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**Quality of Life Outcome and Support Disparities Among
People with More Severe Impairments**

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Abstract

People with intellectual and developmental disabilities (IDD) with more severe impairments often face service disparities. The aim of this study was to explore not only disparities in quality of life outcomes for people with IDD with severe impairments, but also disparities in the supports they receive from disability service organizations. Our analysis of Personal Outcome Measures® interviews from 1,300 people revealed people with severe impairments experienced quality of life disparities in most domains, attributed to the fact that they also received fewer organizational supports than people with less severe impairments. By paying attention to person-centered outcomes, including these disparities, organizations' roles can shift from just providing services to supporting people to achieve the outcomes that are truly important to them.

Keywords: people with severe impairments; intellectual and developmental disabilities; quality of life; disability service organizations

Quality of Life Outcome and Support Disparities Among People with More Severe Impairments

People with intellectual and developmental disabilities (IDD) with more severe impairments often face service disparities, and as a result are less likely to have equal opportunities compared to those people with IDD with less severe impairments. For example, historically, people with more severe disabilities have been institutionalized at higher rates than those with less complex disabilities. Furthermore, even those people with more severe impairments who *are* supported in the community are less likely to actually own their own homes than people with low support needs (Hall et al., 2005; Lulinski-Norris, 2014). Research also suggests, compared to people with less severe impairments, people with more severe impairments also have fewer day-to-day experiences – they have less to do on a daily basis (Beadle-Brown et al., 2016; Felce, 1997).

According to research, people with severe impairments are also less likely to be employed (Carter, Austin, & Trainor, 2012; Hall et al., 2005). Those with severe impairments who are employed are less likely to work in competitive community employment and more likely to work in segregated settings (Carter et al., 2012; Levy & Perry, 2011). People with severe disabilities who are employed also earn less money than people with less severe impairments (Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009), and have fewer interactions at work than those with less severe impairments (Verdonschot et al., 2009). Moreover, it has also been implied that the transition system – which aims to support people with disabilities as they transition between school and work – “could be readily characterized as a ‘bridge to nowhere’ for substantial numbers of youth with severe disabilities” (Carter et al., 2012, p. 50)

People with more severe impairments also face numerous relationship disparities compared to those with less severe impairments. For example, when they are employed, people with more severe impairments have been found to have less close relationships with their co-workers (Verdonschot et al., 2009). People with more severe impairments also tend to have fewer friends than people with less severe impairments (Hall et al., 2005). However, a study by Hall et al. (2005) did find people with severe impairments were just as likely to participate in social activities and have a social life as people with less severe impairments.

In addition to the above disparities, there is also research that suggests people with more severe impairments face many quality of life disparities. Quality of life is based on “common human experiences and unique, individual life experiences” (Schalock et al., 2002, p. 462) while also giving a “sense of reference and guidance from the individual’s perspective, focusing on the person and the individual’s environment” (Brown, Schalock, & Brown, 2009, p. 2). While originally disability quality of life measures were used in clinical contexts to examine the “burden” of disabilities, the conceptualization of these measures has since broadened to be more holistic and multidimensional, containing a wide range of domains, such as: emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; self-determination; social inclusion; empowerment; and, rights (Buntinx & Schalock, 2010; Cieza & Stucki, 2005, p. 1226; Cummins, 1991; Cummins, McCabe, Romeo, Reid, & Waters, 1997; Nota, Soresi, & Perry, 2006; Schalock, 2004; Schalock et al., 2002; Schalock, Keith, Verdugo, & Gómez, 2010). According to research by Petry, Maes, and Vlaskamp (2005) parents and direct support professionals (DSPs) of people with severe impairments reported the ‘domains’ of quality of life less frequently achieved for people with severe impairments were

material well-being, such as the living environment, technical aids, and transportation, and emotional well-being, including individuality, respect, self-esteem, and atmosphere.

Combined, all these disparities highlight areas that need an influx of individualized organizational supports to ensure people with more severe impairments have the same opportunities as people with less severe impairments. In fact, provider organizations and staff can play a key role in facilitating the opportunities of people with severe impairments (Beadle-Brown et al., 2016). For these reasons, the aim of this study was to explore disparities in quality of life outcomes for people with IDD with severe impairments. In addition to exploring disparities in quality of life outcomes, another aim of our study was to examine the role disability service organizations play in maximizing the quality of life of people with severe impairments. To do so, we analyzed Personal Outcome Measures[®] interviews from approximately 1,300 people with IDD.

Methods

Participants

The secondary survey data utilized in this survey were transferred to the researchers with no identifiers; as such the author's institutional research board (IRB) determined it was exempt from full review. Participants for the dataset were originally recruited over approximately two years (January 2015 – December 2016) through organizations in the United States that provide services to people with disabilities, including: 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 services systems. Over the roughly two-year period, 1,341 people with IDD volunteered to participate. While age, gender, and guardianship status were relatively evenly distributed across demographic groups,

the majority of participants were White (74.4%), used verbal/spoken language as their primary communication method (82.2%), and lived in provider owned or operated homes (50.5%) (Table 1).

Daily support needs, which was used as a proxy for severity of impairment, was defined as the average number of hours the person needed support and/or received support services per day, presumably those with the most support – around the clock (24/7) – have more severe impairments than those with less support needs. 64.1% of participants in the sample had high support needs, needing 24/7 around the clock support (Table 1).

Measure

The instrument used in this study was the Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017b), developed by the international non-profit disability organization the Council on Quality and Leadership. The Personal Outcome Measures[®] tool is designed to determine people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. The Personal Outcome Measures[®] includes 21 indicators divided into five factors (domains): my human security; my community; my relationships; my choices; and, my goals.

- *My human security* includes the following indicators:
 - people are safe;
 - people are free from abuse and neglect;
 - people have the best possible health;
 - people experience continuity and security;
 - people exercise rights;
 - people are treated fairly; and,

- people are respected.
- *My community* includes the following indicators:
 - people use their environments;
 - people live in integrated environments;
 - people interact with other members of the community; and,
 - people participate in the life of the community.
- *My relationships* includes the following indicators:
 - people are connected to natural support networks;
 - people have friends;
 - people have intimate relationships;
 - people decide when to share personal information; and,
 - people perform different social roles.
- *My choices* includes the following indicators:
 - people choose where and with whom to live;
 - people choose where to work; and,
 - people choose services.
- *My goals* includes the following indicators:
 - people choose personal goals; and,
 - people realize personal goals.

For every participant, the Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a trained Personal Outcome Measures[®] interviewer has in-depth conversations with the participant with disabilities about each of the indicators (approximately one to two hours). For these conversations, the interviewer follows specific open-ended prompts.

During the second stage of the Personal Outcome Measures[®] interview, the interviewer speaks with someone who knows the participant with 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 (approximately one to two hours).

During the final stage, the interviewer observes the participant in various settings and conducts individual record reviews if necessary. The interviewer then completes decision trees about personal outcomes and individualized organizational supports based on the information gathered in the three stages (for more information about decision trees for each indicator, see The Council on Quality and Leadership (2017b)). Utilizing these decision trees, the interviewers decide if each of the 21 personal outcomes are present (1) or not (0), as well as if each of the individuals organizational supports are in place (1) or not (0). As the measure is person-centered, if there are any discrepancies across stages, the person with IDD's 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, over 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures[®] construct validity was recently confirmed using a principal components analysis (PCA), which retained all 21 indicators and grouped them into the five factors described above (Friedman, 2018). For strengthened reliability, this analysis only included certified interviews; certified interviewers are required to pass reliability tests with an expert interviewer with scores

of at least 85% before being certified to conduct interviews (The Council on Quality and Leadership, 2017a).

Analysis

As we were interested in exploring disparities in quality of life outcomes for people with IDD with severe impairments, we ran an independent samples *t*-test to determine if there were significant differences in total outcomes across people with severe and less severe impairments. Then we ran chi-square tests of independence for each of the 21 outcome indicators to determine significant differences by outcome area.

In order to examine the role disability service organizations play in maximizing the quality of life of people with severe impairments, we also ran an independent samples *t*-test to determine if there were significant differences in total organizational supports across people with severe and less severe impairments. We then ran chi-square tests of independence for each of the 21 organizational supports to determine significant differences by support area.

Results

Across groups, participants had an average of 10.45 outcomes present ($SD = 5.19$) out of 21 (49.8%). They also had an average of 11.14 organizational supports in place ($SD = 5.52$) out of 21 (53.0%). However, there were large differences across the different indicators and group (more severe and less severe) (Table 2).

Personal Outcomes

An independent-samples *t*-test was run to determine if there were differences in overall quality of life between people with severe and less severe impairments. The model was significant, $t(1276) = 10.25$, $p < 0.001$, Cohen's $d = 0.59$, indicating there was a significant

difference in total outcomes for people with severe impairments ($M = 9.48$, $SD = 4.86$) and people with less severe impairments ($M = 12.42$, $SD = 5.00$).

To determine disparities among different quality of life outcomes, chi-square tests were also calculated comparing the frequency of each of the 21 quality of life outcomes in people with less severe and more severe disabilities. Significant interactions were found for the following (18 out of 21) quality of life outcomes: continuity and security; exercise rights; treated fairly; respected; interact with others in the community; live in integrated environments; participate in the life of the community; use environments; intimate relationships; have friends; natural support networks; decide when to share personal information; perform different social roles; choose with where and with whom to live; choose where to work; choose services; choose personal goals; and, realize personal goals (Table 3). There were not significant differences for the following three outcomes: safe; free from abuse and neglect; and, best possible health.

People with severe impairments were less likely to have each of those 18 outcomes present compared to people with less severe impairments (see Table 2). For example, people with severe impairments were 36.1% less likely to choose where and with whom to live than those with less severe impairments. In fact, only 13.0% of people with severe impairments chose where and with whom to live. There were also large disparities across the other outcomes (Figure 1).

Organizational Supports

An independent-samples t -test was run to determine if there were differences in total organizational supports between people with more severe and less severe impairments. The model was significant, $t(1175) = 7.12$, $p < 0.001$, Cohen's $d = 0.43$, indicating there was a

significant difference in total supports for people with severe impairments ($M = 10.30$, $SD = 5.45$) and people with less severe impairments ($M = 12.62$, $SD = 5.23$).

To determine disparities among different quality of life organizational supports, chi-square tests were also calculated comparing the frequency of each of the 21 organizational supports for people with less severe and more severe disabilities. Significant interactions were found for the following (16 out of 21) supports: continuity and security; exercise rights; treated fairly; respected; interact with others in the community; live in integrated environments; participate in the life of the community; use environments; intimate relationships; have friends; natural support networks; perform different social roles; choose where and with whom to live; choose where to work; choose services; and, choose personal goals (Table 4). There were not significant differences in organizational support for the following five supports: safe; free from abuse and neglect; best possible health; decide when to share personal information; and realize personal goals.

People with severe impairments were less likely to have each of the 16 organizational supports present than people with less severe impairments (Table 2). For example, people with severe impairments were supported 16.7% less often to choose their services than people with less severe impairments. In fact, less than a quarter of people with severe impairments (23.5%) were supported to choose their services. There were also large disparities across the other outcomes (Figure 2).

Discussion

The aim of this study was to examine disparities in personal outcomes and organizational supports for people with severe impairments. To do so, we examined not only people with severe impairment's quality of life outcomes, but also differences in the organizational supports people

with severe impairments receive from disability service providers. Our findings revealed people with severe impairments experience quality of life disparities in most areas compared to people with less severe impairments, likely largely attributed to the fact that they also received fewer organizational supports than people with less severe impairments.

While providers cannot necessarily control people's personal outcomes, they do have control over if, and how, they support people with severe impairments. Some of the areas without significant disparities, such as safety or health, although important, are relatively traditional forms of accountability required of disability service organizations. However, as a result of changes in legislation and litigation, such as the Americans with Disabilities Act (ADA) (1990) and *Olmstead v L.C.* (1999), as well as advocacy by people with IDD and their families, there are now increased expectations about what quality means, including related to inclusion, autonomy, and nondiscrimination, beyond these basic types of human security (Buntinx & Schalock, 2010; Verdugo, Jordán de Urrías, Jenaro, Caballo, & Crespo, 2006). Moreover, our findings revealed people with more severe impairments often received less support from organizations than those with less severe impairments amongst almost all other quality of life domains. Not only that, but organizations were also not targeting the outcomes that were present less often for people with severe disabilities.

One of the areas which was particularly lacking related to organizational supports for community integration. People with severe impairments were significantly less likely to be supported by providers to live in integrated environments, interact with others in the community, and use their environments than people with less severe impairments. In fact, people with more severe impairments were even supported less often to choose where and with whom they live compared to people with less severe impairments. Organizations need to provide targeted

supports to people with severe impairments to ensure they have equal opportunities for community integration. This is especially pertinent as litigation, such as *Olmstead*, and regulations, such as the *Medicaid HCBS Settings Rule* (CMS 2249-F/2296-F), have reinforced *all* people with disabilities' right to community integration. Moreover, the HCBS settings rule also reinforces people with disabilities' right to choose, including where and with whom to live, yet only 13% of our sample of 819 people with severe impairments had the opportunity to do so, and only about one-fifth were receiving supports from provider organizations to make these choices.

In addition to large disparities related to community, people with severe impairments were also less likely to choose their services, choose where they worked, and choose their personal goals than people with less severe impairments, *and* less likely to be supported by organizations to make these choices and realize these goals. The HCBS settings rule requires long-term services and supports (LTSS) be directed by peoples' preferences and goals. Rather than placing people into 'slots,' services should be chosen by each person; "services and supports are not outcomes themselves; rather, they facilitate outcomes. They are processes that enable people to achieve their goals" (The Council on Quality and Leadership, 2017b, p. 74)

Another concerning disparity was related to rights. People with more severe impairments were also less likely to receive organizational supports to exercise their rights. Moreover, those with severe impairments with rights violations were also less likely to receive organizational supports for due process (treated fairly). By virtue of citizenship, people with disabilities are entitled to civil rights; however, while in theory civil rights are designed to help protect people against oppressive abuse of power, people with disabilities' civil rights are often violated (Quinn & Degener, 2002). Rights limitations of people with disabilities in the United States, and the lack

of opportunities they experience as a result, have always been deeply intertwined with discrimination, stereotypes, and attitudes towards disability.

The lack of support people with severe impairments receive may be related to these attitudes and the lack of respect they produce. Indeed, people with severe impairments in this study were significantly less likely to be respected than people with less severe impairments. Equity for people with disabilities requires equal opportunities; systemic barriers not only need to be reduced, but conceptualizations of disability need to be shifted so that they recognize the lived experiences of people, rather than simply reflect harmful stereotypes and attitudes. These disparities relate both to inadequate supports for people and negative perceptions about people with severe disabilities' abilities, highlighting a need for not only organizational supports but also provider cultural shifts. They require cultural shifts that move beyond compliance and custodial models of care, to reexamine norms in order to remove assumptions, and add additional emphasis on evidenced based person-centered practices – in order to be accountable to the people with IDD with severe impairments they support. Wehmeyer and Bolding (2001) remind us,

the prevalent assumption is that these individuals [with more severe disabilities] cannot or do not become self-determined, an opinion formed *almost exclusively* on assumptions about individual capacity or the limitations thereof... However, by *addressing issues* pertaining to environment and opportunity, and by providing adequate supports and accommodations, people with [disabilities] can enhance their self-determination and assume greater control of their lives. (p. 374)

It is also important to note that although organizational supports are key, they alone may not be enough. In fact, there were also a few areas in our study where there were not significant

differences in the organizational supports people with less and more severe impairments received (i.e., decide when to share personal information, realize personal goals), yet people with severe impairments still had quality of life disparities in these areas. Moreover, across the groups – people with more and less severe impairments – on average, participants only had about half of the quality of life indicators present, and only had slightly more than half of the organizational supports in place. As such, these findings suggest there needs to be a stronger community LTSS infrastructure to support all people with IDD, but especially people with more severe impairments. In fact, research suggests people with IDD still struggle to be meaningfully included in and engaged with the community in large part because of a lack of community infrastructure (Cullen et al., 1995; Forrester-Jones et al., 2002; Ligas Consent Decree Monitor, 2016, 2017). Moreover, Spagnuolo (2016), argues, “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.’”

In recognition of some of the shortcomings of LTSS in regard to community integration and person-centered design, the Centers for Medicare and Medicaid Services implemented the HCBS settings rule (CMS 2249-F/2296-F) in 2014. The settings rule is an attempt to shift away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of participants’ experiences... [to] establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics. (Centers for Medicare and Medicaid Services, 2014, p. 2)

The rule’s emphasis on person-centered planning also shifts how many states must provide their services, such as away from segregated day services.

By attending to the community infrastructure, as well as these disparities, people with severe impairments will have a better quality of life. True social inclusion requires a multidimensional combination of equitable access and quality, wherein success is measured through self-determination and empowerment;

the narrowest interpretation [of social inclusion] pertains to the neoliberal notion of social inclusion as access... A broader interpretation regards the social justice idea of social inclusion as participation or engagement... the widest interpretation [of social inclusion] involves the human potential lens of social inclusion as success through empowerment... Employing models of possibility instead of models of deficiency... thus supporting broader cultural transformation. (Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010, p. 7).

Limitations

A number of limitations should be noted when interpreting our results. Our data was not representative of people with IDD in the United States, as the majority of the sample was White. While 22 states were represented in the sample, the majority of data came from three states. Participants were recruited through organizations that provide LTSS, particularly those organizations who partner with the Council on Quality and Leadership to conduct Personal Outcome Measures[®] interviews; therefore, this sample may not be representative of all people with IDD, or all service providers. As this was a secondary data analysis, we did not have the ability to ask additional questions or add additional research variables. We also did not explore interactions.

Conclusion

Our study revealed people with severe impairments face a large number of quality of life disparities. These disparities relate to inadequate supports for people, a lack of systemic infrastructure, and negative perceptions about people with severe impairment's abilities. However, people with severe impairments are "demonstrating that they [can] learn content [and achieve things] never imagined possible 30 years ago" (Spooner & Browder, 2015, p. 30). It is critical that provider organizations recognize this and work to ensure people with severe impairments have the best quality of life possible. By paying attention to person-centered outcomes, including these disparities for people with severe impairments, organizations' roles can shift from just service providers to supporting people to achieve the outcomes that are important to them.

References

- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328, (1990).
- Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421. <https://doi.org/10.1111/jar.12200>
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families—Introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 2-6. <https://doi.org/10.1111/j.1741-1130.2008.00202.x>
- Buntinx, W. H., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283-294. <https://doi.org/10.1111/j.1741-1130.2010.00278.x>
- Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*, 23(1), 50-63
- Centers for Medicare and Medicaid Services. (2014). Fact sheet: Summary of key provisions of the 1915(c) Home and Community-Based Services (HCBS) waivers final rule (CMS 2249-F/2296-F). Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf>

- Cieza, A., & Stucki, G. (2005). Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Quality of Life Research, 14*(5), 1225-1237. <https://doi.org/10.1007/s11136-004-4773-0>
- 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>
- Cummins, R. A. (1991). The comprehensive quality of life scale—intellectual disability: An instrument under development. *Australia and New Zealand Journal of Developmental Disabilities, 17*(2), 259-264. <https://doi.org/10.1080/07263869100034481>
- Cummins, R. A., McCabe, M. P., Romeo, Y., Reid, S., & Waters, L. (1997). An initial evaluation of the comprehensive quality of life scale: Intellectual disability. *International Journal of Disability, Development and Education, 44*(1), 7-19. <https://doi.org/10.1080/0156655970440102>
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research, 41*(2), 126-135
- 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. (2018). The Personal Outcome Measures[®]. *Disability and health journal, 11*(3), 351–358. <https://doi.org/10.1016/j.dhjo.2017.12.003>

- Gidley, J. M., Hampson, G. P., Wheeler, L., & Bereded-Samuel, E. (2010). From access to success: An integrated approach to quality higher education informed by social inclusion theory and practice. *Higher Education Policy*, 23(1), 123-147.
<https://doi.org/10.1057/hep.2009.24>
- Hall, I., Strydom, A., Richards, M., Hardy, R., Bernal, J., & Wadsworth, M. (2005). Social outcomes in adulthood of children with intellectual impairment: Evidence from a birth cohort. *Journal of Intellectual Disability Research*, 49(3), 171-182.
<https://doi.org/10.1111/j.1365-2788.2005.00636.x>
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*, 5(4), 1271-1282
- Ligas Consent Decree Monitor. (2016). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fourth annual report of the Monitor*.
- Ligas Consent Decree Monitor. (2017). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fifth annual report of the Monitor*.
- Lulinski-Norris, A. (2014). *Community capacity to provide mental and behavioral health services to people with developmental disabilities [Unpublished dissertation]*. University of Illinois at Chicago.
- Nota, L., Soresi, S., & Perry, J. (2006). Quality of life in adults with an intellectual disability: The evaluation of quality of life instrument. *Journal of Intellectual Disability Research*, 50(5), 371-385. <https://doi.org/10.1111/j.1365-2788.2006.00785.x>
- Olmstead v. LC, No. 98-536, 527 581 (Supreme Court 1999).

- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 35-46
- Quinn, G., & Degener, T. (2002). The moral authority for change: Human rights values and the worldwide process of disability reform. In *The current use and future potential of United Nations human rights instruments in the context of disability* (pp. 3-18). New York: United Nations.
- 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>
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., . . . Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470. [https://doi.org/10.1352/0047-6765\(2002\)040<0457:CMAAOQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2)
- Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2010). Quality of life model development and use in the field of intellectual disability. In *Enhancing the quality of life of people with intellectual disabilities* (pp. 17-32). Rotterdam: Springer Netherlands.
- 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>

- Spooner, F., & Browder, D. M. (2015). Raising the bar: Significant advances and future needs for promoting learning for students with severe disabilities. *Remedial and Special Education, 36*(1), 28-32. <https://doi.org/10.1177/0741932514555022>
- 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.
- Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303-318
- Verdugo, M., Jordán de Urríes, F., Jenaro, C., Caballo, C., & Crespo, M. (2006). Quality of life of workers with an intellectual disability in supported employment. *Journal of Applied Research in Intellectual Disabilities, 19*(4), 309-316
- Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*(5), 371-383.
<https://doi.org/10.1046/j.1365-2788.2001.00342.x>

