Title: Using Electronic Health Records to Characterize Individuals with Intellectual and Developmental Disabilities and Individuals with Autism Spectrum Disorder

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Introduction: Individuals with intellectual and developmental disabilities (IDD) and individuals with Autism Spectrum Disorder (ASD) have high rates of physical and mental health conditions, yet it is unclear how they utilize health care services. The use of electronic health records has recently led to insights on health care utilization in children and with ASD (Cummings et al., 2016). Few studies have included children and adults and individuals with IDD to identify health care needs within a health care system (Weiss et al., 2018). A better understanding of health utilization is needed for individuals with IDD and individuals with ASD to adequately plan health care for these populations across the lifespan.

Method: The demographics, health characteristics, and health service utilization patterns of individuals with IDD and individuals with ASD in a large North Carolina healthcare system were studied using electronic health records. Data from clinical visits from 2015-2017 for individuals with a diagnosis of IDD and/or ASD were drawn from the University of North Carolina Health Care Carolina Data Warehouse. Diagnosis was based upon diagnostic codes from ICD-9 or ICD-10 categories. Clinical visit variables included visit type, visit specific diagnosis, and problem list diagnosis, which represent long-term or historical diagnoses. Employment status was also gathered for those 18 and older. Chi-square tests, one-way ANOVAs, and logistic regressions were performed to examine the extent to which individual characteristics and health service needs differed between individuals with IDD and individuals with ASD.

Results: Overall, 11,272 patients with IDD and/or ASD accessed the University of North Carolina Health Care System across the two years ranging in age from less than 1 year to 99 years. There were 2,513 patients assigned a diagnostic code for ASD. There were more males with ASD (77%:23%) than females compared to individuals with IDD (53.7%:46.3%), \( \chi^2(1) = 440.05, p < .001 \). The ASD group (\( M = 15.12 \) years, \( SD = 11.98 \) years) was significantly younger than the IDD group (\( M = 24.30 \) years, \( SD = 22.19 \) years), \( F(1, 11,270) = 617.02, p < .001 \). Individuals with ASD were more likely to have a diagnosis of anxiety (18.1%) than individuals with IDD (11.8%) controlling for age, \( B = .67, SE = .06, p < .001, OR = 1.96 \) (95% CI: 1.72, 2.22), more likely to have depression controlling for age, \( B = .41, SE = .09, p < .001, OR = 1.41 \) (95% CI: 1.28, 1.80), although rates were similar for both groups (8%), and more likely to have obesity controlling for age, \( B = .27, SE = .10, p = .004, OR = 1.32 \) (95% CI: 1.09, 1.58), although rates were similar for both groups (7%). Individuals with ASD (0.3%) were less likely to have heart disease than individuals with IDD (2.5%), \( B = -.88, SE = .40, p < .001, OR = .42 \) (95% CI: .19, .91), controlling for age. For adults, employment status differed between groups, \( \chi^2(12) = 204, p < .001 \). There were more adults with IDD who were employed full-time (8.0%) than adults with ASD (2.3%), and more adults with ASD (41.5%) were not employed than adults with IDD (34.3%).

Discussion: This is one of the first studies to use electronic health records to compare health services utilization for children and adults diagnosed with ASD and IDD. Patients with ASD and patients with IDD demonstrated different patterns of individual and health characteristics. Individuals with ASD were younger and had higher rates of anxiety, whereas individuals with IDD had higher rates of heart disease. Despite having similar overall rates of obesity and depression, when controlling for age differences, individuals with ASD were more likely to have these diagnoses. The impact of age on findings and the number and type of unique visits per patient will be presented. Planning for both mental health and physical care for individuals with ASD and individuals with IDD is an important priority for both health care providers and policy.
References:


1 University of North Carolina at Chapel Hill TEACCH Autism Program