Symposium Title: Detecting and Understanding Disparities among Children with Autism and Other Developmental Disabilities

Chair: Sandy Magaña¹

Discussant: Lauren Bishop-Fitzpatrick²

Overview: There is a growing body of research documenting disparities among children with autism and other developmental disabilities. A useful framework to analyze these disparities introduced by Kilbourne and colleagues (2006) describes three phases for this research: 1) detecting disparities, 2) understanding disparities and 3) reducing disparities. Each of these phases can investigate disparities at the child/family level, the system/provider level, and the policy level. In this symposium, we present research that examines phases 1 and 2 at the child/family and provider levels. The first presentation focuses on the relationship between the healthcare providers’ response to parental concerns and ethnic disparities in services among children with autism and developmental disabilities. The second presentation examines the relationship between immigrant-related disparities in early intervention and provider cultural competence. Both of these presentations report findings that detect disparities and helps us to understand the reasons for them. The third paper goes more in depth in understanding disparities by using qualitative interviews to learn about barriers to navigate the health care system among Vietnamese and Cantonese speaking parents of children with special health care needs.

Paper 1 of 3

Paper Title: Healthcare Providers’ Responsiveness to Parental Concerns and Ethnic Disparities in Specialty Care Service Receipt among Children with Developmental Disabilities

Authors: Susan Parish³, Sandra Magaña¹, Ester Son⁴, Frances Martínez Pedraza⁵

Introduction: Ethnic disparities exist in access to and quality of healthcare services for children with special healthcare needs, particularly those from Latino ethnicities in comparison to their White, non-Latino peers (Magaña et al., 2012; Newacheck et al., 2012). While these disparities have been well documented, there is limited research about the role of communications between parents and medical providers in relation to these disparities. A prior study indicated that quality indicators mediated the relationship between ethnicity and healthcare utilization among children with developmental disabilities (Parish et al., 2012). To better understand disparities between Latino and White children with autism or other developmental disabilities, we examined whether Latino ethnicity predicted the number of specialty care services among children with severe activity limitations depending on medical providers’ responses to parents’ initial developmental concerns about their child.

Methods: We analyzed parent-reported data from the Pathways telephone survey of randomly selected parents who participated in the 2009-2010 National Survey of Children with Special Health Care Needs. The sample included Latino (N = 96) and White-Non Latino (N = 570) parents of children aged 10 years and younger for whom their parent reported a current diagnosis of autism or other developmental disability (A/DD), as well as severe activity limitations. Children’s specialty service use included current use of behavioral intervention services, occupational therapy, social skills and sensory integration therapy. Parents were asked to identify whether their medical provider responded to their initial concerns in a variety of ways, which were classified as proactive or non-proactive. Responses were analyzed using linear regression, while controlling child age, family income, parental education, urban/rural residence, insurance, regular source of care, and type of diagnosis.

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Results: There was a significant association between ethnicity and the number of specialty care services indicating that parents of Latino children with A/DD and severe activity limitations received fewer specialty services than their White peers. The interaction between ethnicity and provider response was significant such that Latino children whose parents received non-proactive responses from their health care providers were less likely to use specialty services than their White counterparts among children with A/DD who were younger and had severe activity limitations. Latino and White children did not differ in their specialty service use when parents received proactive responses from their child’s medical provider.

Discussion: While further research is needed to more fully understand the relationship between parent-provider communication and ethnic disparities in specialty service use, the parent-medical provider relationship may be a promising point of intervention for future disparity reduction efforts.

References/Citations:
provider CC and WA, were independently associated with their perceptions of service quality. While self-ratings of CC were not related to parents’ ratings of service satisfaction, parents’ WA ratings were related to their service satisfaction.

**Discussion:** Factors contributing to disparities in service receipt associated with parents’ place of birth need to be identified and addressed to improve EI service receipt among immigrant populations. This study provides preliminary evidence for the potential role of provider cultural competence in actual service receipt and parent-perceived quality of services. Further understanding parent expectations and needs in relation to providers’ CC could aid in improving EI service receipt and quality for culturally-diverse young children.

**References/Citations:**

**Paper 3 of 3**

**Paper Title:** Navigating the Health Care System in Community: Perspective from Asian Immigrant Parents of Children with Special Health Care Needs

**Authors:** Esther Son⁴, Nechama Sammet Moring⁶, Leah Igdalsky⁶, & Susan L. Parish³

**Introduction:** Children with special health care needs (CSHCN) face notable disparities in health care access, quality and family-centeredness, despite higher health care utilization rates (Ghandour et al., 2013). Within the population of CSHNC, there are important disparities impacting immigrants and racial/ethnic minorities (Magana et al., 2012). However, little is known about the experiences and needs of Asian immigrant families who have CSHCN in accessing care for their children, and whether these experiences might drive disparities.

**Methods:** We conducted one-on-one interviews with 22 Vietnamese and Cantonese speaking parents of CSHNCs, who identified as Asian immigrants. Participants were recruited through community partners. Interviews were semi-structured, and followed a standardized interview guide that first collected basic demographic data and then asked participants about their experiences accessing health care and other services for their child, met and unmet needs, and their perceptions of the quality and culturally competency of their child’s care. Interviews were conducted in Vietnamese or Cantonese, by a native speaker of that language and audio-recorded, transcribed and translated by professional translators. Analysis was conducted in English, using the translated transcripts and data were analyzed using content analysis and inductive, grounded coding techniques.
Results: Qualitative analysis identified several important barriers to and facilitators of care, some of which overlapped with general population experience, and some which were more unique to Asian immigrants and their children with special health care needs, such as navigating the system as a newcomer. These culturally specific barriers to care were often addressed through the use of community and informal supports, but also impacted participants’ relationships with their health care providers.

Language barriers, including issues with interpreters, impacted participants’ overall quality of care. In other words, participants were generally satisfied with their children’s care, and had strong relationships with their clinicians, who were often culturally “matched.” However, participants experienced several important and culturally specific barriers, including gaps in their understanding of the health care system, language barriers and a sense of alienation that they felt might be due to either their immigrant status or their child’s disability. Parents frequently turned to informal and community supports for assistance in navigating the U.S. health care system.

Discussion: Though this study was conducted in an urban area with many resources to support its large Asian immigrant population, participants still reported significant difficulty in navigating the health care system and obtaining the information and supports they needed. As parents frequently relied on community support and resources, community-based programs may be a successful strategy for further engaging this population and addressing disparities. Further research to understand the drivers of health disparities and policy level solutions is warranted.

References/Citations: