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Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability

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Abstract

Introduction—Ambulatory care sensitive conditions (ACSCs) can be seen as failure of access or management in primary care settings. Identifying factors associated with ACSCs for individuals with an Intellectual Disability (ID) provide insight into potential interventions.

Method—To assess the association between emergency department (ED) ACSC visits and a number of demographic and health characteristics of South Carolina Medicaid members with ID. A retrospective cohort of adults with ID was followed from 2001 to 2011. Using ICD-9-CM codes, four ID subgroups, totalling 14 650 members, were studied.

Results—There were 106 919 ED visits, with 21 214 visits (19.8%) classified as ACSC. Of those, 82.9% were treated and released from EDs with costs averaging $578 per visit. People with mild and unspecified ID averaged greater than one ED visit per member year. Those with Down syndrome and other genetic cause ID had the lowest rates of ED visits but the highest percentage of ACSC ED visits that resulted in inpatient hospitalisation (26.6% vs. an average of 16.8% for other subgroups). When compared with other residential types, those residing at home with no health support services had the highest ED visit rate and were most likely to be discharged back to the community following an ED visit (85.2%). Adults residing in a nursing home had lower rates of ED visits but were most likely to be admitted to the hospital (38.9%) following an ED visit. Epilepsy and convulsions were the leading cause (29.6%) of ACSC ED visits across all subgroups and residential settings.

Conclusion—Prevention of ACSC ED visits may be possible by targeting adults with ID who live at home without health support services.

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Keywords

ambulatory care sensitive conditions; emergency department visits; hospitalisations; ID

Introduction

In the USA, approximately 1.2 million adults (0.5% of people aged 18 years or older) are estimated to have an ID (Brault 2010; Maulik *et al.* 2011). Many children and most adults with ID receive their healthcare coverage through Medicaid (Ervin & Merrick 2014). Compared with the general population, people with ID have poorer health, higher mortality rates and lower quality of healthcare (Perry *et al.* 2014; Slowie & Martin 2014). The health differences experienced by people with ID are, in part, attributed to inadequate primary care (Lennox & Kerr 1997; Balogh *et al.* 2013; Lennox *et al.* 2015). Moreover, people with ID have difficulty accessing care and finding providers who are knowledgeable about health issues that might be exacerbated by their underlying condition (Robertson *et al.* 2014; Lennox *et al.* 2015).

Ambulatory care sensitive conditions (ACSCs) are health problems that should be managed through a combination of outpatient treatment and self-care and, therefore, in many instances, should not require an emergency department (ED) visit or inpatient hospitalisation (Oster & Bindman 2003). Policy makers and researchers have used ACSC hospitalisations and ED visits as indicators of access to – and quality of – primary care (Oster & Bindman 2003; Ansari *et al.* 2006; Agency for Healthcare Research and Quality 2007; Johnson *et al.* 2012; Brownell *et al.* 2014; Bergamo *et al.* 2016).

Previous research has focused on rates of hospitalisation or ED visits for ACSC among the general population, the aged, persons receiving their healthcare coverage from Medicaid and members of racial and ethnic minority groups (Silver *et al.* 1997; Shi *et al.* 1999; Kozak *et al.* 2001; Laditka *et al.* 2003; Oster & Bindman 2003; Caminal *et al.* 2004; Laditka *et al.* 2005; Ansari *et al.* 2006; Agency for Healthcare Research and Quality 2007; Johnson *et al.* 2012; Brownell *et al.* 2014; Bergamo *et al.* 2016; Conway *et al.* 2016). Only recently has the ACSC treatment experience of people with ID been studied. A population-based study in the Canadian province of Manitoba reported that persons with ID had a higher rate of ACSC hospitalisations than people without ID, suggesting opportunities to improve access to – or the quality of – primary care (Balogh *et al.* 2010). Factors associated with ACSC hospitalisations among individuals with ID included demographic and socioeconomic characteristics, the presence of comorbid conditions and having visited a primary care physician in the last year (Balogh *et al.* 2011).

While the work of Balogh and colleagues (Balogh *et al.* 2010; Balogh *et al.* 2011) was instrumental in assessing the association between people with ID and factors associated with ACSC hospitalisation, some key variables that are relevant to the ID population, such as residential service setting, were not assessed. People with ID may qualify for residential services administered by state disability agencies, and it has been suggested that residential service setting might be an important factor to consider in assessing the health of people with ID (Braddock *et al.* 2008; Larson *et al.* 2014). In 2012, an estimated 635 000 (56%)

Americans with ID lived with family members; 207 000 (18%) resided in group homes; 123 000 (11%) lived in supervised community settings; 85 000 (8%) resided in intermediate care facilities (ICFs); 59 000 (5%) lived in host/foster homes; and 28 000 (2%) resided in nursing homes (Rizzolo *et al*. 2013; Larson *et al*. 2014).

