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# Psychiatric hospitalisation among individuals with intellectual disability referred to the START crisis intervention and prevention program

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## Abstract

**Background** Little is known about inpatient psychiatric hospitalisation among adults with intellectual disability (ID) in the United States. Greater research is, therefore, required to inform efforts aimed at preventing this costly and restrictive form of care.

**Methods** Data were from 3299 individuals with ID (mean age = 31 years; SD = 14 years) who were referred to START (Systemic, Therapeutic, Assessment, Resources, and Treatment), a community-based crisis intervention and prevention programme. A random effects logistic regression model was used to examine the association between 11 factors and caregiver report of psychiatric hospitalisation in the past 12 months.

**Results** Twenty eight percent of the sample had at least one psychiatric inpatient stay in the prior year. Factors associated with an increased likelihood of prior hospitalisation included: younger age, diagnosis of a psychotic disorder, a score of >30 on the irritability subscale of the Aberrant Behavior Checklist, increasing number of psychiatric

diagnoses, less severe ID, Black/AA race and not having a home and community waiver.

**Conclusions** Among this high-risk referred group, more than 1 in 4 individuals were hospitalised in the year prior to referral. While results from the analyses will help profile those at risk for hospitalisation, the findings suggest that interventions at the policy level may play an important role in reducing psychiatric hospitalisation.

**Keywords** behavioural health, hospital, intellectual disability, mental health, psychiatric, START

## Introduction

Between 20–40% of individuals with an intellectual disability (ID) suffer from a co-occurring psychiatric disorder, with externalising problems such as aggression often being the most pressing mental health need (Borthwick-Duffy 1994; Deb *et al.* 2001; Emerson 2003; Cooper *et al.* 2007; Morgan *et al.* 2008). Since the de-institutionalization movement in the 1960s, the outpatient mental health systems in the US have failed to meet the needs of individuals with ID and co-occurring challenging behaviors (Krahn *et al.* 2006). One by-product of the fragmented US mental health system is the over reliance on hospital-based services because community-based options are

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unavailable (Mandell *et al.* 2012; Beasley *et al.* 2016). Inpatient care, though necessary at times, is best viewed as one step in a continuum of treatment alternatives in behavioural health care.

Over dependence on the hospital setting without alternative options for community-based treatment was deemed a civil rights violation in the 1999 Olmstead Act (Salzer *et al.* 2006). Reduction of repeat hospitalisations is also an important goal of the Affordable Healthcare Act (ACA), a recent healthcare reform law in the US (Kocher & Adashi 2011). In the UK, the Transforming Care Agenda echoes the intention of the Olmstead and ACA legislature in their call for the immediate discharge of individuals with a learning disability and/or autism to the community when adequate outpatient supports are present (Association of Directors of Adult Social Services 2015).

Use of psychiatric hospital services among those with ID has primarily been studied in Canada and the UK, both of which employ socialised healthcare systems. In Canada, psychiatric conditions are responsible for almost half of all hospitalisations among those with ID (Lunsky & Balogh 2010). Individuals with ID also have higher rates of readmission than the general population of services users in Canada (Lunsky & Balogh 2010). With regard to factors related to psychiatric hospitalisation, Lunsky & Balogh (2010) found increased use of psychiatric hospitalisation services among males and adolescents (ages 15–34 years) and Cowley *et al.* (2005) reported schizophrenia-related disorders as well as mild ID were predictive of hospitalisation. Modi *et al.* (2015) reported only aggression and psychiatric polypharmacy remained significant predictors of hospitalisation in their multivariate analyses, despite examining a host of factors such as age, gender, residence, severity of ID, presence of an autism spectrum disorder (ASD) diagnosis, general medication use, self-injury and severity of psychopathology. Discrepancy between these findings may be due to differences in country (UK [Cowley *et al.* 2005] and Canada [Modi *et al.* 2015; Lunsky & Balogh 2010]) and sampling (e.g. data gathered from a community sample [Cowley *et al.* 2005], a single psychiatric unit [Modi *et al.* 2015] and a population-based study [Lunsky & Balogh 2010]).

