Health Service Utilization Patterns Among Medicaid-Insured Adults With Intellectual and Developmental Disabilities:

Implications for Access Needs in Outpatient Community-Based Medical Services

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Abstract

Limited existing evidence suggests that adults with intellectual and developmental disabilities (IDD) experience substantial disparities in numerous areas of health care, including quality ambulatory care. A multistate cohort of adults with IDD was analyzed for patterns of inpatient admissions and emergency department utilization. Utilization was higher (inpatient [RR = 3.2], emergency department visits [RR = 2.6]) for adults with IDD, particularly for ambulatory care–sensitive conditions (eg, urinary tract [RR = 6.6] and respiratory infections [RRs = 5.5–24.7]), and psychiatric conditions (RRs = 5.8–15). Findings underscore the importance of access to ambulatory care skilled in IDD-related needs to recognize and treat ambulatory care–sensitive conditions and to manage chronic medical and mental health conditions.

Keywords

AS ADULTS with intellectual and developmental disabilities have moved out of institutional placements into community settings over the past several decades, they increasingly access community-based medical services, including primary care practitioners, for their health

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care (Albrecht et al., 2001; Harris, 2006). While the existing evidence of the health needs, utilization patterns, and outcomes for this population is limited, it indicates that adults with intellectual and developmental disabilities are disproportionately high utilizers of health care services (Krahn et al., 2006; Shea et al., 2018) but have poorer health outcomes (Albrecht et al., 2001; Krahn & Fox, 2014; Office of the Surgeon General, 2005), poorer quality of care, and potentially avoidable gaps in utilization patterns (McDermott, Royer, Mann, & Armour, 2018). In addition, these adults have limited access to important components of primary health care (Lennox et al., 2015) including health promotion programs (Havercamp & Scott, 2015; Lewis et al., 2002), timely ambulatory care (Balogh et al., 2010; McDermott et al., 2005), preventive health care such as cancer screenings (Parish & Saville, 2006; Wilkinson et al., 2011), and management of chronic conditions (Havercamp & Scott, 2015; Lewis et al., 2002).

Developmental disabilities are due to mental and/or physical impairments with onset during the developmental period (less than 22 years) expected to continue indefinitely and presenting "substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency" (U.S. Department of Health & Human Services; 2000). Intellectual disability falls within this domain and requires a limitation in both intellectual functioning and adaptive behavior (Schalock et al., 2010).

Although adults with intellectual and developmental disabilities are frequent recipients of state and federal public insurance, the US Public Health service has largely been unable to access representative data about their health to effectively identify and target their specific health needs. This public health informational gap is due to challenges in consistently identifying people with intellectual and developmental disabilities because of difficulties with self-identification of adults with intellectual and developmental disabilities, which results in misclassification. The questions designed to identify people with intellectual and developmental disabilities often overidentify people with age-related cognitive decline and underidentify people with intellectual and developmental disability (Fox et al., 2015; NCBDDD Health Surveillance Work Group, 2009). Currently, there is insufficient evidence regarding health service utilization for this population to design and target interventions to improve utilization patterns and health outcomes.

This study was designed to examine how people with intellectual and developmental disabilities utilize inpatient hospital and outpatient emergency department (ED) services across participating states in a manner that can be compared with utilization in the general population. It was critical to identify specific gaps in access to care and medical conditions that often go underrecognized and undertreated in people with intellectual and developmental disabilities. Evidence is presented regarding health service utilization patterns in one of the largest cross-state cohorts of adults with intellectual and developmental disabilities studied to date.

METHODS

Data sources

Data were collected from the Medicaid Management Information System (MMIS) within each of 4 states included in this analysis: Iowa, Massachusetts, New York, and South Carolina. These states were selected because of their participation in the Centers for Disease Control and Prevention Disability and Health State Program Cooperative Agreement and their data access and capacity in having professional staff with experience and expertise related to the use of the MMIS files. These states have diverse populations, although they do not represent the entire US population. Data extracted from the MMIS included the Medicaid recipient's enrollment status and claims for service utilization, including both fee-for-service claims and managed care encounters, along with associated *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) diagnosis codes (Centers for Disease Control and Prevention, 2011). All data access and related use were performed under data usage approvals obtained according to the procedures for each state MMIS system. When required, protection procedures for human subjects were reviewed and approved by institutional review boards. Only aggregate results were shared among states. SAS 9.4 (SAS Institute Inc, Cary, North Carolina) or Oracle SQL Developer (Oracle Corporation, Redwood Shores, California) was used to conduct analyses.

Identification of Medicaid members with intellectual and developmental disabilities

A cohort of adults aged 18 to 64 years with intellectual or developmental disabilities was identified from MMIS data in a screening period of 2008 to 2013. An upper-age cutoff was applied because of age-based eligibility for Medicare starting at 65 years, which affects the primary payer of medical service claims. Because the data collected within the MMIS can vary by state, state teams worked collaboratively to design coding and analytic methods that would ensure comparability across state cohorts. To identify people with intellectual or developmental disabilities, a standardized algorithm, designed by the team, was applied to the data from each state's MMIS to define the cohort (McDermott et al., 2018).

To identify adults with intellectual and developmental disability for the cohort, Medicaid claims from the screening period of 2008 to 2013 were reviewed to find people with code(s) related to an intellectual or developmental disability included in the algorithm. Adults needed to have 1 inpatient claim or at least 2 other service claims associated with the algorithm's list of diagnoses associated with intellectual and developmental disabilities to be included in the cohort. Adults with additional insurance coverage, such as commercial insurance or Medicare, were excluded since we would not know whether the Medicaid claims presented a full record of heath service utilization during the study period.

To address the use of multiple *ICD-9-CM* diagnostic codes within the intellectual and developmental disability subset for a single person across the time period, a hierarchy (Fox et al., 2015) was used to assign each adult to a single diagnostic subgroup beginning with the most specific diagnosis (eg, genetic causes) to the least specific diagnosis (unspecified intellectual disability). Eight mutually exclusive diagnostic subgroups were identified: Down syndrome/trisomy/autosomal deletions; other genetic conditions such as Lesch-Nyhan

syndrome, tuberous sclerosis, fragile X syndrome, and Prader-Willi syndrome; fetal alcohol syndrome; cerebral palsy; autism or pervasive developmental disorder; and intellectual disability (Fox et al., 2015).

Demographic variables

Demographic variables available from MMIS include the following: gender (male/female), age at first enrollment, insurance status, and average number of years enrolled in Medicaid during the 5-year study period (2008–2013). Because race and ethnicity are optional fields in MMIS, information obtained was incomplete across states and therefore excluded from this analysis.

Health service utilization

Calendar year 2012 was used to quantify health service utilization for the cohort identified in the screening period. Inpatient hospital admissions and outpatient ED visit encounters in 2012 were included in this utilization quantification analysis. The cohort was limited to include adults enrolled in Medicaid at least 11 months in 2012. To focus on acute care inpatient admissions, admissions to extended-stay independent psychiatric facilities and encounters with lengths of stay for more than 25 days were excluded. Emergency department visits resulting in discharge from the ED were considered outpatient ED visits; ED visits resulting in hospital admission from the ED were considered inpatient admissions.

The medical conditions associated with inpatient admission and outpatient ED utilization were categorized on the basis of primary *ICD-9-CM* diagnostic codes associated with the facility claim using the Clinical Classifications Software (CCS), a system of standardized, clinically meaningful categories to organize diagnoses and procedures in *ICD-9-CM*, as developed by the Agency for Healthcare Research and Quality's (AHRQ) Healthcare Cost and Utilization Project (HCUP) (Elixhauser et al., 2015). Diagnoses were organized into larger aggregations of clinically relevant groups using multilevel CCS hierarchical categories.

Benchmarks

Utilization patterns for adults with intellectual and developmental disabilities were benchmarked against the general population using discharge data from the 2012 HCUP National Inpatient Sample (NIS; HCUP, 2012) for inpatient admissions (excluding maternal stays), and the 2012 HCUP Nationwide Emergency Department Sample (NEDS; HCUP, 2012) for outpatient ED discharges. People with intellectual and developmental disabilities represent a small proportion of those included in the HCUP and NEDS data. The use of CCS hierarchical categories by both NIS and NEDS facilitated direct comparison of medical conditions associated with utilization.

Rates of utilization were constructed in the same manner as for the cohort using the number of utilization episodes for CSS category as the numerator, and the number of people surveilled for utilization through HCUP as the denominator, multiplied by 1000 to calculate a rate per 1000 people. Importantly, for this comparison, the HCUP denominator includes people in the population monitored for utilization, not just those with utilization. Relative

risks, because of their robust ability to estimate association regardless of the frequency of the outcome, were used to measure association between having an intellectual or developmental disability and the use of health services relative to the US general population. Relative risks were calculated as ratios of the utilization rate of the cohort (numerator) and the utilization rate of the general adult population (denominator) with 95% confidence intervals based on a Poisson distribution.

RESULTS

The cohort included 72 595 adults with intellectual and developmental disabilities who were eligible for Medicaid, without a second insurer, across the 4 states. The sample size from each state was as follows: Iowa: 4378, Massachusetts: 19 820, New York: 41 031, and South Carolina: 7366. Descriptive statistics of the cohort's demographic factors are included in Table 1. The cohort was skewed toward younger adults (aged 18–24 years) with almost half of the cohort in this age group, with decreasing percentages contained in each increasing age group. A majority of the cohort was male. As shown in Table 1, almost half of the cohort had diagnoses associated with health service claims that permitted assignment to one of the specific intellectual or developmental disability groups based on genetic conditions and syndromes; the remaining cohort members had more generic codes for intellectual disability without specification of its etiology and were assigned to the general intellectual disability category.

Hospital utilization

Table 2 displays the frequency of inpatient admissions and outpatient ED use for cohort members. There was a total of 20 964 inpatient admissions and 71 006 outpatient ED visits, which represented rates of 289 inpatient admissions per 1000 cohort members and 978 outpatient ED visits per 1000 members annually. The majority of cohort members (88%) did not have an inpatient admission during the year; 66% did not have an outpatient ED visit during the year. Most cohort members utilizing the ED with low frequency over the year also did not have inpatient admissions. In comparison with the general adult population, utilization was more than twice as high for adults with intellectual and developmental disabilities for both inpatient admissions (relative risk [RR] = 3.2) and outpatient ED visits (RR = 2.6). The percentage of adults with 1 or more outpatient ED visits (34%) is similar to the general adult population insured by Medicaid (37.7%) in 2011 (though this benchmark also includes ED visits resulting in inpatient admissions) (Centers for Disease Control and Prevention, 2012).

Medical conditions frequently associated with hospital service utilization

The most frequent medical conditions associated with hospital service use are shown in Tables 3 and 4. All 15 leading CCS diagnosis classifications for the cohort showed significantly ($P < .0001$) increased use over the general adult population. The most frequent conditions for inpatient admissions in the cohort were psychiatric conditions of psychotic disorders (25.87 per 1000), including schizophrenia, paranoid states, and other nonorganic and nonspecified psychoses, and mood disorders (19.9 per 1000), including bipolar and depressive disorders. These conditions showed substantially elevated utilization rates over

the general population (RR = 15 and 5.8, respectively). Inpatient utilization was also driven by conditions that may be associated or more frequently seen in people with intellectual and developmental disabilities, including epilepsy (RR = 25), paralysis (RR = 816), gastrointestinal disorders (RR = 6.2), and medical device management (RR = 2.3). Numerous infections also contributed to increased inpatient admissions for this cohort, led by septicemia (RR = 4.6), pneumonia (RR = 5.5), skin infections (RR = 3.6), urinary tract infections (RR = 6.6), and aspiration pneumonia (RR = 24.7). Utilization was also increased for diabetes mellitus with complications (RR = 3.9). In contrast with the top-ranking medical issues in the general population, adults with intellectual and developmental disabilities did not have utilization due to pregnancy among the top-ranking reasons for inpatient admission or ED utilization.

Similar diagnoses were observed in outpatient ED utilization, though the difference in relative use of service was not as dramatically increased as for inpatient admission. Psychiatric-related conditions represented the largest sources of increased outpatient ED utilization compared with the general population (mood disorders RR =13.7, psychotic disorders RR = 20.4). Emergency department utilization was also more largely driven by accidental injuries than was inpatient admission: superficial injuries and contusions (RR = 3.2), sprains and strains (RR = 1.5), and other injuries (RR = 3.9). Emergency department utilization related to open wounds to extremities or disorders of teeth and jaw did not make the top rankings of utilization for the cohort, despite being top-ranking diagnoses for the adult general population.

DISCUSSION

This multistate cohort of adult Medicaid members with intellectual and developmental disabilities demonstrated a 3-fold higher rate of utilization for inpatient admissions and a greater than 2-fold higher rate in outpatient ED use, compared with population benchmarks. Several of the conditions associated with this higher utilization suggest that the need for hospital care may be at least partially modifiable if appropriate community-based services can be provided. Markedly higher inpatient utilization for psychiatric conditions in adults with intellectual and developmental disabilities reinforces the need to assess the adequacy of outpatient mental health treatment options available for people with these disabilities. A substantial portion of health service utilization was also directed at conditions generally considered to be treatable in ambulatory care settings (ambulatory care sensitive conditions), such as urinary tract infections and many types of pneumonia. These diagnoses and the use of the ED for chronic conditions underscore the importance of community-based services and primary care–based health management strategies (Caminal et al., 2004) to recognize and initiate treatment for signs and symptoms of illness for ambulatory care sensitive conditions and chronic conditions such as epilepsy, diabetes, and gastrointestinal disorders, before they require inpatient admission or urgent treatment. As the health practitioners most likely to be consistently involved in the lives of adults with intellectual and developmental disabilities (Sullivan et al., 2011), primary care practitioners need to be skilled in caring for people with these disabilities in order to improve health outcomes and minimize overutilization of hospital services.

Potential limitations

This study demonstrates both the feasibility and the utility of the use of claims data to examine health service utilization patterns in a large, multistate patient sample. However, numerous potential limitations must be considered. First, insurance claims for medical services, the primary purpose of which is to facilitate payment for services rendered, may include artifacts such as selective use of certain diagnostic codes as primary reasons for service. However, these artifacts likely affect claims for both the IDD cohort and the general population, which should produce limited relative bias when comparing these groups. Second, variations in data collection and coding procedures across MMIS systems may affect the cross-state comparability of results. State teams collaboratively developed the methods and used sources with the highest level of cross-state comparability. Third, the study of a Medicaid-only population limits our ability to examine utilization for all adults with intellectual and developmental disabilities, particularly given that many of these adults may be dually eligible for Medicare and Medicaid. This restriction in our cohort selection was necessary because Medicaid may not be the primary payer for medical services in cases of dual eligibility. The restriction did result in a shift toward a younger adult population in our cohort as those who become eligible for Medicare through Childhood Disability Benefits or Social Security Disability Insurance and complete their 2-year waiting period would transition to Medicare beneficiaries and therefore be excluded. This limitation may be addressed in future work utilizing all-payor claims databases that permit review across payment sources. Fourth, the cohort excludes adults who did not receive any care during the case identification period of 2008 to 2013, or whose care never included a diagnostic code related to intellectual or developmental disabilities. The multiyear inclusion methods and use of claims over multiple providers and multiple types of services should ensure that this exclusion is not widespread. Finally, national benchmarks were as a comparison group for multiple reasons. Adults with intellectual and developmental disabilities strive to achieve typical adult health status and service use, so comparisons to national benchmarks are an informative comparison group. In addition, states in this study did not have access to the full set of Medicaid data for benchmarking of utilization. Finally, if Medicaid recipients were used as a comparison, the comparison population would need to be carefully constructed to omit special subgroups with lower relevance for comparability such as pregnant women or people residing in nursing facilities that are overrepresented in state Medicaid populations due to the program's design. However, because medical service claims were compared between 2 different data systems (MMIS and HCUP), there may be differences in the data; as the data sources are both claims data, we anticipate any effect to be minimal.

CONCLUSIONS

This study demonstrates an effective multistate health surveillance strategy using administrative medical claims data to inform the health needs of a population with intellectual and developmental disabilities. Although some higher rates of inpatient and ED utilization may be unavoidable for adults with intellectual and developmental disabilities due to nonpreventable conditions associated with the etiology of their disabilities, evidence collected to date suggests that a portion of health service utilization may be preventable through strategies such as better management of chronic conditions. Additional health

services research is needed to identify strategies for improved access to effective outpatient mental health services and to develop provider techniques to implement earlier care for ambulatory care-sensitive conditions (Lewis et al., 2002).

This study demonstrates an effective cross-state, cross-discipline collaboration to create new models to improve upon the public health evidence for people with intellectual and developmental disabilities. Further cross-discipline collaboration between public health, clinicians, and other disciplines is necessary to use evidence of this nature to identify and test strategies to improve the utilization of health services, the quality of health care received, and ultimately the long-term health of this important population.

Acknowledgments

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Table 1.

Descriptive Characteristics of Adults With Intellectual and Developmental Disabilities Insured by Medicaid in 2012 in 4 US States[a]

	n	Percentage of Sample
Age at enrollment, y		
18–24	33122	45.6
25–34	19037	26.2
35–44	8893	12.3
45–54	6917	9.5
55–64	4626	6.4
Gender		
Male	41787	57.6
Female	30808	42.4
Intellectual and developmental disabilities condition (using group hierarchy)		
Down syndrome/trisomy/autosomal deletions	5386	7.4
Other genetic causes	1737	2.4
Fetal alcohol syndrome	369	0.5
Cerebral palsy	13 533	18.6
Autism spectrum disorders	17 284	23.8
Intellectual disability (all levels)	34 286	47.2
Total	72 595	100

[a]The 4 states included are Iowa, Massachusetts, New York, and South Carolina.

Table 2.

Frequency of Inpatient Admissions and Outpatient Emergency Department Care Among Medicaid-Insured Adults With Intellectual and Developmental Disabilities in 2012

No. of Visits per Adult	Inpatient Admissions		Outpatient ED Visits		Total Inpatient and ED Visits	
	N	N %	N	N %	N	N %
0	64 010	88	48 257	66	45 656	63
1	4960	7	11 870	16	12 022	17
2	1644	2	4958	7	5376	7
3	1459	2	2578	4	2930	4
4	125	0.2	3620	5	1777	2
5	397	1	1312	2	4834	7
Total	72 595	100	72 595	100	72 595	100

Abbreviation: ED, emergency department.

Table 3.

Medical Conditions Most Frequently Associated With Inpatient Admissions in 2012 for Medicaid-Insured Adults With Intellectual and Developmental Disabilities

Rank for Cohort	CCS Code	CCS Description	Total Admissions	Rate per 1000	Relative Risk[a]	95% Confidence Interval
1	659	Schizophrenia and other psychotic disorders	1871	25.8	15.0	14.2-15.5
2	83	Epilepsy/convulsions	1497	20.6	25.1	23.5-26.1
3	82	Paralysis	1454	20.0	816.2	760.8-854.3
4	657	Mood disorders	1447	19.9	5.8	5.5-6.1
5	2	Septicemia (except in labor)	750	10.3	4.6	4.2-4.9
6	122	Pneumonia	669	9.2	5.5	5.1-5.9
7	50	Diabetes mellitus with complications	520	7.2	3.9	3.5-4.2
8	197	Skin and subcutaneous tissue infections	496	6.8	3.6	3.3-3.9
9	159	Urinary tract infection	408	5.6	6.6	5.9-7.1
10	102	Nonspecific chest pain	384	5.3	3.6	3.2-3.9
11	660	Alcohol-related disorders	362	5.0	4.1	3.6-4.5
12	129	Aspiration pneumonitis	351	4.8	24.7	21.9-27.1
13	55	Fluid and electrolyte disorders	330	4.5	5.9	5.2-6.5
14	237	Implant/graft complication	280	3.9	2.3	2.0-2.6
15	155	Other gastrointestinal disorders	222	3.1	6.2	5.3-6.9

Abbreviation: CCS, Clinical Classifications Software.

[a] All 15 diagnoses in Medicaid claims were associated with significantly higher relative risk of inpatient admission ($P < .0001$) in the cohort of adults with intellectual and developmental disabilities than in the benchmark population of US adults (HCUP-NIS; HCUP, 2012).

Table 4.

Medical Conditions Most Frequently Associated With Outpatient Emergency Department Care in 2012 for Medicaid-Insured Adults With Intellectual and Developmental Disabilities

Rank for Cohort	CCS Code	CCS Description	Total ED Visits	Rate per 1000	Relative Risk[a]	95% Confidence Interval
1	239	Superficial injury/contusion	3840	52.9	3.2	3.1–3.3
2	83	Epilepsy/convulsions	3597	49.5	16.2	15.4–16.5
3	251	Abdominal pain	3534	48.7	2.2	2.1–2.3
4	657	Mood disorders	3389	46.7	13.7	13.0–13.9
5	232	Sprain/strain	2549	35.1	1.5	1.4–1.5
6	659	Schizophrenia and other psychotic disorders	2451	33.8	20.4	19.3–20.9
7	244	Other injury/condition	2288	31.5	3.9	3.7–4.0
8	102	Nonspecific chest pain	2196	30.3	1.9	1.8–1.9
9	126	Other upper respiratory tract infection	2022	27.9	2.3	2.1–2.3
10	197	Skin and subcutaneous tissue infections	1750	24.1	2.2	2.0–2.2
11	205	Spondylosis, intervertebral disc disorders, other back problems	1594	22.0	1.4	1.3–1.4
12	84	Headache, including migraine	1572	21.7	1.7	1.5–1.7
13	159	Urinary tract infections	1558	21.5	2.2	2.1–2.3
14	211	Other connective tissue disease	1448	19.9	2.5	2.3–2.6
15	133	Other lower respiratory infections	1429	19.7	3.1	2.9–3.2

Abbreviations: CCS, Clinical Classifications Software; ED, emergency department.

[a] All diagnoses in Medicaid claims were associated with significantly higher relative risk of ED care ($P < .0001$) in the cohort of adults with intellectual and developmental disabilities than in the benchmark population of US adults (HCUP-NEDS; HCUP, 2012).