This study builds on the work by Balogh and colleagues by exploring factors associated with ACSC ED visits among Medicaid members resulting in either inpatient admission or ED discharge. In addition to residential setting, we included ID subgroup (e.g. mild ID), as well as demographics and health characteristics of South Carolina (SC) Medicaid members with ID. While previous studies have analysed the association between ACSC ED visits and Medicaid health insurance coverage, the findings were not assessed for Medicaid members with ID (Oster & Bindman 2003; Gingold *et al*. 2016). A substantial proportion of adults with ID, who are insured by Medicaid, live at home and receive community-based health services and some disability support services from a state authorised disability service provider. Knowing whether ACSC ED visits vary by ID subgroup and residential setting might help in the design of testable interventions to improve access to – or quality of – primary care. The hypotheses for this study were ACSC ED visits among adults with ID: (1) would vary by residential setting and (2) would vary by ID category. We did not have *a priori* hypotheses about the specific patterns of ED visits across categories of ID and residential type, but we did anticipate that ED visit rates would generally be higher for those with less severe disability and for those in less restrictive/less supportive residential settings.

Methods

Data sources

Data housed at the South Carolina Revenue and Fiscal Affairs Office, Health and Demographic Section (H&D) and utilised for this project originated from Medicaid, an all-payer hospital discharge dataset (HDD), the Department of Disabilities and Special Needs and the Department of Social Services. Data use agreements were obtained from participating organisations. The analyses were performed at the H&D, and non-H&D investigators received aggregated estimates for review. Procedures for the protection of human subjects were reviewed and approved by the University of South Carolina institutional review board.

Medicaid is public health insurance that is jointly funded by federal and state governments and provides healthcare coverage to low-income individuals and those with disabilities including many children and most adults with ID (Ervin & Merrick 2014). Data from South Carolina Medicaid claims were searched for ICD-9-CM codes to identify members with ID for the period 2001–2011. Once the ID cohort was identified, additional databases housed at H&D were used to identify covariates and service utilisation. Variables of interest included age, race, sex, rurality of county, residential service setting, years of enrollment, supplemental nutrition assistance, primary care visits, ED visits and subsequent inpatient hospital admission, as well as timing of services.

Case definitions for intellectual disability

We searched the South Carolina Medicaid fee-for-service and HMO claims for ICD-9-CM codes related to ID over the study period. Medicaid members who had one inpatient encounter or two other service encounters (excluding pharmacy claims) with an ID diagnosis code were identified as having an ID. The ICD-9-CM codes used were based on the disability-related condition algorithms available from the chronic conditions data warehouse of the Centers for Medicaid and Medicare Services (Centers for Medicaid and Medicare Services 2013). Members with ID and carrying a diagnosis of cerebral palsy, spina bifida or paralysis due to spinal cord injury or stroke were excluded because these comorbid conditions could have implications for care and could be potential confounders or effect modifiers, impacting both the residential status and the occurrence of ACSCs.

For this analysis, we focused on four subgroups of ID: (1) known genetic cause including Down syndrome; (2) mild; (3) moderate, severe and profound; and (4) unspecified. ID subgroups and corresponding ICD-9-CM codes are shown in Table 1. Adults with ID often receive multiple diagnosis codes from providers; therefore, we developed a hierarchy to assign each individual to a single subgroup. We always selected a more specific code over a general code. Therefore, we started with individuals who had a known genetic cause of ID regardless of the presence of any other codes. We then considered the following subgroups and possible combinations: mild, moderate to profound and unspecified. If a cohort member had a code for mild and unspecified IDs, we assigned him/her to the mild ID group; and if a member had a code for moderate to profound and unspecified ID, we assigned him or her to the moderate to profound ID group. If coded with both mild and moderate to profound IDs, we accepted the code noted on a medical specialty claim (neurology, genetics or psychiatry) over a code from a primary care claim. When there was no difference by provider type, we accepted the code used most often. This method of assigning categories of ID has been described elsewhere (McDermott *et al.* 2017).

Outcome measures were compiled for each year during the study period when cohort members were 22–64 years of age and enrolled at least 11 out of 12 months. All calendar years where member did not meet age and eligibility requirements were excluded.

Ambulatory care case-sensitive condition counts and costs

Once the ID cohort was established, we used an Agency for Health Care Research and Quality (AHRQ) Prevention Quality Indicators data tool to identify ED visits for ACSCs based on ICD-9 diagnosis codes (Agency for Healthcare Research and Quality 2015a). The AHRQ ACSC data tool was applied against an all-payer HDD that included ED visits from all acute-care, civilian hospitals within South Carolina. The data tool required the following elements: diagnosis and procedure fields, admission source and disposition status. ED visits could result in either an inpatient hospitalisation or a member could be treated and discharged from the ED. Visit charges were converted to costs by using the AHRQ Healthcare Cost and Utilisation Project inpatient cost-to-charge ratios (Agency for Healthcare Research and Quality 2013; Agency for Healthcare Research and Quality 2015b) and adjusted for inflation by using the 2010 Personal Health Care and Component Price Indices (D'Hoore *et al.* 1996).

Covariates

Information on residential setting was compiled from Medicaid claims and the Department of Special Needs and divided into the following groups: (1) community settings, including supervised apartment living, assisted living facilities, boarding homes, group homes and community residential care facilities, and (2) nursing home facilities, ICFs for individuals with ID and rehabilitation facilities. ICF for individuals with ID is a Medicaid benefit that provides active treatment inclusive of residential and day services. This is an expensive and highly intensive service available to people with ID, with around-the-clock nurse supervision. If neither of the above residential service setting was identified, residential setting was designated as residing at 'home'. Home was further divided into two categories based on current procedural terminology codes in the Medicaid claims file: (1) members receiving nursing services, adult day services with a health component or personal care services that included medication monitoring (home with health support) and (2) members not receiving such services (home without health support).

Comorbid conditions were identified by using the Charlson comorbidity index, a set of conditions associated with elevated mortality risk and defined by ICD-9-CM codes from claims data (Washington State Rural Health Research Center 2005). We created a dichotomous variable for having at least one comorbidity condition.

Primary care visits were estimated from the Medicaid claims data. A visit was considered primary care if (1) an office, other outpatient clinic or nursing home evaluation and management current procedural terminology code was noted on the encounter claim and (2) the rendering physician specialty was recorded as family practice, general practice, general internal medicine or paediatrician or the service was provided by nurse practitioner. The specific physician specialties were chosen because they are classified as primary care specialties by the American Association of Medical Colleges (Association of American Medical Colleges 2014). The specialists that were excluded are classified as internal medicine subspecialists, such as cardiology, pulmonology, gastroenterology and others. Thus, the internal medicine group classified as primary care providers are general internists, who do typically function as primary care providers in the USA. In addition, all-inclusive visits occurring in federally qualified health departments or rural health centres were counted as primary care visits.

To investigate the potentially preventive effects of primary care, we used an indicator variable to denote if at least one primary care visit occurred in the year prior to the first ACSC visit of each year. We also included other potential confounders of sex, race, age, receipt of Supplemental Nutrition Assistance Program (SNAP) and county type. Sex (male and female), race (white and other), SNAP participation (yes and no) and county type (urban and rural) were dichotomous variables, whereas age was a continuous variable. Eligibility for SNAP requires proof of household or individual income below the federal poverty level. The county type was determined by using the rural urban community area codes (Washington State Rural Health Research Center 2005). Covariate values for the time-varying variables such as residence, age, comorbid conditions and primary care receipt were defined for each calendar year a cohort member was included in the analysis.

Descriptive analyses

In addition to presenting demographic profiles by ID subgroup, we estimated expenditures associated with ACSC visits for the period of 2001–2011 from the all-payer HDD. We calculated the number and percentage of ED visits for those with ID that were due to ACSCs and their associated average and total costs. We stratified by ID subgroup, ACSC disposition (treated in the ED and admitted to the hospital as an inpatient or treated and discharged from the ED) and residential service setting and adjusted for each cohort member's total number of years enrolled.

Statistical approach

Inference on generalised estimating equation (GEE) models assessed whether differences were significant in the number of ACSC services utilised among patients by ID condition group and residential service setting. The referent group consisted of those with mild ID and those living at home with no health management services. Each GEE model was estimated by using the GENMOD procedure in SAS 9.4 (SAS Version 9.4 n.d.) and specified a negative binomial distribution variance with the log link function. This approach is a generalisation of the Poisson regression model that is suitable for overdispersed (relative to the Poisson) count data. Incidence rate ratios were estimated as exponentiated regression coefficient estimates. To account for within-group correlation of repeated observations from the same person, GEE models with repeated statement were estimated to explicitly account for nonindependence. A false discovery rate procedure adjusted for simultaneous tests on multiple factors and adjusted *p*-values are shown (Holm 1979).

This study was funded by the Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities, in partnership with the Association of University Centers on Disability.

Results

For the study period 2001–2011, we identified 14 650 individuals with ID enrolled for at least one calendar year and were between 22 and 64 years of age. The largest subgroup of ID consisted of members with moderate-to-profound ID (37.8%), followed by mild ID (33.8%), unspecified ID (16.4%) and Down syndrome/other genetic causes (11.9%). The descriptive characteristics of South Carolina Medicaid members with ID are shown in Table 2. Unless noted, characteristics are based on a member's first enrolment year during the study period. The majority of members with ID were 22–34 years of age, and this was consistent across ID condition groups. Fifty-one per cent of those with ID were male. Overall, 51.1% of individuals with ID were African American and 43.8% were Caucasian. The racial makeup was similar across ID condition groups with the exception of those with Down syndrome/other genetic causes where 32.6% identified as African American and 62.8% as Caucasian.

