**Symposium Title**: Transforming Healthcare for Autistic People: From Challenges to Solutions

**Chairs**: Brittany Hand[[1]](#footnote-1) and Lauren Bishop[[2]](#footnote-2)

**Overview**: Autistic people experience substantial disparities in their health outcomes and their healthcare utilization and access. For instance, they may face delays in diagnosis, challenges with accessing care, poorer care quality, lower satisfaction with care, and limited access to healthcare providers trained to meet their specific needs. This symposium focuses on characterizing and ameliorating disparities in health and healthcare from childhood through the end of life, featuring two presentations that characterize disparities and two that seek to understand how interventions can ameliorate or exacerbate disparities. The first presentation aims to compare the odds of experiencing a fall and the rate of fall-related injuries between autistic and non-autistic older adults. The results suggest that autistic older adults have significantly higher odds of falling and a higher rate of fall-related injuries compared to non-autistic older adults. These findings highlight the urgent need for targeted fall prevention strategies for autistic older adults to reduce morbidity and mortality. The second presentation aims to compare hospice care utilization between autistic older adults and non-autistic older adults, and to determine if race, sex, region, and rurality influenced these rates. The results suggest that both autistic and non-autistic adults have similar odds of any hospice utilization and similar timing of hospice care, with no significant differences based on sex, race, or rurality. These findings suggest that autistic older adults receive comparable hospice care to their non-autistic peers, highlighting the potential effectiveness of universal health policies in reducing disparities. The third presentation aims to investigate the association between Applied Behavioral Analysis (ABA) receipt and mental health outcomes in autistic youth. The results suggest that those who received ABA were significantly more likely to experience mental health hospitalizations and had longer hospital stays compared to those who did not receive ABA. These findings highlight the need for further research into the potential unintended consequences of ABA on mental health. The final presentation aims to pilot test the feasibility, acceptability, appropriateness, and effectiveness of the PREPARE for Autistic Adults training program for resident physicians. The results suggest that the training was highly feasible, acceptable, and appropriate, with significant improvements in residents’ knowledge about autistic adults. These findings suggest that the training effectively fills a gap in medical education and enhances physicians’ ability to care for autistic adults. Overall, the symposium underscores the critical need for targeted interventions and policies to address healthcare disparities faced by autistic people across the lifespan.

**Paper 1 of 4**

**Paper Title**: Falls and Fall-Related Injuries in Autistic Older Adults: A Critical Public Health Issue

**Authors:** Melica Nikahd,1 Madison Blake,1 J. Madison Hyer,1 Bethany J. Wolf,[[3]](#footnote-3) Brian Patterson,2 Brittany Hand,1 & Lauren Bishop2

**Background:** Fall-related injuries are a major public health issue for older adults. Falls significantly contribute to mortality and morbidity, leading to decreased functional ability, loss of independence, and increased healthcare costs. Autistic older adults may be at greater risk for falls compared to non-autistic older adults due to increased rates of motor coordination difficulties including ataxia, antipsychotic medication use, and epilepsy, all known correlates of falls in the general population. Yet, no research conducted to date characterizes fall prevalence among autistic older adults. Better understanding fall prevalence among autistic older adults is the necessary first step towards developing fall prevention strategies that have the potential to decrease morbidity and mortality. The goals of this study were to compare: (1) the odds of experiencing a fall; and (2) the rate of fall-related injuries between autistic and non-autistic older adults.

**Methods:** We analyzed data from Medicare Standard Analytical Files from 2013-2021 for autistic and non-autistic older adults aged 65+. We selected age 65 as the cutoff because of Medicare eligibility criteria for older adults. The sample included 10,677 autistic older adults and 21,351 non-autistic older adults who were propensity score matched on sex, race, region, rurality, and Medicare enrollment year. We identified falls based on a well-defined set of ICD-9 and ICD-10 diagnostic codes in inpatient or outpatient encounters. We then employed an established algorithm to identify unique falls-related injuries based on clusterings of ICD-9 and ICD-10 diagnostic and procedure codes. Descriptive statistics summarized the characteristics of the beneficiaries and prevalence of falls. Multivariable logistic regression was used to compare the odds of falling between autistic and non-autistic older adults, controlling for the beneficiary’s sex, race, rurality, age, year, region, and Charlson Comorbidity Index score. Finally, we used negative binomial regression to compare the rate of fall-related injuries between autistic and non-autistic older adults.

**Results:** Overall 47.7% (N=5098) of autistic older adults compared to 21.5% (N=4581) of non-autistic older adults had at least one fall. In total, 40.6% (N=4339) of autistic older adults compared to 18.1% (N=3866) of non-autistic older adults had at least one fall-related injury, while 33.8% (N=3605) of autistic older adults and 13.8% (N=2956) of non-autistic older adults had two or more fall-related injuries. Compared to non-autistic older adults, autistic older adults had 3.55 times higher odds of falling (95% CI: 3.36, 3.74, p<0.0001). Finally, the incidence rate of fall-related injuries per year was 3.07 times higher (95% CI: 2.91, 3.25, p<0.0001) for autistic older adults compared to non-autistic older adults.

