Research Topics

Improving the quality of outcome measurement for adults with disabilities receiving community-based services

Edited by
Renata Ticha, Brian Abery and Jan Šiška

Published in
Frontiers in Rehabilitation Sciences

ISSN 1664-8714
ISBN 978-2-83252-185-4
DOI 10.3389/978-2-83252-185-4

About Frontiers

Frontiers is more than just an open access publisher of scholarly articles: it is a pioneering approach to the world of academia, radically improving the way scholarly research is managed. The grand vision of Frontiers is a world where all people have an equal opportunity to seek, share and generate knowledge. Frontiers provides immediate and permanent online open access to all its publications, but this alone is not enough to realize our grand goals.

Frontiers journal series

The Frontiers journal series is a multi-tier and interdisciplinary set of open-access, online journals, promising a paradigm shift from the current review, selection and dissemination processes in academic publishing. All Frontiers journals are driven by researchers for researchers; therefore, they constitute a service to the scholarly community. At the same time, the *Frontiers journal series* operates on a revolutionary invention, the tiered publishing system, initially addressing specific communities of scholars, and gradually climbing up to broader public understanding, thus serving the interests of the lay society, too.

Dedication to quality

Each Frontiers article is a landmark of the highest quality, thanks to genuinely collaborative interactions between authors and review editors, who include some of the world's best academicians. Research must be certified by peers before entering a stream of knowledge that may eventually reach the public - and shape society; therefore, Frontiers only applies the most rigorous and unbiased reviews. Frontiers revolutionizes research publishing by freely delivering the most outstanding research, evaluated with no bias from both the academic and social point of view. By applying the most advanced information technologies, Frontiers is catapulting scholarly publishing into a new generation.

What are Frontiers Research Topics?

Frontiers Research Topics are very popular trademarks of the *Frontiers journals series*: they are collections of at least ten articles, all centered on a particular subject. With their unique mix of varied contributions from Original Research to Review Articles, Frontiers Research Topics unify the most influential researchers, the latest key findings and historical advances in a hot research area.

Find out more on how to host your own Frontiers Research Topic or contribute to one as an author by contacting the Frontiers editorial office: frontiersin.org/about/contact

Improving the quality of outcome measurement for adults with disabilities receiving community-based services

Topic editors
Renata Ticha — University of Minnesota Twin Cities, United States
Brian Abery — University of Minnesota Twin Cities, United States
Jan Šiška — Charles University, Czechia

Citation
Ticha, R., Abery, B., Šiška, J., eds. (2023). *Improving the quality of outcome measurement for adults with disabilities receiving community-based services*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-83252-185-4

Table of contents

frontiers | Frontiers in Rehabilitation Sciences

TYPE Editorial
PUBLISHED 31 March 2023
DOI 10.3389/fresc.2023.1163522

Editorial: Improving the quality of outcome measurement for adults with disabilities receiving community-based services

Renáta Tichá[1]*, Brian Abery[1] and Jan Šiška[2]

[1]Institute on Community Integration, University of Minnesota Twin Cities, St. Paul, MN, United States,
[2]Faculty of Education, Charles University, Prague, Czechia

KEYWORDS

outcome measurement, service quality, quality of life, disability, community-based

Check for updates

OPEN ACCESS

EDITED AND REVIEWED BY
Reuben Escorpizo,
University of Vermont, United States

*CORRESPONDENCE
Renáta Tichá
✉ tich0018@umn.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 10 February 2023
ACCEPTED 07 March 2023
PUBLISHED 31 March 2023

CITATION
Tichá R, Abery B and Šiška J (2023) Editorial: Improving the quality of outcome measurement for adults with disabilities receiving community-based services.
Front. Rehabil. Sci. 4:1163522.
doi: 10.3389/fresc.2023.1163522

Editorial on the Research Topic
Improving the quality of outcome measurement for adults with disabilities receiving community-based services

Most of us, regardless of whether we have a disability, desire to live lives that are characterized as being of high quality. The extent to which people with disabilities are able to live the types of lives they desire is often far more dependent on the availability and effectiveness of the paid and unpaid support they receive from others than for the general population. The capacity to monitor the extent to which the quality of life of people with disabilities reflects their personal goals and dreams and is comparable to that of individuals without disabilities is critical if we are to understand the extent to which community-based services are doing what they are intended to do. Outcome measures are needed that are person-centered and longitudinal to assess various aspects of life as well as the quality of support service recipients receive. These measures need to be sufficiently sensitive to change that the impact of policy, funding, and programmatic changes on the outcomes people experience can be determined over time. They would also preferably have the capacity to be used with different disability populations who receive community support, including people with intellectual and developmental disabilities (IDD), physical disabilities, mental health challenges, traumatic brain injury (TBI)/acquired brain injury (ABI), and age-related conditions.

To be confident that outcome measures associated with community-based services can adequately assess both quality of services and the outcomes people with disabilities experience, data are needed with respect to their reliability, validity, and sensitivity to change. Indicators of quality and unmet support needs as directly perceived by service recipients must be considered paramount when developing, administering, and interpreting results based on these measures. Attempts to formulate frameworks to guide measure development and measure evaluation have not been restricted to the United States and have been underway in many countries for some time now. However, there has been limited collaboration between measure developers internationally.

This special issue of **Frontiers in Rehabilitation Sciences: Disability, Rehabilitation, and Inclusion** is designed to fill this gap in understanding the current landscape of measurement approaches used to assess the quality of services and life outcomes of adults with disabilities in the context of community-based services and support. In this special issue on *Improving the Quality of Outcome Measurement for Adults with Disabilities Receiving Community-Based Services*, we focus on different components and approaches to outcome measurement in 12 original articles from the United States and worldwide.

Utilizing a global perspective, Swenson provided a historical and philosophical context for outcome measurement targeting people with disabilities. She reminded us of the importance of measuring the outcomes from a human rights perspective, understanding that outcome measurement is inherently holoscopic or carefully focused on a certain aspect of the person's functioning or support and therefore in many ways biased.

Several articles highlighted the importance of measuring the quality of community-based services using specific outcome measures. Using data from the US-developed Personal Outcome Measures and Basic Assurances, Friedman investigated how the quality of service provision at different levels (individual, organizational, and environmental) contributes to personal outcomes people with IDD. Bradley and Hiersteiner provided a historical overview of the US-based National Core Indicators-IDD In Person Survey, a tool that most US states use to measure service quality and point out the need for periodic evaluation of such measures to determine their continued utility and validity.

In Ireland, Burke et al. reported on using the Personal Outcome Scale with people with intellectual disabilities (IDs) receiving services in community-based settings to examine the psychometric properties of the measures and the quality of life outcomes experienced by this population.

Articles from Norway, Germany, and the United States point to the shortcomings of the current outcome measurement approaches to service quality. Tøssebro et al. reported the results of their study in Norway on the motivations for outcome measurement, highlighting administrative needs and demands and the ambiguous impact of such measurement on service quality. Rohrmann and Schaedler discussed outcome measurement for people with disabilities in the context of Germany's rather rigid system of services and propose to conceptualize quality assessment as "local quality dialogues for collective learning." Riesen et al. pointed out the inadequacies of traditional outcome measures when assessing employment outcomes for people with the most significant disabilities.

Several articles provide concrete suggestions for modernizing and improving outcome measurement for people with disabilities. In the United States, Bogenschutz et al. reflected on their Virginia Costs and Outcomes Project to point out the importance of utilizing existing linked large datasets, using advanced data analytic techniques, and including the voices of people with disabilities themselves for a comprehensive measurement approach. Caldwell and Machledt made policy-guided recommendations on improving outcome measurement in the context of Home and Community Based Services (HCBS), including establishing a regular stakeholder input mechanism, improving the approach to data collection, and requiring transparent public reporting. Roberts and Abery discussed the historical absence of person-centered approaches to measuring the outcomes of people with disabilities, largely due to the application of the medical model to this population. They described the importance of and ways in which measures can and have recently been designed to reflect the person's experiences with and perspectives on their services and life outcomes.

Two articles take on specific topics within the theme of outcome measurement. Beadle-Brown et al. reported on the results of their mapping of outcome measures of service quality onto transition domains for youth with disabilities. Houseworth et al. discussed the role of risk adjustment in HCBS outcome measurement, identified commonly used risk adjustors, and proposed risk adjustors for consideration when measuring the outcomes of people with disabilities to increase measurement precision.

The topics of this special issue were authored by professionals with extensive experience in policy and practice across different service systems and contributed to the field of outcome measurement in several ways. Some articles focused on defining service quality and the life outcomes people with disabilities experience as part of a broader community. Other articles provided a historical, geographic, and/or policy context for outcome measurement and pointed to existing issues and areas for needed improvement. These include the need for person-centered measures , are capable of being used longitudinally and have adequate sensitivity to change, can be used with multiple disability populations, and possess sufficient psychometric precision (i.e., reliability and validity) to be used in the context of their intended decision-making contexts, and minimize bias.

Author contributions

RT is the issue co-editor and a corresponding author. She has worked with the other two co-editors on conceptualizing and editing articles in this special issue. She has co-authored the editorial. BA is the issue co-editor. He has worked with the other two co-editors on conceptualizing and editing articles in this special issue. He has co-authored the editorial. JŠ is the issue co-editor. He has worked with the other two co-editors on conceptualizing and editing the article in this special issue. He has co-authored the editorial. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's Note

frontiers in Rehabilitation Sciences

ORIGINAL RESEARCH
published: 17 January 2022
doi: 10.3389/fresc.2021.780168

The Impact of Human Service Provider Quality on the Personal Outcomes of People With Intellectual and Developmental Disabilities

Carli Friedman*

The Council on Quality and Leadership (CQL), Towson, MD, United States

Background: Quality of life is multidimensional—influenced by individual, organizational, and environmental factors. As such, when examining personal outcomes, it is also important to consider meso and macro factors that contribute to people with intellectual and developmental disabilities' (IDD's) quality of life. While it is widely acknowledged that organizational factors contribute to people's quality of life, there is less research directly examining how the *quality* of human service providers contributes to people with IDD's personal outcomes. For these reasons, the aim of this study was to explore the relationship between provider quality and people with IDD's personal quality of life outcomes.

Methods: Using a multilevel linear regression we analyzed secondary Personal Outcome Measures® (personal outcomes) and Basic Assurances® (provider quality) data from 2,900 people with IDD served by 331 human service providers.

Results: People with IDD's personal outcomes, regardless of their support needs or other demographics, were significantly impacted by the quality of the human service providers they received services from—the higher the quality of the provider, the more personal outcomes they had present. In addition, the following demographic covariates were correlated with personal outcomes: gender; race; complex support needs; residence type; and organizations that offered therapy services.

Discussion: While quality improvement initiatives may require a great deal of cost and time commitment from providers, our findings suggest the effort translates to improved personal outcomes among people with IDD. The ultimate goal of service providers should be improvement of quality of life among those they support.

Keywords: people with intellectual and developmental disabilities, personal outcomes, quality of life, quality improvement, human service providers

Edited by:
Renata Ticha,
University of Minnesota Twin Cities,
United States

Reviewed by:
Daniel Mont,
Center for Inclusive Policy,
United States
Roger Stancliffe,
University of Minnesota Twin Cities,
United States

***Correspondence:**
Carli Friedman
cfriedman@thecouncil.org

Specialty section:
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

Received: *20 September 2021*
Accepted: *03 December 2021*
Published: *17 January 2022*

Citation:
Friedman C (2022) The Impact of Human Service Provider Quality on the Personal Outcomes of People With Intellectual and Developmental Disabilities.
Front. Rehabilit. Sci. 2:780168.
doi: 10.3389/fresc.2021.780168

BACKGROUND

Quality of life is based on "common human experiences and unique, individual life experiences" [(1), p. 462] while also giving "sense of reference and guidance from the individual's perspective, focusing on the person and the individual's environment" [(2), p. 2]. Disability quality of life measures were originally developed to examine the "burden" of disabilities (3); however, in recognition that the person, family, community, and society all impact quality of life, disability quality of life measures have since broadened to examine physical, material, and emotional well-being, relationships, personal development, rights, inclusion, and self-determination (4). As such, in contrast to process measures that often focus on compliance and regulations, disability quality of life measures should focus on an individualized person-centered definition of quality of life, also called personal outcomes (5). In fact, the Centers for Medicare and Medicaid Services (CMS) reinforced the importance of personal outcomes with the implementation of the Medicaid HCBS settings rule (CMS 2249-F/2296-F); CMS (6) explained, the HCBS Settings Rule would "establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics" (p. 2).

Quality of life is multidimensional—influenced by individual, organizational, and environmental factors (7–10). Therefore, it is important when examining personal outcomes to also consider meso and macro factors that contribute to people with intellectual and developmental disabilities' (IDD's) quality of life. In fact, Simões and Santos (7) note, "it can be said that quality of life may have less to do with a presence of an ID [intellectual disability] and more to do with the opportunities that improve individual's participation in community-based settings. Thus, the supports have a crucial influence on individual's quality of life" (p. 391).

Organizational characteristics and factors, related to the services people with IDD receive and their human service provider/s, contribute to people with IDD's quality of life (10, 11). Examples of organizational factors that can impact people with IDD's personal outcomes include: staff qualifications, satisfaction, leadership, and turnover; residence types and sizes; day activities; organizational culture; person-centered practices; organization size; and locations of service delivery (7, 8, 11, 12). For example, Claes and Van Hove (10) found when staff involved, included, and empowered people with ID, their personal outcomes improved. Moreover, Gómez et al. (8) found differences in personal outcomes among people with disabilities based on not only their individual characteristics, but also the types of services they received. In addition, Flynn et al.'s (11) meta-analysis revealed Active Support—staff training about engagement, independence, and self-determination—lead to increases in the overall engagement of people with ID.

In fact, quality IDD services can be defined by the degree to which human service organizations promote and maximize personal outcomes (5, 13, 14). While quality IDD services used to be defined in relation to compliance, regulatory standards, and organizational processes, there has since been a shift to recognizing quality as "responsiveness to people's outcomes… [and] the continuous discovery and fulfillment of [people with IDD's] needs and desires" [(13), p. 295–300]. Moreover, the United States Department of Health and Human Services notes, "Quality is directly linked to an organization's service delivery approach or underlying systems of care… resources (*inputs*) and activities carried out (*processes*) are addressed together to ensure or improve quality of care (*outputs/outcomes*)" [emphasis original; (14), p. 1].

While it is widely acknowledged that organizational factors contribute to people with IDD's quality of life (4, 7–9, 13), to our knowledge, there is little research *directly* examining how the quality of human service providers contributes to people with IDD's quality of life—their personal outcomes. For these reasons, the aim of this study was to explore the relationship between human service provider quality and personal quality of life outcomes of people with IDD. To do so, we analyzed data from 2,900 people with IDD served by 331 human service providers.

MATERIALS AND METHODS

Data and Participants

This was a secondary data analysis. All data were originally collected from between January 2015 to August 2021 from organizations that provide services to people with IDD, including: residential services; employment and other work/day services; family and individual supports; behavioral health care; service coordination; case management; non-traditional supports (micro-boards and co-ops); and human services systems. The data included 2,900 people with IDD served by 331 human service providers.

Two levels of data were included in the study: level 1 was individual people with IDD, while level 2 was human service providers. In terms of level 1, the average age of people with IDD was 44.79 ($SD = 16.26$; **Table 1**). Slightly more than half of the people with IDD were men (54.7%). Most participants were White (75.7%) and communicated primarily through verbal/spoken language (84.7%). The most common form of decision-making authority (guardianship) was full/plenary guardianship (41.9%), with fewer people having independent decision-making (32.4%), assisted decision-making (22.9%), or other forms of decision-making (2.7%). In terms of complex support needs, 9.3% of people with IDD had complex medical support needs (12+ h of skilled nursing care), 18.2% comprehensive behavior support needs (24-h supervision due to risk of harm), and 7.0% *both* support needs. About half of participants (47.5%) lived in provider owned- or operated-homes; the next most common settings were their own home (22.5%), and family homes (16.6%).

In terms of level 2 demographics, the 331 providers supported an average of 796.52 unduplicated people ($SD = 1{,}163.32$). About half (51.8%) provided services in *both* urban and rural areas, 34.1% in only rural areas, and 14.0% only urban areas. The most common types of services they provided were: community-based employment (85.6%); staffed residential supports (76.3%); community-based day activities (69.6%); and, in-home supports (66.6%). All of the individual (level 1) and provider (level 2) demographic variables served as covariates in the analyses.

Measures and Variables

Personal Outcomes: Personal Outcome Measures® (Level 1: Individual)

Data about people with IDD's quality of life—their personal outcomes—came from the Personal Outcome Measures® (15).

TABLE 1 | Demographics.

Characteristics	*n*	%
Individuals (level 1; *n* = 2,900)		
Age [*n* = 2,369; *M* (*SD*)]	44.79 (16.26)	
Gender (*n* = 2,870)		
Man	1,570	54.7%
Woman	1,300	45.3%
Primary communication method (*n* = 2,870)		
Verbal/spoken language	2,438	84.7%
Other	441	15.3%
Decision-making authority (*n* = 2,851)		
Independent decision-making	925	32.4%
Assisted decision-making	653	22.9%
Full/plenary guardianship	1,195	41.9%
Other	78	2.7%
Race (*n* = 2,864)		
White	2,168	75.7%
Indigenous	82	2.9%
Asian	15	0.5%
Black	507	17.7%
Latinx	60	2.1%
Other	12	0.4%
Multiracial	20	0.7%
Complex support needs (*n* = 2,509)		
None	1,643	65.5%
Complex medical support needs	234	9.3%
Comprehensive behavior support needs	456	18.2%
Both	176	7.0%
Residence (*n* = 2,848)		
Provider owned/operated home	1,352	47.5%
Own home	642	22.5%
Family's home	473	16.6%
Host home or family foster care	102	3.6%
State HCBS group home	73	2.6%
State ICF/DD	27	0.9%
Private ICF/DD	70	2.5%
Nursing home	17	0.6%
Other	92	3.2%
Providers (level 2; *n* = 331)		
Unduplicated number of people supported [*n* = 299; *M* (*SD*)]	796.52 (1,163.32)	
Geographic region (*n* = 299)		
Urban only	42	14.0%
Rural only	102	34.1%
Both urban and rural	155	51.8%
Services provided		
Behavior support services (*n* = 299)	136	45.5%
Therapies (e.g., psychology, physical therapy, occupational therapy, speech/language; *n* = 299)	113	37.8%
Staffed residential supports (*n* = 299)	228	76.3%
Host home, family foster care, or companion home (*n* = 299)	81	27.1%
In-home supports (own home or family home; *n* = 299)	199	66.6%
Community-based employment (*n* = 299)	256	85.6%
Community-based day activities (*n* = 299)	208	69.6%
In-home day activities (*n* = 299)	132	44.1%
Facility-based work/day activities (*n* = 299)	161	53.8%
Respite care (*n* = 299)	149	49.8%
Recreational activities (*n* = 299)	110	36.8%
Transportation activities (*n* = 299)	172	57.5%
Independent support coordination (*n* = 299)	52	17.4%

The Personal Outcome Measures® is a validated, person-centered quality of life tool (16). The Personal Outcome Measures® was developed in 1993 based on focus groups with people with disabilities, family members, and other key stakeholders about what really mattered in people with disabilities' lives. The tool has since been refined through pilot testing, commission of research and content experts, a Delphi survey, feedback from advisory groups, validity and reliability testing, and 30 years of administration (13, 15, 16). For example, the most recent validity testing used a principal component analysis to indicate construct validity and internal consistency (16). In addition, interviewers are required to pass interrater reliability tests with expert interviewers with scores of 85% or higher before being certified to conduct interviews.

The most recent version of the Personal Outcome Measures® (2017) includes 21 indicators (areas of quality of life; see **Table 2**) organized into five factors: My Human Security; My Community; My Relationships; My Choices; and, My Goals. Personal Outcome Measures® administration occurs in three stages. During the first stage, a certified reliable interviewer has an in-depth conversation with the person with IDD about each of the indicators, following specific open-ended prompts. Next, the interviewer speaks with someone who knows the person with IDD well and knows about their organizational supports, and asks them questions about individualized supports and outcomes to fill in any gaps. In the third and final stage, the interviewer may participate in observations or conduct record reviews if needed; otherwise, they complete decision trees [see The Council on Quality and Leadership (15) for decision-trees] based on all information gathered to determine if outcomes are present (1) or not (0). The 21 different indicators are then summed to represent the total number of personal outcomes present for each person with IDD.

Provider Quality: Basic Assurances® (Level 2: Organizational)

Data regarding the quality of human service providers came from the Basic Assurances® (17). The Basic Assurances® is an organizational assessment of non-negotiable requirements for service and support providers, including health, safety, and

TABLE 2 | Quality indicators.

Personal Outcome Measures® Indicators	Basic Assurances® Indicators
My human security	**Rights protection and promotion**
People are safe	The organization implements policies and procedures that promote people's rights
People are free from abuse and neglect	The organization supports people to exercise their rights and responsibilities
People have the best possible health	Staff recognize and honor people's rights
People experience continuity and security	The organization upholds due process requirements
People exercise rights	Decision-making supports are provided to people as needed
People are treated fairly	**Dignity and respect**
People are respected	People are treated as people first
My community	The organization respects people's concerns and responds accordingly
People use their environments	People have privacy
People live in integrated environments	Supports and services enhance dignity and respect
People interact with other members of the community	People have meaningful work and activity choices
People participate in the life of the community	**Natural support networks**
My relationships	Policies and practices facilitate continuity of natural support systems
People are connected to natural supports	The organization recognizes emerging support networks
People have friends	Communication occurs among people, their support staff and their families
People have intimate relationships	The organization facilitates each person's desire for natural supports
People decide when to share personal information	**Protection from abuse, neglect, mistreatment and exploitation**
People perform different social roles	The organization implements policies and procedures that define, prohibit and prevent abuse, neglect, mistreatment and exploitation
My choices	
People choose where and with whom to live	People are free from abuse, neglect, mistreatment and exploitation
People choose where to work People choose services	The organization implements systems for reviewing and analyzing trends, potential risks and sentinel events including allegations of abuse, neglect, mistreatment and exploitation, and injuries of unknown origin and deaths
My goals	Support staff know how to prevent, detect and report allegations of abuse, neglect, mistreatment and exploitation
People choose personal goals People realize personal goals	The organization ensures objective, prompt and thorough investigations of each allegation of abuse, neglect, mistreatment and exploitation, and of each injury, particularly injuries of unknown origin
	The organization ensures thorough, appropriate and prompt responses to substantiated cases of abuse, neglect, mistreatment and exploitation, and to other associated issues identified in the investigation
	Best possible health
	People have supports to manage their own health care
	People access quality health care
	Data and documentation support evaluation of health care objectives and promote continuity of services and supports
	Acute health needs are addressed in a timely manner
	People receive medications and treatments safely and effectively
	Staff immediately recognize and respond to medical emergencies
	Safe environments
	The organization provides individualized safety supports
	The physical environment promotes people's health, safety and independence
	The organization has individualized emergency plans
	Routine inspections ensure that environments are sanitary and hazard free
	Staff resources and supports
	The organization implements a system for staff recruitment and retention
	The organization implements an ongoing staff development program
	The support needs of individuals shape the hiring, training and assignment of all staff
	The organization implements systems that promote continuity and consistency of direct support professionals
	The organization treats its employees with dignity, respect and fairness
	Positive services and supports
	People's individual plans lead to person-centered and person-directed services and supports
	The organization provides continuous and consistent services and supports for each person
	The organization provides positive behavioral supports to people

(Continued)

TABLE 2 | Continued

Personal Outcome Measures® Indicators	Basic Assurances® Indicators
	The organization treats people with psychoactive medications for mental health needs consistent with national standards of care
	People are free from unnecessary, intrusive interventions
	Continuity and personal security
	The organization's mission, vision and values promote attainment of personal outcomes
	The organization implements sound fiscal practices
	Business, administrative and support functions promote personal outcomes
	The cumulative record of personal information promotes continuity of services
	Basic assurances system
	The organization monitors Basic Assurances
	A comprehensive plan describes the methods and procedures for monitoring Basic Assurances

Basic Assurances® indicators are measured both in terms of systems and practices, resulting in 92 total datapoints.

human security metrics; the "*Basic Assurances*® looks at the provision of safeguards from the person's perspective. While the *Basic Assurances*® contain requirements for certain systems and policies and procedures, the effectiveness of the system or the policy is determined in practice, person by person" [(17), p. 8].

The Basic Assurances® was developed in 1971 (originally called "Standards for Services") based on feedback from practitioners, providers, government personnel, advocacy organizations, people with disabilities, and parents about high quality service standards. Since then, it has undergone numerous revisions based on reviews by experts, pilot testing, a Delphi survey, development of a conceptual framework, stakeholder interviews, and 50 years of administration (17–20). To promote reliability, reviewers are required to pass interrater reliability tests with expert reviewers with scores of 85% or higher.

The most recent version of the Basic Assurances® (2015) contain 10 factors: Rights Protection and Promotion; Dignity and Respect; Natural Support Networks; Protection from Abuse, Neglect, Mistreatment and Exploitation; Best Possible Health; Safe Environments; Staff Resources and Supports; Positive Services and Supports; Continuity and Personal Security; and, Basic Assurances® System (a quality assurances monitoring system). Within the 10 factors are 46 different sub-topics, called indicators. For each of the 46 indicators (**Table 2**), both the *system*—"organizational supports that provide the structure for organizational practice" (e.g., policies and procedures)—and actual *practice*—"what is observed in daily operations... how an organization's supports are put into action" (i.e., implementation)—are examined and measured [(17), p. 9]; as a result, the total possible number of indicators present for a provider is 92.

To determine if systems and practices are present for each indicator, expert reviewers collect a number of data points. Sources of data include: interviews with organizational leadership; interviews with people with IDD; focus groups with people with IDD; focus groups with direct support professionals; reviews of the providers' data and records; reviews of organizational policies and regulations; and, observations of a variety of the provider's settings. Using all of these data, the expert reviewers, often working in teams of 2–4 for interrater reliability, determine if each of the indicators are present (1) or not (0) for each system and each practice [see The Council on Quality and Leadership (17) for probes for each indicator]. The 92 different indicator items are then summed to represent the total provider quality for each provider.

Analyses

We first analyzed descriptive statistics (missing data were excluded from all analyses.). Then, to examine the impact of provider quality on the personal outcomes of people with IDD, we used a multilevel linear regression (linear mixed model; all assumptions were met). This method was used to account for the nested structure of the data between individuals with IDD (level 1; $n = 2{,}900$) and providers (level 2; $n = 331$). We first ran an intercept-only unconditional (null) model with only the total personal outcomes from the Personal Outcome Measures® serving as the primary outcome and the random intercept to examine variation in personal outcomes by providers; maximum likelihood estimation was used. In the second model, we entered all demographic variables—the covariate individual-level and provider-level demographic variables were added as fixed-effects. In the third and final model, provider quality from the Basic Assurances® was also added as a fixed-effect variable. Intraclass correlation coefficients (ICCs) were calculated for each model to indicate variance in personal outcomes attributed to different providers; ICC were calculated by dividing the intercept variance by the sum of the intercept and residual variance. Cohen's f^2 was calculated (21) for effect size for the final model.

RESULTS

Descriptive Statistics

The people with IDD in the study had an average of 9.85 out of 21 possible personal outcomes present ($SD = 5.09$). Of people with IDD, 1.5% had 0 outcomes present, 18.8% between 1 and 5 outcomes, 34.8% between 6 and 10 outcomes, 27.9% between 11 and 15 outcomes, 13.9% between 16 and 20 outcomes, and 3.1% all 21 outcomes. Providers in the study had an average

TABLE 3 | The impact of organizational quality on personal outcomes: multilevel linear regression models.

Predictors	Model 1: null model	Model 2: demographic model [B (95% CI)]	Model 3: provider quality [B (95% CI)]
Fixed effects			
Intercept		11.07 (9.21–12.94)***	5.93 (2.96–8.90)***
Individual (level 1)			
Age		−0.001 (−0.01 to 0.01)	−0.006 (−0.02 to 0.007)
Woman (ref: man)		−0.66 (−1.03 to −0.28)***	−0.61 (−1.02 to −0.20)**
Primary communication method: other (ref: verbal/spoken language)		−0.18 (−0.72 to 0.36)	−0.16 (−0.76 to 0.45)
Decision-making authority (ref independent decision-making)			
Assisted decision-making		−0.71 (−1.20 to −0.23)**	−0.90 (−1.43 to −0.36)**
Full/plenary guardianship		−0.15 (−0.67 to 0.38)	−0.15 (−0.73 to 0.42)
Other		−0.51 (−1.63 to 0.61)	−0.54 (−1.77 to 0.68)
Race (ref: white)			
Indigenous		−1.42 (−2.59 to −0.24)*	−1.16 (−2.55 to 0.24)
Asian		−2.90 (−5.52 to −0.28)*	−1.40 (−4.32 to 1.53)
Black		−0.50 (−1.04 to 0.03)	−0.45 (−1.02 to 0.11)
Latinx		−0.07 (−1.57 to 1.44)	−0.16 (−1.73 to 1.40)
Other		−1.11 (−4.08 to 1.85)	−2.04 (−5.28 to 1.20)
Multiracial		−2.44 (−4.55 to −0.34)*	−2.37 (−4.64 to −0.09)*
Complex support needs (ref: none)			
Complex medical support needs		−0.36 (−1.02 to 0.30)	−0.31 (−1.03 to 0.41)
Comprehensive behavior support Needs		−0.99 (−1.52 to −0.46)***	−1.01 (−1.58 to −0.44)***
Both		−0.82 (−1.60 to −0.03)*	−0.83 (−1.66 to −0.01)*
Residence (ref: provider owned/operated home)			
Own home		1.90 (1.36–2.45)***	1.60 (0.98–2.22)***
Family's home		1.50 (0.88–2.11)***	1.44 (0.78–2.10)***
Host home or family foster care		2.51 (1.46–3.55)***	2.48 (1.32–3.63)***
State HCBS group home		−0.97 (−3.19 to 1.25)	−0.87 (−3.08 to 1.35)
State ICF/DD		0.28 (−1.15 to 1.70)	0.004 (−1.48 to 1.49)
Private ICF/DD		−2.49 (−5.26 to 0.27)	−1.73 (−4.95 to 1.49)
Nursing home		0.66 (−0.56 to 1.87)	0.58 (−0.68 to 1.83)
Other		0.41 (−0.87 to 1.68)	−0.06 (−1.47 to 1.35)
Provider (level 2)			
Unduplicated total number of people supported		−0.0004 (−0.0008 to 0.0001)	−0.0004 (−0.00008 to 0.00007)
Geographic region (ref: urban only)			
Rural only		−1.05 (−2.30 to 0.20)	−0.64 (−1.82 to 0.55)
Both urban and rural		−0.34 (−1.73 to 1.05)	−0.35 (−1.64 to 0.94)
Services provided			
Behavior support services (ref: no)		−0.26 (−1.56 to 1.03)	−0.39 (−1.63 to 0.85)
Therapies (ref: no)		1.06 (−0.26 to 2.39)	1.49 (0.26 to 2.72)*
Staffed residential supports (ref: no)		−0.58 (−1.80 to 0.63)	−0.57 (−1.72 to 0.57)
Host home, family foster care, or companion home (ref: no)		−0.25 (−1.52 to 1.03)	−0.57 (−1.76 to 0.61)
In-home supports (own home or family home) (ref: no)		0.62 (−0.47 to 1.71)	0.31 (−0.70 to 1.32)
Community-based employment (ref: no)		0.42 (−0.89 to 1.72)	−0.03 (−1.27 to 1.20)
Community-based day activities (ref: no)		−0.86 (−2.38 to 0.66)	0.21 (−1.27 to 1.70)
In-home day activities (ref: no)		−0.62 (−1.74 to 0.50)	−0.72 (−1.77 to 0.33)
Facility-based work/day activities (ref: no)		−0.25 (−1.41 to 0.91)	0.15 (−0.98 to 1.29)
Respite care (ref: no)		−0.05 (−1.15 to 1.04)	−0.44 (−1.46 to 0.58)
Recreational activities (ref: no)		−0.17 (−1.38 to 1.04)	−0.59 (−1.73 to 0.56)
Transportation activities (ref: no)		0.43 (−0.78 to 1.64)	0.28 (−0.83 to 1.39)
Independent support coordination (ref: no)		0.57 (−0.77 to 1.90)	−0.01 (−1.28 to 1.25)
Basic Assurances®: Total present			0.07 (0.04–0.11)***

(Continued)

TABLE 3 | Continued

Predictors	Model 1: null model	Model 2: demographic model [B (95% CI)]	Model 3: provider quality [B (95% CI)]
Random effects			
Variance (intercept)	9.83 (7.85–12.30)	9.04 (7.04–11.60)	5.61 (4.12–7.64)
Variance (residual)	18.29 (17.32–19.31)	16.94 (15.91–18.05)	17.92 (16.75–19.18)
χ^2 (1)	823.42***	511.00***	271.30***
ICC	0.35 (0.31–0.39)	0.35 (0.31–0.39)	0.24 (0.20–0.28)
Cohen's f^2			0.05
***N* (people with IDD)**	2,838	2,146	1,848

**p < 0.05. **p < 0.01. ***p < 0.001.*

of 69.71 out of 92 possible total Basic Assurances® indicators present (*SD* = 11.66). Of the providers, 3.5% had between 30 and 42 indicators present, 10.1% between 43 and 55 indicators, 31.6% between 56 and 68 indicators, 39.7% between 69 and 81 indicators, and 15.1% between 82 and 92 indicators.

The Relationship Between Provider Quality and People's Personal Outcomes

To explore if personal outcomes differed depending on provider quality, linear multilevel models were utilized. In the first unconditional (null) model, which was calculated without any covariates, the ICC indicated 35.0% of the total variation in personal outcomes is attributed to differences between providers (**Table 3**).

Model 2 incorporated the individual-level and provider-level demographic characteristics (**Table 3**). After adjusting for demographic covariates, the variation in intercepts between providers (ICC) was 34.7%. A number of demographic covariates were significant. Controlling for all other demographic characteristics, women with IDD had fewer personal outcomes present (10.41) than men with IDD (11.07). Controlling for all other variables, people with IDD with assisted decision-making had fewer personal outcomes present (10.36) than people with IDD with independent decision-making (11.07). Controlling for all other variables, Indigenous (9.95), Asian (8.17), and multiracial (8.63) people with IDD had fewer outcomes present than White people with IDD (11.07). Controlling for all other variables, people with IDD with comprehensive behavior support needs (10.08) and *both* complex medical support needs and comprehensive behavior support needs (10.25) had fewer personal outcomes present than people with IDD without any complex support needs (11.07). Controlling for all other variables, compared to people with IDD who lived in provider owned- or operated-homes (11.07), people with IDD who lived in their own home (12.97), family homes (12.57), and host homes or family foster care (13.58) had more personal outcomes present.

Model 3 incorporated provider quality metrics (total Basic Assurances®; **Table 3**). After adjusting for provider quality in Model 3, the variation in intercepts between providers (ICC) reduced to 23.8%, suggesting provider quality partly explains the variation in personal outcomes of people with IDD. The model indicated the more Basic Assurances® indicators their providers had present, the more personal outcomes people with IDD had present—the better the quality of their provider, the better people with IDD's quality of life. For every one Basic Assurance indicator present (out of 92), people with IDD's quality of life increased by 0.07, regardless of their or their providers' demographics (**Figure 1**). For example, controlling for all individual and provider demographics, a person with IDD served by a provider with a score of 35 on the Basic Assurances® is expected to have 8.5 personal outcomes present (out of 21; 40.3%). Whereas, a person with IDD served by a prover with a score of 70 on the Basic Assurances is expected to have 11.0 personal outcomes present (52.4%).

In addition to provider quality, several demographic covariates were also significant in Model 3. Controlling for all other variables, including provider quality, women with IDD had fewer personal outcomes present (5.32) than men with IDD (5.93). Controlling for all other variables, people with IDD with assisted decision-making had fewer personal outcomes present (5.03) than people with IDD with independent decision-making (5.93). Controlling for all other variables, multiracial people with IDD had fewer outcomes present (3.56) than White people with IDD (5.93). Controlling for all other variables, compared to people without complex support needs (5.93), people with IDD with comprehensive behavior support needs (4.92), and people with both complex medical *and* comprehensive behavior support needs (5.10) had fewer personal outcomes present. Controlling for all other variables, compared to people with IDD who lived in provider owned- or operated-homes (5.93), people with IDD who lived in their own home (7.53), family homes (7.37), and host homes or family foster care (8.41) had more personal outcomes present. Controlling for all other variables, people with IDD who received services from providers that offered therapy services had more outcomes present (7.42) than people with IDD who received services from providers that did not offer therapy services (5.93).

DISCUSSION

Reinders and Schalock (22) recognize, "quality of life… equals the actualization of discovered potentialities" (p. 293). People

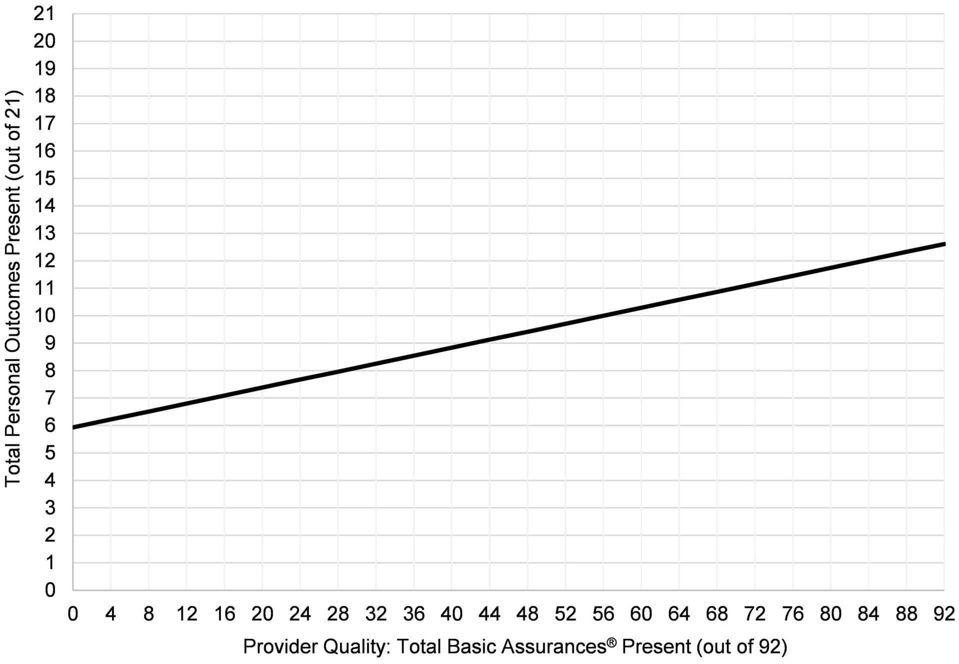


FIGURE 1 | The relationship between provider quality and people with IDD's personal outcomes. Model controls for individual and provider demographics.

with IDD's quality of life is significantly impacted by micro, meso, and macro factors; individual, organizational, and systemic factors simultaneously impact people with IDD's experiences and lives (23). As such, it is important to not only draw attention to people with IDD's personal outcomes, but also the organizational supports they receive to promote those outcomes (3). For these reasons, the aim of this study was to examine the relationship between human service provider quality and people with IDD's personal quality of life outcomes. To do so, we conducted a multilevel linear regression with data from 2,900 people with IDD supported by 331 human service providers. Our findings not only mirror past research which indicates that organizational factors—in additional to individual factors—impact people with IDD's quality of life (10, 22), but also suggest that provider quality *in particular* plays a significant role in people with IDD's personal outcomes.

People with IDD's personal outcomes, regardless of their support needs or other demographics, are significantly impacted by the human service providers they receive services from, and the quality of those providers. As such, provider quality improvement initiatives can significantly improve people with IDD's quality of life. While quality services are multidimensional, people with IDD will not have quality outcomes without a number of foundational elements, including safety, health, and protection from abuse, neglect, and exploitation. Attending to health and safety is particularly important as people with IDD not only face disparities in health, but are also significantly more likely to experience abuse, neglect, mistreatment, and exploitation (24, 25).

Yet, while health and safety are important, they alone do not represent quality services or equal quality of life. Quality services must aim higher than compliance and regulations related to health and safety; instead, quality service provision for people with IDD moves beyond custodial models of care, toward one of a culture that is person-centered, balances duty to care with dignity of risk, promotes informed choice, and honors people with IDD's rights. Provider quality hinges on its commitment to services and supports being responsive to the person—person-centered services and supports. According to self-advocates, "making choices and decisions… 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?" [(26), p. 65]. Therefore, to ensure services are truly person-centered, providers must have high expectations for all people and ensure people with IDD not only have choices, but also that those choices are informed choices. Informed choice requires people have a variety of life experiences and array of options to choose from.

People with IDD in our study also had better outcomes when their provider offered therapy services (e.g., psychology, occupational therapy, physical therapy, speech language pathology, etc.) as part of the service menu. This finding requires further research, especially as our data did not have information if people with IDD were receiving therapy services or which therapy services they were receiving; we believe it would be especially fruitful to explore if this relationship may be related to trauma-informed care practices. Trauma-informed care not only recognizes a significant number of people with IDD face and experience trauma, but also works to create a "culture that emphasizes safety, trustworthiness, choice, collaboration, and empowerment among service providers and service recipients" [(27), p. 37].

In addition, quality services cannot be provided without adequate and efficient business acumen and processes of human services providers; financial stability of providers is paramount as instability is one of the leading reasons for provider collapse (28). Furthermore, a lack of a consistent and well-trained workforce is a threat to organizational quality, quality improvement initiatives, and, ultimately, the personal outcomes of people with IDD (29).

Demographic Characteristics and Personal Outcome Disparities

In addition to provider quality, there were a number of individual factors that impacted people with IDD's personal outcomes, which suggests a need for targeted supports. For example, people with assisted decision-making had fewer personal outcomes present than those with independent decision-making. Moreover, women with IDD had fewer outcomes present than men with IDD; this finding mirrors past research which has found women with disabilities, including IDD, experience disparities in quality of life compared to men with disabilities (8) due to the interaction between ableism and sexism. In our study, multiracial people with IDD also had fewer outcomes present than White people with IDD. In fact, controlling for all other variables, multiracial people with IDD only had 16.9% of personal outcomes present on average. Targeted supports are needed for multiracial people with IDD to counter the systemic inequities they face (30).

People with complex support needs—those with comprehensive behavior support needs, and those with complex medical support needs *and* comprehensive behavior support needs—also had disparities in personal outcomes compared to people without these needs. Past research has suggested that the disparities people with higher support needs face are in large part due to a lack of individualized person-centered organizational supports (31). Problematically, a lack of adequate supports and community infrastructure for people with higher support needs often results in re/institutionalization (32).

In addition, there were a number of differences in people with IDD's quality of life based on where they lived. Regardless of support needs, people with IDD had significantly better outcomes when they lived in their own homes, family homes, and host homes/family foster care than in provider owned- or operated-homes. These findings mirror past research about the advantages of these settings, even compared to other community-based settings (7, 33). In fact, in our study, these settings produced better outcomes even when the quality of the providers was controlled. Those settings people with IDD prefer—individualized settings, like their own homes or family homes, rather than congregate settings, such as group homes and institutions—are also the ones that produce the best outcomes (33). As such, providers should make efforts to ensure people with IDD are able to live in individualized settings, should people with IDD wish to do so.

LIMITATIONS

When interpreting the findings of this study, a number of limitations should be noted. This was a secondary data analysis; as such, we did not have the ability to ask participants follow-up questions or add additional variables. There was a large amount of missing data among the variables, which represents a limitation. There may be other individual or organizational factors which were not explored which may impact people with IDD's quality of life. In addition, while it was outside of the scope of this study, there may also be state or regional factors that impacted people's personal outcomes (9). During the COVID-19 pandemic, the use of virtual data collection was more prevalent; the impact of which is unknown and thus represents a limitation of this study. We did not explore interactions in this study. Finally, it should be noted that this is a cross-sectional, correlational study; as such, no causal relationships have been demonstrated.

CONCLUSION

People with IDD face a number of disparities in quality of life compared to other populations, largely due to systemic inequities and social determinants of health (25). In this study we found people with IDD who were served by higher quality providers had significantly more personal outcomes present, regardless of their demographics or complex support needs. While quality improvement initiatives may require a significant investment of both time and financial resources from providers (5), our findings suggest the efforts translate to improved personal outcomes among people with IDD. The quality of life of people with IDD demands quality person-centered services and supports. The ultimate goal of service providers should be improvement of quality of life among those they support.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary materials, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

REFERENCES

1. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retard.* (2002) 40:457–70. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
2. Brown RI, Schalock RL, Brown I. Quality of life: Its application to persons with intellectual disabilities and their families—Introduction and overview. *J Pol Pract Intellect Disabil.* (2009) 6:2–6. doi: 10.1111/j.1741-1130.2008.00202.x
3. Buntinx WH, Schalock RL. Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *J Pol Pract Intellect Disabil.* (2010) 7:283–94. doi: 10.1111/j.1741-1130.2010.00278.x
4. Schalock RL, Keith KD, Verdugo MÁ, Gómez LE. *Quality of Life Model Development and Use in the Field of Intellectual Disability. Enhancing the Quality of Life of People With Intellectual Disabilities*. Rotterdam: Springer Netherlands (2010). p. 17–32.
5. Kober R, Eggleton IR. Using quality of life to evaluate outcomes and measure effectiveness. *J Pol Pract Intellect Disabil.* (2009) 6:40–51. doi: 10.1111/j.1741-1130.2008.00194.x
6. Centers for Medicare and Medicaid Services. *Fact Sheet: Summary of key provisions of the 1915(c) Home and Community-Based Services (HCBS) waivers final rule (CMS 2249-F/2296-F)*. Baltimore, MD: Author (2014). Available online at: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf (accessed June 13, 2019).
7. Simões C, Santos S. The impact of personal and environmental characteristics on quality of life of people with intellectual disability. *Appl Res Qual Life.* (2017) 12:389–408. doi: 10.1007/s11482-016-9466-7
8. Gómez LE, Peña E, Arias B, Verdugo MA. Impact of individual and organizational variables on quality of life. *Soc Indic Res.* (2016) 125:649–64. doi: 10.1007/s11205-014-0857-6
9. Houseworth J, Stancliffe RJ, Tichá R. Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities. *Res Dev Disabil.* (2018) 83:77–90. doi: 10.1016/j.ridd.2018.08.008
10. Claes C, Van Hove G, Vandevelde S, van Loon J, Schalock R. The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Res Dev Disabil.* (2012) 33:96–103. doi: 10.1016/j.ridd.2011.08.024
11. Flynn S, Totsika V, Hastings RP, Hood K, Toogood S, Felce D. Effectiveness of active support for adults with intellectual disability in residential settings: systematic review and meta-analysis. *J Appl Res Intellect Disabil.* (2018) 31:983–98. doi: 10.1111/jar.12491
12. Beadle-Brown J, Beecham J, Mansell J, Bäumker T, Leigh JS, Whelton B, et al. Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs. *J Appl Res Intellect Disabil.* (2021) 34:42–54. doi: 10.1111/jar.12782
13. Gardner JF, Nudler S, Chapman M. Personal outcomes as measures of quality. *Mental Retard.* (1997) 35:295–305. doi: 10.1352/0047-6765(1997)035<0295:POAMOQ>2.0.CO;2
14. U. S. Department of Health and Human Services Health Resources and Services Administration. *Quality Improvement*. Washington, DC (2011).
15. The Council on Quality and Leadership. *Personal Outcome Measures®: Measuring Personal Quality of Life*. 3rd ed. Towson, MD: Author (2017).
16. Friedman C. The personal outcome measures®. *Disabil Health J.* (2018) 11:351–8. doi: 10.1016/j.dhjo.2017.12.003
17. The Council on Quality and Leadership. *Basic Assurances®: What Really Matters — a Strong Foundation for Success Enhancing Health, Safety and Human Security*. 3rd ed. Towson, MD: Author (2015).
18. The Accreditation Council for the Mentally Retarded. *Standards for Residential Facilities for the Mentally Retarded*. Chicago, IL: Author (1971).
19. The Accreditation Council on Services for People with Developmental Disabilities. *Standards for Services for People With Developmental Disabilities*. Field review ed. Towson, MA (1990).
20. Sparr MP, Smith W. Regulating professional services in ICFs/MR: Remembering the past and looking to the future. *Ment Retard.* (1990) 28:95–9.
21. Selya AS, Rose JS, Dierker LC, Hedeker D, Mermelstein RJ, A. practical guide to calculating Cohen's f^2, a measure of local effect size, from PROC MIXED. *Front Psychol.* (2012) 3:1–6. doi: 10.3389/fpsyg.2012.00111
22. Reinders HS, Schalock RL. How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *Am J Intellect Dev Disabil.* (2014) 119:291–302. doi: 10.1352/1944-7558-119.4.291
23. Verdugo MA, Schalock RL, Keith KD, Stancliffe RJ. Quality of life and its measurement: Important principles and guidelines. *J Intellect Disabil Res.* (2005) 49:707–17. doi: 10.1111/j.1365-2788.2005.00739.x
24. Shapiro J. *The Sexual Assault Epidemic No One Talks About*. Washington, DC: National Public Radio (NPR) (2018). Available online at: https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about (accessed August 24, 2021).
25. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J.* (2015) 8:165–72. doi: 10.1016/j.dhjo.2014.11.002
26. Inclusion International. *Independent but Not Alone: Global Report on the Right to Decide*. London: Author (2014).
27. Keesler JM. A call for the integration of trauma-informed care among intellectual and developmental disability organizations. *J Pol Pract Intellect Disabil.* (2014) 11:34–42. doi: 10.1111/jppi.12071
28. Oss ME. *If 1 in 8 Community-Based Organizations are Insolvent, the Answer Is*? Gettysburg: OPEN MINDS (2018).
29. Friedman C. Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellect Dev Disabil.* (2018) 56:234–50. doi: 10.1352/1934-9556-56.5.234
30. Magaña S, Parish S, Morales MA Li H, Fujiura G. Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellect Dev Disabil.* (2016) 54:161–72. doi: 10.1352/1934-9556-54.3.161
31. Friedman C. Quality of life outcome and support disparities among people with more severe impairments. *Intellect Dev Disabil.* (2020) 58:513–24. doi: 10.1352/1934-9556-58.6.513
32. Lulinski A. *Community Capacity to Provide Mental/Behavioral Health Services to People With Developmental Disabilities* (Unpublished doctoral dissertation). University of Illinois at Chicago, United States (2014).
33. Friedman C. The influence of residence type on personal outcomes. *Intellect Dev Disabil.* (2019) 57:112–26. doi: 10.1352/1934-9556-57.2.112

Conflict of Interest: The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers
in Rehabilitation Sciences

BRIEF RESEARCH REPORT
published: 25 March 2022
doi: 10.3389/fresc.2022.848492

Quality of Life Outcomes in a Community Cohort of Adults With an Intellectual Disability Using the Personal Outcome Scale

Tom Burke[1,2,3*], *Andrew Deffew*[1,4], *Owen Stafford*[1,2], *Caroline Docherty*[3], *Sandra Burke*[1], *Remco Mostert*[5], *Jos van Loon*[5], *Marco Lombardi*[5], *Marianne Vaughan*[1], *Robert Brickell*[1], *Mary Keogh*[1], *Wendy Mahon*[1] and *David O'Halloran*[1,2]

[1] KARE Services, Kilcullen, Ireland, [2] School of Psychology, John Henry Newman Building, University College Dublin, Dublin, Ireland, [3] School of Psychology, National University of Ireland Galway, Galway, Ireland, [4] School of Psychology, University of Limerick, Limerick, Ireland, [5] Hogeschool Ghent, Ghent, Belgium

Objectives: Quality of life (QoL) is a multi-dimensional phenomenon composed of core domains that are influenced by personal characteristics, values, and environmental contributions. There are eight core domains of QoL aligned with both the United Nations and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). The Personal Outcome Scale (POS), is a semi-structured self and proxy instrument that specifically measures these aspects of QoL for people with an intellectual disability.

Methods: A total of 85 people with an intellectual disability and their primary keyworker ($n = 85$) took part in this study. A convenience sample recruitment strategy was employed to recruit participants during the calendar year from January–December 2020. Participants completed the self-report and proxy POS, and clinic-demographic data was also considered.

Results: QoL is higher in those who have a dedicated service planner and also for those with a less severe to profound disability. People who were in gainful employment reported significantly higher QoL as did those availing of outreach and residential services, over and above local services.

Conclusions: This research shows that there are distinct and specific factors that relate to QoL for people with an intellectual disability community-based services in Ireland. Future research could aim to investigate these longitudinally, and specifically how QoL relates to cognitive and functional outcomes.

Keywords: quality of life, intellectual disabilities, community-based services, personal outcome measures, psychological wellbeing

Edited by:
Jan Šiška,
Charles University, Czechia

Reviewed by:
Jacqueline Moodley,
University of Johannesburg,
South Africa
Mary-Ann O'Donovan,
The University of Sydney, Australia

****Correspondence:***
Tom Burke
tom.m.burke@ucd.ie

Specialty section:
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

Received: *04 January 2022*
Accepted: *22 February 2022*
Published: *25 March 2022*

Citation:
Burke T, Deffew A, Stafford O, Docherty C, Burke S, Mostert R, van Loon J, Lombardi M, Vaughan M, Brickell R, Keogh M, Mahon W and O'Halloran D (2022) Quality of Life Outcomes in a Community Cohort of Adults With an Intellectual Disability Using the Personal Outcome Scale. Front. Rehabilit. Sci. 3:848492. doi: 10.3389/fresc.2022.848492

INTRODUCTION

Ensuring people with intellectual disabilities receive proper care and support in society requires a thorough consideration of the individual quality of life (QoL) since an intellectual disability has the potential to hinder one's independence, well-being, and ability to fully engage in the community (1). Fulfilling one's professional responsibilities in the field of intellectual disabilities involves understanding and applying best practices based on relevant conceptual models and frameworks regarding human functioning and disability, QoL, and individualized supports (2). Clinical practice and research in the field of intellectual disability have shown the importance of focusing on a person's QoL, and the mediating role that individualized supports can play in ameliorating the impact of one's disability, enhancing human functioning, and improving QoL overall (3). QoL is a multi-dimensional phenomenon composed of core domains that are influenced by personal characteristics, values, and environmental variables (4). Inherently, QoL is multifaceted and unique to an individual with some constructs that may resonate with many individuals and some with varying value and importance at the individual level (5, 6). As such, QoL can be a challenging concept to measure accurately, psychometrically (7).

There are eight core domains of QoL which are aligned with both the United Nations Convention on the Rights of Persons with Disabilities (4, 8) and with the Quality of Life Consensus Statement from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). The personal outcome scale [POS (9)], has been developed specifically to measure these eight aspects of QoL for people with an intellectual disability, as outlined in more detail below. These core domains of QoL are: personal development; self-determination; interpersonal relations; social inclusion; rights; mental well-being; physical well-being; and financial well-being (10). These eight core QoL domains, measured by the POS, have been assessed across several countries and cultures due to the potential impact of culture on QoL (11–13).

The POS assesses QoL using a semi-structured self-report interview format, as well as a secondary observer report which is used in conjunction with, and not in replacement of, the self-report. The POS is somewhat unique in its measurement of QoL for people with an intellectual disability, as it: (1) is based on a QoL-specific theoretical framework; (2) assesses personal outcomes with guided support in a semi-structured format; and (3) considers multi-informant reporting. To date, studies to test the reliability and validity of the POS have been conducted in the Netherlands (14), Portugal (15–18), Spain (19–21), and Italy (22). In terms of clinical outcomes within these studies, in Portugal it was found that living circumstances were related most to outcomes on the POS (16). Similarly, in the Netherlands, greater independence was associated with higher scores on the POS. As such, the first aim of this study was to investigate the psychometrics of the POS in an Irish sample, and secondly, to consider outcomes for people with an intellectual disability who attend a community-based service in Ireland. A final aim of this study was to investigate clinical- and service-based factors which may relate to QoL, as measured by the POS.

MATERIALS AND METHODS

Setting and Sample

This study took place in a community-based service for people with an intellectual disability in Ireland. A total of 85 people who attend a community-based service for people with an intellectual disability and their primary keyworker ($n = 85$) were the participants. A convenience sample recruitment strategy was employed to recruit participants during the calendar year from January–December 2020. Within the host organization, members of the Quality Assurance Team (QAT: SB, MV, RB, MK, and WM) approached potential participants and informed them of the POS study, following ethical approval. Participants were then invited to take part and provided consent for their data to be used. Members of the QAT are not directly involved in the clinical care of the participants or service users, which may have reduced response bias, i.e., socially desirable responding. The mean age for the total group was 40.08 years ±14.20; 18.8% attended outreach services, 37.6% attended residential services, and 43.5% attended local (day) services. In brief, outreach services can be best described as a flexible and tailored support service for people who have an intellectual disability and high levels of independence, but lower support needs. Local services provide recreation, leisure, and specialized healthcare for people with an intellectual disability during the day. Local services support people with an intellectual disability to live in their communities and promote independent living. Residential services are provided for people with an intellectual disability who are unable to live at home, and they typically live there full-time.

Of the total cohort, 61% had a planner to support them; 52% of the group were in gainful employment at the time of completing the POS. There was a relatively equal gender distribution (52% female); 86% of the total cohort presented with a mild or moderate intellectual disability (29.5 and 56.5%, respectively). This research has been approved by the principal investigators host academic institution's research ethics committee (RECREF: HS-E-21-62).

The Personal Outcome Scale

The personal outcome scale (9) was developed through an iterative process of expert consultation and focus groups with key stakeholders (including clients, family, direct support staff, and experts). The POS can be summed into a "Total Score" comprised of three subdomains (independence, social participation, and well-being), for both self-report and the observer/proxy report. Within these subdomains, there are 8 individual factors associated with the aforementioned QoL framework e.g., physical well-being, with an acceptable psychometric factor structure (19). These eight core domains of this model and measure have been assessed across several countries and cultures due to the potential impact of culture on QoL (11–13). Each QoL factor is broken down into corresponding domains. The Independence factor is broken down into personal development and self-determination domains; the Social Participation factor is broken down into interpersonal relations, social inclusion, and rights domains; and the Well-being factor is broken down into emotional, physical, and material well-being domains. There are six questions related to the domain presented under each section, resulting in a total of 48 questions. Under each question, the person is given 3 answers to choose from. They choose the most appropriate option depending on the extent to which each question applies to them. Under the self-determination domain of the self-report scale, for example, the question, "Can you decide not to do something asked of you?" is followed by the answer choices "always," "sometimes," or "seldom or never," and the person may choose an answer based on their own experiences. The person's answers are then converted into scores using a 3-point Likert scale, with the total score out of a potential 144. The POS is always administered in both formats (self-report and observer/proxy report) to gather QoL data from both the subjective and objective perspectives.

Data Processing and Analysis

Within the group, demographic characteristics were comparatively analyzed using independent samples t-tests with χ^2 used for dichotomized variables, where relevant. MANOVA were used to compare multiple dependent variables (total self-report, total observer-report, and the cumulative total score). Classification for "good" internal validity, using Cronbach's alpha (a), remains at the internationally accepted value $\geq$0.71 and the acceptable was set at $\geq$0.6. Split-half reliability was also assessed using Spearman-Brown coefficient for equal length measures, to complement analyses of internal consistency. Correlations were used to investigate the relationship between self- and proxy-reported outcomes on the POS, and the relationship between age and outcomes. The threshold for statistical significance was set at $p < 0.05$. Statistical analyses were conducted using SPSS (Version 26.0).

RESULTS

Scale Reliability and Correlates

Internal consistency was assessed using split-half reliability on the POS, with an unequal length analysis completed due to the varied number of items per subscale. Overall, the split-half reliability for the POS is 0.857. Scale reliability was completed by measuring the associated Cronbach's alpha on many levels. To investigate the reliability of the POS, the total observed, total self-reported, and a total scale (the summed total of the two aforementioned scales) were investigated. Furthermore, scales and subscales (a: independence, b: social participation, and c: wellbeing); and their subtotals (a: personal development and self-determination; b: interpersonal relationships, social inclusion, and rights; c: emotional wellbeing, physical wellbeing, and material wellbeing) were investigated. **Figure 1** outlines the Cronbach's alpha and correlations of each of the subtests for both self and observer reports.

Considering the self-report first, there was a good scale validity reported for the total scale ($a = 0.79$), the independence ($a = 0.76$), and social participation ($a = 0.75$) subscales. The wellbeing scale ($a = 0.64$) was considered to have acceptable validity as a subscale. Each of the three subtotals within the wellbeing scale i.e., emotional wellbeing ($a = 0.42$), physical wellbeing ($a = 0.56$), and material wellbeing ($a = 0.49$), had reliability scales that would not be considered acceptable as unitary constructs. Similarly, the three constructs of interpersonal relationships ($a = 0.64$), social inclusion ($a = 0.62$), and rights ($a = 0.52$), which make up the social participation subscale, were below the recommended value of $a = 0.7$ for good reliability, with only the first two measures reaching an acceptable validity. Lastly, the independence subscale comprised of the personal development ($a = 0.70$) and self-determination ($a = 0.63$) subtotals, with both meeting the statistical threshold for acceptable reliability.

In terms of the between–within scale correlations, there were significant moderate to strong positive correlations between the total scale and the three subscales of independence ($r = 0.674$, $p < 0.05$), social participation ($r = 0.726$, $p < 0.05$), and wellbeing ($r = 0.684$, $p < 0.05$). There were also significant moderate positive correlations between the subscales, and between the subscales and subtotals, as seen in **Figure 1**. Of note, there were two non-significant correlations on the self-report outcomes. The first was between physical wellbeing and material wellbeing ($r = 0.182$); the second was between emotional wellbeing and material wellbeing ($r = 0.272$), despite each being contained within the wellbeing subscale. The remaining variable set was significantly correlated i.e., physical wellbeing and emotional wellbeing ($r = 0.341$, $p < 0.05$).

Regarding the observer-report and the scale validity, a similar pattern to the self-report was identified. The total scale score ($a = 0.80$) has good internal consistency, as did the independence ($a = 0.80$), and social participation ($a = 0.76$) subscales. Similar to the self-report, the wellbeing subscale ($a = 0.66$) had an acceptable, but not a good, validity. A similar pattern for the subtotals was also reflected with the wellbeing subscale i.e., emotional wellbeing ($a = 0.49$) and physical wellbeing ($a = 0.41$), achieving an unacceptable reliability coefficient. The material wellbeing subscale was reported to have acceptable psychometric properties ($a = 0.69$). The three constructs of interpersonal relationships ($a = 0.64$), social inclusion ($a = 0.63$), and rights ($a = 0.58$), which make up the social participation subscale, reached an acceptable, but not a good, validity. Lastly, the independence subscale comprised of personal development ($a = 0.75$) and self-determination ($a = 0.70$) subtotals, with both meeting the statistical threshold for acceptable reliability.

In relation to the between-within scale correlations for the observer-report, there were significant moderate to strong positive correlations between the total scale and the three subscales of independence ($r = 0.787$, $p < 0.05$), social participation ($r = 0.780$, $p < 0.05$), and wellbeing ($r = 0.707$, $p < 0.05$). There were also significant moderate positive correlations between the subscales and the between the subscales and subtotals, as illustrated in **Figure 1**. Each of the individual subtotals and subscales correlated positively and significantly ($p < 0.05$), with the exception of material wellbeing and emotional wellbeing ($r = 0.131$, $p < 0.05$).

Quality of Life Outcomes

The age of the participants at the time of completing the POS was correlated with the total outcomes to investigate whether a relationship existed. There were no significant associations between participants' age and the total self- or proxy- outcome on the POS. There were also no significant differences noted when participants outcomes were compared on the total self-report POS ($p = 0.575$) or observer-report ($p = 0.445$) when stratified by gender. No significant difference was noted when participant's outcomes were compared when stratified by those who had a planner ($n = 52$), compared to those who did not ($n = 33$) for

TABLE 1 | Outcome on the POS for the total group (N=85), with outcomes reported based on demographic and service-specific information.

Category	Variable	N	Total self-report	Self-report: independence	Self-report: social participation	Self-report: wellbeing	Total observer-report	Observer report: independence	Observer report: social participation	Observer report: wellbeing
Total group		N=85	121.32 ± 10.95	30.79 ± 3.81	41.35 ± 5.89	49.19 ± 3.48	120.96 ± 11.45	30.81 ± 3.93	41.13 ± 5.73	48.92 ± 3.71
Gender	Male	*n* = 41	120.63 ± 10.88	30.68 ± 3.38	41.12 ± 6.10	48.88 ± 3.48	119.97 ± 10.30	30.54 ± 3.89	41.02 ± 5.48	48.71 ± 3.51
	Female	*n* = 44	121.97 ± 11.09	30.89 ± 4.21	41.57 ± 5.66	49.48 ± 3.48	121.88 ± 12.47	31.07 ± 3.99	41.23 ± 6.00	49.11 ± 3.92
Planner	No	*n* = 33	118.00 ± 11.95	29.27 ± 4.20	40.76 ± 6.01	48.00 ± 3.69	116.72 ± 11.32	29.24 ± 4.02	39.55 ± 5.36	47.70 ± 3.57
	Yes	*n* = 52	123.44 ± 9.80	31.75 ± 3.23	41.73 ± 5.77	49.94 ± 3.14	123.65 ± 10.79	31.81 ± 3.56	42.13 ± 5.77	49.69 ± 3.62
Disability	Mild	*n* = 27	125.96 ± 6.96	32.76 ± 1.96	43.04 ± 4.31	50.16 ± 2.98	126.32 ± 7.97	33.48 ± 2.20	43.04 ± 4.88	49.96 ± 3.55
	Moderate	*n* = 48	121.64 ± 11.36	30.65 ± 4.05	41.13 ± 6.10	49.33 ± 3.55	121.02 ± 11.97	30.48 ± 3.91	40.92 ± 6.26	48.87 ± 3.74
	Severe/Profound	*n* = 10	111.20 ± 8.29	26.80 ± 3.04	39.70 ± 6.60	47.30 ± 2.66	109.70 ± 7.04	26.70 ± 3.52	37.90 ± 3.57	47.80 ± 2.82
Service	Residential Service	*n* = 32	123.09 ± 9.20	31.28 ± 3.37	41.06 ± 5.73	50.06 ± 3.29	123.40 ± 11.19	30.94 ± 3.83	41.59 ± 6.12	49.91 ± 3.65
	Local Service	*n* = 37	117.32 ± 12.10	29.41 ± 4.22	40.59 ± 6.10	47.95 ± 3.51	116.37 ± 11.17	29.59 ± 4.07	39.62 ± 5.28	47.84 ± 3.42
	Outreach Services	*n* = 16	127.06 ± 7.98	33.00 ± 2.16	43.69 ± 5.16	50.31 ± 3.00	126.68 ± 8.72	33.37 ± 2.36	43.69 ± 5.12	49.44 ± 4.04
Living arrangements	Community House	*n* = 32	123.09 ± 9.02	31.28 ± 3.37	41.06 ± 5.73	50.06 ± 3.29	123.40 ± 11.19	30.94 ± 3.83	41.59 ± 6.12	49.91 ± 3.65
	Family Home	*n* = 45	119.73 ± 12.49	30.16 ± 4.22	41.62 ± 6.36	48.47 ± 3.54	118.68 ± 11.80	30.36 ± 4.16	40.71 ± 5.79	48.27 ± 3.49
	Lives Independently	*n* = 10	123.25 ± 6.86	32.38 ± 2.32	41.00 ± 2.97	49.75 ± 3.32	124.00 ± 8.48	32.88 ±2.29	41.63 ±3.77	48.63 ±4.71

The POS Total is scored out of a potential maximum score of 144. The Independence subscale has a maximum potential score of 36; The Social Participation subscale has a maximum potential score of 54, as does the Wellbeing subscale. The Self-report and Observer-report have the same scoring structure.

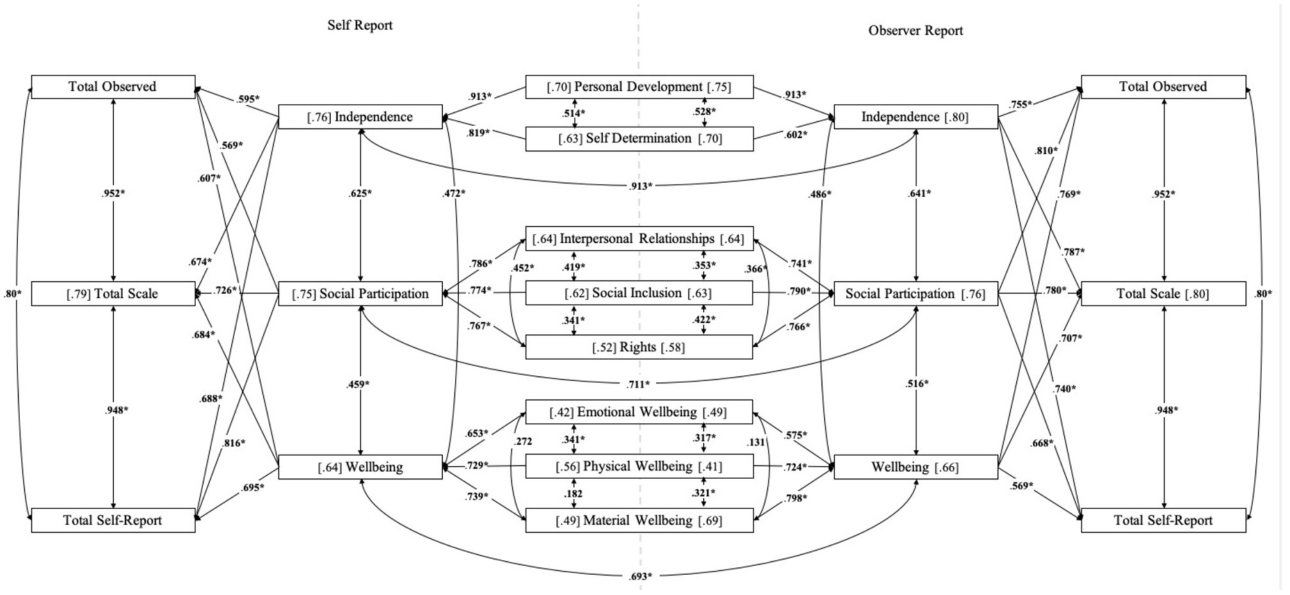


FIGURE 1 | Outcomes relating to the [Cronbach's alpha] and between-within scale (correlations). The left side of the figure relates to the self-report POS outcomes, and the right, demarked by the dashed vertical line, relates to the observer report. Note, a Cronbach's alpha are reported in chain brackets [ ], and ≥60 is considered acceptable. Correlations are reported along the line which relates to the variables in question and significance is represented by *$p \leq 0.05$.

the self-report measure. However, observer-reports indicate that QoL was higher in those with a planner ($p = 0.006$).

Level of disability was considered categorically using MANOVA with Bonferroni *post-hoc* corrections made for multiple comparisons. Outcomes were stratified based on whether participants were within the mild, moderate, or severe/profound range historically i.e., not assessed or confirmed as part of this study. Participants with an intellectual disability in the mild range were reported to have a significantly higher total self-report than people with a severe/profound disability ($p = 0.001$) and not those with a moderate disability ($p = 0.501$). Individuals with a moderate disability were also found to have a significantly higher self-reported total score ($p = 0.021$). A similar pattern was reported for the total observer-report score (mild and severe/profound: $p < 0.001$; moderate and severe/profound: $p = 0.014$). When stratified based on whether a person was in gainful employment or not, there was a significant difference on both the self- and observer-report ($p < 0.000001$, respectively).

Participants were stratified based on the type of service they availed of e.g., residential, local, or outreach services; considering these groupings categorically using MANOVA with Bonferroni *post-hoc* corrections made for multiple comparisons, there were significant differences noted. Participants availing of local services had the lowest QoL for both the total self- and observer-report outcomes (117.32 ± 12.10 and 116.37 ± 11.17, respectively). This was significantly lower than those availing of outreach services (127.06 ± 7.98 and 126.68 ± 8.72: $p = 0.007$; $p = 0.006$), and residential services (123.09 ± 9.20 and 123.40 ± 11.19: $p = 0.027$; $p = 0.025$). There were no significant differences between those availing of residential compared to outreach services. In terms of living arrangements, each person availing of residential services resided at the host institution ($n = 32$; 100%); most participants availing of local services were living in the family home ($n = 36$; 97%), with 1 person living independently; and there was a near-even split between those living in the family home ($n = 9$; 56%) and those living independently (44%; $n = 7$) who attended outreach services. There were no significant differences in self- or observer-reported total outcomes on the POS when stratified by living arrangement. A breakdown of the mean and standard deviation for the total sample on the POS can be seen in **Table 1**, including the above stratifications.

DISCUSSION

The purpose of this study was to investigate outcomes on the POS from both a QoL and psychometric perspective in a community-sample of individuals with an intellectual disability in Ireland. Evidence would suggest that though proxy-report and self-report scores on measures of QoL demonstrate correlation, they do not provide identical information, and comparability may be reduced by external factors such as disability severity or instructions given to proxy respondents (18, 21, 22).

In this study, the correlation was both positive and strong between the total self-report and the total observed scores on the POS ($r = 0.800$; $p < 0.01$). Strong positive correlations were also observed between the self and observer reports on the subdomains (independence: $r = 0.913$; $p < 0.01$, social participation: $r = 0.711$, $p < 0.01$, and wellbeing $r = 0.693$; $p < 0.01$). While the outcomes relate significantly to each other, a key consideration is that information from each respondent should be considered individually and as a complementary yet distinct data. Consequently, as a clinical consideration, the POS self-report interview should always be done where possible, and both outcomes should be considered independently from each other, rather than as a summed total score. Furthermore, our psychometric findings, based on the Cronbach's alpha of the individual eight QoL domains measured, would suggest that the three subdomains (independence, social participation, and wellbeing) should be considered as more reliable psychometric scales rather than the individual components themselves for both the self-report and observer-report. This may be particularly useful to consider if measuring change over time or the impact of an intervention. Each of the well-being components has a low Cronbach's alpha and low intra-factor correlations. This would suggest that well-being interventions should be considered holistically, and that supports need to be multifaceted to maximize the potential positive impact on well-being i.e., incorporating multi-element intervention e.g., emotional and physical well-being together (23).

Our findings are congruent with those from previous studies, which suggest that observer reports may score people with more severe intellectual disability lower on certain QoL domains than the person would score themselves (20); this may also be a reflection of family input for people who have more severe-to-profound intellectual disability. This is demonstrated in **Table 1**. This further highlights the importance of both self-report measures of QoL and the integration of proxy reports.

Simões and Santos (16) compared QoL for people with and without an intellectual disability in Portugal and found that living circumstances had a strong influence on QoL in terms of the rights domain, which is in line with our reported study. Also in line with our findings were those by a group in the Netherlands who reported that people who live more independently and are employed have a higher QoL (14). Specifically in our cohort, people who lived independently had the highest self-reported total score on the POS, as well as the highest total observer-report score. Additionally, adults availing of local services reported the lowest QoL scores, and 97% of these adults were living in the family home. These findings have clinical implications and suggest that living circumstances may have a strong impact on QoL for people with an intellectual disability. The correlation between living more independently and having a higher QoL may be due to enhanced independence and more opportunities to make personal decisions. This could be prospectively measured in the future. Furthermore, a family-based approach to improving QoL (24) could be a consideration for local (day) services, when considering QoL interventions for people with an intellectual disability who avail of their services (25–27).

A strength of this study is the consecutive recruitment, within a calendar year, of a large, well categorized, community-based sample, inclusive of many areas i.e., participants who avail of residential, local, and outreach services. This study is not without limitations. Firstly, the cross-sectional nature of the study does not allow for inferences to be made as to the degree of fluctuation in outcomes over time. Without clinically discreet categories, there is limited information at present as to what represents a "good" QoL or an outcome score or indeed what would represent meaningful or statistical change, both positively or negatively over-time or after specific intervention. A further limitation of the study and scale is the universal administration without modification for severity of disability, and so a person's outcome may be lower due to functional limitations, over and above a reduced QoL *per se*.

There are several prospective avenues for future research with this measure. The POS would benefit from the development and validation of clinically useful outcome ranges, which a baseline and follow-up intervention could be benchmarked against. Currently, in the interim, one could consider a 1, 1.5, and/or 2 standard deviations from the mean scores outlined in **Table 1** as a mild (small), moderate (medium), or severe (large) deviation from this community-based normative sample. Further longitudinal measurements would be of benefit to further elucidate the test–retest reliability of the measure. Research could also investigate the clinical (mood), cognitive, and/or functional (activities of daily living) correlates of the POS, not only to better understand the relational properties of QoL to these outcomes, but to also consider potential avenues to improve, support, or maintain QoL (28). Based on the current study, the POS is shown to be a valid tool for measuring QoL for people with an intellectual disability, within the Irish healthcare system, when the total and subdomains are considered.

To conclude, this research investigated QoL outcomes on the POS and highlights that the subscales and total score are reliable indices. More research is needed to consider the clinical utility of the measure. This research shows that there are distinct and specific factors that are related to QoL for people with an intellectual disability in a community-based service, and future research could aim to investigate these factors longitudinally and specifically to determine how QoL relates to functional outcomes.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by UCD HREC. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

Each of the team were involved in the conceptual development of the manuscript. TB wrote the manuscript. MK, MV, WM, SB, and RB contributed to the data collection and collation. TB and OS completed the data analyses. RM, JL, and ML provided assessment measures. CD and OS contributed to the manuscript. All authors reviewed the manuscript.

FUNDING

This work has been, in part, funded by the Irish Research Council under the New Foundations 2020.

REFERENCES

1. Lombardi M, Croce L, Claes C, Vandevelde S, Schalock RL. Factors predicting quality of life for people with intellectual disability: results from the ANFFAS study in Italy[†]. *J Intellect Dev Disabil.* (2016) 41:338–47. doi: 10.3109/13668250.2016.1223281
2. Buntinx WHE, Schalock RL. Models of disability, quality of life, and individualized supports: implications for professional practice in intellectual disability. *J Policy Pract Intellect Disabil.* (2010) 7:283–94. doi: 10.1111/j.1741-1130.2010.00278.x
3. Bertelli M, Brown I. Quality of life for people with intellectual disabilities. *Curr Opin Psychiatry.* (2006) 19:508–13. doi: 10.1097/01.yco.0000238479.81528.9f
4. Verdugo MA, Navas P, Gómez LE, Schalock RL. The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *J Intellect Disabil Res.* (2012) 56:1036–45. doi: 10.1111/j.1365-2788.2012.01585.x
5. Hensel E, Rose J, Kroese BS, Banks-Smith J. Subjective judgements of quality of life: a comparison study between people with intellectual disability and those without disability. *J Intellect Disabil Res.* (2002) 46:95–107. doi: 10.1046/j.1365-2788.2002.00343.x
6. Hensel E. Is satisfaction a valid concept in the assessment of quality of life of people with intellectual disabilities? A review of the literature. *J Appl Res Intellect Disabil.* (2001) 14:311–26. doi: 10.1046/j.1468-3148.2001.00081.x
7. Townsend-White C, Pham ANT, Vassos MV. Review: a systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours. *J Intellect Disabil Res.* (2012) 56:270–84. doi: 10.1111/j.1365-2788.2011.01427.x
8. Verdugo MA, Gómez LE, Arias B, Navas P, Schalock RL. Measuring quality of life in people with intellectual and multiple disabilities: validation of the San Martín scale. *Res Dev Disabil.* (2014) 35:75–86. doi: 10.1016/j.ridd.2013.10.025
9. van Loon J, Hove G,Schalock R, Claes C. *Personal Outcome Scale*. 1st Ed. Gent, Belgium: Garant Uitgevers nv (2008).
10. Schalock RL. The concept of quality of life: what we know and do not know. *J Intellect Disabil Res.* (2004) 48:203–16. doi: 10.1111/j.1365-2788.2003.00558.x
11. Jenaro C, Verdugo MA, Caballo C, Balboni G, Lachapelle Y, Otrebski W, et al. Cross-cultural study of person-centred quality of life domains and indicators: a replication. *J Intellect Disabil Res.* (2005) 49:734–9. doi: 10.1111/j.1365-2788.2005.00742.x
12. Schalock RL, Verdugo MA, Jenaro C, Wang M, Wehmeyer M, Jiancheng X, et al. Cross-cultural study of quality of life indicators. *Am J Ment Retard.* (2005) 110:298–311. doi: 10.1352/0895-8017(2005)110[298:CSOQOL]2.0.CO;2
13. Wang M, Schalock RL, Verdugo MA, Jenaro C. Examining the factor structure and hierarchical nature of the quality of life construct. *Am J Intellect Dev Disabil.* (2010) 115:218–33. doi: 10.1352/1944-7558-115.3.218
14. Claes C, Van Hove G, Vandevelde S, van Loon J, Schalock R. The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Res Dev Disabil.* (2012) 33:96–103. doi: 10.1016/j.ridd.2011.08.024
15. Simões C, Santos S. Cross-cultural adaptation, validity and reliability of the Escala Pessoal de Resultados. *Soc Indic Res.* (2014) 119:1065–77. doi: 10.1007/s11205-013-0515-4
16. Simões C, Santos S. Comparing the quality of life of adults with and without intellectual disability. *J Intellect Disabil Res.* (2016) 60:378–88. doi: 10.1111/jir.12256
17. Simões C, Santos S, Biscaia R. Validation of the Portuguese version of the personal outcomes scale. *Int J Clin Heal Psychol.* (2016) 16:186–200. doi: 10.1016/j.ijchp.2015.11.002
18. Simões C, Santos S, Claes C. The Portuguese version of personal outcomes scale: a psychometric validity and reliability study. *Intellect Dev Disabil.* (2015) 53:129–42. doi: 10.1352/1934-9556-53.2.129
19. Carbó-Carreté M, Guàrdia-Olmos J, Giné C. Psychometric properties of the Spanish version of the personal outcomes scale. *Int J Clin Heal Psychol.* (2015) 15:236–52. doi: 10.1016/j.ijchp.2015.04.002
20. Carbó-Carreté M, Guàrdia-Olmos J, Peró-Cebollero M, Giné C. Impact of the intellectual disability severity in the Spanish Personal Outcomes Scale. *J Intellect Disabil Res.* (2019) 63:1221–33. doi: 10.1111/jir.12634
21. Guàrdia-Olmos J, Carbó-Carreté M, Peró-Cebollero M, Giné C. Item response theory analysis applied to the Spanish version of the Personal Outcomes Scale. *J Intellect Disabil Res.* (2017) 61:1021–33. doi: 10.1111/jir.12407
22. Balboni G, Coscarelli A, Giunti G, Schalock RL. The assessment of the quality of life of adults with intellectual disability: the use of self-report and report of others assessment strategies. *Res Dev Disabil.* (2013) 34:4248–54. doi: 10.1016/j.ridd.2013.09.009
23. Carr A, Cullen K, Keeney C, Canning C, Mooney O, Chinseallaigh E, et al. Effectiveness of positive psychology interventions: a systematic review and meta-analysis. *J Posit Psychol.* (2021) 16:749–69. doi: 10.1080/17439760.2020.1818807
24. Vanderkerken L, Heyvaert M, Onghena P, Maes B. The relation between family quality of life and the family-centered approach in families with children with an intellectual disability. *J Policy Pract Intellect Disabil.* (2019) 16:296–311. doi: 10.1111/jppi.12317
25. Boehm TL, Carter EW. Family quality of life and its correlates among parents of children and adults with intellectual disability. *Am J Intellect Dev Disabil.* (2019) 124:99–115. doi: 10.1352/1944-7558-124.2.99
26. Staunton E, Kehoe C, Sharkey L. Families under pressure: stress and quality of life in parents of children with an intellectual disability. *Ir J Psychol Med*. (2020) 1–8. doi: 10.1017/ipm.2020.4
27. Rodrigues SA, Fontanella BJB, de Avó LRS, Germano CMR, Melo DG, A. qualitative study about quality of life in Brazilian families with children who have severe or profound intellectual disability. *J Appl Res Intellect Disabil.* (2019) 32:413–26. doi: 10.1111/jar.12539
28. Schalock RL, Baker A, Claes C, Gonzalez J, Malatest R, van Loon J, et al. The use of quality of life scores for monitoring and reporting, quality improvement, and research. *J Policy Pract Intellect Disabil.* (2018) 15:176–82. doi: 10.1111/jppi.12250

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers
in Rehabilitation Sciences

ORIGINAL RESEARCH
published: 29 March 2022
doi: 10.3389/fresc.2022.830175

Risk Adjustment in Home and Community Based Services Outcome Measurement

James Houseworth[1]*, *Tina Kilaberia*[2], *Renata Ticha*[1] *and Brian Abery*[1]

[1] Institute on Community Integration, University of Minnesota Twin Cities, Minneapolis, MN, United States, [2] Betty Irene Moore School of Nursing, University of California, Davis, Davis, CA, United States

The purpose of this study was to review and evaluate existing research that used risk adjusters in disability research. Risk adjustment controls for individual characteristics of persons when examining outcomes. We have conducted a systematic review and an evaluation of existing studies that included risk adjusters for outcomes of people with disabilities receiving services (home or community based). The process included coding each study according to the type(s) of risk adjusters employed and their relation to the specific population and outcomes within a framework. Panels were utilized to prioritize the risk adjusters. Findings indicate that four risk adjusters can be tentatively recommended as potential candidate risk adjusters: chronic conditions, functional disability, mental health status, and cognitive functioning. Holistic Health and Functioning far outweighed other outcomes studied to date. Further, there is a need for testing recommended risk adjusters across multiple outcomes and different populations of people with disabilities.

Keywords: risk adjuster, disability, home and community based services, National Quality Forum, outcome measurement

Edited by:
Nuno Barbosa Rocha,
Polytechnic of Porto, Portugal

Reviewed by:
Patricia Welch Saleeby,
Bradley University, United States
Liliana Teixeira,
Polytechnic Institute of Leiria, Portugal
Chia-Feng Yen,
Tzu Chi University, Taiwan

****Correspondence:***
James Houseworth
house119@umn.edu

Specialty section:
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

Received: *06 December 2021*
Accepted: *09 February 2022*
Published: *29 March 2022*

Citation:
Houseworth J, Kilaberia T, Ticha R and Abery B (2022) Risk Adjustment in Home and Community Based Services Outcome Measurement. Front. Rehabilit. Sci. 3:830175. doi: 10.3389/fresc.2022.830175

INTRODUCTION

Risk adjustment refers to the practice of identifying and including known or potential factors that could be significantly associated (positively or negatively) with the outcome of interest and are only indirectly related to the research/evaluation question under scrutiny (1) and are a type of covariate. Like a risk adjuster, a *covariate* is a variable associated with target outcomes but may not be of interest or only of interest to the extent to which it interacts with another variable. A risk adjuster can be thought of as a covariate that is included as a control to decrease the chances of making an error in interpreting the associations between variables one does care about. Risk adjusters are often incorporated into analyses to adjust results (e.g., magnitude estimates, etc.), and are not reported. **Figure 1** represents this process. Largely, risk adjustment seeks to *level the playing field* by eliminating variance in an outcome due to individual characteristics or contextual factors outside of the control of the people being assessed or compared. When appropriately used, this adjustment can lead to enhanced equity in decisions when interpreting the results in question.

Risk adjustment is increasingly recognized as crucial to health care reimbursement and comparing provider performance in terms of the quality and outcomes of care (2). In practice, risk adjusters are not selected randomly. Risk adjustment for insurance reimbursement purposes is different than for outcome-based research. Risk adjustment for insurance reimbursement focus on

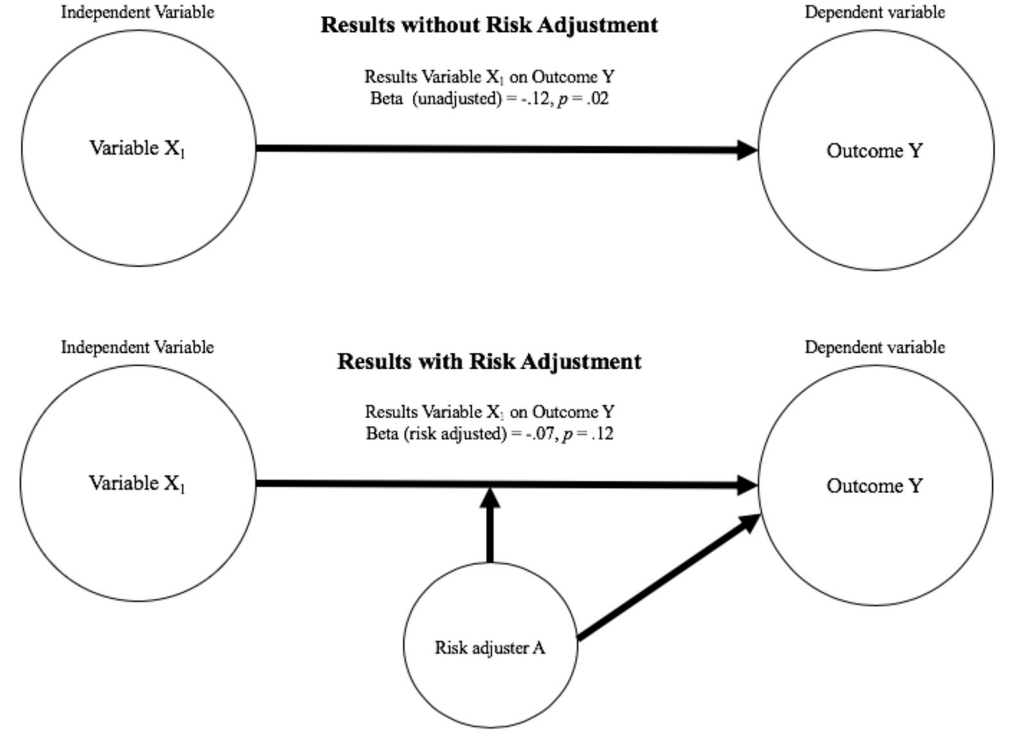


FIGURE 1 | Representation of risk adjusted models.

creating risk scores, scores that adjust based on expectations of costs for care. Risk adjustment for outcomes research are driven by theory after consideration of factors potentially related to outcomes of interest (3). Appropriately implemented, risk adjustment allows for fair comparisons among service providers by accounting for factors beyond the purview of those delivering supports that may affect patient outcomes (e.g., person's age, and severity of disability). Within the healthcare field, risk adjustment research focuses on the complexity and difficulty of accounting for risk adjusters and making statistically-appropriate adjustments (2, 4). While this process is ubiquitous in medical reimbursement, it has the potential to improve measurement and analysis of the quality of life outcomes of recipients of home and community-based services (HCBS). Beyond these methodological benefits, the practice of risk adjustment in HCBS has the potential to lead to increased equity in both policies and decisions regarding service provision and consequently the outcomes experienced by beneficiaries.

When assessing differences in outcomes between groups of people or individuals, it is often necessary account for the characteristics of those under study (5). Research, for example, has demonstrated that age, health condition, and level of disability as well as more malleable factors (e.g., levels of service) may have an impact on the effectiveness of supports and the outcomes people experience (6).

Because a risk adjuster can influence the relationship between a predictor and an outcome, if it is not considered we may mistakenly interpret statistically significant results as indicating the presence of a relationship that in reality does not exist (Type 1 error) or miss a relationship that is of consequence (Type 2 error). The inclusion of risk adjusters not only increases the accuracy of results lowering the probability of Type 1 and Type 2 error, but is critical in terms of ethical considerations. In the absence of its use, for example regulatory agency could erroneously conclude that one support provider is underperforming when the real factors underlying perceived differences between groups are associated with one or more of the characteristics of those receiving services.

The present study considers the role of risk adjustment in the field of disability research, as related to quality of life outcomes for people with five types of disabilities (physical, intellectual and developmental, age-related and psychiatric disability as well as traumatic brain injury). In addition to summarizing current risk adjustment practices in this field, we make recommendations based on our findings as to future risk adjustment practices.

The National Quality Forum and Risk Adjustment

The National Quality Forum (NQF), identifies risk adjustment as a critical step in evaluating outcome measures to empirically ensure threats to validity are addressed. Sociodemographic status (e.g., income, race) has been explored as a potential risk adjuster by the NQF with the goal of setting guidelines for risk adjustment. In 2017, the NQF reviewed 303 measures submitted for its endorsement to assess their suitability to risk adjust social risk factors potentially associated with specific health outcomes. The NQF panel ultimately recommended these social risk factors meet the same criteria for inclusion as clinical or health risk factors [see (7)] noting, however, the lack of a conceptual basis for including social risk adjusters.

Of particular interest to the broader topic of risk adjustment for purposes of the current study, the NQF panel recommended that sociodemographic factors included should have: (1) a conceptual relationship with the outcome of interest, (2) an empirical association with the outcome, (3) variability, (4) presence before any intervention (or care), (5) independence from any intervention or policy change, (6) resistance to change, (7) accurate data that can be feasibly obtained, (8) unique contribution to variance to the outcome, (9) potential contribution to the overall model, and (10) potential face validity and acceptability [(7), pp. 9–10]. We consider these as guidelines in differentiating risk adjusters from covariates.

More recently, the NQF (8) conducted an environmental scan and technical expert panel (TEP) on risk adjustment in an effort to develop guidance for measure developers. This work considered conceptual and statistical methods for risk adjustment identifying that the social factors used in risk adjustment were largely at the person and community level. Community factors were found to come from a variety of socioeconomic and demographic indicators. Comparatively, functional risk factors were all at the individual level and often based on survey information from the people assessed. Fewer functional risk factors were identified with a lack of consensus as to how to define functional status. In terms of statistical methods, regression analyses were most common, however other approaches (e.g., hierarchical linear modeling) were used to better incorporate a range of risk factors.

Other models of risk adjustment share common themes with the NQF panel recommendations. The Centers for Medicare and Medicaid Services (CMS) sought expert recommendations on risk adjustment. The Health and Human Services (HHS)-Operated Risk Adjustment Methodology Meeting reviewed and consolidated these recommendations into a set of ten *Principles of Risk Adjustment* (9). Five of these are similar to the NQF guidelines with recommendations that risk adjusters: (a) be clinically meaningful, (b) predict medical expenditures, (c) have adequate sample sizes, (d) encourage specific coding, and (e) "be internally consistent."

Further support for some of the NQF guidelines comes from the Research Agency for Healthcare Research and Quality (10) who recommend that (a) risk adjustment does not include variables affected by the outcome, (b) the selection of variables be based on background knowledge about the relationship between the variable and the outcome, and (c) the risk adjusters have statistical associations with the outcome.

While we consider these guidelines when selecting risk adjusters, we caution against a "one size fits all" conception of a risk adjuster. As can be seen in the guidelines reviewed, risk adjustment is dependent on theoretical knowledge of the outcome assessed, target population and study aims. It should also be understood that the focus of the NQFs review and its expertise are in the area of *health care*. This is a decidedly different field from that of home and community-based services where outcomes are not as black and white and can rarely be validly assessed on the basis of single items or frequency counts.

The National Quality Forum HCBS Outcome Measurement Framework

In 2006, the U.S. Department of Health and Human Services (HHS) through CMS contracted with the NQF to convene a panel to develop a framework that would guide measurement of HCBS outcomes for people with disabilities. The framework developed by the NQF committee ultimately included 11 domains (e.g., Community Inclusion, Choice and Control, etc.) and 40 subdomains. In our exploration of risk adjustment, we focus on these domains in order to explore how current risk adjustment practices can be used in evaluation and research related to these important quality of life outcomes for HCBS recipients. It should be noted, that the NQF has not engaged in any research in an attempt to validate its framework with stakeholders. However, the authors, as part of the Research and Training Center on HCBS Outcome Measurement, have conducted research with stakeholders that provides evidence of content validity of the framework (11).

Risk Adjustment and Home and Community-Based Services Outcomes

In the field of HCBS outcome measurement, research has demonstrated that outcomes related to choice-making and job attainment are associated with both individual (12–14) and system-level factors (12, 15) suggesting that risk adjustment maybe a useful procedure to consider when examining these outcomes in this area. Even though HCBS outcomes for people with disabilities have been studied extensively, including the influence of covariates, risk adjustment has, to date, not been a common practice.

Risk adjustment in HCBS can be used to enhance informed choice when selecting providers and services and as a way to monitor system quality [see for example (2)]. The failure to take in to account important individual and systemic differences between providers (e.g., age and gender of clients served), may result in ratings providing consumers with information that is neither reliable nor valid. If such efforts at transparency and consumer choice can be combined with risk adjustment, models such as Gressel's (2) can be expanded to support more informed and equitable decision-making.

Challenges of capturing individual level variance that are result of relatively stable individual characteristics can be seen in the experience of disability itself. Conditions that are disabling differ qualitatively as well as with respect to their magnitude. In addition, some of these characteristics (e.g., cognitive capacities) can fluctuate over periods of time. In addition, disability itself entails both human factors as well as those present in the environment (16). The characteristics of person-level factors include disabilities that traverse the domains of physical and mental health, cognitive and functional conditions. Specific disabling conditions can co-occur. An individual may experience intellectual disability as well limitations associated with chronic illness. The combination of person-level factors with challenges people with disabilities experience in the environment (e.g., lack of accessibility), raises the question as to which factors to meaningfully include in risk adjustment. Monitoring disability over time adds another consideration, as disabilities may have different onset, cycle and evolution.

Risk Adjustment and Statistical Methodology

Risk adjustment requires sophisticated statistical techniques. Generally, multivariate methods are used, including analysis of covariance (ANCOVA), regression, structural equation modeling (SEM), as risk adjustment involves evaluating the relationship between variables of interest and outcomes, while simultaneously accounting for risk factors. Used appropriately, these methods allow one to statistically account for the effect of individual factors (that play a role but are uncontrollable) permitting assessment and understanding of those effects separately from the primary factors of interest (6, 17).

Cautions With Respect to the Use of Risk Adjustment

Although risk adjustment techniques have the capacity to improve the interpretation of results related to the outcomes experienced by HCBS beneficiaries, there are caveats. Murtaugh et al. (18) compared simple risk adjusted models for home health care quality to more complex models that employed a stepwise approach. They found similar results but noted there are advantages to simpler models that use risk adjustment to a lesser extent. These trade-offs are particularly important to consider when dealing with small datasets as the inclusion of too many risk adjusters can obscure relationships by spreading variance across multiple variables. It is also important to consider that one loses explanatory power when increasing the number of risk adjusters included in a model (18).

It must also be acknowledged that risk adjustment can be misused. States, managed care organizations, and providers could potentially employ this information as an excuse for poor outcomes. Used appropriately, however, risk adjustment can instead be used to help identify those relatively unchangeable conditions or characteristics of beneficiaries that require the need for additional supports or services if positive HCBS outcomes are to be achieved.

Despite these considerations, the use of risk adjustment techniques in assessing outcomes related to HCBS warrants exploration. Herman et al. (19) in an meta-analysis of risk adjusters found that diagnostic (e.g., illness severity) and demographic (e.g., age) risk adjusters accounted for 6.7% of variance on average and up to 22.8% in models maximizing the use of adjusters. These findings clearly indicate that risk adjustment can make a significant difference in results and their interpretation.

Study Purpose

This study sought to identify and assess individual level risk adjusters of HCBS outcomes for people with several different types of disabilities. In order to reduce complexity and because the majority of the studies identified included individual-level factors, systems-level risk adjusters are not a focus of this article. Study efforts first focused on the identification, cataloging, and evaluation of risk adjusters used in current research within HCBS. A set of risk adjusters common across disability populations was then used in the data collection process. In the final step of the process, the relevance of risk adjusters in relation to HCBS outcomes for people with disabilities, as specified in the domains and subdomains of the NQF's (20) conceptual framework, were reviewed. Based on the study purpose, the following research questions were addressed:

1. What is the population of existing individual risk adjusters used in examining the outcomes of people with disabilities who are HCBS beneficiaries and the frequency of their use?
2. What is relative importance of existing individual risk adjusters in HCBS outcome measurement as determined by experts in the field?
3. With what frequency have the reviewed risk adjusters been used to better understand outcomes in NQF HCBS measurement domains experienced by people with different types of disabilities?

METHOD

Although a systematic review of the literature is a step toward creating a more reliable scientific-basis for confirming or refuting ideas about the use of risk adjusters in disability related-outcome research, this approach suffers from several shortcomings (21). In and of themselves, such reviews do not utilize a systematic tool for combining the results of multiple studies and lack methods necessary to merge findings together to provide a more reliable understanding of outcomes. Their focus is often on statistical significance rather than the magnitude of effects and rarely are critical factors including sample characteristics and study design features factored into outcome evaluations.

While a systematic review aims to provide a comprehensive literature search with pre-defined eligibility criteria, a *meta-analysis* combines and synthesizes findings with statistical models (22). In doing so it statistically assesses effect sizes and models the effect sizes with study characteristics focusing on the magnitude of the effect size (23, 24). Effect sizes are weighed by their precision and in addition to the ability to determine average effect size, one can also estimate the consistency of effects across different studies. The approach also lends itself to the use of moderators to explain observed variations in effect size.

However, a meta-analysis is not always the best solution to understand the impact of one set of variables on others. Research extracted from the extant literature may not include sufficient information to calculate the effect sizes needed for a meta-analysis. A more elementary question is whether there are a sufficient number of primary investigations for a valid meta-analysis to be undertaken in the first place. Although it is theoretically possible to conduct a meta-analysis with only a few studies, drawing conclusions on the basis of small, less than robust and representative samples is likely to lead to unstable results. Another potential reason for using a methodology other than meta-analysis is when the existing research consists of studies with decidedly different objectives, designs, measures, and samples that make it conceptually difficult to combine studies (25). The availability of only a small number of well-conducted empirical studies with representative samples may also indicate that the field is not mature enough to yield useful findings utilizing this approach.

Although there has been a considerable amount of work undertaken in order to better understand the impact of HCBS on beneficiaries, well-designed studies that have utilized risk adjustment remain limited. For this reason, as well as limitations of the existing research in relation to requirements for valid meta-analysis, it would be pre-mature at this time to utilize this approach. As described in the following section, as an alternative we employed a process believed to be more appropriate for the current state of the field. It entailed: (1) the identification of risk adjusters in published HCBS outcome research and their frequency of use; (2) ratings of the importance of the risk adjusters that have be used in HCBS outcome research by technical expert panels; and (3) assessment of the extent to which these risk adjusters have been used to explain HCBS outcomes as specified by NQF HCBS outcome domains (20).

Literature Search and Study Selection

The first phase of the study consisted of a systematic review of literature on potential risk adjusters associated with the outcomes experienced by HCBS beneficiaries with five different types of disability including intellectual and developmental disability, physical disability, psychiatric disability, age-related disability, and traumatic brain injury. We worked within our project team and technical experts to develop a comprehensive list of keywords. Keywords included combinations of the following words and phrases as Boolean operators: quality of life, outcome, community, risk adjustment, risk factor, covariate, disability, intellectual disability (ID), developmental disability (DD), intellectual and developmental disability (IDD), aged, residential support, independent living, transition, Assertive Community Treatment (ACT), mental health, HCBS, physical disability, traumatic brain injury (TBI), mobility disability.

Searches were conducted across disciplines and research areas, including disability, mental health, social work, gerontology, policy, and public health using the following databases: the Cochrane Database of Systematic Reviews, Google Scholar, JSTOR, Academic Search Premier, PsychINFO, Social Work Abstracts, The National Rehabilitation Information Center, CINAHL, Ovid Medline, Social Sciences Citation Index (Web of Science), and PubMed. In addition, the most recently published research was directly reviewed in a variety of disability-focused journals including the American Journal on Intellectual and Developmental Disabilities, Disability and Health Journal, Disability Studies Quarterly, Journal of Community Health, Journal of Community Practice, Journal of Mental Health, Journal of Healthcare for the Poor and Underserved, Journal of Aging and Health, Journal of the American Geriatrics Society, Journal of Aging and Social Policy, Social Work Research, the Gerontologist, the Journals of Gerontology Series B, and Journal of Gerontological Social Work. Using the keywords listed above in the stated databases resulted in an initial set of 263 studies.

Two sets of evaluative criteria to identify high-quality studies were applied. The first seven criteria listed below are based on previously established standards (26). To these criteria three additional standards developed by our research team: recency (i.e., studies published after 2000), quantitative data and statistical analyses used, and samples with adults with disabilities (i.e., individuals ages 18 and above) were added.

The final selection criteria required that: (a) the reviewed study question/objective was described in sufficient detail, (b) study design was clearly described, (c) outcome and exposure measures were well defined, (d) analytic methods were described, (e) study controlled for confounding variables, (f) results were reported in sufficient detail, (g) conclusions were supported by results, (h) study included a targeted disability population aged 18 and older, (i) there was a quantitative aspect to the investigation that was not merely descriptive, (j) analysis included potential risk adjusters via covariates or predictors, and (k) publication date was 2000 or later. After applying these criteria to the initial set of 263 studies, a final dataset of 29 investigations focused on HCBS outcomes associated with the NQF's (20) conceptual Framework for HCBS Outcome Measurement met inclusionary criteria for the present study. **Figure 2** provides more detail in our selection process.

Identification of Risk Adjusters

Each study that met inclusion criteria was assigned a unique ID and coded by two coders who kept detailed notes for each risk adjuster identified. In addition, measurement instrument(s) used, response options/scale of measurement, and target population were coded. Following the selection of that portion of the research literature that met the required criteria, all variables included in statistical models within each of the selected articles were independently identified and cataloged by two coders. These variables included all predictors, covariates, and outcomes. **Table 1** shows a snapshot of the cataloging process. The two coders met weekly with a third team member to compare their coding and confirm that each variable had been entered correctly. Any discrepancies between coders were discussed. The final decision regarding risk adjuster inclusion or exclusion was achieved by consensus between all three researchers.

Using this method, variables were extracted from all studies in the data corpus. Coders identified and listed all variables included in each study, sorted them as either *potential* risk adjusters (predictors and undefined covariates that could be risk adjusters) or outcome variables and entered them into the study database. Variables were coded as outcomes if they were identified by the study author(s) as such and included in a statistical model as an outcome. All variables that were not outcomes included in a statistical model as having a statistically significant relationship with an outcome were coded as potential risk adjusters[1].

---

[1] The distinction between covariates vs. risk adjusters was therefore not made in the present study, and all variables included in statistical models that were significantly associated with an outcome variable were included as potential risk adjusters for the purposes of this study.

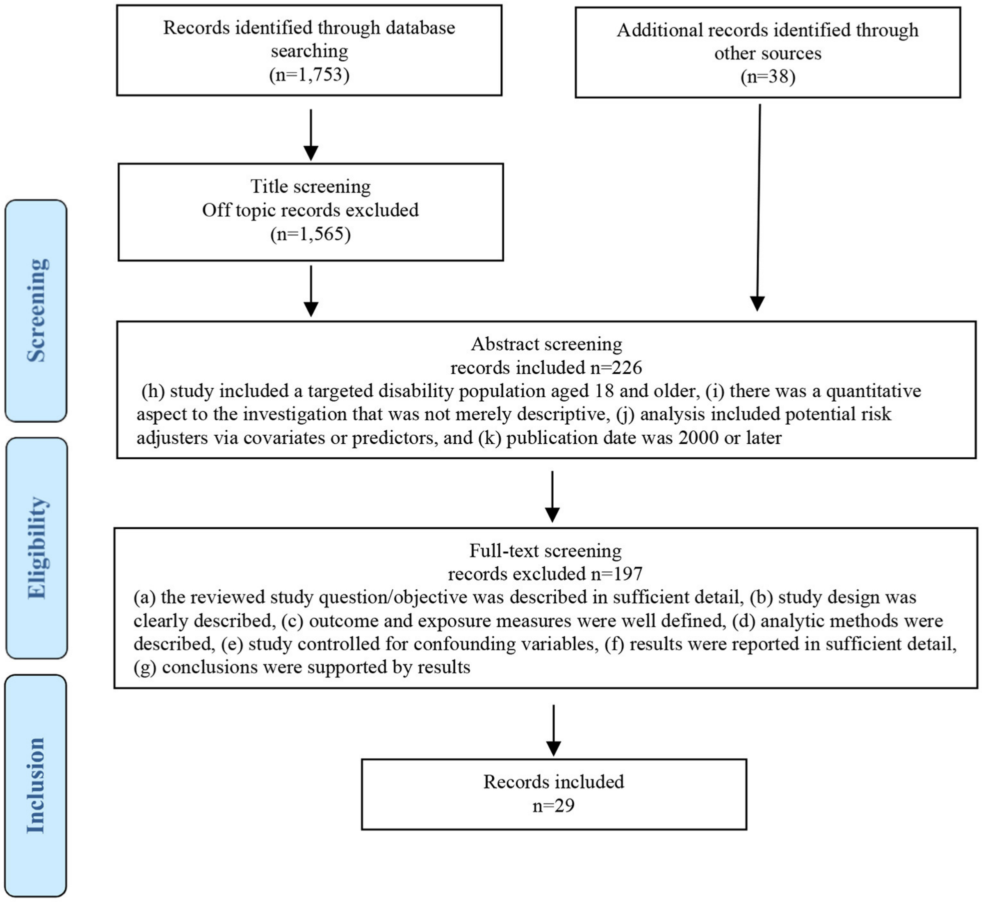


FIGURE 2 | Flow diagram of literature search and selection process.

TABLE 1 | Process of cataloging studies and variables.

Study ID	Study author and year	Include (y/n)	Population	Citation	Predictors (coder 1)	Predictors (coder 2)	Predictors (decision based on agreement)	Outcome (coder 1)	Outcome (coder 2)	Outcome (decision based on agreement)	Notes
1	Jones (2019)	Yes	TBI	APA	Names, measures	Names, measures	Names, measures	Names, measures	Names, measures	Names, measures	

Research Question #1: Coding of Risk Adjusters

Once potential risk adjusters had been entered into the database, they were reviewed and grouped into categories based on their concept of focus and characteristics. Categories are higher order concepts that subsume lower-order concepts that share observations or properties (27, 28). In our case, categories were developed by grouping together shared concepts or characteristics. For example, several studies included depression as a risk adjuster. Although these studies used various instruments to measure depression, the intent to control for depression was the same across studies. Therefore, although depression was measured differently across studies, the risk adjuster that each study identified was the same, and consequently each risk adjuster was labeled using the same code. Using this method, the team grouped all extracted risk adjusters into categories.

New codes and definitions for groups of risk adjusters were developed and updated by coders, a third tiebreaker, and with assistance from the research team at weekly meetings. Any risk adjuster that did not fit an existing category was discussed at weekly meetings with the research team and reviewed to determine whether a new code was justified. Once the codebook was updated to accommodate any new information, final decisions for codes to be applied were determined by consensus. Each risk adjuster received a single code based on the final version of the codebook. The formation of "new" categories ceased at a point at which saturation was reached and new risk adjuster types were not being found. **Table 2** shows the definitions for the final group of risk adjusters developed for the purposes of this study. Once this process was complete, frequency counts could take place indicating the number of eligible studies in which each identified risk adjuster was employed.

Research Question #2: Expert and Internal Ratings of Risk Adjusters

Expert Panel Ratings

The number of times a risk adjuster is included in the literature is not necessarily an indication of its quality. The second phase of this study therefore entailed the convening of TEPs to evaluate the importance, feasibility, and usefulness of the risk adjusters found in the literature.

For our expert panels, we collaborated with scholars in the field of disability and HCBS, including representatives from the field of intellectual and developmental disabilities, traumatic brain injury, physical, psychiatric and age-related disabilities. Technical experts ($n = 16$) were selected from a variety of sources including the leadership committee for the Rehabilitation Research and Training Center on HCBS Outcome Measurement, The National Advisory Committee of the Center, provider agencies, The Association of University Centers on Disability, and state HCBS programs. Members from university settings and/or research centers affiliated with universities were selected not only due to their knowledge of HCBS but on the basis of their work with target populations. The experience of panel members in HCBS and their disability-specific fields ranged from 14 to 35 years. Each TEP member expert was asked to independently rate the quality of the HCBS relevant risk adjusters identified in the literature.

TEP ratings were obtained using the Qualtrics survey platform. Panel members were asked to prioritize which risk adjusters should be included in future research by independently rating them on multiple dimensions (described below) which were submitted to and agreed upon by the TEP prior to administration of the survey.

TEP members rated the priority of each risk adjuster by independently considering its: (1) feasibility, (2) usability, (3) importance, and (4) accuracy. For this study, *feasibility* was operationally defined as the extent to which information for risk adjustment could be captured without undue burden to participants and/or those collecting and using the data. *Usability* was conceptualized as the likelihood that information provided by the risk adjuster in question would be understandable and useful to its intended audience and lead to either quality improvement and better decision making in HCBS. *Importance* was defined as the relevance of the risk adjuster to the lives of HCBS beneficiaries and how likely the risk adjuster would be helpful in explaining outcomes in multiple domains. *Accuracy* was conceptualized as the ability of the risk adjuster to reliably provide the valid information over time and across data sources.

After the initial rating by TEPs, data were compiled and presented to panels for discussion. Based on the feedback provided, operational definitions and dimensions of quality (feasibility, usability, importance, and accuracy) were modified and a final version of the survey re-submitted. This revised

TABLE 2 | Internal definitions used to categorize risk adjusters.

Risk adjuster	Definition
Age	Age in years or age range
Caregiver characteristics	Features of non-staff caregivers relevant to their care of persons with disabilities
Chronic conditions	Presence of long-term physical conditions which may have implications for mortality
Cognition	Current intellectual functioning, including the ability to remember, recall, learn, concentrate, or make decisions
Comorbidity	Co-occurrence of more than one physical and/or mental health-related condition in the same person, simultaneously or sequentially, where one condition may be primary and another secondary
Condition duration	Duration of time since the onset of a condition, injury or change in health status which led to physical or mental health symptoms
Education	Level of or number of years of schooling
Employment	Current employment status and/or type of employment
Ethnicity/Race	Social group with a common national or cultural tradition
Family member demographics	Information about members of the participant's family, such as parents or siblings
Formal supports	Type or amount of support received from care provider networks, government, or organizations—availability, specificity, satisfaction, and overall degree of care received
Functional disability	Level of functionality in daily life in the presence of short or long-term limitations due to a disabling condition or health problem
Health Indicators	Any physiological measure known to predict health outcomes, specifically decreased functionality and morbidity
Income	Amount of money regularly received by household, family, or individual
Length of stay	Duration of stay at a hospital, rehab, or inpatient care facility
Living arrangement	Type of residence in which the individual lives, including the type of facility and with whom they live
Mental health	Indicators of mental health functioning, including mental health diagnoses
Number of children	How many people, usually children, the individual helps take care of or has living in their household
Population type	Membership in a specific disability population
Region	Geographic location
Relationship status	Whether the individual currently has a partner, a spouse, or are not currently in a relationship
Risky behaviors	Engagement in risky or negative behaviors that have implications for the development of health-related conditions or socially undesirable outcomes
Self-efficacy	The individual believes that he or she can engage in the behaviors necessary to exercise choice and control over aspects of their lives
Sex/Gender	Sex or gender of individual, typically self-reported
Social support availability/engagement	Type or amount of support received, either by availability or by choice, from informal or socially close sources such as family, friends, or community
Symptom severity	The degree of physical, mental health, or cognitive symptoms experienced or change in functional status within a given time interval
Use of a proxy	The degree to which the person with a disability answers questions relevant to their care as opposed to some other individual such as a parent or staff member

survey included suggested new risk adjusters and improved operational definitions. After administering this survey, data were summarized and presented back to the panel. Summary data consisted of frequency counts, mean ratings, and standard deviation calculations to determine the average importance and level of agreement for each risk adjuster. After reviewing results, TEPs engaged in discussion and worked toward achieving consensus on a final ranked list of risk adjusters and definitions. In this way, widely-used risk adjusters viewed by TEP members as most critical to develop a better understanding of the outcomes experienced by HCBS beneficiaries were identified.

Internal Ratings With Respect to Target Populations and Outcomes

Following the input of TEP members, an internal panel of research staff independently assessed the selected risk adjusters in terms of their suitability for use with different populations and outcomes. These ratings were undertaken to control for the difference between general covariates (or predictor variables) and variables better suited for risk adjustment (NQF). Utilizing the guidelines provided by the NQF [(7), pp. 9–10] each rater independently assessed the list of risk adjusters. These ratings, in conjunction with TEP evaluation were used in order to: (1) clarify differences between risk adjusters and other covariates, and (2) identify risk adjusters that would be appropriate for use with multiple disability groups and HCBS-related outcomes and to further guide our recommendation process.

Research Question #3: Risk Adjusters and Study Outcomes

A third round of coding was utilized to classify outcomes included in the reviewed studies into conceptual groupings and determine their correspondence with NQF HCBS outcome domains (20) as well as organize outcomes into interpretable categories for analysis. This process entailed two coders independently coding each outcome into NQF outcome domains, plus two additional domains (employment and transportation) identified as of critical importance by stakeholder groups. Following initial coding, the two coders met with a third researcher who served as a mediator and ultimate tiebreaker with respect to outcomes in which there was disagreement between raters.

RESULTS

Research Question #1: Summary of Risk Adjusters by Populations

In order to address the first research question and determine the distribution of existing quantitative risk adjusters used in disability-related research associated with the NQF's (20) HCBS Outcome Measurement Framework, we calculated frequencies both for the overall use of each risk adjuster and separately for each targeted disability group (see **Table 3**).

The most commonly included individual-level risk adjusters were *functional disability* and *chronic conditions*, whereas the least common risk adjusters were caregiver characteristics and number of children. Demographic risk factors, such as age, sex/gender, ethnicity/race, and education level were frequently used as individual risk factors in all likelihood due to their accessibility and known ability to predict variance in outcomes. Physical and mental health-related risk adjusters (e.g., mental health diagnoses), risky behavior (e.g., drug use, smoking), and health indicators (e.g., BMI, BP) were also commonly utilized. This finding reflects the medical nature of much of the research on individuals with disabilities and the large number of studies on aging included in our sample. The described individual-level risk adjusters were identified across all population groups with the most frequently targeted population people with age-related disability ($n = 401$; 50% of total studies). People with psychiatric related disability was the least frequently covered population ($n = 33$).

With regard to the variables overlapping with the internal ratings based on NQF risk adjustment guidelines, we note that age, ethnicity/race, and sex/gender have been commonly used in many fields and population type specific to studies targeting multiple disability populations (e.g., aging and IDD groups).

Research Question #2: Survey Importance Ratings

In order to evaluate the importance, feasibility, and usefulness of existing risk adjusters used in HCBS-related research focused on outcomes included in the NQF framework, a TEP was convened and the ratings of reviewed risk adjusters analyzed. Ratings of risk adjusters by TEP members are shown in **Table 4**. For brevity and to highlight the top-rated risk adjusters, **Table 4** only includes those risk adjusters that were rated in the top half of those found in the literature with respect to importance. Bolded risk adjusters were also rated highly by our internal group of RTC/OM research staff based on NQF guidelines.

As can be seen in **Table 3**, a variety of *individual characteristics* (e.g., cognitive status, functional disability and age), *contextual factors* (e.g., living arrangement, formal supports and services), and health conditions (e.g., diabetes) were rated as having a high level of relevance. Note that some of these variables can be outcomes themselves, namely income and employment.

Research Questions #3: Risk Adjusters and Study Outcomes

In order to address our third research question on the alignment of the reviewed risk adjusters with outcomes identified in peer reviewed articles and organized by NQF domains, we calculated the frequency of use of each risk adjuster. This frequency was based on the percentage each risk adjuster was utilized within each NQF domain across identified outcomes (**Table 5**) provides a summary of these results. Risk adjusters listed in **Table 5** are in the same order as in **Table 2**, from most commonly to least commonly used across reviewed studies.

As can be seen in **Table 5**, studies with outcomes in the NQF domain *Holistic Health & Functioning* included the largest number of risk adjusters, followed by those addressing outcomes across *multiple domains* and *Community Inclusion*. The remaining NQF domains were found to have four or less risk adjusters. NQF domains not included in **Table 5** were found to

TABLE 3 | Individual-level risk adjusters by population group.

Risk adjuster	IDD	MH	Older adult	PD	TBI	Total count	Total % of RAs
Functional disability	25	5	60	16	20	126	15.8
Chronic conditions	17	2	72	20	21	132	16.5
Age	10	4	26	7	8	55	6.9
Mental health	8	4	32	8	9	61	7.6
Cognition	9	0	28	7	11	55	6.9
Sex/gender	7	2	24	5	9	47	5.9
Depression	2	2	17	3	7	31	3.9
Ethnicity/race	1	1	22	1	4	29	3.6
Education	3	2	13	4	6	28	3.5
Health indicators	2	1	11	5	4	23	2.9
Social support availability/engagement	5	2	9	0	6	22	2.8
Formal supports	3	2	7	0	9	21	2.6
Risky behaviors	7	0	10	4	6	27	3.4
Relationship status	1	2	12	0	5	20	2.5
Income	2	1	10	2	4	19	2.4
Living arrangement	4	1	12	0	0	17	2.1
Region	3	0	12	0	1	16	2.0
Symptom severity	0	0	2	4	7	13	1.6
Length of stay	1	0	10	1	1	13	1.6
Employment	4	1	0	1	6	12	1.5
Condition duration	1	0	2	2	5	10	1.3
Comorbidity	0	0	6	0	0	6	0.8
Population type	3	0	1	1	0	5	0.6
Family member demographics	2	0	0	0	1	3	0.4
Self-efficacy	1	0	1	1	0	3	0.4
Use of a proxy	1	0	2	0	0	3	0.4
Caregiver characteristics	0	0	0	0	1	1	0.1
Number of children	0	1	0	0	0	1	0.1
Total count	122	33	401	92	151	799	
Total % by disability group	15.3	4.1	50.2	11.5	18.9		

IDD, intellectual and developmental disability; MH, mental health; PD, physical disability; TBI, traumatic brain injury.

have no studies that included the use of risk adjustment. The most frequently included risk adjuster corresponding to the Holistic Health and Functioning domain was age, followed by gender, functional disability and ethnicity/race. Studies with outcomes across multiple domains included functional disability as most frequent risk adjuster, followed by age sex/gender, mental health and length of stay. Functional disability and age were the most frequently used risk adjusters among studies focused on the Community Inclusion domain of the NQF framework.

DISCUSSION

People with disabilities who receive HCBS experience a variety of outcomes based on their disability and the quantity and quality of services they receive. In the US, presence or absence of needed services, the quality of these supports, and their match to the person's needs vary dramatically between states, regions, and cities (29). When states or agencies evaluate the effectiveness of HCBS these efforts typical focus on directly examining the personal outcomes an individual experiences with covariates sometimes used to control for confounding factors. Unlike the healthcare field, risk adjustment has not been routinely used in HCBS evaluations to adjust results. The need for such adjustment is a result of inequalities that may exist as a result of gender, type and level of disability, quality, type, and intensity of supports, etc. at an individual, organization, or state level. Failure to take such differences into account when interpreting results can lead to an exacerbation of service and outcome inequities.

The purpose of this study was to contribute to the efforts toward making evaluations of service provision more accurate and equitable by conducting a systematic review and expert ratings of using risk adjusters in HCBS. The study was designed to: (a) identify, catalog, and evaluate risk adjusters used in recent HCBS-related research; (b) prioritize a set of risk adjusters that are useful in HCBS-related research across disability populations and, (c) identify the types of risk adjusters used in studies focused on various NQF domains.

TABLE 4 | Average ratings by expert panel of top half of rated individual level risk adjusters.

Risk adjuster	Average rating
Cognition	4.3
Chronic conditions	**4.1**
Living arrangement	4.1
Natural support engagement	4.1
Functional disability	4.1
Age	**4**
Mental health	3.9
Population type	**3.7**
Formal supports and services	3.6
Level of Communication	3.6
Ethnicity/race	**3.6**
Income	3.6
Sex/gender	**3.6**
Comorbidity	**3.6**
Employment	3.6

Mean rating for all risk adjusters was 3.5 (SD = 0.04). Bolded risk adjusters also ranked highly based on internal rankings of research project staff based on NQF guidelines. The potential range rankings was from 1 to 5.

Based on the results of this study, we recommend that four primary risk adjusters be tested in future investigations for use in HCBS outcome measurement. These risk adjusters include: (1) *chronic conditions* (presence of long-term physical conditions that may have implications for mortality); (2) *functional disability* (level of functionality in daily life in the presence of short or long-term limitations due to a disabling condition or health problem); (3) *mental health* (indicators of mental health functioning, including mental health diagnoses); and (4) *cognition* (current intellectual functioning, including the ability to remember, recall, learn, concentrate, or make decisions). These four risk adjusters have been recommended for future testing because they: are not specific to a particular disability population, were rated highly by members of TEPs, matched recommended NQF guidelines for risk adjusters, and included under at least two NQF domains. We excluded demographic risk adjusters from our recommendations since they are commonly used as covariates and we wish to highlight other factors with potentially confounding effects when studying particular outcomes.

The recommendation presented are consistent with the findings of several previous investigations that identified similar factors that control for confounding variables in explaining HCBS-related outcomes. Based on their analyses, the National Core Indicators—Aging and Disabilities (NCI-AD) data collection program, for example, has identified 15 characteristics they recommend as risk adjusters including: the amount of assistance needed for everyday activities and for self-care, overall health, level of hearing, level of vision, presence of a mental health diagnosis, and whether a person forgets things (30). Tichá et al. (31) in the summary findings of predictors based on studies using the NCI – In Person Survey (NCI-IPS) found that at the individual level, challenging behavior, psychiatric diagnosis, and level of ID, had significant explanatory power in accounting for outcomes among people with IDD. Herman et al. (19) identified severity of diagnosis, substance abuse, baseline functioning and quality of life as significant factors in clinical outcomes in their review of literature of risk-adjusting outcomes of mental health and substance-related care. The result of these studies support the four constructs put forth as recommended risk adjusters for further study.

Prioritized Risk Adjusters

This next section summarizes information on the recommended risk adjusters of chronic conditions, functional disability, mental health and cognition based on previous research within the context of risk adjustment in HCBS.

Chronic Conditions

A chronic condition is a persistent or otherwise long-lasting human health condition or disease that lasts for more than 3 months. In the US, 25% of adults have at least two chronic conditions (32). Two frameworks conceptualizing the effect of chronic conditions on disability are the *Disablement Process* (33) and the *International Classification of Functioning, Disability, and Health* (34). Both frameworks posit that health conditions intersect with the environment to lead to activity limitations (35). This intersection is exactly how chronic conditions function as potential risk adjusters in disability research. Some disabilities can be considered primary chronic conditions (e.g., arthritis), while others (e.g., mild arthritis) experienced by a person with IDD could be considered a secondary condition. The accumulation of such conditions among members of a population can make it difficult to disentangle the differences between service delivery approaches when conditions are not evenly distributed between individuals or groups. Research has demonstrated that limitations in role performance due to chronic conditions (e.g., diabetes etc.) can lead to difficulties in performing valued activities (36). Thus, when assessing outcomes, risk adjusting for the prevalence of chronic conditions may capture variance unrelated to the primary disability of interest, thereby improving estimates of other factors (e.g., an intervention) being studied.

Functional Disability

Functional disability has been conceptualized as one's functional status, capacity, limitations, and/or disability status (37, 38) and has been used to better understand physical frailty, fatigue, Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and mobility (39, 40). Currently, however, there is not a uniform definition of functional disability, with each set investigators drawing conclusions based on their own, personal perspectives on the construct.

Risk-adjustment may not always be meaningful with respect to functional disability as it can vary from a long-term limitations to those that are episodic or co-occurring along with other conditions. For example, whereas physical frailty was found to be associated with risk of mild cognitive impairment (39), cause and effect are not known (41). The use of functional disability as a risk adjuster therefore depends on whether the assumed type of a functional disability is a stable trait. For some sub-populations

TABLE 5 | Percentages and frequency of risk adjusters used across NQF domains.

Risk adjusters	Multiple domains ($N = 11$)	Holistic health and functioning ($N = 24$)	Service delivery and effectiveness ($N = 3$)	Community inclusion ($N = 4$)	Choice and control ($N = 2$)	Human and legal rights ($N = 1$)	Caregiver support ($N = 1$)	Employment ($N = 2$)
Functional disability	63.6% (7)	58.3% (14)	66.7% (2)	75.0% (3)	100.0% (2)	100.0% (1)	0.0% (0)	50.0% (1)
Chronic conditions	27.3% (3)	37.5% (9)	66.7% (2)	25.0% (1)	50.0% (1)	100.0% (1)	0.0% (0)	0.0% (0)
Age	54.5% (6)	95.8% (23)	100.0% (3)	75.0% (3)	100.0% (2)	100.0% (1)	0.0% (0)	50.0% (1)
Mental health	45.5% (5)	29.2% (7)	33.3% (1)	50.0% (2)	100.0% (2)	100.0% (1)	100.0% (1)	0.0% (0)
Cognition	27.3% (3)	41.7% (10)	66.7% (2)	50.0% (2)	50.0% (1)	100.0% (1)	100.0% (1)	0.0% (0)
Sex/gender	54.5% (6)	83.3% (20)	66.7% (2)	50.0% (2)	50.0% (1)	100.0% (1)	0.0% (0)	50.0% (1)
Depression	27.3% (3)	41.7% (10)	33.3% (1)	50.0% (2)	50.0% (1)	100.0% (1)	0.0% (0)	0.0% (0)
Ethnicity/race	9.1% (1)	58.3% (14)	33.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Education	9.1% (1)	54.2% (13)	33.3% (1)	50.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Health indicators	9.1% (1)	20.8% (5)	33.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Social support availability/engagement	27.3% (3)	12.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Formal supports	0.0% (0)	20.8% (5)	100.0% (3)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Risky behaviors	0.0% (0)	20.8% (5)	0.0% (0)	0.0% (0)	50.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Relationship status	9.1% (1)	33.3% (8)	66.7% (2)	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Income	9.1% (1)	25.0% (6)	0.0% (0)	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Living arrangement	9.1% (1)	29.2% (7)	33.3% (1)	0.0% (0)	50.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Region	0.0% (0)	8.3% (2)	33.3% (1)	0.0% (0)	50.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Symptom severity	27.3% (3)	12.5% (3)	33.3% (1)	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Length of stay	45.5% (5)	8.3% (2)	0.0% (0)	25.0% (1)	50.0% (1)	100.0% (1)	0.0% (0)	0.0% (0)
Employment	9.1% (1)	16.7% (4)	0.0% (0)	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)
Condition duration	27.3% (3)	16.7% (4)	0.0% (0)	25.0% (1)	0.0% (0)	0.0% (0)	100.0% (1)	0.0% (0)
Comorbidity	0.0% (0)	16.7% (4)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Population type	9.1% (1)	4.2% (1)	0.0% (0)	0.0% (0)	50.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Family member demographics	0.0% (0)	8.3% (2)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Self-efficacy	0.0% (0)	8.3% (2)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Use of a proxy	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Caregiver characteristics	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Number of children	0.0% (0)	4.2% (1)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)

*Numbers is brackets () denote the frequency of studies. Risk adjusters listed same order as **Table 2**, from most commonly used to least commonly used across studies assessed. The NQF domain "System Performance and Accountability" is not included as it was not an outcome in the studies assessed in this analysis. Ns per domain here exceed the 29 studies that are mentioned in the methods section as meeting inclusion criteria due to many studies having included more than 1 outcome included separately in this analysis.*

(e.g., people with TBI or age-related disabilities) functional ability is likely to change over time. For others (e.g., people with IDD) this is not as likely to be the case. Thus, risk-adjusting for the IDD sub-population makes sense whereas it does not for persons with TBI or age-related disability.

Mental Health

The World Health Organization (WHO) defines mental health as a state of well-being in which people realize their own abilities, can cope with the stresses of everyday life, work productively, and are able to make contributions to their communities (34). People with disabilities often experience disadvantage that contributes to poor mental health (e.g., poverty, etc.) (42–44).

Although studies have attempted to appraise mental health in persons with disabilities, this has been challenging due to the heterogeneity among studies with respect to samples, range and type of disability, and mental health interventions under study (45). In addition, the scientific quality of studies at times falls short in terms of incomplete reporting of analyses, lack of clear definitional criteria, and the risk of bias (45, 46). These limitations as well as the myriad of formal and informal factors potentially contributing to mental health outcomes have, thus far, precluded establishing robust evidence as to risk adjusters that would likely generalize to all groups with disabilities.

Risk-adjustment for mental health also requires accounting for both type and severity of mental health conditions as manifested in various disability groups. For example, risk-adjusting for depression and/or anxiety due to congenital disability (e.g., cerebral palsy) may make more sense than adjusting for time-limited depression associated with an injury or stress that can be alleviated by adjustments in the environment.

Cognition

Cognition refers to the mental processes involved in gaining, retaining, and effectively using knowledge to adapt to ones' environment. Cognitive processes include thinking, knowing, remembering, judging, and problem-solving (APA Dictionary of Psychology, 2018). They are higher-level functions that include language, imagination, perception, and planning and can be measured in terms of both cognitive ability and disability. Cognitive disability has been associated with greater risk for less self-efficacy (42), and lower quality of life (47) not only among people with IDD but those with age-related and/or physical disabilities. It is related to the duration a person with age-related disability spend in hospital-level care (48, 49) and has been shown to mediate the relationship between physical activity and lower blood pressure (50). Among individuals with IDD, level of intellectual disability, a measure directly related to cognitive ability, has been associated with lower levels of self-determination (51), less choice-making (12) and lower levels of community-based employment (52–55).

The use of cognition (ability or disability) as a risk adjuster has the potential to help control for a significant amount of variation in outcomes within and between different disability groups. Considering cognition as a risk adjuster can potentially increase the accuracy of comparisons between groups on these outcomes. However, researchers must consider that some groups (e.g., people with age-related disabilities and TBI) can experience significant natural decreases or increases in cognitive capacities over extended periods while others (e.g. people with psychiatric disability) may demonstrate fluctuating capacity over periods as short as a day. Both of these situations can have a significant impact on the reliability of results.

CONCLUSION

The main aim of this study was to review and evaluate risk adjusters currently used in disability-related outcome research. Based on the findings, we have provided recommendations for potential risk adjusters that would appear to merit further empirical investigation that are: (a) not specific to a particular disability population, (b) rated highly by expert panels, (c) matched to the suggested NQF guidelines for risk adjusters, and (d) included under at least two NQF HCBS outcome domains. Based on what we have learned we can conclude that:

1. Demographic characteristics (e.g., gender, race, education level) are the most commonly used risk adjusters suggesting that both their known associations and feasibility are strong factors to consider in risk-adjustment selection. Such risk adjusters can be appropriate to control for unmalleable characteristics, which in turn can increase accuracy of conclusions and comparisons within HCBS.
2. Risk adjustment has most commonly been used in research related to health outcomes. Based upon existing investigations as well as ratings of our TEPs, chronic conditions, functional capacities, mental health condition, and cognition would appear to have the potential to be useful as risk adjusters in models assessing the outcomes experienced by individuals with disabilities. Through the consideration of risk adjustment at the individual level within HCBS, it is likely that the precision with which we are able to match services and supports to the needs of individuals with disabilities and thus improve their outcomes, will increase.

FUTURE DIRECTIONS

Outcome and Population Specificity

Risk adjustment is outcome dependent. Future research is needed to explore the impact of the recommended risk adjusters within the context of specific outcomes and populations within HCBS. Most of the risk adjusters considered in this study were associated with the NQF's Holistic Health and Function domain with few using risk adjustment found to address Human and Legal Rights, Caregiver Support, and Employment; and no risk adjusted observed with respect to Person-Centered Planning and Coordination, Equity, Workforce, or Consumer Leadership in System Development.

In a similar manner, it cannot be expected that a risk adjuster that works effectively with one population with specific levels of support needs will necessarily work well with others. The recommended risk adjusters need to be tested with different populations based on their disability type and intensity of support needs, age, gender, race, etc. to determine whether they function in ways intended and expected.

Level of Risk Adjustment

Although the purpose of this manuscript was to review broadly the state of risk adjustment in the field of disability research and HCBS, we focused on identifying potential risk adjusters at the level of the individual. There are, however, also factors beyond the individual (e.g., at the systems level) that need to be considered when evaluating HCBS outcomes. Such factors include, but are not limited to, available residential opportunities for people with disabilities, levels of support funding, expenditures of supports and services as well as employment policies and availability in different states or regions. Future research should therefore focus of a review and evaluation of system-level outcomes within HCBS.

LIMITATIONS

An extensive search of the literature was undertaken as part of this study, using specific key words and databases to locate studies that utilized risk adjustment. This approach could have led to leaving out relevant studies. In addition, the process used to code risk adjusters used in the existing research associated with various NQF outcome domains and subdomains ended when project staff used specified criteria to make a determination that construct saturation had been achieved. This approach could also have inadvertently led to leaving out relevant studies and risk adjusters.

Another limitation relates to the operational definition used for the construct of "risk adjuster." The difference between a covariate (an *explored* variable in relation to an outcome) and a risk adjuster (an intentionally *controlled* variable in relation to an outcome intended to improve the estimation of relationships in a model) is by no means clearly defined within HCBS or by researchers who investigate outcomes of people with disabilities.

It must also be noted that the distribution of NQF-relayed HCBS outcomes identified in the studies reviewed were limited. The dominance of studies focused on Holistic Health and Functioning demonstrates the medical/health focus of the literature identified for the purposes of this investigation. The lack of studied outcomes that fell into other NQF domains and subdomains could be a result of these outcomes being more often treated as mediators or moderators of health outcomes as opposed to important in their own right. These non-medical and non-service constructs, however, have been identified by the NQF, the University of Minnesota Research and Training Center on HCBS Outcome Measurement as well as a wide variety of stakeholders including people with disabilities themselves as critical and relevant for high quality of life, and should be a focus of study in future research.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

JH drafted the initial version of the manuscript, worked on the analyses, and lead the manuscript creation process. TK assisted with the analyses and writing of the manuscript. RT and BA both contributed to the initial conceptualization of the research and contributed to the writing of the manuscript. All authors contributed to the article and approved the submitted version.

FUNDING

The development of this manuscript was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), federal grant # 90RT5039.

REFERENCES

1. Shaughnessy PW, Hittle DF. *Overview of Risk Adjustment and Outcome Measures for Home Health Agency OBQI Reports: Highlights of Current Approaches and Outline of Planned Enhancements*. Denver, CO: Center for Health Services Research, UCHSC (2002). Available online at: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/downloads/HHQIriskadj.pdf (accessed July 29, 2021).
2. Gressel JW. Development of a quality ranking model for home health care providers. *Health Market Q*. (2013) 30:246–62. doi: 10.1080/07359683.2013.814503
3. Iezzoni LI. Risk adjustment for performance measurement. In: *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects*. Cambridge University Press (2009). p. 251.
4. Jencks SF. Changing health care practices in Medicare's Health Care Quality Improvement Program. *Jt Comm J Qual Improv*. (1995) 21:343–47. doi: 10.1016/S1070-3241(16)30160-2
5. Iezzoni LI, editor. *Risk Adjustment for Measuring Health Care Outcomes (Vol. 3)*. Chicago, IL: Health Administration Press (2003).
6. Fralich JT, Booth M, Keith RG. *Data Quality and Analysis: Managing and Using Home and Community-based Services Data for Quality Improvement*. New Brunswick, NJ: The Community Living Exchange Collaborative at Rutgers Center for State Health Policy and the National Academy for State Health Policy (2006).
7. National Quality Forum. *Risk Adjustment for Socioeconomic Status or Other Sociodemographic Factors*. Washington, DC: National Quality Forum (2014). Available online at: https://www.qualityforum.org (accessed July 29, 2021).
8. National Quality Forum. *Current Practices of Testing Social and Functional Status-Related Risk Factors Within Risk Adjustment Models of Performance Measurement*. Washington, DC: National Quality Forum (2020). Available online at: https://www.qualityforum.org (accessed July 29, 2021).
9. Centers for Medicare and Medicaid Services, Center for Consumer, Information, and Insurance, Oversight. *HHS-Operated Risk Adjustment Methodology Meeting Discussion Paper*. (2016). Available online at: https://www.cms.gov/CCIIO/Resources/Forms-Reports-and-Other-Resources/Downloads/RA-March-31-White-Paper-032416.pdf (accessed July 29, 2021).
10. Velentgas P, Dreyer NA, Nourjah P, Smith SR, Torchia MM, editors. *Developing a Protocol for Observational Comparative Effectiveness Research:*

A User's Guide. Rockville, MD: Agency for Healthcare Research and Quality (2013). Publication No.: 12(13)-EHC099. https://www.ncbi.nlm.nih.gov/books/NBK126190/pdf/Bookshelf_NBK126190.pdf (accessed July 29, 2021).

11. Abery BH, Roberts M, Nyce A, Houseworth J, Ticha R. *Content Validation of the National Quality Forum's HCBS Outcome Measurement FrameworkL Technical Report #1*. Minneapolis, MN: University of Minnesota Rehabilitation Research and Training Center on HCBS Outcome Measurement (2012).
12. Houseworth J, Stancliffe RJ, Tichá R. Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities. *Res Dev Disabil.* (2018) 83:77–90. doi: 10.1016/j.ridd.2018.08.008
13. Wehman P, Chan F, Ditchman N, Kang H. Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: a case control study. *Intellect Dev Disabil.* (2014) 52:296–310. doi: 10.1352/1934-9556-52.4.296
14. Yamamoto SH, Alverson CY. Successful vocational outcomes: a multilevel analysis of self-employment through US vocational rehabilitation agencies. *J Vocat Rehabil.* (2013) 38:15–27. doi: 10.3233/JVR-120617
15. Tichá R, Lakin KC, Larson SA, Stancliffe RJ, Taub S, Engler J, et al. Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellect Dev Disabil.* (2012) 50:486–504. doi: 10.1352/1934-9556-50.06.486
16. Altman BM. Disability definitions, models, classification schemes, and applications. In: Albrecht G, Seelman KD, and Bury M, editors. *Handbook of Disability Studies*. Thousand Oaks, CA: Sage (2001). p. 97–122.
17. Fortinsky RH, Fenster JR, Judge JO. Medicare and Medicaid home health and Medicaid waiver services for dually eligible older adults: risk factors for use and correlates of expenditures. *Gerontologist.* (2004) 44:739–49. doi: 10.1093/geront/44.6.739
18. Murtaugh CM, Peng T, Aykan H, Maduro G. Risk adjustment and public reporting on home health care. *Health Care Financ Rev.* (2007) 28:77.
19. Herman WH, Ma Y, Uwaifo G, Haffner S, Kahn SE, Horton ES, et al. Differences in A1C by race and ethnicity among patients with impaired glucose tolerance in the Diabetes Prevention Program. *Diabetes Care.* (2007) 30:2453–7.
20. National Quality Forum. *Evaluation of the NQF Trial Period for Risk Adjustment for Social Risk Factors*. Washington, DC: National Quality Forum (2017). Available online at: https://www.qualityforum.org (accessed July 29, 2021).
21. Cooper C, Selwood A, Livingston G. Knowledge, detection, and reporting of abuse by health and social care professionals: a systematic review. *Am J Geriatr Psychiatry.* (2009) 17:826–38. doi: 10.1097/JGP.0b013e3181b0fa2e
22. Cheung M, Vijayakumar R. A guide to conducting a meta-analysis. *Neuropsychol Rev.* (2016) 26:121–8. doi: 10.1007/s11065-016-9319-z
23. Pigott T. *Advances in Meta-Analysis.* New York: Springer Science and Business Media (2012).
24. Schmidt FL. History and development of the Schmidt–Hunter meta-analysis methods. *Res Synth Methods.* (2015) 6:232–9. doi: 10.1002/ jrsm.1134.
25. Cheung K, Wang TS, Farrokhyar F, Roman SA, Sosa JA. A meta-analysis of preoperative localization techniques for patients with primary hyperparathyroidism. *Ann Surg Oncol.* (2012) 19:577–83. doi: 10.1245/s10434-011-1870-5
26. Kmet LM, Cook LS, Lee RC. *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. HTA Initiative #13*. Edmonton, AB: Alberta Heritage Foundation for Medical Research (AHFMR) (2004).
27. Creswell JW, Hanson WE, Clark Plano VL, Morales A. Qualitative research designs: Selection and implementation. *Couns Psychol.* (2007) 35:236–64.
28. Corbin J, Strauss A. Developing concepts in terms of their properties and dimensions. In: Corbin J, Strauss A, editors. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. London: Sage (2015). p. 239–268.
29. Larson SA, Eschenbacher HJ, Taylor B, Pettingell S, Anderson L, Sowers M, et al. *In-Home and Residential Long-Term Supports and Services for Persons With Intellectual or Developmental Disabilities: Status and Trends Through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (2020). Available online at: https://icis.umn.edu/files/aCHyYaFjMi/risp_2017 (accessed December 12, 2019).
30. NCI-AD. *National Core Indicators® 2018–19 Aging and Disability (IPS) National Report.* (2019). Retrieved from: https://nci-ad.org/upload/reports/NCI-AD_2017-2018_National_Report_Part_1_FINAL_12-24-19.pdf
31. Tichá R, Hewitt A, Nord D, Larson S. System and individual outcomes and their predictors in services and support for people with IDD. *Intellect Dev Disabil.* (2013) 51:298–315. doi: 10.1352/1934-9556-51.5.298
32. Ward BW, Black LI. State and regional prevalence of diagnosed multiple chronic conditions among adults aged≥ 18 years—United States, 2014. *Morbid Mortal Wkly Rep.* (2016) 65:735–8. doi: 10.15585/mmwr.mm6529a3
33. Institute of Medicine. *Retooling for an Aging America: Building the Health Care Workforce*. (2008). Retrieved from: http://iom.nationalacademies.org/en/Reports/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce.aspx
34. World Health Organization and the World Bank. *World Report on Disability*. Geneva: World Health Organization (2011). Retrieved from: https://www.who.int/disabilities/world_report/2011/report.pdf?ua=1
35. Freeman RD. Tic disorders and ADHD: answers from a world-wide clinical dataset on Tourette syndrome. *Eur Child Adolesc Psychiatry.* (2007)16:15–23.
36. Verbrugge LM, Patrick DL. Seven chronic conditions: their impact on US adults' activity levels and use of medical services. *Am J Public Health.* (1995) 85:173–82. doi: 10.2105/AJPH.85.2.173
37. Gulley SP, Rasch EK, Chan L. The complex web of health: relationships among chronic conditions, disability, and health services. *Public Health Rep.* (2011) 126:495–507. doi: 10.1177/003335491112600406
38. Keysor JJ, Jette AM, LaValley MP, Lewis CE, Torner JC, Nevitt MC, et al. Community environmental factors are associated with disability in older adults with functional limitations: the MOST study. *J Gerontol Ser A: Biomed Sci Med Sci.* (2010) 65:393–399. doi: 10.1093/gerona/glp182
39. Boyle PA, Buchman AS, Wilson RS, Leurgans SE, Bennett DA. Physical frailty is associated with incident mild cognitive impairment in community-based older persons. *J Am Geriatr Soc.* (2010) 58:ds248–255. doi: 10.1111/j.1532-5415.2009.02671.x
40. Wolinsky FD, Bentler SE, Hockenberry J, Jones MP, Obrizan M, Weigel PAM, et al. Long-term declines in ADLs, IADLs, and mobility among older Medicare beneficiaries. *BMC Geriatr.* (2011) 11:1–12. doi: 10.1186/1471-2318-11-43
41. Royall DR, Lauterbach EC, Kaufer D, Malloy P, Coburn KL, Black KJ. Thecognitive correlates of functional status: a review from the Committee on Research of the American Neuropsychiatric Association. *J Neuropsychiatry Clin Neurosci.* (2007) 19:249–65. doi: 10.1176 /jnp.2007.19.3.249
42. Hughes AJ, Beier M, Hartoonian N, Turner AP, Amtmann D, Ehde DM. Self-efficacy as a longitudinal predictor of perceived cognitive impairment in individuals with multiple sclerosis. *Arch Phys Med Rehabil.* (2015) 96:913–9. doi: 10.1016/j.apmr.2015.01.008
43. World Health Organization, and the World Bank. *World Report on Disability.* (2011). Available online at: https://www.who.int/disabilities/world_report/2011/report.pdf (accessed July 29, 2021).
44. National Alliance on Mental Illness (NAMI). *Divert to What? Community Services That Enhance Diversion.* (2020). Available online at: https://www.nami.org/Support-Education/ Publications-Reports/Public-Policy-Reports/Divert-to-What-Community-Services-that-Enhance-Diversion/DiverttoWhat.pdf (accessed July 29, 2021).
45. Koslowski N, Klein K, Arnold K, Koesters M, Schuetzwohl M, Salize HJ, et al. Effectiveness of interventions for adults with mild to moderate intellectual disabilities and mental health problems: Systematic review and meta-analysis. *Br J Psychiatry.* (2016) 209:469–74. doi: 10.1192/bjp.bp.114.162313
46. Gustafsson C, Öjehagen A, Hansson L, Sandlund M, Nyström M, Glad J, et al. Effects of psychosocial interventions for people with intellectual disabilities and mental health problems: A survey of systematic reviews. *Res Soc Work Pract.* (2009) 19:281–90. doi: 10.1177/1049731508329403
47. Black BS, Johnston D, Morrison A, Rabins PV, Lyketsos CG, Samus QM. Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Qual Life Res.* (2012) 21:1379–89. doi: 10.1007/s11136-011-0044-z

48. Noyes K, Bajorska A, Wasserman EB, Weinstock-Guttman B, Mukamel D. Transitions between SNF and home-based care in patients with multiple sclerosis. *NeuroRehabilitation.* (2014) 34:531–40. doi: 10.3233/NRE-141056
49. Arling G, Kane RL, Valerie C, Teresa L. Targeting residents for transitions from nursing home to community. *Health Services Res.* (2010) 45:691–711. doi: 10.1111/j.1475-6773.2010.01105.x
50. Elias MF, Dore GA, Davey A, Robbins MA, Elias PK. From blood pressure to physical disability: the role of cognition. *Hypertension.* (2010) 55:1360–5. doi: 10.1161/HYPERTENSIONAHA.110.149823
51. Wehmeyer ML, Abery BH. Self-determination and choice. *Intellect Dev Disabil.* (2013) 51:399–411. doi: 10.1352/1934-9556-51.5.399
52. Houseworth J, Stancliffe RJ, Tichá R. Examining the national core indicators' potential to monitor rights of people with intellectual and developmental disabilities according to the CRPD. *J Policy Pract Intellect Disabil.* (2019) 16:342–51. doi: 10.1111/jppi.12315
53. Shogren KA, Ward MJ. Promoting and enhancing self-determination to improve the post-school outcomes of people with disabilities. *J Vocat Rehabil.* (2018) 48:187–96. doi: 10.3233/JVR-180935
54. Wehmeyer ML, Palmer SB. Adult outcomes for students with cognitive disabilities three-years after high school: the impact of self-determination. *Educ Train Dev Disabil.* (2003) 2003:131–44.
55. Wehmeyer ML, Shogren KA. Self-determination and choice. In: *Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities.* (2016). p. 561–584.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers
in Rehabilitation Sciences

PERSPECTIVE
published: 31 March 2022
doi: 10.3389/fresc.2022.873325

Don't Look Down: The Limits of Meroscopic Measurement

*Sue Swenson**

United States Department of Education, Washington, DC, United States

The essay examines some problems and opportunities of outcomes measures from a philosophical, political, and human rights perspective. Two suggestions for further effort are included: establish a person-centered outcomes research entity to help make outcomes measures more useful in decision-making and use a human rights framework to understand the impact toward which projects and programs aim.

Keywords: outcomes research, human rights, medical model, social model, intersectionality

Edited by:
Renata Ticha,
University of Minnesota Twin Cities,
United States

Reviewed by:
Shirli Werner,
Hebrew University of Jerusalem, Israel

****Correspondence:***
Sue Swenson
sue.swenson@gmail.com

Specialty section:
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

Received: *10 February 2022*
Accepted: *28 February 2022*
Published: *31 March 2022*

Citation:
Swenson S (2022) Don't Look Down:
The Limits of Meroscopic
Measurement.
Front. Rehabilit. Sci. 3:873325.
doi: 10.3389/fresc.2022.873325

Although he was often mischaracterized as an Aristotelian because he edited the "Introduction to Aristotle" for the University of Chicago Press, Richard McKeon was a strong proponent of pluralism. His commitment was to understand the principles, methods, and interpretations used by any thinker, to understand their work in its own terms, and to escape from the processes of attack and negation that had evolved in academic circles, forcing academics into ever-smaller defensible subject areas. He developed a systemic schema to explain how thinkers might evaluate and appreciate another's project even if it was at odds with their own project. Among the distinctions he made was that between holoscopic first principles, which looked at the part from the perspective of the whole and meroscopic first principles, which looked at the whole from the perspective of the part's simple elements (1). The latter is identified sometimes with Aristotle and the so-called scientific method and involved a separation between the knowers (and their biases) and what is known in a subject matter. I will attempt to identify some of the problems and issues that arise in systems of knowledge about disability when the first principles are universally meroscopic. We need to look up.

Born in medical randomized control trials, expanded in interdisciplinary efforts to prove that social sciences are just as rigorous as medical ones, relied on for decades to help sort proposals for research grants as well as plans and accountability measures for public funding of supports, and required in legislation that authorizes programs, outcome measures are inescapable in modern systems that serve persons with disabilities. They are ripe for rethinking.

Some of the problems of outcomes measures are inherent in the science or the math. Some are moral or ethical. Outcome measures may be the last redoubt of a medical model of disability, rejected by many disability thinkers in favor of the morally acceptable social model. The medical model locates the problems of disability in the person. It is meroscopic. It is supposedly dialectically opposed by the holoscopic social model, which locates the problems of disability in a non-inclusive, non-accommodating society. Even so, most disability services and supports are focused on the individual. This individual focus makes sense if you think of services and supports as something extra to which people are entitled by virtue of their disability. It would be difficult to imagine how the US system of social security disability payments could function without an individual focus. But the focus on the individual can also be a neoliberal fantasy or nightmare of bootstrapping, as if the person alone is responsible, say, for not being able to get or hold a job or for not being "able" to be included and educated in school with everyone else. These are only two examples of activities where the individual clearly must rely on a larger system to become inclusive to achieve goals. But our devotion to individual plans persists. The perseverance of the focus on an individual plan is potentially psychologically destructive to the individual who comes to blame himself or his child for not being able to achieve their goals in the face of systemic denial. That makes it immoral.

Outcome measures are reductive by nature as part of their effort to be "scientific," reducing the topics of interest in a human life down to measurable facts and indicators, just as a clinical trial of a treatment might measure blood levels of an important marker of progression of disease. But a person is not just an organism, and even medical science is now recognizing that an organism might have fundamental differences from others based on genetic codes. Medical science seems to be recognizing that its abundance of outcome measures does not necessarily help clinicians, patients, caregivers, employers, or others who need to make decisions about treatments. The Patient Centered Outcomes Research Institute (www.pcori.org) was created by Congress in 2010 to address this.

PCORI makes grants of about $2.5 billion per year, and its operating budget is around $105 million with a mission of mediating the utility of NIH research, budgeted at about $52 billion, with around $700 million of that being directed to medical rehabilitation research. The rest of the US federal investment in non-medical rehabilitation, habilitation, special education, and accommodations research is probably <$1 billion dispersed through several departments. A person-centered outcomes research institute in rehabilitation designed to help provide information that supports decision-making of disabled persons and their supporters might be imagined, then, in the $50 million range. Of course, the size of the health care market in the US at about 20% of GDP far outstrips the size of the market for rehabilitation: there is certainly more at stake in healthcare in terms of money.

Because the rehab investigator's points of interest are carefully delineated (meroscopic), rather than taking people as they are in the wild, outcome measures represent a truncated model of responsibility, measuring only the consequences of a program or intervention while ignoring the freedom, knowledge, capabilities, and sense of duty of the participants. Functioning much like genetic codes but with a much more direct and constant impact on the evolution of human society, these could be called the mimetic codes (2). As modern medicine is beginning to understand that outcomes of medical interventions may be mediated by the genome of the person, it may be important for rehabilitation researchers to recognize that compared to a genome, a person's gestalt (or the sum of all of their mimetic evolution) is even more complex and subject to learning and change, and probably more difficult to define.

Outcome measures focus only on the intended results and outcomes of a program without having the capability of identifying or reporting unintended consequences. The unintended consequences of behavior interventions can be severe and lifelong, but outcome measures often frame temporary compliance as success. In fact, the goal of a particular intervention may be defined as compliance with a specific instruction but the lifelong implications of entrained or enforced compliance might well include increased vulnerability, loss of a sense of self, and severely impaired self-efficacy.

Outcome measures of interventions and demonstrations seldom report actual financial results and costs. If a project is designed for a specified cohort but only half of the people identified as the target cohort ultimately participate, then the cost of the intervention is twice what was proposed. Likewise, in-kind contributions and opportunity costs of the intervention are generally not included as inputs or results. If a person spends most of their waking hours in treatment or therapy, what has been lost? Especially for children, the loss of opportunities for free play is not trivial. If an intervention requires a parent or family member to implement the intervention "at home," the loss to the child may be especially significant. Such a child may cease to see their parent as a comforting and nurturing presence always on their side and instead see them as another therapist with performance demands.

Outcome measures of social interventions focus on the person of interest and seldom consider what happens to others in their circle of support. Did the mother forgo employment to enable her adult son or daughter's independence or employment? Have her human rights been affected? Did a family experience divorce because of the stress of a "therapy" protocol? Is a personal assistant working at minimum wage and without health insurance? Is a caregiver required to ignore OSHA lifting standards at personal risk? Or worse, is the person with disabilities essentially abandoned to an overwhelmed family caregiver who may be depressed or abusive? The "outcomes" of new funding models like self-determination or self-direction require a closer look.

Outcome measures of systems already in place, rather than interventions or research studies, have responsibilities to the public, framed sometimes as diversity or intersectionality. It is possible to argue that in a public system meant to serve "the public," system outcomes should consist of a sum of outcomes of services and supports provided plus (or minus) the outcomes in the lives of others who received no support or services even though they would be eligible. In other words, an ethical system measures the outcomes for the persons served as well as the persons who should be served. Without this commitment, public services are at risk of overspending on a few people while ignoring many others and counting only the positive outcomes achieved by the few.

Sometimes, too, guardians are praised for the outcomes of their advocacy when they maximize the use of available funds, even when overspending may be negatively impacting the person's ultimate outcomes. This is analogous to a medical patient who does not understand that overtreatment can be as dangerous to their health as under-treatment. For example, if a State requires that all self-directed waiver funds go to direct support wages, a person may be in a position where they are staffed for every waking moment of their day. A man with intellectual disability described this to me as "one person to do the cooking and another to sit on the couch and control the remote." By the way, this man wanted nothing more than to do his own cooking, as he previously had been employed as a cook. He knew how to make hamburgers the way he liked them, but his funding plan meant he could never have that. He knew what he wanted to watch on TV, but he could not have that either. He enjoyed his solitary time, but that was always denied to him. And meanwhile, while this man is overserved, there are others with the same disabilities whose only supports come from their families as they live their lives on a waiting list. A holoscopic view is needed.

Outcome measures are part of an ongoing effort to construct an evidence base and protocols to guide how a person with a disability might be supported. This is especially obvious in educational environments, where recognized evidence is often limited to published peer-reviewed studies. There are several problems that accrue.

First, demonstrations may be carried out in separate or segregated environments for purposes of keeping "clean" data on individuals (a meroscopic goal). Often, schools attempting to duplicate these outcomes will copy the setting because they are trying to "demonstrate fidelity." And yet, a segregated environment is a violation of the human rights and the educational rights of the student, which must be prior to any considerations of intervention fidelity. Why should an intervention ever be tested in a segregated environment in the first place?

Second, students who have multiple or complex disabilities—who live their lives three standard deviations from the mean—are not included in statistical studies of interventions. They simply do not fit the definition. Thus, there is no specific evidence for supports that would "work" for them. Unfortunately, the absence of evidence may be interpreted in cash-strapped educational and human services settings as an excuse to do nothing. Worse, artificial intelligence may ignore or misconstrue their existence completely (3). There is often not a recognized floor of standard treatment or standard of care in education or human services as there is in medicine. This should be an ethical requirement and presumption in all systems that serve people with disabilities given that people with the most complex disabilities might appear nowhere in the hierarchy of evidence other than in the foundation of expert opinion and then again in epidemiological (or systems) studies. Without minimum standards of treatment *for all people*, I do not understand how reports of the outcomes of any targeted intervention can be ethical.

Third, educators are often not trained or supported to carry out and report their own outcome measures. If a teacher notices that a child is calm, focused, and happy when included in a small reading group, and tense and lashing out whenever they are taken into the little room for "direct service," that is an important outcome measure. It should stand up in planning meetings just as well as more incongruent published evidence does. It is important to remember that expert opinion is the foundation of evidence, and teachers and parents are often the only persons who have expertise about a particular child.

Fourth, outcome measures asserting evidence in favor of a particular intervention may be rigged through political processes that organize academic departments or they may slip through the cracks of peer review. No matter how carefully a peer review team is constructed, bad actors can infiltrate and carry their personal animosities or material interests into the review.

A plethora of seemingly positive studies for a single approach may make it seem like this is the only possible intervention. But just because something "works" for a selected sample does not mean it would work for everyone. Likewise, just because one study demonstrates that an approach "does not work" for one or more people does not mean that it cannot work for anyone. Those are both misconstructions of the meaning of statistical studies. And what if a set of studies were all conducted or even funded by persons who engage as professionals in the delivery of that intervention? What if some of them actively agitate to reduce funding to studies of alternative methods, or to deny academic appointments to persons who study alternative methods? This is not, strictly speaking, a problem of outcomes measures alone. It is a problem of research and of universities, and holoscopic. Nevertheless, outcomes can be where bad actors hide.

Fifth, the owners of interventions, whether they can legitimately claim intellectual property or are simply recognized experts in a topic, can use outcome measures in a kind of marketing sleight of hand to convince others that an intervention promises more than it really delivers. Some of these others may be naïve. Some, especially family members, are under enormous pressure or even duress. Some find themselves in a situation where they hope too much or are under pressure to find solutions. These include legislators, administrators of federal, state, and local programs, insurance executives, employers, educators, and families. This marketing is a meta-outcome of outcomes research which provides the tools and rhetoric to people who have their own enrichment as their only goal, or those who believe their own PR. I wish I knew what the answer to this problem could be. As a trained professional marketer, I used to say that you cannot sell a face cream with the same minimal level of evidence that most disability interventions demonstrate. Alas, the US Food and Drug Administration has proven itself quite incapable of regulating even recognized torture perpetrated on people with disabilities in the name of "treatment" with the same brio as it regulates cosmetics.

Outcome measures for human beings are typically not framed in terms of an intervention's likelihood to support or advance the human rights of the person being studied or others who are instrumental. It may be seen as "soft" to do so. Human rights are often reduced to the standards used by an Institutional Review Board where that exists, but these are not likely to be comprehensive enough and they do not touch every situation where outcome measures are used. Indeed, an IRB is more concerned with discovering how the process of a study may itself intrude on human rights, more than it seeks to know whether the ultimate outcome of the study might allow a person to better enjoy or expand their human rights.

A human rights framework is not a requirement of funding designs, but it is easy to see that a human rights framework would provide some of the necessary thinking to compare outcomes across two or more interventions. One intervention may be aimed at creating an outcome of reliable communication support for a person who does not use their voice to speak; simultaneously, another may be designed to help a person practice making sounds that may someday facilitate using their voice to speak. The conflict should be clear: pursuing communication support is a more direct way to achieve self-direction and independence, participation in meaningful education, better health care, the exercise of political, civil, economic, and social rights, and a host of other outcomes that directly impact the human rights of the person.

Perhaps we should make more effort to frame the interventions research we conduct in terms of the human rights the intervention is intended to achieve. Perhaps we can engage in a method of inquiry within an established framework of universal rights consistent with the Universal Declaration of Human Rights (UDHR) and the Convention on the Rights of People with Disabilities (CRPD). Besides being able to explain how the outcomes sought by a research project or program are pertinent to the physical or medical problems faced by the research sample or population, we would be able to discuss not just why we are doing no harm to the persons and their communities but also how these outcomes would help attain or secure their human rights or the human rights of everyone.

None of this is meant to impugn the rigor or intention of social sciences research. People struggle mightily to bring forth new ideas within the strict requirements of government grant applications. It may take more than one effort of inquiry and more than one run at asking why before we arrive at a statement of why a program or intervention supports human rights, or perhaps it will be immediately obvious that there is no connection to human rights at all. If the latter, why should the research or the program be funded with public money?

Sue Swenson and her husband raised three sons, one of whom had multiple and profound disabilities requiring lifelong educational and human services. Sue has served four US presidential administrations in various disability-focused offices, currently on a short-term advisory appointment in special education and rehabilitative services. Sue was educated at the University of Chicago (AB, AM) and holds an MBA from the University of Minnesota. She serves as president of Inclusion International and treasurer of the International Disability Alliance.

The author wrote this commentary outside the scope of their employment with the U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the U.S. Department of Education nor does mention of trade names, commercial products, or organizations imply endorsement of same by the U.S. Government.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

REFERENCES

1. McKeon R. *Freedom and History and Other Essays*. In: McKeon Z, editor. Chicago, IL: The University of Chicago Press (1990). p. 243–56.
2. Csikszentmihalyi M. *The Evolving Self: A Psychology for the Third Millennium (Harper Perennial Modern Classics) Paperback – August 21, 2018*. New York, NY: Harper Collins/Harper Perennial.
3. Treviranus J. *Sidewalk Toronto and Why Smarter Isn't Better*. Available online at: https://medium.datadriveninvestor.com/sidewalk-toronto-and-why-smarter-is-not-better-b233058d01c8 (accessed March 10, 2022).

Author Disclaimer: The author wrote this commentary outside the scope of their employment with the U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the U.S. Department of Education.

Conflict of Interest: The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Rehabilitation Sciences

POLICY AND PRACTICE REVIEWS
published: 28 April 2022
doi: 10.3389/fresc.2022.871178

Promising Practices in the Frontiers of Quality Outcome Measurement for Intellectual and Developmental Disability Services

Matthew Bogenschutz, Parthenia Dinora, Sarah Lineberry, Seb Prohn, Michael Broda and Angela West*

Virginia Commonwealth University, Richmond, VA, United States

Medicaid Home and Community-Based Services (HCBS) for people with intellectual and developmental disabilities (IDD) are vital for supporting people with IDD to live well in their communities, but there are not set standards for monitoring quality outcomes related to HCBS. In this paper, we propose promising practices for improving the quality of HCBS outcome measurement, based both in the literature and our own experience conducting an extensive U.S. state-level study. Specifically, we discuss: (1) using merged administrative datasets, (2) developing high-quality psychometrics that attend to ecological issues in measurement, (3) using advanced statistical analyses, and (4) creating immersive, user-friendly translational dissemination products. We conclude by suggesting what we see as important new frontiers for researchers to consider in order to enhance the quality of HCBS outcome measurement for people with IDD in the future.

Keywords: intellectual and developmental disabilities (IDD), Home and Community Based Services, outcome measurement and valuation, advanced statistics, administrative datasets, co-researchers with disabilities, translational dissemination

OPEN ACCESS

Edited by:
Jan Šiška,
Charles University, Czechia

Reviewed by:
Dana Anaby,
McGill University, Canada
Marguerite Schneider,
University of Cape Town, South Africa

****Correspondence:***
Matthew Bogenschutz
mdbogenschut@vcu.edu

Specialty section:
This article was submitted to
Disability, Rehabilitation, and Inclusion,
a section of the journal
Frontiers in Rehabilitation Sciences

Received: *07 February 2022*
Accepted: *05 April 2022*
Published: *28 April 2022*

Citation:
Bogenschutz M, Dinora P, Lineberry S, Prohn S, Broda M and West A (2022) Promising Practices in the Frontiers of Quality Outcome Measurement for Intellectual and Developmental Disability Services.
Front. Rehabilit. Sci. 3:871178.
doi: 10.3389/fresc.2022.871178

PROMISING PRACTICES IN THE FRONTIERS OF QUALITY OUTCOME MEASUREMENT FOR IDD SERVICES

For people with intellectual and developmental disabilities (IDD) living in the United States, Medicaid Home and Community Based Services (HCBS) often provide access to vital supports for community living. While advocates, researchers, and policymakers have lauded the benefits of HCBS as a part of supporting deinstitutionalization and community integration for people with IDD, little empirical evidence exists to directly link HCBS service usage and expenditures to tangible outcomes for people with IDD or the overall service systems that administer HCBS.

In an era when the focus of policymakers has turned to the need for evidence to tangibly support public expenditures, outcome measurement in HCBS, one of the main mechanisms by which U.S. states provide supports to people with IDD in their communities, is increasingly important. Though there are controversies and critiques about use of evidence-based policymaking [e.g., (1, 2)], the use of evidence to measure HCBS outcomes and effectively disseminate those outcomes to policymakers and advocates is essential for compelling states to adequately resource HCBS as a means of promoting community living for people with IDD.

In this conceptual paper, we (1) outline a rationale for better outcome measurement in Medicaid HCBS for people with IDD, (2) examine four pressing challenges to better outcome measurement and how we have sought to address them, and (3) propose new frontiers for consideration in order to move HCBS outcome measurement into the future. We specifically focus on application to our work's approach to merging administrative datasets, using advanced statistical analyses, centering stakeholder voices, and creating immersive dissemination products. It is important to note that this paper is about a U.S. based study and suggestions may not readily apply in service and policy contexts outside the U.S.

BACKGROUND

Quality Measurement in HCBS

HCBS enables people to live and work as part of their communities instead of residing in costly and segregated nursing homes or institutions (3). In fiscal year (FY) 2017, ∼860,500 people with IDD in the United States used Medicaid IDD HCBS with estimated expenditures totaling $38.71 billion (4).

States that operate HCBS programs are required by the Centers for Medicare and Medicaid Services (CMS), the federal entity that governs Medicaid and Medicaid waiver programs, to measure and improve performance, assure that individual support plans meet the needs of waiver participants, and have effective systems in place to monitor participant health and welfare (5). States monitor compliance with these rules by using self-selected performance measures (6). Although flexibility in choosing performance measures has allowed states to be responsive to their individual needs and priorities, it has also created challenges with conceptualizing and measuring HCBS quality on a national level and for comparing outcomes across states (7, 8).

In recent years, discussions about HCBS quality and the need for national quality measurement standards have intensified (9). From 2014 to 2016, the National Quality Forum (NQF), contracted by the U.S. Department of Health and Human Services (HHS), convened a national stakeholder committee to develop measurement recommendations for monitoring HCBS quality (10). In September 2020, CMS issued a request for comment on a recommended standard measure set for Medicaid-funded HCBS (11). These recommended measures, organized based on quality domains identified by NQF, included the areas of service delivery and effectiveness, person-centered planning and coordination, choice and control, community inclusion, caregiver support, workforce, human and legal rights, equity, holistic health and functioning, system performance and accountability, and consumer leadership in system development (12).

Stakeholder Input in IDD HCBS Quality Measurement

Stakeholder input, including gathering information directly from HCBS program participants with IDD, is fundamental to the CMS quality management strategy (13). In fact, CMS described their approach as "customer obsessed" with considerable participant outcome information integrated into their quality and performance standards (14).

To this end, multiple survey instruments have been used to assess participant experiences and outcomes associated with IDD HCBS. An early example was the Participant Experience Survey for people with intellectual and developmental disabilities (PES-DD). The PES-DD, which was designed to be administered in an interview format, measured IDD program participants' experience with HCBS services and focused on the four priority areas of access to care, choice and control, respect and dignity, and community integration/inclusion (15). A valid and reliable cross-disability HCBS participant survey was later created, which obtained the Consumer Assessment of Healthcare Providers and Systems (CAHPS) trademark and the NQF's endorsement (16). This tool, the HCBS CAHPS, includes questions about access to needed services, providers, case managers, choice of services, medical transportation, personal safety, community inclusion, and empowerment (17).

At the same time, measures outside of CMS were developed to assess user perception of IDD HCBS quality. For example, the Council for Quality and Leadership (CQL) constructed the Personal Outcome Measures (18) and the Human Services Research Institute (HSRI) and National Association of State Directors of Developmental Disability Services (NASDDDS) co-developed the National Core Indicators (19). Measures from the NCI have since been endorsed by the National Quality Forum (20). Both of these surveys are widely used in the United States to measure personal outcomes for people with IDD, including choice, health, safety, community participation, relationships, rights, and employment. The POM is often used to assess service provider quality, while the NCI is primarily used to assess the quality of state-level IDD service systems (19, 21).

Aim and Scope of Paper

Considering the large outlay of public funds and the centrality of HCBS in the lives of many people with IDD and their families, improving the measurement of HCBS outcomes is an essential step toward monitoring system quality across the United States' myriad approaches to disability service provision. In addition, expectations of centering the experiences of people with IDD in the outcome measurement process have become increasingly prominent. Against this background, the current paper outlines four important emerging frontiers in HCBS outcome measurement, each punctuated by real-life applications from our work. We conclude by proposing additional actions that may be taken to improve HCBS outcome measurement and quality assurance in the future.

METHODS

The present article uses the example of one research team's experience, working to improve the quality of HCBS outcome measurement in their state. The research team members come from five academic disciplines (public policy, social work, education, evaluation, and rehabilitation counseling), have a variety of expertise (disability policy, advanced statistics, data management, etc.), and bring a wealth of lived experience as self advocates, family members, allies, service providers, and researchers. The research team has been assembled since 2016, when they began working on a pilot to merge three major datasets (as described below) in order to help policymakers in their state's DD agency and Medicaid agency come to a better understanding of how Medicaid HCBS expenditures related to important life outcomes for people with IDD. Over time, the research team's experience and approach has evolved, leading to the observations presented in this article.

Overview of Virginia Costs and Outcomes Project

Much of this paper is based on the author's experience conducting their Virginia Costs and Outcomes project, which will be described in this section. Broadly, the Costs and Outcomes project is meant to help state-level policymakers, advocates, and other researchers understand how HCBS service expenditures relate to personal and system-level outcomes for adults (age 18+) with IDD, while accounting for individual support needs. Since 2015, we have been working on this project in stages, as described below. Before describing the phases of our project, however, it is necessary to emphasize the importance of careful pre-planning before endeavoring to look at HCBS outcome measurement in progressive new ways.

First, prior to starting our pilot work, there had been extensive relationship building with state DD and Medicaid agencies, which ultimately facilitated access to important datasets. We have continued to maintain close relationships with these agencies as our work has progressed, disseminating white papers for our state stakeholders, briefing them on the project process, and engaging them for input about specific research questions to pursue. We also had to think proactively about matters of research ethics, especially around using administrative data for research purposes. This included inserting explicit statements on the state DD agency's consent documents before we could use administrative data for our purposes, and working with our university's institutional review board to navigate the ethical oversight and review process for a complex administrative dataset that contained potentially sensitive data. Finally, our pre-work required strategy, particularly around our data management and integration process. We needed to ensure that we could link our key datasets at the level of the individual service user with IDD, which we accomplished by including a unique identifier that could be present on all of our data sources. The three datasets we use in our work are as follows:

Medicaid HCBS Expenditures

Furnished to us the state's Medicaid agency, Medicaid HCBS expenditures capture the array of long term services and supports (such as residential, employment/day program, and many other smaller services that people with IDD use long-term). Every HCBS user in Virginia has a Medicaid record.

SIS-A

The state's DD agency allows us to use SIS-A data, which the state uses with every HCBS user in order to assess their support needs. Every HCBS user in Virginia has a SIS-A on record.

NCI-IPS

The state's DD agency, which provides this dataset, randomly selects about 800 HCBS users annually to participate in the NCI-IPS, which measures a wide array of factors related to service usage, personal outcomes, and system-related outcomes. The annual sample of NCI-IPS users provides the base sample for our work and we obtain and merge SIS-A and Medicaid data based on the presence of a person's NCI-IPS record.

Second, our initial pilot work, funded by the Association of University Centers on Disability (AUCD) took place in 2015 and 2016. In this work, our main aim was to establish the feasibility of creating a large combined dataset from three sources with IDD-specific information merged at the individual level: (1) the state's Medicaid HCBS expenditure data for adults with IDD, (2) the state's data from the National Core Indicators - In Person Survey (19), and (3) the state's data from the Supports Intensity Scale-Adult version (22). The Medicaid HCBS data provided us with information about state expenditures per person on a plethora of services and supports, including various types of residential services, day habilitation and employment support services, respite, and case management. These data were available at a minute level of detail, so it was helpful to bundle them into usable units for analyses. The NCI-IPS provided a variety of outcome variables related to health, health service access, social inclusion, relationships, work or other day activities, choices, and rights that we have used as outcomes in our work. The SIS was useful to explore support needs, both overall, and in more specific domains such as medical support needs or behavioral support needs. Results of our pilot are available in Dinora et al. (23), and include findings about patterns of association between extraordinary medical and behavioral support needs and costs and some surprising findings related to residence type and community inclusion.

Third, following our successful pilot, we secured a 3 year research grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to merge the same three datasets for an additional 2 years, and to link those two cohorts of data to begin the construction of a longitudinal linked dataset. As part of this work, we focused on improving psychometrics, specifically by attending to ecological issues that have troubled prior HCBS outcome measurement endeavors, and gave additional focus to the use of advanced statistical analyses.

Finally, in the current fourth phase of our project, funded by a NIDILRR grant running through 2024, we are adding two additional years of data to our merged dataset with linked cohorts, which will enable us to begin exploring the effects of the COVID-19 pandemic on HCBS outcomes and expenditures. In this phase, we will also be merging a fourth dataset, Medicaid managed care medical encounter data, which will help us understand how the frequency and intensity of medical service usage plays a role in personal and system outcomes for people with IDD. In this phase, we are also placing additional attention on stakeholder involvement and translational dissemination, and will have access to the NCI-IPS COVID-19 supplement, which provides information about the impact of the pandemic on people's lives.

Identification of Promising Practices

In preparing to write this manuscript, the project team met to reflect on our experiences with the Virginia Costs and Outcomes project over the past seven years. Our aim was to identify the principal contributions of our work relevant to HCBS, with particular attention on what others may be able to learn from our work, how our progress was supported by prior research, and also where we still feel our project can grow in the measurement of HCBS outcomes within our context.

The vignettes in the promising practices section to follow are the result of that reflective discussion session and focus on four main aspects of our work that we believe are relevant to a wider audience: (1) using merged administrative datasets to improve HBCS outcome measurement for people with IDD, (2) developing high-quality psychometrics that attend to important issues of data and service system ecology, (3) using advanced statistical analyses, and (4) developing engaging, user-friendly dissemination products. For each of these topics, in the sections below we give a brief overview of the literature on the topic, before sharing a synopsis of our experience, which we hope will serve as a starting point for others to consider when engaging in their own efforts to improve HCBS outcome measurement.

PROMISING PRACTICES

Using Merged Data Sources

The best HCBS outcome measurement requires high quality data that are capable of answering questions relevant to policymakers and advocates. However, the quality of data that has traditionally been used to track HCBS outcomes for people with IDD has been challenged by a number of factors, including inability to match fiscal and personal outcome data, and difficulty constructing robust datasets specific to people with IDD.

A number of authors [e.g., (23–25)] have called for better use of large administrative and linked datasets in the IDD field in order to generate a more nuanced portrait of the factors that may promote or inhibit particular outcomes. Though merging administrative datasets has been rare to date, there have been efforts, for example, to merge smart home and wearable technology data with Medicaid data to help understand safety and other personal outcomes for people with IDD (25). Despite such efforts, a national workgroup of leaders in the IDD field recently conducted an assessment of the potential to use administrative data to better understand health outcomes for people with IDD, including by potentially merging datasets, and concluded that current opportunities are limited, in part due to challenges in harmonizing definitions between datasets (26).

The use of administrative datasets to enhance the quality of outcome measurement in HCBS for people with IDD has other limitations as well. After examining several population-based datasets, Havercamp et al. (24) concluded that most datasets had severe limitations, related both to difficulty specifically identifying people with IDD in the dataset (IDD is conflated with other conditions as "cognitive impairment," for instance), and to inadequate inclusion of people with IDD in population-based survey sampling. Wagner et al. (25) noted that many IDD-specific datasets are not robust enough to conduct advanced analysis, providing another significant barrier to using extant datasets to enhance the quality of HCBS outcome measurement for people with IDD.

Application to Virginia Costs and Outcomes

To begin to address some of the known challenges with using administrative and secondary datasets in outcome measurement, the Virginia Costs & Outcomes project endeavored to merge three major IDD-specific administrative datasets at the individual level. UsingVirginia's data from the National Core Indicators-In-Person Survey, the Supports Intensity Scale-Adult Version, and state Medicaid claims we created a large dataset, merged at the individual level and integrated across multiple annual cohorts, to create a robust randomly sampled dataset of people with IDD. The randomness in the sample comes from the state's NCI-IPS sampling method, which contacts about 800 randomly selected HCBS service users annula to solicit participation. We then merge in Medicaid expenditure data and SIS-A data for users with a valid NCI-IPS on record, since all HCBS users have those two datasets available (thus, our sample is bounded primarily by the availability of NCI-IPS records). With this dataset, we have been able to simultaneously account for two of the major drivers of service planning for adults with IDD: the need to carefully steward public funds, and the need to continuously monitor and improve outcomes for people with IDD who use HCBS.

Despite the success in being the first known team to successfully merge these three major datasets, we have continued to find that not all of our most important questions can be answered. Therefore, we are working with state partners in Virginia to obtain and merge Medicaid Managed Care acute encounter data, which will allow for a more granular understanding of healthcare utilization patterns and how they relate to outcomes. Additionally, we are exploring potential opportunities to layer additional, smaller datasets into our analyses, such as records for critical incidents, which would enable us to understand how outcomes and HCBS expenditures are affected after a person with IDD experiences a major traumatic event (e.g., abuse, injury, hospitalization, etc.).

All of this suggests that there are a multitude of possibilities to pursue in terms of merging extant administrative datasets, which each have some utility individually, but which hold significantly more potential for helping us understand HCBS outcomes when merged. In our experience, however, significant work needs to be done before any mergers take place, so researchers may wish to consider merging datasets as a years long investment before fruitful results emerge. Relationships must be built with state agencies, people with disabilities, and their families, processes for ethical compliance must be established, merger processes and unique keys to guide construction of the dataset need to be created well in advance, and a team with specialized skill sets must be assembled. It is also worth noting that conditions need to be right for open collaboration with state agencies, and often a defined policy window will open to facilitate collaboration. In our case, this window opened largely due to a consent decree between the state and the U.D. Department of Justice that was transforming much of the DD system in Virginia, including HCBS. If researchers can make significant initial commitments of time, however, the potential for merged datasets to transform outcome measurement for HCBS for people with IDD is significant.

Developing High Quality Psychometrics

HCBS programs are influenced by both federal and state policy. Therefore, it is essential that we develop measures that can be used in both federal and state contexts. We will summarize our efforts to develop measures for tracking wellness and social outcomes across both federal and state-level ecological contexts.

The need for high-quality, psychometrically sound measurement tools in the IDD field has been well established, as mentioned previously (7, 8). A 2013 review of quality of life assessments for people with intellectual disabilities found that most of the identified instruments were not well validated (27). While most scales reported good to excellent validity, the majority did not report validation with people with varying levels of ID, floor and ceiling effects, or the factor structure of the scale (27). Similarly, Townsend-White and colleagues (28) reported that most quality of life measures had not been replicated and had only been validated by the developers.

Shogren (29) called for researchers to go beyond controlling for contextual factors to actively considering the role of political, cultural, and individual factors in quality of life outcomes for people with IDD. Prior literature on wellness and social outcomes for people with IDD has established the importance of considering the ecological context in which people use services. For example, research using the NCI-IPS found that the state in which people lived was a significant predictor of everyday and support-related choice (30). Similarly, Lu et al. (31) analyzed Medicaid claims data and found significant differences between states in level of adherence to diabetes care guidelines.

Other researchers have specifically examined the impact of state-level policy on outcomes for people with IDD [e.g., (32, 33)]. Sannicandro and colleagues (33) used advanced analytic techniques with a large administrative dataset to explore predictors of employment for adults with IDD. The authors found that people who participated in postsecondary education and lived in states with a higher employment rate for people with disabilities had better employment outcomes than people with the same level of education living in states with lower employment rates (33). Additionally, people who lived in states where a higher percentage of people with IDD were served by vocational rehabilitation had better employment outcomes than people who lived in states where fewer individuals were served (33). These findings reinforce the idea that state political and economic factors impact outcomes for people with IDD.

Application to Virginia Costs and Outcomes

Early in the Cost and Outcomes project, we found that most previously established measurement scales that had been developed from NCI-IPS variables did not perform well with our state's data, potentially due to the ecological issues discussed above [see (34, 35)]. Based on this poor statistical fit of previously developed scales to our data, we decided to develop new scales on our own. Our goal was to create variable clusters from the NCI-IPS that were statistically sound both in our state and using the NCI-IPS national dataset. To date, our team has used NCI-IPS data to create and test two scales: one to measure personal opportunities outcomes and another to measure wellness factors.

Our work began by using Virginia's merged NCI-IPS cohorts from 2017 and 2018 (total *n* of 1,608). Items from the NCI-IPS were initially selected based on their face validity to the relevant construct (wellness or personal opportunities) then examined using polychoric correlations to determine the strength of association between variables. Finally, confirmatory factor analysis (CFA) was used to test various factor structures for the models. This step is noteworthy, given that most scales identified by Li and colleagues (27) did not report testing multiple factor structures for their final model. Our preferred model for wellness included three variable clusters (mental health, behavioral support needs, and cardiac health indicators) and our preferred personal opportunities model contained four clusters of variables (relationships, community participation, rights, and daily choices).

Because we wanted to avoid the ecological issues that have been observed with previous measures developed from the NCI-IPS, we did not want to simply proceed with analyses based solely on state-level data, which may or may not apply in a national ecological context. To address this need, we obtained the NCI-IPS national dataset for 2018 from HSRI and NASDDDS. With their permission, we tested the fit of the two models we developed in our state data on the national dataset to see if they remained statistically sound. Finding good model fit in the national dataset, we tested the models as outcome variables in a series of linear regressions to check their utility and predictive validity. A full accounting of our methods and results may be found in Bogenschutz et al. (36) and Prohn et al. (37).

By using a rigorous method to develop scales to measure key HCBS outcomes for people with IDD and then testing those scales in both state-level and national datasets, we attended to the ecological challenges that have often troubled HCBS outcome measurement and attended to concerns raised by Li and colleagues (27) about statistical rigor in IDD measure development. In doing so, we created measures that have utility both to monitor our state's progress in achieving outcomes, and the ability to look at important outcomes for the nation as a whole.

Using Advanced Statistical Analyses

The way we think about data analytics is shifting rapidly. Researchers in the field have been calling for use of more advanced analytic methods for some time, in a variety of applications such as using algorithms to identify people with IDD in population based or administrative datasets (38), innovating by using state or local level administrative datasets in novel ways (26), or using artificial intelligence in disability research (39, 40).

This last innovation, use of artificial intelligence in IDD research may have the power to be particularly transformative. For instance, while typical statistical methods commonly used in the IDD field are deductive, and therefore subject to the biases of past theory and literature that guide researcher's development of questions to be tested, machine learning is inductive, and driven entirely by the data. Although the potential for bias still exists due to flaws in datasets (especially when using historical data to predict present-day outcomes), the application of machine learning (and related methods such as propensity score matching) in the IDD field could potentially transform our evidence base for policymaking and advocacy, by generating truly data-driven evidence to support HCBS outcome measurement and system transformation.

Though tremendous potential for the use of artificial intelligence and machine learning methods in HCBS outcome measurement exists, so, too, do controversies. In some fields of social science research, most notably criminal justice (41), machine learning has come under scrutiny for potentially enabling the persistence of racial bias in, for example setting bail or determining eligibility for parole, since historical, racially biased samples, have sometimes been used to predict current outcomes. For IDD researchers to use large datasets ethically to help us better measure HCBS outcomes, we will need to find or create large datasets that more adequately represent the experience of HCBS users with IDD, avoid the use of historically biased datasets, be fully transparent about the predictive algorithms being used, and intentionally include the voices of HCBS users with IDD in our study design, implementation, and dissemination processes.

Application to Virginia Costs and Outcomes

In our work, we have employed machine learning to explore patterns of employment and day service utilization outcomes for HCBS users with IDD. To do this, we obtained the entire national NCI-IPS dataset for 2018 and constructed eight empirically-derived profiles of employment and/or day program participation that commonly occurred in the NCI-IPS dataset. Then we used all other variables from the NCI-IPS to train and test an algorithm to predict those eight employment and day program status outcomes. In order to avoid potential bias from past datasets, we did this by training the algorithm based on a randomly selected 80% training sample from the full dataset, and then testing the algorithm against the remaining 20% holdout sample. We tested both classification tree and random forest models, finding best fit based on the random forest algorithm. A full accounting of our procedures may be found in Broda et al. (42).

Our algorithm successfully predicted employment and/or day program participation outcomes with excellent accuracy (92% on the training sample, 82% on the holdout sample). Based on our analysis, the strongest predictors of employment and day program participation were (1) having a goal for employment in one's individual service plan, (2) having volunteer experience, and (3) being able to make one's own daily choices. This study was among the first in the IDD field to examine HCBS outcomes with machine learning, and showed both the feasibility and the practicality of doing so, since the results suggested that employment outcomes may be amenable to improvement with common-sense policy shifts.

Creating Immersive, Accessible Dissemination Products

Outcomes research has a fundamental application to the lives of people with IDD and their families. It can also be a valuable tool for decision-makers when making IDD system investments. Whether at the "person-referenced level" (i.e., quality of life, self-determination) or at the "system-focused level" (i.e., characteristics of the system, services provided), outcomes research can provide valuable information to help inform decision making and service planning (43–45).

However, an ongoing challenge is the availability of clear and accessible information in formats that work best for people with IDD, families, and system-level decision makers (46–48). How we use language, image, audio, and video to convey research findings is a critical consideration when trying to enhance understanding and utility for stakeholders (49).

Social media tools such as Facebook, YouTube, Instagram and TikTok have become an increasingly common way that researchers communicate findings to constituencies (50). In the US, seven in ten people in the general population use some form of social media (51). Just like the general population, people with IDD reportedly are regular consumers of social media (52, 53). With social media there are concerns to consider such as acces, safety, accessibility and availability of support, possible misunderstandings of cyber etiquette, and communication and literacy skills (54). However, social media can be a powerful tool available to researchers to reach important stakeholders.

Additionally, for IDD outcomes research, making findings accessible and actionable to national and state IDD system managers is critically important. Despite this, often there is a considerable gap between researchers and policymakers when research is not clearly and expeditiously translated (2). One strategy with particular promise is distilling primary findings into a brief or summative format. Briefs, that summarize complex information in an accessible format, have been shown to be an effective tool for facilitating the use of research findings in policy decisions (55, 56)].

Application to Virginia Costs and Outcomes

Even the best outcome measurement is worth little unless it reaches policymakers and advocates in an understandable and actionable form. To that end, we have dedicated effort to the use of social media (Facebook Live events, TikTok videos, etc.) to translate complex findings into accessible and immersive products. These social media events regularly reach thousands of people with IDD and their families. Likewise, we have created easy to follow briefs and white papers that decision makers can use to drive program development and implementation in our state.

Through social media we have reached and engaged with new audiences that have posed specific questions about how our research can be used for real-life decision-making. We also are exploring how tools like TikTok, which generally attract a younger audience, can be employed to create conversations with youth as they enter service systems and bring with them new values and expectations about what they want from HCBS and how HCBS can support them to live good lives. Though use of TikTok has become more common among older users, we have also disseminated via Facebook and Instagram, in order to appeal to a broader spectrum of social media users.

We routinely engage with key stakeholders in the quest to get the right type of information to the right people in an accessible and useful way. The self advocate on our research team works directly with a statewide alliance of people representing a number of IDD advocacy groups across the state. They meet regularly to talk about ways that our research can help meet their needs, and they respond to our ideas and findings in a continual feedback loop. Using evaluative strategies, we continue to learn about what people want and need and recognize that flexibility is paramount, as information needs routinely evolve and change and are best addressed when customized for specific audiences (57).

NEXT FRONTIERS

We are proud of our work to date in the Virginia Costs and Outcomes project, and have seen the impact that the above practices can make in the improvement of HCBS outcome measurement and monitoring for people with IDD. Still, we are continually looking for ways to improve, and the items in this section represent ways in which our team, as well as the field of IDD researchers generally, can continue to innovate to improve the quality of HCBS outcome measurement.

Centering of Lived Experience

"Nothing about us, without us," a central adage in the disability community, asserts that concerns that are integral to the lives of people with disabilities must be grounded in the voice of lived experience. This is especially true for research. People with disabilities are primary stakeholders in disability research, either as participants or as recipients of the policies and practices that are shaped by research findings (58). Despite this, people with disabilities, particularly people with IDD, have often been excluded from meaningful participation in research (59–61).

Integrally involving people with IDD in every aspect of the research process has demonstrated benefits. It can result in more relevant research questions grounded in lived experience; data collection methods and protocols that have greater feasibility, more nuanced and informed analyses of data, and improved dissemination strategies that reach end-users (62, 63). The "how" is where it can get more challenging. Co-researchers with IDD have reported challenges with securing needed accommodations to fully contribute to research design and development and have experienced power differentials with other researchers that affect their full participation (64–66).

We, as a field, need to continue work in partnership with people with disabilities so that every stage of the research process is infused with the voice of lived experience. Additionally, our findings must be authentically and accessibly communicated to people with disabilities and their families. Research that is focused on outcomes for people who use community-based services should be a tool that has utility for state or national decision-makers and in planning meetings where decisions are made about which services and supports would work best for people with IDD.

Our primary stakeholders, people with IDD, can be incredible assets to outcomes research in supporting these efforts. We must continue to support and strengthen inclusive research teams so that our research can have the greatest utility, reach, and impact.

Scaling and Testing in Other States

Although promising in many regards, our work is limited by its narrow geographic scope, being confined to just one state. Because state systems vary widely, and since state-level policy and program changes may occur in a particular state but not in others, it is very important to take what we have learned in the Virginia Costs and Outcomes studies and apply it to other states. Doing so would help policymakers, researchers, and advocates come to a better understanding of how HCBS outcomes vary as a function of the policy environment in each state, and would help to gauge the quality of HCBS outcomes within a large national context.

Merging Medicaid HCBS expenditure claims, the SIS, and the NCI-IPS has been a productive exercise in HCBS outcome measurement for our team and for key stakeholders in our state, who have contributed to and benefitted from the work. Plans are currently underway to engage a similar process to merge the same datasets in five additional states, which we believe is an important step toward scaling our data integration method and eventually testing it in additional states. It will also be an opportunity to test our measurement scales for wellness and personal opportunities in other states in order to continue to address ecological issues in HCBS outcome measurement for people with disabilities that have posed such challenges in the past.

Scaling and testing in other states will likely take time and planning, as we have learned from our work. For instance, building relationships with state DD and Medicaid agencies is an ongoing process, developing procedures to embed a matching variable on all datasets to be merged takes coordination with state agencies, managing informed consent issues requires advanced planning and collaboration with ethics review boards, and data sharing agreements can take considerable time to secure. Researchers and state DD service managers in other states would be well served to plan longitudinally before undertaking a data merger process, but if such planning can be done intentionally, the scaling and testing of our (or similar) procedures for merging administrative datasets stands to be transformative for HCBS outcome monitoring for people with IDD.

Translating Findings to Policy Action

Our greatest hope for our work, especially the work to longitudinally merge major administrative IDD datasets, is that it will provide a tool for state policymakers to use to both monitor the IDD service system in our state and to make fiscally responsible improvements to the HCBS system that will support high quality outcomes for people with IDD. Eventually, it is our hope that other states will see such impacts as well. In short, it is our hope that our work will help provide a solid empirical foundation for evidence-based policymaking.

Evidence-based policymaking is, however, unlike evidence-based medicine. Whereas, evidence-based medicine is premised on taking prudent action based on science from carefully planned clinical trials, evidence-based policymaking relies as much on emotion as it does on the rationality of empirical evidence (1). Policymakers and researchers come from different cultures, where policymakers often lack the technical knowledge to read and digest research reports that they often must act upon quickly as a policy window opens, and researchers often do not have the time, resource, or skill to distill technical findings in a meaningful way on tight timelines, leading to a disconnect between research evidence and policy making (2).

Given this disconnect between research evidence and policy making, in our continuing work, we are endeavoring to make greater investments in creating timely, short, and accessible bits of information that are actionable by policymakers. It is our intention that these pieces of information will also be accessible to advocates who influence policymakers, as we have been, and will continue to disseminate them via a variety of social media platforms as well as to advocates and policymakers directly. By making our findings accessible, actionable, and briefly summarized, we are hoping to bridge the research/policy gap, while continuing to conduct research based on innovative analyses and robust merged datasets that illuminate HCBS outcomes for people with IDD. Increasing use of personal narratives that use lived experience of people with IDD and their families to illuminate our empirically derived findings is also on our team's dissemination agenda. Although the effectiveness of narrative-based policy advocacy is not entirely clear (67), it is very much in line with our commitments to center lived experience in our work, and we are hopeful that it will be impactful in bringing voice to empirical findings.

CONCLUSION

Medicaid HCBS provides essential services and supports to help people with IDD live well in their communities, and high quality outcome measurement is crucial to the process of continuously improving HCBS. By looking to promising practices from the field, such as using merged administrative datasets, addressing ecological issues in measurement, and engaging advanced statistical analyses, researchers can contribute to the enhancement of HCBS outcome measurement. Bringing the lived experience of people with IDD and their families directly into the research process, both as co-researchers and as consumers of accessible research results on HCBS, is also essential, as bringing lived experience to the forefront may be highly effective in the evidence-based policymaking process to strengthen and expand high quality HCBS services and supports.

AUTHOR CONTRIBUTIONS

MBo: led conceptualization, writing of most sections, editing, coordination, and core member of the research project being discussed. PD: wrote three segments of the manuscript, contributed substantive feedback on others, contributed to conceptualization of article, and serves as PI of the project being discussed. SL: wrote one segment of the manuscript, gathered and summarized literature, substantively edited, contributed to article conceptualization, and core member of the project being discussed. SP: contributed to manuscript throughout, critically reviewed earlier version of the manuscript, contributed to article conceptualization, and core member of the project being described. MBr: substantively contributed to three of the "promising practices" sections, provided substantive feedback throughout, provided detailed line editing, contributed to article conceptualization, and core contributor to the project described. AW: provided substantive feedback and edits throughout, aided in the conceptualization of article, provided self-advocate insights into how the article is presented, and core member of the research team for the project described. All authors have reviewed and given approval for submission of the manuscript.

FUNDING

This work was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research *via* a grant to the Partnership for People with Disabilities at Virginia Commonwealth University [Grant Number 901FRE0015-02-0].

REFERENCES

1. Cairney P, Oliver K. Evidence-based policymaking is not like evidence-based medicine, so how far should you go to bridge the divide between evidence and policy? *Health Res Policy Syst.* (2017) 15:2–11. doi: 10.1186/s12961-017-0192-x
2. Oliver K, Innvar S, Lorenc T, Woodman J. A systemic review of barriers to and facilitators of the use of evidence by policymakers. *BMC Health Serv Res.* (2014) 14:2. doi: 10.1186/1472-6963-14-2
3. The Arc. *Policy and Advocacy: Medicaid*. (2021). Available online at: https://thearc.org/policy-advocacy/medicaid/#:∼:text=For%20many%20people%20with%20intellectual,segregated%20nursing%20homes%20or%20institutions (accessed January 31, 2022).
4. Larson SA, Eschenbacher HJ, Taylor B, Pettingell S, Sowers M, Bourne ML. *In-Home and Residential Long-Term Supports and Services For Persons With Intellectual or Developmental Disabilities: Status and Trends Through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (2020). Available online at: https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017.pdf (accessed February 1, 2022).
5. Centers for Medicare and Medicaid Services. *Instructions, Technical Guide and Review Criteria*. (2019). Available online at: https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf (accessed February 1, 2022).
6. Lipson DJ. *HCBS Quality Measures Issue Brief: Assessment and Care Planning Measures. Mathematica*. (2019). Available online at: https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measures-brief-1-assessment-care-planning.pdf (accessed February 2, 2022).
7. Academy Health. *Meeting Highlights. Measuring the Quality of Home and Community-Based Services: A Conversation about Strategic Directions for Research and Policy*. (2015). Available online at: https://www.thescanfoundation.org/sites/default/files/academyhealth_hcbs_quality_meeting_handout.pdf (accessed January 31, 2022).
8. Harrington C, Wiener JM, Ross L, Musumeci M. *Key Issues In Long-Term Services and Supports Quality*. Kaiser Family Foundation (2017). Available online at: https://www.kff.org/medicaid/issue-brief/key-issues-in-long-term-services-and-supports-quality/ (accessed January 30, 2022).
9. Quinn K, Weimar D, Gray J, Davies B. Thinking about clinical outcomes in medicaid. *J Ambul Care Manage.* (2016) 39:125. doi: 10.1097/JAC.0000000000000130
10. National Quality Forum. *Quality in Home and Community-Based Services to support community living: Addressing Gaps In Performance Measurement*. (2016). Available online at: https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-

Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_Measurement.aspx (accessed January 30, 2022).

11. Centers for Medicare and Medicaid Services. *Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community Based Services*. (2020). Available online at: https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/measuring-and-improving-quality-home-and-community-based-services-hcbs/index.html (accessed February 1, 2022).
12. Bennett AD, Curtis P, Harrod CS. *Bundling, Benchmarking, And Beyond: Paying for Value In Home-And Community-Based Services*. (2018). Available online at: https://www.milbank.org/wp-content/uploads/2018/07/MMF-HCBS-Report-FINAL.pdf (accessed February 1, 2022).
13. Centers for Medicare and Medicaid Services. *Report to Congress: Identification of Quality Measurement Priorities –Strategic Plan, Initiatives, and Activities*. (2019). Available online at: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/Downloads/CMS-RTC-Quality-Measurement-March-1-2019_508 (accessed February 1, 2022).
14. Schreiber M, Duseja R, Dahlerus C, Suter L. *The Future of Quality Measurement, 2020 and Beyond*. Baltimore, MD: 2020 CMS Quality Conference (2018). Avaialble online at: https://www.cmsqualityconference.com/wp-content/uploads/2020/02/CMS-Quality-Conference-Agenda-2020_PRINT.pdf
15. Potter DEB, McKethan A, Nguyen N. *Long Term Care Quality Alliance Technical Appendices*. (2008). Available online at: https://www.brookings.edu/wp-content/uploads/2012/04/Appendix.pdf (accessed February 1, 2022).
16. Burnett J, Seibert J. *The Medicaid HCBS Experience Of Care Survey HCBS 2013*. (accessed September 11, 2013).
17. Centers for Medicare and Medicaid Services. *Technical Assistance Guide For Administration Of The CAHPS® Home and Community-Based Services Survey*. Available online at: https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbscahps-admin-ta-guide.pdf (accessed January 30, 2022).
18. Friedman C. *Building the Framework for IDD Quality Measures. Towson, Chicago, and Omaha: The Council on Quality and Leadership, the Institute for Public Policy for People with Disabilities, and Mosaic*. (2018). Available online at: https://www.c-q-l.org/wp-content/uploads/2019/12/Building-The-Framework-For-IDD-Quality-Measures-2018.pdf (accessed January 30, 2022).
19. Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services. *In Person Survey 2017-2018 Final Report*. (2019). Available online at: https://www.nationalcoreindicators.org/upload/core-indicators/17-18_IPS_National_Report_PART_I_update_CA_entitlement.pdf (accessed January 30, 2022).
20. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. *National Core Indicators Intellectual and Developmental Disabilities Measures Final Endorsement Announced by the National Quality Forum*. (2022). Available online at: https://www.nasddds.org/wp-content/uploads/2022/01/Final-Press-release-NQF-_HSRI.pdf (accessed January 30, 2022).
21. Council on Quality and Leadership (20). *Personal Outcome Measures 2017. Measuring Outcomes Now and in the Future*. Available online at: https://www.c-q-l.org/wp-content/uploads/2017/04/CQL-Personal-Outcome-Measures-Validation-Report-2017.pdf
22. Thompson JR, Bryant B, Schalock RL, Shogren KA, Tassé MJ, Wehmeyer ML, et al. *Supports Intensity Scale—Adult Version: User's Manual*. Washington, DC: American Association on Intellectual and Developmental Disabilities (2015).
23. Dinora P, Bogenschutz M, Broda M. Identifying predictors for enhanced outcomes for people with intellectual and developmental disabilities. *Intellect Dev Disabil.* (2020) 58:139–57. doi: 10.1352/1934-9556-58.2.139
24. Havercamp SM, Krahn GL, Larson SA, Fujiura G, Goode TD, Kornblau BL, et al. Identifying people with intellectual and developmental disabilities in national population surveys. *Intellect Develop Disabil.* (2019) 57:376–89. doi: 10.1352/1934-9556-57.5.376
25. Wagner JB, Kim M, Tassé MJ. Technology tools: Increasing our reach in national surveillance of intellectual and developmental disabilities. *Intellect Dev Disabil.* (2019) 57:463–75. doi: 10.1352/1934-9556-57.5.463
26. Bonardi A, Krahn G, Morris A, The National Workgroup on State and Local Health Data. *Enriching Our Knowledge: State and Local Data to Inform Health Surveillance of the Population With Intellectual and Developmental Disabilities*. (2019). Washington, DC: Administration on Intellectual and Developmental Disabilities. Available online at: https://doi-org.proxy.library.vcu.edu/10.1352/1934-9556-57.5.390
27. Li C, Tsoi EW, Zhang AL, Chen S, Wang CJ. Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: a systematic review. *J Dev Phys Disabil.* (2013) 25:253–70. doi: 10.1007/s10882-012-9297-x
28. Townsend-White C, Pham ANT, Vassos MV. A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours. *J Intellect Disabil Res.* (2012) 56:270–84. doi: 10.1111/j.1365-2788.2011.01427.x
29. Shogren KA. Considering context: an integrative concept for promoting outcomes in the intellectual disability field. *Intellect Dev Disabil.* (2013) 51:132–7. doi: 10.1352/1934-9556-51.2.132
30. Lakin KC, Doljanac R, Byun SY, Stancliffe R, Taub S, Chiri G. Choice-making among Medicaid HCBS and ICF/MR recipients in six states. *Am J Ment Retar.* (2008) 113:325–42. doi: 10.1352/2008.113.325-342
31. Lu Z, Cogan L, McDermott S, Lauer E, Lindner S, Tracy K, et al. Disparities in diabetes management among Medicaid recipients with intellectual and developmental disabilities (IDD): Evidence from five US states. *Disabil Health J.* (2020) 13:100880. doi: 10.1016/j.dhjo.2019.100880
32. Houseworth J, Stancliffe RJ, Tichá R. Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities. *Res Dev Disabil.* (2018) 83:77–90. doi: 10.1016/j.ridd.2018.08.008
33. Sannicandro T, Parish SL, Fournier S, Mitra M, Paiewonsky M. Employment, income, and SSI effects of postsecondary education for people with intellectual disability. *Am J Intellect Dev Disabil.* (2018) 123:412–25. doi: 10.1352/1944-7558-123.5.412
34. Mehling MH, Tassé MJ. Impact of choice on social outcomes of adults with ASD. *J Autism Dev Disorder.* (2015) 5:1588–602. doi: 10.1007/s10803-014-2312-6
35. Neely-Barnes S, Marcenko M, Weber L. Does choice influence quality of life for people with mild intellectual disabilities?. *Intellect Dev Disabil.* (2008) 46:12–26. doi: 10.1352/0047-6765(2008)46[12:DCIQOL]2.0.CO;2
36. Bogenschutz M, Broda M, Lineberry S, Prohn S. Testing a wellness indicators measure for people with intellectual and developmental disabilities. *Dev Disabil Netw J.* (2021) 2:85–10. doi: 10.1352/2326-6988-10.1.19
37. Prohn S, Dinora P, Broda M, Bogenschutz M, Lineberry S. *Measuring Four Personal Opportunities For Adults With Intellectual and Developmental Disabilities. Inclusion* (2000).
38. Lin E, Balogh R, Cobigo V, Ouellette-Kuntz H, Wilton A, Lunsky Y. Using administrative health data to identify individuals with intellectual and developmental disabilities: a comparison of algorithms. *J Intellect Disabil Res.* (2013) 57:462–77. doi: 10.1111/jir.12002
39. Bertoncelli CM, Altamura P, Vieira ER, Bertoncelli D, Solla F. Using artificial intelligence to identify factors associated with autism spectrum disorder in adolescents with cerebral palsy. *Neuropediatrics.* (2019) 50:178–87. doi: 10.1055/s-0039-1685525
40. Maenner MJ, Yeargin-Allsopp M, Van Naarden Braun K, Christensen DL, Achieve LA. Development of a machine learning algorithm for the surveillance of autism spectrum disorder. *PLoS ONE.* (2016) 11:e0168224. doi: 10.1371/journal.pone.0168224
41. Veale M, Binns R. Fairer machine learning in the real world: mitigating discrimination without collecting sensitive data. *Big Data Soc.* (2017) 4:1–17. doi: 10.1177/2053951717743530
42. Broda M, Bogenschutz M, Dinora P, Prohn S, Lineberry S, Ross E. Using machine learning to predict patterns of employment and day program participation. *Am J Intellect Dev Disabil.* (2021) 126:477–91. doi: 10.1352/1944-7558-126.6.477
43. Kaye HS, Williamson J. Toward a model long-term services and supports system: state policy elements. *Gerontologist.* (2014) 54:754–61. doi: 10.1093/geront/gnu013
44. Kaye HS, Harrington C. Long-term services and supports in the community: toward a research agenda. *Disabil Health J.* (2015) 8:3–8. doi: 10.1016/j.dhjo.2014.09.003