Table 1

Demographics (n = 1,341)

Characteristic	<i>n</i>	%
Age range		
18 to 24	95	7.1%
25 to 34	250	18.6%
35 to 44	223	16.6%
45 to 54	279	20.8%
55 to 64	252	18.8%
65 to 74	122	9.1%
75+	39	2.9%
Gender		
Man	719	53.6%
Woman	613	45.7%
Race		
White	998	74.4%
Black	246	18.3%
American Indian or Alaska Native	54	4.0%
Latinx	29	2.2%
Other	16	1.2%
Primary method of communication		
Verbal/spoken language	1102	82.2%
Face/body expression	169	12.6%
Sign language	16	1.2%
Communication device	14	1.0%
Other	33	2.5%
Guardianship status		
Independent decision making	370	27.6%
Assisted decision making	494	36.8%
Full/plenary guardianship	423	31.5%
Other	35	2.6%
Residence type		
Own home/apartment	284	21.2%
Family's house	213	15.9%
Host family/family foster care	24	1.8%
Provider-operated house or apartment	677	50.5%
Private ICFDD	22	1.6%
State-operated HCBS group home	43	3.2%
State-operated ICFDD	25	1.9%
Other	22	1.6%
Daily support: 24/7 around the clock	819	64.1%

Note. ICFDD = Intermediate care facility for people with developmental disabilities. HCBS = Home and community based services. DSP = direct support professionals.

Table 2
Descriptive Statistics

Indicator	% outcomes present		% organizational supports in place	
	People with severe Impairments	People with less severe impairments	People with severe Impairments	People with less severe impairments
Are safe	83.0%	84.4%	86.0%	84.4%
Free from abuse and neglect	63.8%	69.7%	67.2%	70.7%
Best possible health	69.7%	73.9%	63.4%	67.5%
Continuity and security	46.4%	60.0%	60.4%	71.0%
Exercise rights	36.9%	51.9%	37.4%	49.6%
Treated fairly	52.7%	64.8%	50.6%	55.6%
Respected	52.9%	63.0%	57.2%	68.7%
Interact with others in the community	55.7%	75.4%	57.5%	70.5%
Live in integrated environments	30.0%	64.8%	34.6%	64.0%
Participate in the life of the community	48.4%	60.3%	57.3%	63.5%
Use environments	64.3%	74.9%	66.0%	74.4%
Intimate relationships	40.7%	57.1%	44.4%	52.6%
Have friends	38.4%	52.4%	43.3%	53.8%
Natural support networks	39.1%	62.5%	64.3%	77.2%
Decide when to share personal information	48.7%	55.1%	50.6%	55.6%
Perform different social roles	34.0%	48.1%	30.3%	43.4%
Choose with where and with whom to live	13.0%	49.1%	21.4%	48.6%
Choose where to work	28.0%	40.2%	30.5%	41.2%
Choose services	21.5%	41.7%	23.5%	40.2%
Choose personal goals	40.3%	53.6%	41.2%	51.6%
Realize personal goals	54.2%	58.8%	49.0%	49.9%

Table 3

Disparities in Personal Outcomes

Indicator	χ^2	<i>df</i>	<i>p</i>	ϕ
Are safe	0.24	1	0.63	0.01
Free from abuse and neglect	3.54	1	0.06	0.05
Best possible health	1.20	1	0.27	0.03
Continuity and security	24.31	1	<0.001	0.14
Exercise rights	25.90	1	<0.001	0.14
Treated fairly	13.09	1	<0.001	0.10
Respected	11.07	1	<0.001	0.09
Interact with others in the community	44.39	1	<0.001	0.19
Live in integrated environments	154.32	1	<0.001	0.35
Participate in the life of the community	17.85	1	<0.001	0.12
Use environments	14.23	1	<0.001	0.11
Intimate relationships	29.70	1	<0.001	0.15
Have friends	19.99	1	<0.001	0.13
Natural support networks	70.92	1	<0.001	0.24
Decide when to share personal information	4.71	1	0.03	0.06
Perform different social roles	18.75	1	<0.001	0.12
Choose where and with whom to live	185.94	1	<0.001	0.38
Choose where to work	21.17	1	<0.001	0.13
Choose services	18.70	1	<0.001	0.20
Choose personal goals	19.78	1	<0.001	0.13
Realize personal goals	5.92	1	0.02	0.07

Table 4
Disparities in Organizational Supports

Indicator	χ^2	<i>df</i>	<i>p</i>	ϕ
Are safe	0.59	1	0.44	0.02
Free from abuse and neglect	1.68	1	0.20	0.04
Best possible health	2.16	1	0.14	0.04
Continuity and security	15.70	1	<0.001	0.11
Exercise rights	18.55	1	<0.001	0.12
Treated fairly	25.53	1	<0.001	0.15
Respected	15.81	1	<0.001	0.11
Interact with others in the community	23.37	1	<0.001	0.14
Live in integrated environments	116.42	1	<0.001	0.30
Participate in the life of the community	4.81	1	0.03	0.06
Use environments	9.76	1	0.00	0.09
Intimate relationships	9.68	1	0.00	0.09
Have friends	12.25	1	<0.001	0.09
Natural support networks	24.55	1	<0.001	0.14
Decide when to share personal information	1.90	1	0.17	0.04
Perform different social roles	20.19	1	<0.001	0.13
Choose where and with whom to live	15.04	1	<0.001	0.28
Choose where to work	15.04	1	<0.001	0.11
Choose services	38.70	1	<0.001	0.18
Choose personal goals	12.87	1	<0.001	0.10
Realize personal goals	1.91	1	0.17	0.04

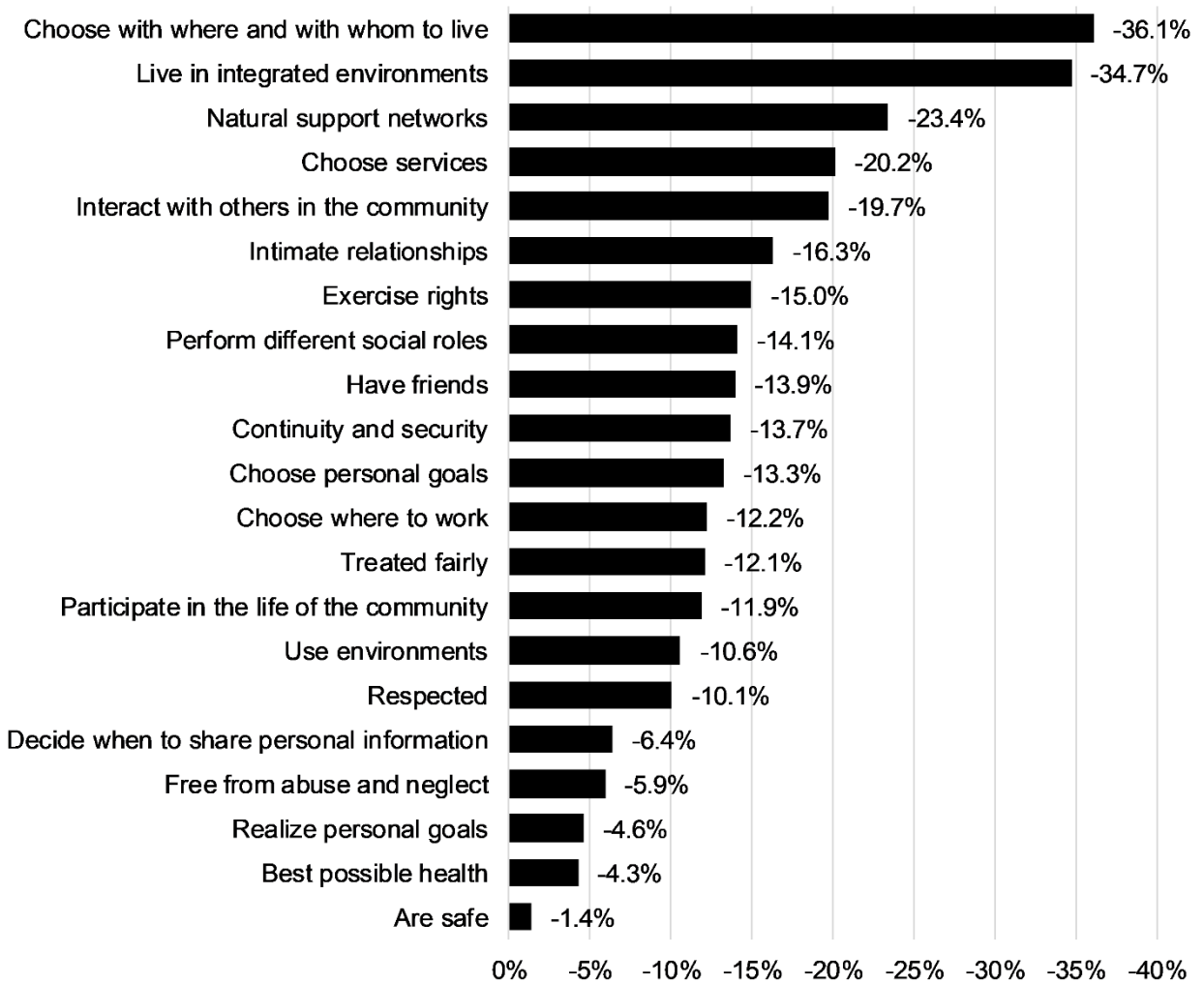


Figure 1. Personal outcome disparities for people with severe impairments.

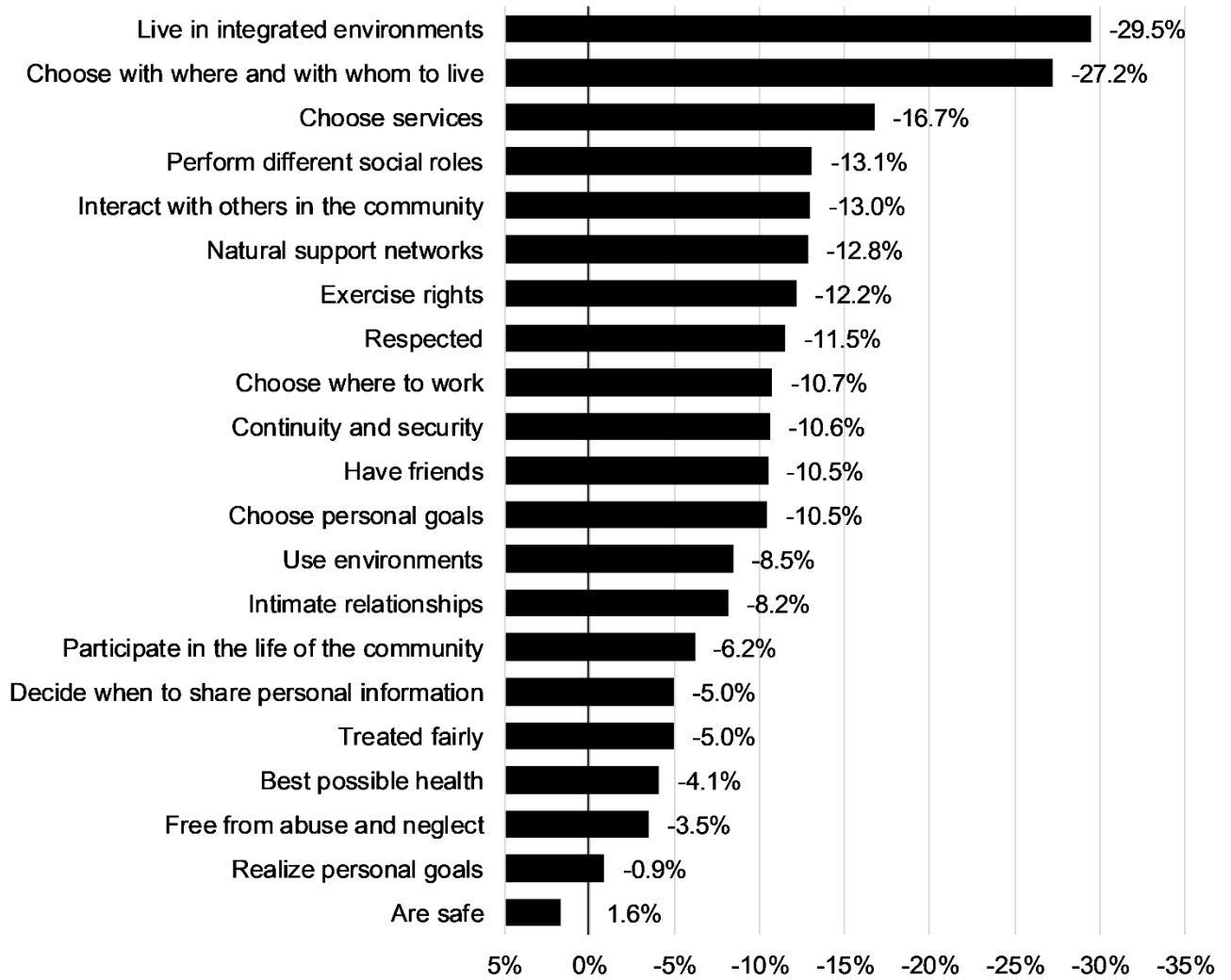


Figure 2. Disparities in organizational supports for people with severe impairments.