

Research

Social Determinants of Health, Emergency Department Utilization, and People with Intellectual and Developmental Disabilities



SOCIAL DETERMINANTS AND EMERGENCY DEPARTMENT VISITS

Social Determinants of Health, Emergency Department Utilization, and People with Intellectual and Developmental Disabilities

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Acknowledgements:

Thank you to the State Developmental Disabilities Department for collaborating. Thank you to Mary Kay Rizzolo for reviewing this manuscript and providing feedback.

Citation:

Friedman, C. (2021). Social determinants of health, emergency department utilization, and people with intellectual and developmental disabilities. *Disability and Health Journal*, 14(1). <https://doi.org/10.1016/j.dhjo.2020.100964>

Abstract

Background. People with intellectual and developmental disabilities' (IDD's) health is largely dependent on the government services they receive. Medicaid managed care has emerged as one mechanism used to provide services to people with disabilities in an attempt to reduce costs. In managed care, there has been an emphasis on reducing emergency department visits and hospital admissions in an effort to reduce expenditures.

Objective. The purpose of this exploratory study was to examine the impact social determinants of health –“conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (n.p.)¹ – had on the emergency department utilization of people with IDD.

Methods. We had the following research question: what is the relationship between social determinants and emergency department utilization (visits) among adults with IDD? To explore this research question, a negative binomial regression analysis was used with secondary social determinant outcomes data (from Personal Outcome Measures[®]) and emergency department visit data from a random sample of 251 people with IDD. We also examined relationships with participants' demographics.

Results. Our findings revealed for every one unit increase in the number of social determinant outcomes present, there was a 7.97% decrease in emergency department visits. There were also significant relationships between emergency department visits, and complex support needs, intellectual disability level, primary communication method, and residence type.

Conclusions. Social determinants are critical to promote the quality of life and health equity of people with IDD.

Keywords: Medicaid managed care; social determinants of health; personal outcome measures; emergency department utilization; hospital visits.

**Social Determinants of Health, Emergency Department Utilization,
and People with Intellectual and Developmental Disabilities**

Compared to nondisabled people, people with intellectual and developmental disabilities (IDD) experience health disparities and have significantly poorer health². For example, people with IDD have age related health conditions more frequently and earlier than nondisabled people³. In addition, people with IDD are more likely to have cardiovascular disease, osteoporosis, hypertension, and many other health concerns compared to nondisabled people⁴. Despite the fact that people with IDD face many health disparities, these disparities are not necessarily due to people with IDD's health behaviors or impairments alone. Instead, people with IDD's social circumstances, access to healthcare services, high rates of poverty, environments, social seclusion, and ableism – social determinants of health – all contribute to people with IDD's health⁵. Social determinants of health are “conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (n.p.)¹. In fact, people with IDD's health and quality of life are largely dependent on the government services they receive⁶.

In the United States, many people with IDD receive long-term services and supports (LTSS). LTSS are community- or facility-based services for people who need support to care for themselves because of disability, age, or functional limitations. LTSS for people with IDD includes not only acute health care services, but also wrap-around services, such as residential habilitation, personal care services, and employment or day services among others, which often make their services unique to other populations⁷. In fact, in the largest funding system for people with IDD, Medicaid Home and Community Based Services (HCBS) waivers, less than 5% of the total projected spending was allocated for traditional acute care services in fiscal year 2015⁷.

Despite community LTSS being more prevalent than ever before, many states are grappling with a limited fiscal landscape. Medicaid managed care has emerged as one mechanism states use in an attempt to reduce costs and/or operate in a limited fiscal landscape. Medicaid managed care “provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member per month (capitation) payment for these services” (n.p.)⁸. Although implementation differs by state, managed care is frequently associated with alternative payment models. In contrast to traditional fee-for-service (FFS) models that reimburse based on the *number* of services provided, under alternative payment models, MCOs are incentivized to maximize profits and minimize service costs⁹. One way they can do so is by employing value-based payments (VBP), which focus on the *quality* of the services provided – the outcomes – rather than the number of services provided. The Centers for Medicare and Medicaid Services notes, “shifting the focus away from volume of care” incentivizes “providers to improve coordination of care efforts” (p. 6)¹⁰.

