

# Research

Quality of Life Outcomes of Older  
Adults with Severe Disabilities

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**Reference:**

Friedman, C. (2019). Quality-of-life outcomes of older adults with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 44(4), 237-250.  
<https://doi.org/10.1177/1540796919879227>

### Abstract

People with disabilities who age may have unique experiences and face different challenges than people without disabilities who acquire disabilities as they age. These unique challenges may be especially pertinent for people with severe disabilities who already face disparities in quality of life. Yet, there is little research specifically about the quality of life of older adults with severe disabilities, a population that has continued to grow due to advances in medicine and social supports. This study's aim was to explore quality of life outcomes of older adults with severe disabilities. We analyzed Personal Outcome Measures<sup>®</sup> data from 800 people with severe disabilities aged 55 years old and older. Findings revealed most older adults with severe disabilities had less than half of the quality of life outcomes present. Specifically, we found that while most older adults with severe disabilities were healthy, safe, and free from abuse and neglect, the overwhelming majority were lacking in community integration, relationships, choice, and opportunities. Our findings suggest the lack of quality of life outcomes amongst older adults with severe disabilities were largely attributed to an absence of supports. When older adults with severe disabilities received individualized organizational supports, they had better quality of life.

*Keywords:* severe disabilities, older adults, quality of life, services and supports

### Quality of Life Outcomes of Older Adults with Severe Disabilities

The lifespan of people with disabilities has increased significantly over time due to large societal changes, such as deinstitutionalization; an influx of rights, opportunities, and inclusion; and improvements in medical care (Lauer & McCallion, 2015; McCallion, McCarron, Fahey-McCarthy, & Connaire, 2012; O'Leary, Cooper, & Hughes-McCormack, 2017; Roebroek, Jahnsen, Carona, Kent, & Chamberlain, 2009; Thomas & Barnes, 2010; Thornicroft, 2011). Longer life expectancy means people with disabilities are more likely to be exposed to age-related diseases and other conditions that can make their lives more challenging or require adjustment (Coyle, Kramer, & Mutchler, 2014; McCallion et al., 2012). Moreover, there may be “interactions of aging and lifelong disability” (Davidson, Heller, Janicki, & Hyer, 2004, p. 2), wherein although aging people with disabilities may have some similar experiences with people who age into disability, they likely also have different experiences (Coyle et al., 2014). For example, the quality of life of older adults with physical disabilities is impacted not only by social dimensions, such as relationships and social roles, but also by the control they have over their lives (Levasseur, Desrosiers, & Noreau, 2004a, 2004b; Levasseur, Desrosiers, & Tribble, 2008; Levasseur, Tribble, & Desrosiers, 2009). Older adults with physical disabilities that have relationships, social roles, and control over their lives reported having higher quality of life than those older adults with physical disabilities without these things.

Despite advances in life expectancies, many people with disabilities still have significantly lower life expectancies than people without disabilities (Lauer & McCallion, 2015; O'Leary et al., 2017; Roebroek et al., 2009; Thomas & Barnes, 2010; Thornicroft, 2011). For example, people with intellectual and developmental disabilities (IDD) have life expectancies that are 20 years less than people without disabilities (Lauer & McCallion, 2015; O'Leary et al.,

2017). Lower life expectancy rates have been linked with higher impairment severity, support needs, and frailty (Bilotta et al., 2010; Lauer & McCallion, 2015; O'Leary et al., 2017).

In addition to higher mortality rates, research has also suggested that people with severe disabilities in general face quality of life disparities compared to people with less severe disabilities (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010). Although to our knowledge there is no research specifically about the quality of life of older adults with severe disabilities, there is some research about the quality of life of people with severe disabilities more broadly. Proxy research conducted with mothers of young adults with severe disabilities (18 to 24) found that mothers reported activities, hobbies, recreation, basic needs, and social roles as important parts of their adult child's quality of life (McIntyre et al., 2004). The mothers also reported work, communication, health, and consistency as less important to their adult child's quality of life (McIntyre et al., 2004). Vos et al. (2010) conducted proxy research with direct support professionals about the subjective well-being (mood, interest, and pleasure) of people with severe and profound disabilities (not older adults in particular). In doing so, they found that direct support professionals rated the subjective well-being of people with profound disabilities as lower than people with mild, moderate, or severe disabilities. While they looked at the correlations between age (across disability severity) and subjective well-being, the findings were not significant.

