Title: Identifying the Needs of Culturally Diverse Children and Youth with ASD in Central Texas: Results from a Mixed-Methods Needs Assessment

Authors: Sandy Magaña, Sandra B. Vanegas

1University of Texas at Austin, 2Texas State University

Introduction: Research on Autism Spectrum Disorder (ASD) has found that early detection and treatment is important towards minimizing the impact of ASD on child development, adaptive behavior, functional independence (Reichow, 2012). Although much is known about the prevalence and diagnosis of ASD through surveillance studies conducted by the Centers for Disease Control and Prevention, little is known about the unique experiences of Texan families. Texas is unique in that it is comprised of a racial/ethnically (58.3% reported racial/ethnic minority) and linguistically (36% speak non-English language in home) diverse population. Subsequently, it is important to assess service access and receipt in Central Texas to determine if available services and supports are adequate for the needs of the community. Research has also found significant disparities in access to services and outcomes among racial and ethnic minority groups and in rural communities (Nguyen et al, 2016), which have yet to be studied in Central Texas. The purpose of this needs assessment study is to fill these gaps in knowledge and determine the diagnostic and service needs of children with ASD and their families in Central Texas utilizing a mixed-methods approach.

Method: Parents of children with ASD who were between 0 and 21 years of age were recruited through community agencies, schools, and parent support groups in Central Texas. Parents were invited to participate in a survey (online, paper) which assessed the following topics: ASD Diagnostic Process and Experience, Current Therapy and Services, Access to ABA Services, Parent Beliefs about ASD, Community Views and Knowledge about ASD, and Changing Health Care for ASD. Parents were also invited to participate in focus groups to obtain more detailed information about their experience. Focus groups were led by one or both authors and a graduate student. All focus groups were audio recorded and transcribed for analyses. The survey (online, paper) and focus groups were also available in English and Spanish. To date, 58 parents have completed the survey (English n = 49; Spanish n = 9) and 19 parents have participated in focus groups (English n = 8; Spanish n = 11).

Result: Preliminary analyses of the survey compared the experiences of Latino and non-Latino White families of children with ASD. These analyses showed that non-Latino White families were more likely to have been provided with information about available services when they received an ASD diagnosis (58.3%) than Latino families (18.2%). Furthermore, a greater proportion of Latino families reported having to travel a long distance to receive an ASD evaluation (40.0%) when compared to non-Latino White families (8.3%). Results from the focus groups found significant needs for all families, specifically in the form of a “one-stop shop” that would include a diagnostic team with bilingual clinicians, therapeutic services to address unique needs of children with ASD, family resources (e.g., social skills, parent training/counseling, advocacy training), and greater facilitation and guidance post-diagnosis and during periods of transition.

Discussion: The goal of this study was to identify the needs of children with ASD and their families in Central Texas utilizing a mixed methods approach. The preliminary findings suggest that coordinated services are needed to ensure that all children with ASD have equitable access to diagnostic and therapeutic services. Furthermore, these findings suggest a greater need to incorporate cultural and linguistic diversity in the systems of care to adequately address the needs of a highly diverse community. The results of this research will help inform the development and implementation of evidence-based practices in the assessment, diagnosis, and treatment of ASD in Central Texas.

References/Citations