Title: Parent Perspectives on the Future of Their Young Adults with and without Developmental Disabilities

Authors: Elina Veytsman1, Megan Ledoux1, Giselle Salina1, Bruce Baker2, Jan Blacher 1,2

Introduction: The literature on outcomes for young adults with intellectual and developmental disabilities (IDD) paints a bleak picture, as demonstrated by low rates of participation in the employment, education, and social arenas (Howlin et al., 2004, 2013; Kraemer et al., 2003; Shattuck et al., 2012). Little is known about how these outcomes relate to parents’ goals for their young adults across diagnostic groups (Rehm et al., 2012). As a group, parents often play a crucial role in the transition to adulthood for young adults with IDD, offering financial and/or emotional support, helping access services, and identifying employment, educational, and social opportunities. Thus, understanding the perspectives of parents is critical for improving transition outcomes. We assessed parents’ goals for their young adults with autism spectrum disorder (ASD) and/or intellectual disability (ID), with a comparison group of parents of typically developing (TD) young adults.

Methods: Participants include a subsample of families participating in the Collaborative Family Study (CFS), a 17-year longitudinal study investigating the developmental trajectories of youth with ID, ASD, or TD. As part of an ongoing follow-up study, 74 semi structured interviews have been completed with parents, exploring their experiences during their child’s transition to adulthood. In a preliminary content analysis, 31 parent interviews (25 mothers, 5 fathers, 1 grandmother) of 26 young adults ages 20-22 (males=19, females=7; IDD=17, TD=9) were analyzed for themes related to parents’ expressed goals for their young adults. In addition, young adults completed questionnaires regarding their transition outcomes, and specific questions were selected to examine whether parent goals align with young adult transition outcomes. Ongoing analyses will examine the relationship between goals and outcomes with the larger sample.

Results: Preliminary analysis revealed that parents’ most commonly reported goals across both groups (i.e., IDD and TD) fell into four categories: employment (i.e., meaningful career, finding employment; 61% of parents), independence (i.e., financial, living independently, daily living skills; 42%), social (friendships, marriage/relationship; 39%), and educational (39%) goals. Young adult transition outcomes related to these goal categories were as follows: 50% had a paid job; 15% were employed for more than 20 hours per week; 69% were living with their parents; 77% had at least two close friends; and 85% were enrolled in some type of educational program. Surprisingly, Spearman’s rho correlation revealed that young adults whose parents reported employment as a goal were less likely to be employed ($r=-.43, p$)

Discussion: Parents’ most commonly reported goals for their young adults were employment and independence; in contrast to parental desires, young adults overall reported low rates of employment and independent living. In this preliminary sample, parents reported similar types of goals for their young adults, regardless of TD or IDD status. However, parents of TD youth were more likely to emphasize the goal of their young adult finding a meaningful career, while parents of IDD youth may simply desire that their young adults find a job. Understanding the nuances of parents’ goals will generate more meaningful intervention targets for transition planning.

References/Citations:

1. University of California, Riverside. Graduate School of Education.
2. University of California, Los Angeles, Department of Psychology