

Research

Organizational Supports to Promote
the Community Integration of
People with Dual Diagnosis



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**Organizational Supports to Promote the Community Integration of People with Dual
Diagnosis**

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Abstract

One of the most common reasons people with intellectual and developmental disabilities (IDD) return to institutions is because of maladaptive behaviors. This study's aim was to examine the impact organizational supports can have on the community outcomes of people with dual diagnosis – those with IDD and psychiatric disabilities. We analyzed secondary Personal Outcome Measures[®] interview data from 533 people with dual diagnosis. Findings revealed people with dual diagnosis were significantly more likely to have community outcomes present when they received individualized organizational supports. In addition, we found a number of disparities in organizational supports, including related to guardianship, communication method, and residence type. A more robust service system is necessary to ensure people with dual diagnosis are integrated into their communities.

Keywords: Dual diagnosis, community living, intellectual and developmental disabilities, psychiatric disabilities

Organizational Supports to Promote the Community Integration of People with Dual Diagnosis

In 2017, an estimated 46.6 million adults (ages 18 or older) in the United States had a psychiatric disability in the previous year according to the Substance Abuse and Mental Health Services Administration (2018). This figure represents 18.9% of all adults in the United States (Substance Abuse and Mental Health Services Administration, 2018). Like the general population, people with intellectual and developmental disabilities (IDD) also commonly have psychiatric disabilities. Estimates vary because of differences in diagnostic tools, limited sample sizes, differences in settings across studies, and overlapping and similar presentations of IDD and psychiatric symptoms (Buckles, Luckasson, & Keefe, 2013; Deb, Thomas, & Bright, 2001). However, according to a literature review by Borthwick-Duffy (1994) estimates suggest the co-occurrence of IDD and psychiatric disability, referred to as dual diagnosis, ranges from 10% to over 80%. Einfeld, Ellis, and Emerson's (2011) systematic review also found dual diagnosis rates between 30%-50% in children and adolescents with intellectual disabilities. Meanwhile, Allott, Francey, and Velligan (2013) found people with IDD to be three to five times more likely to have a psychiatric disability than the general population.

Although the rate of dual diagnosis varies widely, estimates suggest people with IDD are just as, if not more, likely to have a psychiatric disability as the general population. The lack of recognition regarding the prevalence of dual diagnosis, and the lack of appropriate services and community infrastructure as a result, can make successful community living challenging for people with dual diagnosis. For example, people with dual diagnosis, and those with IDD who simply present 'behavioral challenges,' are more likely to be institutionalized than people with IDD without psychiatric disabilities or 'behavioral challenges;' and they are also often the last to

be released from institutions (Charlot & Beasley, 2013; McIntyre, Blacher, & Baker, 2002). As a result of inadequate community services and supports, people with dual diagnosis also have less successful community transitions, and are at risk for re-institutionalization (Lulinski, 2014; Mansell, 2006).

The Community Infrastructure

The institutional census peaked in 1967 but has steadily been declining since at an annual average rate of 5% nationwide (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). In fact, deinstitutionalization has resulted in the closure of 171 public institutions in 43 states as of 2015 (Braddock et al., 2015). *Olmstead v LC* (1999) has played a significant role in the continued deinstitutionalization of people with IDD. *Olmstead* requires states provide people with disabilities services in the most integrated setting possible rather than unnecessarily segregate them. Moreover, *Olmstead* also declares states have an affirmative obligation to offer long-term services and supports (LTSS) in the least restrictive setting possible (Supreme Court of the United States, 1999).

The shift to community-based settings, rather than institutional ones, has resulted in better outcomes for people with IDD, including those with more severe impairments (Lakin, Larson, & Kim, 2011; Larson & Lakin, 1989; Mirenda, 2014; Young, 2006). Although community living results in better outcomes than institutional living, many people with IDD in the community remain isolated (Forrester-Jones et al., 2002). Moreover, due to a poor community infrastructure, one of the most common reasons for re-institutionalization of people with IDD is maladaptive behaviors (e.g., harm to self and/or others, property destruction) (Causby & York, 1991; Intagliata & Willer, 1982; Lulinski-Norris, Rizzolo, & Heller, 2012; Lulinski, 2014). For example, Lulinski's (2014) study found 91% of people who returned to

institutions in Illinois did so because of behavioral issues – and the lack of community infrastructure to provide the necessary services and supports for people with psychiatric disabilities in a behavioral crisis.

The lack of appropriate community infrastructure for mental health is not a problem limited to services for people with IDD, however; many people with psychiatric disabilities without IDD have simply moved from state institutions to other institutional settings, such as nursing homes because of a lack of community infrastructure to support them (Aschbrenner, Grabowski, Cai, Bartels, & Mor, 2011; Bagenstos, 2012; Blair & Espinoza, 2015; Davis, Fulginiti, Kriegel, & Brekke, 2012; Geller, 2006). Although Medicaid is the largest provider of mental health services in the United States, it allows states flexibility in how they provide mental health services; as a result, services for mental health, including for people with IDD, vary widely by state (Mann & Hyde, 2013; The Henry J. Kaiser Family Foundation, 2012). For example, Friedman, Lulinski, and Rizzolo's (2015) study of fiscal year (FY) 2013 Home and Community Based Services (HCBS) waivers, the largest provider of LTSS for people of IDD, revealed only 0.1% of the 685,000 waiver participants were projected to receive mental/behavioral health services. Moreover, in FY 2015, only 0.1% of national IDD waiver spending was projected for crisis services (Friedman, 2017).

For these reasons, the aim of this study was to examine the impact organizational supports can have on the community outcomes (i.e., using their environments, living in integrated environments, interacting with other members of the community, and participating in the life of the community) of people with dual diagnosis. To do so, we analyzed secondary Personal Outcome Measures[®] interview data from approximately 533 people with dual diagnosis. We examined the relationship between people's community outcomes and the

organizational supports they received. In addition, in order to determine where organizational supports are most needed, we also explored which people with dual diagnosis were most or least likely to have organizational supports in place related to community integration.

Methods

Participants

The secondary survey data (data collected by others) were transferred to the researchers with no identifiers; institutional research board (IRB) determined it was exempt from full review. Data was originally collected over a one-year period (January 2018 to December 2018) from hundreds of organizations, including local, county, and state governments, that provided any type of the following services to people with IDD: service coordination; case management; family and individual supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); and, human service systems. Data were collected from 533 people with dual diagnosis (IDD and any type of psychiatric diagnosis, such as mood disorder, anxiety, depression, etc.). While age and gender were relatively evenly distributed across demographic categories, the majority of participants were White (71.7%) and used verbal/spoken language as their primary communication method (83.4%; Table 1). The majority of participants (59.8%) lived in provider owned or operated homes, their own homes (17.1%), or family homes (10.2%).

Measure

The data came from Personal Outcome Measures[®] interviews (The Council on Quality and Leadership, 2017b); the Personal Outcome Measures[®] is a person-centered quality of life tool that measures self-determination, choice, self-advocacy, and organizational supports. The Personal Outcome Measures[®] tool includes 21 indicators divided into five factors: my human

security; my community; my relationships; my choices; and, my goals. My community, the factor of interest in this study, includes the following indicators:

- *People use their environments* – full access to the physical and built environments they inhabit, with appropriate accommodations when applicable;
- *People live in integrated environments* – social integration;
- *People interact with other members of the community* – contact with a variety people in a variety of settings in order to engage people in, and with, the community; and,
- *People participate in the life of the community* – active participation based on peoples' interests and preferences; making use of everything the community has to offer (The Council on Quality and Leadership, 2017b).

Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a certified Personal Outcome Measures[®] interviewer has in-depth conversations with the participant with disabilities about each of the indicators. During these conversations, the interviewer follows specific open-ended prompts to guide the discussion and gather data for decision making. During the second stage, 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 third and final stage, the interviewer observes the participant in various settings if necessary, and then completes decision trees about the indicator questions (Table 2 details the items for My Community) based on all of the information gathered to determine if outcomes are present (yes (1); no (0)) and if organizational supports are in place (yes (1); no (0)). Individual record reviews are also conducted as needed. As the measure is

person-centered, if there are any discrepancies across stages, the person with disabilities' answers are the ones used.

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, 25 years of administration, commission of research and content experts, a Delphi survey, feedback from advisory groups, and validation analyses (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures[®] has construct validity (Friedman, 2018b), and is reliable, as all interviewers are required to pass reliability tests with at least 85% agreement before being certified (The Council on Quality and Leadership, 2017a).

Variables and Analysis

The data were analyzed to examine the following research questions: how do organizational supports facilitate the community outcomes of people with dual diagnosis? We first conducted descriptive statistics. Then, in order to examine the impact organizational supports can have on between people with dual diagnosis' community outcomes, we ran a series of binary logistic regression models with the four community areas of the Personal Outcome Measures[®]: use their environments; live in integrated environments; interact with other members of the community; and, participate in the life of the community. For each binary logistic regression model, the organizational support for the community area served as the independent variable (IV) and the outcome for the same community area served as the dependent variable (DV). For example, for people live in integrated environments, the IV was if the organizational support for people live in integrated environments was in place (yes (1); no (0)) and the DV was

if the personal outcome for people live in integrated environments was present (yes (1); no (0)). Bonferroni's correction (.0125) was used to account for using multiple models.

In addition, we also explored, of those with dual diagnosis, who was most/least likely to have organizational supports in place related to community integration. To do so, we aggregated the four community indicators related to organizational supports and this new variable became the DV. We then ran a linear regression model with the demographic variables serving as the IVs. (It should be noted for this analysis primary communication method types were combined because of widely unequal cell distribution; as a result, the variables were verbal communication versus other methods.)

Results

Approximately two-thirds of participants ($n = 355$, 66.6%) used their environments, while slightly fewer interacted with other members of the community ($n = 296$, 55.5%). Slightly less than half of the participants lived in integrated environments ($n = 253$, 47.5%) or participated in the life of the community ($n = 233$, 43.7%).

In terms of individualized organizational supports, 66.8% of participants ($n = 356$) were provided with organizational supports to use their environments, 44.3% ($n = 236$) to live in integrated environments, 59.7% ($n = 318$) to interact with other members of the community, and 58.2% ($n = 310$) to participate in the life of the community.

The Impact of Organizational Supports on Community Outcomes of People with Dual Diagnosis

A binary logistic regression model examining the relationship between organizational supports (IV) and personal outcomes (DV) for *people use their environments* was significant, - $2LL = 294.04$, $\chi^2(1) = 384.95$, $p < 0.001$. The model, which correctly classified 91.9% of cases,

explained 72.4% (Nagelkerke R^2) of variance. The dual diagnosis term was significant ($p < 0.001$; Table 3). According to the model, people with dual diagnosis who received organizational supports were 112.78 times more likely to use their environments than people who did not receive organizational supports.

A binary logistic regression model examining the relationship between organizational supports (IV) and personal outcomes (DV) for *people live in integrated environments* was significant, $-2LL = 305.00$, $\chi^2(1) = 432.53$, $p < 0.001$. The model, which correctly classified 91.6% of cases, explained 74.2% (Nagelkerke R^2) of variance. The dual diagnosis term was significant ($p < 0.001$). According to univariate statistics, people with dual diagnosis who received organizational supports were 136.06 times more likely to live in integrated environments than people with dual diagnosis who did not receive organizational supports.

A binary logistic regression model examining the relationship between organizational supports (IV) and personal outcomes (DV) for *people interact with other members of the community* was significant, $-2LL = 520.36$, $\chi^2(1) = 211.99$, $p < 0.001$. The model, which correctly classified 80.9% of cases, explained 43.9% (Nagelkerke R^2) of variance. The dual diagnosis term was significant ($p < 0.001$). According to univariate statistics, people with dual diagnosis who received organizational supports were 18.07 times more likely to interact with other members of the community than people with dual diagnosis who did not receive organizational supports.

A binary logistic regression model examining the relationship between organizational supports (IV) and personal outcomes (DV) for *participate in the life of the community* was significant, $-2LL = 3479.89$, $\chi^2(1) = 250.56$, $p < 0.001$. The model, which correctly classified 80.3% of cases, explained 50.3% (Nagelkerke R^2) of variance. The dual diagnosis term was

significant ($p < 0.001$). According to univariate statistics, people with dual diagnosis who received organizational supports were 35.93 times more likely to participate in the life of the community than people with dual diagnosis who did not receive organizational supports.

Disparities in Organizational Supports for those with Dual Diagnosis

We also wanted to explore, of those with dual diagnosis, who was most/least likely to have organizational supports in place for the four community indicators (use their environments; live in integrated environments; interact with other members of the community; and, participate in the life of the community). To do so, we ran a linear regression models with the total community organizational supports in place as the DV, and demographic characteristics as the IVs (i.e., gender, race/ethnicity, primary communication method: verbal, guardianship type, residence type, age). The model was significant, $F(19, 467) = 2.63$, $p < 0.001$, $R^2 = 0.10$. The following variables were significant: guardianship – other; primary communication method – verbal; residence type – provider owned or operated home; and, residence type – ICFDD. According to the model, people with dual diagnosis who had independent decision-making had more community organizational supports in place (2.06 out of 4) than people with ‘other’ forms of guardianship (0.59 out of 4). People who primarily communicated through verbal communication had more community organizational supports in place (2.64 out of 4) than people who primarily used other forms of communication (e.g., facial/body expression, sign language, communication devices; 2.06 out of 4). People who lived in their own homes had more community organizational supports in place (2.06 out of 4) than people who lived in provider owned or operated homes (1.55 out of 4) and people who lived in ICFDD (1.06 out of 4).

Discussion

A lack of community infrastructure to support people with dual diagnosis can hinder people with dual diagnosis' community integration. As such, the purpose of this study was to explore the impact organizational supports can have on the community outcomes of people with dual diagnosis. Findings revealed people with dual diagnosis were more likely to live in integrated environments, use their environments, interact with other members of the community, and participate in the life of the community when they received individualized organizational supports.

In fact, according to our data, for example, people with dual diagnosis were 136 times more likely to live in integrated environments – have the outcome present – when they received individualized organizational supports. Individualized organizational supports for the four community indicators of the Personal Outcome Measures[®] require human service organizations to first know what integration means to the person and their preferences for interactions with community members, know what the person would like to do in their community and how often they would like to engage in community activities, and know if the person can access their environments (The Council on Quality and Leadership, 2017b). Organizations must assess the person's interest and ability for access and use of their environment, and assess the type and frequency of interaction the person has with members of the community. Organizations must also promote opportunities for integration and interaction with community members, provide the person with access to information about options for community participation, provide support for the person to do the things they wants to do in the community, and provide modifications, if applicable, to promote maximum access to the community. By ensuring person-centered organizational supports are in place, human service organizations are not only facilitating people with dual diagnosis' community outcomes, but also their quality of life.

Although *all* people with dual diagnosis should have person-centered organizational supports, our findings revealed a number of disparities in supports for community integration even amongst people with dual diagnosis themselves that need to be targeted and prioritized. For example, people whose primary communication method was verbal were more likely to receive supports from organizations regarding community outcomes than people who primarily communicated through communication devices, sign language, facial/body expressions, or other methods, even when all other characteristics were controlled. This finding suggests disability service organizations may not be adequately supporting people who primarily communicate through other means – there needs to be more intentionality about creating organizational supports for people with alternative communication methods with dual diagnosis so they too can benefit from community integration.

People who lived in provider owned or operated homes, and ICFDD were also significantly less likely to be supported by organizations to have community indicators present compared to people who lived in their own homes. While this seems like a natural conclusion, especially since it includes settings like ICFDD, provider owned or operated settings are *supposed* to be more community based than institutions, yet they often poorly supported people with dual diagnosis to have community integration. These findings may reflect transinstitutionalization – the systemic movement from one institutional setting to another type of institution (Blair & Espinoza, 2015; Friedman, 2019; O'Mahony, 2013; Prins, 2011; Sisti, Segal, & Emanuel, 2015; Wachtler & Bagala, 2013); “the legacy of institutionalization and congregate care has shaped current residential services, meaning that ‘services today have become standardized, inflexible and unaccountable to those they serve’” (Spagnuolo, 2016, n.p.). While people with IDD as a group continue to be isolated, even in community settings (Bratt &

Johnston, 1988; Cullen et al., 1995; Forrester-Jones et al., 2002; Hammel et al., 2008), our findings reveal people with dual diagnosis may be particularly so. Attention to these disparities is necessary to expand the community integration of people with dual diagnosis, particularly in these settings.

In addition, a significant proportion of people with dual diagnosis in this study did not have the community outcomes present. For example, an overwhelming majority of people dual diagnosis status did not have the outcome present for *participate in the life of the community*, which includes not only participating, but also the person being satisfied with the type and frequency of their participation. As such, we believe these findings suggest the need for a stronger community infrastructure to support people with dual diagnosis. Doing so is necessary to ensure services and supports abide by the rights put forth by the Americans with Disabilities Act (1990), *Olmstead*, and the *Medicaid HCBS Settings Rule* (CMS 2249-F/2296-F), which have reinforced *all* people with disabilities have a right to community integration.

Having an adequate community infrastructure requires a robust and continuous system of services to support people's mental and behavioral health needs. For example, Friedman (2018a) found when human service organizations provided people with IDD with continuous and consistent services and supports, people were eight times less likely to exhibit 'behavioral issues.' Moreover, when organizations implemented ongoing staff development for their employees, behavioral issues amongst people with IDD were eight times less likely (Friedman, 2018a). By having a robust person-centered service system that attends to the factors underlying 'behavioral issues' – not only physiological ones, but also factors related to a lack of meaningful opportunities – these behaviors not only decrease, but as a result, so does the probability that

people will be re-institutionalized as a result of these behaviors (Causby & York, 1991; Friedman, 2018a; Intagliata & Willer, 1982; Lulinski-Norris et al., 2012; Lulinski, 2014).

Limitations

When interpreting our findings, a number of limitations should be considered. The majority of our sample was White; however, this percentage was similar to the United States population. Moreover, although participants represented 22 states, three states (New York, Tennessee, and South Dakota) were represented most frequently. There was also an unequal distribution across some of the variables in our study which may have impacted the significance of those findings. Finally, as this was as a secondary data analysis, we did not have the opportunity to add additional questions or variables.

Conclusion

To promote the community integration of people with IDD with dual diagnosis a number of disparities need to be addressed. States need to recognize the lack of community infrastructure and gaps in service provision hinder the quality of life of people with dual diagnosis. As community living is significantly more cost effective than institutions, states can redistribute resources to expand LTSS provision to reduce disparities, reduce waiting lists, and build a more comprehensive network of services and supports. Moreover, attention to these disparities requires provider transformation to a system that moves beyond custodial models of care, and introduces evidenced based, person-centered practices. A stronger and more robust service system is necessary to ensure people with dual diagnosis have the same opportunities as not only people with IDD without psychiatric disabilities, but also nondisabled people.

References

- Allott, K. A., Francey, S. M., & Velligan, D. I. (2013). Improving functional outcome using compensatory strategies in comorbid intellectual disability and psychosis: A case study. *American Journal of Psychiatric Rehabilitation, 16*(1), 50-65.
<https://doi.org/10.1080/15487768.2013.762306>.
- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328, (1990).
- Aschbrenner, K., Grabowski, D. C., Cai, S., Bartels, S. J., & Mor, V. (2011). Nursing home admissions and long-stay conversions among persons with and without serious mental illness. *Journal of aging & social policy, 23*(3), 286-304.
<https://doi.org/10.1080/08959420.2011.579511>.
- Bagenstos, S. R. (2012). The past and future of deinstitutionalization litigation. *Cardozo L. Rev., 34*(1), 1-48. <https://doi.org/10.2139/ssrn.2005301>.
- Blair, T. R., & Espinoza, R. T. (2015). Medicare, Medicaid, and mental health care: historical perspectives on reforms before the US congress. *Jama, 314*(21), 2231-2232.
<https://doi.org/10.1001/jama.2015.13328>.
- Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17-27.
<https://doi.org/10.1037/0022-006X.62.1.17>.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.

- Braddock, D., Hemp, R., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in intellectual and developmental disabilities: 2017* (11th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Bratt, A., & Johnston, R. (1988). Changes in life style for young adults with profound handicaps following discharge from hospital care into a “second generation” housing project. *Mental Handicap Research, 1*(1), 49-74. <https://doi.org/10.1111/j.1468-3148.1988.tb00005.x>.
- Buckles, J., Luckasson, R., & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010. *Journal of Mental Health Research in Intellectual Disabilities, 6*(3), 181-207. <https://doi.org/10.1080/19315864.2011.651682>.
- Causby, V. D., & York, R. O. (1991). Predictors of success in community placement of persons with mental retardation. *The British Journal of Mental Subnormality, 37*(72), 25-34. <https://doi.org/10.1179/bjms.1991.004>.
- Charlot, L., & Beasley, J. B. (2013). Intellectual disabilities and mental health: United States–based research. *Journal of Mental Health Research in Intellectual Disabilities, 6*(2), 74-105. <https://doi.org/10.1080/19315864.2012.715724>.
- Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S., & Stanley, A. (1995). The effects of deinstitutionalization on adults with learning disabilities. *Journal of Intellectual Disability Research, 39*(6), 484-494. <https://doi.org/10.1111/j.1365-2788.1995.tb00568.x>.

- Davis, L., Fulginiti, A., Kriegel, L., & Brekke, J. S. (2012). Deinstitutionalization? Where have all the people gone? *Current psychiatry reports*, *14*(3), 259-269.
<https://doi.org/10.1007/s11920-012-0271-1>.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disabilities. I: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disabilities Research*, *45*(6), 495-505.
<https://doi.org/10.1046/j.1365-2788.2001.00374.x>.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, *36*(2), 137-143.
<https://doi.org/10.1080/13668250.2011.572548>.
- Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (2002). The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*, *17*(7), 741-758. <https://doi.org/10.1080/0968759021000068469>.
- Friedman, C. (2017). A national analysis of Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual and Developmental Disabilities*, *55*(5), 281-302. <https://doi.org/10.1352/1934-9556-55.5.281>.
- Friedman, C. (2018a). *Building the framework for IDD quality measures*. Towson, Chicago, and Omaha: The Council on Quality and Leadership, the Institute for Public Policy for People with Disabilities, and Mosaic.

- Friedman, C. (2018b). The Personal Outcome Measures[®]. *Disability and health journal*, 11(3), 351–358. <https://doi.org/10.1016/j.dhjo.2017.12.003>.
- Friedman, C. (2019). The influence of residence type on personal outcomes. *Intellectual and Developmental Disabilities*, 57(2), 112-126. <https://doi.org/10.1352/1934-9556-57.2.112>.
- Friedman, C., Lulinski, A., & Rizzolo, M. C. (2015). Mental/behavioral health services: Medicaid Home and Community-Based Services 1915(c) waiver allocation for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 53(4), 257-270. <https://doi.org/10.1352/1934-9556-53.4.257>.
- Geller, J. L. (2006). The evolution of outpatient commitment in the USA: from conundrum to quagmire. *International journal of law and psychiatry*, 29(3), 234-248. <https://doi.org/10.1016/j.ijlp.2005.09.003>.
- Hammel, J., Jones, R., Smith, J., Sanford, J., Bodine, C., & Johnson, M. (2008). Environmental barriers and supports to the health, function, and participation of people with developmental and intellectual disabilities: report from the State of the Science in Aging with Developmental Disabilities Conference. *Disability and health journal*, 1(3), 143-149. <https://doi.org/10.1016/j.dhjo.2008.05.001>.
- Intagliata, J., & Willer, B. (1982). Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes. *American Journal of Mental Deficiency*, 8(1), 34-49
- Lakin, K. C., Larson, S. A., & Kim, S. (2011). *Behavioral outcomes of deinstitutionalization for people with intellectual and/or developmental disabilities: Third decennial review of U.S. studies, 1977-2010* (Vol. 21): Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

- Larson, S. A., & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Research and Practice for Persons with Severe Disabilities*, 14(4), 324-332. <https://doi.org/10.1177/154079698901400411>.
- Lulinski-Norris, A., Rizzolo, M., & Heller, T. (2012). *An analysis of movement from state operated developmental centers in Illinois*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.
- Lulinski, A. (2014). *Community capacity to provide mental/behavioral health services to people with developmental disabilities (Unpublished doctoral dissertation)*. University of Illinois at Chicago, Chicago.
- Mann, C., & Hyde, P. S. (2013). *Coverage of behavioral health services for children, youth, and young adults with significant mental health conditions*. Retrieved from Baltimore: <http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-05-07-2013.pdf>
- Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability*, 31(2), 65-76. <https://doi.org/10.1080/13668250600686726>.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, 46(3), 239-249. <https://doi.org/10.1046/j.1365-2788.2002.00371.x>.
- Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2947 (January 10, 2014) (to be codified at 42 C. F. R. pts. 430, 431, 435, 436, 440, 441, 447).

- Mirenda, P. (2014). Revisiting the mosaic of supports required for including people with severe intellectual or developmental disabilities in their communities. *Augmentative and Alternative Communication*, 30(1), 19-27.
<https://doi.org/10.3109/07434618.2013.875590>.
- O'Mahony, C. (2013). *Diversion: A comparative study of law and policy relating to defendants and offenders with mental health problems and intellectual disability (doctoral dissertation)*. NUI Galway, Galway, Ireland.
- Olmstead v. LC, No. 98-536, 527 581 (Supreme Court 1999).
- Prins, S. J. (2011). Does transinstitutionalization explain the overrepresentation of people with serious mental illnesses in the criminal justice system? *Community mental health journal*, 47(6), 716-722. <https://doi.org/10.1007/s10597-011-9420-y>.
- Sisti, D. A., Segal, A. G., & Emanuel, E. J. (2015). Improving long-term psychiatric care: bring back the asylum. *Jama*, 313(3), 243-244. <https://doi.org/10.1001/jama.2014.16088>.
- Spagnuolo, N. (2016). Building back wards in a 'post' institutional era: Hospital confinement, group home eviction, and Ontario's treatment of people labelled with intellectual disabilities. *Disability Studies Quarterly*, 36(4). <https://doi.org/10.18061/dsq.v36i4.5279>.
- Substance Abuse and Mental Health Services Administration. (2018). *Key substance use and mental health indicators in the United States: Results from the 2017 National Survey on Drug Use and Health (HHS Publication No. SMA 18-5068, NSDUH Series H-53)*. Retrieved from Rockville: <https://www.samhsa.gov/data/report/2017-nsduh-annual-national-report>
- Supreme Court of the United States. (1999). *Syllabus. Olmstead V. L. C. (98-536) 527 U.S. 581*. Retrieved from <https://www.law.cornell.edu/supct/pdf/98-536P.ZS>

The Council on Quality and Leadership. (2017a). *The Personal Outcome Measures® 2017:*

Measuring outcomes now and into the future. Towson, MD: The Council on Quality and Leadership.

The Council on Quality and Leadership. (2017b). *Personal Outcome Measures®: Measuring personal quality of life* (3rd ed.). Towson, MD: Author.

The Henry J. Kaiser Family Foundation. (2012). Medicaid benefits: Public health and mental health clinics (clinic services by an organized facility or clinic not part of a hospital).

Retrieved from <http://kff.org/medicaid/state-indicator/clinic-services-by-an-organized-facility-or-clinic-not-part-of-a-hospital-public-health-and-mental-health-clinics/>

Wachtler, S., & Bagala, K. (2013). From the asylum to solitary: Transinstitutionalization. *Albany Law Review*, 77(3), 915-930

Young, L. (2006). Community and cluster centre residential services for adults with intellectual disability: Long-term results from an Australian-matched sample. *Journal of Intellectual Disability Research*, 50(6), 419-431. <https://doi.org/10.1111/j.1365-2788.2006.00788.x>.

Table 1

Demographics of Sample (n = 533)

Characteristic	<i>n</i>	%	Characteristic (cont.)	<i>n</i>	%
Age range (<i>n</i> = 516)			Guardianship (<i>n</i> = 528)		
18 to 24	53	10.3	Independent decision making	133	25.2
25 to 34	111	21.5	Assisted decision making	176	33.3
35 to 44	114	22.1	Full plenary guardianship	211	40.0
45 to 54	80	15.5	Other	8	1.5
55 to 64	95	18.4	Residence type (<i>n</i> = 519)		
65 to 74	52	10.1	Provider owned/operated home	299	59.8
75+	11	2.1	Own home	89	17.1
Gender			Family home	53	10.2
Man	297	55.7	Host family or family foster care	16	3.1
Woman	236	44.3	ICFDD (private and state)	15	2.9
Race (<i>n</i> = 527)			Other	14	2.7
White	378	71.7	Primary method of communication (<i>n</i> = 531)		
Black	112	21.3	Verbal/spoken language	443	83.4
Latinx	25	4.7	Face/body expression	67	12.6
Other	15	2.8	Sign language	8	1.5
			Communication device	1	0.2
			Other	12	2.3

Note. ICFDD = Intermediate care facility for people with developmental disabilities. HCBS = Home and community based services. DSP = direct support professionals. People could select more than one race

Table 2

Decision Making Questions for Each Indicator

Indicator	Outcome decision tree	Organizational support decision tree
People use their environments	<ul style="list-style-type: none"> • Does the person have maximum access to each of the physical environments they frequent: at home; at work; in the community? • Does the person use the physical environments he or she frequents? (p. 41) 	<ul style="list-style-type: none"> • Does the organization know if the person can access his or her environments at home, at work, and in the community? • Has the organization assessed the person's interest and ability for personal access and use of environments at home, at work, and in the community? • Have modifications been made to promote maximum access and use for the person, if needed and requested, at home, at work, and in the community? (p. 41)
Live in integrated environments	<ul style="list-style-type: none"> • Does the person use the same environments used by people without disabilities? (for living, work, school, community (leisure, shopping, banking, places of worship, etc.)? (p. 44) 	<ul style="list-style-type: none"> • Does the organization know what integration means to the person, or are efforts being made to learn about the person's preferences? • Do services and supports for the person promote opportunities for integration? (p. 44)
Interact with other members of the community	<ul style="list-style-type: none"> • Is there direct interaction between the person and others in the community? • Is the type of interaction satisfactory to the person? • Is the frequency of interaction satisfactory to the person? (p. 47) 	<ul style="list-style-type: none"> • Has the organization assessed the type of interactions the person has with other members of the community? • Has the organization assessed the frequency of the person's interaction with other members of the community? • Does the organization know the person's preferences for interaction, or are efforts being made to learn about the person's preferences? • Does the organization provide support for the person to access opportunities for interaction with others, if needed and requested? (p. 47)

Participate in the life of the community	<ul style="list-style-type: none"> • 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? (p. 50) 	<ul style="list-style-type: none"> • Does the organization know what the person would like to do in their community or are efforts being made to learn about the person's preferences? • Does the organization know how often the person would like to engage in community activities or are efforts being made to learn about the person's preferences? • Does the organization provide the person with access to information about options for community participation? • Does the organization provide support for the person to do the things he or she wants to do? (p. 50)
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Note. See The Council on Quality and Leadership (2017b) for more information, including the information gathering questions.

Table 3

The relationship between organizational supports and community outcomes

Support in Place	O. R.	95% C.I.	
		Lower	Upper
People use their environments	112.78	60.22	211.21
Live in integrated environments	136.06	70.62	262.15
Interact with other members of the community	18.07	11.62	28.09
Participate in the life of the community	35.93	19.84	65.06

Note . Each support represents a different model.

Table 4

Disparities in Organizational Supports in Place for People with Dual Diagnosis

Demographic variable	<i>B</i>	<i>SE</i>	<i>t</i>
Constant	2.06	0.34	6.08***
Race (ref: White)			
Black	0.17	0.16	1.08
Latinx	-0.28	0.31	-0.90
Other	-0.01	0.43	-0.02
Gender: woman	0.06	0.13	0.45
Guardianship (ref: independent decision making)			
Assisted decision making	-0.06	0.18	-0.34
Full plenary guardianship	-0.06	0.18	-0.32
Other	-1.47	0.57	-2.60**
Primary communication method: verbal	0.58	0.19	3.04**
Residence type (ref: own home)			
Family home	-0.25	0.26	-0.97
Host family or family foster care	-0.23	0.38	-0.60
Provider owned or operated home	-0.51	0.18	-2.87**
ICFDD	-1.00	0.42	-2.38*
Other	-0.35	0.41	-0.87
Age (ref: 18 to 24)			
25 to 34	-0.08	0.24	-0.34
35 to 44	0.34	0.24	1.42
45 to 54	0.18	0.26	0.70
55 to 64	0.16	0.26	0.63
65 to 74	0.39	0.29	1.35
75+	-0.32	0.54	-0.58