To our knowledge, there is no published study specifically examining psychiatric hospital use among

adults with ID in the US. This is critical because it is unclear if the international literature extends to individuals in the US given the large differences in health systems across jurisdictions.

Reducing dependence on costly and restrictive services, such as inpatient hospitalisation, by supporting and promoting access to high-quality community-based care is a key goal of START (Systemic, Therapeutic, Resources, Treatment), a tertiary care crisis intervention programme that provided data for the present study. First developed in 1989, START employs a well-trained, multidisciplinary work-force that aims to improve the care of individuals with ID and a co-occurring mental health issue and/or challenging behaviour. To date, two studies have examined START. A four-year study of 89 families using START services showed promising outcomes, including a significant reduction in emergency service use as well as improvements in service experiences (Beasley 2002). This was followed by a comparative analysis conducted in the state of Tennessee ( $n = 15$ ) showing a reduction in emergency service use and associated costs among those in START when compared with a group of wait list controls (Fahs *et al.* 2007). The present study represents the inaugural effort of START to describe the prevalence and correlates of psychiatric hospitalisation services among their cohort upon referral.

In the present study, a total of eleven predisposing, enabling and need factors were examined within the Andersen model of healthcare use. Based on prior studies, it was hypothesised that an increased probability of past year hospitalisation would be associated with younger age, male gender, less severe ID, higher caregiver ratings of aggressive behaviours, increased number of psychiatric diagnoses and diagnosis of a psychotic disorder.

## Methods

The START program supports individuals with ID and behavioural health needs through a three-stage crisis intervention model. The primary level of intervention aims to inhibit the onset of difficulty by building capacity in the system to better understand and address the needs of the population. The secondary level of intervention seeks to detect and accurately address conditions or difficulties in order

to prevent exacerbation, and the tertiary level of intervention attempts to stabilise someone after an acute condition is presented. If factors that increase the likelihood of psychiatric admission can be identified, this understanding will be critical to early identification and prevention of acute/emergent care, a critical goal of START. As of 2015, there are START programmes in nine states across the USA. Data from six of these sites were included in the present study. More information about START can be found here: <http://www.centerforstartservices.com>.

### Sampling, inclusion criteria and data collection procedures

Data from six START states – state 1 ( $n = 108$ ), state 2 ( $n = 502$ ), state 3 ( $n = 349$ ), state 4 ( $n = 603$ ), state 5 ( $n = 428$ ) and state 6 ( $n = 1309$ ) – were included in this study. States are located in geographically diverse regions, including the northeast, southeast and south western parts of the USA. Participants were referred to START from a host of sources, including emergency responders, local providers, hospitals and emergency rooms, developmental disabilities services coordinators and outpatient providers.

Criteria for referral to START included a diagnosis of a developmental disability along with the presence of challenging behaviours and/or a diagnosed mental health condition. Most individuals in START have ID (93%) or ASD (23%); however, a few individuals ( $n = 103$ ; 3%) had a general developmental disability diagnosis. More than 80% of referrals reported aggression as the primary reason for referral, and many also reported that the individual was at risk of losing their home or placement in the community because of these challenges. A total of 832 individuals were excluded from this study because of either missing data on the study outcome ( $n = 389$ ) or they were residing in a lock door facility, such as an inpatient hospital, prison or long-term facility, at the time of the survey ( $n = 443$ ). The final sample included 3299 individuals.

The START model relies on data to provide feedback to state and local policy makers, project managers and administrators as they assess the effectiveness of START services. To capture such crucial information, START has built and refined a custom online database, the START Information Reporting System. This data entry platform, which is

accessed through an internet browser, captures all of the measures described below by the START coordinator. All data gathered were captured during the baseline/intake assessment; thus, these results shed light on the prevalence and correlates of hospitalisation prior to when START begins. The effect of START on reducing hospitalisation is the topic of previous (Beasley 2002; Fahs *et al.* 2007) and future research. All information entered and extracted from START Information Reporting System is fully de-identified and was used for the present study, which was approved by the governing institutional IRB.

### The Andersen model

Drawing from the economic and social-psychological literature in creating what is described as a ‘behavioural model’ for service use, the Andersen model has been widely used to predict and understand the use of health and support services (Andersen 1968; Andersen 1995; Beasley 2002). The model classifies variables into three domains: (1) predisposing factors that reflect a tendency toward service use; (2) enabling factors to define resources that may either help to promote or avoid service use; and (3) need factors pertaining to the individual’s illness or disability that may indicate requirements for service use.

### Predisposing factors

Typically, predisposing factors in the Andersen Model represent socio-demographic characteristics of the individual. Data on age (4–16 years, 7%; 17–21 years, 21%; 22–25 years, 18%; 26–35 years, 23%; 36–45 years, 13%; 46–55 years, 11%; >56 years, 7%), gender ( $n = 2202$ ; 61% male), ASD diagnosis ( $n = 762$ ; 23%), race (63% Caucasian,  $n = 1383$ ; 26% Black/African-American,  $n = 566$ ; 3% other race,  $n = 57$ ; 8% Hispanic,  $n = 183$ ), and severity of ID [(no ID/borderline,  $n = 202$ ; 7%) (mild,  $n = 1501$ ; 53%), (moderate,  $n = 831$ ; 29%), and (severe/profound,  $n = 288$ ; 10%)] are included as predisposing factors in the present study. Data from predisposing factors were gathered at baseline from the caretaker during the intake interview, except for ASD diagnosis and severity of ID, which were procured via medical records provided by the caretaker. State of residence,

which was modeled as a 6 level variable, and year of referral were also included at this level.

### Enabling factors

Enabling factors are often couched in terms of the environmental resources available to the individual that promote or discourage health service utilisation. In the present study, two variables represented this stratum: (1) residential setting, a 3-level variable measured as paid/supportive community setting (e.g., a group home;  $n = 1082$ ; 39%), with the family ( $n = 1305$ ; 46%), or 'other' ( $n = 432$ ; 15%); and (2) receipt of the home and community-based waiver ( $n = 1250$ ; 50%).

All individuals in this study received physical health care and a minimal array of mental health services under Medicaid health insurance. However, some individuals received additional services under the home and community-based waivers programme (Centers for Medicare and Medicaid Services 2012). Waivers are designed to provide supplementary, long-term community-based services to individuals who are at risk for institutional care. Access to waiver services is based on state criteria approved by the federal government. Given the limited availability of slots, not all individuals who meet criteria received access to the home and community-based waivers. What is provided under the waivers varies from state to state, but supports may include case management, supports in home, supported employment, personal care and additional medical services. What exact services were afforded under the waivers was not gathered in the present study.

### Need factors

The primary tool for assessing psychiatric needs was the Aberrant Behavior Checklist (ABC); a well-known, heavily cited and psychometrically sound measure of psychiatric symptoms for individuals with ID and/or ASD (Aman *et al.* 1985; Aman *et al.* 1995). To reduce collinearity in the model due to high correlations among the subscales, the present study only employed the irritability subscale, which represents a measure of externalising symptoms such as aggression and affective lability. The ABC irritability scale was modelled as a 4-level variable, including scores from 0 to 9 (22%), 10–19 (30%), 20–29 (29%), and 30–45 (19%).

Additional need factors were studied. These included the presence of a psychotic/schizophrenia diagnosis ( $n = 615$ , 19%), number of chronic medical conditions (zero diagnoses,  $n = 1621$ , 19%; 1 diagnosis,  $n = 979$ , 30%; 2 diagnoses,  $n = 408$ , 12%, and 3+ diagnoses,  $n = 291$ , 9%), and number of psychiatric diagnoses (zero diagnoses,  $n = 1232$ , 37%; 1 diagnosis,  $n = 896$ , 27%; 2 diagnoses,  $n = 702$ , 21%, and 3+ diagnoses,  $n = 469$ , 14%). Similar to ASD and ID, presence of a chronic medical condition and number of psychiatric diagnoses were gathered via medical chart review. A total of 17 medical disorders (e.g. speech, vision, GI, and dental) and 11 psychiatric syndromes (e.g. bipolar, anxiety, depression, and impulse control disorders) were assessed. Both conditions were collapsed into a single, categorical variable given the low frequency of many diagnoses and to reduce the risk of over fitting the model.

### Outcome, design and analysis

The current study employed a cross-sectional, retrospective design based on individuals and/or their caregivers' reported history of psychiatric hospitalisation over the past year. A random effects logistic regression model was used to model the dichotomous outcome, coded as '1' for past year psychiatric hospitalisation and '0' for not. A random effect was placed on study site, in which there were a total of 28 sites nested across the six states, to account for the slightly stronger association between observations within sites ( $p = 0.03$ , 95% CI = 0.01–0.06) compared with across sites. To ease interpretation, the log odds ratios (or beta coefficients) from the logit model were exponentiated as odds ratios (OR) and can be interpreted as the conditional odds of psychiatric hospitalisation (i.e. while holding all other variables in the model constant) in one group (e.g. males) compared with the reference group (e.g. females).

To account for missing data in the regression model, multiple imputation via chained equations was employed (van Buuren *et al.* 1999). Data were imputed on the following missing variables: race (33% missing), funding/insurance status (24%), ABC scores (45% missing), severity of ID (14%), and setting (14%). Use of MI was necessary to produce the correct standard errors and maintain the sample

size when compared with case-wise deletion (van Buuren *et al.* 1999); see the Result Section below for sensitivity analyses regarding the influence of missing data. All variables included in the analysis were used in the imputation model under the assumption of missing at randomness (Schafer & Graham 2002). A total of 25 imputed datasets were estimated and analysed using the *mixt* command suite in STATA 12.0 (College Station, TX, USA). All models included robust standard errors to account for potential model misspecification, variance inflation factor scores of less than three supported minimal concern about collinearity, and alpha was set at 0.05 for all variables.

## Results

### Descriptives

A total of 930 (28%) individuals in the START programme reported at least one hospitalisation in the prior year. Table 1 stratifies characteristics of the sample among those who were or were not psychiatrically hospitalised in the past year. To minimise multiple comparisons, general trends are reported.

Prevalence of psychiatric hospitalisation was quite similar across five of the six states (24–37%), with one state in the Northeast having noticeably lower rates (10%). Those who experienced hospitalisation were younger (e.g. 32% of those age 4–16 vs. 20% of those age >56 years). The distribution of gender and ASD diagnosis was very similar across outcome; however, those who were Black/AA were more likely to experience hospitalisation. There was also a clear linear relationship between severity of ID and hospitalisation, such that those with no/borderline ID were over three times more likely to experience a hospitalisation compared with those with severe/profound ID (41% vs. 14%). No difference in history of hospitalisation was seen between those who lived in a supported setting compared with those living with family members. However, those in the ‘other’ category were more likely to experience hospitalisation. Having more medical diagnoses was not associated with having a history of psychiatric hospitalisation. However, there was a monotonic increase in the probability of hospitalisation as the number of psychiatric diagnoses increased.

Individuals with a psychotic/schizophrenia diagnosis were also roughly two times more likely than others without such a diagnosis to have been hospitalised in the year prior to intake. Lastly, those with the highest ABC irritability scores (>30) were more likely to have been hospitalised in the past year (e.g. 36% vs. 26% for those with a score <10).

### Multivariate analyses

Table 2 displays the results from the random effects logistic regression model examining correlates of past psychiatric hospitalisation. Beginning with predisposing variables, for individuals between 17 and 21 years of age, there was a 33% decrease in the likelihood of hospitalisation in the past year compared with youth 4–19 years of age. Individuals who were 46–55 and >56 years of age were 62% and 72% less likely to be hospitalised in the past year compared with youth 4–19 years of age. While gender or ASD diagnosis never approached statistical significance, individuals who were Black/AA were 37% more likely to experience hospitalisation compared with Whites. Those with moderate or severe/profound ID were 30% and 66% less likely to be psychiatrically hospitalised compared with those with mild ID, respectively. Those with no ID/borderline ID, however, were 84% more likely to be psychiatrically hospitalised in the past year. Lastly, there was also no effect of time (or year) across the models, and two states were significant in the model.

The final set of variables included enabling and need factors. For enabling factors, individuals who did not receive supports through a home and community-based waiver were 41% more likely to be hospitalised and individuals who were not living with family or in a supportive setting, the ‘other’ category, were 84% more likely to be hospitalised. For need factors, increasing number of medical conditions was not associated with psychiatric hospitalisation, while there was a significant (positive) linear effect of psychiatric diagnoses; such that increasing psychiatric diagnoses was associated with increased odds of hospitalisation. The presence of a psychotic disorder was the strongest variable in the model, representing almost a threefold increase in hospitalisation compared with those without such a diagnosis. Lastly, individuals with an ABC irritability score >30 were nearly 61% more likely to be psychiatrically



**Table 1** Sample characteristics stratified by history of psychiatric hospitalisation in the past year

Variable	No psychiatric hospitalisation in the past year	Psychiatric hospitalisation in the past year
Sample size, N(%)	2369 (72)	930 (28)
Year, N(%)		
2011	200 (82)	44 (18)
2012	344 (75)	117 (25)
2013	701 (76)	222 (24)
2014	680 (64)	379 (36)
2015	444 (73)	168 (27)
State, N(%)		
State 1	82 (76)	26 (24)
State 2	451 (90)	51 (10)
State 3	231 (66)	118 (34)
State 4	398 (66)	205 (34)
State 5	269 (63)	159 (37)
State 6	938 (72)	371 (28)
Age		
4-16 years	166 (68)	78 (32)
17-21 years	465 (68)	222 (32)
22-25 years	431 (73)	161 (27)
26-35 years	547 (71)	219 (28)
36-45 years	308 (71)	124 (29)
46-55 years	278 (77)	83 (23)
>56 years	174 (80)	43 (20)
Gender, N (%)		
Female	894 (70)	380 (30)
Male	1475 (73)	550 (27)
Race, N (%)		
White	981 (71)	402 (29)
Black/AA	350 (62)	216 (38)
Other Race	37 (65)	20 (35)
Hispanic	121 (66)	62 (34)
ASD, N (%)		
Diagnosis	1788 (70)	749 (30)
No Diagnosis	581 (76)	181 (24)
Level of ID, N (%)		
No ID/Borderline	119 (59)	83 (41)
Mild	999 (67)	502 (33)
Moderate	630 (76)	201 (24)
Severe/profound	248 (86)	40 (14)
Residential setting, N (%)		
Supported	746 (69)	336 (31)
Family	930 (71)	375 (29)
Other	221 (51)	211 (49)
Receipt of disability waiver, N(%)		
Yes	881 (73)	327 (27)
No	819 (63)	489 (37)
Number of psychiatric diagnoses, N(%)		
No diagnosis	924 (75)	308 (25)
1 Diagnosis	656 (73)	240 (27)
2 Diagnoses	486 (69)	216 (31)
3+ Diagnoses	303 (65)	166 (35)
Number of medical diagnoses, N(%)		

**Table 1.** (Continued)

Variable	No psychiatric hospitalisation in the past year	Psychiatric hospitalisation in the past year
No Diagnosis	1 153 (71)	468 (29)
1 Diagnosis	718 (73)	261 (27)
2 Diagnoses	294 (72)	114 (28)
3+ Diagnoses	204 (70)	87 (30)
Psychotic disorder diagnosis, N(%)		
No	2044 (76)	640 (24)
Yes	325 (53)	290 (47)
ABC irritability score, N(%)		
0–9	286 (74)	103 (26)
10–19	396 (73)	150 (28)
20–29	376 (71)	151 (29)
30–45	213 (64)	122 (36)

ID, intellectual disability; ASD, autism spectrum disorder; ABC, Aberrant Behavior Checklist.

hospitalised in the past year compared with those with a score of 0–9.

### Sensitivity analyses

To better understand the robustness of the study findings in the presence of missingness, several sensitivity analyses were conducted including: (1) testing each variable with any missingness (i.e. race, funding/insurance status, the ABC irritability score, severity of ID and setting) at the bivariate level; (2) running a case-wise multivariate analysis that only included individuals with complete data (34% of the entire sample,  $n = 1128$ ); and (3), re-running the multiple imputation model while leaving out one of the three variables with a large amount of missingness (i.e. the ABC irritability score, race and funding/insurance) to examine how the other two variables with large amounts of missingness changed in the presence of this variable being removed.

Results from the bivariate analysis were consistent, for each of the five variables, with the overall study findings. For the multivariate case-wise analysis, four of the five variables were again consistent with the study findings. Race was the only variable that did not reach statistical significance, although the direction and magnitude of effects were nearly identical to those reported in the overall study findings. When the multiple imputation model was run leaving out each variable (one at a time), the ABC irritability score and

insurance/funding variable remained unchanged in statistical significance and direction. However, Black/AA race remained in the same direction and magnitude as the imputed model but did not reach statistical significance when the ABC irritability score was removed from the model. Taken together, these data suggest the overall study findings are generally robust, thus use of the full imputation model is warranted because multiple imputation is most methodologically appropriate approach to managing missing data (van Buuren *et al.* 1999; Schafer & Graham 2002), except for AA/Black race. We believe caution should be exercised regarding interpretation of race and recommend further research into this variable.

### Discussion

To our knowledge, this is the first study to examine variables associated with recent psychiatric hospitalisation among adults with ID in the USA. With data from over 3000 individuals, our findings indicate that previous psychiatric inpatient admissions were common among our START referred group, as over a quarter of the sample were psychiatrically hospitalised in the year prior to referral. We found several factors were associated with prior hospitalisation. Correlates included predisposing, enabling and need factors. It is important to note that individuals are referred to START for a host of



**Table 2** Random effects logistic regression models examining correlates of psychiatric hospitalisation

Variable	Odds ratio	Robust standard error	95% Confidence interval	t-value	P-value
<b>Age</b>					
4–16 years	Ref	Ref	Ref	Ref	Ref
17–21 years	0.77	0.17	0.49–1.21	–1.13	0.26
22–25 years	0.60	0.14	0.38–0.94	–2.22	0.03
26–35 years	0.58	0.14	0.36–0.94	–2.22	0.03
36–45 years	0.54	0.13	0.34–0.87	–2.55	0.01
46–55 years	0.38	0.09	0.22–0.64	–3.72	<0.001
>56 years	0.28	0.09	0.15–0.54	–3.79	<0.001
<b>Race</b>					
White	Ref	Ref	Ref	Ref	Ref
Black/AA	1.37	0.17	1.08–1.74	2.56	0.01
Other	1.24	0.37	0.68–2.25	0.71	0.48
Hispanic	1.06	0.24	0.69–1.64	0.27	0.79
Female gender	0.94	0.09	0.78–1.13	–0.67	0.50
ASD Diagnosis	0.88	0.14	0.64–1.22	–0.77	0.44
<b>Level of ID</b>					
Mild	Ref	Ref	Ref	Ref	Ref
Moderate	0.70	0.06	0.59–0.83	–4.05	<0.001
Severe/profound	0.41	0.08	0.28–0.60	–4.56	<0.001
No ID/borderline ID	1.78	0.35	1.21–2.61	2.92	0.004
Year	1.06	0.08	0.93–1.22	0.91	0.36
<b>State</b>					
State 1	Ref	Ref	Ref	Ref	Ref
State 2	0.71	0.10	0.54–0.94	–2.36	0.02
State 3	0.21	0.03	0.15–0.28	–10.48	<0.001
State 4	0.87	0.35	0.39–1.91	–0.35	0.72
State 5	1.03	0.35	0.53–2.01	0.09	0.93
State 6	1.10	0.16	0.82–1.46	0.66	0.51
<b>Setting</b>					
Paid/supportive	Ref	Ref	Ref	Ref	Ref
Other	1.84	0.36	1.25–2.71	3.13	0.002
Family	0.74	0.11	0.55–0.99	–2.00	0.04
<b>State ID waiver</b>					
Yes	Ref	Ref	Ref	Ref	Ref
No	1.41	0.12	1.18–1.67	3.94	<0.001
Psychotic–schizophrenia disorder	2.86	0.25	2.42–3.41	12.0	<0.001
<b>Number of psychiatric diagnoses</b>					
0	Ref	Ref	Ref	Ref	Ref
1	1.22	0.10	1.04–1.44	2.43	0.01
2	1.49	0.17	1.19–1.67	3.47	0.001
3+	2.05	0.31	1.52–3.41	4.69	<0.001
<b>Number of medical diagnoses</b>					
0	Ref	Ref	Ref	Ref	Ref
1	0.94	0.15	0.69–1.28	–0.38	0.70
2	1.05	0.14	0.81–1.37	0.38	0.70
3+	1.03	0.13	0.81–1.31	0.25	0.80
<b>ABC Irritability score, N(%)</b>					
0–9	Ref	Ref	Ref	Ref	Ref
10–19	1.05	0.17	0.76–1.46	0.32	0.75
20–29	1.13	0.20	0.79–1.60	0.68	0.50

**Table 2.** (Continued)

Variable	Odds ratio	Robust standard error	95% Confidence interval	t-value	P-value
Age					
30–45	1.61	0.33	1.07–2.42	2.34	0.02

ID, intellectual disability; ASD, autism spectrum disorder; ABC, Aberrant Behavior Checklist.

reasons, including the need for crisis evaluation and prevention services as well as START coordination (i.e. specialised outreach and consultation to both the system and individual). In most cases, the individual or the individual's system of support is in crisis, and in many cases, both are in crisis. As such, individuals referred for START services represent a high-risk group and may not be representative of the general US population of individuals with ID.

Beginning with individual characteristics in the predisposing model, several variables were significant in the multivariate analyses. Consistent with our hypotheses and previous research, less severe ID and younger age were robust correlates of hospitalisation. Lunskey & Balogh (2010) reported increased psychiatric hospitalisation use among younger individuals; however, Cowley *et al.* (2005) and Modi *et al.* (2015) did not support this finding. Thus, further research in the USA is needed to better understand if age is related to psychiatric hospitalisation among individuals with ID. Decreasing severity of ID was also associated with increased likelihood of past year psychiatric hospitalisation, a finding not consistent with Modi *et al.* (2015) but supported by Cowley *et al.* (2005). Further research is therefore needed to better understand if those with more severe ID are in less need of psychiatric hospitalisation or if this finding represents a gap in care because the relationship between severity of ID and psychopathology is unclear (Borthwick-Duffy 1994; Cooper *et al.* 2007).

Counter to our hypotheses, race was associated with the study outcome, whereas ASD diagnosis and gender were not. For gender, this is notable because males are disproportionately referred to START, suggesting they may be at higher risk for hospitalisation, yet such was not the case. Our finding is in line with previous research by Modi *et al.* (2015)

and Cowley *et al.* (2005) who found no association between gender and hospitalisation. For ASD, previous research has related this diagnosis to psychiatric emergency department use (Kalb *et al.* 2012); however, those findings failed to replicate for inpatient hospitalisation in this sample. Lastly, we were surprised to find that Blacks/AAs were 37% more likely to be hospitalised than Caucasians prior to referral to START because there is no reason to suspect race reflects an increased need for psychiatric hospitalisation (Buchanan & Carpenter 2005). This finding is an important avenue for future research employing stronger methods such as a cohort and/or claims-based study.

The second set of variables included two enabling factors. Living with the family, compared with a paid supportive setting such as a group home, was not associated with a statistically significant difference in past year hospitalisation. This finding contrasts with those reported by Modi *et al.* (2015) and Hemmings *et al.* (2009) who found living at home was associated with increased use of psychiatric hospital services. While the 'other' setting was associated with an increased risk of hospitalisation, this variable is difficult to interpret as the data did not identify the exact location of setting.

The most notable variable at this level of modelling was whether or not individuals received the Home and community-based waiver. People who did not have a waiver were 40% more likely to be psychiatrically hospitalised in the past year compared with individuals who received supports through the home and community-based waiver. This finding is not surprising as individuals served under a home and community-based waiver are eligible to receive a variety of direct supports including case management, day supports, supported employment and additional medical services; all of which are not usually available

under standard Medicaid health insurance. These data are line with previous research suggesting that prevention of psychiatric inpatient admissions may be possible with improved access to outpatient services. For instance, Mandell *et al.* (2012) found use of respite services was associated with lower rates of psychiatric inpatient admissions for youth with ASDs enrolled in Medicaid. In a UK-based study among 96 youth admitted to a psychiatric inpatient unit, Smith & Berney (2006) concluded that about 18% of admissions were “avoidable” and occurred primarily because of a lack of community-based services. For adults, Beasley (2002) and Fahs *et al.* (2007) found receipt of START services resulted in decreased psychiatric hospitalisations.

The final set of variables included the individuals’ clinical characteristics. The presence of a diagnosis of a psychotic disorder was the strongest variable in the overall model, representing almost a threefold increase in the likelihood of hospitalisation compared with those without such a diagnosis. This finding is consistent with our hypotheses and Cowley *et al.* (2005) but inconsistent with Modi *et al.* (2015). The finding requires replication because a previous study found that clinicians without expertise in ID tend to over diagnose psychotic disorder in this population (Lunsky & Bradley 2007).

Increased number of psychiatric diagnoses, but not medical diagnoses, was also positively associated with prior hospitalisation. The null finding for medical diagnosis may be a product of under-detection and under-reporting of medical problems among this population, a known problem that has been previously documented (Kwok & Cheung 2007). Perhaps useful to clinicians was the finding that the highest level of ABC irritability scores, or a score >30, was associated with past year psychiatric hospitalisation; a finding that stands in contrast to Modi *et al.* (2015). This finding should be interpreted with caution because the ABC was employed after hospitalisation, rather than prior. As such, the ability of the ABC to predict hospitalisation cannot be confirmed by the present study.

The present study has several important implications for future research. First, reconciling these findings with previous research is difficult because those studies were conducted in other countries that are based on socialised medical healthcare systems. Therefore, future research based

in the USA is clearly needed. Second, the present study employed a retrospective design that is particularly susceptible to recall bias and the measurement of independent variables were taken after, rather than prior, to the study outcome. Future research using prospective designs employing more objective information (e.g. claims data) and careful measurement of time sensitive variables (e.g. physical- and psycho-pathology) is greatly needed. Third, understanding geographic variability in psychiatric hospitalisation across US states and regions among those with ID requires further elucidation because the present study derived its sample from only six states. Fourth and finally, while the present study identified numerous factors related to psychiatric hospitalisation, interactions between these variables were not explored and should be an important avenue for future research.

There are also several important limitations and strengths of this study that warrant noting. For limitations, this includes substantial missing data on several critical variables, lack of structured and validated diagnostic assessments and unknown selection/referral biases. For strengths, this study included a large and diverse sample, evaluation of numerous variables across a range of domains, use of a standardised metric of psychopathology and novel findings about a topic that has received little attention in the USA.

## Conclusions

This study provides important insights into the factors related to past year psychiatric hospitalisation among a large, community-based sample of individuals with ID. Investigation of this topic is important because this population is at elevated risk for mental health problems and behavioural challenges, and little is known about use of inpatient psychiatric services among individuals with ID in the USA (Borthwick-Duffy 1994; Deb *et al.* 2001; Emerson 2003; Cooper *et al.* 2007; Morgan *et al.* 2008). In our community-based cohort, past year psychiatric hospitalisation was high (28%), warranting investigation into correlates of this costly and restrictive service. The factors with the strongest associations to hospitalisation were predisposing (younger age, less severe ID) and need (presence of a psychotic disorder diagnosis, increased number of

psychiatric diagnoses); however, the role of enabling variables (receipt of home and community-based Medicaid waivers) suggests interventions at the policy level may play an important role in reducing psychiatric hospitalisation.

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