**Discussion:** We found that autistic older adults had significantly higher odds of falling and had a higher rate of fall-related injuries compared to non-autistic older adults, with nearly half of autistic older adults having at least one fall. These findings underscore the urgent need for targeted fall prevention strategies developed for autistic older adults. Implementing tailored fall prevention strategies has the potential to reduce morbidity and mortality among autistic older adults.

**Paper 2 of 4**

**Paper Title**: Evaluation of Equity in Hospice Care Utilization Among Medicare-Enrolled Autistic Older Adults

**Authors**: Lauren Bishop,2 Melica Nikahd,1 Bethany J. Wolf,4 Brian W. Patterson,2 Anne Longo,1 Deondray Radford,1 Emma Krantz,1 J. Madison Hyer,1 & Brittany N. Hand1

**Introduction:** Better identification of autistic people and increased life expectancy for people with intellectual and developmental disabilities have given rise to an urgent need to better understand end-of-life care in autistic people. Although research suggests significant and pervasive disparities in the prevalence of co-occurring physical and mental health conditions in adulthood among autistic people, a more limited body of research assesses disparities in healthcare access and utilization among autistic adults, particularly at the end of life. Our primary objective was to compare hospice care utilization of autistic older adults to that of non-autistic older adults. The secondary objective was to determine if race, sex assigned at birth, region, and rurality altered rates of utilization in autistic older adults compared to non-autistic older adults.

**Methods:** We analyzed hospice claims from Medicare, which insures Americans over 65 years and covers hospice costs. We used data on a 100% sample of Medicare beneficiaries from Medicare’s Standard Analytical Files (SAF) Limited Dataset. Our sample included 5,468 autistic older adults and 10,934 matched population comparison older adults who died during 2013-2021. We used variable ratio propensity score matching to match two population comparison beneficiaries to one autistic older adult; beneficiaries were matched exactly on sex, race, region, and rurality, while age and year of death were matched with a caliper of 0.2. We used multivariable logistic regression to compare these groups on the odds of any, early, intermediate, and late hospice utilization. We defined early hospice utilization as at least 28 days before death, intermediate as 4-27 days before death, and late as within 3 days of death. Interaction terms assessed whether effects were modified by beneficiary’s sex, race, or rurality. In a sensitivity analysis, we repeated our analyses in unmatched samples.

**Results:** Overall, our autistic older adult and matched population comparison groups had similar odds of any hospice utilization (OR: 1.05; 95% CI: 0.98-1.13). Our autistic older adult and population comparison groups had similar odds of utilizing early hospice (OR: 1.01; 95% CI: 0.91-1.11), intermediate hospice (OR: 1.03; 95% CI: 0.95-1.13), and late hospice (OR: 1.07; 95% CI: 0.96-1.19). In our multivariable models evaluating the impact of other known inequities (Table 2), we did not find significant interactions between autism diagnostic status and sex, race, or rurality. Results were similar in the unmatched samples.

**Discussion:** We found that autistic older adults and older adults in our population comparison group had similar odds of hospice utilization and experienced similar timing of hospice utilization. Further, we found that hospice utilization differences between autistic and population comparison beneficiaries were not moderated by sex, race, or rurality, though known disparities related to sex, race, and rurality were present in both groups. Given the body of literature documenting health disparities in autistic people, our findings are heartening, suggesting autistic older adults experience similar receipt and timing of hospice as non-autistic peers. Our findings highlight the potential power of health policies that provide zero cost, universal benefits in reducing healthcare utilization disparities among autistic people.

**Paper 3 of 4**

**Paper Title**: The Association between Mental Health Hospitalizations and Applied Behavior Analysis Receipt among Autistic Youth

**Authors**: Nahime G. Aguirre Mtanous,2 Jamie Koenig,2 Melica Nikahd,1 J. Madison Hyer,1 Brittany N. Hand,1 & Lauren Bishop2

**Introduction:** Applied Behavioral Analysis (ABA) is a widely used intervention for autistic children. While intended to improve autistic children’s social functioning and reduce problem behaviors, in recent years, autistic self-advocates have critiqued the use of ABA as contributing to adverse mental health outcomes in adulthood. There has, however, been limited quantitative research on the association between childhood ABA receipt and mental health outcomes. This study aimed to investigate the association between ABA receipt and mental health outcomes.

**Method:** We used de-identified, individual-level healthcare records from the 2012-2020 IBM MarketScan Commercial Claims and Encounters Database. Autistic youth who had at least one outpatient ABA encounter (N=18103) were propensity score matched to autistic youth (N=18103) who never received ABA on the basis of sex, age, US region of residence, super-rurality, amount of follow-up time, intellectual disability, mood disorder, anxiety disorder, and psychotic disorder. We used ICD-9 and ICD-10 diagnostic codes to identify mental health diagnoses and hospitalizations. Demographic variables included sex, age, US region of residence, and super-rurality. We calculated descriptive statistics and used negative binomial regression with a log link and log(person years) offset to assess average rates of mental health inpatient hospitalization and length of hospital stay. We then used logistic regression with log(person years) offset to assess odds of suicidality and post-traumatic stress disorder (PTSD) diagnoses for ABA compared to non-ABA groups.

**Results:** Both the ABA and non-ABA groups were 79.6% male and relatively evenly distributed across the US. Clinically, 5% had intellectual disability, 10.3% had a mood disorder, 25.2% had an anxiety disorder, and 3.6% had a psychotic disorder. Adjusting for sex, region, super-rurality, baseline age, intellectual disability, anxiety disorders, mood disorders, and psychotic disorders, those in the ABA group were 1.39 (95% CI: 1.19-1.63) times more likely to experience a mental health hospitalization (p<0.001). Those in the ABA group had 46% (95% CI: 1.25-1.71, p<0.001) higher rates of mental health hospitalizations and 32% (95% CI: 1.07-1.64, p<0.05) longer lengths of stay across inpatient stays compared with the non-ABA group. There were no differences detected between the ABA and non-ABA groups on the likelihood of PTSD diagnoses or suicidality.

**Discussion:** This study found significantly higher odds of experiencing a mental health hospitalization and a significantly longer length of stay for mental health hospitalizations among autistic youth who received ABA. Of note, our sample of autistic youth were matched on demographic factors including mood, anxiety, and psychotic disorders, suggesting similar baseline levels of mental health needs. Findings warrant future examination of the potential unintended consequences of ABA. Future research should seek to leverage longitudinal data that tracks mental health outcomes in autistic youth over a longer follow-up period to better understand the association between ABA dosage and mental health outcomes, particularly in young and middle adulthood.

**Paper 4 of 4**

**Paper Title**: “It’s made me a better doctor”: Resident physicians’ experiences with an adult autism training designed with autistic adults and family members

**Authors**: Brittany Hand,1 Daniel Gilmore,1 J Madison Hyer,1 Holden DeVassie,1 Deondray Radford,1 PREPARE for Autistic Adults Advisory Board,1 Lisa Juckett,1 Christopher Hanks,1 Susan Havercamp,1 Daniel Coury[[4]](#footnote-4)

## **Introduction:** Physicians rarely receive training in providing care for adults with disabilities, like autistic adults, in their medical education. Many physicians have low self-efficacy in meeting autistic adults’ needs. We partnered with autistic adults and family members of autistic adults to develop an innovative autistic adult-focused training program for resident physicians called Promoting Residents’ Excellence in Patient-centered cARE (PREPARE) for Autistic Adults. The training includes six pre-recorded presentations, six case studies with accompanying “Why is this case important?” videos, and two standardized patient encounters to pilot test feasibility, acceptability, appropriateness, and effectiveness of PREPARE for Autistic Adults.

**Methods:** In this single-group pre-test post-test pilot study, we recruited residents from Internal Medicine, Family Medicine, and Internal Medicine and Pediatrics at one institution. The training was delivered virtually over eight weeks and consisted of six pre-recorded lectures, six facilitator-led case studies, and two standardized patient encounters. Participants completed an autism knowledge assessment before and after the training. After the training, they also completed the Feasibility of Intervention Measure (FIM), Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM) and completed qualitative interviews. Quantitative data were analyzed with descriptive statistics, and changes in autism knowledge were analyzed with Wilcoxon-signed rank tests. Qualitative interviews were analyzed using thematic analysis.

**Results:** Fourteen residents consented to participate and N=11 completed the post-test. Most FIM, AIM, and IAM items had a median of 5 (highest possible score) for the training as a whole and for each of the individual components, indicating strong feasibility, acceptability, and appropriateness. The median completion rate was 76.9% of all training components, indicating high completion rates. Examination of change in participants’ knowledge revealed a median increase of 11.8 points (Interquartile Range: 5.9-17.6; p=0.015). We interviewed 11 participants. Qualitative analysis revealed four themes. First, “flexibility facilitates feasibility” highlighted how the more flexible the training is, the more feasible it is for participants to participate in. Second, “high-value experiences increase acceptability” captured how hearing from autistic adults in the “Why is this case important?” videos and standardized patient encounters is a rich experience, and how the training offered participants a safe space to practice newly learned skills that required leaving their comfort zone. Third, “other practicalities affecting implementation” captured other factors that either increased or decreased feasibility, acceptability, and appropriateness, including that some topics or strategies were still unclear to participants at the end of the training and would benefit from additional clarity. Fourth, “it’s made me a better doctor,” highlighted that participants felt the training filled a gap in their medical education and that participants are already applying their newly learned skills in clinical practice or have thought about how they would apply them.

**Discussion:** Results suggest PREPARE for Autistic adults is perceived as highly feasible, acceptable, and appropriate, can be carried out with good completion rates, and significantly improves residents’ knowledge about autistic adults. Next, we will make refinements to the training and conduct a waitlist-controlled study among residents measuring self-efficacy, attitudes and beliefs, and knowledge about providing care for autistic adults.

1. The Ohio State University [↑](#footnote-ref-1)
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4. Nationwide Children’s Hospital [↑](#footnote-ref-4)