The most prevalent VBP performance measures in 2019 were: follow-up after hospitalization; hospital readmission rates; emergency department utilization; patient/consumer satisfaction; and, access to care models¹¹. Many VBP measures relate to emergency department visits and hospital admissions because they are associated with increased expenditures; by reducing these visits, there should be a reduction in healthcare costs^{10, 12}. While there is a dearth of research about managed care and VBP for LTSS for people with IDD¹³, in large part because until recently they have been carved out¹⁴, a few studies have examined the emergency department utilization of people with IDD receiving managed care. For example, Yamaki et al.¹⁵ found people with IDD enrolled in managed care visited the emergency department less

frequently than people with IDD not receiving managed care. Likewise, Yamaki et al.¹⁶ found managed care resulted in reductions in emergency department utilization by people with IDD; the authors attribute this reduction to fewer visits for non-emergencies and mental/behavioral health needs.

While less is known about how social determinants of health impact the emergency department utilization of people with IDD, research indicates a number of social determinants are associated with emergency department utilization for other people with disabilities, and nondisabled people. For example, lower socioeconomic status, financial hardship, and homelessness are all associated with more frequent emergency department visits¹⁷⁻²⁴. Geographic location is also correlated with hospitalization, rehospitalization, and hospital expenditures; this relationship is largely due to inadequate housing, poor housing conditions, neighborhood crime, air quality/pollutants, public transit (or the lack thereof), food insecurity, and low income neighborhoods having fewer resources^{17, 21, 22, 25-27}. Education and occupation are both correlated with emergency department use²¹. Access to health services, and health insurance decreases emergency department use, so does an increased number of physicians per capita^{21, 22}. In addition care coordination also reduces emergency department use²¹. While supportive relationships can reduce the use of emergency departments, social isolation can increase use^{21, 22}. For children in particular, caregiver psychological distress can also increase emergency department use¹⁷.

While the aforementioned social determinants may also impact the emergency department utilization of people with IDD, less is known not only about correlates of people with IDD's social determinants of health, but also about correlates of their emergency department utilization. Yet, people with IDD are a unique population – people with IDD not only face health disparities compared to nondisabled people *and* people with other disabilities³, they often also

receive a different set of services to support their needs, even compared to people with other disabilities^{6, 28-30}. As such, they often also incur higher health care costs^{28, 31}. Unlike acute health care which tends to be episodic, People with IDD most commonly receive lifelong, wrap-around LTSS specifically designed for people who would otherwise require institutional care²⁹. For example, LTSS for people with IDD often include/address social determinants (e.g., employment, transportation, residential supports). Moreover, unlike other populations, people with IDD's health and quality of life is also often dependent on these services.^{6, 32, 33} For all of these reasons and more, "scholars caution against generalizing from such research to a population with a substantially different health profile" (p. 1521).⁶

Building off prior research about emergency department utilization and managed LTSS for people with IDD, the purpose of this exploratory study is to explore the impact social determinants of health can have on emergency department utilization of people with IDD. We had the following research question: what is the relationship between social determinants and emergency department utilization (visits) among adults with IDD? In doing so, we analyzed secondary Personal Outcome Measures[®] Social Determinant of Health Index data, and emergency department utilization data from a random sample of 251 people with IDD.

Methods

Data

This was a secondary data analysis. Data were originally collected from adults who received services from one state developmental disabilities department. The state developmental disabilities department service recipients were randomly selected to participate in Personal Outcome Measures[®] interviews in 2018. The state developmental disabilities department then pulled the applicable incident reporting data about the sample that human service organizations in the state are required to provide to them on a regular basis, particularly emergency department visit data from 2016 through 2018. The data were then coded with identifiers and all personal identifiers were removed. The data were then transferred to the research team.

Participants

Our sample included a total of 251 people with IDD (Table 1). Gender was relatively evenly distributed among men (52.19%) and women (47.81%). Most participants were White (72.65%) and had a primary communication method of verbal/spoken language (80.08%). Almost a quarter (24.30%) of participants utilized independent decision-making, 48.21% assisted decision-making, 24.70% full/plenary guardianship, and 2.79% used an 'other' form of decision-making. Participants most often resided in provider-owned or -operated homes (38.25%), their own home/apartment (31.08%), and family homes (22.71%). The mean age of participants was 47.47 (SD = 14.75).

Two variables were utilized as a proxy for impairment severity: intellectual disability level; and, complex support needs. Intellectual disability diagnosis level included people's clinical (DSM) intellectual disability diagnosis level. Intellectual disability diagnosis level was classified into four categories: mild, moderate, severe, and profound. In our sample, 40.00%

were diagnosed with a mild intellectual disability, 33.06% moderate, 13.88% severe, and 13.06% profound. The second proxy was complex support needs, including complex medical support needs and comprehensive behavioral support needs. People with complex medical support needs required skilled nursing care 12+ hours per day. People with comprehensive behavioral support needs required 24-hour supervision due to risk of dangerous behavior (e.g., harm to self or others). In our sample, 77.05% did not have complex support needs, 6.15% had complex medical support needs, 12.30% had comprehensive behavioral support needs, and 4.51% had both complex medical support needs and comprehensive behavioral support needs.

Variables

Dependent variable. Our dependent variable (DV) was the number of emergency department visits. This variable included every single time a person in the sample visited an emergency department, regardless of the type of incident, injury sustained, or injury severity. These data included three years: 2016 through 2018.

Independent variables. The main independent variable (IV) from this study was derived from the Social Determinants of Health Index. The Social Determinants of Health Index is aimed at helping disability service providers examine the social determinants of those they support. The Social Determinants of Health Index was developed by mapping the *Healthy People 2020* SDOH framework¹ and other literature with the Personal Outcome Measures[®], a valid and reliable person-centered quality of life tool³⁴. *Healthy People 2020*'s SDOH framework highlights five key areas of SDOH: economic stability; education; social and community context; health and health care; and, neighborhood and built environment¹. According to *Healthy People 2020*, examples of issues underlying economic stability include employment, food insecurity, housing instability, and poverty¹. Examples underlying education include early childhood education and

development, enrollment in higher education, high school graduation, and language and literacy¹. Examples of social and community context include civic participation, discrimination, incarceration, and social cohesion¹. Examples of health and health care include access to health care, access to primary care, and health literacy¹. Examples of neighborhood and built environment include access to foods that support healthy eating patterns, crime and violence, environmental conditions, and quality of housing¹.

Based on the *Healthy People 2020*'s social determinants of health framework key areas (i.e., economic stability; education; social and community context; health and health care; and, neighborhood and built environment), as well as other literature regarding social determinants of health, the Social Determinants of Health Index is comprised of the following 11 outcomes from the Personal Outcome Measures[®]: people interact with other members of the community; people participate in the life of the community; people perform different social roles; people choose where to work; people choose where and with whom to live; people exercise rights; people are treated fairly; people are respected; people experience continuity and security; people have the best possible health; and, people are safe. (More information about each of these outcomes, including descriptions, can be found at The Council on Quality and Leadership³⁵). For each participant, the total number of outcomes they had present (out of the above 11) served as their Social Determinants of Health Index score. The higher the score people had on the Social Determinants of Index, the more social determinants (outcomes) they had present – the higher score, the better. The Social Determinants of Health Index has been validated utilizing an exploratory factor analysis³⁶.

Participant demographics were also utilized as independent variables. These variables were utilized not only to explore relationships between demographics and emergency department

utilization, but also because research suggests demographics can impact people with IDD's outcomes.^{37, 38} In particular, the following variables were utilized: age; complex support needs; gender; guardianship status; intellectual disability diagnosis; primary method of communication; race; and, residence type.

Analysis

We had the following research question: what is the relationship between social determinants and emergency department utilization (visits) among adults with IDD? We utilized a negative binomial model to examine the relationship between the number of emergency department visits, social determinants of health index outcomes, and participant demographics. Based on goodness of fit indicators, a negative binomial model was better suited than a Poisson distribution.

Results

The average person had 4.59 of the 11 possible social determinant outcomes present (41.72%), ranging from 0 social determinant outcomes present (0%) to 10 outcomes present (90.91%). The number of emergency department visits within the three-year period ranged from 0 to 64 visits per person, with an average of 3.73 visits per person across the three years (SD = 6.93; 1.24 visits a year per person on average).

A negative binomial regression analysis examining the association between emergency department visits, social determinants of health index outcomes, and participant demographics was significant, $\chi^2(19) = 113.16, p < 0.001$. Social determinants of health index outcomes was a significant predictor of the number of emergency department visits (Table 2). For every one unit increase in the number of social determinant outcomes present, there was a 7.97% decrease in emergency department visits (incident rate ratio (IRR) = 0.92, $p = 0.034$).

A number of participant demographics were also significant. Compared to people without complex support needs, people with complex medical support needs had a 321.44% increase in emergency department visits (IRR = 4.21, $p < 0.001$), comprehensive behavioral support needs a 122.55% increase (IRR = 2.23, $p = 0.0012$), and both complex medical support needs and comprehensive behavioral support needs a 310.24% increase (IRR = 4.10, $p < 0.001$). Compared to people with an intellectual disability diagnosis of mild, people with an intellectual disability diagnosis of profound had a 135.25% increase in emergency department visits (IRR = 2.35, $p = 0.0092$). Compared to people who primarily communicated with verbal communication, people who primarily communicated through facial/body expressions had a 44.49% decrease in emergency department visits (IRR = 0.56, $p = 0.047$), and people who primarily communicated through 'other' methods had a 74.67% decrease in emergency department visits (IRR = 0.25, $p =$

0.026). Compared to people who lived in provider owned- or operated-homes, people who lived in family homes had a 51.74% decrease in emergency department visits (IRR = 0.48, $p = 0.0030$).

Discussion

Adults with IDD not only face health inequities, but also incur higher annual health care costs than people without IDD²⁸. Cost-cutting strategies, such as the shift to managed care, are increasingly common. The purpose of this exploratory study was to examine the impact social determinant outcomes can have on the frequency of emergency department visits by people with IDD. Our findings revealed that those people with IDD with more social determinant outcomes present visited the emergency department less often than those people with fewer social determinant outcomes present.

Although health and safety are critical for people with IDD, particularly given the health disparities people with IDD face^{2,3} and the high rates of abuse, neglect, mistreatment and exploitation for people with IDD³⁹, health and safety alone are insufficient to demonstrate quality services. Instead, social determinants are critical to promote the health equity and quality of life of people with IDD. Health equity, “the absence of avoidable, unfair, or remediable differences among groups of people” (n.p.)⁴⁰, requires more than preventing or limiting disease – health services alone cannot remedy poor health⁴¹. Instead, people’s health is largely determined by their social and physical environments – “the roots of most health inequalities and of the bulk of human suffering are social: the social determinants of health” (p. 39)⁴².

Improving people with IDD’s health, and by extension reducing their emergency department utilization, is a much larger issue than physical health alone – social and physical environments, and structural impacts can serve to facilitate or hinder people with IDD’s health. Our findings suggest that by paying attention to social determinants – facilitating those community integration, choice, engagement and relationships, rights, and respect outcomes, among others – we can reduce emergency department utilization. Not to imply that people

should not utilize the emergency department if they need to do so, but fewer visits to the emergency department is indicative of better health, more continuity in people's lives, better preventative care, increased community-based health services, and increased quality of life¹⁶. In addition, reduced emergency department visits can also result in reduced expenditures, as emergency department visits and hospital admissions are a main source of increased healthcare expenditures¹².

The finding of our study parallel existing research about the impact social determinants of health have on the emergency department utilization of the general population more broadly¹⁷⁻²⁷. For example, past research has found that social isolation can increase how often people visit the emergency department, while supportive relationships can help reduce this frequency^{21, 22}. This mirrors our research which suggests that participating in the life of the community, performing social roles, and interacting with other members of the community can decrease how frequently people with IDD visit the emergency department. Our research also suggests factors related to economic stability – continuity and security, employment, and education – can impact the emergency department utilization of people with IDD; existing research similarly suggests a correlation between socioeconomic status, occupation, and education, and emergency department visits in nondisabled people and people with other disabilities¹⁷⁻²⁴. In addition, people's geographic location, neighborhoods, and the built environment can impact their utilization of emergency departments^{17, 21, 22, 25-27}; neighborhoods and built environments were also part of the Social Determinants of Health Index (i.e., people are safe, choose where and with whom to live, participate in the life of the community), which was associated with emergency department utilization of people with IDD in our study. Research also indicates that nondisabled people's access to healthcare services is correlated with emergency department utilization^{21, 22}; this too

was included as part of the social determinants of health index (i.e., best possible health) and thus was associated with emergency department utilization of people with IDD in our study. As our research was exploratory, more research is needed to determine if different areas of the social determinants of health index are associated with emergency department utilization of people with IDD more than others.

To promote the health and quality of life of people with IDD, we need to facilitate outcomes related to social determinants through the implementation of individualized organizational supports to assist the person to achieve their outcomes. In addition, VBP metrics for the managed LTSS of people with IDD encourage more than just emergency department utilization – it is critical they also pay attention to social determinants. Prioritizing VBP metrics related to social determinants will also serve to encourage organizational supports related to social determinants as, by their very nature, VBP metrics incentivize providers to reach those outcomes and improve their service delivery.

In addition, there were significant relationships between emergency department visits and a number of participant demographics. For example, people with IDD who lived in a family member's home had a decrease in emergency department visits compared to people with IDD who lived in provider owned- or operated-homes. This finding mirrors past research which has found that people with IDD have better quality of life outcomes, including health and safety, when they live in family homes compared to provider owned- or operated-homes.⁴³ Moreover, in addition to increased requirements in provider owned/operated homes compared to family homes, providers tend to exercise caution to limit risk and liability (K. Dunbar, personal communication, February 13, 2020), both of which could lead to them bringing people with IDD

to emergency room departments out of an abundance of caution or because of policies and regulations.

In addition, people who primarily communicated through facial/body expressions and ‘other’ methods had a decrease in emergency department visits compared to people who primarily communicated through verbal/spoken language. It may be that support staff are better at understanding when people who communicate through verbal/spoken language need to visit the emergency department compared to people who primarily communicate with facial/body expressions. As such, support staff may need better training not only about how to monitor people’s health, particularly for those people who do not communicate with words, as well as about communication techniques to use with those people who do not communicate with words (e.g., gestures, visual cues, vocalizations, objects, etc.).

Finally, both variables used as a proxy for impairment severity – intellectual disability diagnosis and complex support needs – were associated with an increase in emergency department visits. While this may in part be due to their impairments, it is important to recognize that people with more severe impairments face quality of life disparities, attributed to the fact that they tend to receive fewer organizational supports to facilitate their quality of life^{37, 38}. For these reasons, it is crucial that VBP metrics for managed LTSS for people with IDD recognize the disparities people with more severe impairments face regarding quality of life outcomes and supports – quality services and supports “demand adequate services for everyone – people with more complex or significant disabilities cannot be left behind in the shift to managed care simply because of fiscal concerns” (p. 8)⁴⁴.

Limitations

When interpreting these findings, a number of limitations should be considered. First, although this was a random sample (and the demographics largely paralleled the wider demographics of that state), the participants all represented one state. Moreover, all participants were receiving services from the state developmental disabilities department. As this was a secondary data analysis, we did not have the ability to add additional questions or variables. There may be interactions or confounding variables which impact people with IDD's emergency department and/or health care access which were not explored; as such, we believe future research should continue to explore emergency department utilization and social determinants of health of people with IDD in more depth. In addition, we also recommend future studies examine if social determinants impact the emergency department utilization of people with IDD differently than with people with other disabilities.

Conclusion

This exploratory study examined the relationship between the social determinants of health of people with IDD and the frequency people with IDD visited the emergency department. Although this study found a significant relationship between social determinants of health and reduced emergency department utilization, much more research is needed to provide an adequate evidence-base for IDD VBP metrics, as well as best practices for managed care for people with IDD more broadly. This is particularly pertinent as there is conflicting research about the cost effectiveness and quality of managed care more broadly, as well as a dearth of evidence-based research and best-practices for managed LTSS for people with IDD^{9, 13, 45}. Regardless of when, or if, managed care moves into the IDD LTSS system, attention to people with IDD's social determinants will prove beneficial to increase people with IDD's quality of life and health equity.

Acknowledgements

Declaration of Interest:

The author reports no conflicts of interest.

Funding:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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Table 1

Participant Demographics (n = 251)

Variable	<i>n</i>	%
Complex support needs (<i>n</i> = 244)		
Don't have complex support needs	188	77.05
Complex medical support needs	15	6.15
Comprehensive behavioral support needs	30	12.30
Both types of support needs	11	4.51
Gender		
Man	131	52.19
Woman	120	47.81
Guardianship status		
Independent decision making	61	24.30
Assisted decision making	121	48.21
Full/plenary guardianship	62	24.70
Other	7	2.79
Intellectual disability diagnosis level (<i>n</i> = 245)		
Mild	98	40.00
Moderate	81	33.06
Severe	34	13.88
Profound	32	13.06
Primary method of communication		
Verbal/spoken language	201	80.08
Face/body expression	43	17.13
Other	7	2.80
Race (<i>n</i> = 245)		
White	178	72.65
Black	63	25.71
Other	7	2.86
Residence type		
Provider-owned or -operated home	96	38.25
Own home/apartment	78	31.08
Family's house	57	22.71
Other	20	7.97

Note. Participants could have more than one race. ICFDD = Intermediate Care Facility for People with Developmental Disabilities. HCBS = Home and Community Based Services.

Table 2
Results of the Negative Binomial Analysis

Variables	Incident rate ratio (95% confidence interval)	<i>p</i>
(Intercept)	2.71 (1.22 - 6.02)	0.015
Social determinants of health index outcomes present	0.92 (0.85 - 0.99)	0.034
Demographics		
Age (in years)	1.01 (1.00 - 1.02)	0.27
Complex support needs		
Complex medical support needs	4.21 (2.21 - 8.44)	< 0.001
Comprehensive behavioral support needs	2.23 (1.37 - 3.62)	0.0012
Both	3.95 (1.92 - 8.14)	< 0.001
Gender: woman (ref: man)	1.33 (0.96 - 1.85)	0.088
Guardianship status (ref: independent decision-making)		
Assisted decision making	1.16 (0.77 - 1.75)	0.47
Full/plenary guardianship	0.65 (0.39 - 1.09)	0.10
Other	0.54 (0.16 - 1.86)	0.33
Intellectual disability diagnosis level (ref: mild)		
Moderate	0.97 (0.66 - 1.41)	0.86
Severe	1.43 (0.85 - 2.41)	0.18
Profound	2.35 (1.24 - 4.48)	0.0092
Primary method of communication (ref: verbal/spoken)		
Face/body expression	0.56 (0.31 - 0.99)	0.047
Other	0.25 (0.08 - 0.85)	0.026
Race (ref: White)		
Black	0.93 (0.63 - 1.38)	0.71
Other	0.64 (0.22 - 1.89)	0.42
Residence type (ref: provider owned/operated home)		
Own home/apartment	0.86 (0.58 - 1.28)	0.46
Family's house	0.51 (0.31 - 0.83)	0.0068
Other	1.81 (0.94 - 3.47)	0.076

