Title: Unmet health care needs and health care quality in youth with autism spectrum disorder with and without intellectual disability

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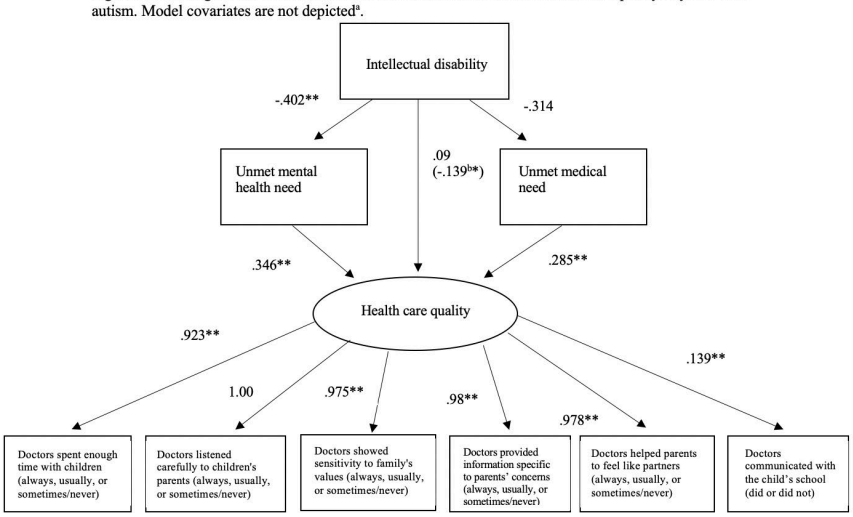
Introduction: Intellectual disability (ID) is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior (American Psychiatric Association, 2013) that frequently co-occurs with autism spectrum disorder (ASD) yet has received little attention in the ASD health services literature. For non-ASD individuals with ID, there is general agreement that the mainstream health system has struggled to provide adequate care to this population (Anderson et al., 2003). A review of access to health care among persons with ID determined that unmet medical and mental health needs were common (Larson et al., 2005). When individuals with ID are able to access health care services, the quality of care is of concern. Caregivers of youth with ID often report dissatisfaction with the health care their children and adolescents have received (Man & Kangas, 2019). This investigation sought to examine associations between comorbid ID and unmet physical and mental health care needs in children and adolescents with ASD. In addition, this study aimed to investigate associations between co-occurring ID and health care quality in youth with autism.

Method: Data from this study were acquired from three waves of the National Survey of Children's Health (NSCH; United States Census Bureau, 2016, 2017, & 2018), which was a nationally representative caregiver-report survey. Analyses for this study included a racially and economically diverse group of 2,189 youth 6-17 years old (M = 12.23). ASD and ID diagnoses were based on whether the caregiver responded to the NSCH that the child had ever been diagnosed by a health care provider with the condition, and that they currently have the condition. Youth were identified as having unmet medical or mental health care needs if their caregiver reported on the NSCH that they did not receive needed medical or mental health care in the past 12 months. Differences between individuals with ASD with and without comorbid ID in unmet mental and medical health care needs were examined with chi-square tests. Based on theory and available research, a structural equation model (SEM) was constructed with health care quality as a composite variable of several items from the NSCH (see Figure 1). For all indicators of health care quality, children who did not have a health care visit in the past 12 months were excluded. Model fit was assessed with Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and Standardized Root Mean Square Residual (SRMR) (Hu & Bentler, 1999).

Results: Chi-square tests indicated that the frequency of unmet mental health care needs ($\chi^2(1) = 13.48$, $p < .001$), but not unmet medical care needs ($\chi^2(1) = 2.43$, $p = .119$), was significantly higher among individuals with ASD with comorbid ID than those without ID. Model-fitting parameters for the SEM were indicative of good overall fit: CFI = .991; RMSEA = .042; SRMR = .071 (Hu & Bentler, 1999). Figure 1 presents the estimated SEM for the ASD sample (n = 2,005). Among youth with ASD, the presence of comorbid ID was significantly associated with past-year unmet mental health need (B = -.402, p = .002); past-year unmet medical care need was not significantly associated with comorbid ID (B = -.314, p = .231). The direct path coefficient from ID to health care quality was not significant (B = .09, p = .423); however, the total effect of ID on health care quality was significant (B = -.139, p = .04). Further examination of indirect effects found that the significant total effect of ID on health care quality in youth with ASD was mediated by unmet mental health need (B = -.139, p = .003).

Discussion: The results indicated that youth with ASD and comorbid ID had greater unmet mental health services needs than youth with ASD without comorbid ID; results also revealed that unmet mental health need mediated the relationship between ID and worse health care quality. It may be that unmet mental health needs affect the quality of health care services due to poor alliance and rapport between doctors and patients. Although comorbid psychiatric conditions are common in persons with ID, the evidence base for the effectiveness of mental health treatments for this population is limited (Bhaumik et al., 2011). This investigation highlights the importance of further research into emotional-behavioral treatments for youth with ASD and comorbid ID. This population has notable unmet needs for psychological and psychiatric care; and this study suggests that their unmet mental health needs negatively impact the overall quality of their health care and experiences with health care providers.

Figure 1. Path diagram for unmet medical and mental health needs and health care quality in youth with autism. Model covariates are not depicted[a].



[a]Child age, child sex, child race, child ASD severity (i.e., mild or moderate/severe), single parent household, family household income, and type (i.e., public, private, or both) and consistency (i.e., continuous or gap in coverage) of child's insurance coverage were included as covariates in the prediction of unmet medical need, unmet mental health need, and composite health care quality.
[b]Total effect
***p < .001, **p < .01, *p < .05

References:

American Psychiatric Association (2013). *The diagnostic and statistical manual, fifth edition (DSM-5)*. Washington DC: APA Press.

Anderson, L., Larson, S. A., Lakin, K. C., & Kwak, N. (2003). Health insurance coverage and health care experiences of persons with disabilities in the NHIS-D. *DD Data Brief*, *5*(1), 1-12.

Bhaumik, S., Gangadharan, S., Hiremath, A., & Russell, P. S. S. (2011). Psychological treatments in intellectual disability: the challenges of building a good evidence base. *The British Journal of Psychiatry*, *198*(6), 428-430.

Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, *6*(1), 1-55.

Larson, S., Anderson, L., & Dlojanac, R. (2005). Health promotion for persons with intellectual and developmental disabilities. In Nehring, W. (Eds.), *Access to Health Care*. Washington: American Association on Mental Retardation.

Man, J., & Kangas, M. (2019). Service satisfaction and helpfulness ratings, mental health literacy and help seeking barriers of carers of individuals with dual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(1), 184-193.

United States Census Bureau. (2016). *2016 NSCH Data Release*. https://www.census.gov/data/datasets/2016/demo/nsch/nsch2016.html.

United States Census Bureau. (2017). *2017 NSCH Data Release*. https://www.census.gov/data/datasets/2017/demo/nsch/nsch2017.html.

United States Census Bureau. (2018). *2018 NSCH Data Release*. https://www.census.gov/data/datasets/2018/demo/nsch/nsch2018.html

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