

Patient Outcomes Associated With Tailored Hospital Programs for Intellectual Disabilities

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Approximately 1.2 million adults in the United States have an intellectual disability, representing 0.5% of the population 15 years or older.¹ Although they make up a small portion of the US population, those with intellectual disabilities have complex needs that stem from having limitations in intellectual functioning and adaptive behaviors.² Individuals with intellectual disabilities face barriers to receiving high-quality healthcare³ and commonly have unidentified health problems that require additional attention, such as problems with sensory impairment; behavioral, medication, or lifestyle problems; and potential health problems that require additional screening or testing.⁴

The majority of healthcare providers, however, receive little information, either during their clinical training or on the job, about how to ensure that the needs of patients with intellectual disabilities are met. In a survey of primary care nurses, just one-third indicated that they had received training on caring for patients with an intellectual disability during their initial training program and just 37% had received training after becoming a nurse.⁵ Additionally, nurses were unaware of the increased risk for many health conditions that require clinical monitoring or intervention, such as hearing or visual impairment, depression and other mental health problems, and autism. Compounding these issues, nurses have expressed less positive attitudes about patients with intellectual disabilities that may ultimately affect the quality of care.⁶ Evidence also suggests that many general practitioners, despite knowing that they serve an important role in ensuring the health of individuals with intellectual disabilities, do not routinely address the important health issues of these individuals.⁷ Clinicians have often received limited education, either as medical students or in practice, on the unique needs of this population, limiting development of the competencies and skills needed to work and experience caring for them.⁸⁻¹⁰ Although consensus guidelines have been proposed for caring for patients with intellectual disabilities in the primary care setting,¹¹ these guidelines have not yet become the standard of care. Consensus guidelines have yet to be developed for caring for patients with intellectual disabilities in the acute care setting.

ABSTRACT

OBJECTIVES: Hospitals have begun designing programs tailored to patients with intellectual disabilities to address their specific healthcare needs and social determinants of health. This study aimed to determine whether these programs improve hospital outcomes for patients with intellectual disabilities.

STUDY DESIGN: This cross-sectional, retrospective study analyzed data for patients with a primary or secondary diagnosis of intellectual disability and/or autism who were discharged from 5 hospitals participating in Vizient's Clinical Data Base/Resource Manager between January 2010 and September 2018.

METHODS: Generalized linear regression models were constructed to test the association between tailored program status and length of stay, cost, and cost per day, and a binary logistic regression model was constructed to test the association between tailored program status and 30-day readmission. A secondary analysis stratified patients by 3M All Patient Refined Diagnosis Related Groups grouper (the standard for inpatient classification) admission severity of illness (ASOI) score.

RESULTS: Of the 6618 patients included in the study, 29% were treated at hospitals with tailored programs. After controlling for patient demographic characteristics and clinical factors, patients treated at hospitals without programs had higher total costs (relative risk [RR], 1.06; $P = .038$) and cost per day (RR, 1.11; $P < .001$). Patients with an extreme ASOI score who were treated at hospitals without programs had significantly longer stays (RR, 1.38; $P = .001$), higher total cost (RR, 1.42; $P < .001$), and higher cost per day (RR, 1.10; $P = .025$) than patients treated at hospitals with programs.

CONCLUSIONS: Providing tailored programs for patients with intellectual disabilities is a promising strategy for improving inpatient care for this population.

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Individuals with intellectual disabilities have a similar prevalence of physical health conditions (eg, cardiovascular disease, cerebrovascular disease, lung conditions, diabetes) as other adults, yet those with moderate and severe intellectual disabilities have a life expectancy that is almost 20% shorter.^{12,13} Further, this population may have slightly higher rates of hospitalization¹⁴ and poorer hospital experiences and outcomes compared with other adults. Patients with intellectual disabilities have substantially longer hospital lengths of stay, more intensive care unit admissions, and more unexpected complications compared with other patients receiving treatment for psychoses in academic medical centers¹⁵ and have higher preventable readmission rates than other adult patients.¹⁶ In a systematic review of studies on the hospital experiences of individuals with intellectual disabilities, Iacono and colleagues identified several themes that may explain poor hospital experiences, including failure to provide appropriate care, lack of knowledge and skills among hospital staff, and poor or negative attitudes about patients with intellectual disabilities.¹⁷

To address these gaps in the care provided to individuals with intellectual disabilities, a few hospitals have implemented programs tailored to this population. In the United Kingdom, researchers have recommended that hospitals use intellectual disability liaison models of care, implement specific care pathways, and educate staff on communicating with and caring for this population.¹⁸ Adoption of similar programs has taken place in the United States but on a much smaller scale.¹⁹⁻²¹ Although research has not yet rigorously evaluated the success of these programs in improving outcomes for patients with intellectual disabilities in the United States, programs tailored to other populations who commonly experience difficulties navigating the healthcare system have improved patient care outcomes, including access, length of stay, cost, and patient satisfaction.²²⁻²⁴

The objective of this study was to evaluate whether hospital programs tailored to patients with intellectual disabilities have improved outcomes, including length of stay, cost, and readmission. We hypothesized that patients would have shorter length of hospital stay, lower hospital cost of care, and lower hospital cost per day and be less likely to be readmitted when treated at hospitals with programs tailored to patients with intellectual disabilities.

METHODS

Overview

This cross-sectional, retrospective study analyzed data for patients with a primary or secondary diagnosis of intellectual disability and/or autism from 5 hospital members of Vizient's Clinical Data Base. An amendment to an existing application was approved by the Rush University Medical Center Institutional Review Board.

TAKEAWAY POINTS

- ▶ Providing tailored programs for patients with intellectual disabilities is a promising strategy for improving hospital outcomes.
- ▶ After adjustment for patient demographic and clinical factors, patients treated in hospitals without such programs had 6% higher total costs and 11% higher cost per day.
- ▶ Tailored programs were associated with the largest impact for patients with extreme severity of illness upon admission; patients treated in hospitals without tailored programs had 38% longer length of stay, 42% higher total costs, and 10% higher cost per day, after adjusting for patient demographic and clinical factors.
- ▶ Future research should examine best practices in inpatient programs for these patients.

Sample

Of the 5 hospitals included in this study, 2 offered hospital programs tailored to patients with intellectual disabilities and 3 did not offer such programs. These hospitals were selected based on responses to a telephone or electronic questionnaire about program offerings tailored to this population (**eAppendix Table 1** [eAppendix available at ajmc.com]). A hospital was considered to have a tailored program if it provided at least 1 of the following elements: staff education, use of patient coordinators, community outreach, or utilization of care plans tailored to inpatients with intellectual disabilities. One hospital that was classified as offering tailored programs provided online training to nurses and support staff across patient care units and other settings, such as the laboratory, operating room, and recovery room. The other hospital provided patients with a specialized coordinator, provided online training for nurses, provided both patient and family education to help those with intellectual disabilities maintain a healthy lifestyle, and incorporated training on caring for patients with intellectual disabilities into the medical school curriculum.

This study included 6618 discharges between January 2010 and September 2018 with a primary or secondary diagnosis of intellectual disability or autism. *International Classification of Diseases, Tenth Revision* diagnosis codes included F70 through F73, F78, F79, Q90X, Q91X, Q92X, Q93X, F84.0, F84.2, F84.5, and F84.9, and *International Classification of Diseases, Ninth Revision* diagnosis codes included 317, 318.X, 319, 758XX, and 299.0. The study was limited to patients 18 years or older who were discharged alive from the index hospital stay. Patients with missing cost information (n = 102) were excluded.

Data

Deidentified data were obtained from Vizient's Clinical Data Base. Vizient is an alliance of integrated delivery networks, academic medical centers, community hospitals, pediatric hospitals, and non-acute care providers. The Clinical Data Base is populated with administrative billing data that hospitals provide from their data warehouses and are used for submitting claims to health insurers. The administrative billing data include patient demographic characteristics and admission and discharge information (eg, charges, diagnosis codes). Vizient calculates the hospital cost for each discharge using the charges submitted by the hospital, the

TABLE 1. Description of Included Hospitals (N = 5)

Hospital Characteristic	n (%)
Hospital type	
Academic medical center	4 (80)
Teaching hospital	1 (20)
Location	
Northeast	2 (40)
Midwest	3 (60)
Bed count	
300-499	1 (20)
500-699	3 (60)
700-899	1 (20)

hospital cost-to-charge ratio from the Medicare cost report, and wage index adjusted for geographic region.

Variables

Independent variable. Hospitals were classified as having a tailored program if they provided staff education, had specific patient coordinators, provided community outreach, or had specific care plans for inpatients with intellectual disabilities. Hospitals that indicated that they did not have any inpatient programs specifically for patients with intellectual disabilities were classified as not having a tailored program.

Dependent variables. The outcomes included hospital length of stay (days), hospital total cost of care, and readmission to the same hospital within 30 days after discharge. Hospital cost of care was measured in dollars by total cost and cost per day, and costs were adjusted to 2018 dollars using the Medical Care component of the Consumer Price Index.²⁵ Additionally, each patient’s 2018 adjusted total cost was divided by the respective length of stay to calculate the cost per day.

Additional variables. Analyses were adjusted for patient demographic characteristics and clinical factors. Patient demographic characteristics included race/ethnicity (Caucasian, African American, Hispanic, Asian/other, or unknown), sex (male or female), age (18-30, 31-50, 51-64, or ≥65 years), number of comorbidities (0, 1, 2, 3, 4, or ≥5), payer (commercial, Medicare, Medicaid, or other), discharge destination (home, home health, or transferred to a new facility), and admission year. Clinical characteristics included 3M All Patient Refined Diagnosis Related Groups grouper admission severity of illness (ASOI; minor, moderate, major, or extreme) and the most prevalent major diagnostic categories (MDCs): MDC 19, mental disorders; MDC 01, nervous system; MDC 06, digestive system; MDC 04, respiratory system; MDC 18, infectious/parasitic; MDC 05, circulatory system; MDC 08, musculoskeletal system; MDC 11, kidney/urinary tract; and other MDC codes.

