Title: Exploring What Latino Parents and Caregivers Know and Believe About Diagnosing Autism Spectrum Disorders

Authors: Lucía I. Floríndez, MA1, Daniella C. Floríndez, MPH1

Introduction: Of the 1 in 68 children diagnosed with autism spectrum disorders (ASD) in the United States (Centers for Disease Control and Prevention [CDC], 2010), the prevalence varies significantly across racial and ethnic groups. Documented disparities exist regarding autism diagnosis for Latino children. When compared to White children, previous research has shown that Latino children are diagnosed at a later age (Mandell, Listerud, Levy, & Pinto-Martin, 2002), are less likely to be diagnosed even when meeting autism criteria (Mandell et al., 2009), and more likely to be misdiagnosed (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Given these issues surrounding accurately diagnosing Latino children with ASD, it is necessary to explore what Latino parents, caregivers, and community members understand about ASD diagnosis. The purpose of this study is to investigate what 18 Latino families know and believe about diagnosing autism, and the psychosocial, familial, medical, and cultural factors that inform their health beliefs.

Methods: Narrative interviews with 18 Latino families (8 families with a typically developing child aged 6-12 and 10 families with a child with ASD aged 6-12) were conducted to identify the factors that impact their in-home oral care routines, including how the presence of ASD may alter their habits. Family units consisted of at minimum, the primary caregiver, and included other family members who provided care for the enrolled child. Each family was interviewed twice in their native language (Spanish or English) for approximately 1-2.5 hours each session. As a secondary line of questioning, families were probed to discuss their perceptions of ASD, including describing the disorder and their experiences involving ASD. Interviews were transcribed verbatim and analyzed by 3 coders using in vivo and thematic coding schemas to identify patterns across the data.

Results: Five themes pertaining to where Latino parents and caregivers obtained their knowledge and details about their beliefs about ASD diagnosis were identified. The first, Misconceptions, explained the various fallacies perpetuated in the Latino community about ASD, including that their child is “broken” or cursed. The second theme, Parents as students and teachers, described how parents had to learn about their child’s diagnosis to then be able to educate others and act as their child’s advocate. Next, Role of Family was related to the influence of family members on sharing information and opinions, including the reluctance in some extended families to acknowledge that a child has ASD. Following, Outside Influence clarified the information provided by non-family members, including health care providers, community members, or social network connections. The last theme, Cultural Stigma, focused on information that originated from the family’s cultural background, including religious and folk discussions, situating the ASD diagnosis within Latino culture.

Discussion: Researching how Latino parents, caregivers, and community members perceive Autism diagnosis will help illuminate how health information is communicated within this at-risk population, and inform the development of future targeted education and intervention programs. Further research is necessary to understand how these beliefs about Autism relate to quality of care in this population.

References/Citations: