Managed Care and Value-Based Payment: The Relationship Between Quality of Life Outcomes and Emergency Room Utilization

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Abstract

Although Medicaid managed care is a growing service model, there is limited evidence-base regarding quality and value-based payment standards for people with intellectual and developmental disabilities (IDD). This study examined the relationship between emergency room utilization and quality of life outcomes. We analyzed secondary Personal Outcome Measures® quality of life and emergency room utilization data from 251 people with IDD. According to our findings, people with IDD with continuity and security in their lives, and who participated in the life of the community had fewer emergency room visits, regardless of their impairment severity or dual diagnosis status. As such, the number of emergency room visits needed, and thus the potential expenditures associated, may be reduced by focusing on quality outcomes.

Keywords: Medicaid managed care; Long-term services and supports; quality of life; emergency room utilization

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People with intellectual and developmental disabilities (IDD) experience health disparities when compared to nondisabled people – they have significantly poorer health than nondisabled people (Ouellette Kuntz, 2005). For example, compared to nondisabled people, people with IDD are more likely to have hypertension, cardiovascular disease, osteoporosis, and many other health concerns (Haveman et al., 2010). In addition, people with IDD often experience age related health conditions earlier and more frequently than nondisabled people (Glasson, Dye, & Bittles, 2014; Nochajski, 2000; World Health Organization, 2001). People with IDD's health disparities are only in part due to their impairments and genetics; social circumstances, environmental conditions, access to healthcare services, poverty, social exclusion, and ableism – social determinants of health – play a large role in people with IDD's health (Taggart & Cousins, 2014). In fact, in the United States, people with people with disabilities' health and quality of life are largely impacted by the government services they receive (Burns, 2009b; Frank, Goldman, & Hogan, 2003; citation removed for review).

As a result of the unique needs of people with IDD, services and supports are often unique, even compared to people with other types of disabilities (Braddock, Hemp, Tanis, Wu, & Haffer, 2017; Burns, 2009b; Lunsky, De Oliveira, Wilton, & Wodchis, 2019; citation removed for review). Long-term services and supports (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 in the United States often includes not only traditional acute care health services, but more wrap-around services, such as residential habilitation, supports for people to live in their own homes or family homes, day habilitation, employment supports, and many more (citation removed for review). In fact, of the $25.6 billion projected for the Medicaid Home and Community Based Services (HCBS) waiver services for people with IDD – the largest funder of LTSS for people with IDD in the United States – in fiscal year (FY) 2015, less than 5% of the total projected spending was allocated for traditional acute care services (Braddock et al., 2017; citation removed for review).

In the United States, Medicaid funds the majority of government spending (federal, state and local; 76% in FY 2015) for people with IDD (Braddock et al., 2017). During the Great Recession (2007-2009), the proportion of Medicaid spending going toward people with IDD dropped (Braddock et al., 2015). Although states have allocated more funds toward community supports and institutional care in wake of recovery from the Great Recession, the community infrastructure for LTSS is lacking (Braddock et al., 2015). For example, there are large waiting lists for services, with approximately half a million people with IDD waiting for Medicaid HCBS alone as of 2016 (The Henry J. Kaiser Family Foundation, n.d.). As states grapple with an inadequate and underfunded service system, Medicaid managed care has rapidly become a growing service model in the United States (Williamson et al., 2017).

Medicaid Managed Care

The Centers for Medicare and Medicaid Services (CMS; n.d.-a) explain, Medicaid managed care

> is a health care delivery system organized to manage cost, utilization, and quality. 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.)

As of July 2014, 55 million people were enrolled in managed care in the United States (Centers for Medicare and Medicaid, n.d.-a).

The purported aims of managed care are to not only increase the quality of health services but also to reduce program costs. Although the way in which states implement managed care varies widely (Carmody, 2019), managed care is associated with alternative payment models. Traditionally, a fee-for-service (FFS) model has been used to provide Medicaid services. In a FFS model, reimbursement for services is based on the number of services provided. For example, there would be a reimbursement for the number of times a person with IDD had sessions with a therapist, regardless of if, or how, those services produced favorable outcomes. Under alternative payment models, MCOs are incentivized to minimize service costs, and maximize profits (Yamaki, Wing, Mitchell, Owen, & Heller, 2018). One such mechanism employed to do so is value-based payments (VBP), also called value-based reimbursement. VBP shift from focusing on the *number* of services provided in FFS, to the *quality* of those services – the outcomes. Value-based thinking recognizes emphasis on quality ultimately results in reduced health care costs. The Centers for Medicare and Medicaid Services (n.d.-b) notes, “shifting the focus away from volume of care” incentivizes “providers to improve coordination of care efforts;” in doing so, “states can begin to move toward a more proactive, population-based service delivery system rather than reactive, individual-focused care” (p. 6).

In 2019, the most prevalent performance measures in VBP contracts were: follow-up after hospitalization; hospital readmission rates; emergency room utilization; patient/consumer satisfaction; and, access to care models (Oss, 2019). Increased emergency room visits and hospital admissions are associated with increased expenditures (Blaskowitz, Hernandez, & Scott, 2019). As such, as indicated by their prevalence as performance measures, reducing hospital admissions and emergency room utilization is one mechanism used to reduce healthcare costs (Blaskowitz et al., 2019; Centers for Medicare and Medicaid, n.d.-b). However, it should be recognized that these common VBP measures are more traditionally associated with acute care than LTSS (Oss, 2019). The lifelong nature of LTSS require a different set of services and supports than other models, such as acute health care, which tends to be more episodic (Carmody, 2019). In addition, for managed care for people with IDD in particular, there is a lack of agreement regarding measurable and meaningful outcomes (Carmody, 2019, August 28; citation removed for review).

Medicaid Managed Care and People with Intellectual and Developmental Disabilities

In fact, there is little research about the quality standards which should be employed for managed LTSS for people with IDD in general. This is in large part due to the fact that despite managed care existing for almost two decades, it is still infrequently used for LTSS for people with IDD (Burns, 2009a). As of 2017, 19 states enrolled some portion of people with IDD in managed care; however, people with IDD in LTSS are mostly carved out of managed care, with only nine states covering HCBS for people with IDD through managed care (Lewis, Eiken, Amos, & Saucier, 2018). One of the few studies to examine managed care expenditures and outcomes for people with IDD found that managed care did not reduce acute health expenditures; instead, managed care was cost-neutral (Yamaki et al., 2018). However, when Yamaki, Wing, Mitchell, Owen, and Heller (2017) examined managed care provision in Illinois they found those people with IDD receiving managed care utilized the emergency room less frequently than people with IDD not receiving managed care. Similarly, Yamaki, Wing, Mitchell, Owen, and Heller (2019) found managed care for people with IDD resulted in reductions in emergency department utilization, which Yamaki et al. (2019) attributed to a reduction of visits related to non-emergencies, and mental/behavioral health conditions. One of the few other studies to examine emergency room utilization of people with IDD, Blaskowitz et al. (2019), found that correlates of emergency room utilization included age, multiple chronic health conditions, psychiatric disabilities, cerebral palsy, neurological disabilities, and polypharmacy.

Purpose

Although managed care, in theory, represents an opportunity to facilitate outcomes and quality while reducing costs, there is little evidence-base regarding managed LTSS for people with IDD. This lack of research is pertinent not only because managed care is becoming more prominent for people with IDD, but also because people with disabilities' health and quality of life is "particularly sensitive to the accessibility of their health care" (Burns, 2009a, p. 1521). As such, more research is needed not only about managed care for people with IDD more broadly, but also specifically regarding VBP, emergency room utilization, and outcomes. For this reason, the aim of this exploratory study was to determine the relationship between people with IDD's emergency room utilization and their quality of life outcomes. In doing so, we analyzed secondary Personal Outcome Measures® quality of life data, and emergency room utilization data from 251 people with IDD.

Methods

Data and Participants

This was a secondary data analysis. Data were originally collected from adults (age 18+) 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 room visit data from 2016 through 2018. All personal identifiers were removed and the data were coded with identifiers; then the data were transferred to the research team.

Our secondary dataset included a total of 251 people with IDD (Table 1). Gender was relatively evenly distributed among men (52.19%) and women (47.81%). The mean age of participants was 47.47 (*SD* = 14.75). The most common disabilities (in addition to intellectual disability) 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. Most participants were White (72.65%) and had a primary communication method of verbal/spoken language (80.08%). Participants most often resided in provider-owned or -operated homes (38.25%), their own home/apartment (31.08%), and family homes (22.71%).

Variables

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

Independent variables. The independent variables (IVs) from this study were derived from Personal Outcome Measures® interviews conducted in 2018. The Personal Outcome Measures® determines 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, 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 (citation removed for review; The Council on Quality and Leadership, 2017a).

The Personal Outcome Measures® includes 21 indicators divided into five factors: My Human Security; My Community; My Relationships; My Choices; and, My Goals. *My human security* includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people experience continuity and security; people exercise rights; people are treated fairly; and, people are respected. *My community* includes the following indicators: people use their environments; people live in integrated environments; people interact with other members of the community; and, people participate in the life of the community. *My relationships* includes the following indicators: people are connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; and, people perform different social roles. *My choices* includes the following indicators: people choose where and with whom to live; people choose where to work (includes what they do during the day and retirement); and people choose their services. *My goals* includes the following indicators: people choose personal goals; and, people realize personal goals.

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 disabilities about each of the indicators. For these conversations, the interviewer follows specific open-ended prompts. If the person being interviewed has significant impairments and/or does not communicate with words, a series of techniques are applied to enhance communication, including augmentative alternative communication, observation, visual cues, photos, gestures, preference testing, and/or use of objects (Overpeck, 2019). During the second stage of the Personal Outcome Measures® interview, the interviewer speaks with someone who knows the participant with disabilities best, and knows about organizational supports, 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)). Using these decision trees, the interviewer determines if each of the 21 personal outcomes are present (1) or not (0).

Control variables. Three demographic variables were used as controls (CVs). The first CV was intellectual disability level. This variable included 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. 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 24/7 around the clock supports (yes or no); this variable also served as a proxy for impairment severity, as presumably those with more support have higher support needs. Almost three-quarters (74.19%) of the sample (*n* = 184) received 24/7 around the clock support, while 25.81% (*n* = 64) received less than 24/7 around the clock support daily.

Our third CV was dual diagnosis status (yes or no); dual diagnosis commonly refers to those people with IDD who also have a psychiatric disability. In our sample, 60.32% of people (*n* = 149) had a dual diagnosis, while 39.68% (*n* = 98) did not.

Analysis

This study's research question was: what is the relationship between quality of life outcomes and emergency room utilization (visits)? To explore this research question, a multiple linear regression model was used with 21 quality of life indicators from the Personal Outcome Measures® serving as the IVs and emergency room visits serving as the DV. We also controlled for the intellectual disability level, 24/7 around the clock supports, and dual diagnosis status.

Results

Twenty-one different areas of quality of life were explored using the Personal Outcome Measures® (Table 2). The quality of life indicators present most often across the participants were: people are safe (87.65%), people live in integrated environments (76.49%), and, people use their environments (74.50%). The indicators present least often were: people choose where and with whom to live (13.15%), people choose their services (14.34%), and people exercise rights (19.52%).

The number of emergency room 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), which is comparable to 1.24 visits a year per person. 82 people had no emergency room visits in the three-year period, 120 people between 1 and 5, 28 people between 6 and 10, 6 people between 11 and 15, 9 people between 16 and 20, 3 people between 21 and 25, and 3 people more than 26 (see Figure 1).

We ran a multiple linear regression model to explore the relationship between different areas of quality of life (the 21 personal outcomes) and emergency room utilization, controlling for intellectual disability level, dual diagnosis, and 24/7 support. The model was significant, F (26, 238) = 1.77, $p = 0.015$, $R^2 = 0.42$. The following IVs were significant: people experience continuity and security ($t = -2.00$, $p = 0.046$), and people participate in the life of the community ($t = -2.86$, $p = 0.005$; Table 3). The control variable 24/7 around the clock supports was also significant ($t = 2.78$, $p = 0.006$).

According to the model, controlling all other variables, people who experienced continuity and security had 1.20 emergency room visits within the three-year period (an average of 0.40 visits per person per year), whereas people who did not experience continuity and security had 3.57 emergency room visits within the same time period (an average of 1.19 visits per person per year). In addition, controlling all other variables, people who participated in the life of the community had 0.37 emergency room visits in the three-year period (an average of 0.12 visits per person per year), whereas people who did not participant in the life of the community had 3.57 emergency room visits within the three-year period (an average of 1.19 visits per person per year). There was also a significant relationship with the control variable, 24/7 supports; controlling for all other variables, people with 24/7 around the clock support had 6.97 emergency room visits in the three-year period (an average of 2.32 visits per person per year), versus people with less than 24/7 daily supports who had 3.57 (an average of 1.19 visits per person per year).

Discussion

Adults with IDD incur higher annual health care costs than people without IDD (Lunsky et al., 2019). In a reduced fiscal landscape, many states are moving to Medicaid managed care, including for people with IDD. Both because emergency room utilization is one of the most prevalent VBP metrics, and because there is a lack of research about quality outcomes for service provision for people with IDD, the aim of this exploratory study was to examine the relationship between people with IDD's quality of life and their emergency room utilization. In doing so, the findings of this study revealed the majority of the emergency room visits were made by a very small proportion of people. In fact, less than 10% of people in the sample made up more than half of the total emergency room visits. For example, one person alone used the emergency room 64 times within the three-year period, which is an average of two visits to the emergency room a month; that is not indicative of a person who is experiencing stable services or physical or mental health, or a person who has a high quality of life. Not to imply people should not visit the emergency room if they need to do so – certainly many visits were warranted and necessary – but there are likely ways to reduce or divert emergency room visits, such as with attention to preventative care or with adequate community-based health services (Yamaki et al., 2019). According to our findings, the number of emergency room visits needed, and thus the potential expenditures associated, may also be reduced by focusing on increasing quality. In particular, our findings revealed people with IDD who experienced continuity and security, and who participated in the life of the community, visited the emergency room less often, regardless of their impairment severity or having a dual diagnosis.

Continuity and Security

Continuity and security involves not only having the economic security and resources to meet ones' basic needs, but also the amount of change people have in their lives – the continuity of their residential setting, roommates/housemates, guardians, provider organizations, direct support professionals (DSPs), and so on. A lack of continuity and security significantly hinders people with IDD's quality of life; in fact, research with approximately 1,300 people with IDD found those who experienced continuity and security had almost double the quality of life outcomes present compared to those who did not experience continuity and security (7.81 out of 21, and 13.71 out of 21 respectively; citation removed for review).

Unfortunately, not only do a lot of people with IDD not experience financial security due to living in poverty (Fremstad, 2009), but they often do not experience continuity and security due to the DSP workforce 'crisis.' There is an astronomically high annual turnover rate for DSPs, with the average provider organization seeing 30-70% turnover a year (American Network of Community Options and Resources, 2017; Bogenschutz, Hewitt, Nord, & Hepperlen, 2014; Keesler, 2016b; Micke, 2015; Wolf-Branigin, Wolf-Branigin, & Israel, 2007). This turnover is often referred to as a 'crisis,' despite having existing for decades, because of how it impacts not only DSPs themselves, but also service providers and people with IDD citation removed for review). Not only does turnover place a tremendous financial burden on providers (Hewitt & Larson, 2007), turnover can also hinder the quality of life and community integration of people with IDD (Britton Laws, Kolomer, & Gallagher, 2014; citation removed for review; Robbins, Dilla, Sedlezky, & Johnson Sirek, 2013; Smergut, 2007; Venema, Otten, & Vlaskamp, 2015). For example, research by (citation removed for review) found DSP turnover can negatively hinder people with IDD's human security, relationships, choices, achievement of goals, and community access and integration, all of which are not only quality of life indicators, and can also 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.).

As suggested by our findings, continuity and security may not only impact people with IDD's quality of life as a whole, but also may impact their emergency room utilization. As a result, based on our findings and past research, we believe the quality and stability of the DSP workforce should be considered a quality indicator of services for people with IDD. In fact, a number of thought leaders in the IDD field have suggested,

> possible mechanisms to improve workforce issues [should] include incentivizing organizations for DSP retention, recruitment, and training. There should be quality/outcome measures around the workforce because of the ripple effect it has on people with disabilities. It may also be beneficial to have value-based payments to DSPs who help support people with disabilities to reach their goals/outcomes because they are helping the person… achieve outcomes. (citation removed for review)

Moreover, not only can emphasizing the stability of the DSP workforce likely improve quality outcomes of people with IDD, doing so will also reduce expenditures. One way reducing turnover will decrease expenditures is because filling vacancies can cost up to $5,000 per DSP as a result of recruitment and training costs (Raustiala et al., 2015). In fact, estimates suggest DSP turnover costs $784 million annually in the United States (Hewitt & Larson, 2007). In addition, the findings of this study suggest that facilitating people with IDD's continuity and security is also associated with reduced emergency room hospitalization. Emergency room visits and hospital admissions are a main source of increased healthcare expenditures (Blaskowitz et al., 2019).

Participating in The Life of the Community

The other indicator that was found to correlate with emergency room visits was people participate in the life of the community. People with IDD that participated in the life of the community – had the outcome present – had significantly fewer emergency room visits compared to people who did not participate in the life of the community; in fact, according to the model, people who participated in the life of the community were expected to have nine times fewer emergency room visits. This finding was evident regardless of the person's intellectual disability level, dual diagnosis status, or the amount of support they received.

The potential reduction in emergency room use may be a result of the positive outcomes associated with community integration (Beadle Brown et al., 2016; Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Larson, Lakin, & Hill, 2013; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004). Not only is community living associated with better outcomes, including for people with mere severe impairments (Lakin et al., 2011; Mirenda, 2014; Young, 2006), community living and community integration are also social determinants of health. For example, the physical and social neighborhood and communities people inhabit are SDOH (Kim, Chen, & Spencer, 2012; Raphael, 2006). Neighborhood conditions serve to either facilitate or hinder people's physical and mental health, their health and risk behaviors, and their physical activity (Currie et al., 2009). For example, the presence of community-based resources and community recreational and leisure opportunities can promote health (Compton & Shim, 2015; United States Office of Disease Prevention and Health Promotion, n.d.). In addition, 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, ableism, including social exclusion and isolation, often serves as a social determinant of health for people with disabilities, and can negatively contribute to mental and physical health (Emerson et al., 2011).

Isolation and loneliness have also been tied to negative health outcomes (Emerson et al., 2011; Hawkley & 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). For example, research has found social isolation and loneliness to be correlated with increased likelihood of diabetes, hypertension, arthritis, emphysema, depression, anxiety, cognitive decline, poor cardiovascular health, earlier mortality, suicidal ideation, and many other health outcomes (Hawkley & Capitanio, 2015; Leigh-Hunt et al., 2017; Smith et al., 2018; Tomaka et al., 2006). As such, the social connectedness and social capital created as a result of participating in the life of the community likely positively impacts people with IDD's health outcomes and can result in fewer emergency room visits. Increased connections with community members may also result in an increased number of people that look out for people with IDD and help them reduce and/or avoid injury as a result.

People who participate in the life of the community may also have a reduced number of emergency room visits because they may be more fulfilled, and as a result have fewer mental/behavioral events that require emergency room visits. For example, people who are more fulfilled may have fewer self-injurious behaviors. Participating in the life of the community not only includes making use of everything the community has to offer but also doing so based on people’s interests and preferences. As a result, people may ‘act out’ less or have fewer so-called problematic behaviors when having the opportunity to participate in the life of the community.

Although not significant in our model, the following variables were also correlated with lower emergency room visits when no other control variables were in place: people use their environments; people interact with other members of the community; and, people choose where and with whom to live. These correlations also suggest community integration not only has positive benefits but may reduce emergency room use. As such, we believe VBP programs for IDD services need to include community outcomes, especially regarding if, and how, people participate in the life of the community.

Impairment Severity

Although not the main aim of our study, we did examine the relationship between emergency room utilization and impairment severity (24/7 around the clock supports) in the form of a control variable. Our findings revealed that people with 24/7 around the clock support visited the emergency room more often than those without 24/7 around the clock support. Although this finding may seem intuitive since many people with more severe impairments often have more significant needs, it is also important to note that people with IDD with more severe impairments experience quality of life disparities, largely attributed to the fact that they receive fewer individualized supports from provider organizations to facilitate their outcomes (citation removed for review). In fact, research suggests people with more severe impairments have fewer day-to-day experiences, and have fewer relationships than people with less severe impairments (Beadle Brown et al., 2016; Felce, 1997; Hall et al., 2005), both of which are social determinants of health (World Health Organization, 2006, 2010). In addition, as aforementioned, community living and community integration can serve as social determinants of health, yet, people with more severe impairments also often face disparities in organizational supports that promote community integration (citation removed for review). As a result, a number of factors can result in increased emergency room use for people with 24/7 around the clock supports beyond just health itself. As such, when creating VBP metrics for people with IDD it is important to consider the disparities in quality of life outcomes and supports people with more severe impairments face. 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” (citation removed for review).

Further Implications

The aim of the study was to explore the relationship between quality of life and emergency room utilization particularly because of the emphasis on, and prioritization of, emergency room utilization in the current VBP and managed care landscape. We have suggested a number of recommendations regarding managed care above, such as community integration and DSP workforce stability as potential VBP metrics. However, our findings regarding the positive benefits of continuity and security, and community integration have wider implications beyond just managed care. There is a large body of evidence highlighting the benefits of community integration for people with IDD (e.g., Beadle Brown et al., 2016; Hemp et al., 2014; Larson et al., 2013; Mansell & Beadle-Brown, 2004; Mirenda, 2014; Young, 2006); this manuscript adds to this body of literature by evidencing yet another possible benefit of community integration – community integration may also reduce how often people with IDD visit the emergency room. Yet, many people with IDD remain isolated and implementation of *Olmstead* has been slow in many states (Cullen et al., 1995; Forrester-Jones et al., 2002; citation removed for review; Ligas Consent Decree Monitor, 2016, 2017). Recent regulation and policy additions aim to change that by expanding and strengthening the community infrastructure. For example, 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, 2014, n.p.). Moreover, disability advocates have been pushing for the Disability Integration Act (H.R.2472 and S.910), which aims to end Medicaid's institutional bias, in favor of community based long-term services and supports (ADAPT, n.d.).

In addition, our findings suggest continuity and security can also play a large role in if, and how, people with IDD visit the emergency room. DSPs can play a crucial role in the quality of life of people with IDD (Britton Laws et al., 2014; citation removed for review; Robbins et al., 2013; Smergut, 2007; Venema et al., 2015); as such, one of the broader policy implications of our findings is related to the tenure of DSPs and the DSP 'crisis.' A number of changes are needed to reduce DSP turnover, including an increase in DSP wages, an increase in training, and the professionalization of the direct support workforce (Bogenschutz et al., 2014; Britton Laws et al., 2014; Hasan, 2013; Keesler, 2016a; Micke, 2015; National Alliance for Direct Support Professionals, 2013; Robbins et al., 2013; Smith et al., 2015). Until DSP turnover is reduced, states will not be able to meet the demands of community services or adequately support people with IDD.

Limitations

When interpreting these findings, a number of limitations should be considered. First, although this was a random sample, the participants were all from one state and receiving services from the state developmental disabilities department. It should also be noted that many people in this sample had higher support needs and had dual diagnosis; this may have been related to the proxy variables used in this study. As this was a secondary data analysis, we did not have the ability to add additional questions or variables. We also did not explore interactions between variables. Finally, we would like to remind readers that correlation does not equal causation.

Conclusions

To our knowledge, this study was one of the first to explore the relationship between people with IDD's emergency room utilization and their quality of life outcomes. Although this study found that continuity and security, and community participation were significantly correlated with reduced emergency room 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. In fact, despite states increasingly moving to managed care, there is conflicting research about the benefits of managed care for people with disabilities in the United States, particularly regarding cost effectiveness and quality (Bindman, Chattopadhyay, Osmond, Huen, & Bacchetti, 2004; Burns, 2009a, 2009b; Caswell & Long, 2015; Coughlin, Long, & Graves, 2008; Duggan & Hayford, 2013; Premo, Kailes, Schwier, & Richards, 2003; Wegman et al., 2015; Williamson, Fitzgerald, Acosta, & Massey, 2013; Williamson, 2015; Williamson et al., 2017).

As a result of this conflicting evidence regarding managed care quality, it is particularly important to recognize that although health is a foundational building block, health services alone do not equate quality LTSS for people with IDD. Instead, many other factors and social determinants impact the health and quality of life of people with IDD. As such, there must be a recognition that the whole person must be supported, and doing so can ultimately translate into financial savings, including through reduced emergency room visits. If, or when, managed care moves to the IDD LTSS system, it must be done in a way that is not only evidenced-based, but also centers on the wants, needs, and quality of life of people with IDD; managed care for people with IDD must not only be *value-based*, but also *valuable* to people with IDD.

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Figure 1. Number of emergency room visits per person in the three-year period.

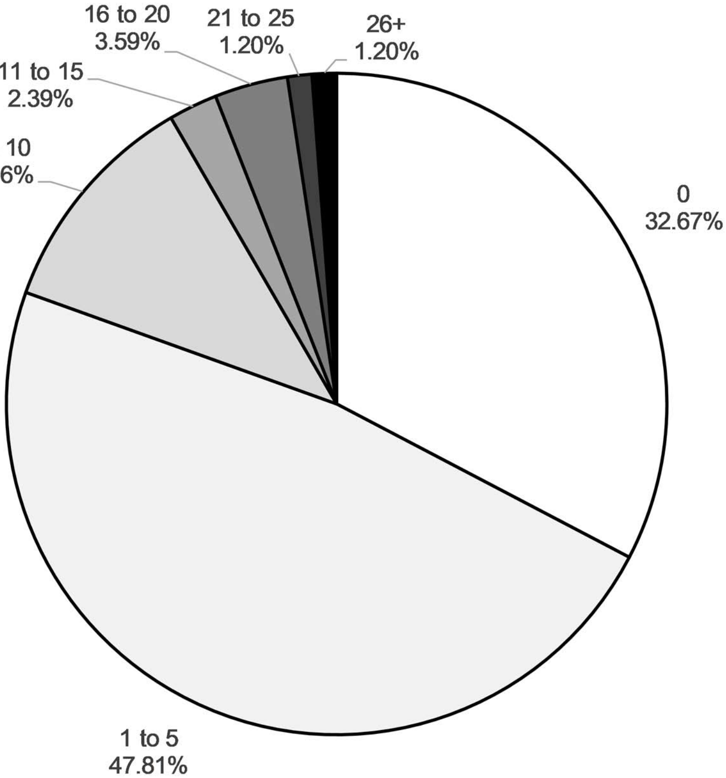
16 to 20
3.59%
21 to 25
1.20%
26+
1.20%
11 to 15
2.39%
6 to 10
11.16%
0
32.67%
1 to 5
47.81%

Table 1

Participant Demographics (n = 251)

Variable	*n*	%
Disabilities other than intellectual disability (*n* = 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 (*n* = 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
State-operated ICFDD	1	0.40
Other	1	0.40
Intellectual disability level (clinical diagnosis; n = 245)		
Mild	98	40.00
Moderate	81	33.06
Severe	34	13.88
Profound	32	13.06
24/7 support (*n* = 248)		
Yes	184	74.19
No	64	25.81
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. ICFDD = Intermediate Care Facility for People with Developmental Disabilities. HCBS = Home and Community Based Services.

Table 2

Descriptive Statistics

Outcome	% Present
People are safe	87.65
People are free from abuse and neglect	47.41
People have the best possible health	62.55
People experience continuity and security	23.51
People exercise rights	19.52
People are treated fairly	29.08
People are respected	30.29
People use their environments	74.50
People live in integrated environments	76.49
People interact with other members of the community	72.11
People participate in the life of the community	51.39
People are connected to natural supports	32.27
People have friends	37.45
People have intimate relationships	33.86
People decide when to share personal information	27.09
People perform different social roles	37.85
People choose where and with whom to live	13.15
People choose where to work	31.87
People choose services	14.34
People choose personal goals	37.45
People realize personal goals	44.62

Table 3

Correlates of Emergency Room Utilization Over Three Years

Variable	*B*	*SE B*	*β*	*t*
(Constant)	3.57	2.07		1.72
People are safe	-1.01	1.41	-0.05	-0.71
People are free from abuse and neglect	-1.08	0.97	-0.08	-1.11
People have the best possible health	-0.74	1.01	-0.05	-0.74
People experience continuity and security*	-2.37	1.18	-0.14	-2.00
People exercise rights	0.70	1.51	0.04	0.46
People are treated fairly	1.14	1.36	0.07	0.84
People are respected	0.39	1.17	0.03	0.33
People use their environments	-1.67	1.18	-0.10	-1.42
People live in integrated environments	1.00	1.21	0.06	0.83
People interact with other members of the community	-1.31	1.18	-0.08	-1.11
People participate in the life of the community**	-3.20	1.12	-0.23	-2.86
People are connected to natural supports	0.96	1.15	0.06	0.83
People have friends	1.34	1.05	0.09	1.29
People have intimate relationships	1.40	1.13	0.09	1.25
People decide when to share personal information	0.67	1.14	0.04	0.59
People perform different social roles	-0.19	1.08	-0.01	-0.17
People choose where and with whom to live	-1.32	1.49	-0.06	-0.88
People choose where to work	0.49	1.12	0.03	0.44
People choose services	-1.65	1.55	-0.08	-1.07
People choose personal goals	1.50	1.05	0.10	1.43
People realize personal goals	0.52	0.98	0.04	0.53
Intellectual disability level (ref: mild)				
Moderate	0.51	1.08	0.03	0.48
Severe	-1.15	1.46	-0.06	-0.79
Profound	1.04	1.57	0.05	0.67
24/7 support (ref: less than 24/7 support)**	3.41	1.23	0.21	2.78
Dual diagnosis (ref: IDD only)	0.91	1.02	0.06	0.89

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