic to western medicine.

Bailey reports several implications for practice have emerged so far.

- Families of Puerto Rican and Mexican heritage vary widely in terms of awareness, use, and satisfaction with services, and the family characteristics commonly believed to influence these outcomes generally did not seem to be related. Professionals should be careful to not draw general conclusions about Latino families; thus, again, emphasizing the need for an individualized approach.
- Clearly for some families, providing written materials in Spanish or a translator would be of both functional help as well as send an important message about the program's willingness to be responsive to individual differences.
- Although it is critical to understand the history, traditions, and values of various cultures, "it is probably a disservice and a misrepresentation to assume that members of immigrant groups do not subscribe to what we consider a modern approach to services," said Bailey.



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Others working with Bailey are Debra Skinner and Patricia Rodriguez at FPG, and Vivian Corea at the University of Florida.

Helping parents understand research

One important barrier to obtaining informed consent while enrolling people in studies is a lack of true comprehension of what a given study involves. Most consent forms used by researchers to get permission from those participating in research are at a college reading level. Parents who have limited reading are especially vulnerable in this situation. With that in mind, a team head by FPG researcher Frances Campbell is examining better ways to explain research procedures to parents when seeking their permission.

Working with parents representing a range of literacy levels, the team is evaluating how information is comprehended when it is presented in four ways.

- 1 A traditional printed consent form
- 2 A graphically enhanced consent form
- 3 A video-enhanced consent procedure
- 4 A procedure in which the parent interacts with a computer using a video and a touch screen

Parents will be recruited for a hypothetical study and assigned to one of the above consent procedures. The research capitalizes on FPG's expertise in research involving children and vulnerable populations, such as low-income families. Other researchers working with Campbell are Barbara Goldman and Maria L. Boccia.

Fragile X children

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 in Virginia and the Carolinas.

Children in these two studies are now moving into kindergarten and first grade. Researchers Don Bailey and Deborah Hatton say that while most parents are pleased with the transition from preschool programs to kindergarten and from

problems more of a challenge than mental retardation.

- By the second grade, virtually all parents of fragile X children request specialized services, even those who had

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kindergarten to first grade, such transitions can create anxiety.

been adamant about inclusion in preschool and kindergarten.

OTHER EARLY FINDINGS

- Placement in classes is driven more by the resources of school systems rather than the goals in the Individualized Education Plans.
- Some parents shop around and look at classes that they think would be best for their child, and then they try to secure the label necessary for getting the child into that class.
- Fragile X is not an eligibility category for receiving services, and so children are given different labels, depending in part on schools' resources and eligibility requirements and in part on the desires of the parents.
- While most fragile X children may be mentally retarded, that label can be misleading for teachers. In many cases, teachers find attention and hyperactivity disorders and behavior

Translating instruments

Researchers Syndee Kraus and Robin McWilliam are translating two broad-based questionnaires (*Brass Tacks: The Family Report* and *Children's Engagement Questionnaire*) into Spanish and will test and disseminate them so that early intervention specialists can do a better job capturing the "voice" of Latino families who receive these services.

Brass Tracks measures the family's perceptions of services they are receiving and what is important to them. *The Children's Questionnaire* measures the family perceptions of their children's persistence, social behavior, and attentiveness.

"We want to ensure that our practices with these families and their children are based on first-hand perceptions rather than making assumptions based on previously gathered research data from members of other cultures," says McWilliam. **ed**