Title: Perceived Barriers to Autism Spectrum Disorder Services

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Introduction: Despite state and federal efforts to improve service access over the years, disparities persist in access to diagnostic and treatment services for autism spectrum disorder (ASD; Kalkbrenner et al., 2011). These disparities indicate a need to develop policy, practice, and family-level strategies to address ASD service barriers. Research about how families experience coordination of diagnostic and intervention services, including perceived barriers, can inform development of efforts to this end. The goal of this study was to investigate current patterns in perceived barriers experienced in accessing diagnostic and intervention services, including the most common barriers associated with evidence-based interventions.

Method: Included participants (N=88) from 20 different states completed a Qualtrics survey consisting of original questions and a validated measure of ASD symptom severity, the Autism Spectrum Disorder – Diagnostic, Child Version (Matson & González, 2007). Questions about evidence-based practice (EBP) and non-EBP interventions were based on classifications from the National Autism Center (2015). Survey respondents were primary caregivers (92% female; 85% Caucasian) of children with ASD (77% male; 79% Caucasian; mean age=11.49 years).

Results: Descriptive analyses revealed that 85% of caregivers reported barriers to diagnostic services ($M=1.68$, $SD= 1.38$). The most commonly perceived barriers included long waitlists (55%), professionals stating that the child would “grow out of it” or that symptoms were due exclusively to some comorbidity (38%), and scheduling difficulties (22%). Sixteen percent reported family disagreement as a diagnostic barrier. Logistic regression did not reveal demographic factors associated with higher likelihood of experiencing misplaced professional reassurances as a barrier. Sixty-four percent of caregivers reporting on treatment had discontinued an EBP for a reason designated as a barrier, and 62% had discontinued at least one non-EBP. Most commonly discontinued EBPs were Applied Behavior Analysis-based therapy, speech therapy, and early intervention packages. EBPs were commonly discontinued due to eligibility changes, out of pocket expense, and “other.” Commonly discontinued non-EBPs included occupational therapy, special diet/vitamins, and sensory integration. Non-EBPs were most often discontinued due to inefficacy, expense, and “other.” Four caregivers reported having used chelation or hyperbaric chamber. Demographic factors related to greater number of barriers reported for diagnostic services or EBPs and factors predictive of time between receiving an ASD diagnosis and beginning treatment for ASD symptoms were investigated via multiple regressions. While not statistically significant, a trend emerged for ethnic minorities to report a greater number of barriers and for ethnicity to be correlated with length of time between diagnosis and treatment. Higher family income correlated with increased reporting of barriers to EBPs. Follow-up Kruskal-Wallis analysis revealed that individuals with private insurance only reported more barriers to EBP interventions, followed by those covered by both public and private insurance as opposed to public insurance only. Regarding desired future services, the majority of respondents desired EBPs (though many non-EPBs were also desired), with out of pocket expense and scheduling/time constraints cited as barriers.

Discussion: Caregivers in this sample reported experiencing multiple barriers to diagnostic and treatment services for their children with ASD. Despite some insurance coverage, many families report out of pocket cost as a significant barrier to services. Considerations regarding how to help families navigate scheduling conflicts and insurance systems (particularly when a child is covered by both private and public insurance) may further increase service access. Further research into why so many caregivers are reporting reassurances from professionals as a barrier to diagnosis is warranted.

References/Citations: