Symposium Title: Physical and Mental Health in Adults on the Autism Spectrum

Chair: Lauren Bishop-Fitzpatrick

Discussant: Julie Lounds Taylor

Overview: Physical and mental health conditions that present with autism spectrum disorder (ASD), as well as their management, are nearly universal parts of the lived experience for people on the autism spectrum. Indeed, people on the autism spectrum may have a life expectancy that is 2-3 decades shorter than that of the general population which likely results from increased physical and psychiatric morbidity throughout life in people with ASD. Like in the general population, physical and mental health problems are likely to emerge in adulthood and intensify as people on the autism spectrum age. As the population of adults diagnosed with ASD grows and the large wave of children diagnosed with ASD in the late 1990s and early 2000s enters adulthood and progresses into middle age over the next 10 years, it is imperative to develop prevention strategies and policy solutions that have the potential to meet the unique needs of this growing population. This symposium focuses on three presentations about the physical and mental health problems that present with ASD and whether organizations and systems are prepared to provide evidence-based services to improve health management. The first presentation describes prevalence of physical and mental health problems in a population-level sample of middle aged and older adults on the autism spectrum, and tests whether physical and mental health problems are more or less prevalent in adults with and without co-occurring intellectual disability. The second presentation describes the physical and mental health problems of individuals who died by suicide, comparing adults with and without ASD. The final presentation identifies clinician training needs and organization- and systems-level barriers to providing evidence-based mental health services to autistic adults. This symposium will conclude with a discussion that ties the presented papers to current initiatives within the Interagency Autism Coordinating Committee working group: ‘Addressing the Health Needs of People on the Autism Spectrum.’

Paper 1 of 3

Paper Title: The Impact of Intellectual Disability on the Physical and Mental Health of Middle Aged and Older Adults on the Autism Spectrum

Authors: Lauren Bishop-Fitzpatrick & Eric Rubenstein

Introduction: A nascent body of preliminary evidence suggests that autistic adults live shorter lives (Hirvikoski et al., 2015) and have more physical and mental health problems (Bishop-Fitzpatrick et al., 2018; Croen et al., 2015) compared to the general population. Since so little is known about the larger population of middle aged and older adults on the autism spectrum, it is imperative to leverage existing population-level data to characterize their physical and mental health to inform individual and systems-level prevention efforts that can help people on the autism spectrum live long, healthy, and self-determined lives in their communities. This study describes the physical and mental health of a unique sample of all middle aged and older Wisconsin Medicaid beneficiaries with an identified autism spectrum disorder diagnosis and tests differences between those autistic adults with and without co-occurring intellectual disability.

Methods: Data were obtained directly from the Wisconsin Department of Health Services under a limited data use agreement. Participants were 143 middle aged and older adults on the autism spectrum with two lifetime Medicaid claims for an ICD-9 or ICD-10 code corresponding to autism, Asperger’s disorder, or pervasive developmental disorder not otherwise specified on two different days. We examined service claims from all providers (inpatient, outpatient, long-term care, home health, and dental) for health conditions between 2012-2015. We categorized these conditions based on an established system for grouping ICD-9

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codes (immune conditions, cancer, cardiovascular risk factors, cardiovascular disease, endocrine disorders, neurologic disorders, gastrointestinal disorders, sleep disorders, psychiatric conditions; Croen et al., 2015) while also presenting prevalent individual conditions. We calculated unadjusted and adjusted odds ratios (aOR; adjusting for sex, race, and age) using logistic regression comparing those with intellectual disability to those without.

**Results:** Many physical and mental health problems, including immune conditions (70.6%), cardiovascular disease (49.0%), cardiovascular disease risk factors (46.2%), sleep disorders (85.3%), gastrointestinal disorders (49.7%), neurologic conditions (55.9%), and psychiatric disorders (72.0%) were highly prevalent in our full sample. When comparing odds of the categorized conditions between those with and without ID, we saw increased but not statistically significant odds of neurologic disorders and gastrointestinal disorders and decreased but not statistically significant odds for immune conditions, cardiovascular disease and its risk factors, and psychiatric disorders in middle aged and older adults on the autism spectrum with co-occurring intellectual disability. Post-hoc analyses of neurological and psychiatric conditions identified significantly increased odds in autistic adults with intellectual disability of epilepsy (aOR=2.20; 95% CI=1.0, 5.1) and significantly decreased odds of anxiety (aOR=0.48; 95% CI=0.2, 1.0) and depression (aOR=0.25; 95% CI=0.1, 0.6).

**Discussion:** This is the first US study to use claims data to characterize the physical and mental health problems of middle aged and older adults on the autism spectrum with and without intellectual disability. Our findings suggest that people on the autism spectrum have a high prevalence of health problems in midlife and old age, regardless of intellectual disability status. However, autistic adults with intellectual disability were more likely to have an epilepsy diagnosis and less likely to have anxiety or depression. While more research is needed to confirm these findings and understand mechanisms, our results underscore the importance of prevention for high prevalence of physical and mental health problems in autism at the individual and systems level for autistic adults both with and without co-occurring intellectual disability.

**References/Citations:**


**Paper 2 of 3**

**Paper Title:** Mental and Physical Health Conditions Observed in Cases of Suicide Deaths with and without Autism Spectrum Disorder

**Authors:** Anne V. Kirby,3 Amanda Bakian,3 Deborah Bilder,3 Yue Zhang,3 & Hilary Coon3

**Introduction:** Available evidence suggests individuals with autism spectrum disorder (ASD) may be at higher risk for death by suicide than the general population (Hirvikoski et al., 2016). Suicide is known to be highly associated with mental health conditions such as anxiety, bipolar disorder, depression, personality disorders, psychosis, and substance abuse (Chesney et al., 2014). However, numerous physical health conditions have been associated with higher rates of suicide as well. Examples of physical health conditions associated with higher rates of suicide after adjustment for age and sex include asthma, brain injury, cancer, diabetes, epilepsy, and pain conditions (Ahmedani et al., 2017). The current study is a preliminary investigation of co-occurring mental and physical health conditions observed in individuals with ASD who died by suicide.

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3 University of Utah
Methods: Secondary data analysis was conducted with state-level data in Utah. Secure linkages were performed to match medical billing data (i.e., ICD-9 and ICD-10 codes) to a statewide database of individuals determined by the state medical examiner to have died by suicide. Billing data was provided from the two largest healthcare systems in Utah (covering >85% of the state) as well as from the Utah Population Database, which houses all inpatient codes from hospitals throughout the state. An additional linkage was performed to a statewide database of individuals with an ASD diagnosis (the Utah Registry of Autism and Developmental Disorders) to identify verified ASD cases. Preliminary analyses included descriptive statistics and chi-squared tests to compare ASD and non-ASD groups.

Results: Billing codes were available for 7,284 individuals who died by suicide between 1998-2017: 47 individuals with ASD (i.e., ASD suicide decedents) and 7,237 other individuals (i.e., non-ASD suicide decedents). ASD suicide decedents were more likely than non-ASD suicide decedents to have had documented anxiety (64% vs. 32%, p<0.001), attention-deficit or impulsivity conditions (45% vs. 6%, p<0.001), bipolar or cyclical mood disorders (51% vs. 16%, p<0.001), depression (85% vs. 47%, p<0.001), psychosis (45% vs. 10%, p<0.001), post-traumatic stress (21% vs. 6%, p<0.001), obsessive-compulsive disorder (19% vs. 3%, p<0.001), personality disorders (30% vs. 9%, p<0.001), sleep disorders (47% vs. 23%, p<0.001), and substance abuse problems (53% vs. 37%, p<0.05). ASD decedents were also more likely to have had documented asthma (34% vs. 15%, p<0.001), epilepsy/seizures (18% vs. 9%, p<0.001), and obesity (21% vs. 9%, p<0.05). No significant differences were identified for autoimmune disorders (4% vs. 4%), cancer (6% vs. 9%), diabetes (13% vs. 11%), eating disorders (6% vs. 2%), gastrointestinal symptoms (40% vs. 29%), or brain injury (9% vs. 5%). Additional conditions will be included in further analyses.

Discussion: Depression and anxiety were the most common co-occurring conditions among individuals with ASD who died by suicide. Results indicate that these and other mental and physical health conditions were more common among individuals with ASD who died by suicide than among other suicide cases. Because co-occurring condition rates are reportedly high in ASD, future studies are needed to compare rates of these conditions with individuals with ASD who have not died by suicide. However, these preliminary findings suggest that both mental and physical health conditions should be considered in future studies, and in the development of suicide risk assessments and prevention approaches for individuals with ASD.

References/Citations:

Paper Title: What Do Community Mental Health Clinicians and Agency Leaders Need to Treat Autistic Adults?

Authors: Brenna B. Maddox, Samantha Crabbe, David S. Mandell

Introduction: Many autistic adults struggle with untreated psychiatric conditions (Roux, Shattuck, Rast, Rava, & Anderson, 2015). A shortage of trained clinicians is one of the most commonly reported barriers to their receiving quality mental healthcare (Cheak-Zamora & Teti, 2015). No studies have interviewed community mental health (CMH) clinicians and agency leaders about their specific needs to provide mental health care to autistic adults. The objectives of this study were to identify (1) clinician training needs to work effectively with autistic adults with co-occurring psychiatric conditions, and (2) organization- and systems-level barriers to providing evidence-based treatment to autistic adults in CMH centers.

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Methods: We completed semi-structured interviews with 44 CMH clinicians and 11 agency leaders (84% female; 82% white) from six agencies. Clinicians included psychotherapists, case managers, and intake coordinators. Agency leaders included clinical and executive directors of various service lines. All interviews were audio-recorded and professionally transcribed for analyses. Transcripts were analyzed in an iterative process using both inductive and deductive approaches.

Results: Most participants had no training or education about autistic adults. The most requested topics for clinician training included core autism traits and how those affect treatment progress, along with effective treatment strategies for autistic adults with co-occurring psychiatric conditions such as anxiety and depression. Many interviewees wanted autistic adults to be actively involved in the training program, in order to hear first-person perspectives. Another common theme was the need to increase coordination between the developmental disability and mental health systems, which currently operate in a disconnected way.

Discussion: Our current mental health system fails many autistic adults, but previous research has not investigated barriers and facilitators to address this problem. This study directly informs priority training needs for clinicians and needed changes at the agency level. Effective mental health services could greatly improve the quality of life for many autistic adults; however, significant work is needed to make this goal a reality.

References/Citations: