

# Research

The Impact of People with Disabilities Choosing  
Their Services on Quality of Life Outcomes



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Services on Quality of Life Outcomes**

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### Abstract

**Background.** In recognition of the importance of services and supports that are defined and chosen by the recipient with disabilities, there has been a shift toward person-centered services. Quality person-centered services not only aim to ensure people have control over their own lives, but also to improve individually defined outcomes.

**Objective.** The aim of this study was to explore the relationships between people with disabilities (PWD) choosing their services and their quality of life (QOL).

**Methods.** We had two main research questions: 1) what factors predict PWD choosing their services – who was most/least likely to choose their services?; and, 2) how does choosing their services impact the QOL of PWD? To examine these questions, we analyzed Personal Outcome Measures<sup>®</sup> interviews from approximately 1,100 PWD.

**Results.** Our findings have revealed that when PWD are able to choose their services, the impact can be widespread.

**Conclusions.** By ensuring PWD are able to choose their services, organizations are not only facilitating self-determination, but, ultimately, improving PWD's QOL.

*Keywords:* person-centered services; quality of life; people with disabilities; self-determination

## Introduction

Self-determination is a philosophy that “seeks to maximize autonomy and choice and ensures that persons with disabilities are empowered to live as independently as possible” (p. 118)<sup>1</sup>. Self-determination can include not only people with disabilities (PWD) speaking out about what is important to them and what they want, but also being charge of daily decisions<sup>2</sup>. According to self-advocates,

Making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?<sup>3</sup>

One of the largest obstacles PWD often face when trying to make self-determined choices, are people, such as support staff, or provider organizations which appropriate PWD’s decisions or limit PWD’s control<sup>2</sup>, thereby hindering their choice making abilities.

In recognition of the importance of services and supports that are defined and chosen by the recipient with disabilities, there has been a shift toward person-centered services. In fact, the Affordable Care Act (Section 2402(a)) requires all states receiving federal funds not only have service systems that are accountable to the choices of people receiving home and community-based services (HCBS) or community-based long-term services and supports (TLSS), but also emphasize self-direction and independence.<sup>4</sup>

Moreover, the Centers for Medicare and Medicaid Services’ (CMS’s) relatively new HCBS settings rule (CMS 2249-F/2296-F) prioritizes person-centered planning and requires services be driven by peoples’ preferences and goals (Medicaid Program, 2014)<sup>5</sup>. CMS notes

HCBS must “optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them” (p. 1)<sup>6</sup>.

Quality person-centered services not only aim to ensure people have control over their own lives, but also to improve individually defined outcomes.<sup>4</sup> As such, 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”<sup>7</sup>. Person-centered plans should assist PWD with achieving personally defined outcomes by delivering services that center PWD’s choices<sup>4</sup>.

Self-determined choices in healthcare, including people’s abilities to choose their services and providers, leads to increased satisfaction with those providers and increased satisfaction with the services and supports they receive<sup>8</sup>. Moreover, increase satisfaction with ones services and supports can lead to an increase in self-management as well as a sense of locus of control over ones’ life<sup>9</sup>, both of which are critical to physical and psychological well-being<sup>10</sup>. In fact, regulations and policies that prohibit choice can lead to a loss of locus of control and autonomy<sup>11</sup>.

The ability to direct ones’ services and supports may be particularly critical for PWD, who already face more disparities. PWD’s ability to choose services and providers that are a better fit for them and their needs is also a predictor of health outcomes for PWD<sup>12, 13</sup>. Moreover, this increased quality of health leads to an increased quality of life.

The rise of consumer empowerment and patients’ rights movements, and the emphasis on person-centered planning and self-determination, came *directly* out of understandings that quality of life (QOL) was dependent on these concepts<sup>14</sup>. Because of the emphasis on personally defined outcomes, it is important that quality of life, a construct particularly important in the

disability field because of its necessity to demonstrate the effectiveness of services programs and interventions, be person-centered. Originally, disability QOL measures were only used in medical context to measure the “burden” of disability<sup>15, 16</sup>. However, in recognition that the person, family, community, and society can all impact QOL, modern QOL measures have since shifted to be more holistic and include not only health but also inclusion, empowerment, self-determination, and person-centered planning<sup>16</sup>.

For these reasons, the aim of this study was to explore the relationships between PWD choosing their services and their QOL. We had two main research questions: 1) what factors predict PWD choosing their services – who was most/least likely to choose their services?; and, 2) how does choosing their services impact the QOL of PWD? To examine these questions, we analyzed secondary Personal Outcome Measures<sup>®</sup> interviews from approximately 1,100 PWD.

## Methods

### Participants

The purpose of this study was to explore the relationships between PWD choosing their services and their QOL. To do so, this study utilized a secondary data analysis. Participants were original recruited for this study over one year (January 2017 – December 2017) through organizations in the United States that provide services to PWD, 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. In total, 1,078 PWD consented to participate. The majority of participants were White (71.2%), had high support needs (24/7) (51.2%), lived in provider owned/operated homes (43.8%), and used verbal/spoken language as their primary communication method (76.1%). Approximately one-quarter of participants (25.9%) had more severe impairments. Age, gender, and guardianship status were more evenly distributed. Participant demographics are presented in Table 1.

### Measure

The instrument used in this study was the Personal Outcome Measures<sup>®7</sup>, which is designed to determine person-centered QOL of PWD, including self-determination, choice, self-advocacy, and supports. The Personal Outcome Measures<sup>®</sup> includes 21 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; 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.

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 following specific open-ended prompts. During the second stage, the interviewer speaks with someone who knows the PWD and their organizational supports, such as a direct support professional, and asks them questions about individualized supports and outcomes to fill in any gaps. During the final stage, the interviewer observes the participant in various settings, and then completes the indicator questions about personal outcomes and individualized supports based on the information gathered in the three stages. Individual record reviews are also conducted as needed.

The Personal Outcome Measures<sup>®</sup> has been continuously refined over the past two decades through pilot testing, 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups<sup>7</sup>. Moreover, the Personal Outcome Measures<sup>®</sup> has construct validity<sup>17</sup>, the construct validation met Kaiser's and Cattell's criterion for factor retention for reliable loadings, and had a 'meritorious' Kaiser-Meyer-Olkin value. All interviewers also need to pass reliability tests with at least 85% agreement before being certified<sup>18</sup>.

### **Variables and Analysis**

The main variables of this study were "people choose their services." The decision tree for determining if the outcome was present or not is presented in Table 2.



SPSS 23 was used for analysis. This study's first research question was: what factors predict PWD choosing their services – who was most/least likely to choose their services? To examine this research question, demographic variables (excluding QOL outcomes) were run in a binary logistic regression model as the independent variables (IVs) with “people choose services” as the dependent variable (DV). It should be noted the following categories were combined because of low frequencies of each of the groups: races/ethnicities (i.e., Asian, other Pacific Islander, Native Hawaiian, other were combined into an ‘other’ category); primary communication methods (i.e., communication device and sign language combined with ‘other’); and daily support (i.e., on call – support as needed was combined with ‘0 to 3 hours/day’).

The second research question was: how does choosing their services impact the QOL of PWD? Binary logistic regression models were run with “people choose services” as the IV in each of the models with the other 20 QOL indicators as DVs in different models; we also controlled for impairment severity in each of the models. Bonferroni's correction ( $p = .003$ ) was used to account for the use of multiple models.

## Results

For the choosing their services outcome, people were asked about services/supports, goals, and providers in the following categories: home; employment; health; case management; and community. Across those categories, 36.8% of participant selected the services/supports they received, most often selecting their community providers and least often their employment providers (Table 3). Across the categories, 57.2% of participants selected their goals, most often selecting their goals for health, and least often for employment. In addition, 40.3% of participants selected their providers, most often selecting their community providers and least often their home providers. In terms of selecting their staff, participants were asked if they selected their staff for home and employment services; 31.6% of participants selected their staff. In total, less than one-third of participants ( $n = 335$ , 31.1%) had the outcome present for people choose their services (see Table 2 for decision tree).

### Likelihood to Choose Services

A binary logistic regression model was run to determine who was most/least likely to choose their services; the model was significant,  $-2LL = 774.28$ ,  $\chi^2(44) = 171.16$ ,  $p < .001$ . The model, which correctly classified 74.2% of cases, explained 28.7% (Nagelkerke  $R^2$ ) of variance. According to the model, the following variables were significant: age, average daily support, guardianship, impairment, primary communication method, race, managed care organization, and residence type. See Table 4 for odds ratios.

According to univariate statistics, controlling for all other variables, PWD aged 18 to 24 were 2.74 times less likely than people 25 to 34 to choose their services, 2.56 times less likely

than people 45 to 54, 2.89 times less likely than people 55 to 64, and 4.34 times less likely than people 75 and older. Controlling for all other variables, people who received an average of 6 to 12 hours of daily support, 12 to 23 hours, and 24/7 around the clock support were all less likely (2.86, 7.69, and 5.26 times respectively) to choose their services than people who receive support as needed to up to 3 hours of daily support. people with assisted decision making and full/plenary guardianship were significantly less likely (1.82 and 1.89 times respectively) to choose their services than people with independent decision making, controlling for all other variables. People with the following impairments were all significantly less likely to choose their services than people with other impairments: behavior challenges (2.56 times), brain injury (10.00 times), and, intellectual and developmental disabilities (IDD) (2.56 times). People who primarily communicated through facial/body expressions were 1.86 times more likely to choose their services than people who primarily used verbal communication. Black PWD were 1.88 times less likely to choose their services than White PWD, even controlling for all other variables. Controlling for all other variables, Native American people were 4.07 times more likely to choose their services than White people. People who received services from a managed care organization were 1.82 times more likely to choose their services than those who did not receive services from a managed care organization. People who lived in family homes were 3.23 times less likely to choose their services than people who lived in their own homes. Moreover, people who lived in provider owned or operated homes were 1.59 times less likely to choose their services and people in 'other' settings, 3.33 times less likely to choose their services.

### **Choosing Services and Quality of Life**

Binary logistic regression models were also run to determine the impact of choosing services (IV) on the other 20 QOL indicators (DVs), while controlling for impairment severity

(CV). Findings revealed, controlling for impairment severity, PWD who choose their services were significantly more likely to be safe, be free from abuse and neglect, have best possible health, have continuity and security, exercise rights, be treated fairly, be respected, use their environments, live in integrated environments, interact with other members of the community, participate in the life of the community, have friends, have intimate relationships, decide when to share personal information, perform social roles, choose where and with whom to live, choose where to work, choose personal goals, and realize personal goals (19 out of 20 outcomes). See Table 5 and Figure 1. There was no significant difference in people's natural support networks when they choose their services.

## Discussion

PWD's ability to choose their services increases the likelihood they receive the services they want and need, thereby likely increasing the quality of their services and their QOL. As such, the impact of service choice may be widespread as it was correlated with improved QOL in almost every metric in our study. For example, PWD in our study who chose their services were twice as likely to realize their personal goals than people who did not choose their services.

### Impact on Human Security

The ability to choose ones' services and supports can not only result in those services and supports being more applicable to PWD's needs, but also in increased satisfaction with the services and supports they receive<sup>8</sup>. For example, when people have an increased locus of control over their lives by being able to choose their services and supports and providers that fit better with their needs, they have better health outcomes<sup>12, 13</sup>. By selecting their services and supports – and as a result ensuring those services and supports are better suited towards their needs – there is more of an emphasis on achieving outcomes as *personally defined* by the PWD. When services and supports are more applicable to their needs, they more likely to have those outcomes present. For example, our findings revealed, people are more likely to better human security outcomes, such as safety, freedom from abuse, health, and rights, when they choose their services. Although these findings provide evidence of the benefits of PWD choosing their services, in no way should their fundamental human security be dependent on their ability to choose their services – human security should be non-negotiable. For example, PWD in our study were three times more likely to be free from abuse and neglect when they choose their services, despite the fact the United Nations Universal Declaration of Human Rights<sup>19</sup> and Convention on the Rights of Persons with Disabilities (CRPD)<sup>20</sup> recognize freedom from abuse and neglect, and safety, as

fundamental. Similarly, according to the United Nations, health is a fundamental human right<sup>21</sup>, yet the people who chose their services in our study were three times more likely to have health outcomes present.

According to the CRPD, PWD are entitled to human rights and fundamental freedoms to the same extent as nondisabled people<sup>20</sup>. Moreover, by virtue of citizenship, PWD are also entitled to civil rights. Thus, our findings that people who do not choose their services are more likely to experience rights limitations and less likely to receive appropriate due process when rights limitations are imposed (treated fairly) is concerning; according to the United Nations High Commissioner for Human Rights all people should have the same rights, and as such, have the same responsibilities associated with those rights<sup>22</sup>.

### **Impact on Community and Social Integration**

Findings also revealed, PWD who choose their services are significantly more likely to choose where and with whom to live, live in integrated environments, use their environments, interact with other members of the community, and participate in the life of the community. When priorities are defined by PWD, rather than organizational structures or operations, the services and supports they receive to meet those goals will be better tailored to them and, as a result, better suited to meet their needs. As a result, there may be more opportunities to integrate into and with their community than with inflexible and standardized services. Cultures of providers must change to detach from traditional custodial congregate care models by removing biases. Services driven by PWD, transform PWD from passive recipients of services to active consumers<sup>23</sup>

Both the Americans with Disabilities Act (ADA; 1990) and *Olmstead v. LC* (1999) reinforce PWD's rights to be in the community. Yet, research has found many PWD, especially

people with IDD, continue to be isolated even in the community<sup>25</sup>. In recognition of some of these shortcomings, the Medicaid introduced the settings rule in an attempt to facilitate meaningful community integration.<sup>6</sup> When Medicaid LTSS truly aligns with the intent of the settings rule, the rule's emphasis on person-centered planning will not only shift how many states must provide their services – hopefully strengthening the community infrastructure – but, based on this study's findings, may also result in more integration as a result of people choosing their services. These forms of community inclusion are critical.

Indeed, when PWD are able to choose their services, they are more likely to be not only physically integrated but socially as well. As a result of a lack of opportunities and social isolation, PWD currently experience more loneliness, see their friends less often, and have less close relationships with their friends than nondisabled people<sup>26</sup>. Yet, our findings revealed PWD who choose their services are more likely to not only have friends and intimate relationships, but also to perform different social roles. Community is not just a place one physically goes to, but “a place people have a stake in, a place people feel they belong”<sup>27</sup>.

### **Addressing Service Choice Disparities**

As a result of both the potential benefits of choosing services on QOL, and the disparities that were unearthed in this study, there needs to be targeted supports to ensure all PWD have equal opportunities to choose their services. People with behavior challenges, brain injury, and IDD were less likely to choose their services than people with other disabilities, even when impairment severity and support needs were controlled. Findings also revealed people with higher daily support needs were less likely to choose their services, but there was no significant relationship between service choice and impairment severity. These findings may relate to the *perceptions* of PWD's abilities rather than their *actual* abilities. Although today there are more

nuanced understandings of people with disability than historically, disability is often still synonymous with ideas of dependency, pathology, and difficulties<sup>28</sup>. As such, conceptualizations of PWD as incapable, incompetent, or low ability are not only widely exaggerated, they also result in paternalism<sup>29</sup>, all of which limit PWD's choices, including their ability to choose their services.

Thus, ensuring PWD have equal opportunities, including the opportunity to choose their services, requires not only attention to disparities, such as by supporting people with IDD to choose their services more often, but also attention to more widespread and ingrained ideas about disability, capability, and independence/interdependence. In alignment with interdependence – “[a] cultural value of supporting one another” – having support or assistance does not mean PWD are not self-determined or capable (p. 320)<sup>30</sup>.

These attitudes about PWD's abilities may be a remnant of historical congregate care models of institutionalization, whose legacy has resulted in standardized and inflexible services<sup>31</sup>. Indeed, our findings revealed people who lived in provider owned or operated homes were less likely to choose their services than people who lived in their own homes, reflecting the systemic move of congregate deficit-based culture from traditional institutions to modern community-based services.

PWD living in family homes were also less likely to choose their services than people who lived in their own homes. While this may be related to well-intended choices of family members, there is a potential that people were over-supporting people to the extent it limited their choices. Avoidance of risk is often built into the physical and social environments of PWD, particularly people with IDD<sup>32</sup>. However,



it is difficult to learn how to make decisions and handle risk if the chance to undertake either of these activities is denied... these experiences tend to be denied by parents anxious to minimize risk... [they are] keen to encourage decision-making in theory but unwilling to allow choices that result in very minimal risky behavior... where [they] felt it legitimate to intervene and control. (p. 261)<sup>33</sup>

Family involvement may also be why transition age PWD (aged 18 to 24) were less likely to choose their services than older people (25-34, 45-64, 75+).

Even those who have assisted decision making and full plenary guardianship should be able to help choose their services. This is especially pertinent as our findings revealed even when controlling for impairment severity and support needs, people under guardianship were less likely to be able to choose their services. The United States guardianship system, tends to give guardians broad sweeping powers, instead of limiting guardianship to those particular areas where an individual needs assistance; it “rarely limit[s] the guardian’s authority” (p. 173)<sup>34</sup> because

courts find it difficult to ascertain the precise areas of decision making with which the individual needs assistance; courts deem it necessary to avoid confusion about the scope of the guardian’s authority; or courts wish to avoid the need for additional future proceedings to expand the scope of a more limited initial order. (174-175)<sup>34</sup>

Salzman <sup>34</sup> goes so far as to argue the current sweeping guardianship system violates the ADA and *Olmstead* because it limits decision making rights and does not support people in a least restrictive manner.

Another disparity unearthed in this study was the finding that Black people were significantly less likely to choose their services than White people. While problematic, this is perhaps not surprising given widespread and systemic racism, especially for PWD of color<sup>35</sup>. In the United States, as a result of racism, people of color commonly experience inequities, including in healthcare<sup>36</sup>. For example, a study by Murphy-Berman, Berman, Campbell<sup>37</sup> found people used excuses to rate Black people, but not White people, lower priority and less deserving in health care determinations. In addition to wider systemic racism that needs to be dismantled, on the micro level, disability service organizations need to be more intentional about counteracting these inequalities to ensure Black PWD have the same opportunities to direct their services as White people.

Counter to these findings, Native American PWD in our study were more likely to choose their services than White PWD, which does not reflect past research which has found Native Americans face immense disparities in health and healthcare and are more likely to live in poverty<sup>38</sup>. For these reasons, and because the significant difference diminishes when not controlling for other variables, we believe these findings are sample specific, possibly related to confounding relationships and interactions, the unequal distribution of the sample, and/or factors about these participants themselves. Future research should explore if this finding can be duplicated, and if so, explore potential explanations.

Finally, according to our findings, people who receive support from a managed care organization were *more* likely to be supported to choose their services than those not receiving managed care. Medicaid managed care is the privatization of Medicaid service provision. Although it aims to manage cost and extend quality, there is conflicting research about managed care's benefits for PWD, including its quality and the cost effectiveness<sup>39,40</sup>. Although our study

found PWD were more likely to choose their services when they received managed care, this runs counter to other research that has also found people with IDD less likely to self-manage their health when they receive managed care<sup>41</sup>. Moreover, our analysis did not examine the interaction between disability type, managed care, and choosing services; it may be that people with certain disabilities are more or less likely to choose their services on managed care than other disabilities. As this service delivery model is rapidly growing in frequency in the United States, evidenced-based standards and guidelines about managed care provision for PWD are more critical than ever.

### **Limitations**

When interpreting our findings, a number of limitations should be considered. One limitation was this was a convenience sample and not necessarily representative of the disability community. The majority of our sample was White, and had IDD, which is not representative of the disability community in the United States. Moreover, although participants represented 20 states, three states (i.e., New York, Tennessee, and South Dakota) were represented most frequently. There was also an unequal distribution across some of the variables in our study; for example, only 23 people were Native American, which may have impacted the significance of findings. Finally, as this was as a secondary data analysis, we did not have the opportunity to add additional questions or variables. For example, although it followed a decision tree involving many aspects that must be present, ‘people choose their services’ was a binary variable.

### **Conclusion**

The shift toward person-centered services recognizes the importance of services and supports as chosen by the person, and their preferences. Accordingly, quality person-centered services must not only allow PWD choice making opportunities, but also ensure outcomes are also individually defined. The aim of this study was to explore if and how PWD choosing their services impacts their person-centered QOL outcomes. Our findings revealed that when PWD are able to choose their services, the impact can be widespread. By ensuring PWD are able to choose their services, organizations are not only facilitating self-determination, but, ultimately, improving PWD's QOL.

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Table 1

*Demographics of Sample (n = 1,078 )*

Characteristic	n	%	Characteristic (cont.)	n	%
Age range			Primary method of communication		
18 to 24	109	10.1%	Verbal/spoken language	820	76.1%
25 to 34	222	20.6%	Face/body expression	138	12.8%
35 to 44	172	16.0%	Communication device	15	1.4%
45 to 54	170	15.8%	Sign language	12	1.1%
55 to 64	174	16.1%	Other	16	1.5%
65 to 74	95	8.8%	Residence type		
75+	36	9.3%	Own home/apartment	222	20.6%
Disability			Family's house	147	13.6%
Anxiety disorder	145	13.5%	Host family/family foster care	27	2.5%
Autism spectrum disorder	112	10.4%	Provider owned/operated home	472	43.8%
Behavior challenges	135	12.5%	State operated HCBS group home	21	1.9%
Brain Injury	24	2.2%	State operated ICFDD	22	2.0%
Cerebral palsy	123	11.4%	Other	29	2.7%
Down syndrome	50	4.6%	Daily support		
Hearing loss- severe or profound	31	2.9%	On call - support as needed	13	1.2%
Impulse-control disorder	92	7.6%	0 to 3 hours/day	46	4.3%
Intellectual/developmental disability	771	71.5%	3 to 6 hours/day	94	8.7%
Limited or no vision- legally blind	39	3.6%	6 to 12 hours/day	94	8.7%
Mood disorder	181	16.8%	12 to 23 hours/day	57	5.3%
Other mental illness/psychiatric diagnosis	116	10.8%	24/7 - around the clock	552	51.2%
Personality/psychotic disorder	93	8.6%	Other	36	3.3%
Physical disability	50	4.6%	Quality of life outcomes		
Seizure disorder/ neurological problem	176	16.3%	Are safe	821	76.2%
Gender			Free from abuse and neglect	661	61.3%
Man	572	53.1%	Best possible health	709	65.8%
Woman	473	43.9%	Continuity and security	526	48.8%
Race/ethnicity			Exercise rights	481	44.6%
White	767	71.2%	Treated fairly	578	53.6%
Black	149	13.8%	Respected	553	51.3%
Latinx or Hispanic	24	2.2%	Use their environments	729	67.6%
Native American	23	2.1%	Live in integrated environments	500	46.4%
Other (Asian, Native Hawaiian, Pacific Islander, etc.)	22	2.0%	Interact with others in community	635	58.9%
Guardianship			Participate in life of the community	488	45.3%
Independent decision making	300	27.8%	Natural support networks	541	50.2%
Assisted decision making	276	25.6%	Friends	413	38.3%
Full/plenary guardianship	359	33.3%	Intimate relationships	448	41.6%
Other	29	2.7%	Decide when to share personal info	539	50.0%
Impairment severity (more severe)	279	25.9%	Perform different social roles	382	35.4%
Managed care organization	210	19.5%	Choose where and with whom to live	280	26.0%
			Choose where to work	355	32.9%
			Choose personal goals	491	45.5%
			Realize personal goals	595	55.2%

Table 2

*People Choose Their Services Outcome Determination*

Suggested questions for information gathering	Decision tree (answers must be yes to all)
What services are you receiving?	The participant must select the services and/or supports that they receive
When, where, and from whom do you receive the services?	The participant must have services and/or supports that focus on the their goals
Who decided what services you would receive?	The participant must have choices about service provider organizations
If you did not decide, what was the reason?	The participant must have choices about direct support professionals/staff
How did you decide who would provide the service?	
Are these the services you want?	
Do you have enough services? Are they meeting your needs and expectations?	
Can you change services or providers if you so choose?	

Table 3

*Descriptive Statistics*

Variables	<i>n</i>	%
Select their services		
Home	351	32.6
Employment	255	23.7
Health	444	41.2
Case management	365	33.9
Community	566	52.5
Select their goals		
Home	590	54.7
Employment	553	51.3
Health	688	63.8
Case management	591	54.8
Community	659	61.1
Select their providers		
Home	360	33.4
Employment	389	36.1
Health	446	41.4
Case management	410	38.0
Community	568	52.7
Select their staff		
Home	354	32.8
Employment	327	30.3
People choose their services - outcome present	335	31.1

Table 4  
*Likelihood to Choose Services*

Variable	Odds Ratio	95% confidence interval	
Age range (ref: 18 to 24)			
25 to 34	2.74*	1.27	5.91
35 to 44	1.98	0.88	4.45
45 to 54	2.56*	1.14	5.72
55 to 64	2.89**	1.29	6.45
65 to 74	1.39	0.56	3.46
75+	4.34**	1.47	12.77
Average daily support (ref: on call to 3 hours/day)			
3 to 6 hours/day	0.42	0.17	1.02
6 to 12 hours/day	0.35*	0.15	0.84
12 to 23 hours/day	0.13***	0.05	0.37
24/7 - around the clock	0.19***	0.09	0.42
Other	1.24	0.40	3.89
Guardianship (ref: independent decision making)			
Assisted decision making	0.55*	0.34	0.88
Full/plenary guardianship	0.53*	0.34	0.84
Other	1.13	0.40	3.22
Impairment			
Anxiety disorder	1.21	0.74	1.97
Autism spectrum disorder	0.75	0.41	1.39
Behavior challenges	0.39**	0.20	0.76
Brain Injury	0.10*	0.01	0.85
Cerebral palsy	0.91	0.51	1.63
Down syndrome	1.12	0.51	2.47
Hearing loss- severe or profound	0.80	0.28	2.28
Impulse-control disorder	0.69	0.33	1.44
Intellectual/developmental disability	0.39***	0.24	0.62
Limited or no vision- legally blind	0.75	0.30	1.86
Mood disorder	0.98	0.62	1.54
Other mental illness/psychiatric diagnosis	1.25	0.74	2.13
Personality/psychotic disorder	0.93	0.51	1.72
Physical disability	0.77	0.33	1.77
Seizure disorder/ neurological problem	0.70	0.43	1.13
Impairment severity: more severe impairment	0.79	0.52	1.22
Primary communication method (ref: verbal)			
Facial/body expression	1.86*	1.05	3.31
Other (including communication device and sign language)	0.98	0.40	2.43
Race (ref: White)			
Native American	4.07*	1.05	15.75

Black	0.53*	0.30	0.95
Latinx	0.60	0.12	2.91
Other	0.59	0.12	3.06
Receives services from a managed care organization	1.82**	1.18	2.80
Residence type (ref: own home)			
Family home	0.31***	0.16	0.60
Host family or family foster care	1.02	0.38	2.75
Provider owned/operated home	0.63*	0.40	0.99
State-operated HCBS group home	0.74	0.22	2.54
ICFDD (private and state)	0.37	0.07	2.00
other	0.30*	0.10	0.91
Woman (ref: man)	0.99	0.69	1.43

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*Note.* \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 5

*Impact of Service Choice on Quality of Life: Binary Logistic Regression Models (controlling for impairment severity)*

Model	-2LL	df	$\chi^2$	$R^2$ (Nagelkerke)	O.R.	95% C.I.	
Are safe***	820.67	2	27.23	0.05	2.71***	1.79	4.09
Free from abuse and neglect***	1074.00	2	49.88	0.08	3.03***	2.20	4.19
Best possible health***	1011.33	2	36.31	0.06	2.73***	1.94	3.84
Continuity and security***	1082.51	2	97.08	0.14	4.41***	3.24	6.01
Exercise rights***	995.90	2	180.37	0.26	8.00***	5.75	11.12
Treated fairly***	1033.89	2	135.66	0.20	6.30***	4.49	8.84
Are respected***	1040.17	2	124.65	0.18	5.81***	4.16	8.12
Use environments***	942.49	2	56.58	0.09	3.52***	2.41	5.15
Integrated environments***	1121.35	2	54.63	0.08	2.60***	1.94	3.48
Interact with others in community***	1082.13	2	46.74	0.07	2.88***	2.09	3.96
Participate in life of the community***	1138.15	2	36.61	0.06	2.41***	1.81	3.22
Natural supports*	1166.44	2	8.75	0.01	1.39*	1.05	1.85
Friends***	1113.91	2	27.73	0.04	2.17***	1.62	2.90
Intimate relationships***	1108.11	2	49.66	0.08	2.76***	2.06	3.69
Decide when to share personal information***	1111.69	2	58.99	0.09	3.17***	2.34	4.30
Perform different social roles***	1062.95	2	66.92	0.10	3.35***	2.50	4.51
Choose where and with whom to live***	819.88	2	167.27	0.26	7.92***	5.62	11.14
Choose where to work***	999.68	2	91.04	0.14	4.21***	3.10	5.70
Choose personal goals***	1056.00	2	123.40	0.18	5.48***	3.98	7.55
Realize personal goals***	1147.88	2	14.02	0.02	1.73***	1.29	2.32

*Note.* \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ . The independent variable (IV) for each model was "choose services - outcome present." Impairment level was also controlled for every model but is not shown. O.R. = Odds ratio. C.I. = Confidence interval.

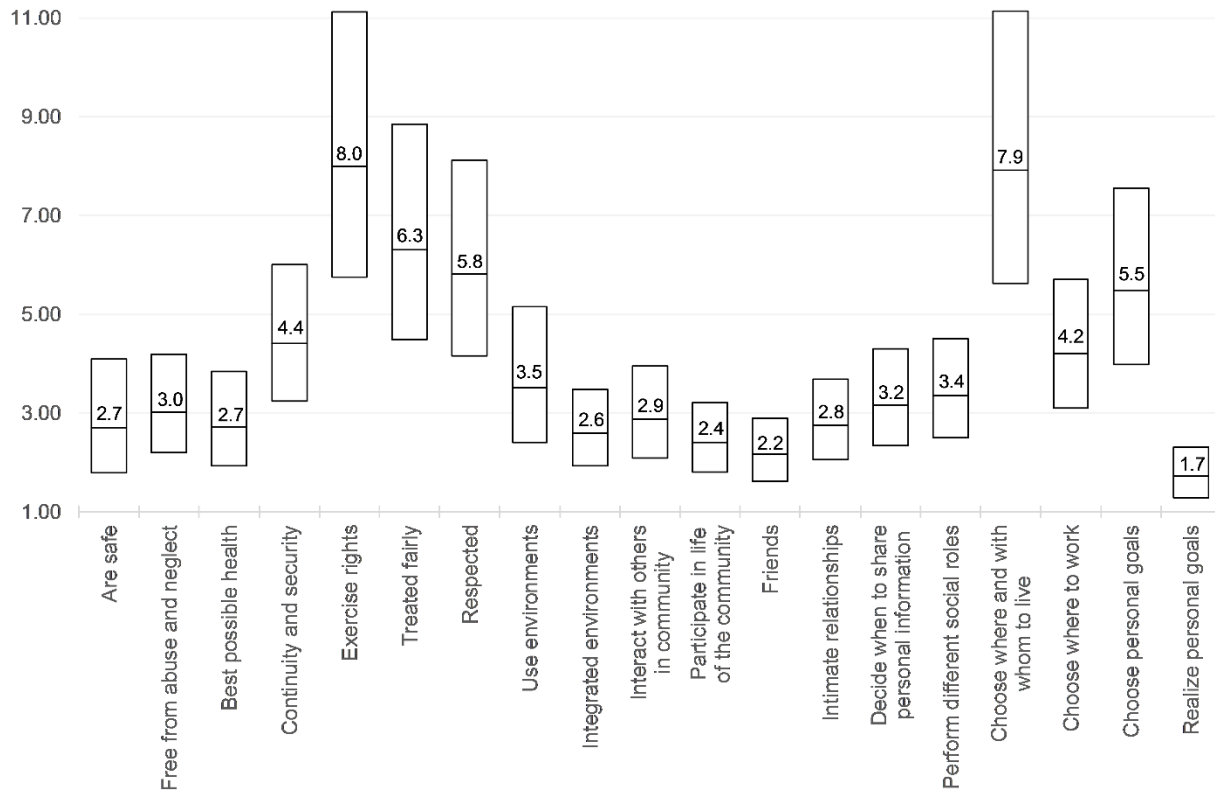


Figure 1. Impact of choosing services on quality of life indicators (odds ratios).