Symposium Title: Addressing ASD Service-Use Disparities across the Lifespan in Minority Populations

Chair: Monica L. Gordillo¹

Discussant: Sandy Magaña²

Overview: Most of our knowledge of health disparities among individuals with autism is based on studies of preschool- or school-aged children. A limited number of studies have documented that as adults with autism continue to get older, the need for more and different types of services increases while overall service access decreases (Turcotte, Mathew et al., 2016). Additionally, individuals from demographic minority backgrounds are most detrimentally impacted by service disparities regardless of age or symptom presentation (Magaña et al., 2012; Shattuck et al., 2011). Therefore, it is important to examine disparities across the life course.

A framework has been outlined to ensure that progress is made in research toward eliminating health disparities (Kilbourne et al., 2006). This framework consists of three consecutive phases through which research must: 1) identify and define the nature of disparities, 2) understand the mechanisms maintaining disparities, and 3) create and implement interventions to reduce disparities. Each presentation in this symposium will directly correspond with a phase from this framework. The first presentation will identify and provide an in-depth characterization of service-use disparities present among transition-aged individuals with autism and their families. Of the demographic populations discussed in the first presentation, subsequent presentations will address existing disparities particularly within Latino families with ASD. The second presentation will discuss community perspectives on designing a culturally-appropriate intervention for Latino families of adults with autism. The final presentation will discuss a community-based approach to intervention delivery for Latino families of preschool-aged children with autism. This symposium will illustrate the stages of health disparities research that will inform future disparities research within intellectual and developmental disability populations.

Paper 1 of 3

Title: Racial, Ethnic, and Socioeconomic Disparities Over the Transition to Adulthood among Adolescents and Young Adults with Autism Spectrum Disorders: A Systematic Review

Authors: Jenna Sandler Eilenberg,¹ Madison Paff,³ Ashley Johnson Harrison,³ Kristin Long, ¹

Introduction: The transition from youth to adulthood is a time of extended exploration, and decisions made during this period significantly influence the trajectory of adult outcomes (Osgood, 2005). For individuals with ASD, navigating this transition may be especially challenging due to deficits in social communication and adaptive behavior (Senland & Higgins-D’Alessandro, 2016). In addition, adult systems of care are less coordinated, and racial/ethnic minority and low-income young adults are more likely to be underserved (Friedman, Warfield, & Parish, 2013). Although diagnostic and service disparities and their impacts have been well-documented in the early childhood research on ASD (Bishop-Fitzpatrick, Minshew, & Eack, 2017), few studies have examined autism service disparities over the life course. This systematic review aims to: (1) summarize findings from the extant literature to explain patterns of service use according to race, ethnicity, and socioeconomic characteristics across dimensions of transition to adulthood, (2) assess the methodological rigor of included studies, and (3) inform next steps for a research agenda to address race/ethnicity and SES-based disparities over the transition to adulthood among youth with autism.

Method: Literature searches were conducted in PsycINFO, MEDLINE/PubMed, the Cumulative Index to Nursing & Allied Health Literature (CINAHL), and Education Resources Information Center (ERIC) using the following search terms: (adult* OR

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postsecondary) AND (autism) AND (transition). The search was limited to peer-reviewed articles published between January 1997 and January 2018, because the Individuals with Disabilities Education Act of 1997 significantly expanded the provisions about school-based transition planning for children with disabilities (Individuals with Disabilities Education Act of 1997, 20 U.S.C. § 1400 (1997)). Articles were included if they 1) were empirical, 2) focused on transition-age youth (ages 14-25 years) with autism, 3) included information about transition-related planning, service use, and/or young adult outcomes related to the following domains: education, employment, living arrangements, health & mental health, social participation, safety & risk, identity, and family well-being, and 4) presented interpretable outcomes by race, ethnicity, and/or socioeconomic status. Studies meeting inclusion criteria were rated for scientific merit, and findings were extracted and summarized.

