

HCBS SETTINGS RULE AND OUTCOMES

The Impact of Home and Community Based Settings (HCBS) Final Settings Rule Outcomes on Health and Safety

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Abstract

Despite physically relocating *into* the community, many people with intellectual and developmental disabilities (IDD) fail to be meaningfully included *in* the community. The Home and Community Based Services (HCBS) Settings Rule was introduced to expand community integration, person-centered services, and choice. The aim of this exploratory study is to examine the potential impact of HCBS Settings Rule implementation, specifically by examining how the presence of HCBS Settings Rule outcomes impact three areas of health and safety. We analyzed secondary Personal Outcome Measures[®] data relating to the HCBS Settings Rule, and emergency room visits, abuse and neglect, and injuries data from 251 people with IDD. Findings indicate a clear need to improve HCBS Settings Rule related areas of people's lives.

Keywords: Medicaid Home and Community Based Services (HCBS) Settings Rule; community living; emergency room utilization; safety

The Impact of Home and Community Based Settings (HCBS) Final Settings Rule Outcomes on Health and Safety

In the United States, services for people with intellectual and developmental disabilities (IDD) have shifted from an institutional model to a community model. While the institutional model limited people with IDD's rights and opportunities and kept them segregated, the community model's aim is community integration and person-centered planning – services and supports prioritized by the person with IDD. In fact, the institutionalization of people with IDD has been on a downward trend since 1967 due to a number of factors including advocacy from people with disabilities and their families, and state and federal initiatives resulting in the downsizing of institutions and expansion of community alternatives (Braddock, 2007; Braddock et al., 2015; Trent, 1994). Another contributor to deinstitutionalization was the introduction of Medicaid Home and Community Based Services (HCBS), which allow states to provide services and supports in the community for those people who might otherwise need institutional care.

Today in the United States, Medicaid provides the majority of federal funding for people with IDD (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). Of that funding, approximately two-thirds is provided by Medicaid HCBS 1915(c) waivers, making them the largest funder of long-term services and supports (LTSS) for people with IDD (Braddock et al., 2017). Medicaid HCBS waivers, which were developed in 1981 as an alternative to institutional care, allow states to 'waive' the three main provisions of the Social Security Act (i.e., state-wideness, comparability, and income and resource rules) in order to tailor services for particular underserved populations that would otherwise require institutional based care (U.S. Department of Health and Human Services, 2000). These customized programs give states the flexibility to determine target groups (e.g., people with IDD, older adults, people with HIV/AIDs), services, participant direction

options, provider qualifications, health and welfare strategies, and cost-effective delivery systems at the state level (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015).

HCBS waiver funding has far surpassed institutional funding to become the largest funding stream for LTSS for people with IDD because of cost effectiveness, the benefits of community living, and the preferences of people with IDD (Braddock et al., 2015; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). Yet, despite these radical shifts in institutionalization and the advantage of HCBS, people with IDD still struggle to be meaningfully included in and engaged with the community, in large part because of a lack of community infrastructure (Cullen et al., 1995; Forrester-Jones et al., 2002; Friedman, 2019a; Ligas Consent Decree Monitor, 2016, 2017). This is one of the many reasons the Department of Health and Human Services' Community Living initiative introduced a new HCBS regulation in 2009, called the HCBS Final Settings Rule (CMS 2249-F/2296-F). 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" (Centers for Medicare and Medicaid Services, 2014b, n.p.). As such, the rules shift "away from defining home and community-based settings by 'what they are not,' and toward defining them by the nature and quality of participants' experiences" (Centers for Medicare and Medicaid Services, 2014a, p. 2). The HCBS Settings Rule, which was implemented in 2014, "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" (Centers for Medicare and Medicaid Services, 2014a, p. 2).

The HCBS Settings Rule involves regulatory changes that states must implement if they are to continue to receive Medicaid funding for HCBS (Centers for Medicare and Medicaid Services, 2014b). There are also specific requirements for providers of HCBS. One of the main focuses of the HCBS Settings Rule is community access and inclusion; the HCBS Settings Rule has clear requirements enforcing community-based settings. States and providers are not only required to provide community opportunities, but those opportunities must also be meaningful (Centers for Medicare and Medicaid Services, 2014b; State of Tennessee, n.d.). People receiving HCBS must be integrated, and should be supported to have full access to the greater community, including for employment, to the same degree as people not receiving HCBS (Centers for Medicare and Medicaid Services, n.d.). The setting must be selected by the person from a range of options, including non-disability specific settings; people must have the option of a private unit and should be able to choose their roommates (Centers for Medicare and Medicaid Services, n.d.). In addition, settings must not only ensure privacy, dignity and respect, and freedom from coercion and restraint, but also facilitate autonomy, independence, and choice. These changes mean that people with disabilities must also have access to things such as keys to their homes and their own money.

The HCBS Settings Rule also emphasizes person-centered services and choice. People should be able to choose their services and supports as well as who provides those services (Centers for Medicare and Medicaid Services, n.d.). People must be able to choose where they live and with whom. People with disabilities should have choice about factors such as when they have visitors, where they work, and what services they receive. As such, the HCBS Settings Rule is focused around person-centered planning; LTSS must be directed by the individuals' preferences and goals (Centers for Medicare and Medicaid Services, 2014b). Particular attention

is drawn to person-centered planning to promote community participation, employment, education, and healthcare, all of which could require shifts in how states and provider organizations provide services (Centers for Medicare and Medicaid Services, 2014a, 2014b). For example, under the new HCBS Settings Rule, states will find they need to move away from segregated day services in order to meet person-centered planning and community participation requirements.

Although the HCBS Settings Rule regulations may appear straightforward, ensuring that people with IDD have meaningful community inclusion and integration requires a complex overhaul of a system where currently people have more so been physically relocated in the community rather than meaningfully integrated into it (Friedman, 2019a; Friedman & Spassiani, 2017). For this reason, the Centers for Medicare and Medicaid Services (CMS) requires states develop and submit state transition plans (STP), which document the process of change to comply with the new rules. As of September 2019, only 16 states had received final approval from CMS for their transition plan. This is despite the fact that the original deadline for final approval was 2019. In mid-2017, the deadline was extended to 2022 (Neale, 2017) in recognition that more work was needed to turn the regulations of the HCBS Settings Rule from theory to actual implementation. As such, currently the HCBS Settings Rule remain relatively abstract theory and aims, and has yet to become practice.

While not specifically about the HCBS Settings Rule, research suggests tenants of the HCBS Settings Rule, such community integration, employment opportunities, physical environments, educational opportunities, social exclusion, etc., can play a role in either facilitating or hindering people's quality of life and health (Abbott & Elliott, 2017; Compton & Shim, 2015; Emerson et al., 2011; Raphael, 2006; United States Department of Health & Human

Services, 2015; United States Office of Disease Prevention and Health Promotion, n.d., n.p.; World Health Organization, 2010). For example, segregation and social exclusion both negatively impact people's health and lead to worse health outcomes (Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010). Kim, Chen, and Spencer (2012) explain, social stratification emerges as a consequence of persistently biased social and economic policies that favor a majority group holding power. As a result, social stratification puts those with less power and fewer resources at risk for differential exposure and vulnerability to health and mental health problems, as well as the consequences of these problems. (p. 346)

The potential impact factors such as community integration, employment opportunities, and environments can have on people's health may be particularly important for people with disabilities as they have significantly poorer health than nondisabled people because of health inequities and socioeconomic disadvantages (Altman & Bernstein, 2008; Emerson et al., 2011; Iezzoni, 2011; Krahn, Walker, & Correa-De-Araujo, 2015). For these reasons, the aim of this exploratory study is to examine the potential impact of HCBS Settings Rule implementation on people with IDD, specifically by examining how the presence of HCBS Settings Rule outcomes impact three areas of people's health and safety. We had the following research questions:

1. what is the relationship between HCBS Settings Rule outcomes and emergency room utilization (visits)?
2. what is the relationship between HCBS Settings Rule outcomes and incidents of abuse and neglect?
3. what is the relationship between HCBS Settings Rule outcomes and injuries?

To explore these questions, we analyzed secondary Personal Outcome Measures[®] quality of life

data pertaining to the HCBS Settings Rule, and data regarding emergency room visits, incidents of abuse and neglect, and injuries from a random sample of 251 people with IDD.

Method

Data and Participants

This was a secondary data analysis. Data were originally collected from adults with IDD 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 them. This included emergency room visit data, abuse and neglect incident data, and injury data from 2016 through 2018. All personal identifiers were removed, and the data were coded with identifiers; the data were then transferred to the research team.

Our secondary dataset included a total of 251 people with IDD (Table 1). Gender was relatively evenly distributed amongst men (52.19%) and women (47.81%). Most participants were White (72.65% (mirrors state population)) and had a primary communication method of verbal/spoken language (80.08%). The most common disabilities (in addition to IDD) were seizure disorder/neurological problems (29.96%), anxiety disorders (25.10%), and mood disorder (22.27%). Almost a quarter (24.30%) of participants had 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 ($SD = 14.75$).

Variables

Dependent variables. We had different dependent variables (DV) for each of our three different research questions: emergency room visits; incidents of abuse and neglect; and, injuries. Emergency room visits was comprised of every single time a person in the sample visited an emergency room, regardless of the type of incident or severity. Incidents of abuse and neglect included every single allegation of abuse, neglect, and exploitation, both physical and emotional, regardless of if they were substantiated or not. Injuries included every single time a person was injured, regardless of the severity of the injury; examples include burns, lacerations, loss of consciousness, fractures, and so on. Each of the DVs were comprised of three years of data: 2016 through 2018.

Independent variables. The independent variable (IV) for this study was HCBS Settings Rule outcomes, derived from Personal Outcome Measures[®] interviews conducted in 2018. The Personal Outcome Measures[®] measures people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. 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 key stakeholders about what really mattered in their lives. The Personal Outcome Measures[®] has been continuously refined over the past two decades through pilot testing, a 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).

