The Challenge of Social Experiences for Children with Disabilities

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Study Population

A total of 46 families participated in Boundary Crossings, a three-phase, longitudinal, urban ethnographic study of African American families, each raising a child with special healthcare needs. The children’s ages ranged from birth to eight years upon their enrollment in the study. Diagnoses varied greatly and included cerebral palsy, sickle cell anemia, brachial plexus injuries, and autism, to name a few. For the present analysis, data were drawn from four selected families to represent both common and unique challenges related to social participation for children with disabilities and their families.

Methods

NARRATIVE PHENOMENOLOGY

Children are “socially occupied beings.” Social experiences, which take shape in informal play, school settings, and structured community recreation, are important for all children. While previous research has established challenges of participation for children with special needs, little has been done to understand the particularities of daily life and the work families do to facilitate social experiences.

Data Analysis

Multiple methods of analysis were performed, including narrative and thematic approaches to identify key themes. Interpretation of data drew on existing research literature and conceptual frameworks, including stigma, communities of practice, and figured worlds. Triangulation was applied during data collection and analysis to strengthen validity.

In some cases, multiple variables were recognized as influences on social participation, including disability, race, and/or socioeconomic status. However, this analysis specifically focused on factors related to disability experiences for mothers and their children.

Background

MEDIATORS OF PARTICIPATION

Self

Economic

Cultural

Race

Environmental

Family

Physical

Transportation

School

Cognitive

Policy

Stigma

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Narrative Excerpts

Halie’s mom: “She’s normal to me, but, in society’s eyes. Because, um, I see how people look when she has on a dress and they see the scars all the way down her legs. Or if she has on little tops, they see the scar on her neck, you know, and they’re looking... And I would really like for people to recognize her for who she is and not what she looks like.”

Halie’s approach (as told by her mom): “...just this year... And this is something that she originated because I wouldn’t ask questions...Halie wrote a note to the teacher in confidence, slid her the note, and asked if she could stand up in front of the class and tell them what the scars were all about so that they wouldn’t ask questions and they wouldn’t tease her.”

Unified Pathway: Mother and Child working together to achieve goal(s)

Divergent Pathway: Mother and Child building toward goal(s)

Funding

• "Boundary Crossings: Resurrecting Cultural Competence" (R01 HD 38878, 2000–2005), funded by the National Institute of Child Health and Human Development.

• "Boundary Crossings: A Longitudinal and Ethnographic Study" (R01 HD 38878, 2000–2004), funded by the National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development, National Institutes of Health; and "CROSSING: Cultural Boundaries: An Ethnographic Study" (505 060745, 1996–1999), funded by the Maternal and Child Health Bureau.

Primary Themes

Negotiation of Developmental Trajectories

Each child’s developmental trajectory was at risk in the face of challenging social experiences. Within the families’ stories, management of social barriers was sometimes co-managed by the mother and child along a unified path. In other cases, children attempted to manage constraints on participation separately from the work of their mothers.

Identity and Alignment

Themes of marginalization are based on unique qualities and abilities of the child and family emerged across families’ stories. Alignment in groups, such as those with peers, in classrooms, and in the community, became a primary mediator of experience. Families varied in their choice to align with disability groups or to push towards integration with typically-developing peers to support development in a range of social settings.

Stigma

Profound examples emerged of how stigma affects family roles and how family roles affect stigma. Both the mother and child’s identity, sense of self, and social engagements were affected by perceived and realized marginalization. Strategies reflective of passing were taken up by some children and also their mothers to engage with peers with less resistance.

Acknowledgements

Sincere thanks are extended to all of the Boundary Crossings families, who graciously shared their stories to facilitate a deeper understanding of their everyday experiences. Additional appreciation to Drs. Mary Lawlor and Florence Clark for their collaboration.

Selected References


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