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> Choosing Home: The Impact of Choosing Where to Live on People with Intellectual and Developmental **Disabilities' Emergency Department Utilization**

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Running head: CHOOSING HOME AND EMERGENCY DEPARTMENT USE

Choosing Home: The Impact of Choosing Where to Live on People with Intellectual and

Developmental Disabilities' Emergency Department Utilization

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Abstract

Social determinants of health are conditions, factors, and environments that impact people's health. One such metric of people's health is emergency department utilization, but there is less research exploring how social determinants impact the emergency department use of people with intellectual and developmental disabilities (IDD). This exploratory study examined the relationship between people with IDD choosing where and with whom to live – a social determinant of health – and emergency department utilization. We analyzed secondary Personal Outcome Measures[®] data, and emergency department data from 251 people with IDD. Our findings revealed people with IDD who chose where and with whom to live had a 74% decrease in emergency department visits, regardless of their impairment severity. Choice in housing may improve people with IDD's health outcomes.

Keywords: Community living; community integration; intellectual and developmental disabilities; housing; emergency department utilization; social determinants of health

Choosing Where to Live: The Impact on People with Intellectual and Developmental Disabilities' Emergency Department Utilization

Social determinants of health are conditions, factors, and environments that impact people's health and quality of life. For example, education, employment, relationships, and many other factors can either facilitate or hinder people's health (United States Office of Disease Prevention and Health Promotion [ODPHP], n.d.). Housing is one such factor that can significantly impact people's health (Kim et al., 2012; Raphael, 2006; World Health Organization, 2006). For example, homelessness as well as housing insecurity or instability can create health disparities (Compton & Shim, 2015; Lauder et al., 2007). A lack of housing affordability can also hinder people's health (ODPHP, n.d.). The quality of one's housing also serves as a social determinant of health (ODPHP, n.d.).

In addition to the physical housing structure itself, the physical and social neighborhoods and communities where the housing is located can impact people's health (Kim et al., 2012; Raphael, 2006). Residential segregation serves as a social determinant, negatively impacting people's health (ODPHP, n.d.). Neighborhood conditions as well as the resources in those neighborhoods can either hinder or facilitate health (Currie et al., 2009). For example, neighborhoods with violence, crime, and pollution and environmental toxins hinder health (Compton & Shim, 2015; United States Department of Health & Human Services [HHS], 2015). Neighborhoods which are food deserts as well as those that lack affordable, accessible, and reliable transportation hinder people's health (Abbott & Elliott, 2017; Braveman & Gottlieb, 2014; Compton & Shim, 2015; Frier et al., 2018). Alternatively, neighborhoods with sidewalks, accessibility, green space, and aesthetic elements can facilitate people's health (Compton & Shim, 2015; HHS, 2015; ODPHP, n.d.).

Housing, Community Living, and People with Intellectual and Developmental Disabilities

People with intellectual and developmental disabilities (IDD) have a long and historied relationship with housing. For decades, most people with IDD were segregated and forced into institutions. For a number of reasons, including the advocacy by, and preferences of, people with IDD and their families, changes in rules and regulations, litigation, and changes to long-term services and supports (LTSS), including the introduction of Home and Community-Based Services (HCBS), the majority of people with IDD have been deinstitutionalized, with most people with IDD now living in community based settings (Braddock et al., 2015; Braddock et al., 2017; Trent, 1994). However, despite deinstitutionalization, not only are many people with IDD not given the opportunity to choose which community-based setting they live in, many people with IDD are still not meaningfully included in, and engaged with, their communities (Cullen et al., 1995; Forrester-Jones et al., 2002; Friedman, 2019a, 2020c; Ligas Consent Decree Monitor, 2016, 2017). This lack of choice and community integration is one of many reasons that the HCBS Settings Rule (CMS 2249-F/2296-F) was introduced in 2014 (the compliance deadline is 2022). The HCBS Settings Rule aims to "develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living" (emphasis mine; Centers for Medicare and Medicaid Services [CMS], 2014b, n.p.). The HCBS Settings Rule "establish[es] a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics" (CMS, 2014a, p. 2).

The HCBS Settings Rule is centered around community, choice, and control, including person-centered services and supports. For example, HCBS recipients should not only be able to choose their services, but also who provides their services (CMS, n.d.). In addition, the Settings

Rule stipulates that people must be able to choose where they live and who they live with. The person must be provided with a range of housing options to choose from, including nondisability specific settings. People must have the option of a private unit and should be able to choose their roommates. The Settings Rule also says that people must have choices regarding how they decorate their rooms, when they have visitors, and so on.

Not only does the Settings Rule promote choice and community integration when it comes to housing, other tenets of the Settings Rule, such as those about physical environment, social inclusion, community integration, etc., address social determinants of health. For example, segregation, neighborhoods, housing conditions, and social exclusion – all of which are addressed by the rule – are all social determinants of health, leading to negative health outcomes if they are not addressed (Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010).

One metric of people's health is how often they visit the emergency department. Blaskowitz et al. (2019), one of the few other studies to examine emergency room utilization of people with IDD, found that correlates of emergency department utilization included age, multiple chronic health conditions, psychiatric disabilities, cerebral palsy, neurological disabilities, and polypharmacy. However, less is known about how social determinants may impact people with IDD's emergency department utilization. While there is less research about how social determinants impact people with IDD's emergency department use, research highlights that a number of social determinants are associated with emergency department utilization for people with other disabilities, and nondisabled people. For example, geographic location is correlated with hospitalization, rehospitalization, and hospital expenditures. Inadequate and poor housing, social isolation, and neighborhoods having crime, pollution, and lack of transit are all associated with increased emergency department use (Beck et al., 2012; Bellis et al., 2011; Doan et al., 2018; Holzer et al., 2014; Lax et al., 2017; Muenchberger & Kendall, 2010).

Purpose

This exploratory study builds off prior research about community living, emergency department utilization, and social determinants of health for people with IDD by examining the impact housing can have on emergency department utilization of people with IDD. In particular, we had the following research question: what is the relationship between people with IDD choosing where and with whom to live in the community, and emergency department utilization? We hypothesized that choosing where and with whom to live would be associated with greater health – fewer emergency department visits – because of the benefits of choice and self-determination more broadly, as well as because people with IDD tend to choose certain settings (i.e., individual and family homes) which are associated with better outcomes (Friedman, 2019a, 2020c; Hemp et al., 2014; Larson et al., 2013). To explore this research question, we analyzed secondary Personal Outcome Measures[®] data, and emergency department utilization data from a random sample of 251 people with IDD who lived in home and community-based settings.

Methods

Data and Participants

This study was a secondary data analysis; the data were originally collected from adults who received services from one state developmental disabilities department. The adults with IDD were randomly selected to participate in Personal Outcome Measures[®] interviews in 2018. The state developmental disabilities department also 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 2018. Personal identifiers were removed from all data and it was then transferred to the research team.

The sample included a total of 251 people with IDD (Table 1). Most participants were White (72.65%) and had a primary communication method of verbal/spoken language (80.08%). Gender was relatively evenly distributed among men (52.19%) and women (47.81%). The mean age of participants was 47.47 (SD = 14.75). Participants most often resided in provider-owned or -operated homes (38.25%), their own home/apartment (31.08%), and family homes (22.71%), with fewer people living in host homes/family foster care (5.98%) and other community-based settings (1.99%). Almost a quarter (24.30%) of participants utilized independent decisionmaking, 48.21% assisted decision-making, 24.70% full/plenary guardianship, and 2.79% used an 'other' form of decision-making.

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: 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. Complex support needs included complex medical support needs – requiring skilled nursing care 12+ hours per day – and comprehensive behavior support needs – requiring 24-hour supervision due to risk of harm or dangerous behavior. In our sample, 6.15% had complex medical support needs, 12.30% had comprehensive behavior support needs, 4.51% had both complex medical support needs and comprehensive behavior support needs, 4.51% had both complex medical support needs and comprehensive behavior

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 in 2018, regardless of the type of incident, injury sustained, or injury severity.

Independent Variables

Our independent variable (IV) about choosing where and with whom to live came from the Personal Outcome Measures[®]. The Personal Outcome Measures[®] is a person-centered quality of life tool. The Personal Outcome Measures[®] was developed over 25 years ago based on findings from focus groups with people with disabilities, their family members, and other stakeholders about what really mattered in their lives. Since then it has been continuously refined over the past two decades through pilot testing, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures[®] has construct validity, and reliability, as all interviewers need to pass reliability tests with at least 85% agreement before being certified (Friedman, 2018; The Council on Quality and Leadership, 2017a).

Administration of the Personal Outcome Measures[®] occurs in three stages. In the first stage, an interviewer has an in-depth conversation with the person with IDD about each of the different topics, called indicators, following specific open-ended prompts. In the second stage, the interviewer speaks with someone who knows the participant with disabilities well and knows about organizational supports (e.g., case manager or direct support professional), and asks them questions about individualized supports and outcomes to fill in any gaps. During the final stage, observations and record reviews are conducted if needed. Finally, the interviewer completes decision trees based on all information gathered to determine if outcomes and supports are present. The Personal Outcome Measures[®] includes 21 indicators divided into five factors: My Human Security; My Community; My Relationships; My Choices; and, My Goals. My Choices includes the following indicator: people choose where and with whom to live. Suggested questions for interviewers regarding this indicator include:

- "How did you choose where to live?
- What options did you have to choose from?
- How did you decide who would live with you?
- What do you like about your living situation?
- What would you like to be different?
- Who decided where and with whom the person would live? (question for supporter)
- What options and experiences did the person have in order to make choices? (question for supporter)
- If the person did not choose, why not?" (question for supporter) (The Council on Quality and Leadership, 2017b, p. 69)

For this outcome to be considered present (yes (1); no (0)), answers to all four of the following questions must be yes:

- "Does the person have options about where and with whom to live?
- If the answer is *Yes*, do the options include generic (non-disability specific) community settings and the possibility of a private room or home?
- Does the person decide where to live?
- Does the person select with whom he or she lives?" (The Council on Quality and Leadership, 2017b, p. 70)

In addition, the following demographic variables were used as IVs as they might impact emergency department utilization and/or be associated with choice in housing: age; complex support needs; decision-making authority; gender; intellectual disability diagnosis; primary method of communication; race; and residence type.

Analysis

We had the following research question: what is the relationship between choosing where and with whom to live in the community, and emergency department utilization? We utilized a negative binomial model to examine the relationship between the number of emergency department visits, and choosing where and with whom to live, impairment severity, and residence type. (Both Poisson and negative binomial models are used to analyze count data, such as the number of times a person visited the emergency department.) Based on goodness of fit indicators, a negative binomial model was better suited than a Poisson distribution.

Results

Of the participants, 13.15% choose where and with whom to live (outcome present; n = 33), while 86.85% did not (n = 218). The number of emergency department visits within the oneyear period ranged from 0 to 16 visits per person, with an average of 1.35 visits per person per year (SD = 2.45; see Figure 1 and Table 1).

A negative binomial regression analysis examining the association between emergency department visits, choosing where and with whom to live, and participant demographics was significant, $\chi^2 (20) = 75.90$, p < 0.001. Choosing where and with whom to live was a significant predictor of the number of emergency department visits (Table 2). Holding all other variables constant, people with IDD who chose where and with whom to live had a 74.23% decrease in

emergency department visits compared to people with IDD who did not choose (IRR = 0.26, p < 0.001).

In addition, holding all other variables constant, compared to people without complex support needs, people with complex medical support needs had a 231.01% increase in emergency department visits (IRR = 3.31, p = 0.004), comprehensive behavior support needs a 110.92% increase (IRR = 2.11, p = 0.01), and both complex medical support needs and comprehensive behavioral support needs a 199.46% increase (IRR = 3.27, p = 0.003). Holding all other variables constant, people with a diagnosis of severe intellectual disability had a 111.23% increase in emergency department visits (IRR = 2.11, p = 0.02) compared to people with a diagnosis of mild intellectual disability. Holding all other variables constant, people who primarily communicated through facial/body expressions had a 65.67% decrease in emergency department visits (IRR = 0.34, p = 0.003) compared to people who primarily communicated through facial/body expressions had a 65.67% decrease in emergency department visits (IRR = 0.34, p = 0.003) compared to people who primarily communicated through facial/body expressions had a 65.67% decrease in emergency department visits (IRR = 0.34, p = 0.003) compared to people who primarily communicated through verbal/spoken language. Age, decision-making authority, gender, race, and residence type were not significant.