Statistical Analysis

A χ^2 test was used to test the association between readmission and tailored program status, and Mann-Whitney *U* tests were used to

test the association of length of hospital stay, total cost, and cost per day with tailored program status.

A binary logistic regression model was constructed to test the association between readmission and tailored program status, and generalized linear regression models were constructed for the association of length of stay, total cost, and cost per day with tailored program status. The regression model for length of stay was fit with a negative binomial distribution and log link function, and the regression models for total cost and cost per day were fit with a gamma distribution and log link function. All regression models were adjusted for patient demographic characteristics and clinical factors. In a secondary analysis, patient discharges were stratified by ASOI score, and similar regression models were constructed. Data were analyzed via SPSS 22 Premium software (IBM Corporation; Armonk, New York).

RESULTS

Characteristics of the Study Population

Of the 5 hospitals in the study, 4 were academic medical centers (ie, healthcare organizations that include both a hospital and a medical school) and 1 was a teaching hospital (Table 1). Hospitals with a tailored program were located in the Midwest and Northeast regions, and those without tailored programs were located in similar geographic regions. Hospitals with a tailored program had 500 to 699 beds, whereas hospitals without a tailored program had either 300 to 499 beds or 700 to 899 beds.

The sample included 6618 patients, with 29% receiving treatment in a hospital with a tailored program (Table 2). Patients treated in hospitals with tailored programs were less likely to be Caucasian, more likely to have commercial insurance, more likely to have a major ASOI, and more likely to have a primary diagnosis of a nervous system condition compared with those treated at hospitals without tailored programs (Table 2; full description of sample in eAppendix Table 2).

Unadjusted Comparison of Patients Treated Without Hospital Programs

Of the patients treated at hospitals with a tailored program, 16% were readmitted within 30 days, whereas 17% were readmitted at hospitals without programs (*P* = .366) (Table 2). Median length of stay was 4 (interquartile range [IQR], 2-9) days for patients treated at hospitals with tailored programs and 5 (IQR, 3-10) days for patients treated at hospitals without programs (*P* < .001). Total cost of care was \$9636 (IQR, \$5606-\$21,939) for patients treated at hospitals with a program and \$9435 (IQR, \$5077-\$19,140) for patients treated at hospitals without a program (*P* = .001). The cost of care per day was \$2272 (IQR, \$1691-\$3187) for patients treated at hospitals with a program and \$1721 (IQR, \$1250-\$2790) for patients treated at hospitals without a program (*P* < .001).

Adjusted Comparison of Patients Treated Without Hospital Programs

After adjusting for patient demographic characteristics and clinical factors, patients treated at hospitals without programs tailored to

intellectual disabilities were found to have higher total cost (relative risk [RR], 1.06; $P = .038$) and cost per day (RR, 1.11; $P < .001$) (Table 3). Differences in length of stay and 30-day readmission were not associated with tailored program status. Average severity score was associated with longer length of stay, higher total cost and cost per day, and greater likelihood of 30-day readmission.

Stratification by ASOI

Median length of stay, total cost and cost per day, and 30-day readmission were substantially higher for patients with extreme ASOI compared with patients with lower ASOI (eAppendix Table 3). Patients with extreme ASOI who were treated at hospitals without a tailored program had longer stays (RR, 1.38; $P = .001$), higher total costs (RR, 1.42; $P < .001$), and higher cost per day (RR, 1.10; $P = .025$), but they were less likely to be readmitted (odds ratio, 0.60; $P = .040$) (Table 4). Cost per day was significantly higher for patients in hospitals without tailored programs for all ASOIs. For both length of stay and total cost, the magnitude of the association with presence of a tailored program was largest for patients with an extreme ASOI. Length of stay, total cost, and 30-day readmission were not associated with tailored program status for patients with a minor or moderate ASOI.

DISCUSSION

In this retrospective study of patient records for 6618 discharges between January 2010 and September 2018, we found that individuals treated at hospitals with programs tailored to patients with intellectual disabilities had significantly lower total costs than patients treated in hospitals without tailored programs, but they had similar readmission rates and hospital lengths of stay. Although care at hospitals with tailored programs was more expensive in the bivariate tests, we found that tailored programs were associated with lower total cost and cost per day after controlling for patient demographic characteristics and clinical factors. This finding may be explained by the fact that a larger proportion of patients in hospitals with tailored programs were classified as having a major ASOI. Outcomes were significantly better, including shorter length of stay and lower cost of care, for patients at hospitals with tailored programs who had the highest ASOI scores.

