USC University of Southern California

The Challenge of Social Experiences for Children with Disabilities

Carol E. Haywood, MOT, OTR/L, PhD student, and Mary C. Lawlor, ScD, OTR/L

USC Division of Occupational Science and Occupational Therapy
at the Ostrow School of Dentistry of USC

Research Overview

Study Population

A total of 46 families participated in *Boundary Crossings*[1,2,3], a three-phase, longitudinal, urban, ethnographic study of African American families, each raising a child with special healthcare needs. The children's ages ranged 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[1] was chosen to facilitate an understanding of the particularities of lives as lived. Data reflecting each family's experiences were gathered through narrative interviews, observation in the families' homes, clinics, communities, and in collective narrative groups[4,5]. Field notes were kept throughout the study from all of the researchers involved. Additionally, data incorporated the perspectives of healthcare providers, including the families' physicians and therapists.

The subset of families' stories for this analysis were analyzed across time, as the longitudinal nature of the data allowed observers to understand how challenges were ongoing, fluid, and pervasive, and how children and their families came to experience and manage the influence of illness and disability on participation differently over time. The focused, representative sample in this analysis allowed for extensive narrative analysis.

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 frames, including stigma[6], communities of practice[7], and figured worlds[8]. Triangulation[9] was applied during data collection and data 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.

Funding

- "Boundary Crossings: Resituating Cultural Competence" (2 R01 HD 38878, 2005–2011), 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" (MCJ 060745, 1996–1999), funded by the Maternal and Child Health Bureau.

Background

Mediators of Participation

Self[10, 11]	Economic[13]	Culture[10, 11]
Family[10, 11]	Race	Environmental Access[13]
Home[12]	Physical Ability[13]	Transportation[12]
School[12]	Cognitive Skills	Policy[11,12]
	Stigma[13, 14]	

Children are "socially occupied beings"[15]. 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.

Narrative Excerpts

** Pseudonyms have been used to protect anonymity.*

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

- Jenny's* mom: "Yeah…part of me… you know, raising her, were my fears of what people were gonna say and how people were gonna treat her and the lack of resources that we had. But when I step out of the picture because I have to step out of the picture because I have to send you [Jenny] into a public setting where you're at school… Um… I'm not there, so I can't protect you. Because if I hover over you… you're gonna be so… dependent upon me that you can't even function out there."
- Speaking to her daughter: "nothin' is gonna come easy… You're getting older, you're thinking for yourself, you have your own goals and ideas, you have your own ambitions… what can I do to help support you and the things you wanna do?"

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."

Divergent Pathway:
Mother and Child working separately towards same goal(s)

Halie's approach *(as told by her mom)*:
"…but this year… And this is something that she originated because I didn't have any idea…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."

Primary Themes

Negotiation of Developmental Trajectories

Each child's developmental trajectory was at risk in the face of challenging social experiences[16]. 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[7] based on unique qualities and abilities of the child and family emerged across families' stories. Alignment[16] 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[6]. Strategies reflective of *passing*[6] 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.

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