Discussion

Where someone lives – both in terms of the physical housing and the neighborhood – are social determinants of health, hindering or promoting health and quality of life (Compton & Shim, 2015; Currie et al., 2009; Kim et al., 2012; Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010). For example, residential segregation, which people with IDD have historically experienced, results in health inequities (ODPHP, n.d.). However, our research suggests that if people with IDD are able to choose where and with whom they live in the community – a right of which they are entitled to according to the HCBS Settings Rule – this may positively impact their health outcomes, reducing emergency department utilization. In

particular, regardless of their impairment severity or other demographics, people who chose where and with whom to live had a 74% decrease in emergency department visits compared to people with IDD who did not choose.

This reduction in emergency department use associated with people with IDD choosing where and with whom they live may be due to the fact that people with IDD are more likely to prefer integrated and individualized settings (e.g., their own homes or apartments, family homes), rather than congregate care (e.g., group homes, institutions; Friedman, 2020c; Hemp et al., 2014; Larson et al., 2013). People with IDD who live on their own or with families also tend to have better quality of life outcomes than people who live in other settings (Friedman, 2019a). In addition, research has found that people that are isolated have poorer health outcomes (Emerson et al., 2011; Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010).

People with IDD who choose where they live may also pick settings that provide care that is more tailored and individualized to suit their needs. As such, they may have better health and be less likely to visit the emergency department as a result. Furthermore, research suggests people with IDD prefer settings which are person-centered and that have resources and opportunities, less crime, and better transit (Friedman, 2020c), all of which are associated with better outcomes and reduced emergency department use for other populations (Beck et al., 2012; Bellis et al., 2011; Doan et al., 2018; Holzer et al., 2014; Lax et al., 2017; Muenchberger & Kendall, 2010).

People with IDD who choose their homes and who they live with may also select settings with or near their friends or family, or at least with people they get along with and can turn to for support. It is not uncommon for people with IDD to not be able to choose who they live with, and experience tenuous relationships with roommates and housemates as a result (Friedman,

12

2020c). In addition, choosing to live near friends or family may also benefit people with IDD as it likely reduces loneliness, which has been tied to negative health outcomes (Emerson et al., 2011; Hawkley & Capitanio, 2015; Larsson, 2013; Lauder et al., 2007; Leigh-Hunt et al., 2017; Smith et al., 2018; Tomaka et al., 2006; World Health Organization, 2006, 2010). For example, research has found that supportive relationships can reduce the use of emergency departments by nondisabled people (Lax et al., 2017; Muenchberger & Kendall, 2010). In fact, having social capital can help facilitate people's health and quality of life (Larsson, 2013; Lauder et al., 2007; World Health Organization, 2006, 2010).

While residence type itself was not a significant variable in our model, when all the other demographic variables were not controlled – were not included – there *was* a significant relationship between emergency department visits and residence type. Without the other control variables, compared to people who lived in provider owned or operated settings, people who lived in family homes had a significant decrease in emergency department visits (52.88% decrease, p = 0.003) and people in 'other community-based settings' a significant increase (156.12% increase, p = 0.048). Out of those people who choose where and with whom to live in our study (had the outcome present), 48.48% lived in family homes and 30.30% lived in their own home. Meanwhile, 93.75% of people who lived in provider homes in our sample did not choose where and with whom to live (did not have the outcome present). Thus, our findings suggest, not only can the act of choosing potentially reduce emergency department visits, so too can the actual settings one chooses. As such, we believe it would be fruitful for future research to explore these relationships and interactions further.

In addition to our findings about choosing where and with whom to live, we found that people who primarily communicated through facial/body expressions were less likely to visit the emergency department than people who primarily communicated through verbal/spoken language. Support staff may be better at communicating with, and picking up cues about, people who primarily utilize verbal/spoken language, and as such, they may be more aware of when people who use verbal/spoken language need to visit the emergency department compared to those who primarily use facial/body expressions to communicate. There may also be an interaction between primary communication method and who is supported to choose where to live; future research should explore this.

We also found people with complex medical and/or behavior support needs as well as those with diagnosis of 'severe' intellectual disabilities were more likely to visit the emergency department. This finding seems intuitive since people in these categories typically have more significant needs. However, it is important to recognize that people with more complex needs face disparities in organizational supports to promote their quality of life (Friedman, 2020b). For example, people with more complex needs often face disparities in organizational supports that promote community integration (Friedman, 2020b), which can serve as a social determinant of health. In addition, this finding may be related to the fact that many people with complex support needs in our study did not choose where or with whom to live. Providers need to make sure people with more complex support needs are given the opportunity to do so. Furthermore, it would be beneficial to have more systems to support people with complex needs in the community, such as an increase in preventative and routine care to help prevent or divert situations escalating to needing emergency department care. For example, attention to preventative care and adequately community-based health services can help reduce emergency department visits (Yamaki et al., 2019). Quality services and supports "demand adequate

services for everyone – people with more complex or significant disabilities cannot be left behind" (Friedman, 2019b, p. 8).

Implications for Policy and Practice

Given most people with IDD in our study did not choose where they lived or who they lived with, as well as because making these choices may reduce emergency department utilization, people with IDD need to be supported to choose where and with whom to live. Doing so requires real person-centered services. Currently, person-centered planning is often more theory than practice (Friedman, 2019b, 2020c; Spagnuolo, 2016). For example, Friedman's (2020c) study found that people with IDD across the United States had a lack of choices, not only about housing settings, but also in their day-to-day lives. In fact, Spagnuolo (2016), argues, "the legacy of institutionalization and congregate care has shaped current residential services, meaning that 'services today have become standardized, inflexible and unaccountable to those they serve" (n.p.). In contrast, true person-centered services should be individualized, offering choices, and aligning services to meet people's wants and needs. CMS (2014a) notes HCBS must "optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them" (p. 1).

In the context of choice, we would be amiss if we did not point out that those people who are opposed to the HCBS Settings Rule, which aims to promote people's choices and community integration, often invoke the language of choice albeit in a different way – to instead advocate for their ability to choose segregated settings (Friedman, 2020c). In fact, some believe that deinstitutionalization and community integration efforts have "ruined" the choices of parents of people with IDD with higher support needs (Friedman, 2020c, p. 33). While our findings suggest choice may be associated with a reduction in emergency department utilization, we caution that

these findings should be interpreted alongside the preponderance of evidence that people with IDD, including those with higher support needs, have better outcomes in the community (Friedman, 2019a; Lakin et al., 2011; Mirenda, 2014; Young, 2006). In fact, research indicates the very tenants of the HCBS Settings Rule are associated with improved outcomes for people with IDD (Friedman, 2020a).

The HCBS Settings Rule is one such attempt to ensure HCBS recipients have more choice and control over their services, including regarding where and with whom they live in the community. The Settings Rule encourage states to develop and utilize innovative strategies to increase community living (CMS, 2014b). As the Settings Rule not only aims to expand people with IDD's choice and control, but also because research suggests compliance with the Settings Rule can increase people with IDD's health and safety (Friedman, 2020a), it is important for the Settings Rule to be implemented with fidelity. Yet, the deadline for states to come into compliance has already been delayed once from 2019 to 2022 (Neale, 2017). Moreover, problematically, the Settings Rule does not include oversight mechanisms or increased funding to ensure consistent compliance.

In addition to improving HCBS and coming into compliance with the Settings Rule, it is important to note that a large proportion of people with IDD are still waiting to receive services in the first place. In fact, 589,940 people with IDD were waiting for Medicaid HCBS services as of 2018, and the number continues to grow (The Henry J. Kaiser Family Foundation, n.d.). People on waiting lists have an utter lack of choices regarding where they live. In addition, the United States more broadly suffers from a lack of affordable housing, especially accessible affordable housing (Joint Center for Housing Studies of Harvard University, 2016). As such, there needs to be a reduction in not only waiver waiting lists, but also an increased availability of affordable and accessible housing.

Moreover, while efforts, such as the HCBS Settings Rule, are being made to improve the quality of LTSS and HCBS recipients' experiences, as states grapple with limited resources, they are also making changes in an attempt to promote cost savings. For example, states are increasingly moving to Medicaid managed care, which "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" (CMS, n.d.-a, n.p.). One metric managed care often uses to reduce expenditures is emergency department visits (CMS, n.d.-b; Oss, 2019). While there is less evidence-base regarding managed LTSS for people with IDD (Tallant & Dembner, 2019), our findings suggest there is a potential to reduce emergency department utilization, and by extension for cost savings, by ensuring people with IDD have the opportunity to choose where and with whom they live.

Limitations

A number of limitations should be noted when interpreting our findings. The participants in this study all came from one state and were receiving services from the state's developmental disabilities department. This study was also a secondary data analysis; as such, we did not have the ability to add additional questions or variables. For example, there may be differences within individual residence types themselves which impact choice and emergency department utilization. The choices people make may also be impacted by their past experiences. There may also be differences in people's emergency department visits, in terms of services needed, admittance, and/or length of stay. We believe these limitations also represent opportunities for future study.

Conclusion

People with IDD have a long history of not only being denied the opportunity to choose where they live, but also of being segregated. While new rules and regulations have aimed to remedy this by expanding community living and promoting outcomes, the need for reduced expenditures also represents a threat to community integration. In this study we explored if, and how, having people with IDD choose where and with whom to live can impact emergency department utilization, which may also produce cost savings. In doing so, we found that when people with IDD chose where and with whom they lived there was a 74% decrease in emergency department visits compared to people with IDD who did not choose. As such, our findings suggest choice in housing may improve people with IDD's health outcomes. However, we must honor people with IDD's right to choose where and with whom they live in the community regardless of its impact on health outcomes.

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Severe 34 13.88 1.68 3.11 Profound 32 13.06 1.47 2.27 Primary method of communication 201 80.08 1.49 2.65 Face/body expression 43 17.13 0.86 1.32 Other 7 2.80 0.29 0.49 Race ($n = 245$) $white$ 178 72.65 1.43 2.62 Black 63 25.71 1.19 2.15 Other 7 2.86 0.86 1.21 Residence type 7 2.86 0.86 1.21 Residence type 7 2.86 0.81 1.51 3.12 Family's house 57 22.71 0.72 1.74 Host home/family foster care 15 5.98 0.71 1.14	Mild	98	40.00	1.46	2.49
Profound3213.061.472.27Primary method of communication 201 80.08 1.49 2.65 Face/body expression43 17.13 0.86 1.32 Other7 2.80 0.29 0.49 Race ($n = 245$) 178 72.65 1.43 2.62 Black 63 25.71 1.19 2.15 Other7 2.86 0.86 1.21 Residence type 7 2.86 0.86 1.21 Residence type 78 31.08 1.51 3.12 Family's house 57 22.71 0.72 1.74 Host home/family foster care 15 5.98 0.71 1.14	Moderate	81	33.06	1.15	2.32
Primary method of communication 201 80.08 1.49 2.65 Face/body expression 43 17.13 0.86 1.32 Other7 2.80 0.29 0.49 Race ($n = 245$) 178 72.65 1.43 2.62 Black 63 25.71 1.19 2.15 Other7 2.86 0.86 1.21 Residence type 7 2.86 0.86 1.21 Residence type 7 2.86 1.51 1.86 Own home/apartment 78 31.08 1.51 3.12 Family's house 57 22.71 0.72 1.74 Host home/family foster care 15 5.98 0.71 1.14	Severe	34	13.88	1.68	3.11
Verbal/spoken language 201 80.08 1.49 2.65 Face/body expression 43 17.13 0.86 1.32 Other 7 2.80 0.29 0.49 Race $(n = 245)$ 178 72.65 1.43 2.62 Black 63 25.71 1.19 2.15 Other 7 2.86 0.86 1.21 Residence type 7 2.86 0.86 1.21 Residence type 78 31.08 1.51 3.12 Family's house 57 22.71 0.72 1.74 Host home/family foster care 15 5.98 0.71 1.14	Profound	32	13.06	1.47	2.27
Face/body expression43 17.13 0.86 1.32 Other7 2.80 0.29 0.49 Race $(n = 245)$ 7 2.65 1.43 2.62 Black 63 25.71 1.19 2.15 Other7 2.86 0.86 1.21 Residence type7 2.86 0.86 1.21 Residence type7 2.86 0.86 1.21 Residence type7 2.86 0.86 1.21 Residence type 57 22.71 0.72 1.74 Host home/family foster care 57 5.98 0.71 1.14	Primary method of communication				
Other72.800.290.49Race $(n = 245)$ 72.800.290.49White17872.651.432.62Black6325.711.192.15Other72.860.861.21Residence type72.860.861.21Provider-owned or -operated home9638.251.511.86Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	Verbal/spoken language	201	80.08	1.49	2.65
Race $(n = 245)$ 17872.651.432.62Black6325.711.192.15Other72.860.861.21Residence type $1000000000000000000000000000000000000$	Face/body expression	43	17.13	0.86	1.32
White17872.651.432.62Black6325.711.192.15Other72.860.861.21Residence type9638.251.511.86Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	Other	7	2.80	0.29	0.49
Black6325.711.192.15Other72.860.861.21Residence type72.860.861.21Provider-owned or -operated home9638.251.511.86Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	Race $(n = 245)$				
Other72.860.861.21Residence typeProvider-owned or -operated home9638.251.511.86Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	White	178	72.65	1.43	2.62
Residence type 96 38.25 1.51 1.86 Own home/apartment 78 31.08 1.51 3.12 Family's house 57 22.71 0.72 1.74 Host home/family foster care 15 5.98 0.71 1.14	Black	63	25.71	1.19	2.15
Provider-owned or -operated home9638.251.511.86Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	Other	7	2.86	0.86	1.21
Own home/apartment7831.081.513.12Family's house5722.710.721.74Host home/family foster care155.980.711.14	Residence type				
Family's house5722.710.721.74Host home/family foster care155.980.711.14	Provider-owned or -operated home	96	38.25	1.51	1.86
Host home/family foster care155.980.711.14	Own home/apartment	78	31.08	1.51	3.12
	Family's house	57	22.71	0.72	1.74
Other community-based settings $5 1.99 4.00 5.69$	Host home/family foster care	15	5.98	0.71	1.14
<u> </u>	Other community-based settings	5	1.99	4.00	5.69