Implications for Clinical Practice

Given that hospitals with tailored programs had lower costs overall, without increasing the risk of readmission within 30 days, hospital

programs tailored to patients with intellectual disabilities are a promising approach for improving the quality and value of care. These programs include staff education, use of patient coordinators, participation in community outreach, and/or utilization of care plans for inpatients with intellectual disabilities. As previous research has shown, patients with intellectual disabilities tend to have poorer health outcomes than other adults,^{15,16} which may be attributed to the fact that this population has specific healthcare needs and social determinants of health that require specialized care and postdischarge care coordination.³ In particular, these challenges include communicating symptoms with providers, understanding diagnoses and follow-up care, having various support systems and personal routines depending upon discharge destination, and practicing healthy behaviors without guidance. Consequently, patients with intellectual disabilities are 3.6 times more likely to have costs of hospital care within the top decile compared with other adults.²⁶

TABLE 2. Characteristics of Patients in Hospitals With and Without Tailored Programs for Intellectual Disabilities (N = 6618)

	In Hospital With Tailored Program (n = 1909)	In Hospital Without Tailored Program (n = 4709)	P
Race/ethnicity, n (%)			<.001
Caucasian	992 (52.0)	3389 (77.4)	
African American	597 (31.3)	708 (15.0)	
Hispanic	163 (8.5)	204 (4.3)	
Asian/other	110 (5.8)	276 (5.9)	
Unknown	47 (2.5)	132 (2.8)	
Male, n (%)	1060 (55.5)	2734 (58.1)	.059
Age in years, n (%)			<.001
18-30	777 (40.7)	1992 (42.3)	
31-50	713 (37.3)	1401 (29.8)	
51-64	293 (15.3)	959 (20.4)	
≥65	126 (6.6)	357 (7.6)	
≥5 comorbidities, n (%)	238 (12.5)	638 (13.5)	.180
Payer, n (%)			<.001
Commercial	612 (32.1)	864 (18.3)	
Medicaid	485 (25.4)	1564 (33.2)	
Medicare	785 (41.1)	2238 (47.5)	
Other	27 (1.4)	43 (0.9)	
Major or extreme ASOI, n (%)	850 (44.5)	1794 (38.1)	<.001
Transferred to another facility, n (%)	452 (23.7)	959 (20.4)	.007
Primary diagnosis classification of MDC 19 (mental disorders), n (%)	300 (15.7)	1642 (34.9)	<.001
Outcomes			
Length of stay in days, median (IQR)	4 (2-9)	5 (3-10)	<.001
Total cost in \$, median (IQR)	9636 (5606-21,939)	9435 (5077-19,140)	.001
Cost/day in \$, median (IQR)	2272 (1691-3187)	1721 (1250-2790)	<.001
Readmitted within 30 days, n (%)	310 (16.2)	808 (17.2)	.366

ASOI indicates admission severity of illness; IQR, interquartile range; MDC, major diagnostic category.

TABLE 3. Multivariate Results: Length of Stay, Total Cost, Cost per Day, and Readmission in Absence of Tailored Programs for Intellectual Disabilities*

	Length of Stay		Total Cost		Cost per Day		30-Day Readmission	
	RR (95% CI)	P	RR (95% CI)	P	RR (95% CI)	P	OR (95% CI)	P
No tailored program	0.92 (0.78-1.08)	.291	1.06 (1.00-1.12)	.038	1.11 (1.08-1.15)	<.001	1.03 (0.97-1.10)	.302
Race/ethnicity								
African American	1.07 (0.90-1.28)	.427	0.86 (0.81-0.92)	<.001	0.91 (0.88-0.94)	<.001	0.98 (0.92-1.05)	.597
Hispanic	1.11 (0.84-1.48)	.452	0.91 (0.82-1.01)	.068	0.89 (0.84-0.94)	<.001	0.96 (0.85-1.08)	.475
Asian/other	0.82 (0.60-1.12)	.213	1.06 (0.96-1.17)	.273	1.02 (0.96-1.07)	.608	1.01 (0.91-1.13)	.809
Unknown	1.02 (0.67-1.55)	.938	1.26 (1.10-1.45)	<.001	0.99 (0.92-1.08)	.858	1.25 (1.07-1.46)	.006
Sex								
Female	0.92 (0.80-1.05)	.216	1.01 (0.96-1.05)	.788	1.00 (0.98-1.03)	.089	1.00 (0.95-1.05)	.970
Age in years								
31-50	0.96 (0.81-1.15)	.664	1.03 (0.97-1.10)	.291	1.03 (0.99-1.06)	.110	1.00 (0.93-1.07)	.955
51-64	0.84 (0.67-1.04)	.099	0.99 (0.92-1.07)	.844	0.98 (0.94-1.02)	.398	0.95 (0.87-1.03)	.228
≥65	0.85 (0.63-1.14)	.273	1.02 (0.92-1.13)	.781	0.98 (0.92-1.04)	.493	1.00 (0.89-1.13)	.989
Comorbidities								
1	1.35 (1.15-1.90)	.002	1.00 (0.93-1.08)	.984	0.96 (0.92-1.01)	.092	1.03 (0.95-1.12)	.493
2	1.31 (1.00-1.70)	.046	0.97 (0.89-1.04)	.363	0.94 (0.90-0.98)	.005	0.99 (0.91-1.09)	.862
3	1.52 (1.15-2.00)	.003	0.92 (0.85-1.01)	.064	0.94 (0.89-0.98)	.009	0.99 (0.90-1.09)	.832
4	1.67 (1.24-2.25)	.001	0.91 (0.82-1.00)	.042	0.91 (0.86-0.97)	.001	0.99 (0.89-1.11)	.914
≥5	2.02 (1.51-2.70)	<.001	1.05 (0.95-1.15)	.369	0.95 (0.90-1.00)	.049	1.11 (1.00-1.24)	.057
Payer								
Medicaid	1.06 (0.88-1.29)	.525	0.87 (0.82-0.93)	<.001	0.90 (0.86-0.93)	<.001	1.03 (0.95-1.11)	.458
Medicare	0.97 (0.80-1.19)	.786	0.84 (0.78-0.90)	<.001	0.91 (0.88-0.95)	<.001	0.97 (0.90-1.05)	.443
Other	0.56 (0.25-1.25)	.157	0.71 (0.57-0.89)	.002	0.87 (0.77-0.99)	.032	0.87 (0.67-1.13)	.302
ASOI								
Moderate	1.38 (1.09-1.74)	.008	1.21 (1.13-1.30)	<.001	0.98 (0.94-1.02)	.235	1.28 (1.18-1.39)	<.001
Major	1.74 (1.36-2.23)	<.001	1.61 (1.50-1.74)	<.001	0.93 (0.89-0.97)	<.001	1.79 (1.64-1.96)	<.001
Extreme	1.57 (1.15-2.14)	.004	3.30 (2.98-3.66)	<.001	1.07 (1.00-1.13)	.037	3.18 (2.83-3.58)	<.001

ASOI indicates admission severity of illness; OR, odds ratio; RR, relative risk.

*Models control for primary diagnosis classification, discharge destination, and discharge year. Reference category includes Caucasian, male, aged 18 to 30 years, 0 comorbidities, commercial insurance, minor ASOI, discharge destination of home, primary diagnosis classification of mental disorder (major diagnostic category 19), and 2010 admission year.

We found that patients with extreme ASOI who were treated in a hospital without a tailored program had higher total costs but a lower risk of readmission. This potential inverse association between hospital days and subsequent readmissions should be further examined. Because we had access only to same-hospital readmissions, there are at least 2 plausible explanations. First, the longer hospital stay may have reduced the need for unplanned hospital readmissions, despite the fact that these patients did not receive care within a hospital with a tailored program. Alternatively, hospitals with tailored programs for patients with intellectual disabilities may have garnered stronger patient and family loyalty to the hospital, particularly for patients with long stays that increased the likelihood that the patient would return to the same hospital rather than seek care at a different hospital. Hospitals need to ensure that the most complex patients with intellectual disabilities receive individualized supports and services that address their unique needs, including additional support in carrying out discharge plans

and coordination with family and community services to ensure that the discharge instructions can be carried out. Attention to the discharge planning process for patients with intellectual disabilities is consistent with the Agency for Healthcare Research and Quality's national quality goals and the Re-Engineered Discharge (part of Project RED) developed by Boston University Medical Center.²⁷

Implications for Education

Although it is clear that patients with intellectual disabilities have unique needs, most providers are not properly trained to ensure that these needs are met. Both nurses and physicians have reported that they do not receive enough training as students for treating this population.^{5,8,10} The hospitals with programs tailored to patients with intellectual disabilities in this study offered staff training to address this issue. Medical and nursing programs should factor these findings into their curricula to ensure that future providers have the competencies to appropriately care for this population.²⁸

TABLE 4. Adjusted Outcomes for Absence of Tailored Program by ASOI*

ASOI	Length of Stay		Total Cost		Cost per Day		Readmission	
	No Tailored Program RR (95% CI)	P	No Tailored Program RR (95% CI)	P	No Tailored Program RR (95% CI)	P	No Tailored Program OR (95% CI)	P
Minor	0.97 (0.82-1.15)	.697	1.01 (0.88-1.16)	.883	1.12 (1.03-1.23)	.012	1.17 (0.71-1.94)	.544
Moderate	0.93 (0.85-1.03)	.180	0.95 (0.87-1.03)	.192	1.08 (1.03-1.13)	.001	0.94 (0.72-1.21)	.608
Major	1.04 (0.93-1.16)	.511	1.13 (1.03-1.24)	.012	1.16 (1.10-1.23)	<.001	0.93 (0.71-1.20)	.563
Extreme	1.38 (1.14-1.67)	.001	1.42 (1.22-1.67)	<.001	1.10 (1.01-1.19)	.025	0.60 (0.37-0.98)	.040

ASOI indicates admission severity of illness; OR, odds ratio; RR, relative risk.

*A separate regression model was constructed for each ASOI category for each outcome. Each model controls for patient race/ethnicity, sex, age, primary insurance, number of comorbidities, discharge destination, primary diagnosis classification of mental disorder (major diagnostic category 19), and 2010 admission year.

Further, hospitals should incorporate similar staff training to improve care for patients with intellectual disabilities.

Limitations and Implications for Future Research

Patients with intellectual disabilities have worse outcomes and shorter life expectancies than other adults,¹³⁻¹⁶ and they experience significant but often overlooked disparities in access to high-quality care. These disparities, at least in part, stem from a lack of services needed to address their unique needs.²⁹ Tailored programs may be a step in the right direction to eliminate these disparities. Given the small number of hospitals with tailored programs included in this study, we were unable to examine the effect of individual program components (eg, nurse training, staff training, patient coordinators) on patient outcomes. Future research should examine whether some program components are more important than others for improving the quality of care. Additionally, although our results provide insight into the impact of tailored programs for patients with intellectual disabilities, we did not examine whether their hospital outcomes differed from those of other patients. Prior research has demonstrated that individuals with intellectual disabilities receive hospital care of poor quality,¹⁷ but the extent to which tailored programs help close the quality gap between patients with and without intellectual disabilities is not yet known. Finally, although tailored programs were available at these hospitals, the patients included in the study may not have received services from the tailored programs or received care or assistance from staff trained through the tailored programs. Future research should examine the effect of these programs on patients who used these programs compared with other patients who did not.

CONCLUSIONS

Patients with intellectual disabilities treated in hospitals with tailored programs had lower costs, without increasing the risk of readmission, suggesting that these programs are a promising approach for improving care. Cost reductions may be attributed to the fact that tailored programs reduce challenges faced by this population when receiving healthcare, thereby improving their experiences with the healthcare system. These findings demonstrate a clear need for standards of care and comprehensive, competency-based provider

education for treating patients with intellectual disabilities. CMS and The Joint Commission should incorporate regulatory standards to ensure high-quality care for patients with intellectual disabilities as part of hospital certification and accreditation. Hospitals should adopt programs tailored to patients with intellectual disabilities to provide better care for this population. ■

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REFERENCES

- Brault MW. Americans with disabilities: 2010. US Census Bureau website. census.gov/library/publications/2012/demo/p70-131.html. Published July 2012. Accessed February 11, 2020.
- Schalock RL, Borthwick-Duffy SA, Bradley VJ, et al. *Intellectual Disability: Definition, Classification, and Systems of Supports*. 11th ed. Washington, DC: American Association on Intellectual Disabilities; 2010.
- Emerson E. *Challenging Behaviour: Analysis and Intervention in People With Severe Intellectual Disabilities*. 2nd ed. Cambridge, UK: Cambridge University Press; 2001.
- Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. *Br J Gen Pract*. 2006;56(523):93-98.
- Melville CA, Finlayson J, Cooper SA, et al. Enhancing primary health care services for adults with intellectual disabilities. *J Intellect Disabil Res*. 2005;49(pt 3):190-198. doi: 10.1111/j.1365-2788.2005.00640.x.
- Lewis S, Stenfort-Kroese B. An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *J Appl Res Intellect Disabil*. 2010;23(4):355-365. doi: 10.1111/j.1468-3148.2009.00542.x.
- Lennox NG, Diggins J, Ugoni A. Health care for people with an intellectual disability: general practitioners' attitudes, and provision of care. *J Intellect Dev Disabil*. 2000;25(2):127-133. doi: 10.1080/13269780050033544.
- Fredheim T, Haavet OR, Danbolt LJ, Kjongsberg K, Lien L. Intellectual disability and mental health problems: a qualitative study of general practitioners' views. *BMJ Open*. 2013;3(3). pii: e002283. doi: 10.1136/bmjopen-2012-002283.
- Williamson A, Allan L, Cooper SA, Morrison J, Curtice L. The general practitioner interface with people with intellectual disabilities and their supports. *Eur J Gen Pract*. 2004;10(2):66-67. 70. doi: 10.3109/13814780409094236.
- Ryan TA, Scior K. Medical students' attitudes towards health care for people with intellectual disabilities: a qualitative study. *J Appl Res Intellect Disabil*. 2016;29(6):508-518. doi: 10.1111/jar.12206.
- Sullivan WF, Berg JM, Bradley E, et al. Colloquium on Guidelines for the Primary Health Care of Adults With Developmental Disabilities. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician*. 2011;57(5):541-553. e154-e168.
- Horwitz SM, Kerker BD, Owens PL, Zigler E. The health status and needs of individuals with mental retardation. Special Olympics website. dotorg.brightspotcdn.com/af/87/5834a3734eb7b21bf1660296df71/healthstatus-needs.pdf. Updated December 18, 2000. Accessed February 11, 2020.
- Pajta K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res*. 2000;44(pt 5):591-599. doi: 10.1046/j.1365-2788.2000.00280.x.
- Skorpen S, Nicolaisen M, Langballe EM. Hospitalisation in adults with intellectual disabilities compared with the general population in Norway. *J Intellect Disabil Res*. 2016;60(4):365-377. doi: 10.1111/jir.12255.

15. Ailey SH, Johnson T, Fogg L, Friese TR. Hospitalizations of adults with intellectual disability in academic medical centers. *Intellect Dev Disabil*. 2014;52(3):187-192. doi: 10.1352/1934-9556-52.3.187.
16. Kelly CL, Thomson K, Wagner AP, et al. Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. *J Intellect Disabil Res*. 2015;59(9):835-844. doi: 10.1111/jir.12193.
17. Iacono T, Bigby C, Unsworth C, Douglas J, Fitzpatrick P. A systematic review of hospital experiences of people with intellectual disability. *BMC Health Serv Res*. 2014;14:505. doi: 10.1186/s12913-014-0505-5.
18. Backer C, Chapman M, Mitchell D. Access to secondary healthcare for people with intellectual disabilities: a review of the literature. *J Appl Res Intellect Disabil*. 2009;22(6):514-525. doi: 10.1111/j.1468-3148.2009.00505.x.
19. Criscione T, Kastner TA, Walsh KK, Nathanson R. Managed health care services for people with mental retardation: impact on inpatient utilization. *Ment Retard*. 1993;31(5):297-306.
20. Sowney M, Barr DG. Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *J Adv Nurs*. 2006;55(1):36-45. doi: 10.1111/j.1365-2648.2006.03881.x.
21. Friese T, Ailey S. Specific standards of care for adults with intellectual disabilities. *Nurs Manag (Harrow)*. 2015;22(1):32-37. doi: 10.7748/nm.22.1.32.e1296.
22. Washington DL, Bean-Mayberry B, Mitchell MN, Riopelle D, Yano EM. Tailoring VA primary care to women veterans: association with patient-rated quality and satisfaction. *Womens Health Issues*. 2011;21(4 suppl):S112-S119. doi: 10.1016/j.whi.2011.04.004.
23. Costantini O, Huck K, Carlson MD, et al. Impact of a guideline-based disease management team on outcomes of hospitalized patients with congestive heart failure. *Arch Intern Med*. 2001;161(2):177-182. doi: 10.1001/archinte.161.2.177.
24. Kertesz SG, Holt CL, Steward JL, et al. Comparing homeless persons' care experiences in tailored versus nontailored primary care programs. *Am J Public Health*. 2013;103(suppl 2):S331-S339. doi: 10.2105/AJPH.2013.301481.
25. Consumer Price Index. US Bureau of Labor Statistics website. www.bls.gov/cpi. Accessed February 20, 2019.
26. Lunskey Y, De Oliveira C, Wilton A, Wodchis W. High health care costs among adults with intellectual and developmental disabilities: a population-based study. *J Intellect Disabil Res*. 2019;63(2):124-137. doi: 10.1111/jir.12554.
27. Jack B, Paasche-Orlow M, Mitchell S, Forsythe S, Martin J. Re-Engineered Discharge (RED) toolkit. Agency for Healthcare Research and Quality website. ahrq.gov/hai/red/toolkit/index.html. Published March 2013. Accessed February 11, 2020.
28. Ailey S, Lamb K, Friese T, Christopher BA. Educating nursing students in clinical leadership. *Nurs Manag (Harrow)*. 2015;21(9):23-28. doi: 10.7748/nm.21.9.23.e1304.
29. Ouellette-Kuntz H, Garcin N, Lewis ME, Minnes P, Martin C, Holden JJ. Addressing health disparities through promoting equity for individuals with intellectual disability. *Can J Public Health*. 2005;96(suppl 2):S8-S22.

