

Intellectual and Developmental Disabilities

The Impact of Continuity and Security on Quality of Life

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Abstract:	Continuity and security includes people with intellectual and developmental disabilities (IDD) not only having resources to meet their basic needs, but also includes the amount of change and disruption people have in their lives and the control they have over that change. We explored the impact of continuity and security on people with IDD's (n = 325) quality of life by analyzing Personal Outcome Measures interviews. Continuity and security not only significantly increased overall quality of life, it also positively impacted two-thirds of the different outcomes, ranging from health to relationships to rights. A stronger community infrastructure is needed to promote the continuity and security, and, by extension, quality of life of people with IDD.

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Abstract

Continuity and security includes people with intellectual and developmental disabilities (IDD) not only having resources to meet their basic needs, but also includes the amount of change and disruption people have in their lives and the control they have over that change. We explored the impact of continuity and security on people with IDD's ($n = 325$) quality of life by analyzing Personal Outcome Measures interviews. Continuity and security not only significantly increased overall quality of life, it also positively impacted two-thirds of the different outcomes, ranging from health to relationships to rights. A stronger community infrastructure is needed to promote the continuity and security, and, by extension, quality of life of people with IDD.

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The Impact of Continuity and Security on the Quality of Life of People with Intellectual and Developmental Disabilities

Continuity and security includes people with intellectual and developmental disabilities (IDD) not only having the resources to meet their basic needs, but also includes the amount of change and disruption people have in their lives and the control they have over that change, especially as compared to nondisabled people (The Council on Quality and Leadership, 2017). People with disabilities not only have less economic security and are more likely to live in poverty than nondisabled people (Pinilla-Roncancio & Alkire, 2021) – financial insecurity hinders the continuity and security of people with IDD – the government services people with IDD receive also significantly impact their health, quality of life, and continuity and security (Burns, 2009). For example, for people with IDD the period between secondary education and adult services is often referred to as a “transition cliff” (Podmostko, 2007) because of a lack of continuity in services. In fact, people with IDD’s “dependence on [human service] organization[s] often links changes in people’s lives to organizational changes” (The Council on Quality and Leadership, 2017, p. 25).

Due to an underfunded service system, and the resulting lack of resources and funding, and DSP turnover, many IDD service providers struggle to adequately support people with IDD (ANCOR Foundation & United Cerebral Palsy, 2021; citation removed for review). The Centers for Medicare and Medicaid Services (CMS) notes,

appropriate and timely provision of home and community-based services can delay or prevent institutionalization, improve quality of life, and keep long-term care costs lower... But success in implementing these options depends upon having a sufficient the labor supply. (Robbins et al., 2013, p. 2)

Direct support professional (DSP) turnover is a barrier to community integration (American Network of Community Options and Resources, 2014; Britton Laws et al., 2014; Smergut, 2007; Venema et al., 2015). People with IDD's health and quality of life is also significantly hindered by DSP turnover (citations removed for review). In fact, people with IDD who experience DSP turnover are 6.3 times less likely to have continuity and security (citations removed for review).

In particular, people with IDD with higher support needs, including those with behavior support needs – who are already at higher risk for reinstitutionalization (Lulinski, 2014; Mansell, 2006) – are more likely to experience DSP turnover (citations removed for review), thereby further threatening their continuity and security. In addition, people with IDD who live in congregate and larger settings are more like to experience DSP turnover than people who live in their own homes or with family (citation removed for review). People with IDD in congregate settings also have fewer choices about where and with whom they live (citation removed for review), thereby making them more dependent on the service system and more vulnerable to disruptions in continuity and security as a result.

As a result of the many factors which can hinder the continuity and security of people with IDD, the aim of this study was to explore the impact of continuity and security (or lack thereof) on people with IDD's quality of life. To do so, we analyzed secondary Personal Outcome Measures (POM) interviews conducted with 325 people with IDD to determine the relationship between continuity and security and people with IDD's overall quality of life, as well as each individual outcome area.

Methods

Measure

The POM (The Council on Quality and Leadership, 2017) is a person-centered quality of life tool used in human services, most commonly with people with IDD. The POM includes 21 quality of life indicators (outcomes): 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; people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in community life; people remain connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; people perform social roles; people choose where and with whom to live; people choose where to work; people choose services; people choose personal goals; and, people realize personal goals.

Administration of the POM occurs in three stages. First, the interviewer has guided, in-depth open-ended conversations with the person receiving support about each of the indicators. Second, the interviewer speaks with someone who knows the person with IDD and about their organizational supports and outcomes. Finally, if needed, the interviewer may observe the participant in various settings or review records if more information is needed; otherwise, the interviewer completes decision-trees using the data gathered to determine if each of the 21 outcomes are present (1) or not (0). The POM has construct validity (citation removed for review); in addition, all interviewers are required to pass reliability tests with at least 85% agreement with expert interviewers prior to being certified.

Data and Participants

This study was an analysis of secondary POM data; as such, our institutional review board (IRB (human subjects research ethics approval)) determined it was exempt from review. The data were originally collected between March 1, 2020 and May 6, 2021 from organizations, including

local, county, and state governments, that provide human services to people with IDD. The sample includes a total of 325 people with IDD. The average age of people with IDD in our study was 45.4 ($SD = 15.5$). Most participants were White (74.9%) and primarily communicated through verbal/spoken language (87.1%; Table 1). Approximately half of participants (52.3%) were men. Approximately one-quarter of participants (22.8%) had comprehensive behavior support needs (requiring 24-hour supervision due to risk of harm), while fewer (16.0%) had complex medical support needs (12+ hours of skilled nursing care). The most common decision-making authority was full/plenary guardianship (46.3%), with fewer people having independent decision-making (31.4%), or assisted decision-making (22.3%). The most common residential type was provider owned/operated homes (46.0%), with fewer people living in their own home (26.4%), family homes (18.6%), and ‘other’ settings (9.0%).

The participants had an average of 9.4 ($SD = 4.2$) total quality of life outcomes present (out of 20). The most present outcomes were: people are safe (81.2%); people choose personal goals (65.5%); and, people have the best possible health (64.0%; Table 1). The least present outcomes were: people participate in the life of the community (25.5%); people choose services (28.9%); and, people have friends (35.7%).

Variables

The main variable utilized in this study was “people experience continuity and security” from the POM. Following the interview process, suggested questions for the open-ended discussion with the person with IDD about continuity and security include:

- “How long have your support staff worked with you?”
- Do you have the consistency you need in the staff who work with you?
- What would cause you to make changes in your current situation?

- Is there anything you do not want to change?
- What is your source of income?
- Do you have enough money to pay expenses (food, rent, clothing, health care, insurance, transportation, leisure activities)?
- How do you protect your personal property and other resources?
- Are there things you have to do without? If so, what are they and why can't you have them?
- Is your financial situation acceptable? If yes, why? If no, what do you want to change?
- Have you experienced any changes?
- How do you feel about these changes?" (The Council on Quality and Leadership, 2017, p. 26)

Suggested questions for the open-ended discussion with the person who knows the person with IDD well include:

- "What does the person consider to be important issues that would affect his or her continuity and security?
- Does the person feel secure in his or her living and working situations?
- Does the person feel secure financially?
- What has the person told you is important for continuity and security?
- If the person has indicated concerns, what are they and what was done about them?" (The Council on Quality and Leadership, 2017, p. 26)

Utilizing all of the data gathered, the interviewer completes the following decision-tree probes:

- "Does the person have economic resources to meet his or her basic needs?

- Have changes occurred over the past two years in any of the following areas: change in place of residence; change in roommate/housemate; change in employment/employer; change in other daytime activities; change in relationship status; change in guardian; change in natural support network; change in provider organization; change in direct support staff; change in financial resources available; other changes important to the person?
- Who was responsible for the change (person, guardian, family, provider, employer, or other)?
- Is the control over changes similar to that exercised by other people?” (The Council on Quality and Leadership, 2017, p. 27)

For the outcome to be considered present (1; not present (0)): the person must have economic resources to meet their basic needs; their control over changes must be similar to people not receiving services; changes must be due to the person’s informed personal choice; changes must not have had an impact on people’s lives; and, the changes must have been planned in advanced to minimize the disruption (The Council on Quality and Leadership, 2017). Decision-trees for the other outcomes are available at The Council on Quality and Leadership (2017).

Analysis

People with IDD’s continuity and security was first examined using descriptive statics. We then utilized a linear regression model to explore the relationship between continuity and security (independent variable (IV)) and total quality of life outcomes (present sum out of 20; dependent variable (DV)); while doing so, we controlled (CV) for all participant demographics. To examine the impact of continuity and security on each of the individual outcomes, we conducted a series of logistic regression models with continuity and security as the IV and each of the 20 different

outcome areas as the DV in different models; participant demographics served as the CVs in each model.