Table 1Demographics and Descriptive Statistics (n = 251)

Note. Participants could have more than one race.

	Incident rate ratio		
Variables	(95% confidence interval)	n	
(Intercept)	0.92 (0.39 - 2.20)	$\frac{p}{0.86}$	
Choose where and with whom to live (outcome present)	0.92 (0.39 - 2.20) 0.26 (0.12 - 0.56)	0.001	
Age	1.00 (0.99 - 1.02)	0.001	
Complex support needs (ref: none)	1.00 (0.99 - 1.02)	0.79	
Complex medical support needs	3.31 (1.47 - 7.48)	0.004	
Comprehensive behavioral support needs	2.11 (1.19 - 3.74)	0.01	
Both	3.27 (1.44 - 7.38)	0.003	
Decision-making authority (ref: independent decision-making)	· · · · ·		
Assisted decision-making	1.52 (0.91 - 2.52)	0.11	
Full/plenary guardianship	0.92 (0.50 - 1.70)	0.79	
Other	0.41 (0.09 - 1.84)	0.24	
Woman (ref: man)	1.29 (0.87 - 1.90)	0.21	
Intellectual disability diagnosis (ref: mild)			
Moderate	0.74 (0.47 - 1.17)	0.20	
Severe	2.11 (1.14 - 3.91)	0.02	
Profound	2.15 (0.99 - 4.65)	0.05	
Primary method of communication (ref: verbal/spoken language)			
Face/body expression	0.34 (0.17 - 0.69)	0.003	
Other	0.19 (0.03 - 1.09)	0.06	
Race (ref: White)			
Black	0.91 (0.57 - 1.45)	0.68	
Other	0.85 (0.24 - 3.05)	0.81	
Residence type (ref: provider owned or operated home)			
Own home	0.79 (0.51 - 1.24)	0.31	
Family home	0.79 (0.45 - 1.39)	0.42	
Host home/family foster care	0.45 (0.16 - 1.27)	0.13	
Other community-based settings	2.13 (0.76 - 5.98)	0.15	

Table 2Results of the Negative Binomial Analysis

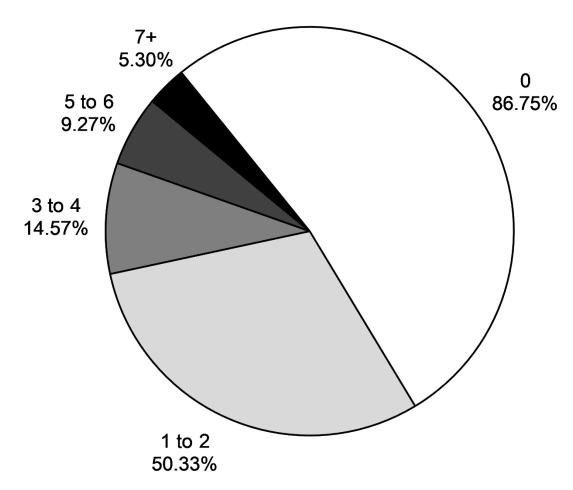


Figure 1. Number of emergency department visits.