

Title: Service access during the transition to adulthood for youth with Autism Spectrum Disorder: The role of parental advocacy

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Introduction: When youth with autism spectrum disorder (ASD) leave high school, they move into an adult service system that is under-funded and hard to navigate. Difficulty accessing disability services has significant implications for those youth, as it leads to challenges obtaining and maintaining work and post-secondary education. In a recent study, researchers suggested that improving parents' ability to advocate on behalf of their son or daughter is a promising avenue to improve service access and youth outcomes (Burke et al., 2019; Taylor et al., 2017). Although there is evidence for this relationship in other disability populations (Burke & Heller, 2017; Gary et al., 2019), associations between parent advocacy and service access have yet to be directly tested among youth with ASD. The current study addressed this gap by examining the individual and parental correlates of service access, and how these correlates differ for youth with ASD in high school versus out of high school.

Method: Participants included 163 parents of transition-aged youth with ASD 15 to 27 years of age, who were participating in a randomized controlled trial. Parents averaged 51.20 years of age ($SD = 7.26$) at baseline and most were mothers (87.4%) and White (83.4%). For the current analysis, we used baseline data from the randomized controlled trial. The dependent variable, number of services youth were receiving, was measured using service questions from the National Longitudinal Transition Study-2 (NLTS-2). Independent variables related to the youth included those that have been shown to predict service access in previous research: high school exit status (in high school vs. out of high school), co-occurring intellectual disability (yes/no), race/ethnicity (white non-Hispanic vs. others), gender (male vs. female), social communication impairments (Social Responsiveness Scale-Second edition; Constantino & Gruber, 2012), and adaptive behaviors (Vineland Adaptive Behavior Scales-Third Edition; Sparrow et al. 2016). The following independent variables related to parents were included: household income, depressive symptoms (Depression Anxiety Stress Scales; Lovibond & Lovibond, 1995), family empowerment (Family Empowerment Scale; Koren et al., 1992), knowledge about the disability service system (Taylor et al., 2017), advocacy activities (Burke & Hodapp, 2016), and connectedness to the disability field (Taylor et al., 2016). Because the number of services was not normally distributed, non-parametric statistics were used in all analyses.

Results: Youth received a median of 4 services, with a range from 0 to 11. Youth in high school received a median of 5 services (range = 0 - 11), while youth who exited high school received a median of 3 services (range = 0 - 11). Ordinal regression was used to examine predictors of the number of services that youth were receiving. Across the entire sample, youth who were in high school (versus out of high school), who were White non-Hispanic (versus Hispanic or non-White) and who had lower adaptive behaviour scores were receiving more services, odds ratios (ORs) = 2.37, 2.59, 0.97, respectively, $ps < .05$. In terms of parent factors, youth whose families had higher incomes and whose parents had more advocacy activities were likely to be receiving more services, ORs = 1.16 and 1.12, respectively, $ps < .05$. We next ran ordinal regressions separately predicting number of services for those who were in high school versus those who had exited high school. Parent advocacy activities predicted service access for both groups, ORs = 1.10 for in high school and 1.15 for out of high school, respectively, $ps < .05$. Youth characteristics of adaptive behaviour and race/ethnicity predicted service access while youth were in high school, ORs = 0.97 and 2.96, respectively, $ps < .05$. Family income predicted service access after high school, OR = 1.20, $p < .05$; youth whose families had higher incomes received more services. No indicator of youth functioning predicted number of services after high school exit.

Discussion: These analyses suggest that both individual and family factors are associated with the number of services that youth received. Notably, though youth factors predicted service access for youth who were in high school, it was family factors that predicted service access after high school exit. This is consistent with previous work showing the family income predicted changes in behaviour problems after youth with ASD left high school, but not while they were in high school (Taylor & Seltzer, 2010). These findings highlight the need for additional research to better understand the role of families in promoting service access during the transition to adulthood.

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