Results

Of the people with IDD in our sample, 35.2% o experienced continuity and security, while 64.8% did not experience continuity and security (Table 2). Most people (94.7%) had the economic resources to meet their basic needs. The most prevalent changes in people's lives within the past two years were changes in: activities (63.6%); support staff (62.8%); roommates (38.3%); and, residence (29.4%; Table 2). Less than half of people with IDD (38.7%) had control over the changes in their lives similar to that exercised by other people.

Impact of Continuity and Security on Overall Quality of Life

We utilized a linear regression model to explore the relationship between continuity and security and overall (total) quality of life outcomes, while controlling for participant demographics. The model was significant, $F(13, 218) = 7.45, p < 0.001, R^2 = 0.32$. According to the model (Table 3), people with IDD who experienced continuity and security had a significantly higher quality of life than people with IDD who did not experience continuity and security. Controlling for participant demographics, people with IDD who did not experience continuity and security had 6.77 outcomes present (out of 20; 33.9%), while people with IDD who experienced continuity and security had 10.90 outcomes present (54.5%).

Impact of Continuity and Security on Different Outcome Areas

We also explored the relationship between continuity and security, and each of the 20 different areas of quality of life. To do so, we used binary logistic regression models with each of the 20 different outcomes as the DV for each model, and continuity and security as the IV, and demographic variables as the CVs. Findings revealed continuity and security significantly

increased the likelihood of 14 of the 20 outcome areas being present: people are free from abuse and neglect; people have the best possible health; people exercise rights; people are treated fairly; people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in the life of the community; people are connected to natural support networks; people have friends; people decide when to share personal information; people choose where and with whom to live; and, people choose services.

Controlling for all demographics, people with IDD who experienced continuity and security were 2 times more likely to live in integrated environments (Table 4). The probability of people with IDD living in integrated environments was 53.8% when they experienced continuity and security compared to 34.3% when they did not experience continuity and security. People with IDD who experienced continuity and security were 3 times more likely to: be free from abuse and neglect; interact with other members of the community; participate in the life of the community; and be connected to natural support networks. For example, when people with IDD experienced continuity and security the probability of being free from abuse and neglect was 63.5% versus 38.3% when they did not experience continuity and security. People with IDD who experienced continuity and security were 4 times more likely to: use their environments; have friends; have the best possible health; be respected; decide when to share personal information; choose where and with whom to live; and choose services. For example, the probability of having friends was 44.1% when people with IDD experienced continuity and security and 16.0% when they did not experience continuity and security. People with IDD who experienced continuity and security were 5 times more likely to be treated fairly. When people with IDD experienced continuity and security the probability of being treated fairly was 65.5% compared

to 29.3% when they did not experience continuity and security. People with IDD who experienced continuity and security were 6 times more likely to exercise rights; the probability of exercising rights was 17.1% when people with IDD did not experience continuity and security, compared to 55.5% when they did experience continuity and security.

Discussion

The aim of this study was to explore how continuity and security impacted people with IDD's quality of life. Our findings revealed, regardless of their demographics, people with IDD who experienced continuity and security had almost double the quality of life outcomes present than people with IDD who did not experience continuity and security. In fact, continuity and security positively impacted two-thirds of the different outcome areas, ranging from health to relationships to rights to control over ones' life.

In addition to increasing quality of life more broadly, continuity and security is a social determinant of health – “conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (United States Office of Disease Prevention and Health Promotion, n.d., n.p.). For example, one study found continuity and security was associated with a 66% decrease in emergency department visits among people with IDD (citation removed for review). In our study, continuity and security significantly increased the probability of people with IDD having the best possible health (from 61.6% to 87.0%).

Our findings also suggest continuity and security helps facilitate people with IDD's control over their lives and services. For example, people with IDD who experienced continuity and security were 4.4 times more likely to choose where and with whom to live than people with IDD who did not experience continuity and security. This increase in choosing where and with

whom to live likely has a ripple effect as people with IDD are more likely to prefer individualized settings, such as living in their own homes or with family, which are associated with better outcomes (citation removed for review; Hemp et al., 2014; Larson et al., 2013). In fact, person-centered practices and self-determined choices in general are associated with better health outcomes and quality of life (Beatty et al., 2003; Drum et al., 2005; Infurna et al., 2011; Schalock, 2004).

While continuity and security increased the likelihood of people with IDD having choices, it is also important to note that most people with IDD in our study did not have choices, and choice-related outcomes were some of the least present outcomes. For example, the probability of people with IDD choosing their services was less than 18% regardless of if they experienced continuity and security (17.4%) or not (7.5%). While the lack of choices people with IDD in our study had is concerning, it is unfortunately not uncommon (citation removed for review). As such, there must be a concerted effort to expand person-centered practices.

People with IDD who experienced continuity and security were also more likely to have and be satisfied with their relationships and be more integrated into their communities. Both community integration and social relationships improve the quality of life of people with IDD (Fulford & Cobigo, 2018; Lafferty et al., 2013; Petrina et al., 2014; Petrina et al., 2016; Ward et al., 2013). Conversely, a lack of continuity and security makes it more difficult to build and maintain lasting relationships. Promoting the continuity and security of people with IDD may be one such way to facilitate the integration and relationships of people with IDD. Doing so is particularly important as people with IDD are more likely to be isolated, lonely, have fewer close friends and romantic partners, and see their friends less, largely due to a lack of opportunities for

creating and maintaining relationships (Fulford & Cobigo, 2018; Petrina et al., 2014; Petrina et al., 2017; Pottie & Sumarah, 2004).

Continuity and security, especially less DSP turnover, may also lead to stronger relationships between people with IDD and DSPs. Stability and consistency of DSPs will lead to DSPs being more likely to know the person's wants and needs, better suited to help facilitate their services in person-centered ways, and less likely to make assumptions about what people are 'capable' of. These changes, in addition to the increased control over one's life associated with continuity and security, may be why continuity and security was associated with people with IDD being more likely to exercise their rights, for example. In our study, regardless of their demographics, when people with IDD experienced continuity and security, the probability of them exercising rights increased from 17% to 56%. While an increase in rights and treated fairly is certainly beneficial, the fact that a lack of continuity and security hindered people's rights is also concerning given the inherent nature of rights. As a result of this important and multifaceted relationship, we believe more research should be conducted to explore the complex interplay between continuity and security, and people with IDD exercising rights.

Implications

To promote people with IDD's quality of life, efforts must be made to facilitate people with IDD's continuity and security. Not only did only 35% of the people with IDD in our study experience continuity and security, only 39% had control over the changes in their lives to a similar degree as other people. The instability that comes with a lack of continuity and security can lead to increases in adverse mental and behavioral health symptoms (American Psychological Association, 2020; Centers for Disease Control and Prevention, 2020). As suggested by this study, it can also reduce people with IDD's quality of life, including the

choices they have about their lives, the ways they integrate into their communities, their ability to exercise their rights, and many more.

The IDD service infrastructure is underfunded and fractured (ANCOR Foundation & United Cerebral Palsy, 2021). As a result of the important role DSPs play in promoting the health, safety, and quality of life of people with IDD (citations removed for review), as well as the DSP turnover ‘crisis’ that has existed for decades, the DSP workforce must be stabilized. To do so, proposed strategies include increasing reimbursement rates and wages for DSPs, increasing training for DSPs, recognizing the profession as a Department of Labor standard occupation classification, and the professionalizing the workforce (Bogenschutz et al., 2014; Keesler, 2016; Micke, 2015; National Alliance for Direct Support Professionals, 2013, n.d.; Robbins et al., 2013; Smith et al., 2019).

Given almost 40% of people with IDD in our study experienced a change in roommates and almost 30% changed residences within the last 2 years, structures and systems that promote affordable, accessible, and stable housing for people with IDD must be strengthened (McCormick et al., 2019; Schaak et al., 2017). Not only does HCBS play a key role in housing security for people with IDD, it also facilitates the continuity and security of people with IDD and of disability service providers; as such, HCBS should also be expanded and strengthened (ANCOR Foundation & United Cerebral Palsy, 2021; McCormick et al., 2019; Wong, 2020). In fact, the Autistic Self Advocacy Network (n.d.), The Arc of the United States (2020), and ANCOR Foundation and United Cerebral Palsy (2021), among others, have called for the HCBS Infrastructure Act to be passed. The Act:

“would make structural improvements in the HCBS program by investing in funding to (1) assist states to comply with the HCBS Settings Rule, (2) implement

quality measurement, (3) expand employment opportunities, (4) supercharge workforce development efforts, (5) promote employment for people with disabilities, (6) improve case management, (7) assist states in developing community housing, and (8) address necessary changes to HCBS to address COVID-19 risk.” (ANCOR Foundation & United Cerebral Palsy, 2021, p. 18)

Finally, to facilitate continuity and security, disability poverty must be remedied (Pinilla-Roncancio & Alkire, 2021; Pulrang, 2020; Vallas & Cortland, 2021); disabled journalist Andrew Pulrang (2020) notes, “money is probably the single most effective and flexible tool for dealing with any disability. It buys access, security, even respect... it absolutely cushions the practical effects and complications of ableism” (n.p.).

Limitations

When interpreting this study’s findings, a number of limitations should be noted. All of the participants were service recipients, which likely impacted their continuity and security. This was not a random or representative sample. Due to the COVID-19 pandemic, some interviews may have been conducted virtually rather than in-person as is typical. We did not explore interactions. This was a secondary data analysis – we did not have the ability to add additional variables or ask participants follow up questions.

Conclusions

Our findings revealed those people with IDD who did not experience continuity and security had significantly worse quality of life, both overall and within a wide variety of areas. While continuity and security alone will not automatically result in a high quality of life, people with IDD will be hard pressed to have good quality of life without it. A stronger and more stable

community infrastructure is needed to promote the continuity and security, and by extension, quality of life of people with IDD.

References

- American Network of Community Options and Resources. (2014). *Ensuring a sustainable work force for people with disabilities: Minimum wage increases can not leave direct support professionals behind*. Author.
- American Psychological Association. (2020). *Stress in the time of COVID-19*.
<https://www.apa.org/news/press/releases/stress/2020/stress-in-america-covid.pdf>
- ANCOR Foundation, & United Cerebral Palsy. (2021). *The case for inclusion 2021: A special report on the sustainability of community disability services in America*.
https://caseforinclusion.org/application/files/2416/1376/5849/Case_for_Inclusion_2021_Special_Report.pdf
- Autistic Self Advocacy Network. (n.d.). *The institutional bias: What it is, why it is bad, and the laws, programs, and policies which would change it*.
<https://autisticadvocacy.org/actioncenter/issues/community/bias/>
- Beatty, P. W., Hagglund, K. J., Neri, M. T., Dhont, K. R., Clark, M. J., & Hilton, S. A. (2003). Access to health care services among people with chronic or disabling conditions: patterns and predictors 1. *Archives of physical medicine and rehabilitation*, 84(10), 1417-1425. [https://doi.org/10.1016/S0003-9993\(03\)00268-5](https://doi.org/10.1016/S0003-9993(03)00268-5)
- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities*, 52(5), 317-329. <https://doi.org/10.1352/1934-9556-52.5.317>
- Britton Laws, C., Kolomer, S. R., & Gallagher, M. J. (2014). Age of persons supported and factors predicting intended staff turnover: A comparative study. *Inclusion*, 2(4), 316-328.
<https://doi.org/10.1352/2326-6988-2.4.316>

- Burns, M. E. (2009). Medicaid managed care and health care access for adult beneficiaries with disabilities. *Health services research, 44*(5p1), 1521-1541.
<https://doi.org/10.1111/j.1475-6773.2009.00991.x>
- Centers for Disease Control and Prevention. (2020). Mental health, substance use, and suicidal ideation during the COVID-19 pandemic — United States, June 24–30, 2020. *Morbidity and Mortality Weekly Report, 69*(32), 1049-1057.
- Drum, C. E., Krahn, G., Culley, C., & Hammond, L. (2005). Recognizing and responding to the health disparities of people with disabilities. *Californian Journal of Health Promotion, 3*(3), 29-42. <https://doi.org/10.32398/cjhp.v3i3.647>
- Fulford, C., & Cobigo, V. (2018). Friendships and intimate relationships among people with intellectual disabilities: A thematic synthesis. *Journal of Applied Research in Intellectual Disabilities, 31*(1), e18-e35. <https://doi.org/10.1111/jar.12312>
- Hemp, R., Braddock, D., & King, M. (2014). Community-based Medicaid funding for people with intellectual and developmental disabilities. *National Conference of State Legislatures LegisBrief, 22*, 1-2.
- Infurna, F. J., Gerstorf, D., Ram, N., Schupp, J., & Wagner, G. G. (2011). Long-term antecedents and outcomes of perceived control. *Psychology and aging, 26*(3), 559-575.
<https://doi.org/10.2139/ssrn.1750253>
- Keesler, J. M. (2016). *An evaluation of individual and organizational factors in predicting professional quality of life among direct support professionals in intellectual/developmental disability services [Doctoral dissertation]*. State University of New York at Buffalo.

- Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, 28(8), 1074-1088. <https://doi.org/10.1080/09687599.2012.758030>
- Larson, S., Lakin, C., & Hill, S. (2013). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1977 to 2010. *Research and Practice for Persons with Severe Disabilities*, 37(4), 235-246. <https://doi.org/10.2511/027494813805327287>
- Lulinski, A. (2014). *Community capacity to provide mental/behavioral health services to people with developmental disabilities* [Unpublished doctoral dissertation]. University of Illinois at Chicago.
- 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>
- McCormick, L., Schwartz, A., & Passerini, C. (2019). Housing for people with disabilities: A review of state Olmstead and HUD consolidated plans. *Journal of Planning Education and Research*, Advanced online publication, 1-15. <https://doi.org/10.1177/0739456X19844567>
- Micke, H. (2015). *Causes and solutions for high direct care staff turnover* [Master of Social Work Clinical Research Paper]. St. Catherine University & University of St. Thomas.
- National Alliance for Direct Support Professionals. (2013). *credentialing guidebook for direct support professionals*. National Alliance for Direct Support Professionals. https://www.nadsp.org/wp-content/uploads/2016/08/NADSP_Credentialing_Guidebook_FINAL_8.23.13.pdf

- National Alliance for Direct Support Professionals. (n.d.). *Establish a direct support professional standard on occupational classification*. <https://nadsp.org/DSP-SOC/>
- Petrina, N., Carter, M., & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 8*(2), 111-126. <https://doi.org/10.1016/j.rasd.2013.10.016>
- Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2016). Perceived friendship quality of children with autism spectrum disorder as compared to their peers in mixed and non-mixed dyads. *Journal of Autism and Developmental Disorders, 46*(4), 1334-1343. <https://doi.org/10.1007/s10803-015-2673-5>
- Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2017). Friendship satisfaction in children with autism spectrum disorder and nominated friends. *Journal of Autism and Developmental Disorders, 47*(2), 384-392.
- Pinilla-Roncancio, M., & Alkire, S. (2021). How poor are people with disabilities? Evidence based on the global multidimensional poverty index. *Journal of Disability Policy Studies, 31*(4), 206-216. <https://doi.org/10.1177/1044207320919942>
- Podmostko, M. (2007). *Tunnels and cliffs: A guide for workforce development practitioners and policymakers serving youth with mental health needs*. National Collaborative on Workforce and Disability for Youth & Institute for Educational Leadership.
- Pottie, C., & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation, 42*(1), 55-66. [https://doi.org/10.1352/0047-6765\(2004\)42<55:FBPWAW>2.0.CO;2](https://doi.org/10.1352/0047-6765(2004)42<55:FBPWAW>2.0.CO;2)

Pulrang, A. (2020). *COVID-19 teaches us a lot about differences in the disability community.*

Forbes. <https://www.forbes.com/sites/andrewpulrang/2020/04/30/covid-19-teaches-us-a-lot-about-differences-in-the-disability-community/?sh=308996a17714>

Robbins, E., Dilla, B., Sedlezky, L., & Johnson Sirek, A. (2013). *Coverage of direct service workforce continuing education and training within medicaid policy and rate setting: A toolkit for state medicaid agencies.* National Direct Service Workforce Resource Center.

<https://www.medicaid.gov/sites/default/files/2019-12/dsw-training-rates-toolkit.pdf>

Schaak, G., Sloane, L., Arienti, F., & Zovistoski, A. (2017). *Priced out: The housing crisis for people with disabilities.* Technical Assistance Collaborative & Consortium for Citizens with Disabilities. <https://www.tacinc.org/wp-content/uploads/2020/04/priced-out-in-2016.pdf>

Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203-216. <https://doi.org/10.1111/j.1365-2788.2003.00558.x>

Smergut, P. (2007). Minimizing turnover among support counselors through a value based culture. *Journal of Nonprofit Management*, 11(1), 28-39.

Smith, D., Macbeth, J., & Bailey, C. (2019). *Moving from crisis to stabilization: The case for professionalizing the direct support workforce through credentialing.* Community Bridges Consulting Group, National Alliance for Direct Support Professionals, & National Leadership Consortium on Developmental Disabilities.

<https://www.nadsp.org/wp-content/uploads/2019/02/Moving-from-Crisis-to-Stabilization-Credentialing-Report.pdf>

The Arc of the United States. (2020). *Medicaid/LTSS: HCBS Infrastructure Improvement Act introduced in Senate*. <https://insider.thearc.org/2020/02/18/medicaid-ltss-hcbs-infrastructure-improvement-act-introduced-in-senate/>

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

United States Office of Disease Prevention and Health Promotion. (n.d.). *Social determinants of health*. Author. <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>

Vallas, R., & Cortland, M. (2021). The safety net program Congress forgot. *The Hill*. <https://thehill.com/blogs/congress-blog/politics/550027-the-safety-net-program-congress-forgot>

Venema, E., Otten, S., & Vlaskamp, C. (2015). The efforts of direct support professionals to facilitate inclusion: The role of psychological determinants and work setting. *Journal of Intellectual Disability Research*, 59(10), 970-979. <https://doi.org/10.1111/jir.12209>

Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22-32. <https://doi.org/10.1352/1934-9556-51.01.022>

Wong, A. (2020). *Freedom for some is not freedom for all*. Disability Visibility Project. <https://disabilityvisibilityproject.com/2020/06/07/freedom-for-some-is-not-freedom-for-all/>

Table 1

Demographics (n = 325)

Characteristic	<i>n</i>	%
Gender (<i>n</i> = 321)		
Man	170	52.3%
Woman	151	47.0%
Race (<i>n</i> = 319)		
White	239	74.9%
Black	60	18.8%
Other	22	6.9%
Primary communication method (<i>n</i> = 319)		
Verbal/spoken language	278	87.1%
Other	41	12.9%
Decision-making (<i>n</i> = 309)		
Independent	97	31.4%
Assisted decision-making	69	22.3%
Full/plenary guardianship	143	46.3%
Complex medical support needs (<i>n</i> = 250)		
Yes	40	16.0%
No	210	84.0%
Comprehensive behavior support needs (<i>n</i> = 250)		
Yes	57	22.8%
No	193	77.2%
Residence (<i>n</i> = 311)		
Provider owned/operated home	143	46.0%
Own home	82	26.4%
Family home	58	18.6%
Other	28	9.0%
Quality of Life outcomes (present)		
People are safe	266	81.2%
People are free from abuse and neglect	160	49.2%
People have the best possible health	208	64.0%
People exercise rights (<i>n</i> = 324)	134	41.4%
People are treated fairly	168	51.7%
People are respected	175	53.8%
People use their environments	195	60.0%
People live in integrated environments	175	53.8%
People interact with other members of the community	117	36.0%
People participate in the life of the community	83	25.5%
People are connected to natural support networks	104	32.0%
People have friends	116	35.7%

People have intimate relationships	115	35.4%
People decide when to share personal information	153	47.1%
People perform different social roles	119	36.6%
People choose where and with whom to live	116	35.7%
People choose where to work	147	45.2%
People choose services	94	28.9%
People choose personal goals	213	65.5%
People realize personal goals	195	60.0%

Note. Participants could be from more than one race.

Table 2

Descriptive Statistics

Variable	% yes
Continuity and security	35.2%
Person has economic resources to meet their basic needs	94.7%
Change in (within 2 years):	
Activities	63.6%
Support staff	62.8%
Roommate	38.3%
Residence	29.4%
Employment	29.2%
Financial resources	17.3%
Relationship	15.6%
Support network	14.0%
Provider organization	10.0%
Guardian	3.2%
Other	8.8%
Control over changes similar to that exercised by other people	38.7%