The average length of time enrolled in Medicaid when a member was 22–64 years of age during the 11-year study period was 7.3 years for ID overall; it was lowest for those with mild ID (6.6 years) and highest for those with moderate-to-profound ID (7.9 years). SNAP benefits were provided to 49.8% of those with ID and a majority (69.0%) lived in urban

areas. At least one comorbid condition was present in 38.0% of those with ID and ranged from 32.3% for those with mild ID to 47.4% for those with unspecified ID. The most common comorbidity indicated for those with mild and unspecified IDs was a mental health condition. A majority of those with ID (80.7%) had at least one primary care visit during the study period. By ID subgroup, having had at least one primary care visit during study period ranged from 79.0% for those with moderate-to-profound ID to 86.7% among those with Down syndrome/other genetic causes. Overall, 49.5% of those with ID lived at home with health services, 8.3% lived in the community in a group home or other supervised living arrangement, and 7.3% lived in a nursing home, ICF or other institutional setting. We presumed home without health services for the remaining 35.0%.

A total of 107 032 years were studied (an average of 7.3 years per person). Over the 11-year period, there were 106 919 ED visits, and 21 214 (19.8%) of those were determined to be for ACSCs; see Table 3. For most ED ACSC visits (82.9%), members were treated in the ED and discharged. The average length of stay for the 3630 ACSC visits with subsequent inpatient admission was 4.9 days. The average costs of an ED ACSC visit with an inpatient hospital admission were $7474 and $578 if treated and discharged. Those with mild and unspecified IDs had the highest unadjusted overall ED and ED due to ACSC rate per member (on average over one ED visit per member per year and one ACSC ED visit every 4 years), while those with Down syndrome and other genetic cause group had the lowest ACSC rate per member. However, this subgroup had the highest percentage of visits requiring an inpatient stay. The home with no service monitoring of a member’s health had the highest overall ED and ACSC ED use rates. Nursing and group home members had the highest percentage of visits requiring an inpatient stay. Costs were highest for the Down syndrome and other genetic cause members and for those living in a nursing home or ICF.

The leading causes of ACSC visits are shown in Table 4. All ID subgroups and residential settings had a similar constellation of conditions accounting for the majority of ACSC ED visits. Notably, epilepsy was the leading cause of ACSC ED visits overall and across all ID subgroups and residential settings.

Adjusted incidence rate ratios for ACSC ED treated and discharged and ED visits requiring an inpatient hospitalisation are shown in Table 5. The ACSC ED treated and released discharge rates for the Down syndrome and moderate-to-profound ID condition groups were lower than those with mild ID subgroup rates (by 26.1% and 14.9%, respectively). No statistically significant difference was noted for the unspecified and mild ID subgroup comparison. Compared with home without nursing or adult day services with a health component, all three residential service settings had lower ACSC ED treated and released rates (range 16.1% to 31.5%). Those with Down syndrome had a 30.6% higher rate of ACSC ED treated and admitted to hospital in comparison with those with mild ID. There was no difference for treated and admitted to hospital noted among moderate-to-profound and unspecified IDs compared with mild. Compared with home without nursing or adult day services, those living in a group home and home with health service setting had lower ACSC treated and hospital admission rates (21.2% and 15.3% less respectively), whereas those living in a nursing home had 38.1% higher ACSC treated and hospital admission rates.

Considering all variables in the models, women had 13.2% higher ACSC ED treated and discharged rates than men, and adults who were Caucasian experienced 10.5% lower rates than African American and other races. Those who were enrolled in the SNAP had 73.4% higher ACSC ED treated and discharged rates than those not receiving food stamps. Sex, race and nutrition assistance were not significant predictors of treated and subsequent hospitalisation rates. The presence of comorbidities greatly influenced both outcome measures. Having a primary care visit in the preceding year was associated with being more likely to have ACSC ED (treated and discharged or treated and admitted to the hospital) than not having a primary care visit −19.1% and 13.6%, respectively. Urban residence was associated with a 20% lower ACSC ED treated and admitted to hospital rate compared with those living in rural areas.

Discussion

This study assessed ACSC ED visits resulting in an inpatient hospitalisation or ED discharge and associated expenditures among people with ID controlling for ID subgroup, residential setting and other factors specific to SC Medicaid members. Adults with ID who lived at home or in unsupervised community settings without agency provided home support had higher rates of ACSC ED visits that resulted in discharge back to the community compared with adults with ID who live in group homes or other supervised environments or who live at home with health support services. Alternatively, ED utilisation that resulted in hospital admissions was highest in those living in nursing homes or other highly managed environments. Also, our findings revealed that adults with ID classified as mild and unspecified had higher rates of ACSC ED visits compared with adults with ID who have known genetic conditions or moderate or severe ID classifications. We found that Medicaid members with ID between 2001 and 2011 experienced over 21 000 potentially avoidable visits to the ED with costs exceeding $35 million. The findings show that ACSC ED visits, rates of discharge, inpatient hospitalisation and costs vary by ID subgroup and residential setting. It is noteworthy that the rank order of the ACSC diagnoses was similar across ID subgroup and residential setting, and these conditions represent opportunities to improve access to – or quality of – ambulatory care.

According to the National Hospital Ambulatory Medical Survey (CDC National Center for Health Statistics 2011), there were 44.5 ED visits per 100 people in 2011 and percentage of visits resulting in a hospital admission was 11.9%. In comparison, the average, unadjusted ED visit rate in 2011 for SC Medicaid members with ID was 110.5 visits per 100 people. The percentage of ED visits among SC Medicaid members with ID resulting in a hospital admission was 12.2%. Although members with Down syndrome and other genetic causes of ID and those with moderate-to-profound ID ED visit rates were high (66.6 and 77.5 per 100 members, respectively) in comparison with the national average, members with mild and unspecified IDs experienced an ED visit rate three times as great as the national average (145.2 and 152.6 per 100 members, respectively).

We are aware of only two recent studies examining all-cause ED visits, for a wide range of reasons, in adults with ID due to any cause (Venkat *et al.* 2011; McDermott *et al.* 2015). Neither of these studies focused on ED visits associated with ACSC. Each study focused on

a cohort of individuals with ID, one included a group with Fragile X syndrome and a comparison group with other types of ID. While neither study considered residential setting, they did demonstrate that adults with ID had a higher rate of ED utilisation than adults in the general population, and those with significant comorbidities had higher rates of utilisation than those who did not. In a previous study, women with ID were found to have better rates of adherence with breast and cervical cancer screening if they lived in more managed settings (Xu *et al.* 2017).

We surmise that the reason people with mild and unspecified IDs and those who live in home settings without support had higher rates of ACSC visits to the ED is likely related to the fact that these individuals have less supervision by staff and the recognition of developing symptoms might be delayed, until the condition becomes more urgent. In fact, adults with mild ID might not qualify for either residential or other support services and have to rely on themselves, family or friends to identify signs and symptoms that would require a primary care appointment. In addition, it is possible that adults with mild and unspecified IDs might not have an established relationship with a primary care provider, in part because they have challenges with scheduling, communication, transportation and other aspects of coordinating their own healthcare.

Among those living in nursing homes and other settings where resident health is monitored and care provided, higher rates of ACSC hospital admission following an ED visit might be attributed to a greater prevalence and severity of comorbidity. Subsequent studies should explore this potential reason for the variation in rates of ACSC ED visits and subsequent hospitalisations across residential setting for adults with ID.

We found that having at least one primary care visit was associated with slightly but significantly increased rates of ED visits. This is counter-intuitive, as it is widely believed that improved access to primary care services can reduce rates of unnecessary ED use(Mann 2014), including visits due to an ACSC (NH Department of Health & Human Services 2005). We believe that the most likely explanation for the higher rate of ED visits due to ACSC among those who had a primary care visit is that there are underlying factors such as presence and severity of chronic diseases, and potentially individual or family attitudes related to seeking healthcare in general, that are associated with the propensity to seek both outpatient care and ED care. Additional research is needed to investigate this possibility.

Previous studies have used the Andersen Behavioural Model of Health Service Utilisation (Balogh *et al.* 2010; Balogh *et al.* 2011) to investigate risk factors for ACSC hospitalisation for individuals with ID, including age, race, sex, poverty status and the health status of individuals. This study contributes to the literature by including residential setting as a control variable in the model. Our finding that individuals with ID who live at home without health support services were more likely to have an ACSC ED visit and be discharged to the community compared with those living in a nursing home, ICF, other institutions or home with health support services is intriguing and may present an opportunity for intervention. Indeed, cost savings might be realised if this vulnerable population residing at home could be referred to disability accessible patient-centred medical homes that provide continuous and coordinated care (Machlin & Carper 2007; Agency for Healthcare Research and Quality

2012). The group of adults with ID who live at home, without home-based health supports, might be more likely to respond to preventive interventions, compared with the more medically challenged groups who reside in nursing home, ICF or other institutions.

This study has several limitations. First, we relied on diagnosis codes so the data likely included some errors and some lack of precision. For example, a provider may not have access to intelligence testing results for a person with borderline intellectual function and erroneously diagnose him or her with ID. Alternatively a nonspecific code for ID may be used when in fact an individual has an identifiable ID syndrome but has not been worked-up. Second, we did not use variables that described the specific services and support that each individual received in their community residential living environment. Therefore, we cannot make any determinations about why rates of ED visits for ACSC varied across residential setting. Third, it is possible that some individuals diagnosed with an ACSC in the ED setting actually had an underlying condition that would not have been amenable to outpatient care. For example, an individual could present with epilepsy but ultimately be diagnosed with a brain tumour causing intractable seizures. Even the most carefully developed system for providing high-quality primary care might not be capable of preventing all ACSC visits. Fourth, we did not consider how common ACSCs were in the IDD population in comparison with the general population. Fifth, the focus on ACSC ED visits presents an incomplete picture of the quality of care related to ACSC. Combining non-ED admission inpatient data with ED data presents a more complete picture (Agency for Healthcare Research and Quality 2007). This was beyond the scope of this analysis but would be an important contribution of future work. Sixth, our analyses present findings for South Carolina and might not be generalisable to other states and territories. Expanding this work to other states is a direction for future work.

Because ED visits are expensive compared with ambulatory care treatment, pinpointing why people with ID have difficulty accessing and/or receiving quality primary care is important if economic efficiencies are to be realised. In the meantime, care providers that support people with ID who live at home without support services might consider recommending them to disability accessible patient-centred medical homes that provide continuous and coordinated care.

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Table 1

ICD-9-CM codes, diagnosis descriptions and subgroupings used to identify adults with an ID

Diagnosis description	ICD-9-CM diagnosis codes	Subgroup
Down syndrome	758	Down syndrome and other genetic causes
Chromosomal anomalies and autosomal deletion syndromes	758.1, 758.2, 758.31, 758.32, 758.33 and 758.39	Down syndrome and other genetic causes
Fragile X syndrome	759.83	Down syndrome and other genetic causes
Tuberous sclerosis	759.5	Down syndrome and other genetic causes
Prader–Willi syndrome	759.81	Down syndrome and other genetic causes
Moderate-to-profound ID	318.0, 318.1 and 318.2	Moderate to profound
Mild ID	317	Mild
Unspecified ID	319	Unspecified

Table 2

Adults with ID identified from the South Carolina Medicaid data aged 22–64 years, 2001–2011

	All conditions		Down syndrome and other genetic causes		Mild ID		Moderate-to-profound ID		Unspecified ID	
Total	14 650	100.0%	1 746	11.9%	4 955	33.8%	5 542	37.8%	2 407	16.4%
Age group										
22–34 years	7 781	53.1%	1 003	57.4%	3 105	62.7%	2 722	49.1%	951	39.5%
35–44 years	2 964	20.2%	341	19.5%	903	18.2%	1 171	21.1%	549	22.8%
45–54 years	2 511	17.1%	278	15.9%	621	12.5%	1 068	19.3%	544	22.6%
55–64 years	1 394	9.5%	124	7.1%	326	6.6%	581	10.5%	363	15.1%
Sex										
Male	7 478	51.0%	859	49.2%	2 389	48.2%	2 979	53.8%	1 251	52.0%
Female	7 172	49.0%	887	50.8%	2 566	51.8%	2 563	46.2%	1 156	48.0%
Race										
Caucasian	6 422	43.8%	1 096	62.8%	1 978	39.9%	2 309	41.7%	1 039	43.2%
African American	7 484	51.1%	569	32.6%	2 717	54.8%	2 955	53.3%	1 243	51.6%
Other race/missing	744	5.1%	81	4.6%	260	5.2%	278	5.0%	125	5.2%
Avg length of time Medicaid (SD) in years	7.3 ± 3.7		7.3 ± 3.6		6.6 ± 3.8		7.9 ± 3.6		7.3 ± 3.6	
Supplemental nutrition assistance										
Yes	7 291	49.8%	587	33.6%	3 202	64.6%	2 177	39.3%	1 325	55.0%
No	7 359	50.2%	1 159	66.4%	1 753	35.4%	3 365	60.7%	1 082	45.0%
Resident county type										
Rural	4 538	31.0%	484	27.7%	1 525	30.8%	1 770	31.9%	759	31.5%
Urban	10 112	69.0%	1 262	72.3%	3 430	69.2%	3 772	68.1%	1 648	68.5%
Residence										
NH, ICF, hospital of other state facility	1 063	7.3%	170	9.7%	84	1.7%	639	11.5%	170	7.1%
Group home/supervised living	1 209	8.3%	114	6.5%	389	7.9%	552	10.0%	154	6.4%
Home with health service support	7 254	49.5%	854	48.9%	2 368	47.8%	3 245	58.6%	787	32.7%
Home with no health service support	5 124	35.0%	608	34.8%	2 114	42.7%	1 106	20.0%	1 296	53.8%
Comorbidities (Charlson index)										
Present during study period	5 573	38.0%	597	34.2%	2 045	41.3%	1 790	32.3%	1 141	47.4%
Primary care										

	All conditions		Down syndrome and other genetic causes		Mild ID		Moderate-to-profound ID		Unspecified ID	
Had primary care visit during study period[†]	11 822	80.7%	1 514	86.7%	3 986	80.4%	4 378	79.0%	1 944	80.8%

[†]We do not know why 20% of individuals have no primary care visit. Several possible explanations for why we might not be identifying a primary care visit for these individuals include the following: They receive their primary care from the emergency department (ED), they saw a specialist for care, primary care is provided at their residence (e.g. intermediate care facility, ICF), they had a primary care visit without an evaluation and management code, or they might not be seeking care.

Table 3

Number, rate and associated costs* of ACSC ED visits resulting in an inpatient admission or ED discharge for South Carolina Medicaid members with ID aged 22–64 years, 2001–2011

		# ED visits			# ED visits due to ACSC					Calculated variables						
Study year	# members enrolled	Total	Admitted	Discharged	Total	Admitted	Discharged	Admitted cost	Discharged cost	ED rate/ member	ACSC rate/ member	% ACSC admitted	ACSC admitted cost*/ member	ACSC admitted cost*/visit	ACSC discharged cost*/ member	ACSC discharged cost*/visit
Total	107 032	106 919	16 176	90 743	21 214	3 630	17 584	27 174 005	10 389 829	0.9989	0.1982	17.1	254	7486	97	591
2001	8 889	7 643	1 445	6 198	1 563	350	1 213	2 163 276	516 406	0.8598	0.1758	22.4	243	6181	58	426
2002	9 103	7 976	1 370	6 606	1 575	279	1 296	2 048 769	594 720	0.8762	0.1730	17.7	225	7343	65	459
2003	9 273	8 435	1 494	6 941	1 682	303	1 379	2 519 301	711 467	0.9096	0.1814	18.0	272	8315	77	516
2004	9 470	8 759	1 488	7 271	1 609	302	1 307	2 153 321	745 337	0.9249	0.1699	18.8	227	7130	79	570
2005	9 586	9 225	1 542	7 683	1 829	336	1 493	2 469 544	817 813	0.9623	0.1908	18.4	258	7350	85	548
2006	9 671	9 639	1 461	8 178	1 916	315	1 601	2 212 252	903 037	0.9967	0.1981	16.4	229	7023	93	564
2007	9 763	10 295	1 446	8 849	2 074	334	1 740	2 201 920	1 053 581	1.0545	0.2124	16.1	226	6593	108	606
2008	9 906	10 352	1 467	8 885	2 083	324	1 759	2 633 370	1 172 787	1.0450	0.2103	15.6	266	8128	118	667
2009	10 175	11 152	1 512	9 640	2 273	375	1 898	3 302 519	1 302 938	1.0960	0.2234	16.5	325	8807	128	686
2010	10 430	11 544	1 496	10 048	2 168	341	1 827	2 533 497	1 197 448	1.1068	0.2079	15.7	243	7430	115	655
2011	10 766	11 899	1 455	10 444	2 442	371	2 071	2 936 237	1 374 295	1.1052	0.2268	15.2	273	7914	128	664
Average	9 730	9 720	1 471	8 249	1 929	330	1 599	2 470 364	944 530	0.9943	0.1973	17.3	253	7474	96	578

		# ED visits			# ED visits due to ACSC					Calculated variables						
11-year averages by ID subgroup and residence	# members enrolled	All visits	Admitted	Discharged	All visits	Admitted	Discharged	Admitted cost	Discharged cost	ED rate/member	ACSC rate/member	% ACSC admitted	ACSC admitted cost/member	ACSC admitted cost/visit	ACSC discharged cost/member	ACSC discharged cost/visit
Down syndrome and other genetic	1 165	703	137	566	163	43	119	385 543	81 613	0.5992	0.1386	26.6	328	8 911	69	659
Mild ID	2 989	4 192	606	3 586	769	119	650	854 028	362 199	1.3931	0.2552	15.9	286	7 174	119	549
Moderate-to-profound ID	3 980	2 678	390	2 288	567	92	475	716 411	288 387	0.6716	0.1421	16.3	180	7 756	72	596
Unspecified ID	1 596	2 147	338	1 809	431	76	354	514 382	212 332	1.3471	0.2701	18.0	322	6 809	134	587
Nursing home, ICF/ID, hospital	757	414	135	279	93	37	56	353 992	48 802	0.5607	0.1271	38.9	479	9 634	69	855
Group home and community supervised living	1 289	977	210	767	197	45	153	338 171	107 514	0.7616	0.1544	22.7	264	7 770	81	680
Home with health services	4 494	4 517	689	3 828	849	139	711	1 031 255	406 198	1.0143	0.1907	16.3	233	7 505	93	573
Home with no health services	3 190	3 811	436	3 376	789	110	679	746 945	382 016	1.1711	0.2416	14.8	238	6 760	114	546

ACSC, ambulatory care sensitive condition; ED, emergency department; ICF, intermediate care facility.

Table 4

ACSC visit diagnoses by frequency for Medicaid members with ID aged 22–64 years, 2001–2011 (total visits = 21,214).

ACSC type	ICD-9-CM codes and descriptions	*N*	%
Epilepsy	Grand Mal and other epileptic conditions [345] and convulsions [780.3]	6288	29.64
Respiratory	Asthma [493], bacterial pneumonia [481, 482.2, 482.3, 482.41, 482.42, 482.9, 483, 485, 486], chronic obstructive pulmonary disease [466.0, 491, 492, 494, 496], tuberculosis (nonpulmonary) [012–018] and pulmonary tuberculosis [011]	3054	14.4
ENT	Severe ear, nose, and throat infections [382, 462, 463, 465, 472.1]	2761	13.01
UTI	Kidney/urinary infection [590.0, 599.0, 599.9, 595.0, 595.9]	2528	11.92
Diabetes	Diabetes [250.0–250.3, 250.8–250.9]	2250	10.61
Dehydration	Volume depletion [276.5]	1503	7.08
Dental	Dental conditions [521–523, 525, 528]	1112	5.24
Circulatory	Angina [411.1, 411.8, 413], congestive heart failure [402.01, 402.11, 402.91, 428, 518.4] and hypertension [401.0, 401.9, 402.00, 402.10, 402.90]	919	4.33
Skin	Cellulitis [681, 682, 683, 686] and skin grafts with cellulitis {DRGs: 263 and 264}	494	2.33
Immunisations	Vaccine preventable conditions [032, 033, 037, 041.5, 045, 052.1, 052.9, 055–056, 070.0–070.3, 072, 320.3, 390, 391, 771.0]	186	0.88
The remaining 119 ACSC visits were due to pelvic inflammatory disease [614], failure to thrive [783.41], iron deficiency anaemia [280.1, 280.8, 280.9] and nutritional deficiencies [260–262, 268.0, 268.1]			

ACSC, ambulatory care sensitive condition.

Table 5

Model results – incidence rate ratios to predict ACSC ED visits for people with ID

	Emergency department visit: treated and discharged to community						Emergency department visit: treated and admitted to hospital					
	Estimate	**Standard error**	**Adjusted *p*-value**	**aIRR**	**Lower aIRR**	**Upper aIRR**	**Estimate**	**Standard error**	**Adjusted *p*-value**	**aIRR**	**Lower aIRR**	**Upper aIRR**
ID subgroup[†]												
Down syndrome	−0.3015	0.0602	0.0002	0.740	0.657	0.832	0.2673	0.0964	0.0092	1.306	1.081	1.578
Unspecified ID	0.0566	0.0678	0.4524	1.058	0.927	1.209	0.0295	0.0964	0.7599	1.030	0.853	1.244
Moderate-to-profound ID	−0.1607	0.0561	0.0078	0.852	0.763	0.951	−0.1687	0.0872	0.0675	0.845	0.712	1.002
Sex[‡]												
Female	0.1238	0.0465	0.0121	1.132	1.033	1.240	−0.0639	0.0678	0.4032	0.938	0.821	1.071
Race[§]												
White	−0.1108	0.0477	0.0283	0.895	0.815	0.983	−0.0429	0.0679	0.5678	0.958	0.839	1.094
Supplemental nutrition assistance[¶]												
Yes	0.5502	0.0551	0.0002	1.734	1.556	1.932	−0.0432	0.0723	0.5711	0.958	0.831	1.104
Residence[††]												
NH, ICF, hospital of other state facility	−0.3777	0.0943	0.0002	0.685	0.570	0.825	0.3227	0.0926	0.0011	1.381	1.152	1.655
Group home/supervised living	−0.2829	0.0693	0.0002	0.754	0.658	0.863	−0.2386	0.0845	0.0082	0.788	0.667	0.930
Home with health service support	−0.1754	0.0408	0.0002	0.839	0.775	0.909	−0.1661	0.0714	0.0283	0.847	0.736	0.974
Comorbidity[‡‡]												
Yes	1.9104	0.0374	0.0002	6.756	6.278	7.270	2.9967	0.0629	0.0002	20.019	17.697	22.644
Primary care visit[§§]												
Yes	0.1747	0.0368	0.0002	1.191	1.108	1.280	0.1275	0.0571	0.0341	1.136	1.016	1.271
County type[¶¶]												
Urban	−0.0634	0.0483	0.2303	0.939	0.854	1.032	−0.2276	0.075	0.0048	0.796	0.688	0.922
Age	−0.0115	0.0017	0.0002	0.989	0.985	0.992	0.0155	0.0033	0.0002	1.016	1.009	1.022

ACSC, ambulatory care sensitive condition; aIRR, adjusted incidence rate ratio; ED, emergency department.

[†]Mild ID served as the reference group.

[‡]Male served as the reference group.

[§] African American/other races served as the reference group.

[¶] No served as the reference group.

[††] Home with no health service support served as the reference group.

[##] No served as the reference group.

[§§] No served as the reference group.

[¶¶] Rural served as the reference group.