For every participant, the Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a trained Personal Outcome Measures[®] interviewer has an in-depth conversation(s) with the participant with IDD about each of the indicators. For these conversations, the interviewer follows specific open-ended prompts. During the second stage of the Personal Outcome Measures[®] interview, the interviewer speaks with someone who knows the participant with IDD best, and knows about organizational supports to the person, such as a case manager or direct support professional, and asks them questions about individualized supports and outcomes to fill in any gaps. During the final stage, if further information is required, the interviewer observes the participant in various settings and conducts individual record reviews. The interviewer then completes decision trees about personal outcomes based on the information gathered in the three stages (for more information about decision trees for each indicator, see The Council on Quality and Leadership (2017b)).

The Personal Outcome Measures[®] includes 21 areas of quality of life, called indicators. We applied the crosswalk between the HCBS Settings Rule and the Personal Outcome Measures[®] (Melda & Smith, 2014) to select indicators that aligned with the HCBS Settings Rule. The following 11 indicators were utilized:

- People use their environments,
- People live in integrated environments,
- People interact with other members of the community,
- People participate in the life of the community,
- People exercise rights,
- People choose where and with whom to live,
- People choose where to work,

- People choose services,
- People choose personal goals,
- People are respected, and
- People are free from abuse and neglect.

People's aggregate score on the 11 indicators was then utilized as their HCBS Settings Rule outcome score.

Control variables. Two demographic variables were used as controls (CVs). The first CV was intellectual disability level. This variable was comprised of people's intellectual disability level according to their clinical DSM diagnosis; intellectual disability level was classified into four categories: mild intellectual disability, moderate intellectual disability, severe intellectual disability, and profound intellectual disability. Diagnosis level was utilized as a proxy for severity of impairment; research suggests people with more severe impairments face disparities in outcomes (Beadle-Brown et al., 2016; Friedman, 2019b; Petry, Maes, & Vlaskamp, 2005). Forty percent of the sample ($n = 98$) was diagnosed with a mild intellectual disability, 33.06% moderate ($n = 81$), 13.88% severe ($n = 34$), and 13.06% profound ($n = 32$).

Our second CV was dual diagnosis status (yes or no); dual diagnosis commonly refers to those people with IDD who also have a psychiatric disability. Dual diagnosis was utilized as a variable because research has found a relationship between community living, institutionalization, and dual diagnosis – as a result of a lack of community infrastructure to support them, people with dual diagnosis are often the last to be released from institutions as well as are more likely to be re-institutionalized (Charlot & Beasley, 2013; Lulinski, 2014; Mansell, 2006; McIntyre, Blacher, & Baker, 2002). In our sample, 60.32% of people ($n = 149$) had a dual diagnosis, while 39.68% ($n = 98$) had IDD but did not have a psychiatric disability.

Analysis

This study's first research question was: what is the relationship between HCBS Settings Rule outcomes and emergency room utilization (visits)? To explore this research question, a multiple linear regression model was used with the HCBS Settings Rule outcomes variable serving as the IV and the number of emergency room visits serving as the DV. We also controlled for the intellectual disability level, and dual diagnosis status. It should be noted the assumption of normality was not met; however, the sample size was sufficiently large to compensate (Field, 2013; Lumley, Diehr, Emerson, & Chen, 2002).

This study's second research question was: what is the relationship between HCBS Settings Rule outcomes and incidents of abuse and neglect? To explore this research question, a multiple linear regression model was used with the HCBS Settings Rule outcomes variable serving as the IV and incidents of abuse and neglect serving as the DV. We controlled for the intellectual disability level and dual diagnosis status. Again, the assumption of normality was not met, but the sample size was sufficiently large to compensate (Field, 2013; Lumley et al., 2002).

This study's third research question was: what is the relationship between HCBS Settings Rule outcomes and injuries? To explore this research question, a multiple linear regression model was used with HCBS Settings Rule outcomes variable serving as the IV and the number of injuries serving as the DV; we controlled for the intellectual disability level and dual diagnosis status. The assumption of normality was not met. However, the sample size was sufficiently large to compensate (Field, 2013; Lumley et al., 2002).

Results

On average, people scored 4.69 out of the possible 11 HCBS Settings Rule outcomes present ($SD = 2.29$), ranging from 0 outcomes present to 10 outcomes present across the

participants. More than half of the participants (61.75%) had fewer than 6 of the possible 11 HCBS Settings Rule outcomes present (see Figure 1).

The number of emergency room visits ranged from 0 to 64 per person in the three-year period, with an average of 3.73 visits ($SD = 6.93$). The number of abuse and neglect incidents ranged from 0 to 29 per person in the three-year period, with an average of 1.23 incidents ($SD = 2.77$). The number of injuries ranged from 0 to 44 per person in the three-year period, with an average of 1.63 injuries ($SD = 3.83$).

Emergency Room Visits

We ran a multiple linear regression model to explore the relationship between HCBS Settings Rule outcomes (IV) and emergency room visits (DV), while controlling for clinical intellectual disability level and dual diagnosis status (CVs). The model was significant, $F(5, 240) = 2.74, p = 0.040, R^2 = 0.055$. The HCBS Settings Rule outcomes term was significant, $t = -3.01, p = 0.003$ (Table 2). According to the model, the more HCBS Settings Rule outcomes a person has present, the fewer emergency room visits they are expected to have. For example, controlling for all other variables, a person with one of the possible 11 HCBS Settings Rule outcomes present is expected to visit the emergency room 4.77 times in three-years (an average of 1.59 times a year), whereas a person with five HCBS Settings Rule outcomes present is expected to visit the emergency room 2.42 times in three-years (an average of 0.81 times a year; see Figure 2).

Abuse and Neglect

We also ran a multiple linear regression model to explore the relationship between HCBS Settings Rule outcomes (IV) and abuse and neglect incidents (DV), while controlling for clinical intellectual disability level and dual diagnosis status (CVs). The model was significant, $F(5,$

240) = 3.62, $p = 0.004$, $R^2 = 0.071$. HCBS Settings Rule outcomes and dual diagnosis terms were significant, $t = -2.52$, $p = 0.013$ and $t = 2.35$, $p = 0.020$ respectively (Table 2). According to the model, the more HCBS Settings Rule outcomes a person has present, the fewer incidents of abuse and neglect they are expected to experience. For example, controlling for all other variables, a person with one of the possible 11 HCBS Settings Rule outcomes present is expected to experience 1.58 incidents of abuse and neglect in a three year period (an average of 0.53 a year), whereas a person with five of the possible 11 HCBS Settings Rule outcomes present is expected experience 0.80 incidents in three-years (an average of 0.27 times a year; see Figure 3). The CV dual diagnosis status was also significant – people with dual diagnosis experienced significantly more incidents of abuse and neglect than people with IDD without psychiatric disabilities. For example, controlling for all other variables, people with dual diagnosis are expected to experience 2.64 incidents of abuse and neglect in three-years (an average of 0.88 a year), whereas people with IDD without psychiatric disabilities are expected to experience 1.77 incidents in three-years (an average of 0.59 times a year).

Injuries

Finally, we ran a multiple linear regression model to explore the relationship between HCBS Settings Rule outcomes (IV) and injuries (DV), while controlling for clinical intellectual disability level and dual diagnosis status (CVs). The model was significant, $F(5, 240) = 3.52$, $p = 0.004$, $R^2 = 0.070$ (Table 2). HCBS Settings Rule outcomes and dual diagnosis were significant, $t = -2.50$, $p = 0.013$ and $t = 2.32$, $p = 0.021$ respectively. According to the model, the more HCBS Settings Rule outcomes a person has present, the fewer injuries are expected. For example, controlling for all other variables, a person with one of the possible 11 HCBS Settings Rule outcomes present is expected to have 1.48 injuries in three-years (an average of 0.49 a

year), whereas a person with five of the possible 11 HCBS Settings Rule outcomes present is expected to have 0.48 injuries in three-years (an average of 0.16 times a year; see Figure 4). The CV dual diagnosis status was also significant – people with dual diagnosis experienced significantly more injuries than people with IDD without psychiatric disabilities. For example, controlling for all other variables, people with dual diagnosis are expected to have 2.93 injuries in three-years (an average of 0.98 a year), whereas people with IDD without psychiatric disabilities are expected to have 1.73 injuries in three-years (an average of 0.58 times a year).

Discussion

If implemented with fidelity, the HCBS Settings Rule has the potential to radically transform not only the IDD LTSS service system, but also people with IDD's lives. Yet, much work needs to be done to uphold the principles set forth by the HCBS Settings Rule. Not only have most states not received final approval for their transition plans, many people with IDD remain isolated and do not receive person-centered services and supports (Cullen et al., 1995; Forrester-Jones et al., 2002; Friedman, 2019a; Ligas Consent Decree Monitor, 2016, 2017). In fact, the people with IDD in our study lacked many of the HCBS Settings Rule related outcomes. Most of the participants in our study had few HCBS Settings Rule outcomes present, with the majority of participants scoring fewer than 5 of the possible 11 outcomes present; we believe this finding not only reflects how much the HCBS Settings Rule is needed, but also how much system transformation is truly necessary to change the HCBS Settings Rule from policy to practice.

While our findings indicate a clear need to improve HCBS Settings Rule related areas of people with IDD's lives, they also suggest that by increasing outcomes related to the HCBS Settings Rule, we will not only see increases in areas of people's quality of life, but also their

health and safety. For example, our findings revealed a significant relationship between HCBS Settings Rule outcomes, and people with IDD's emergency room utilization, wherein people with more HCBS Settings Rule outcomes present visited the emergency room less often. Needing to constantly visit the emergency room is reflective of a life not only lacking in continuity and stability, but also a hindered quality of life. Moreover, the very medical and behavioral needs which result in hospitalizations, can also lead to re/institutionalization. In fact, one of the most common reasons people with IDD return to institutions is because of complex needs (Causby & York, 1991; Intagliata & Willer, 1982; Lulinski-Norris, 2014; Lulinski-Norris, Rizzolo, & Heller, 2012; Trent, 1994). In addition, as emergency room visits and hospitalizations are a leading cause of expenditures, a reduction in emergency room visits may also lead to reduced costs and expenditures (Blaskowitz, Hernandez, & Scott, 2019; Centers for Medicare and Medicaid, n.d.), which could then be reinvested in community-based LTSS for people with IDD.

Our findings also suggest that the more HCBS Settings Rule outcomes people have present – the more their lives reflect the aims set forth by the HCBS Settings Rule – the less likely they are to experience abuse and neglect. Abuse and neglect are a particularly prominent issue for people with IDD as people with IDD are significantly more likely to be victims of abuse and neglect than nondisabled people or people with other disabilities. In fact, estimates suggest 25-67% of people with IDD have experienced some form of abuse or mistreatment (Baladerian, Coleman, & Stream, 2013). Moreover, people with IDD are seven times more likely to be victims of sexual assaults than nondisabled people (Shapiro, 2018). As a result of the serious risk of harm people with IDD face, a recent Joint Report from the U.S. Department of Health and Human Services (HHS), Office of Inspector General, Administration on Community

Living, and Office for Civil Rights (2018) concluded, incidences of abuse and neglect “are not isolated incidents but a systemic problem” (p. 3). As such, cultural and structural change is needed to reduce the plethora of abuse and neglect people with IDD face. Although the HCBS Settings Rule will not by itself solve these disparities in abuse and neglect, our findings suggest it may play a role in helping reduce them. In fact, the HCBS Settings Rule draws particular attention to reducing risk factors, facilitating health and welfare, and ensuring people have freedom from coercion and restraint (Melda & Smith, 2014; Neale, 2017).

Finally, our findings also suggest that if people have HCBS Settings Rule outcomes present, they have fewer injuries. The HCBS Settings Rule aims to ensure people are integrated rather than segregated, are participating in meaningful activities, including those of ones’ choosing, and are having richer and more fulfilling lives, all of which serve as social determinants of health. 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” (United States Office of Disease Prevention and Health Promotion, n.d., n.p.). For example, the physical and social neighborhood and communities people inhabit are social determinants of health (Compton & Shim, 2015; Currie et al., 2009; Kim et al., 2012; Raphael, 2006; United States Office of Disease Prevention and Health Promotion, n.d.). Moreover, segregation, social stratification, and social exclusion all negatively impact people’s health (Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010). For example, research has found that residential segregation often produces health inequities (United States Office of Disease Prevention and Health Promotion, n.d.). In addition, isolation and loneliness have also been tied to negative health outcomes (Emerson et al., 2011; Hawkey & Capitanio, 2015; Larsson, 2013; Lauder, Kroll, & Jones, 2007; Leigh-Hunt et al.,

2017; Smith, Jackson, Kobayashi, & Steptoe, 2018; Tomaka, Thompson, & Palacios, 2006; World Health Organization, 2006, 2010). As social determinants of health can either hinder or facilitate people's health, we believe the link between reduced injuries and HCBS Settings Rule outcomes is reflective of the impacts of social determinants of health. However, more research is needed to explore the intermediary factors that specifically lead people to have fewer injuries.

Although not the aim of our study, we did explore the relationship between the health and safety factors, and dual diagnosis status as a CV. In doing so we found that people with dual diagnosis – IDD and psychiatric disabilities – had worse health and safety outcomes than people with IDD who did not have psychiatric disabilities. As a result, and because a lack of community infrastructure to support people with dual diagnosis can hinder community living, we believe it is important to draw attention to the lack of appropriate, adequate, and community-based services and supports for people with dual diagnosis. This lack of adequate services can majorly hinder the community living of people with dual diagnosis, particularly as it one of the leading reasons people with dual diagnosis are the last to be released from institutions, have less successful community transitions, and are most at risk for reinstitutionalization (Charlot & Beasley, 2013; Lulinski, 2014; Mansell, 2006; McIntyre et al., 2002). As such, in order to align with the requirements of the HCBS Settings Rule, particular attention must be drawn to having a robust service system for people with dual diagnosis.

Limitations

When interpreting these findings, a number of limitations should be considered. Although the sample was random, the participants were all from one state and 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. For example, we did not have data about

the lasting impact of abuse and neglect, or other similar factors related to the incidents of emergency room visits, abuse and neglect, and injuries. As it was outside of the scope, we also did not explore interactions between variables. The models also explained low amounts of variance; however, our aim was to examine the relationships and not necessarily the best predictors of the three health and safety outcomes. Finally, we also believe these limitations should be interpreted as avenues for future study. While this study was, to our knowledge, one of the first to explore these relationships, it should in no way be the last. We encourage additional research, not only to further evidence-base for the impact of the HCBS Settings Rule, but also to further the quality of life of people with IDD.

Conclusion

The aim of this study was to examine the potential impact of HCBS Settings Rule implementation on people with IDD, specifically by examining how the presence of HCBS Settings Rule outcomes impact three areas of people's health and safety. In doing so, we found that the HCBS Settings Rule has the potential to not only increase community integration and choice, but also to reduce emergency room visits, incidents of abuse and neglect, and injuries. The HCBS Settings Rule represents a tremendous opportunity to improve people with IDD's quality of life and help ensure the LTSS service system is person-centered and outcome oriented.

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Table 1
Participant Demographics (n = 251)

Variable	<i>n</i>	%
Disabilities other than intellectual disability (<i>n</i> = 247)		
Seizure disorder/neurological problems	74	29.96
Anxiety disorders	62	25.10
Mood disorder	55	22.27
Personality/psychotic disorder	46	18.62
Cerebral palsy	41	16.60
Behavioral challenges	33	13.36
Autism spectrum disorder	30	12.15
Impulse-control disorder	29	11.74
Limited or no vision - legally blind	15	6.07
Physical disability	11	4.45
Down syndrome	9	3.64
Hearing loss - severe or profound	8	3.24
Alzheimer's disease	2	0.81
Brain injury	2	0.81
Other psychiatric diagnosis	35	14.17
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
Primary method of communication		
Verbal/spoken language	201	80.08
Face/body expression	43	17.13
Sign language	3	1.20
Communication device	1	0.40
Other	3	1.20
Race (<i>n</i> = 245)		
White	178	72.65
Black	63	25.71
Latinx	5	2.04
Asian	1	0.41
Other	1	0.41
Residence type		

Provider-owned or -operated home	96	38.25
Own home/apartment	78	31.08
Family's house	57	22.71
Host family/family foster care	14	5.58
State-operated HCBS group home	4	1.59
Other	2	0.80
Intellectual disability level (clinical diagnosis; n = 245)		
Mild	98	40.00
Moderate	81	33.06
Severe	34	13.88
Profound	32	13.06
Dual diagnosis (IDD and psychiatric disability; n = 247)		
Yes	149	60.32
No	98	39.68

Note. Participants could have more than one disability or race. HCBS = Home and Community Based Services.

Table 2

Multiple Linear Regression Models

Variables	Emergency room visits				Abuse and neglect incidents				Injuries			
	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>B</i>	<i>SE</i>	β	<i>t</i>
(Constant)	5.35	1.38		3.88***	1.77	0.54		3.25**	2.00	0.75		2.65**
HCBS Settings Rule Outcomes Clinical intellectual disability level (ref: Mild)	-0.59	0.19	-0.19	-3.01**	-0.19	0.08	-0.16	-2.52*	-0.27	0.11	-0.16	-2.50*
Moderate	0.42	1.05	0.03	0.40	0.15	0.42	0.03	0.36	0.85	0.58	0.10	1.48
Severe	-0.68	1.40	-0.03	-0.48	-0.89	0.55	-0.11	-1.60	-0.08	0.77	-0.01	-0.11
Profound	0.97	1.45	0.05	0.67	-0.58	0.57	-0.07	-1.00	-0.55	0.80	-0.05	-0.69
Dual diagnosis (ref: IDD only)	1.73	0.94	0.12	1.83	0.88	0.37	0.15	2.35*	1.20	0.52	0.15	2.32*

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

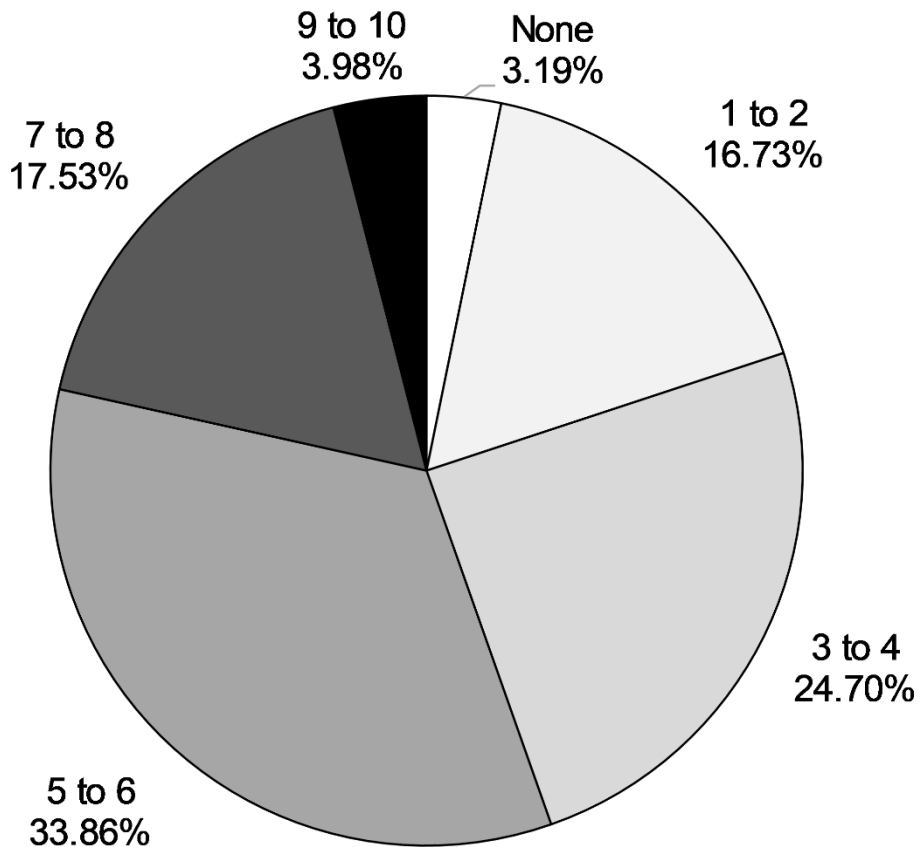


Figure 1. HCBS Settings Rule outcomes present across participants. HCBS = Home and Community Based Services.

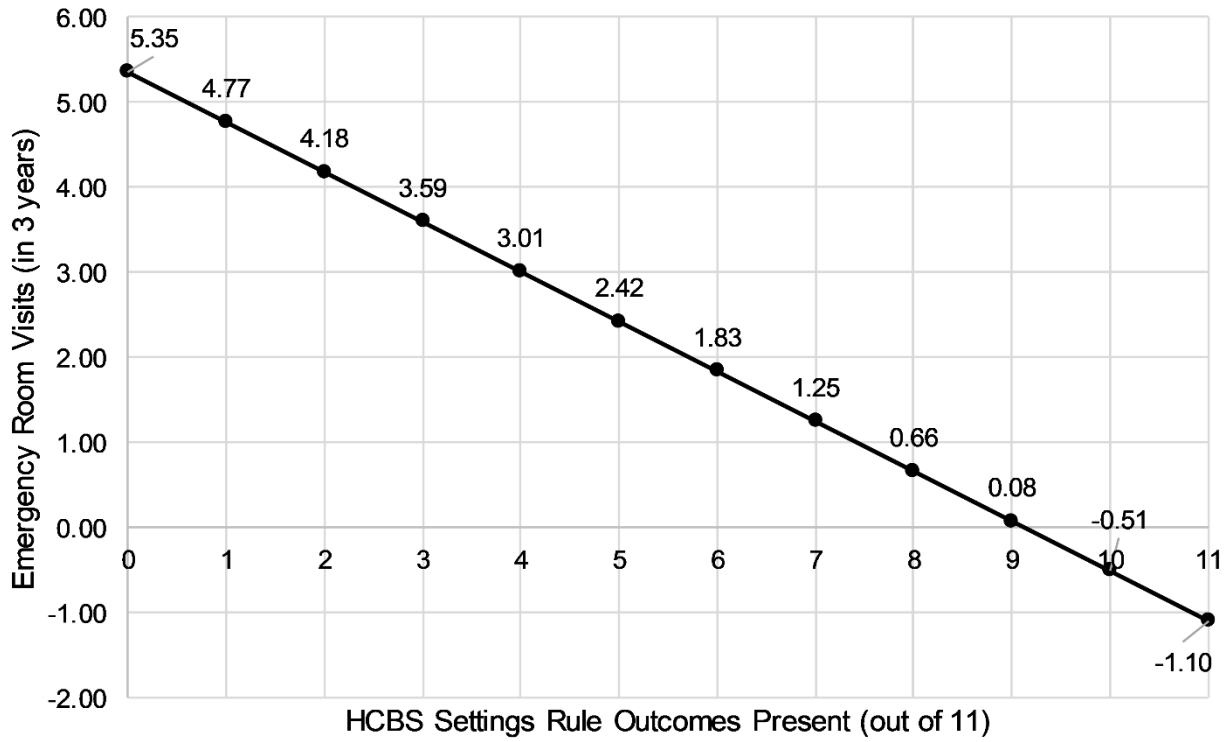


Figure 2. Relationship between HCBS Settings Rule outcomes and emergency room visits in three years (controlling for intellectual disability level and dual diagnosis). HCBS = Home and Community Based Services.

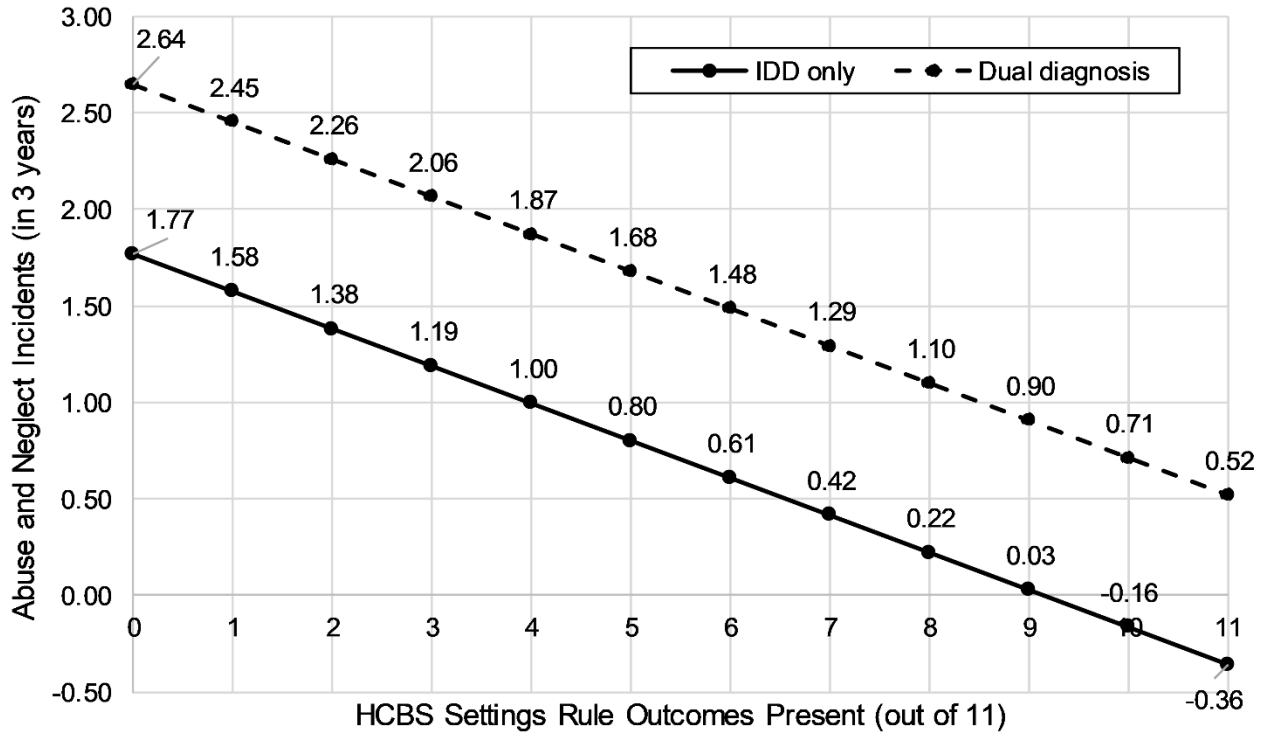


Figure 3. Relationship between HCBS Settings Rule outcomes and abuse and neglect incidents in three years (controlling for intellectual disability level). HCBS = Home and Community Based Services.

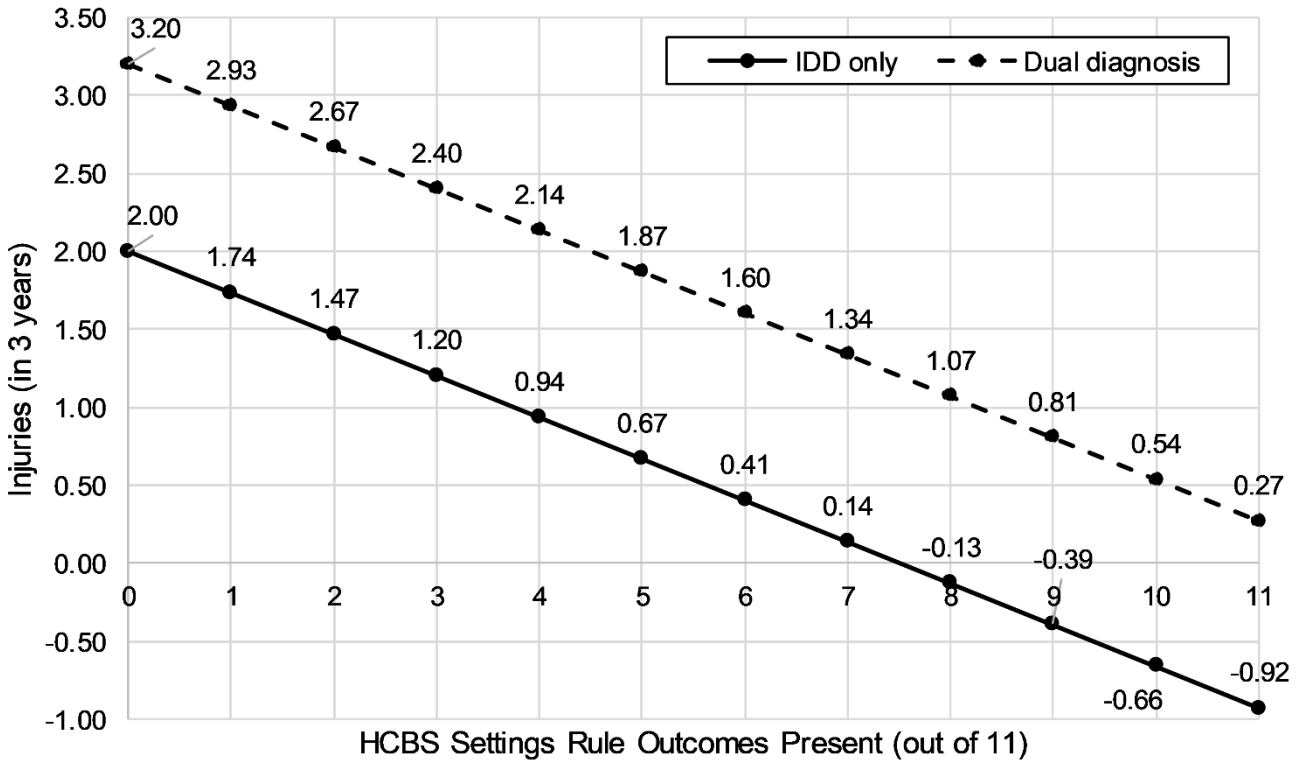


Figure 4. Relationship between HCBS Settings Rule outcomes and injuries in three years (controlling for intellectual disability level). HCBS = Home and Community Based Services.