Research

The Personal Outcome Measures®

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The Personal Outcome Measures®

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Abstract

Background. The Personal Outcome Measures® is a person-centered tool to measure the quality of life (QOL) of people with disabilities, especially those who receive long term services and supports. While the outcomes examine people's satisfaction with their lives in a wide range of areas, the organizational supports determine if service agencies are appropriately supporting people with disabilities to ensure people with disabilities have the best possible QOL. The Personal Outcome Measures® has been administered to tens of thousands of people with disabilities and older adults over its twenty-five years of existence.

Objective. In order for the Personal Outcome Measures® to adequately measure the QOL of people with disabilities, it must continuously be refined in alignment with the advances made by people with disabilities, and the disability service system. Therefore, the purpose of this study was to re-validate the Personal Outcome Measures®.

Methods. A Principal Components Analysis was used to analyze data from 1,473 people with disabilities to determine if any indicators needed to be removed as well as the underlying structure of the Personal Outcome Measures®.

Results. The analysis revealed the Personal Outcome Measures® has construct validity. It also found that the 21 indicators fall into five underlying factors: my human security; my community; my relationships; my choices; and, my goals.

Conclusions. Taken together these twenty-one indicators and five factors represent a multifaceted and comprehensive QOL assessment that aims to improve the lives of people with disabilities.

Keywords: Quality of life; organizational supports; personal outcomes; person-centered measure; long term services and supports

Introduction

Quality of life (QOL) contains a wide range of domains, such as: emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; self-determination; social inclusion; and, rights[1-5]. QOL is based on "common human experiences and unique, individual life experiences"[4] while also giving "sense of reference and guidance from the individual's perspective, focusing on the person and the individual's environment"[6]. A particularly important construct in the disability field, QOL is a vital construct for service programs and interventions so they can demonstrate the effectiveness of those programs and services[7, 8].

Yet, because of its complexity, QOL can be "difficult to quantify empirically"[7]. Disability QOL measures have shifted from their early origins; originally QOL measures were used in medical contexts to examine the "burden" of disabilities of the population of interest[4, 9, 10]. The conceptualization of QOL has since broadened to include more holistic definitions of health, inclusion, and empowerment[11]. One of the reasons for this shift was a recognition that the person, family, community, and society all impact QOL[4, 12]. Another reason was advances in the field of disability, in terms of empowerment, self-determination, person-centered planning, and self-advocacy[1, 4, 12, 13]. In the past few decades there have also been significant advances in terms of rights and equality of people with disabilities (PWD), particularly in the areas of autonomy, non-discrimination, and inclusion with new policy, legislation, and conventions (e.g., Americans with Disabilities Act, *Olmstead* v *L.C.,* United Nations Convention on the Rights of Persons with Disabilities, etc.)[10, 14].

These shifts lead to QOL's reconceptualization so that it is a more multidimensional construct[1, 2, 4, 5, 7, 8, 12-15] that recognizes "that personal, family, community, and societal well-

being emerge from complex combinations of [scientific, medical, and technological] advances plus values, perceptions, and environmental conditions"[1]. Research suggests modern QOL measures should also call attention to multiple levels of systems – micro, meso, and macro – which operate simultaneously to impact people's experiences[1, 12]. As such, QOL measures for PWD should pay attention not only to personal outcomes but also support needs[10]. Similarly, many researchers have noted the need for both objective and subjective components in modern QOL scales[2-4, 12, 14, 16].

Cummins[13, 16] and Cummins, McCabe, Romeo, Reid, Waters [2] have also suggested even if they are created for PWD in mind, QOL measures should be applicable to the general population. One of the faults with many QOL scales for people with disabilities is that by focusing on the needs of PWD, the measure omits many important areas of life[2]. Cummins clarifies,

> there exists an identifiable set of core, essential, and fundamental building-blocks of life quality that are common to us all… it is possible to create generic QOL instruments that can be validly employed with any human group irrespective of culture, socioeconomic status or disability. Such instruments would then represent the 'gold standard' for QOL measurement because their values are directly comparable between groups and individuals.[13]

Along with these changes, there has been a call to strengthen the evidence-base of QOL models, particularly the reliability and validity[1, 6, 16]. Schalock [1] also recommends triangulation, and "use of qualitative and quantitative methods to measure the overlapping, but distinct facets of the QOL construct"[1].

The Personal Outcome Measures®[17] was developed as a multifaceted comprehensive measure of QOL of PWD while also paying attention to the key role organizational support can play in improving individual outcomes. Unlike other QOL measures that define quality as mere compliance with organization standards, the Personal Outcome Measures® focuses on a person-centered definition of QOL, including choice, self-advocacy, self-determination, and community inclusion. The original Personal Outcome Measures® was developed in the early 1990s based on focus groups with people with intellectual and developmental disabilities, people with psychiatric disabilities, family members, and key stakeholders. As a result, 30 indicators were developed, falling into the following domains, or factors: personal goals; choice; social inclusion; relationships; rights; dignity and respect; health; environment; security; and satisfaction. Although developed with PWD and to be used with PWD, the indicators are applicable to the general population as well. The Personal Outcome Measures® was then piloted with three disability service organizations, and field tested in the United States and Canada.

In 1997, a factor analysis was used to revalidate the Personal Outcome Measures®, resulting in a reduction from 30 indicators to 24 by removing and/or combining a number of indicators. In 2005, the second edition of the Personal Outcome Measures® was refined through feedback from 15 years of administration, research and content experts, and a Delphi survey[17]. Based on these findings, the Council on Quality and Leadership (CQL) introduced a revised edition of the Personal Outcome Measures® in 2005, which organized the 21 indicators into three categories: My Self, My World, and My Dreams.

There have been significant changes in the disability community and disability service system since the Personal Outcome Measures® was last revised in 2005. For example, the state-operated institutional census continues to decline, especially spurred in part by a number of cases

that enforce *Olmstead v. L.C.*[18]. The fiscal landscape has also changed significantly since 2005 because of the Great Recession (2007-2009); as the fiscal landscape has improved from the Great Recession, there has been an increase in both institutional care and community supports for PWD[18]. Another notable change has been the rule and regulation changes from the Centers for Medicare and Medicaid Services (CMS), including the HCBS final settings rule (CMS 2249-F/2296-F), which prioritizes person-centered planning and community integration[19].

The Personal Outcome Measures® has been administered to tens of thousands of PWD and older adults over its twenty-five years of existence. It has been utilized by service organizations, including governments, around the world but most frequently in the United States, Canada, and Australia, that provide any type service to PWD. Organizations utilize the measure to facilitate the QOL of those they serve, improve their service provision, and direct person-centered planning. In order for the Personal Outcome Measures® to adequately measure the QOL of PWD, it must continuously be refined in alignment with the advances made by PWD, and the disability service system. Therefore, the purpose of this study was to re-validate the Personal Outcome Measures®. To do so, a Principal Components Analysis (PCA) was used to determine if any changes were needed to the variables included, and to determine the underlying structure of the Personal Outcome Measures® and the composite scores for the factors underlying the Personal Outcome Measures®.

Methods

Participants

Participants with disabilities were recruited over a two-year period (January 2015 to January 2017) from hundreds of organizations, including local, county, and state governments, that provide any type of the following services to PWD: service coordination; case management; family and individual supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); and, human service systems. 1,473 PWD participated in this study; participant demographics are presented in Table 1.

Instrument

The Personal Outcome Measures® is a person-centered QOL measure that focuses on outcomes and supports. The second edition of the Personal Outcome Measures®[17], which was revised in 2005, was organized into three categories: My Self, My World, and My Dreams. *My Self* included the following indicators: people are connected to natural support networks; people have intimate relationships; people are safe; people have the best possible health; people exercise rights; people are treated fairly; people are free from abuse and neglect; people experience continuity and security; and, people decide when to share personal information. *My World* included the following indicators: people choose where and with whom they live; people choose where they work; people use their environments; people live in integrated environments; people interact with other members of the community; people perform different social roles; and, people choose services. *My Dreams* included the following indicators: people choose personal goals; people realize personal goals; people participate in the life of the community; people have friends; and, people are respected.

Procedure

The Personal Outcome Measures[®] is administered in three stages by interviewers who need at least 85% reliability before being certified to administer the Personal Outcome Measures[®20]. In the first stage of administration, an interviewer has an in-depth conversation about each of the Personal Outcome Measures[®] indicators with the participant with disabilities. The interviewer follows specific open-ended prompts for each of the indicators. In the second stage of administration, the certified interviewer interviews provider staff (e.g., direct support professionals, support staff supervisor, service coordinators, case managers), not as a proxy measure, but for follow up – particularly about the organizational supports – and to fill in any gaps if applicable. In the final stage of administration, the interviewer may observe the participant in various settings or review records if needed. When all data is collected, the interviewer completes the indicator questions about personal outcomes and individualized organizational supports (scoring whether the outcome or support were present or not). The multiple data sources are a form of triangulation to strengthen the data's validity[21]. However, because of its basis in person-centered philosophy, if there are any conflicting accounts, the person with disabilities' views and opinions override that of the follow-up interview with staff.

Data Screening

To demonstrate the construct validity of the Personal Outcome Measures[®], Personal Outcome Measures[®] data from 2015 and 2016 were collected from approximately 1,450 interviews. The Personal Outcome Measures[®] data from these interviews were entered into the database and analyzed using SPSS 23. The data were screened for administrative errors and missing data. (Missing data was skipped.) The minimum amount of data for factor analysis was satisfied, providing a ratio of over 67 cases per variable[22].

Results

A PCA using an oblique (varimax) rotation was to determine if all of the indicator variables were still relevant after changes in the disability field and industry – if any needed to be reduced – as well as provide a description of the relationship between variables – identify and compute composite scores for the factors underlying the Personal Outcome Measures®. Sampling adequacy using the Kaiser-Meyer-Olkin measure was .89 and Bartlett's test of sphericity was found to be significant (χ^2 (210) = 6380.96, $p<.001$). PCA results revealed the indicators loaded into a total of five factors with eigenvalues that exceeded 1.00; the five factor solution explained a cumulative variance of 50.8% for the 21 items' scores (Table 2). Initial eigen values indicated that the first factor explained 26.5% of the variance. The second, third, fourth, and fifth factors had eigen values just over one and explained 6.9%, 6.6%, 5.6% and 5.2% of the variance respectively (see Figure 1).

A minimum factor loading of 0.30 was required for a variable's interpretation on a factor. All 21 items loaded on the five factors (Table 2). Labels for these factors are: my human security (7 items); my community (4 items); my relationships (5 items); my choices (3 items); and, my goals (2 items). *My human security* includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people are treated fairly; people are respected; people experience continuity and security; and, people exercise rights. *My community* includes the following indicators: people interact with other members of the community; people live in integrated environments; people participate in the life of the community; and people use their environments. *My relationships* includes the following indicators: people have intimate relationships; people have friends; people are connected to natural support networks; people decide when to share personal information; and, people

perform social roles. *My choices* includes the following indicators: people choose where and with whom to live; people choose services; and, people choose where they work. *My goals* includes the following indicators: people realize personal goals; and, people choose personal goals. Cronbach's alpha was used to determine internal consistency for each of the components: .73 for my human security, .67 for my community, .64 for my relationships, .63 for my choices, and .48 for my goals.

Table 3 provides descriptive data for the Personal Outcome Measures® across participants. The mean score of participants suggest they are more likely to have community ($M = .55, SD = .35$), human security ($M = .54, SD = .25$), and goals ($M = .51, SD = .40$) than relationships ($M = .46, SD = .32$) or choices ($M = .29, SD = .34$). A means analysis conducted in order to examine the differences among the components for the different demographic groups reveal few differences across the factors based on gender or age (Table 4). However, the were wider differences in terms of race/ethnicity, primary communication method, guardianship status, residence type, daily support needs, and disability type.

Discussion

QOL of PWD is complex and multidimensional; in order to tease out that complexity, and expand the evidence-base of QOL measures for PWD, the aim of this study was to re-validate the Personal Outcome Measures[®]. Utilizing a PCA, we found five underlying themes of the Personal Outcome Measures[®]: my human security; my community; my relationships; my choices; and, my goals.

Personal Outcome Measures[®]: The Five Factors

My human security. *Human Security* includes essential non-negotiable human and civil rights. In our definition, we invoke the United Nations (UN) concept which "link[s] various humanitarian, economic, and social issues in order to alleviate human suffering and assure security"[28]; human security "encompasses human rights, good governance, access to education and health care and ensuring that each individual has opportunities and choices to fulfill his or her potential"[29]. Former UN High Commissioner for Refugees Sadako Ogata [30] explains, essential elements of human security include:

> the possibility for all citizens to live in peace and security within their own
>
> borders; … people should enjoy without discrimination all rights and obligations -
>
> including human, political, social, economic and cultural rights; ... social
>
> inclusion - or having equal access to the political, social and economic policy
>
> making processes, as well as to draw equal benefits from them; … [and]
>
> establishment of rule of law and the independence of the justice system. Each
>
> individual in a society should have the same rights and obligations and be subject
>
> to the same set of rules.[30]

While our definition of human security includes a wide range of rights, from the right to access one's possessions to the right to privacy, there is also a requirement of freedom from physical or mental harm, including abuse, neglect, exploitation, and mistreatment. People who receive services must be treated the same as people who do not; they must have dignity and respect, social stability, continuity, and security. People must have sufficient resources to meet their basic needs, as well as have person-centered services.

