Title: Environmental Barriers and Facilitators Impacting the Healthcare Experiences of Bilingual Latino Families of Children with Autism Spectrum Disorder in Los Angeles County

Authors: Amber M. Angell, PhD, OTR; Leah I. Stein Duker, PhD, OTR/L

Introduction: Parents of children with autism spectrum disorder (ASD) report that their children's primary care physicians (PCPs) are "not good" at addressing autism-specific needs, and PCPs themselves report a lack of self-perceived confidence and need for greater education about ASD (Carbone et al., 2013; Golnik et al., 2009). Latino families of children with ASD report even greater barriers than white families of children with ASD in accessing high-quality, family-centered healthcare for their children (Broder-Fingert et al., 2013). There is a dearth of research, however, focusing on environmental factors influencing the healthcare experience. As recognized by the International Classification of Functioning, Disability, and Health (ICF), environmental factors (e.g., physical, social, attitudinal, and political environments in which people live and conduct their lives) have the potential to facilitate or constrain function (WHO, 2009). Understanding the environmental barriers and facilitators impacting the healthcare experiences of Latino families of children with ASD has the potential to reduce these documented healthcare disparities (Magaña et al., 2012). Therefore, the purpose of this study was to understand the environmental barriers and facilitators impacting the healthcare experiences of bilingual Latino families of children with ASD in Los Angeles County.

Method: This study utilizes a subsample obtained from a 12-month ethnography carried out in two phases. Phase 1: Two audio-recorded interviews were conducted with 12 families (19 parents, 1 grandmother) to understand experiences obtaining an ASD diagnosis and services for children. Six of these families were then recruited using heterogeneity sampling to continue to Phase 2: Narrative interviews and observation of 6 families (11 parents, 7 children with ASD) in home, clinic, school, and community contexts. Children's health records provided data triangulation. For this study, we identified healthcare stories using NVivo 10 software and a narrative analytic approach, resulting in a subcorpus of 10 interviews, 2 observations of PCP visits, and 2 fieldnotes. Both authors coded the subcorpus using the ICF environmental factors to describe and categorize barriers and facilitators to healthcare as experienced by the families. Each author coded separately then discussed and resolved any differences.

Results: Common environmental barriers impacting families' healthcare experiences were found in ICF categories Support and Relationships (e.g., lack of perceived support from PCP); Attitudes (e.g., perceived negative attitudes of PCP towards ASD and/or ASD symptomaticity, PCPs not taking health-related reports of child symptoms seriously, and disapproval of utilization of complementary and alternative medicine (CAM) treatments); and Education and Training (e.g., lack of adequate ASD-specific and CAM-related training for PCPs). Most parents viewed their child’s PCP as helpful for dealing with the child’s physical illnesses but “hands off” in addressing the child’s ASD-specific symptoms and developmental and behavioral challenges. All parents reported that they learned about ASD resources without support from their PCP, and half of the families preferred the perceived “proactive treatment plans” utilized by CAM providers to address their child’s behavioral, developmental, and/or sleep challenges. Environmental facilitators included Support and Relationships and Attitudes (e.g., PCPs who were open to learning about ASD and acknowledged parental expertise were perceived by parents as partners, even if the PCP was not an ASD expert).

Discussion: Findings suggest that the perceived “hands off” nature of PCPs in addressing the child’s ASD-related developmental and behavioral challenges may be perceived by Latino parents as a lack of support and failure to provide expected guidance, and could negatively impact parent-provider trust and communication. PCPs might better meet families’ needs for support and education by engaging with and educating parents about the safety and efficacy of a wider range of ASD treatments. These findings have implications for both PCP and parent education.

References/Citations:


