

Research

The Relationship between Participating in the Community, Significant Support Needs, and Emergency Department Utilization



**The Relationship Between Participating in the Community, Significant Support Needs, and
Emergency Department Utilization**

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Abstract

Community integration is preferred by people with intellectual and developmental disabilities; community integration is also associated with positive outcomes. Yet, many people with intellectual and developmental disabilities, especially with higher support needs, remain isolated. This exploratory study examined the relationship between community integration, significant support needs, and emergency department utilization of people with intellectual and developmental disabilities ($n = 251$) by analyzing secondary Personal Outcome Measures[®] interview data. We found an interaction between community integration and comprehensive behavior support needs, wherein people with intellectual and developmental disabilities with comprehensive behavior support needs who participated in the life of the community had 78% fewer emergency department visits than those people with comprehensive behavior support needs who did not participate in the community. Not only is community integration preferred by people with intellectual and developmental disabilities, our research suggests it can also produce improved health outcomes for those with comprehensive behavior support needs.

Keywords: Community integration; community inclusion; people with intellectual and developmental disabilities; emergency department utilization; behavior support needs

The Relationship Between Participating in the Community, Significant Support Needs, and Emergency Department Utilization

Over the last 5 decades, the state institution census of people with intellectual and developmental disabilities (IDD) has decreased 85% in the United States, an average of 5% per year (Braddock et al., 2015; Braddock et al., 2017). This steady decline is a result of advocacy, policies, legislation, and shifting perspectives (Braddock et al., 2017). While more people with IDD live in the community today than ever before, a sizeable proportion of people with IDD, especially with higher support needs, still live in institutions (Braddock et al., 2017). In addition, those people with IDD who do live in the community, often experience social isolation (Forrester-Jones et al., 2002; Friedman, 2019, 2020b; Ligas Consent Decree Monitor, 2017).

The Path to Community Integration

For decades in the United States, most people with IDD who did not live with their families were forced into institutions. However, in the 1950s and 1960s, increasing reports of poor care created a public consciousness regarding the conditions of institutions. In 1963, spurred by advocacy by people with IDD and their families, President Kennedy called for a reduction in institutionalized people (Trent, 1994). Additional rulings, regulations, and legislation also increased deinstitutionalization. For example, ruling that people should receive treatment, not custodial care, *Wyatt v. Stickney* (1972) eventually resulted in the closing of most of Alabama's institutions. The Americans with Disabilities Act (ADA; 1990) mandated integration of people with disabilities, with the later *Olmstead v L.C.* (1999) ruling, which is based on the ADA, arguing that institutions illegally segregate people with disabilities. Although *Olmstead* was a landmark ruling on community integration, it has often required class-action lawsuits for actual implementation.

Today, most people with IDD in the United States live in community-based settings (Braddock et al., 2015; Braddock et al., 2017; Trent, 1994). Deinstitutionalization and the shift to community integration has resulted in better outcomes for people with IDD, including those with higher support needs (Beadle-Brown et al., 2016; Friedman, 2019; Lakin et al., 2011; Larson et al., 2013; Miranda, 2014). For example, compared to institutional settings, people with IDD in the community have increased self-determination, larger social networks, increased choice, increased participation in community life, and many more outcomes (Beadle-Brown et al., 2016; Larson, Lakin, & Hill, 2013). Despite community living being associated with better outcomes, many people with IDD living in the community are still not meaningfully included in, nor engaged with, their communities (Forrester-Jones et al., 2002; Friedman, 2019, 2020b; Ligas Consent Decree Monitor, 2017).

Community as Social Determinant of Health

Social isolation, exclusion, and segregation are all social determinants of health, leading to negative health outcomes if not addressed (Emerson et al., 2011; Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010). Social determinants of health are conditions, factors, and environments that impact people's health and quality of life. While community integration can promote health outcomes, segregation and isolation can hinder ones' health. The neighborhood one lives in, as well as the social neighborhoods and communities one inhabits, can impact people's health (Kim et al., 2012; Raphael, 2006). For example, it is beneficial for people's health when neighborhoods have accessibility, sidewalks, green space, and/or aesthetic elements (Compton & Shim, 2015; United States Department of Health & Human Services, 2015; United States Office of Disease Prevention and Health Promotion, n.d.). Conversely, health is hindered when neighborhoods have violence, crime, and/or pollution (Compton &

Shim, 2015; United States Department of Health & Human Services, 2015; United States Office of Disease Prevention and Health Promotion, n.d.). Moreover, while segregation is harmful to people's health, relationships, such as those build through community integration, can promote health and reduce health inequities – while loneliness can hinder people's health, social capital can help facilitate it (Larsson, 2013; United States Department of Health & Human Services, 2015; United States Office of Disease Prevention and Health Promotion, n.d.; World Health Organization, 2006, 2010).

One such example of social determinants impacting health is the link between social determinants and emergency department utilization. For example, while less is known about this relationship for people with IDD, for nondisabled people and people with other disabilities, housing and community integration are correlated with hospitalization, rehospitalization, and hospital expenditures. Inadequate and poor housing, neighborhoods having crime and/or pollution, and social isolation are all associated with increased emergency department use (Doan et al., 2018; Holzer et al., 2014; Lax et al., 2017; Muenchberger & Kendall, 2010). Meanwhile, as opposed to social isolation, having supportive relationships and social networks, such as those that are developed and strengthened through community integration, can reduce people's use of emergency departments (Lax et al., 2017; Muenchberger & Kendall, 2010).

There is less research about how social determinants impact the emergency department utilization of people with IDD. This is especially true for people with higher support needs, who often face disparities in outcomes, including those related to social determinants of health, such as related to employment, relationships, and community integration (Beadle-Brown et al., 2016; Carter et al., 2012; Hall et al., 2005). This study builds off both literature that documents the positive benefits of community integration for people with IDD, as well as literature regarding

community as a social determinant of health for other populations. As such, the aim of this exploratory study was to examine the relationship between community integration, significant support needs, and emergency department utilization of people with IDD. Our research question was: what is the relationship between people with IDD participating in the life of the community, complex medical support needs, comprehensive behavior support needs, and emergency department utilization? To explore this question, we analyzed secondary Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017b) interview data from a random sample of 251 people with IDD.

Methods

Data and Participants

This study involved secondary data; as such, IRB determined it was exempt from human subjects review. The data in this secondary analysis came from one state developmental disabilities department, particularly, from adults with IDD who received services from the department. Each year, the state selects a random sample of service recipients with IDD and conducts a person-centered quality of life interview using the Personal Outcomes Measures[®] (The Council on Quality and Leadership, 2017b). The state developmental disabilities department transferred this data, as well as data about emergency department utilization for these participants, to the research team after removing all identifiers.

Our secondary data included a total of 251 people with IDD (Table 1). Of the participants, 52.19% were men and 47.81% were women. The mean age of participants was 47.47 (SD = 14.75). Of the 251 participants, 72.65% were White, 25.71% were Black, and 2.86% were from another race. Participants had the following intellectual disability clinical

diagnoses: mild (40.00%); moderate (33.06%); severe (13.88%); and, profound (13.06%).

Participants most commonly lived in provider-owned or -operated homes (38.25%).

Dependent Variable

The dependent variable (DV) in this study was the number of emergency department visits: every single time a person visited an emergency department, regardless of the type of incident or illness, or injury/illness severity. This variable contained three-years: 2016 to 2018.

Independent Variables

Our first independent variable (IV) was participating in the life of the community, which came from the Personal Outcome Measures[®], a quality of life person-centered planning discovery tool. Initially, the Personal Outcome Measures[®] was developed based on findings from focus groups with people with disabilities, family members, and other stakeholders about what mattered most in their lives. Since then, the Personal Outcome Measures[®] has been refined through various methods, including pilot testing, a Delphi survey, reviews by research and content experts, feedback from advisory groups, and validity and reliability testing (Friedman, 2018; The Council on Quality and Leadership, 2017a, 2017b).

Administration of the Personal Outcome Measures[®] includes a trained and certified interviewer having in-depth conversation/s with the person with IDD about their quality of life, following specific open-ended prompts. For people with higher support needs and/or people that communicate without words, a variety of techniques are used to aid communication. Examples include visual cues, photos, gestures, augmentative alternative communication, preference testing, and object (Overpeck, 2019). Moreover, if wanted by the person with IDD or if needed a family member, friend, or staff member can support the person's participation in the interview.

After this first interview with the person with IDD, the interviewer then interviews someone who knows the person with IDD well and knows about the organizational supports they receive, such as a support coordinator, or support staff. In the last stage of data collection, the interviewer may do record reviews or do observations of the person if necessary. Then, the interviewer uses all of the data collected to complete decision-trees to determine the presence of quality of life outcomes and supports.

The Personal Outcome Measures[®] includes 21 quality of life indicators, one of which is: “people participate in the life of the community.” Suggested questions for interviewers regarding this indicator include:

- “What kinds of things do you do in the community? How often?”
- What kinds of recreational or fun things do you do in your community? How often?
- How do you know what there is to do?
- Who decides where and with whom you go?
- Is there anything you would like to do in your community that you don’t do now? What do you need to make this happen?
- What supports do you need to participate as often as you’d like in community activities?
- Do you know what the person would like to do in his or her community? (question for supporter)
- Is the person encouraged and assisted to use a broad variety of community resources? (question for supporter)
- Is training provided if the person needs it? (question for supporter)
- Is support provided if the person needs it?” (question for supporter) (The Council on Quality and Leadership, 2017b, p. 49)

Using all of the data gathered, the interviewer completes the following decision-tree questions to determine if this outcome is considered present:

- “Does the person participate in the life of their community?”
- Is the person satisfied with the type of participation they have?
- Is the person satisfied with the frequency of their participation?” (The Council on Quality and Leadership, 2017b, p. 50)

For the outcome to be considered present (yes (1), no (0)), answers to all three of the following decision-tree questions must be yes. Personal Outcome Measures[®] interviews were conducted in 2018.

Two additional variables were used as IVs as they can impact emergency department utilization and/or be associated with community integration: complex medical support needs, and comprehensive behavior support needs. Complex medical support needs were those people with IDD who required skilled nursing care 12+ hours per day. In our sample, 10.70% ($n = 26$) people had complex medical support needs. Comprehensive behavior support needs were those people with IDD who required 24-hour supervision due to risk of harm or dangerous behavior. In our sample, 16.80% ($n = 41$) people had comprehensive behavior support needs.

Analysis

We had the following research question: what is the relationship between participating in the life of the community, complex medical support needs, comprehensive behavior support needs, and emergency department utilization? To examine this research question, we utilized a negative binomial model to explore the relationship between the number of emergency department visits (DV), and participating in the life of the community (outcomes present), complex medical support needs, and comprehensive behavior support needs, as well as the interactions between

the IVs; we controlled for all other demographics. Based on goodness of fit indicators, a negative binomial model was better suited than a Poisson distribution.

Results

Of the people with IDD in this study, 51.39% ($n = 129$) participated in the life of the community, while 48.61% ($n = 122$) did not. The average number of emergency department visits was 3.73 visits per person across the three years ($SD = 6.93$). Of the participants, 32.67% ($n = 82$) visited the hospital 0 times in three-years, 47.81% ($n = 120$) 1 to 5 times, 11.15% ($n = 28$) 6 to 10 times, 2.39% ($n = 6$) 11 to 15 times, 3.59% ($n = 9$) 16 to 20 times, and 2.39% ($n = 6$) 21+ times.

A negative binomial regression analysis examining the association between emergency department visits, participating in the life of the community, complex medical support needs, comprehensive behavior support needs, and interactions was significant, $\chi^2(17) = 105.30$, $p < 0.001$ (Table 2). Controlling for all other variables (including community participation), people with IDD with complex medical support needs had a 193.85% increase in emergency department visits compared to people without complex medical support needs ($IRR = 2.94$, $p = 0.01$). Controlling for all other variables, people with IDD with comprehensive behavior support needs had a 189.07% increase in emergency department visits compared to people without comprehensive behavior support needs ($IRR = 2.89$, $p < 0.001$). There was also a significant interaction between participating in the life of the community and comprehensive behavior support needs. People with IDD with comprehensive behavior support needs who participated in the life of the community had a 78.02% decrease in emergency department visits compared to people with comprehensive behavior support needs who did not participate in the life of the community ($IRR = 0.22$, $p = 0.01$). There were no other significant interactions.

Two control variables were also significant. People with IDD with a diagnosis of “profound” had an 88.53% increase in emergency department visits compared to people with IDD with a diagnosis of “mild” (OR = 1.89, $p = 0.02$). People with IDD who lived in a family home had a 62.16% decrease in emergency department visits compared to people with IDD who lived in provider-owned or -operated homes (OR = 0.38, $p < 0.001$).

Discussion

Community living and community integration are not only preferred by people with IDD and their families, they are also associated with positive outcomes, such as adaptive behavior, health, self-determination, and quality of life, including for people with higher support needs (Beadle-Brown et al., 2016; Friedman, 2019, 2020b; Lakin et al., 2011; Larson et al., 2013; Mirenda, 2014). The aim of this exploratory study was to examine the relationship between people with IDD participating in the life of the community, significant support needs, and emergency department utilization.

Findings from our study revealed, controlling for community participation, people with IDD with significant support needs – complex medical support needs and people with comprehensive behavior support needs – used the emergency department more often compared to people without these complex support needs (194% and 189% more respectively). Similarly, people with a diagnosis of “profound” intellectual disability used the emergency department more than those with a diagnosis of “mild” (89% more). While people with significant support needs have more physical or mental health needs that may require visiting the emergency department more often than people without these support needs, it is important to note that people with significant support needs face disparities in organizational supports to promote their quality of life, including related to community integration (Friedman, 2020a). For example,

Friedman's (2020a) study of 1,300 people with IDD found while half of people with IDD without significant support needs were supported to choose where they lived, less than one-quarter of people with significant support needs were supported to do so. Disparities in the organizational supports people with significant support needs receive are problematic because organizational supports help facilitate personal outcomes. For example, one study found people with dual diagnosis – IDD and psychiatric disabilities – who had organizational supports in place were significantly more likely to not only live in integrated environments, but also interact with other members of their community (Friedman, 2021).

Our findings also revealed an interaction between community integration and comprehensive behavior support needs. People with IDD with comprehensive behavior support needs who participated in the life of the community had 78% fewer emergency department visits than people with IDD with comprehensive behavior support needs who did not participate in the life of the community. It is important to note that the etiology of what is considered 'challenging' behavior is multidimensional – the locus is not necessarily internal or due to people with IDD's impairments, sometimes it is environmental (Poppes et al., 2010). 'Challenging' behavior may be due to secondary conditions – such as a way to express pain or a medical, psychological, or dental condition (Brown et al., 2013; Gentile, 2019; Poppes et al., 2010). In fact, having a lack of experiences and opportunities, as well as facing isolation, can lead people with IDD to participate in 'challenging' behavior (Gentile, 2019, n.p.; Poppes et al., 2010). Perhaps, as a result of participating in the life of the community, people with comprehensive behavior support needs are more fulfilled and have fewer unmet needs as a result. It may also be that these people with IDD were defined as having behavior support needs because of behavior that was exacerbated or caused by segregation and/or isolation in the first place.

While more research is needed to explore the interplay between community integration, people with IDD with comprehensive behavior support needs, and emergency department utilization, it is important to note that people with comprehensive behavior support needs are more likely to be institutionalized and re-institutionalized in large part due to a lack of community infrastructure to support them (Lulinski, 2014). As such, and because of the positive benefits associated with participating in the life of community, for not only all people with IDD but people with IDD with comprehensive behavior support needs in particular, a stronger community infrastructure is needed to support people in the community. Preventative care and adequate community-based health services may not only help reduce emergency department visits (Yamaki et al., 2019), but may also, as a result, lead to a decrease in institutionalization and re-institutionalization.

Limitations

A number of limitations should be considered when interpreting our findings. First, this was a secondary data analysis. As such, we did not have the ability to add additional questions or variables. In addition, although this was a random sample, the participants were all from one state. All participants were also receiving services from the state developmental disabilities department. Finally, it is important to note that correlation does not equal causation.

Conclusion

For decades people with IDD, especially those with significant support needs, were segregated and isolated from their communities (Trent, 1994). While deinstitutionalization is more common than ever before, many people with IDD who live in the community are still not integrated into their communities (Forrester-Jones et al., 2002; Friedman, 2019; Ligas Consent Decree Monitor, 2017). The research in this study adds to countless others which emphasize the benefits of

community integration for people with IDD with higher support needs. In this study, participation in the life of the community was associated with fewer emergency department visits for people with IDD with comprehensive behavior support needs. Thus, not only is community integration preferred by people with IDD (Friedman, 2020b; Larson et al., 2013), our research suggests it may also produce improved health outcomes for people with comprehensive behavior support needs. A strong community infrastructure is needed to ensure *all* people with IDD, regardless of support needs, can experience, and, as a result, benefit from, community integration.

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Table 1

Participant Demographics (n = 251)

Variable	<i>n</i>	%
Comprehensive behavior support needs (<i>n</i> = 244)		
Yes	41	16.80
No	203	83.20
Complex medical support needs (<i>n</i> = 244)		
Yes	26	10.70
No	218	89.30
Gender		
Man	131	52.19
Woman	120	47.81
Intellectual disability diagnosis level (<i>n</i> = 245)		
Mild	98	40.00
Moderate	81	33.06
Severe	34	13.88
Profound	32	13.06
Race (<i>n</i> = 245)		
White	178	72.65
Black	63	25.71
Other	7	2.86
Residence type		
Provider-owned or -operated home	96	38.25
Own home/apartment	78	31.08
Family's house	57	22.71
Other	20	7.97

Note. Participants could have more than one race.

Table 2

Results of the Negative Binomial Analysis

Variable	Incident rate ratio (95% confidence interval)	<i>p</i>
(Intercept)	2.21 (1.10 - 4.44)	0.03
Participate in the life of the community (outcome present)	0.79 (0.54 - 1.16)	0.22
Complex medical support needs	2.94 (1.25 - 6.90)	0.01
Comprehensive behavioral support needs	2.89 (1.65 - 5.06)	< 0.001
Complex medical support needs X Comprehensive behavior support needs	0.71 (0.18 - 2.74)	0.62
Participate in the life of the community X Comprehensive behavior support needs	0.22 (0.07 - 0.70)	0.010
Participate in the life of the community X Complex medical support needs	1.13 (0.34 - 3.80)	0.84
Participate in the life of the community X Complex medical support needs X Comprehensive behavior support needs	1.82 (0.23 - 14.68)	0.57
Controls		
Age	1.00 (0.99 - 1.02)	0.55
Intellectual disability diagnosis (ref: mild)		
Moderate	1.08 (0.74 - 1.56)	0.70
Severe	1.18 (0.72 - 1.91)	0.51
Profound	1.89 (1.12 - 3.19)	0.02
Race (ref: White)		
Black	1.06 (0.72 - 1.57)	0.77
Other	0.60 (0.21 - 1.73)	0.34
Residence type (ref: Provider-owned or -operated home)		
Own home/apartment	0.84 (0.57 - 1.24)	0.38
Family's house	0.38 (0.24 - 0.59)	< 0.001
Other	1.69 (0.90 - 3.19)	0.10
Woman (ref: man)	1.29 (0.92 - 1.82)	0.14