Table 3
Continuity and Security, and Total Quality of Life Outcomes

Variable	<i>t</i>	<i>SE B</i>	<i>B [95% confidence interval]</i>
Constant	4.20***		6.77 [3.59 - 9.94]
Continuity and security (ref: not present)	6.82***	0.41	4.13 [2.94 - 5.32]
Control variables			
Age	0.67	0.04	0.01 [-0.03 - 0.05]
Woman (ref: man)	-1.91	-0.11	-1.06 [-2.15 - 0.03]
Race (ref: White)			
Black	2.08*	0.13	1.50 [0.08 - 2.92]
Other	0.21	0.01	0.26 [-2.12 - 2.64]
Primary communication method: Verbal (ref: other)	1.90	0.12	1.56 [-0.06 - 3.18]
Decision-making (ref: independent)			
Full/plenary guardianship	-3.05**	-0.22	-2.07 [-3.40 - -0.73]
Assisted decision-making	-1.29	-0.09	-1.01 [-2.55 - 0.53]
Complex medical support needs (ref: no)	-0.51	-0.03	-0.38 [-1.86 - 1.10]
Comprehensive behavior support needs (ref: other)	-0.99	-0.06	-0.68 [-2.03 - 0.68]
Residence (ref: provider owned/operated)			
Own home	1.84	0.12	1.19 [-0.09 - 2.47]
Family home	1.45	0.10	1.25 [-0.45 - 2.95]
Other	0.12	0.01	0.12 [-1.91 - 2.15]

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

Table 4

Impact of Continuity and Security on Other Areas of Quality of Life

Model	-2LL	df	χ^2	R^2	B	Wald
People are safe	183.38	12	18.72	0.14	1.25	5.70
People are free from abuse and neglect	255.3	12	48.26***	0.26	1.03	8.97
People have the best possible health	251.81	12	32.20**	0.19	1.43	13.27
People exercise rights	231.48	12	64.39***	0.34	1.80	25.46
People are treated fairly	264.37	12	39.19***	0.22	1.52	19.75
People are respected	264.56	12	39.00***	0.22	1.44	18.22
People use their environments	254.29	12	36.36***	0.21	1.35	12.69
People live in integrated environments	255.21	12	48.28***	0.26	0.80	5.20
People interact with other members of the community	250.69	12	28.10**	0.17	1.11	10.76
People participate in the life of the community	201.00	12	24.14*	0.16	1.16	9.68
People are connected to natural support networks	220.53	12	42.30***	0.25	1.23	12.54
People have friends	247.29	12	25.62*	0.16	1.42	17.69
People have intimate relationships	254.67	12	30.55**	0.18	0.50	2.26
People decide when to share personal information	251.56	12	51.01***	0.28	1.46	18.09
People perform different social roles	250.16	12	25.78*	0.16	0.07	0.04
People choose where and with whom to live	208.46	12	68.93***	0.38	1.48	14.23
People choose where to work	257.21	12	40.78***	0.23	0.31	0.84
People choose services	186.39	12	53.69***	0.33	1.49	15.28
People choose personal goals	230.14	12	41.21***	0.24	0.40	1.10
People realize personal goals	250.56	12	42.87***	0.24	0.09	0.07

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$. All models control for participant demographics.

Predicted probability		
and security: No	and security: Yes	Odds ratio [95% confidence interval]
24.0%	52.5%	3.49* [1.25 - 9.76]
38.3%	63.5%	2.79** [1.43 - 5.45]
61.6%	87.0%	4.18*** [1.94 - 9.03]
17.1%	55.5%	6.03*** [3.00 - 12.11]
29.3%	65.5%	4.59*** [2.34 - 8.98]
22.1%	54.5%	4.22*** [2.18 - 8.18]
19.1%	47.6%	3.84*** [1.83 - 8.05]
34.3%	53.8%	2.23*** [1.12 - 4.45]
13.3%	31.7%	3.03*** [1.56 - 5.86]
9.0%	23.9%	3.20** [1.54 - 6.67]
10.3%	28.3%	3.41*** [1.73 - 6.73]
16.0%	44.1%	4.15*** [2.14 - 8.04]
49.1%	61.4%	1.65 [0.86 - 3.17]
42.9%	76.4%	4.30*** [2.20 - 8.42]
13.9%	14.8%	1.07 [0.55 - 2.10]
6.9%	24.5%	4.37*** [2.03 - 9.40]
30.9%	37.9%	1.37 [0.70 - 2.66]
4.5%	17.4%	4.42*** [2.10 - 9.32]
75.4%	82.1%	1.50 [0.70 - 3.20]
68.9%	70.8%	1.10 [0.55 - 2.18]