My community. PWD have a right to be in the *community*, to access and interact with the world around them. Both the *Americans with Disabilities Act* (1990) and *Olmstead v. L.C.* (1999) require people receive services in the most integrated settings possible – people who are receiving human services and supports must have the same opportunities to access the community as other citizens. Moreover, the Medicaid Home and Community Based Services (HCBS) settings rule (CMS 2249-F/2296-F) also requires states to provide meaningful community opportunities through their Medicaid HCBS programs, which is critical for people with intellectual and developmental disabilities in particular as community integration is often dependent on service provisions[31].

The Personal Outcome Measures® recognizes the difference between community access and community integration, with the latter being the ultimate goal. While the characteristics of community may vary depending on personal preferences, as with all people, people who receive supports are integral community members, and should be supported to fulfill multiple social roles in the community.

My relationships. *Relationships*, be they with biological or chosen family, friends, or romantic partners, produce a sense of belonging. *Relationships* are personally defined, ranging from who one chooses to share information with, to a deep level of intimacy and familiarity. The

Personal Outcome Measures® notes relationship are links to the greater world that create a blanket of security, and help people who receive supports play social roles. Social capital, the impact of social ties and relationships, promotes personal outcomes[32].

"Decide when to share personal information" fits in My Relationships because it depends on a level of trust with others, that is ones' relationships with them – it is about being able to control how the information is shared and most importantly who it is shared with. It is not uncommon for PWD to not be given the option of who sees their personal files[32]; however, when services are appropriately person-centered they should have the ability to do so.

Relationships are particularly important for PWD, as they often have a lack of opportunities for relationships and are often socially isolated[33]. Moreover, relationships with peers with disabilities can produce greater self-acceptance, less internalized stigma, and more camaraderie[34].

My choices. *Choice* is the ability to make decisions that affect one's life and community. Central to *choice* are self-determination, participation, and autonomy. Organizations must accommodate peoples' preferences so they can get what they want and need. Participant direction has grown exponentially throughout long-term services and supports, particularly because of its benefits of increased choice, control, satisfaction, quality of life, independence, empowerment, and physical and emotional well-being[35].

My goals. *Goals* reflect aims for the future, including direction, dreams, and aspirations. While *goals* do not need to be realistic or achievable, they do need to be person-centered. Goals not only rely on participant direction and person-centered philosophy to ensure people are truly working towards goals of their choosing, but for many PWD, this factor requires opportunity. There are often lower expectations for PWD because of prejudicial attitudes, low expectations,

and exaggeration of difference[36]. Equity of opportunity requires PWD not only be supported, especially to reduce systemic barriers, but also, if they are to truly have equal opportunities, they must have the opportunity to take risks. Organizations need to support people who receive services to have experiences and opportunities that help them meet personal milestones.

Changes from the 2005 Edition to Present

In the 2005 edition of the Personal Outcome Measures®, indicators were organized into three factors: my self; my world; and my dreams. However, in this 2017 edition, we found five underlying factors: my human security; my community; my relationships; my choices; and, my goals. While the analysis did not reveal any indicators needed to be removed, the indicators were largely re-organized under the five new factors (Table 5). While we believe these changes are due in part to the fact that the 2005 edition was based on feedback from content and research experts, and a Delphi survey rather than organized directly from a factor analysis (such as in the 1997 edition), we also believe changes in the disability community have also impacted the quality of life of PWD and are reflected in the 2017 edition accordingly. For example, areas such as participating in the life of the community are no longer considered dreams but have been cemented as civil rights that all PWD are entitled to thanks to legislation and litigation. The growth of deinstitutionalization and shift toward ever-expanding community opportunities is now reflected in a standalone factor – my community. Another example is people are respected, which was previously organized into my dreams, perhaps because of stereotypes, negative attitudes, and other injustices. However, because of people with intellectual and developmental disabilities' advocacy, the term "mental retardation" has since been reframed as pejorative.[37] As a result of these shifts, respect is now fittingly recognized as a non-negotiable in the 2017 edition of the Personal Outcome Measures®.

Differences Across Groups

According to our findings there were a number of differences across groups on each of the five factors. People who lived in private intermediate care facilities for individuals with developmental disabilities (ICFDD) had some of the lowest scores across all five factors – they were less likely to have human security, community, relationships, choices, and goals. This finding mirrors past research which has found institutional settings to be the most restrictive and result in worse outcomes; community based settings are also preferred by the majority of PWD[38].

In terms of disability type, overall people with cerebral palsy, brain injuries, and eating disorders tended to score lowest on factors two, three, and five – my community, my relationships, and my goals, respectively. As the aim of this study was to validate the Personal Outcome Measures®, and not to explore statistically significant differences, we did not explore interactions between variables. There may have been interactions between daily hours of support, and disability type, that impacted these findings. This is especially pertinent because with average daily support, which could be considered a proxy measure of impairment severity, 24 hour support scored lowest on all five factors. Similarly, alternative methods of communication, such as sign language, and facial/body expression, frequently scored lowest on many of the factors; again, this may be due to confounding relationships with impairment severity and/or support needs. However, it may also be due to a lack of opportunities, such as described above. Ones' ability to have choices and goals should not depend on ones' communication method or level of support needed.

While there were a number of participant characteristics that produced few differences across the five factors, such as gender and age, in terms of race/ethnicity, Asian people had some of the lowest scores on each of the five factors. While with only 17 Asian participants this may

be indicative of an unequal distribution of races/ethnicities in our sample, it is also possible there are ethnic and cultural differences at play. More research is needed to determine if such findings are replicable and statistically significant across wider and more diverse samples.

Limitations

A number of limitations should be noted when interpreting our results. Our sample was not representative of the disability community as a whole or in the United States. The majority of our participants had intellectual and/or developmental disabilities, and were White. Moreover, although there are techniques to use the Personal Outcome Measures® with people with alternative forms of communication (e.g., sign language, facial/body expressions, communication devices), the majority of participants used verbal/spoken language as their primary communication method. Another limitation that should be noted is the participants in our study were recruited through organizations that provide long term services and supports, including with those who partnered with the Council on Quality and Leadership to conduct interviews and pursue accreditation. As a result, these organizations may not be representative of service providers in general.

It should be noted that not all of the factors' Cronbach's alphas were high. While not all of the Cronbach's alphas were high, Cronbach's alpha is impacted by the number of items on the scale[23, 39, 40]; indeed, the factors with lower Cronbach's alpha (e.g., goals, choices) had fewer indicators. Moreover, a number of scholars have questioned the use of Cronbach's alpha because of its strict assumptions[40, 41]. Despite low Cronbach's alpha, the analysis met both Kaiser's[24] and Cattell's[25] criterion for factor retention had reliable loadings[26], and had a 'meritorious' Kaiser-Meyer-Olkin value according to Hutcheson & Sofroniou[27]. Moreover, conceptually it makes sense for My Goals to have a low Cronbach's alpha because despite both relating to goals,

"people choose their goals" and "people realize goals" are not necessarily related for many people with disabilities. In fact, less than half of participants (45.7%) were working on goals they choose. People with disabilities are often denied the opportunity to choose their goals, which one of the main reasons the HCBS settings rule places so much emphasis on person-centered planning[19]. Future editions of the Personal Outcome Measures® should consider creating more items regarding this factor of the scale to sufficiently address the intricacies of what is being measured.

The aim of this study was to validate the Personal Outcome Measures®. As such, although descriptive differences across groups were discussed, statistical analyses were not utilized to compare across these groups. As a result, we also did not examine interactions between groups. Future studies should use statistical analyses to determine significant differences across groups, while also looking at interactions.

Conclusion

The Personal Outcome Measures® is a person-centered tool to measure the quality of life of PWD, especially those who receive long term services and supports. While the outcomes examine people's satisfaction with their lives in a wide range of areas, the organizational supports determine if service agencies are appropriately supporting PWD to ensure PWD have the best possible QOL. In addition to being reliable[20], this study has found the Personal Outcome Measures® to be a tool with construct validity. In doing so, as a result of findings from a PCA, reflecting changes in the disability community and disability service industry, the newest Personal Outcome Measures® has twenty-one indicators organized into five factors: my human security; my community; my relationships; my choices; and, my goals. Taken together these five factors represent a comprehensive QOL assessment. QOL measurement should "enable people to move toward a meaningful life they enjoy and value"[4]; by examining personal outcomes as well as individualized organizational supports, the Personal Outcome Measures® is a multifaceted and comprehensive tool to do just that.

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Table 1
Demographics of Sample (n = 1473)

Characteristic	n	%	Characteristic (continued)	n	%
Age range			Gender		
18 to 24	94	6.4	Man	759	51.9
25 to 34	283	19.3	Woman	672	45.9
35 to 44	242	16.5	Race		
45 to 54	293	20.0	White	1068	73.0
55 to 64	257	17.6	Black or African American	262	17.9
65 to 74	122	8.3	American Indian or Alaska Native	52	3.6
75+	39	2.7	Hispanic, Latinx, or Spanish Origin	37	2.5
Disability			Asian	17	1.2
Intellectual/developmental disability	1337	91.4	Native Hawaiian or other Pacific Islander	3	0.2
Seizure disorder/neurological problems	297	20.3	Other	10	0.7
Mood disorder	197	13.5	Guardianship status		
Cerebral Palsy	187	13	Independent decision making	406	27.8
Anxiety disorders	179	12.2	Assisted decision making (supported and limited guardianship)	509	34.8
Behavioral challenges	162	11.1	Full/plenary guardianship	453	31.0
Other mental illness/psychiatric diagnosis	156	10.7	Other	40	2.7
Autism spectrum disorder	147	10.2	Residence type		
Personality/psychotic disorder	146	10.0	Own home/apartment	311	21.3
Physical disability	93	6.4	Family's house	227	15.5
Impulse-control disorder	88	6.0	Host family/family foster care	25	1.7
Down syndrome	81	5.6	Provider operated house or apartment	708	48.4
Hearing loss - severe or profound	68	4.6	Private ICFDD	25	1.7
Limited or no vision - legally blind	45	3.1	State operated HCBS group home	46	3.1
Brain injury	36	2.5	State operated ICFDD	25	2.7
Alzheimer's disease or other dementia	32	2.2	Other	41	2.8
Eating disorder	12	0.8	Weekly support		
Chemical dependency/substance abuse	11	0.8	On call - support as needed	31	2.1
Prader-Willi syndrome	5	0.3	0 to 3 hours/day	72	4.9
Other disabilities not listed	50	3.4	3 to 6 hours/day	99	6.8
Primary method of communication			6 to 12 hours/day	171	11.7

Verbal/spoken language	1188	82.3	12 to 23 hours/day	77	5.3
Face/body expression	174	12.1	24/7 - around the clock	865	59.1
Sign language	14	1	Other	51	3.5
Communication device	16	1.1			
Other	33	2.3			

Note. Participants could have more than one disability.

Table 2

Factor Loadings and Communalities

	Factor					
Item	My Human Security	My Community	My Relationships	My Choices	My Goals	Communality (h^2)
Are safe	0.73					0.45
Free from abuse and neglect	0.64					0.38
Best possible health	0.63					0.40
Treated fairly	0.49					0.52
Are respected	0.43					0.51
Continuity and security	0.42					0.41
Exercise rights	0.35					0.55
Interact with others in the community		0.75				0.57
Live in integrated environments		0.70				0.57
Participate in life in the community		0.66				0.63
Use environments		0.63				0.48
Intimate relationships			0.66			0.53
Have friends			0.61			0.54
Natural supports			0.61			0.44
Decide when to share personal information			0.40			0.47
Perform social roles			0.33			0.44
Choose where and with whom to live				0.84		0.66
Choose services				0.78		0.64
Choose where to work				0.48		0.42
Realize personal goals					0.84	0.56
Choose personal goals					0.70	0.49

Table 3

Descriptive Statistics of the Personal Outcome Measures®

Indicator	M
Factor 1: My Human Security	0.54
Are safe	0.81
Free from abuse and neglect	0.65
Best possible health	0.70
Treated fairly	0.57
Are respected	0.55
Continuity and security	0.49
Exercise rights	0.43
Factor 2: My Community	0.55
Interact with others in the community	0.61
Live in integrated environments	0.42
Participate in life in the community	0.51
Use environments	0.67
Factor 3: My Relationships	0.46
Intimate relationships	0.46
Have friends	0.43
Natural supports	0.47
Decide when to share personal information	0.51
Perform social roles	0.39
Factor 4: My Choices	0.29
Choose where and with whom to live	0.26
Choose services	0.29
Choose where to work	0.33
Factor 5: My Goals	0.51
Realize personal goals	0.57
Choose personal goals	0.46

Table 4

Demographic Characteristics by Average Factor Score

Description	Factor 1		Factor 2		Factor 3		Factor 4		Factor 5	
	M	SD	M	SD	M	SD	M	SD	M	SD
Age range										
18 to 24	0.50	0.27	0.46	0.34	0.46	0.34	0.30	0.36	0.60	0.37
25 to 34	0.54	0.24	0.61	0.33	0.47	0.32	0.34	0.35	0.62	0.39
35 to 44	0.54	0.26	0.56	0.36	0.47	0.33	0.30	0.37	0.50	0.39
45 to 54	0.55	0.25	0.58	0.36	0.45	0.30	0.29	0.35	0.47	0.39
55 to 64	0.56	0.23	0.55	0.34	0.45	0.31	0.27	0.32	0.47	0.42
65 to 74	0.57	0.26	0.56	0.33	0.43	0.32	0.30	0.33	0.47	0.42
75+	0.58	0.23	0.52	0.32	0.39	0.29	0.28	0.33	0.36	0.38
Disability										
Intellectual/developmental disability	0.53	0.25	0.56	0.35	0.43	0.32	0.24	0.32	0.47	0.40
Autism spectrum disorder	0.55	0.25	0.56	0.35	0.47	0.32	0.23	0.34	0.44	0.36
Cerebral palsy	0.51	0.27	0.48	0.38	0.40	0.30	0.21	0.32	0.41	0.40
Down syndrome	0.60	0.23	0.62	0.30	0.49	0.31	0.28	0.35	0.48	0.39
Seizure disorder/neurological problems	0.56	0.24	0.57	0.34	0.44	0.30	0.20	0.29	0.42	0.41
Mood disorder	0.50	0.24	0.58	0.34	0.43	0.31	0.21	0.30	0.50	0.38
Anxiety disorders	0.50	0.25	0.58	0.31	0.40	0.32	0.22	0.32	0.48	0.39
Behavioral challenges	0.51	0.24	0.56	0.34	0.46	0.34	0.20	0.28	0.48	0.39
Other mental illness/psychiatric diagnosis	0.51	0.26	0.55	0.35	0.46	0.31	0.33	0.35	0.51	0.39
Personality/psychotic disorder	0.52	0.24	0.59	0.36	0.43	0.30	0.22	0.31	0.53	0.38
Physical disability	0.57	0.24	0.52	0.35	0.46	0.29	0.17	0.27	0.45	0.40
Impulse-control disorder	0.53	0.23	0.64	0.34	0.47	0.34	0.20	0.28	0.55	0.40
Hearing loss - severe or profound	0.58	0.26	0.61	0.33	0.44	0.29	0.24	0.32	0.45	0.39
Limited or no vision - legally blind	0.62	0.22	0.57	0.37	0.55	0.29	0.26	0.39	0.45	0.42
Brain injury	0.42	0.23	0.45	0.40	0.34	0.36	0.26	0.31	0.55	0.38
Alzheimer's disease or other dementia	0.56	0.27	0.58	0.34	0.43	0.36	0.28	0.34	0.40	0.38
Eating disorder	0.51	0.24	0.43	0.37	0.38	0.35	0.17	0.32	0.40	0.39
Chemical dependency/substance abuse	0.50	0.25	0.63	0.38	0.46	0.38	0.50	0.42	0.60	0.46
Prader-Willi syndrome	0.55	0.35	-	-	-	-	-	-	-	-
Other disabilities not listed	0.59	0.25	0.57	0.37	0.54	0.34	0.48	0.40	0.71	0.37
Gender										
Man	0.56	0.24	0.58	0.34	0.47	0.32	0.31	0.36	0.52	0.40
Woman	0.51	0.26	0.53	0.36	0.44	0.31	0.29	0.34	0.50	0.41
Race										
White	0.54	0.25	0.55	0.34	0.45	0.32	0.30	0.35	0.52	0.40
Black or African American	0.57	0.24	0.63	0.36	0.49	0.33	0.32	0.26	0.49	0.40
American Indian or Alaska Native	0.57	0.27	0.49	0.37	0.49	0.32	0.51	0.37	0.66	0.43
Hispanic, Latinx, or Spanish	0.45	0.24	0.50	0.31	0.40	0.25	0.27	0.35	0.44	0.38

Origin										
Asian	0.43	0.32	0.25	0.24	0.27	0.29	0.17	0.33	0.38	0.43
Native Hawaiian or other Pacific Islander	-	-	-	-	-	-	-	-	-	-
Other	0.31	0.29	0.25	0.27	0.20	0.31	-	-	0.42	0.38
Primary method of communication										
Verbal/spoken language	0.53	0.25	0.57	0.34	0.46	0.32	0.32	0.35	0.54	0.40
Sign language	0.49	0.31	0.48	0.33	0.41	0.36	0.21	0.28	0.46	0.41
Communication device	0.63	0.25	0.50	0.41	0.53	0.28	0.22	0.33	0.47	0.44
Face/body expression	0.59	0.24	0.50	0.36	0.42	0.29	0.19	0.30	0.35	0.37
Other	0.62	0.21	0.63	0.32	0.46	0.32	0.18	0.30	0.50	0.42
Guardianship status										
Independent decision making	0.51	0.27	0.56	0.36	0.48	0.33	0.42	0.37	0.58	0.39
Assisted decision making (supported and limited guardianship)	0.56	0.24	0.61	0.34	0.46	0.31	0.20	0.29	0.46	0.39
Full/plenary guardianship	0.54	0.25	0.50	0.33	0.43	0.31	0.30	0.35	0.52	0.41
Other	0.51	0.23	0.51	0.38	0.42	0.34	0.25	0.33	0.53	0.43
Residence type										
Own home/apartment	0.54	0.24	0.69	0.30	0.47	0.33	0.44	0.40	0.58	0.41
Family's house	0.61	0.23	0.71	0.31	0.57	0.30	0.32	0.36	0.48	0.40
Host family/family foster care	0.55	0.26	0.71	0.32	0.42	0.32	0.13	0.24	0.59	0.42
Provider operated house or apartment	0.52	0.26	0.47	0.34	0.41	0.31	0.24	0.30	0.48	0.39
Private ICFDD	0.41	0.28	0.25	0.28	0.32	0.32	0.17	0.31	0.40	0.32
State operated HCBS group home	0.56	0.25	0.38	0.35	0.54	0.33	0.28	0.38	0.50	0.39
State operated ICFDD	0.52	0.24	0.48	0.31	0.56	0.33	0.26	0.32	0.85	0.28
Other	0.51	0.29	0.52	0.31	0.40	0.34	0.35	0.35	0.58	0.47
Daily support										
On call - support as needed	0.67	0.25	0.82	0.26	0.68	0.36	0.71	0.37	0.77	0.34
0 to 3 hours/day	0.54	0.25	0.78	0.28	0.61	0.28	0.62	0.32	0.78	0.32
3 to 6 hours/day	0.53	0.25	0.63	0.33	0.51	0.31	0.37	0.36	0.51	0.39
6 to 12 hours/day	0.62	0.22	0.70	0.30	0.54	0.30	0.37	0.37	0.49	0.41
12 to 23 hours/day	0.60	0.23	0.62	0.33	0.52	0.31	0.41	0.39	0.55	0.45
24/7 - around the clock	0.52	0.25	0.49	0.34	0.40	0.31	0.21	0.29	0.48	0.40
Other	0.50	0.27	0.62	0.34	0.54	0.34	0.50	0.38	0.64	0.38

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

Table 5

Reorganization of Indicators Between 2005 and 2017 Editions

Indicator	2017	2005
Are safe	My human security	My self
Free from abuse and neglect	My human security	My self
Best possible health	My human security	My self
Treated fairly	My human security	My self
Are respected	My human security	My dreams
Continuity and security	My human security	My self
Exercise rights	My human security	My self
Interact with others in the community	My community	My world
Live in integrated environments	My community	My world
Participate in life in the community	My community	My dreams
Use environments	My community	My world
Intimate relationships	My relationships	My self
Have friends	My relationships	My dreams
Natural supports	My relationships	My self
Decide when to share personal information	My relationships	My self
Perform social roles	My relationships	My world
Choose where and with whom to live	My choices	My world
Choose services	My choices	My world
Choose where to work	My choices	My world
Realize personal goals	My goals	My dreams
Choose personal goals	My goals	My dreams

Figure 1. Scree Plot.