Result: In total, 44 studies were included (42 quantitative, 1 qualitative, and 1 mixed methods). Fourteen studies (32%) analyzed data from the National Longitudinal Transition Study-2 and five studies (11%) analyzed data from the Research Services Administration database. Methodological limitations were common, particularly with regard to measurement validity and reliability. In terms of outcomes, low-income and racial/ethnic minority youth with ASD tended to be less likely to participate in transition planning meetings, enroll in post-secondary education, find competitive employment after high school, live independently, participate in social activities, and receive health care transition services than their White and higher income peers with ASD. These findings were documented consistently in studies that included nationally representative samples, whereas findings were mixed across studies with less representation from minority and low-income participants. Themes that emerged from a qualitative study with Latina mothers of adults with disabilities included: the expectation that their adult children with disabilities would continue living in the family home after high school, strong worries about their children’s interest in dating and sexual relationships, lack of resources in Spanish, incongruity between health care providers’ advice and families’ wishes, and fear about discrimination against young adults with disabilities in the workplace.

Discussion: The literature indicates that there are racial, ethnic, and socioeconomic disparities across many domains of transition to adulthood. Compared to their White and higher-income peers, racial/ethnic minority and low-income youth are more likely to be disconnected from opportunities and services after high school. Disconnection from services in the years immediately following high school graduation has been shown to increase risk for a myriad of negative long-term outcomes, such as poverty, mental health problems, and unemployment (Brown, 1996; Brown & Emig, 1999; Wald & Martinez, 2003). Given that disparities during this period are likely to set up trajectories of poorer functioning across the lifespan for minority or low-income youth with ASD, future research should explore the mechanisms of these disparities as a critical first step to addressing them. Given the extremely limited availability of qualitative data on this topic and the strong potential for qualitative data to contextualize quantitative findings and deepen our understanding of the processes underlying these disparities, qualitative work is an important future direction.

References/Citations:
Paper Title: Cultural Considerations for Future Planning: Focus on Latino Families of Adults with Autism

Authors: Monica L. Gordillo¹, Gael Orsmond¹, Kristin Long¹

Introduction: Adults with autism often lack services to adequately address their medical, psychosocial, occupational, and academic needs (Mandell, 2013; Wolf & Ventola, 2014). Similarly, disparities in access to needed care have been well-documented among Latino communities (Agency for Healthcare Research and Quality, 2014). Latino adults with autism are a population that lie at the intersection of these two groups who are not accessing needed services and are largely underrepresented in research. In fact, no previous study has developed an intervention that is clinically and culturally appropriate for the autism service needs of Latino communities. The present project will address this research gap by developing a family-based program (Siblings FORWARD) to engage Latino and non-Latino siblings of adults with autism in future planning. This project targets siblings, as many siblings have expressed a desire to become involved in future planning, but are often excluded from this process (Arnold, Heller, & Kramer, 2012). Program development is currently being done in collaboration with diverse families and their service providers to maximize acceptability, feasibility, and cultural sensitivity of the new program. The goal of this presentation is to compare diverse community perspectives on how to develop a program that meets families’ future planning needs as well as to present culturally-diverse reactions to specific program components. Latino perspectives will be used to formulate considerations for future program development that aims to be sensitive to Latino culture.

Methods: English- and Spanish-speaking adults on the autism spectrum, siblings, and service providers who serve diverse clientele were recruited through community organizations. Data collection is ongoing; to date, 32 Latino and non-Latino participants have participated, including 12 siblings of adults with autism, 14 service providers, and 6 adults with autism. Qualitative interviews or focus groups lasted approximately an hour and a half and were audio-recorded. Recordings were transcribed verbatim, checked for accuracy, coded, and analyzed using applied thematic analysis. Transcripts were coded in the language in which the interview occurred (i.e., Spanish transcripts were not translated into English) to retain cultural nuances.

Results: Regardless of ethnicity, families and service providers strongly endorsed the need for an autism future planning program; this need was reported to be even stronger for the Latino community. Service providers noted that very little future planning occurs among the Latino families they serve, and they explained that it may be difficult for Latinos to envision a distant future when they live day-to-day. The experience of stigma related to autism among Latinos was discussed as a possible mechanism underlying siblings’ knowledge gaps or lack of acceptance of the autism diagnoses. The idea of a program developed specifically for Latino adult siblings was well received; siblings are more likely to speak the language of providers, understand or quickly absorb how service systems work, and be more adept than parents at incorporating technology into a future planning program (e.g., utilizing telehealth approaches). A potential barrier identified for a program that involves siblings was the seemingly diminished role of the parent figure, which may not align with familial values. Recommendations specific to Siblings FORWARD included: increasing parental involvement, addressing how services apply to undocumented immigrants, emphasizing autism psychoeducation, and using more active recruitment methods to ensure Latino family participation.

Discussion: The present study provides evidence suggesting that the family-based program focusing on ASD future planning (Siblings FORWARD) will address critical service gaps present in culturally-diverse adult autism communities. Given the lack of culturally appropriate evidence-based programs for Latinos, there is a particular need for more programs that are developed in collaboration with Latino communities. Generally, aspects of Siblings FORWARD were in line with Latino cultural values (e.g., the family-based nature). Recommendations to increase cultural appropriateness were provided by participants (e.g., addressing...
immigration issues relevant to service systems). To the best of our knowledge, this is the first program being developed for the Latino community that addresses service use disparities for adults with autism. Findings illustrate how critical for program effectiveness it is to involve culturally-diverse communities in intervention development research.

References/Citations:


**Paper 3 of 3**

**Paper Title:** Perspectives of Promotoras and Parents on a Family-Centered Pilot Intervention for Promoting Participation among Latino Children with Autism Spectrum Disorder

**Authors:** Yue Xu4, Mansha Mirza4, Ashley Stoffel4, Sandy Magaña2

**Introduction:** Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder affecting one in 99 children in the United States (Baio et al., 2018). Latino children represent a growing population with Autism Spectrum Disorder (ASD; Pattern et al., 2012). Recent studies show that Latino children with ASD or another developmental disability, compared with White children, have a consistent pattern of lower health care access, utilization, and quality (Parish et al., 2012). Additionally, Latino children are more likely to be diagnosed later and are less likely to receive specialty ASD treatments than White children (Magaña et al., 2013). Consequently, there is an urgent need for family-centered interventions targeted at Latino parents of young children with ASD. The current study involved a family-centered pilot occupational therapy intervention for promoting participation among pre-school aged Latino children with autism spectrum disorder. The intervention was delivered in two formats — by an occupational therapist alone or by an occupational therapist paired with a community health worker (also known as promotor). Acceptability and usefulness of the intervention and two delivery formats was examined using qualitative methods.

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Methods: Ten Latino mother/child dyads were enrolled in a pilot randomized trial with two intervention groups; five received the 8-week intervention from an occupational therapist, the remaining received services co-delivered by an occupational therapist (OT) and a trained promotora, who was also parent of a child with ASD. Six Latino parents (three from each intervention groups) and three bilingual bicultural promotoras were recruited to participate in separate focus groups to provide feedback on the acceptability of and satisfaction with the pilot intervention. Focus groups were audio- recorded, transcribed, and translated into English. Two researchers reviewed the transcripts independently, identified preliminary themes, and developed a coding list. Both researchers then coded the transcripts independently using a content analysis approach. Inter-coder agreement was evaluated and coding discrepancies were resolved through consensus and discussion. Descriptive codes were then organized into broader thematic categories. A third researcher, who was bilingual in Spanish, conducted a peer review of the thematic scheme.

Results: Parents from both intervention groups reported that promotoras and the OT helped achieve participation goals they had identified for their children. These goals included participation in self-care, play, education, and social communication. Promotoras and parents from both intervention groups recommended delivering treatment sessions more frequently and increasing the overall duration of the intervention. Parents who received services from both the OT and promotora expressed benefits of having a peer parent (promotora) co-deliver the program. However, one parent emphasized that a professional OT should be present at all sessions. Overall, parents stated that promotoras provided affirmative, emotional, as well as informational support, and they played an important role in the team given their shared experiences as a parent of a child with ASD. Promotoras involved in delivering the intervention valued the opportunity to share with other parents their own experiences of stigma and discrimination. They saw this experiential knowledge as complementary to the occupational therapist’s professional knowledge. They also appreciated opportunities to work with the OT as a team, to discuss challenges encountered with families, and problem solve barriers.

Discussion: To our knowledge, no previous study has implemented a family-centered intervention co-delivered by occupational therapists and promotoras to increase participation in everyday activities among preschool age Latino children with ASD. This innovative service delivery mechanism can potentially broaden the reach of occupational therapy to isolated and underserved communities. Additionally, the pairing of promotoras and providers helps ensure the cultural sensitivity of the intervention. Overall, our results show that promotoras can be an important service provider working in collaboration with OTs. This service delivery mode is feasible, and is a promising strategy to address health disparities faced by Latino families of children with ASD.

References/Citations: