

Symposium Title: Co-Occurring Psychiatric Conditions in People with Autism, Intellectual Disability, or Down Syndrome: Prevalence Rates and Service Use Across the Lifespan

Chair: Brenna Maddox¹

Discussant: Lauren Brookman-Fraze^{2,3,4}

Overview: Co-occurring psychiatric conditions received relatively little attention in intellectual and developmental disabilities research until recent years. A growing body of work now shows that autistic people of all ages are at a higher risk for experiencing mental health problems, relative to people without autism. Co-occurring psychiatric conditions and behavioral concerns often prompt treatment referral for individuals with intellectual and developmental disabilities and are associated with adverse effects for the entire family. While recent research and clinical attention have led to significant advances in our ability to assess and treat co-occurring problems in people with intellectual and developmental disabilities, there are still substantial gaps that remain in our understanding of the prevalence rates of psychiatric conditions and service use patterns of both psychosocial and psychopharmacological treatments. This symposium includes three presentations about mental health conditions present in people with intellectual or developmental disabilities and related community-based mental health services. The symposium takes a lifespan approach, with studies including children, adolescents, and adults. The first presentation focuses on the prevalence of mental health conditions in adults with autism compared to adults with intellectual disability and Down syndrome in a large Medicaid-enrolled sample. The second presentation characterizes patterns and predictors of parent-reported psychotropic medication use for children with autism receiving publicly-funded mental health services. The final presentation focuses on a suicide prevention intervention for adolescents and adults on the autism spectrum. The symposium will conclude with a discussion led by Dr. Lauren Brookman-Fraze about the clinical implications of these novel research findings and future directions for improving community mental health services for children, adolescents, and adults with intellectual and developmental disabilities.

Paper 1 of 3

Paper Title: Mental Health Issues in Adults with Autism, Intellectual Disability, and Down Syndrome in a State Medicaid System

Authors: Lauren Bishop⁵, Kiley McLean⁵, Eric Rubenstein⁶

Introduction: Mental health conditions that present with autism spectrum disorder (ASD) and other intellectual and developmental disabilities impact quality of life (Mason et al., 2018) and adult outcomes (Bishop-Fitzpatrick et al., 2016). Mental health conditions are more prevalent in autistic adults compared to adults in the general population (Croen et al., 2015; Lai et al., 2019). Yet, service-system level estimates that examine differences between adults with ASD and other developmental disabilities and the co-occurrence of mental health conditions within adults with intellectual and developmental disabilities can inform systems level treatment approaches. Our objective was first to determine the prevalence of mental health conditions in

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adults with ASD compared to adults with intellectual disability and Down syndrome in a large, single-state Medicaid fee-for-service sample. We then assessed group differences in number of co-occurring mental health conditions.

Methods: We assessed Medicaid claims for adults (≥ 21 years) who had two claims for an intellectual or developmental disability on two different days ever during their Medicaid enrollment. Participants were included if they had ICD-9 or ICD-10 codes for ASD, intellectual disability (ID), or Down syndrome (DS) as described in our previous work (Bishop-Fitzpatrick & Rubenstein, 2018; Rubenstein & Bishop, 2019). We analyzed claims from 2008-2018. Mental health condition claims were extracted from codes from Center for Medicaid Studies Chronic Conditions Data Warehouse for depression, anxiety, bipolar disorder, schizophrenia, and personality disorders. We categorized our case groups into exclusive categories (ASD without ID, ASD with ID, ID, and DS). We calculated 11-year prevalence (2008-2018). Mental health conditions were considered prevalent if a beneficiary had two or more claims for a mental health condition at any time in the period. We then created a variable to assess the co-occurrence of depression and anxiety (two or more claims for both depression and anxiety). Finally, we created a count variable of co-occurring mental health conditions (range: 1 through 5) and tested group differences in number of co-occurring mental health conditions using an ANCOVA model adjusting for age and sex.

Results: In the 11-year period assessed, Wisconsin Medicaid had 4,775 unique beneficiaries with ASD without ID; 2,738 with ASD with ID; 18,429 with ID without ASD; and 3,484 with DS. In line with male to female sex ratio in ASD, 73% of enrollees with ASD alone and 68% with ASD with ID were male, compared to 52% of enrollees with ID and 51% of enrollees with DS being male. The majority of the sample in each case group was white, although there were considerable missing race data. More than half the ASD without ID group was less than 30 years old in their first year of claims. Further description of enrollment age and enrollment trends can be found in Rubenstein and Bishop (2019). Overall, 65.2% (N=3,114) of the ASD without ID group, 70.9% (N=1,941) of the ASD with ID group, 48.5% (N=8,944) of the ID group, and 28.4% (N=989) of the DS group had a mental health condition. The most prevalent condition was in all groups was anxiety (ASD no ID: 48.5%; ASD with ID: 48.4% ASD: ID: 30.0%; DS:17.3%). The ASD no ID group had the highest prevalence of depression (37.3%) with similar prevalence for the ASD without ID group (28.7%) and ID group (N=788 of (29.3%). Bipolar disorder was more prevalent in the ASD with ID group (37%) compared to the ASD without ID group (27.4%). Schizophrenia was prevalent in 9.6% of the ASD without ID group; 15.0% of the ASD with ID group; 15.2% of the ID group; and 1.6% of the DS group. Personality disorders were similar in the ASD without ID group (11.7%) ASD with ID group (13.0%) (and the ID group(9.1%) Both depression and anxiety were prevalent in 27.8% of the ASD without ID group; 20.2% of the ASD with ID group; 18.5% of the ID group; and 6.3% of the DS group. For total of mental health conditions, prevalence by group differed significantly. Mean number of mental health conditions was 1.35 (SD=1.30) in the ASD without ID group, 1.42 (SD=1.29) in the ASD with ID group, 1.27 (SD=1.36) in the ID group, and 0.42 (SD=0.77) in the DS group.

Discussion: People with intellectual and developmental disabilities are likely to have co-occurring mental health conditions. Whether this is intrinsic to the IDD, are a result of disparity, or have a yet-to-be determined etiology, appropriate treatment is critical. Based on the extent of mental health services, especially in the ASD groups, investment in prophylactic mental health treatment for this population may be a way to improve outcomes and costs for a Medicaid system. Further exploration into the low prevalence for these conditions in the DS group is needed and may serve as a guidepost for improving outcomes in the ASD and ID groups.

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Paper 2 of 3

Paper Title: Psychotropic Medication Use by Children with ASD in Publicly-Funded Mental Health Services

Authors: Barbara Caplan^{2,3}, Colby Chlebowski^{2,3}, Gina May⁷, Mary Baker-Ericzén^{3,4,8}, Willard Connor², Lauren Brookman-Fraze^{2,3,4}

Introduction: Use of psychotropic medications for children is common in routine community mental health services. Understanding patterns of psychotropic medication use is imperative for children with autism spectrum disorder (ASD), whom demonstrate high rates of co-occurring psychiatric conditions (Brookman-Fraze et al., 2017), medication use, and polypharmacy (Mandell et al., 2008). As publicly-funded mental health (MH) services play an important role in providing care with children with ASD, the present study seeks to: (1) characterize patterns of parent-reported psychotropic medication use for children with ASD in publicly-funded MH services, and (2) assess child and family factors associated with medication use.

Methods: Participants were 202 children with ASD ages 5-13 years drawn from a community effectiveness trial of AIM HI (“An Individualized Mental Health Intervention for ASD”) conducted in 29 publicly-funded outpatient and school-based mental health programs in Southern California. A majority of participants were Latinx (60%) and reported household incomes below \$35,000 (62%). Parents reported child psychotropic medication use as well as ratings of caregiver strain (CGSQ) and parental sense of competence (PSOC) at baseline. Child clinical characteristics, including autism severity (SRS-2), cognitive ability (WASI-II or DAS-II), and behavior problems (ECBI), were also assessed at baseline.

Results: Nearly half (49.5%) of participant children with ASD were reported to use one or more psychotropic medications in the past 6 months. The average number of medications used was 0.72 (SD = 0.90, range = 0 to 5). These rates varied by medication class, including: stimulants (28.7%), antipsychotics (16.3%), SSRIs (13.9%), and alpha 2 agonists (13.9%). Non-Hispanic White Ethnicity (compared to Hispanic), lower cognitive functioning, and meeting criteria for ADHD all significantly predicted higher likelihood of medication use in multiple predictor models. Predictors for specific medication class varied: ADHD, lower ASD symptom severity, and more intensive behavior problems (stimulants); higher ASD symptom severity (SSRIs); ADHD, higher ASD symptom severity, higher cognitive functioning, and higher caregiver strain (alpha-2 agonists). There were no significant predictors of antipsychotic use.

Discussion: Rates of any psychotropic medication use are comparable to epidemiological samples of children with ASD (Madden et al., 2017). Findings substantiate the high prevalence of psychotropic medication use by children with ASD in publicly-funded mental health settings and links to specific clinical presentations by medication, which may inform care improvement efforts.

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Paper 3 of 3

Paper Title: Tailoring the Safety Planning Intervention for Autistic Adolescents and Adults

Authors: Brenna Maddox¹, Samantha Crabbe⁹, David Mandell⁹, Shari Jager-Hyman⁹

Introduction: Suicide is a leading cause of premature death in autistic people (Hirvikoski et al., 2016). Autistic individuals are significantly more likely to think about and attempt suicide than the general population (Cassidy et al., 2014; Croen et al., 2015). No research has studied the effectiveness of suicide interventions for autistic individuals. This study examines the potential of adapting the Safety Planning Intervention (SPI; Stanley & Brown, 2012), an evidence-based suicide prevention intervention, for autistic adolescents and adults. The short-term goal is to examine community clinicians' perceptions of using SPI with autistic clients. The long-term goals are to 1) partner with stakeholders to extend the reach and impact of SPI, and 2) enhance the mental health and well-being of autistic individuals.

Methods: Using an online survey, we queried clinicians (n = 121; 82.6% female, mean age = 37 years) about their clinical experience managing suicide risk in autistic clients. We also interviewed 17 autistic adolescents and adults (59% male, mean age = 28 years), 12 family members (83% female, mean age = 56 years), and 31 clinicians who work with autistic clients (81% female, mean age = 43 years). All interviews were audio-recorded, transcribed, and imported into NVivo for analysis. We used an iterative coding process to identify recurrent themes.

Results: Only 17.4% of surveyed clinicians reported using the SPI with autistic clients, and 24% reported feeling very confident in their ability to intervene with an autistic client at risk for suicide. Interviewed stakeholders reported both advantages (e.g., written, stepwise plan is a good fit) and disadvantages (e.g., difficulties with generalizing the plan outside session; concerns about impulsivity as a barrier to implementation) of using SPI with autistic adolescents and adults. Given negative experiences with inpatient hospitalization for suicide-related events, autistic individuals and their family members were enthusiastic about a suicide prevention strategy that can be implemented in outpatient settings. Suggested modifications included: altering the language to be more direct; decreasing the emphasis on social supports; increasing education about internal coping strategies; emphasizing rehearsal to increase comfort with the intervention; involving family members; incorporating visual supports; and leveraging technology.

Discussion: Stakeholders supported modifying SPI for autistic individuals and provided valuable recommendations for how to do so. Next steps include pilot testing and further refining the adapted SPI. Researching the topics of co-occurring psychiatric concerns and mental health treatments is a high priority for stakeholders in the autistic community (Frazier et al., 2018).

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