

Hear Our Voice: Parents of Children with Disabilities from Mexico

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Abstract

This purpose of this study was to examine the perceptions of parents with children with disabilities towards their children and how Mexican society treats their children. Using a focus group with a translator four middle class parents were interviewed about their children with disabilities in Guadalajara, Mexico. At a later date two other parents were individually interviewed using the same questions. The children's ages ranged from 4 to 25 and disabilities included autism, mental retardation, learning disabilities, brain damage, and cerebral palsy. Parents' answers were compared to research on United States families and reported cultural family trends in Mexico. The middle-class families in Mexico perceptions were closer to those in the United States than what has previously been reported about Mexican families. This supports Zuniga's (2004) admonishment that professionals need to meet and personally get to know families from different cultures. Future research should look at families with children with disabilities in Mexico from different economic classes.

Research available on disability in Mexico and the meaning that disability has for the child and his/her family is extremely limited. Recognizing that Mexico is the single largest contributor to the immigrant population of the United States and that many immigrant families, like families everywhere, face issues of child health and disability, faculty from the Panuska College of Professional Studies of the University of Scranton traveled to Mexico to establish a dialogue with universities clinic and hospital personnel, schools, and parents in order to increase our understanding of the role that disability plays in that country.

Travelers represented an interdisciplinary group of U.S. professionals in special education, occupational therapy, physical therapy and hospital administration. The group visited university, government, and community-based agencies to gather data regarding the provision of healthcare, education and rehabilitation services to children with disabilities in Mexico. The focus of this paper is our work with middle class families of children with disabilities. Zuniga (2004) describes the important characteristics that professionals working with Hispanic immigrant families who have children with disabilities should understand. Zuniga states that the beliefs professionals hold about Hispanic families may be stereotypical and so it is important that professionals view their beliefs with some skepticism until they know the family individually. Many of the cultural beliefs about disability do not apply to the growing middle class in Mexico. The middle-class believes less in the folk remedies and reasons for disability's occurrence as the middle class has acquired more education and sophistication.

The author individually interviewed five parents, three mothers and two fathers, whose children attend a special education facility. In 2006 the author returned to Mexico to interview

the mother of a young man with cerebral palsy. When her son was diagnosed, this family proactively founded a school for children with Cerebral Palsy and therefore was of particular interest to the author.

Open-ended questions were asked of the six families. Their children ranged in age from 4 years of age to 28 years of age. The disabilities of their children included Down syndrome, autism, brain damage, defect in the myelin of the brain, learning disability with ADD/ADHD and cerebral palsy.

The questions were the following:

- How were you told about your child's disability? Age of identification was dependent upon the disability. Parents reported that the disability was seen at birth, 40 days after birth, and when four of the children were slow in reaching normal developmental milestones. This occurred anywhere from several months of age to several years of age.
- Why do you think your child was born with a disability? This question was specifically asked because some of the literature reports that Mexican families are fatalistic and superstitious about the reason a child is born with a disability. Zuniga reports that many Mexican-heritage people believe that the evil eye caused the disability or someone puts a hex on the child out of jealousy and that caused the disability. None of the six families we interviewed ascribed to this belief. They reported that there was birth trauma, birth defects or that the cause was not known. However, the mother of a child with autism reported that her child's doctor blamed her for her child's disability.
- What are your child's strengths and needs? All parents reported that their children had both strengths and needs. There was a sincere desire of all parents for their children to be independent and live a productive life to the extent that they are able. One young man with

cerebral palsy uses adaptive technology in the form of a communication device in the United States and in Mexico.

- Has your extended family accepted your child with disabilities? Most families stated that their extended family has accepted the child with disabilities. One parent said that it was very difficult for her husband to accept his child with cerebral palsy and that his siblings accused her of loving the child with cerebral palsy more than them. Because she spent so much time aiding the child with cerebral palsy her husband took over the education of the other children. Another mother stated that she was asked by a relative if she had sinned. She reported that the Mexican culture is not a culture that accepts people with disabilities. The culture has visions of beautiful people, not people with disabilities.

- What are your dreams for your child? One mother stated that she doesn't dream. She sees continuous progress as long as he goes to the best schools. Since he was the youngest of her children she really did not look beyond the present. All parents hoped their child would be independent and have some way to support themselves. Several expressed concern about what would happen to their children when the parents were no longer able to take care of them. One mother stated that she was extremely concerned about what would happen to her son after she was gone because she was not sure his siblings would be willing to assist him. The six Mexican families interviewed expressed many of the same concerns as parents of disabled children in the United States. We agree with Zuniga professionals must get to know the family individually before they make judgments based on stereotypical beliefs. If professionals don't take the time to get to know the family, there will be no chance to develop a true family/professional partnership.

Reference

Zuniga, M.E. (2004). Families with Latino Roots. In E.W. Lynch, & M.J. Hanson (Eds.), *Developing cross-cultural competence*. Baltimore, MD: Paul H. Brookes.