

# Suicidal ideation and self-inflicted injury in Medicare enrolled autistic adults with and without co-occurring intellectual disability

Brittany N. Hand, PhD, OTR/L,<sup>1</sup> Teal W. Benevides, PhD, MS, OTR/L,<sup>2</sup> Henry J. Carretta, PhD, MPH<sup>3</sup>

<sup>1</sup>School of Health and Rehabilitation Sciences, College of Medicine, The Ohio State University

<sup>2</sup>Department of Occupational Therapy, College of Allied Health Sciences, Augusta University

<sup>3</sup>Department of Behavioral Sciences and Social Medicine, College of Medicine, Florida State University

## Corresponding Author:

Brittany N. Hand, PhD, OTR/L 453 W 10th Ave  
228E Atwell Hall  
Columbus, OH 43210  
(office) 614-366-2646  
Email: [hand.58@osu.edu](mailto:hand.58@osu.edu)

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## **Abstract**

Suicidality is significantly more common in autistic adults than the general population, yet the factors that increase risk for suicidality among autistic adults remain largely unknown. We identified characteristics associated with suicidal ideation and suicide attempts/self-inflicted injury in a U.S. national sample of Medicare-enrolled autistic adults. We conducted a case–control study of autistic adults aged 18–59 years (n=21,792). Younger age, white race, depression disorders, and psychiatric healthcare utilization were associated with increased odds of suicidal ideation and suicide attempts. Co-occurring intellectual disability was associated with significantly greater odds of a suicide attempt, but lower odds of suicidal ideation. Findings underscore the need for improved methods to identify ideation prior to attempt among adults with autism and intellectual disability.

## Introduction

Autism is a pervasive developmental disorder that globally affects function across the lifespan. Although literature describing health outcomes among autistic adults<sup>1</sup> is emerging, much of this research suggests high levels of disability, decreased health related quality of life, and increased mortality risk (Woolfenden et al. 2012). Specifically, a national evaluation of mortality in Sweden identified that risk of all-cause mortality was significantly higher among autistic adults, as compared to the general population across a 22-year time period (Hirvikoski et al. 2016). Of particular concern is the increased reporting of suicidality among autistic adults.

Risk of suicide and suicidal ideation received recent research attention within the autism field, due to reports of high prevalence (Zahid and Upthegrove 2017). For example, one study of individuals diagnosed as autistic during adulthood in the United Kingdom found that approximately 66% of the sample reported suicidal ideation, which was nine times higher than self-reported prevalence of suicidal ideation in the general population (Cassidy et al. 2014). In addition to higher prevalence of suicidal ideation, autistic adults are almost twice as likely as non-autistic adults to attempt suicide (Zahid and Upthegrove 2017) and tend to use more lethal means (Kato et al. 2013). As such, autistic adults have a significantly higher risk of death by suicide than the general population (Hirvikoski et al. 2016; Kirby et al. 2019). Collectively, these findings have resulted in increased efforts to identify factors associated with increased risk of suicidality in this population to inform targeted prevention efforts.

Recently, Cassidy et al. (2018) identified that individuals on the autism spectrum may be at greater risk for suicidal ideation if they report having to 'camouflage' (i.e., assume a non-autistic identity to fit in), have greater unmet support needs, and demonstrate self-injurious behaviors. Additionally, some studies have found differences in suicide risk between males and females (e.g. Pelton and Cassidy 2017; Zahid and Upthegrove 2017), while others have not (Kirby et al. 2019). Similar to risk of suicide in the general population, mood disorders such as depression and anxiety have been linked with increased risk in autistic adults (Zahid and Upthegrove 2017). Emerging evidence also suggests that autistic individuals who are over 10 years of age, Black or Hispanic, and from lower socioeconomic status have increased risk of suicidality (Mayes et al. 2013).

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<sup>1</sup> We refer to adults on the autism spectrum as 'autistic adults', in congruence with acceptable standards regarding identity-first language preferred by many diagnosed adults (e.g. Kenny et al. 2016).

Due to a variety of barriers in healthcare access and quality of care in the U.S. for autistic adults (e.g., Nicolaidis et al. 2013, 2015), examining a U.S. sample of publicly insured autistic adults is essential to inform policy-makers and healthcare practitioners. Current understanding of suicidality in autism is primarily based on: (1) studies with small sample sizes (Hedley and Uljarević 2018); (2) studies relying on self-report, which leave out those without the ability to participate through survey methods (e.g., Cassidy et al. 2018); and (3) studies that rely on death records, which would only capture suicide attempts resulting in death (e.g., Hirvikoski et al. 2016). To date, little work has been done to study suicidality in autistic adults using nationwide U.S. healthcare claims data. The objective of the present study, therefore, was to use claims data to identify the prevalence of and characteristics associated with medical encounters for suicidal ideation and suicide attempts/self-inflicted injuries among a national sample of Medicare-enrolled autistic adults.

## **Methods**

### **Data Source and Study Period**

Data used for this study were derived from 100% U.S. Medicare Limited Data Set Standard Analytic Files (SAF), specifically the Inpatient and Outpatient files, containing de-identified beneficiary-level billing claims for healthcare encounters during the years 2012–2017. The SAF Outpatient data used in this study contained billing claims for medical encounters originating from institutional outpatient providers such as hospital outpatient departments, rural health clinics, renal dialysis facilities, outpatient rehabilitation facilities, Federally Qualified Health Centers, and community mental health centers. SAF Inpatient data used in this study contained billing claims for medical encounters originating from hospital admissions data, including hospital admissions from emergency departments (ED). Professional service claims from non-institutional professional providers, including physicians, physician assistants, clinical social workers, nurse practitioners were not included. The study period, from which we extracted outcomes, was defined as the 48-month window of time immediately following the beneficiary's first recorded date of service.

### **Study Design**

We used a case–control study design to identify the prevalence of the outcomes of interest (suicidal ideation or a suicide attempt/self-inflicted injury) and characteristics associated with increased odds of these outcomes in autistic adults at any time during the 48-month study period.

### **Autism Sample Identification**

Our sample consisted of Medicare beneficiaries who were (a) enrolled in Fee-for-Service for at least 1 month; and (b) aged 18–59 years on the first recorded date of service within our available claims years, which comprises those individuals who were likely eligible for Medicare based on a disability determination. Beneficiaries were identified as having ‘autism’ if they had at least one claim for an inpatient or outpatient encounter with an autism diagnosis in 2012 or 2013, as defined by International Classification of Diseases, 9th edition (ICD-9) codes 299.0, 299.00, and 299.01 or ICD10 codes F84.0 and F84.5.

### **Case and Control Definition**

From the sample of autistic adult beneficiaries who were eligible for inclusion in this analysis, we defined cases as those with at least one claim for an inpatient or outpatient encounter during the study period for suicidal ideation or a suicide attempt/self-inflicted injury. Suicidal ideation was identified by a diagnostic code of V62.84 (ICD-9) or R45.851 (ICD-10). Suicide attempts/self-inflicted injuries were identified by the presence of any other ICD-9 or ICD10 code classified as ‘suicide/self-inflicted injury’ by the Healthcare Utilization Project (HCUP) Clinical Classification Software (CCS) (HCUP 2016). HCUP CCS is a publicly-available program that identifies conditions based on the diagnosis codes included in the medical billing claim and groups them into a smaller number of clinically meaningful categories. The category of ‘suicide/self-inflicted injury’ included diagnostic codes for intentional self-inflicted suffocation, drowning, firearm wounds, poisoning (e.g., carbon monoxide, overdoses, etc.), injuries sustained from blunt or sharp objects, and other mechanisms of self-injury. FFS claims include a mortality indicator but do not specify the: (1) underlying cause of death, which would be required to identify suicide, or (2) intent to die, which would be required to distinguish suicidal from non-suicidal self-injury. For the purpose of this study, we will refer to this outcome as ‘suicide attempt’ as opposed to ‘suicide/self-inflicted injury’ due to the severity of the mechanisms of self-injury captured by a majority of the ICD codes in this CCS category. Controls constituted any autistic adults who met inclusion criteria but did not have a medical billing claim with a diagnosis of suicidal ideation or a suicide attempt during the study period.

### **Measures**

Independent variables for this study included: age, sex, race/ ethnicity, dual eligibility for Medicare and Medicaid at any time during the study period, bipolar depression, unipolar depression, intellectual disability (ID), number of psychiatric-related emergency department (ED) visits, and number of psychiatric-related

inpatient hospitalizations. Existing literature guided the variable selection based on a potential association with suicidality. We extracted demographic characteristics for each beneficiary from the SAF denominator files from 2012 to 2013. Beneficiaries were considered to have bipolar depression if they had an inpatient or outpatient encounter with an ICD-9 code classified as 'bipolar disorders' by the HCUP CCS (CCS level 5.8.1) or ICD-10 code of F31 at any time during the study period. Unipolar depression was identified based on the presence of at least one inpatient or outpatient claim with an ICD-9 code classified as 'depressive disorders' by the HCUP CCS (CCS level 5.8.2) or ICD-10 codes of F32–F33. Intellectual disability (ID) was determined based on the presence of ICD-9 codes 317–319 or ICD-10 codes of F70–F79. The number of psychiatric-related ED visits and inpatient hospitalizations were calculated as the total number of visits of each type with a diagnosis code for 'mental illness,' as defined by the HCUP CCS (CCS level 5), during the study period.

### **Statistical Analysis**

We summarized demographic characteristics descriptively. Due to the rarity of cases of suicidal ideation and suicide attempts (~ 4% of the study sample), we analyzed the data cross-sectionally using multivariable logistic regression to identify characteristics associated with an encounter for suicidal ideation or a suicide attempt at any time during the study period. We used the Hosmer–Lemeshow test to examine goodness-of-fit for the logistic regression models and obtained a 95% confidence interval (CI) by bootstrapping on 25% subsamples 500 times. All analyses were performed using SAS statistical software, version 9.4.

### **Results**

We identified 21,792 autistic adults, of whom n=941 (4.3%) met the definition for cases of suicidal ideation and n=903 (4.1%) met the definition for cases of a suicide attempt/ self-inflicted injury. Approximately 4% of beneficiaries (n=1105) were not enrolled in Medicare FFS for the full 48-month study period. Death was the most common reason for termination of entitlements (n=931, 84.3%). Approximately 6.3% (n=70) had nonpayment of their premium during one or more months, n=17 (1.5%) voluntarily withdrew from Medicare part A or B for one or more months, and n=87 (7.9%) had Medicare part A or B entitlements terminated for other reasons.

Beneficiary demographics are provided in Table 1. Most beneficiaries were male (74.5%), dually eligible for Medicare and Medicaid (87.3%), and white (75.3%) or black (17.1%). Overall, 24.0% of beneficiaries had bipolar depression, 21.5% had unipolar depression, and 39.7% had a cooccurring ID. Bipolar

and unipolar depression were more common among those with suicidal ideation than among those without suicidal ideation. Additionally, those with suicidal ideation tended to have higher frequencies of hospitalizations and ED visits for psychiatric concerns and tended to be younger than were those without suicidal ideation. Of the 943 patients with suicidal ideation, 283 (30.1%) also had at least one encounter during the study period for a suicide attempt/self-inflicted injury. Intellectual disability was more common among those with a suicide attempt (63.0%) than among those without a suicide attempt (38.7%). Similar to those with suicidal ideation, those with a suicide attempt had higher prevalence of bipolar and unipolar depression and more frequent psychiatric hospitalizations and ED visits than those without.

Table 2 shows the results of the logistic regression models estimating the odds of a medical encounter for suicidal ideation (area under the curve [AUC] = 0.93; Hosmer–Lemeshow  $p = 0.26$  95% CI 0.24–0.27) or a suicide attempt/self-inflicted injury (AUC = 0.81; Hosmer–Lemeshow  $p = 0.24$ , 95% CI 0.22–0.26). Overall, characteristics associated with study outcomes were similar for suicidal ideation and suicide attempts except for the presence of co-occurring ID and dual eligibility. Specifically, while ID associated with a 24% decrease in the odds of suicidal ideation, it was associated with nearly a twofold increase in the odds of a suicide attempt. Additionally, those who were dually eligible for Medicare and Medicaid were 55% more likely to have a suicide attempt than those who were not, but no difference was found for those with and without dual eligibility in the odds of suicidal ideation.

## **Discussion**

Suicidality is an important indicator of mental health outcomes and mental health related quality of life. A growing body of literature suggests that suicidality is significantly more common in autistic adults than the general population (Cassidy et al. 2014; Hirvikoski et al. 2016; Kato et al. 2013; Kirby et al. 2019; Zahid and Upthegrove 2017). The present study builds upon and adds a unique contribution to this literature. This is the first study, to our knowledge, to describe the prevalence of, and characteristics associated with, suicidal ideation and suicide attempts/self-inflicted injury in a large, national sample of autistic adults in the United States. Additionally, this study is novel in that we used medical billing data to examine these outcomes, which: (1) likely includes individuals for whom survey methods would not be accessible, unlike self-report studies; and (2) captures suicide attempts and self-injury not resulting in death, unlike studies of death records.

### **Prevalence Estimates**

Suicidal Ideation. Our results showed that 4.3% of autistic adult beneficiaries included in this study had at least one medical encounter for suicidal ideation. This estimate is similar to prevalence estimates for the general population, which are approximately 3–4% (Han et al. 2015; Substance Abuse and Mental Health Services Administration 2014). While Cassidy et al. (2014) found an estimated prevalence of suicidal ideation of 66% among autistic adults, differences in methodology and data sources (i.e., self-report survey vs. medical billing records) preclude direct comparisons with the findings of our study. It is important to note that our results may represent a conservative estimate, as not all autistic adults with suicidal ideation will seek or receive medical attention.

Suicide Attempts/Self-inflicted Injury. With regard to suicide attempts/self-inflicted injury in autistic adults, the present study found a prevalence of 4.1%. Compared with the general population, in which 0.4–0.6% of adults attempt suicide (Han et al. 2015; Substance Abuse and Mental Health Services Administration 2014), the results of this study suggest that suicide attempts were 6.5–10 times more common in our sample of autistic adult Medicare beneficiaries. Within the autistic population, our results suggest a substantially higher prevalence of suicide attempts than indicated in existing literature. Specifically, a prior study by Croen et al. (2015) found that only 1.8% of autistic adults had a medical encounter for a suicide attempt. In part, however, the differences in study populations may explain these differences in prevalence estimates; Croen et al. examined a privately insured sample of autistic adults residing in Northern California, whereas the present study consisted of a national sample of Medicare-enrolled autistic adults. Future studies will be necessary to examine the extent to which geography and/or insurance status are associated with suicide attempts in autistic adults.

### **Risk Factors**

Overall, we found that characteristics associated with suicidal ideation were similar to characteristics associated with suicide attempts/self-inflicted injury in autistic adults. Consistent with existing literature on factors associated with suicidality in the general population (Bachmann 2018) and autistic adults (Cassidy et al. 2018), our results showed that unipolar and bipolar depression were among the variables most strongly associated with suicidal ideation and suicide attempts. Given that mental health conditions are disproportionately more common among autistic adults (Croen et al. 2015), this finding underscores the need for greater screening efforts for suicidality in this population as a whole.



Our results also support the increasing call for better screening and identification of suicidality, especially among those autistic individuals with intellectual disability. In this study, autistic adults with co-occurring intellectual disability had significantly lower odds of a medical encounter for suicidal ideation but significantly greater odds of a suicide attempt/self-inflicted injury. While our data do not provide reasons for increased risk for suicide attempts among those with autism and intellectual disability, the literature points to likely factors such as difficulty with communication (Nicolaidis et al. 2015), the use of primarily self-report for suicidal ideation (e.g. Hedley and Uljarević 2018), and poor access to services (Cassidy et al. 2018). For healthcare providers, the combination of autism and intellectual disability may complicate the screening and identification of suicide risk. The signs and symptoms of depression or suicidal ideation may be different in those with autism and ID (Perry et al. 2001), and efforts to improve understanding of this population are warranted. Specific research is needed to validate non-speaking tools or physiological measures to better identify suicidality in those with autism and ID.

### **Methodologic Considerations**

We acknowledge several limitations to the present study. First, there are some limitations inherent to the use of medical billing data. Our identification of autistic adults was based solely on medical billing records. A number of variables potentially associated with suicidal ideation or suicide attempts/self-inflicted injuries could not be controlled for in this study as they are not contained in routine Medicare billing data (e.g., socioeconomic status, severity of autistic traits, perceived need to camouflage autistic traits, unmet healthcare needs). Additionally, instances where an individual did not receive medical attention or was found deceased would not be included in these data, as there would be no record of medical treatment. We were also unable to capture any encounters for suicidal ideation or suicide attempts treated by non-institutional outpatient providers (e.g., physicians, physician assistants, clinical social workers, and nurse practitioners) due to the type of outpatient records used in this study. Therefore, our findings likely constitute a conservative estimate of the prevalence of suicidal ideation and suicide attempts/self-inflicted injuries in Medicare-enrolled autistic adults.

Second, distinguishing medical billing records for suicidal self-injury from non-suicidal self-injury is not possible using currently-available HCUP CCS software. As non-suicidal self-injury is increasingly documented in the autism literature (e.g., Maddox et al. 2017), utilizing methods that will allow for this distinction will be an important consideration for future work.

Third, we were unable to analyze trends in suicidal ideation and suicide attempts longitudinally due to the relatively low prevalence of these behaviors (approximately 4% of total sample). Future prospective cohort studies are warranted to study the prevalence of suicidality in autistic adults over time and to elucidate possible age-related trends in suicidality (e.g., transition-aged vs. middle aged vs. older adults).

Finally, the findings of this study may only generalize to autistic adults covered by Medicare. Beneficiaries in our study first became eligible for social security income and/ or disability income by virtue of a formal disability determination by the Social Security Administration, which led to subsequent Medicare eligibility. As such, these autistic adults may have functional limitations and other characteristics that make them dissimilar to working age autistic adults in general. Nevertheless, this population is understudied and will be increasingly important as autistic children in more recent birth cohorts age into adulthood and the prevalence of autistic adults rises correspondingly.

This study also has a number of methodologic strengths. Specifically, this study is the first, to our knowledge, to identify a large nationwide sample of autistic adults with history of suicidal ideation and suicide attempts. As such, the data reflect a broader understanding of suicide in autism than any single state data source or survey. Our study also includes a wide representation of adults across the lifespan and reflects the expected proportion of those with ID (Baio et al. 2018). The representation of autistic adults with co-occurring ID in the present study addresses a gap in existing literature, as many studies to-date have not represented, or have under-represented, this subgroup (Hedley and Uljarević 2018).

### **Conclusion**

The present study offers a valuable contribution to existing literature on suicidality in autism by identifying risk factors in a national sample of Medicare-enrolled autistic adults. Consistent with existing literature, our findings demonstrated that co-occurring mental health conditions, such as unipolar and bipolar depression, are associated with increased odds of suicidal ideation and suicide attempts/self-inflicted injuries in autistic adults (Cassidy et al. 2018). Our study also points to intellectual disability as being associated with significantly greater odds of suicide attempts in this population. There are multiple challenges inherent in communication and access to services among those with autism and ID, suggesting the need for additional efforts aimed at the identification of those at risk of a suicide attempt or suicidal ideation.

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### **Compliance with Ethical Standards**

Conflicts of interest. The authors declare that they have no conflicts of interest.

Research Involving Human Participants. The Institutional Review Board of The Ohio State University reviewed and approved this study as exempt, non-human subjects research as this study constituted a secondary analysis of de-identified data.

Informed Consent. Not applicable, as this study does not constitute human subjects research.

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**Author affiliations:**

Brittany N. Hand, PhD, OTR/L is an Assistant Professor in Health and Rehabilitation Sciences at The Ohio State University in Columbus, Ohio, USA.

Teal W. Benevides, PhD, OTR/L is an Associate Professor in the Department of Occupational Therapy, College of Allied Health Sciences, Augusta University, USA.

Henry Carretta is an Assistant Professor in the Department of Behavioral Sciences and Social Medicine, College of Medicine, Florida State University, USA.

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Table 1 Demographic and clinical characteristics of a national sample of autistic adults enrolled in Medicare during 2012–2017

	Suicidal ideation		Suicide attempt		Total (n = 21,792)
	Yes (n = 941)	No (n = 20,851)	Yes (n = 903)	No (n = 20,889)	
Male, frequency (%)	644 (68.4)	15,588 (74.8)	633 (70.1)	15,599 (74.7)	16,232 (74.5)
Years of age in 2012, median (IQR)	28 (22, 36)	36 (26, 47)	32 (24, 44)	36 (26, 46)	35 (26, 46)
Race, frequency (%)					
White	777 (82.6)	15,634 (75.0)	758 (83.9)	15,653 (74.9)	16,411 (75.3)
Black	92 (9.8)	3626 (17.4)	79 (8.7)	3639 (17.4)	3718 (17.1)
Hispanic	37 (3.9)	701 (3.4)	36 (4.0)	702 (3.4)	738 (3.4)
Other or unknown	27 (2.9)	775 (3.7)	27 (3.0)	775 (3.7)	802 (3.7)
Unknown	8 (0.9)	115 (0.6)	3 (0.3)	120 (0.6)	123 (0.6)
Dually eligible, frequency (%)	836 (88.8)	18,194 (87.3)	822 (91.0)	18,208 (87.2)	19,030 (87.3)
Intellectual disability, frequency (%)	467 (49.6)	8180 (39.2)	569 (63.0)	8078 (38.7)	8647 (39.7)
Bipolar depression, frequency (%)	715 (76.0)	4522 (21.7)	525 (58.1)	4712 (22.6)	5237 (24.0)
Unipolar depression, frequency (%)	755 (80.2)	3922 (18.8)	443 (49.1)	4234 (20.3)	4677 (21.5)
Psych hospitalizations, median (IQR)	3 (1, 7)	0 (0, 1)	2 (0, 5)	0 (0, 1)	0 (0, 1)
Psych ED visits, median (IQR)	6 (3, 15)	1 (0, 3)	6 (3, 13)	1 (0, 3)	1 (0, 3)

1. IQR interquartile range, Psych psychiatric, ED emergency department



Table 2 Odds ratios (OR) and 95% confidence intervals (CI) from logistic regression models estimating the odds of at least one medical encounter for suicidal ideation or a suicide attempt during the 48-month study period in Medicare-enrolled autistic adults

	Suicidal ideation		Suicide attempt	
	OR	95% CI	OR	95% CI
Years of age (in 2012)	0.94 <sup>‡</sup>	0.93–0.95	0.98 <sup>‡</sup>	0.98–0.99
Female	1.14	0.96–1.36	1.12	0.96–1.31
Race				
White (ref)				
Black	0.68 <sup>+</sup>	0.52–0.88	0.51 <sup>‡</sup>	0.40–0.65
Hispanic	0.93	0.62–1.41	1.04	0.72–1.50
Other/unknown	0.78	0.52–1.18	0.78	0.53–1.15
Dually eligible	1.09	0.85–1.40	1.54 <sup>‡</sup>	1.20–1.98
Bipolar depression	4.51 <sup>‡</sup>	3.79–5.37	2.36 <sup>‡</sup>	2.03–2.76
Unipolar depression	8.54 <sup>‡</sup>	7.12–10.24	1.78 <sup>‡</sup>	1.52–2.08
Intellectual disability	0.76 <sup>+</sup>	0.64–0.90	1.92 <sup>‡</sup>	1.64–2.24
Number of Psych hospitalizations <sup>a</sup>	1.20 <sup>‡</sup>	1.18–1.23	1.05 <sup>‡</sup>	1.03–1.07
Number of Psych ED visits <sup>a</sup>	1.04 <sup>‡</sup>	1.03–1.05	1.06 <sup>‡</sup>	1.05–1.07

1. OR odds ratio, CI confidence interval, Psych psychiatric, ED emergency department

2. <sup>+</sup>p < 0.01, <sup>‡</sup>p < 0.001, <sup>‡‡</sup>p < 0.0001

3. <sup>a</sup>It should be noted that temporality between study outcomes and psychiatric healthcare utilization was not examined. That is, the psychiatric hospitalizations and ED visits were identified without regard to their temporal relationship with claims for suicidal ideation or attempts