Moreover, as quality of life is person-centered, people with more severe disabilities may have different priorities when it comes to quality of life than people with less severe disabilities (McIntyre et al., 2004). For example, independence may be less important to some people with disabilities—especially people with severe disabilities—that favor the concept of

interdependence; as a result, having less independence may not negatively impact their view of their quality of life. These different perceptions of quality of life may be particularly true as people with severe disabilities age; however, there is little to no research specifically about the quality of life of older adults with severe disabilities, a population that not only faces unique experiences and needs, and quality of life disparities, but also will continue to grow in number in future years (Evenhuis et al., 2001; McCallion et al., 2012; McIntyre et al., 2004; Vos et al., 2010).

In this study, we explored the quality of life outcomes of older adults with severe disabilities. We analyzed Personal Outcome Measures<sup>®</sup> data from 800 people with severe disabilities, aged 55 years old and older. We also examined the impact organizational supports can have on personal outcomes. Finally, we explored disparities in outcomes and supports amongst older adults with severe disabilities. In doing so our research questions were: (1) What is the overall quality of life of older adults with severe disabilities?; (2) what is the relation between personal outcomes and organizational supports?; and, (3) what disparities exist in personal outcomes and organizational supports amongst older adults with severe disabilities?

## **Method**

### **Measures of Quality of Life and Support**

This study was based on secondary analyses of data gathered using the Personal Outcome Measures<sup>®</sup>, developed by The Council on Quality and Leadership (2017b). The Personal Outcome Measures<sup>®</sup> was developed over 25 years ago based on findings from focus groups with people with disabilities, their family members, and other key stakeholders (e.g., professionals, researchers, allies) about what really mattered in their lives. The tool has been continuously refined over the past two decades through pilot testing, commission of research and content

experts, a Delphi survey, feedback from advisory groups, and over 25 years of administration (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures<sup>®</sup> has established construct validity utilizing a principal component analysis (Friedman, 2018b).

The Personal Outcome Measures<sup>®</sup> tool is designed to determine people with disabilities' quality of life in a person-centered manner, including self-determination, choice, self-advocacy, and supports. The Personal Outcome Measures<sup>®</sup> includes 21 indicators divided into five factors (domains): (a) my human security; (b) my community; (c) my relationships; (d) my choices; and, (e) my goals. *My human security* includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people experience continuity and security; people exercise rights; people are treated fairly; and, people are respected. *My community* includes the following indicators: people use their environments; people live in integrated environments; people interact with other members of the community; and, people participate in the life of the community. *My relationships* includes the following indicators: people are connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; and, people perform different social roles. *My choices* includes the following indicators: people choose where and with whom to live; people choose where to work (includes what they do during the day and retirement); and people choose their services. *My goals* includes the following indicators: people choose personal goals; and, people realize personal goals.

For every participant, the Personal Outcome Measures<sup>®</sup> administration occurs in three stages. In the first stage, a trained Personal Outcome Measures<sup>®</sup> interviewer has in-depth conversations with the participant with disabilities about each of the indicators. For these conversations, the interviewer follows specific open-ended prompts. If the person being

interviewed has significant impairments and/or does not communicate with words, a series of techniques are utilized to enhance communication, including augmentative alternative communication, observation, visual cues, photos, gestures, preference testing, and/or objects (Overpeck, 2019). In addition, if necessary and/or wanted by the person being interviewed, a friend, family member, or staff member can support the person with disabilities to participate in the interview. During the second stage of the Personal Outcome Measures<sup>®</sup> interview, the interviewer speaks with someone who knows the participant with disabilities best, and knows about organizational supports. This participant is selected by the person with disabilities or the organization; the participant may be a case manager or direct support professional. The participant is asked questions about individualized supports and outcomes to fill in any gaps in knowledge from the first stage. During the final stage, if further information is required, the interviewer observes the participant in various settings and conducts individual record reviews. The interviewer then completes decision trees about personal outcomes 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 interviewer decides if each of the 21 personal outcomes are present (1) or not (0), as well as if each of the 21 individual organizational supports are in place (1) or not (0).

For example, in regard to the indicator ‘people have friends’, examples of questions the interviewer may use to guide their conversation with the person with disabilities include: “How do you define friendship? With whom do you like to spend time?; What do you like to do with friends?; Do you spend enough time with them?; Besides seeing your friends, what other kinds of things do you do to stay in contact?” (The Council on Quality and Leadership, 2017b, p. 56).



Utilizing all of the data gathered, the interviewer would first complete the decision tree for the outcome for ‘people have friends:’ “Does the person have friends?; Is the person satisfied with the number of friends they have?; and, Is the person satisfied with the amount of contact with their friends?” (The Council on Quality and Leadership, 2017b, p. 57). The answers to all of these questions must be ‘yes’ for the outcome to be considered present. Examples of questions that may be used to guide the second interview regarding organizational supports include: “How do you know if the person needs support to develop or maintain friendships?; How do you assist the person to overcome barriers to this outcome?; and, What organizational practices, values, and activities support this outcome for the person?” (The Council on Quality and Leadership, 2017b, p. 56). To determine if organizational support is considered in place, the interviewer completes the following decision tree: “Does the organization know the person’s preference and need for friends?; and, Are supports provided to assist the person with developing, maintaining, and enhancing friendships, if needed?” (The Council on Quality and Leadership, 2017b, p. 57). The answer to both of these questions must be ‘yes’ for the organizational support to be considered in place for people are friends.

### **Reliability**

This study included only interviews conducted by certified interviewers. In addition to attending an intensive week-long training, to become certified, people must participate in practice interviews, observation, and coaching. Certified interviewers are also required to pass interrater reliability tests with an expert interviewer. During this test, they complete a Personal Outcome Measures® interview and their findings must be in compliance with the expert interviewer with at least 85% consistency (The Council on Quality and Leadership, 2017a). They are also required to participate in at least 10 hrs of continuing education and a minimum of 20

interviews in their two-year certification term to maintain their certification. The Council on Quality and Leadership certifies hundreds of people across the United States each year; the data in this dataset come from approximately 190 interviewers.

### **Participants**

The secondary survey data were transferred to the researchers without individual or organizational identifiers. The participants in this study were persons for whom Personal Outcome Measures<sup>®</sup> were collected over a four-year period (January 2015 to Spring 2019). The dataset included 4,088 people with disabilities; 30.11% ( $n = 1,231$ ) were 55 yrs old or older (Neugarten, 1974). People 54 yrs old or younger, or those who did not have data about age, were removed from the sample. Daily support needs was used as a proxy for severity of the impairment. Daily support needs was defined as the average number of hrs the person needed support and/or received support services per day; presumably those with the most support – around the clock (24/7) – had more severe disabilities. Of the 1,231 older adults, 64.99% ( $n = 800$ ) had around the clock supports. Those people without around the clock supports, or those without information about daily support needs, were removed from the sample. As a result, the total sample size was 800 older adults with more severe disabilities.

The 800 participants ranged in age from 55 to 97; the mean age of participants was 65.50 ( $SD = 7.97$ ). The majority of participants were White (81.96%,  $n = 636$ ). The most prevalent primary method of communication was verbal/spoken language (73.84%,  $n = 587$ ). Also, most participants lived in provider-owned or -operated homes (74.97%,  $n = 596$ ). See Table 1.

### **Data Analysis**

**Quality of life outcomes.** To explore quality of life outcomes, we utilized descriptive statistics. We aggregated each of the 21 personal outcomes to explore participants' total personal

outcomes. We also aggregated each of the 21 individualized organizational supports to explore participants' total organizational supports. In addition, we used descriptive statistics to examine trends in outcomes and supports across participants in each of the 21 indicator areas.

**The relation between personal outcomes and organizational supports.** As we were interested in examining the impact of organizational supports on personal outcomes, we explored this relation both for total outcomes (aggregate), and each of the 21 outcome indicators. We utilized a Pearson Correlation to explore the relation between total organizational supports and total outcomes. We also ran a series of binary logistic regression models to explore the relation between each of the 21 supports (independent variables; IVs) and each of the 21 outcomes (dependent variables; DVs). For example, we explored how receiving individualized organizational supports to have friends (IV), increased or decreased the odds of older adults with severe disabilities having friends (outcomes present; DV). Given the lack of literature regarding quality of life of older adults with severe disabilities, this research is exploratory. As such, there were no specific hypotheses; rather, we were interested in testing all of the supports individually to explore their impact on different areas of quality of life. Bonferroni correction (0.0024) was used to counteract running multiple models.

**Disparities in outcomes and supports.** To explore disparities in personal outcomes and organizational supports amongst older adults with severe disabilities, we utilized multiple linear regression models. To do so, the total personal outcomes present and the total organizational supports in place were utilized as the DVs for each model. We utilized all of the demographic variables (i.e., age, gender, disability type, race, primary method of communication, guardianship status, and residence type) as the IVs to determine disparities in personal outcomes and organizational supports across particular groups of older adults with severe disabilities.

## Results

### Quality of Life Outcomes and Organizational Supports

The participants had an average of 10.22 ( $SD = 5.05$ ) outcomes present (out of the possible 21; 48.7%). While total outcome scores ranged from 0 to 21, 14.65% of participants scored between 0 and 4, 31.36% between 5 and 9, 33.29% between 10 and 14, 16.45% between 15 and 19, and 4.24% between 20 and 21. We also explored each of the 21 indicators individually for both outcomes and supports (see Table 2). The top three outcomes were: people are safe (84.73%); people have the best possible health (69.59%); and, people use their environments (68.25%). The bottom three outcomes were: people choose where and with whom to live (16.54%); people choose services (28.82%); and, people choose where to work (33.33%).

Participants had an average of 11.00 ( $SD = 5.58$ ) organizational supports in place (out of the possible 21, 52.4%). While total organizational support scores ranged from 0 to 21, 14.14% of participants scored between 0 and 4, 24.04% between 5 and 9, 33.80% between 10 and 14, 18.89% between 15 and 19, and 7.97% between 20 and 21. The top three organizational supports were: people are safe (85.73%); people have the best possible health (70.71%); and, people use their environments (69.89%; see Table 2). The bottom three organizational supports were: people choose where and with whom to live (20.10%); people choose services (29.07%); and, people perform different social roles (34.59%).

### The Relation Between Personal Outcomes and Organizational Supports

A Pearson correlation was computed to assess the relation between total organizational supports and total quality of life outcomes; the model was significant,  $r = 0.898$ ,  $n = 761$ ,  $p < 0.001$ . There was a strong positive correlation between organizational supports and quality of life

outcomes, suggesting the more organizational supports an older adult with severe disabilities receives, the more quality of life outcomes they have present.

In addition to exploring the relation between total outcomes and supports, we were also interested in examining the relation between each of the individual 21 indicators' outcomes and supports. All of the 21 models were significant (see Table 3), indicating that when an organizational support is in place for an indicator, it significantly increases the odds of the outcome being present. For example, when individualized organizational supports were in place to support people to perform different social roles, older adults with severe disabilities were 60.67 times more likely to have the outcome 'people perform different social roles' present. Across all of the 21 topic areas, the impact of organizational supports on the odds of outcomes being present ranged from 9.91 times (people are free from abuse and neglect) to up to 278.73 times (people decide when to share personal information) more likely when a support was present.

### **Disparities in Outcome and Supports**

Finally, we were also interested in exploring disparities in outcomes and supports amongst older adults with severe disabilities. There was a significant relation between participants' demographics and their outcomes,  $F(29, 734) = 3.46, p < 0.001, R^2 = 0.13$ . The following variables were significant: age; gender; disability: intellectual/developmental; disability: behavioral challenges; disability: brain injury; guardianship; and residence type. There was also a significant relation between participants' demographics and their organizational supports,  $F(29, 726) = 2.92, p < 0.001, R^2 = 0.11$ . The following variables were significant: age; gender; disability: intellectual/developmental; disability: behavioral challenges; disability: brain injury; disability: 'other' disabilities not listed; guardianship; and residence type. See Table 4.

### Discussion

Older adults with disabilities may have unique experiences and face different challenges than older adults who acquire disabilities as a result of old age; this is especially true for people with severe disabilities. Yet, to our knowledge, there is very little research about the quality of life of older adults with severe disabilities. The aim of this study was to explore the quality of life outcomes of older adults with severe disabilities. Our findings revealed the majority of older adults with severe disabilities had fewer than half of the 21 quality of life outcomes present. In fact, only 2.44% of participants ( $n = 19$ ) had all 21 outcomes present.

Furthermore, we found that while most older adults with severe disabilities in our sample were healthy and safe, and free from abuse and neglect, the overwhelming majority were lacking in community integration, relationships, and choice and opportunities. While health, safety, and protection from abuse and neglect are important and foundational, especially given the high rates of abuse people with disabilities face (Baladerian, 2013; Shapiro, 2018; U.S. Department of Health and Human Services, Office of Inspector General, Administration on Community Living, & Office for Civil Rights, 2018), they in and of themselves do not represent quality of life – many more things are important to make life meaningful. For example, indicators related to relationships – people perform different social roles, people have intimate relationships, people are connected to natural supports, and people have friends – were amongst some of the least frequently present outcomes. Yet, research has found relationships tend to enhance peoples' quality of life; benefits of social relationships include improved emotional well-being, more favorable mental health, increased sense of belonging, stronger self-worth, and lowered stress (Fulford & Cobigo, 2018; Petrina, Carter, & Stephenson, 2014; Ward, Atkinson, Smith, & Windsor, 2013). Moreover, for people with disabilities in particular, relationships with peers

with disabilities can increase self-acceptance, decrease internalized stigma, and help people navigate an ableist world (Chernomas, Clarke, & Marchinko, 2008).

In addition to relationships, many of the areas of quality of life that were least present amongst older adults with severe disabilities related to choice, opportunity, and civil rights, such as people choose where and with whom to live, people choose services, people choose where to work, people choose personal goals, and people exercise rights. For example, only 16.50% of the 800 older adults with severe disabilities in our sample chose where and with whom to live. Yet, according to the Medicaid Home and Community Based Settings (HCBS) settings rule (Centers for Medicare and Medicaid Services, 2014b), long-term services and supports should be directed by peoples' preferences and goals. The Centers for Medicare and Medicaid Services notes HCBS must "optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them" (2014a, p. 2). In addition, the Americans with Disabilities Act (1990) and *Olmstead v L.C.* (1999) have also reinforced people's right to choice and community integration. Despite having the right to live in and be integrated into the community, our findings revealed approximately two-thirds of older adults with severe disabilities did not live in integrated environments. This indicator on the Personal Outcome Measures<sup>®</sup> simply requires that people use the same environments used by people without disabilities (for living, work, school, community [leisure, shopping, banking, places of worship, etc.]), yet the overwhelming majority of participants did not have this item present (The Council on Quality and Leadership, 2017b). Clearly a stronger community infrastructure, especially for older adults with severe disabilities, is necessary to support people to live in integrated environments.

Our findings also suggest the lack of quality of life outcomes amongst older adults with severe disabilities was largely attributed to the lack of organizational supports. The majority of participants received approximately half of the 21 possible organizational supports. Moreover, only 5.01% of our sample ( $n = 39$ ) received individualized organizational supports for every area of quality of life. While organizations cannot always control the presence of personal outcomes, organizations do have control over the individualized supports they provide to facilitate those outcomes. Our findings indicate, when people receive organizational support for a personal outcome, they have a significantly higher likelihood of having that outcome in their lives. For example, when individualized organizational supports were in place, older adults with severe disabilities were 43 times more likely to participate in the life of the community. Organizational supports related to participating in the life of the community entail knowing what the person would like to do in their community, knowing how often the person would like to engage in community activities, providing the person with access to information about options for community participation, and providing support for the person to do the things they want to do. In essence, these are all basic parts of person-centered services – knowing the person’s preferences, providing them with true informed choice and opportunities, and providing supports to help facilitate those preferences. Unfortunately, often person-centered practices are philosophies, rather than practices (Friedman, 2018a). A cultural shift is necessary for true person-centered practices to succeed.

Organizations can begin making these changes by targeting the disparities unearthed in this study. For example, people with full/plenary guardianship and ‘other’ forms of guardianship had fewer quality of life outcomes present compared to people with independent decision-making. In the United States, courts tend to give guardians broad sweeping powers, and “rarely



limit the guardian's authority" (Salzman, 2011, p. 173). Salzman (2011) argues that the current United States sweeping guardianship system violates the Americans with Disabilities Act (1990) and Supreme Court decision *Olmstead v. L.C.* (1999) because it does not limit decision-making rights in the least restrictive manner. However, as a result of the emphasis on self-determination and empowerment, there has been a movement in the United States to shift from broad sweeping powers of guardianship to supported decision-making, which is a less restrictive guardianship model that creates opportunities for people with disabilities to exercise legal decision-making capacity (Gooding, 2013; Salzman, 2011; VanPuymbrouck, 2017). Future research should examine whether there is a relation between supported decision-making and quality of life outcomes.

Participants with IDD and participants with brain injury both had lower quality of life outcomes than participants with other types of disabilities. These disparities may in part be due to the fact that people with IDD and brain injury also received fewer organizational supports than people with other disabilities. It may also be due in part to the hierarchy of disability, wherein both the disability community and people without disabilities favor certain disabilities over other disabilities; for example, people with physical disabilities are often placed higher on the hierarchy than people with IDD (Caldwell, 2011; Charlton, 1998; Deal, 2003; McClimens & Taylor, 2003). These disparities may also be related to a tendency to focus on duty to care for people with cognitive disabilities, while minimizing risk and emphasizing health and safety beyond all else. There is a "perceived trade-off between autonomy and safety" (Heller, Arnold, van Heumen, McBride, & Factor, 2012, p. 77). While health and safety are indeed important and foundational, they alone do not comprise quality of life. Instead, many other social determinants

play a large role not only in people's quality of life but their health as well (U. S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, n.d.).

Older men (versus women) with severe disabilities had fewer quality of life outcomes. While more research is necessary to determine the reasons behind this disparity, it may be due to the fact that men also received fewer organizational supports than women. There may also be an interaction between gender and age as research suggests women without disabilities tend to live longer than men without disabilities (Austad, 2006; Zarulli et al., 2018).

Older adults with severe disabilities who lived in an intermediate care facility for people with developmental disabilities (ICFDDs) had fewer quality of life outcomes present than older adults with severe disabilities who lived in their own homes. This finding is consistent with research that has found better outcomes in community-based settings than institutional settings (Beadle-Brown et al., 2016; Larson, Lakin, & Hill, 2013). Although those opposed to deinstitutionalization often argue that people need more care than the community can provide and that institutions result in higher quality care (Bagenstos, 2012), research has found people with severe disabilities benefit from deinstitutionalization and community residential supports, and have better outcomes in the community (Lakin, Larson, & Kim, 2011; Miranda, 2014; Young, 2006).

Our findings also revealed a significant relation between the age of older adults and their quality of life outcomes. Organizations may pay more attention to the oldest old (80 and older) and provide them with more support to facilitate their outcomes as a result. Moreover, this finding may also be due to the fact that although research suggests many older adults without disabilities expect to acquire more impairments as they age, increased challenges do not necessarily impact their perceptions on their quality of life as long as they psychologically adapt

(Levasseur et al., 2008). As the existing research about this phenomenon is not specific to older adults with severe disabilities, it would be beneficial to conduct further research to explore if this trend continues amongst older adults with severe disabilities.

### **Future Research and Implications for Practice**

Because older adults with severe disabilities are a growing population, more research is necessary regarding the quality of life of older adults with severe disabilities. For example, as our findings also revealed the significant impact organizational supports can have on the quality of life outcomes of older adults with severe disabilities, future research should be conducted to explore organizational policies and procedures aimed at supporting older adults with severe disabilities. Older adults with severe disabilities are a unique population that require person-centered supports; without an adequate evidence-base, organizations not only might not know how to adequately provide support but also may unintentionally reinforce the disparities unearthed in this study. Moreover, in addition to being an indicator of the quality of people's lives, quality of life data are also critical for social and public policy (Gellert, 1993). Such data can help guide public policy, including prevention or intervention efforts, as well as funding (Gellert, 1993). Furthermore, quality of life as a construct is particularly important to the disability field as it can demonstrate the effectiveness of service programs and interventions (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Lee, Harrington, Louie, & Newschaffer, 2008).

Moreover, organizations can also conduct the Personal Outcome Measures<sup>®</sup> with the older adults with severe disabilities they support in order to facilitate service provision. By examining an individual person's score, organizations can determine where to target supports and services to facilitate the person's quality of life. For example, if an older adult with severe

disabilities scored high in terms of safety outcomes, but low in terms of social roles, the provider could be intentional about implementing services to facilitate the person's opportunities for social roles. Organizations can also aggregate Personal Outcome Measures<sup>®</sup> scores across all of the older adults with severe disabilities they support to determine opportunities for improvement across their service lines. Doing so will also allow them to compare the outcomes and supports of older adults with severe disabilities to the other populations they support to determine if, and where, disparities exist, and to utilize this information to design programs to help reduce these disparities.

### **Limitations**

When interpreting these results, a number of limitations should be noted. First, the majority of our sample was White, which does not mirror the demographics of the United States. Data also only reflects people receiving some sort of formal services. As this was a secondary data analysis, the researcher did not have the ability to ask additional questions or add additional research variables. Also, exploring interactions was outside the scope of this study. Interviewer reliability was tested at the time of certification, rather than necessarily during these interviews. Moreover, although Bonferroni correction was used to control for the use of multiple models, Bonferroni correction is a conservative measure. We believe these limitations should also be interpreted as opportunities for future study.

### **Conclusions**

As a result of advances in not only medical care and health services but also societal changes, people with severe disabilities are living longer than ever before. While this presents us with new opportunities to support people with severe disabilities, it also will challenge the service system in new and profound ways. How the service system is prepared to support people

with severe disabilities as they age, including as they age in place, is largely unknown. This is particularly pertinent as the findings of this study revealed that the quality of life of older adults with severe disabilities is significantly impacted by the receipt of organizational support. As such, findings from this study regarding older adults with severe disabilities' personal outcomes and the organizational supports they received should be utilized to facilitate the quality of life of people with disabilities as they age.

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Table 1  
*Participant Demographics (N = 800)*

Variable	<i>n</i>	%	<i>M</i>	<i>SD</i>	Variable (continued)	<i>n</i>	%
Age in years			65.51	7.97	Primary method of communication ( <i>n</i> = 795)		
Disabilities ( <i>n</i> = 786)					Verbal/spoken language	587	73.84
Intellectual/developmental disability	709	90.20			Face/body expression	171	21.51
Seizure disorder/neurological problems	169	21.50			Sign language	9	1.13
Mood disorder	145	18.45			Communication device	6	0.75
Anxiety disorders	132	16.79			Other	22	2.77
Behavioral challenges	128	16.28			Race ( <i>n</i> = 776)		
Other mental illness/psychiatric diagnosis	94	11.96			White	636	81.96
Personality/psychotic disorder	80	10.18			Black	99	12.76
Physical disability	75	9.54			Latinx	18	2.32
Impulse-control disorder	72	9.16			Indigenous American	16	2.06
Limited or no vision - legally blind	51	6.49			Asian	5	0.64
Hearing loss - severe or profound	40	5.09			Native Hawaiian or Other Pacific Islander	1	0.13
Brain injury	17	2.16			Other	3	0.39
Other disabilities not listed	75	9.54			Residence type ( <i>n</i> = 795)		
Gender ( <i>n</i> = 794)					Provider-owned or -operated home	596	74.97
Man	401	50.50			Own home/apartment	107	13.46
Woman	393	49.50			ICFDD (state or private)	40	5.03
Guardianship status ( <i>n</i> = 785)					Host family/family foster care	18	2.26
Independent decision making	169	21.53			State-operated HCBS group home	18	2.26
Assisted decision making	304	38.73			Nursing home or assisted living facility	4	0.50
Full/plenary guardianship	280	35.67			Family's house	3	0.38
Other	32	4.08			Other	9	1.13

*Note.* Participants could have more than one disability or race. ICFDD = Intermediate Care Facility for People with Developmental Disabilities; HCBS = Home and Community Based Services.

Table 2

*Outcomes Present and Supports in Place By Indicator*

Indicator	% Outcomes present	% Supports in place
People are safe	84.73	85.73
People are free from abuse and neglect	62.36	68.80
People have the best possible health	69.59	70.71
People experience continuity and security	49.31	64.29
People exercise rights	48.56	50.87
People are treated fairly	57.70	56.52
People are respected	57.14	60.58
People use their environments	68.25	69.89
People live in integrated environments	33.58	35.26
People interact with other members of the community	59.97	60.83
People participate in the life of the community	45.38	55.90
People are connected to natural supports	39.05	62.78
People have friends	41.85	48.19
People have intimate relationships	38.39	40.85
People decide when to share personal information	52.95	55.40
People perform different social roles	35.47	34.59
People choose where and with whom to live	16.54	20.10
People choose where to work	33.33	34.88
People choose services	28.82	29.07
People choose personal goals	44.67	45.97
People realize personal goals	53.01	48.74

Table 3  
*Relationship Between Organizational Supports and Personal Outcomes*

Indicator	$\chi^2$	$R^2$	OR	95% CI
People are safe*	259.91	0.49	48.96	[28.75, 83.39]
People are free from abuse and neglect*	193.98	0.30	9.91	[7.00, 14.03]
People have the best possible health*	256.87	0.39	16.25	[11.19, 23.61]
People experience continuity and security*	358.67	0.48	35.17	[21.45, 57.66]
People exercise rights*	608.98	0.71	95.87	[59.02, 155.75]
People are treated fairly*	671.81	0.77	156.87	[91.73, 268.27]
People are respected*	641.66	0.74	147.66	[84.81, 257.09]
People use their environments*	567.94	0.71	126.49	[73.88, 216.54]
People live in integrated environments*	565.93	0.71	101.81	[61.46, 168.66]
People interact with other members of the community*	462.08	0.60	43.00	[28.36, 65.21]
People participate in the life of the community*	428.30	0.56	42.52	[26.63, 67.87]
People are connected to natural supports*	842.79	0.33	16.32	[10.29, 25.87]
People have friends*	395.85	0.53	29.19	[19.58, 43.52]
People have intimate relationships*	686.89	0.51	25.78	[17.57, 37.82]
People decide when to share personal information*	738.96	0.81	278.73	[148.88, 521.85]
People perform different social roles*	494.85	0.64	60.67	[38.62, 95.30]
People choose where and with whom to live*	386.84	0.65	112.65	[60.60, 209.41]
People choose where to work*	550.19	0.69	92.24	[56.78, 153.10]
People choose services*	590.52	0.75	171.15	[96.51, 303.51]
People choose personal goals*	690.93	0.78	177.59	[102.28, 308.36]
People realize personal goals*	581.74	0.69	87.62	[53.61, 143.22]

*Note.* \* $p < 0.001$ . The independent variable in each model was the organizational support for that indicator; the dependent variable was the personal outcome for that indicator.  $\chi^2$  = Chi-squared;  $R^2$  = Nagelkerke; OR = odds ratio.



Table 4  
Correlates of Personal Outcomes and Supports

Variables	Outcomes				Supports			
	<i>B</i>	<i>SE</i>	$\beta$	<i>t</i>	<i>B</i>	<i>SE</i>	$\beta$	<i>t</i>
Constant	9.17	1.76		5.21***	9.70	1.99		4.87***
Age (in years)	0.07	0.02	0.11	3.00**	0.07	0.03	0.09	2.49*
Woman (ref: Man)	0.88	0.37	0.09	2.39*	0.91	0.41	0.08	2.20*
Disabilities								
Intellectual/developmental disability	-2.72	0.68	-0.16	-3.99***	-2.21	0.76	-0.12	-2.89**
Seizure disorder/neurological problems	-0.29	0.44	-0.02	-0.66	-0.57	0.50	-0.04	-1.13
Mood disorder	-0.94	0.48	-0.07	-1.94	-0.68	0.55	-0.05	-1.24
Anxiety disorders	-0.43	0.51	-0.03	-0.84	-0.86	0.57	-0.06	-1.51
Behavioral challenges	1.47	0.53	0.11	2.77**	1.84	0.60	0.12	3.06**
Other mental illness/psychiatric diagnosis	-0.28	0.56	-0.02	-0.50	-0.13	0.62	-0.01	-0.21
Personality/psychotic disorder	-0.99	0.61	-0.06	-1.63	-0.71	0.68	-0.04	-1.04
Physical disability	-0.37	0.63	-0.02	-0.58	0.39	0.71	0.02	0.54
Impulse-control disorder	-0.19	0.64	-0.01	-0.30	-0.44	0.71	-0.02	-0.61
Limited or no vision - legally blind	-0.25	0.85	-0.01	-0.29	0.11	0.93	0.00	0.12
Hearing loss - severe or profound	-0.39	0.77	-0.02	-0.51	-0.47	0.86	-0.02	-0.55
Brain injury	-2.60	1.27	-0.08	-2.04*	-2.94	1.42	-0.08	-2.07*
Other disabilities not listed	0.81	0.70	0.05	1.16	1.63	0.79	0.08	2.07*
Race (ref: White)								
Black or African American	0.77	0.57	0.05	1.35	0.59	0.64	0.04	0.93
Latinx	-2.13	1.19	-0.06	-1.79	-2.05	1.42	-0.05	-1.45
Indigenous American	-0.03	1.44	-0.001	-0.02	1.36	1.54	0.03	0.88
Other	1.49	1.87	0.03	0.80	3.52	2.08	0.06	1.69
Primary method of communication (ref: spoken language)								
Face/body expression	0.81	0.49	0.07	1.67	0.78	0.55	0.06	1.42
Other (e.g., communication device, sign language)	-0.62	0.92	-0.02	-0.67	0.15	1.02	0.01	0.15
Guardianship status (ref: independent decision making)								
Assisted decision making	-0.60	0.51	-0.06	-1.18	-1.15	0.57	-0.10	-2.00*

Full/plenary guardianship	-1.52	0.51	-0.14	-2.98**	-1.46	0.57	-0.13	-2.56*
Other	-2.11	1.02	-0.08	-2.07*	-3.19	1.14	-0.11	-2.80**
Residence type (ref: own home)								
Provider-owned or -operated home	-0.47	0.56	-0.04	-0.84	-0.25	0.62	-0.02	-0.41
ICFDD, nursing home and assisted living	-2.28	0.95	-0.10	-2.40*	-2.54	1.07	-0.10	-2.37*
Host family/family foster care	-2.21	1.25	-0.07	-1.76	-1.84	1.40	-0.05	-1.31
State-operated HCBS group home	0.14	1.33	0.004	0.10	0.76	1.53	0.02	0.49
Other (includes family homes)	-0.54	1.65	-0.01	-0.33	-1.79	1.84	-0.04	-0.98

*Note.* \* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$ .  $B$  = unstandardized beta.  $SE$  = standard error.  $\beta$  = standardized beta.  $t$  = test statistic.