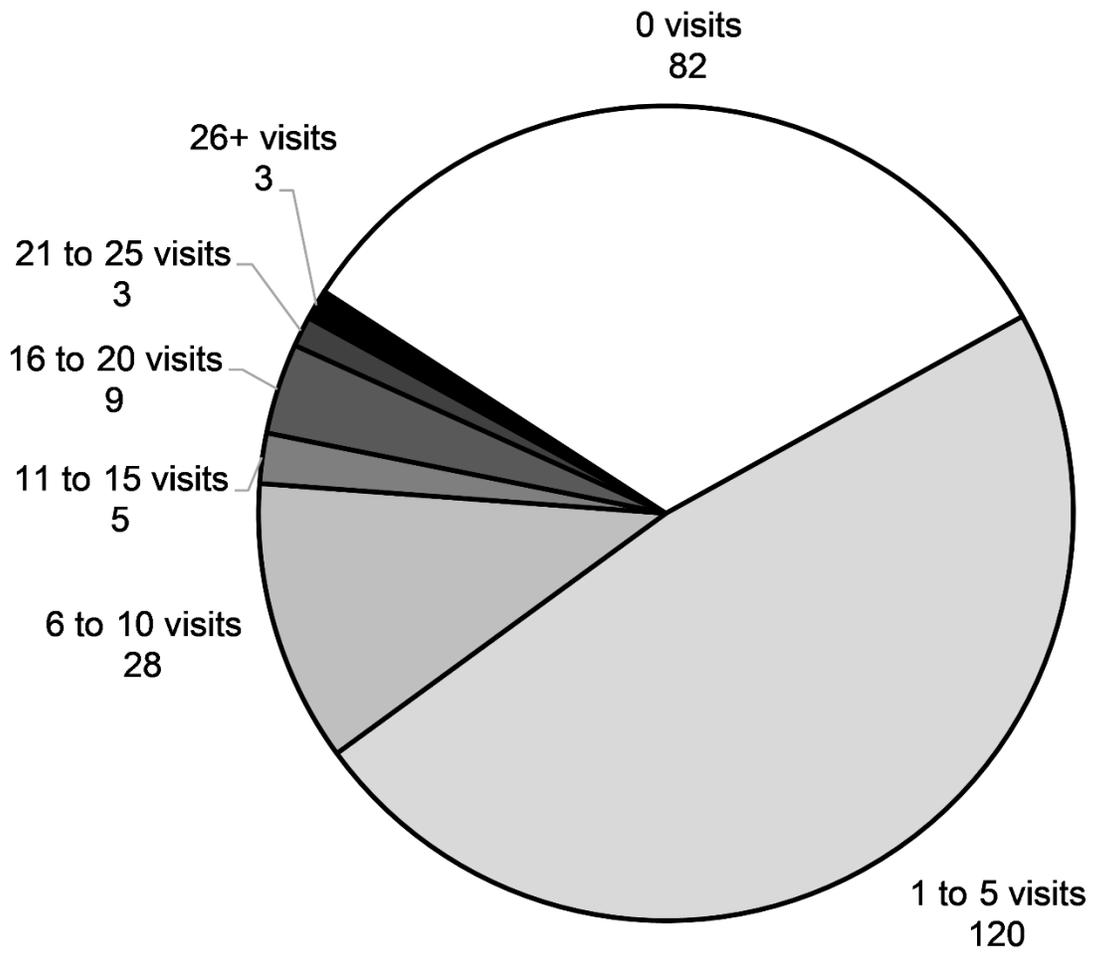


Figure 1. Emergency department visits per person over a three-year period.