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eAppendix Table 1. Survey Questions

Name of Hospital:							
Does your hospital offer programs tailored to inpatients with intellectual disabilities? Programs include staff training, use of patient navigators, participation in community outreach, or utilization of care plans.							
Staff Training for Patients with ID		Patient Navigators for Patients with ID		Community Outreach for Patients with ID		Care Plans for Patients with ID	
Question	Answer	Question	Answer	Question	Answer	Question	Answer
Yes/no?		Yes/no?		Yes/no?		Yes/no?	
How many?		Who are they?		To whom?		Describe	
Departments?		Weekly patient load?		How many times/year?			

eAppendix Table 2. Characteristics of Patients in Hospitals with and without Tailored Programs, N= 6,618

	In Hospital with Tailored ID Program N = 1,909	In Hospital without Tailored ID Program N = 4,709	p-value
Race/Ethnicity, n (%)			<0.001
Caucasian	992 (52.0)	3,389 (77.4)	
African American	597 (31.3)	708 (15.0)	
Hispanic	163 (8.5)	204 (4.3)	
Asian/Other	110 (5.8)	276 (5.9)	
Unknown	47 (2.5)	132 (2.8)	
Sex, n (%)			0.059
Male	1,060 (55.5)	2,734 (58.1)	
Female	849 (44.5)	1,975 (41.9)	
Age, n (%)			<0.001
18-30	777 (40.7)	1,992 (42.3)	
31-50	713 (37.3)	1,401 (29.8)	
51-64	293 (15.3)	959 (20.4)	
65+	126 (6.6)	357 (7.6)	
Comorbidities, n (%)			0.180
0	269 (14.1)	723 (15.4)	
1	435 (22.8)	1,117 (23.7)	
2	415 (21.7)	1,015 (21.6)	
3	335 (17.5)	738 (15.7)	
4	217 (11.4)	482 (10.2)	
5+	238 (12.5)	638 (13.5)	
Payor, n (%)			<0.001

	In Hospital with Tailored ID Program N = 1,909	In Hospital without Tailored ID Program N = 4,709	p-value
Commercial	612 (32.1)	864 (18.3)	
Medicaid	485 (25.4)	1,564 (33.2)	
Medicare	785 (41.1)	2,238 (47.5)	
Other	27 (1.4)	43 (0.9)	
Admission Severity Score, n (%)			<0.001
Minor	335 (17.5)	656 (13.9)	
Moderate	724 (37.9)	2,259 (48.0)	
Major	659 (34.5)	1,314 (27.9)	
Extreme	191 (10.0)	480 (10.2)	
Discharge Destination, n (%)			0.007
Home	1,212 (63.5)	3,075 (65.3)	
Home Health	245 (12.8)	675 (14.3)	
Transferred to New Facility	452 (23.7)	959 (20.4)	
Primary diagnosis classification, n (%)			<0.001
MDC 19 - Mental Disorders	300 (15.7)	1,642 (34.9)	
MDC 01 - Nervous System	591 (31.0)	484 (10.3)	
MDC 06 - Digestive System	153 (8.0)	314 (6.7)	
MDC 04 - Respiratory System	132 (6.9)	311 (6.6)	
MDC 18 - Infectious/Parasitic	96 (5.0)	349 (7.4)	
MDC 05 - Circulatory System	74 (3.7)	272 (5.8)	
MDC 08 – Musculoskeletal	94 (4.9)	217 (4.6)	
MDC 11 - Kidney/Urinary Tract	63 (3.3)	216 (4.6)	
Other MDC Codes	408 (21.4)	904 (19.2)	
Admission Year, n (%)			0.075

	In Hospital with Tailored ID Program N = 1,909	In Hospital without Tailored ID Program N = 4,709	p-value
2010	169 (8.9)	400 (8.5)	
2011	196 (10.3)	421 (8.9)	
2012	218 (11.4)	436 (9.3)	
2013	201 (10.5)	562 (11.9)	
2014	219 (11.5)	604 (12.8)	
2015	215 (11.3)	540 (11.5)	
2016	228 (11.9)	574 (12.2)	
2017	252 (13.2)	617 (13.1)	
2018 (through September)	211 (11.1)	555 (11.8)	
Outcomes			
Length of stay, Median (IQR)	4 (2, 9)	5.0 (3, 10)	<0.001
Total Cost, Median (IQR)	9,636 (5,606, 21,939)	9,435 (5,077, 19,140)	0.001
Cost/Day, Median (IQR)	2,272 (1,691, 3,187)	1,721 (1,250, 2,790)	<0.001
Readmitted within 30 days, n (%)	310 (16.2)	808 (17.2)	0.366

eAppendix Table 3. Length of Stay, Cost, and Readmission by Admission Severity Score, N = 6,618

Severity Score	N	Length of Stay		Total Cost		Cost per Day		Readmission	
		Median (IQR)	p-value	Median (IQR)	p-value	Median (IQR)	p-value	n (%)	p-value
			<0.001		<0.001		<0.001		<0.001
Minor	991	3.0 (2.0, 6.0)		6,745 (3817, 12836)		1,821 (1227, 3187)		105 (10.6)	
Moderate	2,983	5.0 (3.0, 9.0)		8,250 (4650, 15679)		1,599 (1178, 2448)		457 (15.3)	
Major	1,973	5.0 (3.0, 9.0)		10,896 (6187, 21646)		2,179 (1636, 3124)		414 (21.0)	
Extreme	671	11.0 (6.0, 22.0)		27,879 (13752, 56420)		2,580 (1787, 3,677)		142 (21.2)	