45. Shogren KA, Bradley VJ, Gomez SC, Yeager MH, Schalock RL, Borthwick-Duffy S, et al. Public policy and the enhancement of desired outcomes for persons with intellectual disability. *Intellect Dev Disabil.* (2009) 47:307–19. doi: 10.1352/1934-9556-47.4.307
46. Gilson CB, Bethune LK, Carter EW, McMillan ED. Informing and equipping parents of people with intellectual and developmental disabilities. *Intellect Dev Disabil.* (2017) 55:347–60. doi: 10.1352/1934-9556-55.5.347
47. Lavis JN, Robertson D, Woodside JM, McLeod CB, Abelson J. How can research organizations more effectively transfer research knowledge to decision makers? *Milbank Q.* (2003) 81:221–48. doi: 10.1111/1468-0009.t01-1-00052
48. Terras MM, Jarrett D, McGregor SA. The importance of accessible information in promoting the inclusion of people with an intellectual disability. *Disabilities.* (2021) 1:132–50. doi: 10.3390/disabilities1030011
49. Waight M, Oldreive W. Investigating accessible information formats with people who have learning disabilities. *Learn Disabil Pract.* (2021) 24:23–30. doi: 10.7748/ldp.2020.e2031
50. Van Eperen L, Marincola FM. How scientists use social media to communicate their research. *J Transl Med.* (2011) 9:1–3. doi: 10.1186/1479-5876-9-199
51. Pew Research Center. *Social Media Use in 2021*. (2021). Available online at: https://www.pewresearch.org/internet/2021/04/07/social-media-use-in-2021/
52. Ramsten C, Martin L, Dag M, Hammar LM. Information and communication technology use in daily life among young adults with mild-to-moderate intellectual disability. *J Intellect Disabil.* (2020) 24:289–308. doi: 10.1177/1744629518784351
53. Shpigelman CN, Gill CJ. How do adults with intellectual disabilities use Facebook? *Disabil Soc.* (2014) 29:1601–16. doi: 10.1080/09687599.2014.966186
54. Caton S, Chapman M. The use of social media and people with intellectual disability: a systematic review and thematic analysis. *J Intellect Dev Disabil.* (2016) 41:125–39. doi: 10.3109/13668250.2016.1153052
55. Arnautu D, Dagenais C. Use and effectiveness of policy briefs as a knowledge transfer tool: a scoping review. *Human Soc Sci Commun.*(2021) 8:1–14. doi: 10.1057/s41599-021-00885-9
56. Arcury TA, Wiggins MF, Brooke C, Jensen A, Summers P, Mora DC, et al. Using "policy briefs" to present scientific results of CBPR: farmworkers in North Carolina. *Prog Commun Health Partner.* (2017) 11:137–47. doi: 10.1353/cpr.2017.0018
57. Chinn D, Homeyard C. Easy read and accessible information for people with intellectual disabilities: is it worth it? a meta-narrative literature review. *Health Expect.* (2017) 20:1189–200. doi: 10.1111/hex.12520
58. Mmatli TO. Translating disability-related research into evidence-based advocacy: the role of people with disabilities. *Disabil Rehabil.* (2009) 31:14-22. doi: 10.1080/09638280802280387
59. Coons KD, Watson SL. Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *J Dev Disabil.* (2013) 19:14.
60. Feldman MA, Bosett J, Collet C, Burnham-Riosa P. Where are persons with intellectual disabilities in medical research? a survey of published clinical trials. *J Intellect Disabil Res.* (2014) 58:800–9. doi: 10.1111/jir.12091
61. Rios D, Magasi S, Novak C, Harniss M. Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies. *Am J Public Health.* (2016) 106:2137–44. doi: 10.2105/AJPH.2016.303448
62. O'Brien P, McConkey R, García-Iriarte E. Co-researching with people who have intellectual disabilities: Insights from a national survey. *J Appl Res Intellect Disabil.* (2014) 27:65–75. doi: 10.1111/jar.12074
63. Williamson HJ, van Heumen L, Schwartz AE. Photovoice with individuals with intellectual and/or developmental disabilities: lessons learned from inclusive research efforts. *J Commun Based Res Pract*. (2020) 3:8. doi: 10.33596/coll.45
64. Bigby C, Frawley P. Reflections on doing inclusive research in the "Making Life Good in the Community" study. *J Intellect Dev Disab.* (2010) 35:53–61. doi: 10.3109/13668251003716425
65. Bigby C, Frawley P, Ramcharan P. Conceptualizing inclusive research with people with intellectual disability. *J Appl Res Intellect Disabil.* (2014) 27:3–12. doi: 10.1111/jar.12083
66. Conder J, Milner P, Mirfin-Veitch B. Reflections on a participatory project: the rewards and challenges for the lead researchers. *J Intellect Dev Disabil.* (2011) 36:39–48. doi: 10.3109/13668250.2010.548753
67. Fadlallah R, El-Jardali F, Monier M, Hemadi N, Arif K, Langlois E, et al. Using narrative to impact health policy-making: a systematic review. *Health Res Policy Syst.* (2019) 17:26. doi: 10.1186/s12961-019-0423-4

Author Disclaimer: The views expressed herein do not necessarily represent those of the funder.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Rehabilitation Sciences

ORIGINAL RESEARCH
published: 11 May 2022
doi: 10.3389/fresc.2022.878338

The Ambiguous Impact of Performance Measurement on Service Quality

Jan Tøssebro[1,2]*, *Odd Morten Mjøen*[1,3] *and Rebekka Bruteig*[1]

[1] NTNU Social Research, Trondheim, Norway, [2] Department of Social Work, Norwegian University of Science and Technology, Trondheim, Norway, [3] Department of Mental Health, Norwegian University of Science and Technology, Trondheim, Norway

Background: Performance measurement is growing in importance as a management tool in services for disabled people.

Aim: The aim of this article is to add to the existing literature by exploring (a) the motivation for the introduction of such measurements, (b) the reasoning behind the choice of current indicators, and (c) the impact of performance measurements on service delivery.

Methods: (1) A study of documents (national and, if available, also local) on the motivation for, choice of, and implementation of quality measurements, and (2) interviews with top and middle managers in community services for people with intellectual disabilities or mental health difficulties.

Results: A varied set of motivations have been identified, including the intention to introduce a more facts-based and transparent governance, the need for information that supports the management of scarce resources, and as a tool in the development of service quality for users. The motivation appears to be dependent on level of government, and the attitude among service unit managers tends to be ambivalent; they want performance measurements but cannot see how to measure the important aspects of service quality. The choice of actual indicators is subject to a process bias; that is, one measures what is easily available in administrative systems. The results concerning impact on services are less clear and also context dependent. We have identified usage in the search for cost-cutting possibilities, defense against critique, and that reporting runs the risk of reinforcing routinization of services.

Discussion: The possible impact on services is discussed. Layers of ambiguity are outlined, as measurements can be tools both for quality development and in the defense of current services against "unrealistic demands" from the media or stakeholders. The measurements tend to be used more as sources of governance information than tools for quality development.

Conclusion: The impact of quality measurement is rather ambiguous. On the one hand, it functions as a tool for budget control, whereas on the other hand, unit managers call for better measurement of user outcomes and expect that such measurement can balance the current preoccupation with input indicators, such as expenditures.

Keywords: performance measurement, community services, disability, management, quality

Edited by:
Jan Šiška,
Charles University, Czechia

Reviewed by:
Teodor Mladenov,
University of Dundee, United Kingdom
Šárka Kánová,
University of West Bohemia, Czechia

Correspondence:
Jan Tøssebro
jan.tossebro@ntnu.no

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *17 February 2022*
Accepted: *20 April 2022*
Published: *11 May 2022*

Citation:
Tøssebro J, Mjøen OM and Bruteig R (2022) The Ambiguous Impact of Performance Measurement on Service Quality. Front. Rehabilit. Sci. 3:878338. doi: 10.3389/fresc.2022.878338

INTRODUCTION

Performance and quality measurements are increasingly used for a wide range of purposes in disability services and policies. This includes increasing importance as a management tool—for monitoring, reporting, evaluation, comparison, accreditation, and as input to service development. In this context, one important issue is whether measurements are reliable and relevant to service quality. Studies of national standards for accreditation suggests that this is not always the case (1, 2). A substantial effort is being made to improve these types of measurements, among others, by making them more oriented toward outcomes for service users (3, 4).

The measurement of service quality can, however, also be viewed as a part of a more pervasive trend in the management of health and care services to use a wide set of performance measurements. In this broader perspective, it is important to ask what is measured in practice, how performance measurements are used as management tools, and how this impacts the services and the everyday lives of service users (i.e., the "doing" of performance measurements). This is about intended purposes, but equally important, whether there are unintended consequences. This issue has not been given much attention in research on disability services (5), but it has been explored in more depth in general studies of public governance (6, 7).

The introduction and widespread use of performance measurements can be seen as a "child" of the so-called New Public Management (NPM) (8, 9), including, but not limited to, the marketization that in many cases followed such reforms in governance. The motivation for the introduction of performance indicators within NPM is linked to principles like transparency, accountability, and benchmarking. Transparency means among others that (a) politicians should know whether one gets value for money, (b) that users should be informed before making choices on service provider (whether they have a choice or not), and that information on quality should be publicly available. Accountability concerns the "purchasers" need to evaluate whether providers deliver according to the agreed-upon contract, and the need of management to document the performance of the services they are heading. It is thus part of quality assurance systems. Benchmarking has to do with monitoring developments over time and determining how a service compares with other similar services, as a means of uncovering needs for action. Overall, the measurement of facts is intended to make the whole process less reliant on the discretion or opinions of professionals.

Although the arguments for performance measurements appear, at least partly, both reasonable and timely, it has been launched heavy criticism regarding the practical consequences for public services (6). One has pointed to the risk of goal displacement (7, 10, 11) as a possible consequence of among others:

- *Tunnel vision*: one sees what is measured, and aspects of care that are not measured lose importance— "what is counted is what counts."
- *Target fixation*: a complex goal structure is reduced to a few easily measurable aspects (10).
- *Strategic behavior*: staff and management adapt their behavior to the indicators rather than to the mission of the service—"indicators replace goals."
- *Process bias*: one tends to measure what is easily measured. In practice, this easily slips into input factors (such as staff education) or process descriptors (such as completion of duties/tasks) (12), whereas social aspects and quality of care are given less attention (10, 13).

In current practice, the terms quality indicators and performance measurements are sometimes used interchangeably, but sometimes does the former primarily refer to user outcomes, while the latter is wider and includes a number of input (production) factors and process descriptors. These are very different kinds of measurements used for different purposes but are nevertheless part of the same trend in public governance. In Norway, where this study is conducted, the term "quality indicators" is typically used as an overall concept, but with the risk that a possible process bias transforms the concept from user outcomes to the measurement of input and process indicators. In this article, such a possible transformation will be addressed. We therefore use performance measurement in a broad sense as our main concept and look into the employment of many types of indicators, including user outcomes as well as process and input descriptors.

It is an empirical question whether intended aspects or more questionable side-effects will dominate the "doing" of performance measurements. The impact obviously partly depends on the quality, accuracy, and orientation of the indicators in use as well as how it is used as a management tool and the extent to which one is able to minimize the possible impact of pitfalls. Determining the impact of performance measurements is thus an empirical task, but this can hardly produce simple or generalizable answers, as the impact is dependent on the context and the practical use of the indicators. Thus, what we will outline is more like a landscape where one needs to be aware of contradictory and ambiguous processes. The aim of this article is thus to add to the existing literature on quality measurement in disability services by exploring this landscape in one country: Norway. In this study, we aimed to (i) address the intentions or motivation behind the introduction of performance measurements, (ii) describe the indicators currently in use (i.e., the choice of indicators), and (iii) broaden our understanding of the "doing" of performance indicators.

The Norwegian Setting

This empirical study took place in Norway. Many countries introduced performance measurements in response to the marketization of services (2), but this was slightly different in Norway. Although some private providers exist, their role is negligible in community disability services. The main service provider is the local authorities (municipalities). A purchaser-provider split was nevertheless introduced, partly to prepare for possible marketization and partly to professionalize decisions about levels of support (i.e., to protect decisions against the potential self-interest of people involved in service provision). The introduction of performance measurements was linked in some cases to this purchaser-provider split, but there was also a general shift from a social-policy reasoning focused on living conditions to a reasoning that addressed the role of quality issues in the internal control systems that became mandatory in health and care services in the 1990s (14). In 1995, the Norwegian Board of Health Supervision launched an action plan aimed at the introduction of quality development and management as core components of such internal control systems (15).

Performance measurement did not initially play a vital role in this. Instead, theories on quality development in organizations, with explicit reference to Deming's cycle (16), was influential. This theory is based on ideas such as continuous development, involvement of all parties, reflection, and management engagement. Indicators played a minor role compared to reflection among managers and employees and their actions to improve on identified shortcomings. After 2000, the approach of the national government gradually transitioned away from a "reflective process" and assumed a "measurement" orientation. Peoples' opinions came to be viewed as subjective and should be replaced by facts. In the early phases, the shift was accompanied by a warning: the measurement of hard facts should be a supplement, not a replacement, for professional discretion (17). Some years later, this warning was forgotten, and quality quantification came to the forefront. In 2011, the Directorate of Health was given the task of developing national quality indicators for the entire health and care sector. This includes state-run hospitals and specialized medical services, and a range of services organized by the local authorities, including nursing homes, care for elderly people living at home, general practitioners, child health centers, services for people abusing substances—and community services for disabled people. Thus, community services for disabled people tend to be organized as a part of this large and rather mixed local health and care sector.

The local authorities were in 2011 by law obliged to have a quality assurance system for local/municipal health and care services, but it was—and still is—optional to use the national indicators. Local authorities in Norway have substantial autonomy in how they organize and perform their duties, including whether they use performance measurements and which they adopt. The practical consequence was a rather uneven development between local authorities and across service sectors. The system is much more elaborate, for instance, in education or employment services than in care. Within the health and care sector, it is more developed in short-term treatment services, such as hospitals, while in community care for disabled people, it is less developed. According to a 2014 overview (18), 60% of Norway's more than 400 municipalities, including all the larger municipalities, had introduced performance indicators in their governance system. Among municipalities using such indicators, more than 80% had introduced them into the health and care sector. The study found, however, that there was general agreement among respondents from local authorities that quality measurement was particularly challenging in the community care sector, as there were few available indicators that actually measured quality. Despite reservations, local authorities nevertheless aimed to make performance measurement a core tool in the management of local health and care services.

METHODS

The data employed in this article is from a qualitative study of the "making" and "doing" of quality indicators in parts of the community health and care sector in Norway, including nursing homes, services for people with mental health difficulties, and people with intellectual disabilities. The data used in this article are from the running of group homes/clustered housing and activity centers for people with intellectual disabilities or mental health challenges. Data from nursing homes or personal assistance schemes are not included. The data comprises policy documents, indicator-based quality reports, interviews with two levels of management, focus groups with people working on the implementation of performance indicators, observations at a meeting between developers of performance measurements and stakeholders, and a dialogue conference. The data sources vary with the above-listed sub-objectives of this article (motivation, choice, and "doing") and is outlined accordingly.

The data on motivation for the introduction of performance measurements differs between levels of the governance system: the national level, the local authority level, and the service unit level. At the national level, data on motivation is primarily extracted from policy documents, such as white papers, circulars, and recommendations from the government or the Directorate of Health. Relevant documents from 1995 to 2020 are studied with a special focus on arguments related to governance principles, quality assurance, and performance measurement. The issue of performance measurement was rarely raised in disability policy documents but primarily in documents addressing the local health and care sector in general, including community care for disabled people.

At the local authority level, few or no documents exist that convey the motivation behind performance measurement. Our primary data source at this level is management interviews. We have conducted interviews with directors (top managers) for the entire local health and care sector in five local authorities, one medium-sized and four large—by Norwegian standards. We also conducted an interview with a former local health and care director that had the reputation of being an innovator in the introduction of performance measurements at the local level. Two focus group interviews were conducted with professional civil servants working on the development and choice of performance indicators as well as interviews with seven service unit managers. All interviews were conducted in 2021.

The service unit managers were at the middle level (the level above first-line managers) and responsible for several community settings (mainly group homes/clustered housing and activity centers) and a staff of 100–500 people. These managers are in a key position regarding performance measurement, as they prepare reports for top management and initiate possible actions to improve quality at the service level. They are accountable for performance and for keeping the budgets. Five of the informants headed services for people with intellectual disabilities, and two services for people with mental health difficulties.

The interviews addressed all the sub-objectives (motivation, choice, and "doing"). The motivation questions addressed why performance measurements were introduced, what they were meant to achieve, and the purpose for which they were used (monitoring, reporting, comparison, etc.,). The interviewees were also asked to share their personal opinions about and experiences with these types of indicators. The data on motivation collected from the interviews were supplemented by points raised during the dialogue conference (see details below).

The data sources on choice of indicators were partly a mapping of actual choices (existing indicators), partly interviews on the reasoning behind choices, and partly issues service units were expected to report on. The mapping included proposed national indicators (Directorate of Health) and indicators used locally. There also exist a collaboration among larger municipalities to establish common indicators in order to facilitate comparisons with each other (benchmarking)—the so-called ASSS collaboration (Aggregerte Styringsdata for Samarbeidende Storkommuner—aggregated performance data for collaborating large municipalities). The indicators used in this collaboration was also included in our mapping. Interviewees were the same individuals as mentioned above. The interviews addressed which indicators were chosen and why, what service units reported on, and reservations they held about the quality and validity of the chosen measurements. We also observed a meeting between developers of performance measurements and representatives of disability associations about the choice of indicators in services for people with intellectual disabilities. The meeting occurred because the city council had asked for regular reports on the quality of services for this group of users and that stakeholders should be involved in the choice of indicators. Representatives from three user associations and three civil servants who work for the local authority participated in this conversation.

The question about the "doing" of performance measurements is primarily addressed at the service level. The main data source for this issue is thus interviews with the same service unit managers that were mentioned above. Interviewees discussed what they saw as the positive and more problematic effects of performance measurements, including what they believed was the future potential of such measurements. The informants were given opportunities to raise issues that they found relevant and to express their opinions. We also organized a one-day dialogue conference on the impact of performance measurement on services (November 2021). Participants represented six local authorities (two large, two medium-sized, and two small), one labor union, one professional organization, three associations for disabled people, and one non-governmental organization (NGO). There were 36 participants in total. The people from local authorities represented top management in the health and care sector ($n = 2$), professional civil servants involved in systems for quality assurance ($n = 8$), service unit managers ($n = 7$), first-line managers ($n = 7$), and representatives for direct care staff ($n = 2$). The conference covered the types of performance measurements currently in use, their perceived benefits, potential problems, and how they can be improved.

One limitation of the current study is a lack of data from street-level staff. To account for this, we have added data to the "doing" section that comes from an earlier study that took place in group homes for disabled people (2017). We employ data from three focus groups with 14 experienced staff members working in group homes (19).

The interview data was analyzed as follows: Interviews were recorded and transcribed verbatim, and the software package NVivo version 12 was used to support data management and retrieval. The authors began by carefully reading the transcripts to gain an understanding of the content. Transcripts were analyzed with an inductive approach through thematic content analyses to identify common patterns and themes (20). All authors examined and revised the themes and responses related to the sub-objectives (motivation, choice, and "doing"). Interview data were compared, clustered, and placed in preliminary themes. This process continued iteratively until a set of themes, each containing sub-themes that captured the range of experiences and views, were identified.

RESULTS

Motivation

National Level—Facts-Based and Transparent Governance

Initially, in the 1990s, the motivation for creating quality assurance systems was rather implicit. The objective was simply to increase awareness and pay more systematic attention to quality and systems for quality assurance (15, 21). The arguments for more systematic use of performance measurements emerged gradually and was linked in the beginning to the need for measurable standards if the local authority decided to purchase services from private providers. This was followed by the recommendation that the municipal council should establish standards on sufficient quality of services, purchased or not, that could be used as a benchmark in the evaluation of current services (17).

More elaborate arguments for quality/performance measurements were introduced in the 2011 law on local health and care services (22) and developed in a follow-up white paper (23). The arguments were highly influenced by New Public Management and can be summarized as follows:

- *Facts based governance*: There is a need to base evaluations, monitoring, and reports on facts. The role of opinions and discretion should be reduced, not necessarily in the day-to-day delivery of services, but for purposes of governance.
- *Transparency*: Policymakers (the municipal council) should be able to monitor whether one gets value for money, whether services are of a sufficient quality, and that the level of non-conformance is acceptable. Furthermore, users and the public should be informed about the quality of the services.
- *Benchmarking*: When monitoring whether services perform well, it is necessary to have a benchmark. The standard for comparison could be explicit local standards, changes over time, other service units under the same local authority, or services in other jurisdictions.
- *Governance*: The performance measurements should be employed as input to the local system of governance. This applies to a) reporting, b) input to performance reviews, such as regular review meetings between top management and unit

managers, and c) be the basis for internal evaluation and plans for quality development.

- *User focus*: Although the focus is on the governance system, sensitivity to user needs is addressed in all policy documents, and in the context of performance measurement, this is transformed into a recommendation to employ user surveys.

These points relate to the explicit discussion of quality indicators, but because the need for data related to governance purposes is linked to the introduction of quality measurement, some duality exists. Thus, there was also introduced statistical reporting to the national government on number of users, services and expenditures in local health and care. This information is meant for national planning and governance purposes and discussed as part of the performance measurement system (24) but is not subject to the above guidelines.

Local Authority Level—Management of Resources

The attention paid to performance measurements varies considerably between local authorities depending on the population size of the municipality. Larger municipalities tend to view performance measurements as important in the development of the health and care sector, for monitoring, planning, and funding of services. Smaller municipalities find the situation more transparent and feel less of a need for quantification: "I do not see the need for such indicators. The service users are our neighbors" (unit manager).

For larger municipalities, the need for indicators is perceived in the context of governance of the service sector and efficient management of resources. There is a need to monitor the current state of services, assess use of resources, and evaluate to what extent one gets value for money. This is partly related to transparency. Numbers are seen as an efficient way of creating an overview and communicating information, both internally amongst administration and externally to the municipal council and the public:

> *It would be good if we could illustrate as much as possible with numbers. This is about communicating to the municipal council. To explain issues based on a few tables is easier and makes it easier to understand.* (Unit manager)

However, issues related to benchmarking or comparison appear to be more important. The larger municipalities participate in the ASSS-collaboration and thus cooperate when it comes to performance measurement. The use of common indicators is intended to provide an opportunity to learn from each other, as the municipality can analyze areas where it, for instance, spends more (or less) than comparable municipalities. This is seen in the context of self-assessment ("how do we perform?") and applies to expenditures, use of resources, and, in principle, the outcome or quality for users. However, measuring quality for users is viewed as complicated and, in general, one misses better quality-relevant measurements.

A few directors in the local health and care sector and one unit manager were explicit that performance measurement could also be a tool in the management of expectations. They argued that an important challenge is (what they perceive as) increasing expectations of families, which exceed what is possible to deliver within the current resource situation. The municipalities face criticisms about the level and quality of services from media, politicians, families, and user organizations. The management believes that performance measurement could be helpful in sorting out "fair" from "unfair" criticisms, for instance by showing statistics on consumer levels of satisfaction or levels of expenditures compared to other municipalities.

Quality improvement was also an issue, but it was less striking in the interviews with top management when it came to use of indicators. One should, however, note that the majority of the top manager interviewees expressed reservations about performance measurements due to the lack of or dubious relevance of user outcome measures. The input and process indicators were generally considered to be of sufficient quality, but some expressed concerns about the reliability of comparisons between municipalities.

In summary, the top management of local authorities pointed to quality development, transparency, and the need to assess performance, but issues related to the efficient management of resources and the governance of the sector were at the forefront of their motivation.

Service Level—Tools for Quality Development of Services

At the service level, unit managers are ambivalent to performance measurement. On the one hand, they ask for more systematic use of such indicators, but on the other hand, they doubt that the complexity of the service can be adequately represented by a limited set of indicators:

> *It is difficult to develop good indicators of quality. I think it would be good to have more indicators. We should measure more.* (Unit manager)
>
> *One cannot really measure quality, only whether a task is done and documented or not.* (Unit manager)

The unit managers' arguments for performance indicators addressed the need to monitor service quality and access more hard facts, better tools for the identification of areas in need of improvement, data on changes over time, and input to quality improvement. Unit managers also argued that more measurement of user outcomes could facilitate a shift in focus in their annual reviews with top management because such indicators could strengthen the focus on topics other than budget issues. They see user outcome measurement as a tool that can be used to increase the focus on service quality. Like the top managers, some of the unit managers recognize the communication advantages of numbers (i.e., communication to the municipal council, top management, and user representatives). They also believe that performance measurement would be a useful communication tool in service development talks with staff. Furthermore, they look for opportunities to learn from others and see the potential of comparisons across units.

Their ambivalence is related to the relevance of performance indicators. Unit managers do not see how quality can be measured in a simple, reliable, and valid manner. Their general approach to quality development is more qualitative and in keeping with the logic of quality cycles, and they fear that measurement by numbers will be biased, irrelevant, or of no use. They are especially skeptical about the possibility of measuring the quality of everyday life issues in long-term (often life-long) care, whereas it would be more relevant in short-term units with more clear-cut treatment goals. In keeping with this, we note fewer reservations in the more treatment-oriented units for people with mental health issues. One should, however, keep in mind that among our interviewees, only one unit manager concluded that performance measurements are unwanted since they are based on a type of logic that conflicts with the ethos of the service. Most unit managers expressed ambivalence about this point and asked for the tools that quality indicators eventually can become. A representative statement is:

> *What are actually good indicators or measurements of the quality of personalized in-home services? Can some-one please provide me the book of answers to that?* (Unit manager)

There are some similarities between motivations at the local authority and service levels but in a context that is strikingly different. The meaning of performance measurement for unit managers is mainly about outcomes for users (i.e., the quality of services) rather than efficient management of the local health and care sector.

The Choice of Measurements

National Level—The Need for Better Measurement of User Outcomes

The approach to the choice of measurements at the national level is dual. Municipalities are expected to report on a fixed set of variables that are plugged into the national monitoring system (mainly statistics on users, services, and expenditures). However, when it comes to performance measurements employed at the local or service levels, national documents are less specific. In keeping with the general principles in the division of labor between levels of government in Norway, the national government can decide which tasks the local authorities should deliver but not how this is performed or organized. Thus, the choice of indicators or measurements at the local or service levels is up to the local authorities, and the same applies to the extent to which local authorities use measuring as a part of their quality assurance system. One should, however, note three recommendations from the national government:

- Existing performance measurements tend to rely mostly on input and process indicators, and there is a need to develop more indicators on user outcomes.
- User surveys should be among the measurements.
- The Directorate of Health should develop a set of national quality indicators that the local authorities can chose to employ.

The national indicators proposed by the Directorate have been gradually developed and consisted of 174 indicators in 2020. The majority address specialized treatments in hospitals. Only 31 apply to local health and care. These local level indicators are heavily biased toward nursing homes, and only nine indicators are relevant for community disability services. Among these nine indicators, two address staff (% with relevant education, sick leave statistics), two are on waiting lists, and five on numbers receiving specific services. There appears to be agreement that the nationally proposed indicators for community care need improvement and that current indicators do not align with general guidelines for quality indicators (i.e., more on user outcomes). Therefore, for the next planning period, the Directorate of Health is asked to prioritize the development of indicators for this service sector.

Local Authority and Service Levels—the Back-Door of Administrative Systems

There appears to be two general "principles" guiding the development of indicators at the municipal level. The first is that one hardly looks to the national indicators, and unit managers were generally not even aware that these indicators existed. Sick-leave statistics and the proportion of staff with relevant education are frequently used locally and recommended nationally, but this similarity appears to be by coincidence rather than because municipalities employ national indicators. Second, the preferred indicators are those that can be automatically produced through the current administrative systems, which are primarily input and process indicators:

> *It is rather homemade, and we sort of approach indicators through the back-door of our administrative and accounting systems.* (Top management)
> *We are mainly using what could be generated from our existing administrative and accounting systems, and in a few cases, we count manually what cannot be generated automatically.* (Top management)

There is currently some optimism about what can be retrieved through this back-door in the near future, as this region of Norway is establishing a new comprehensive administrative IT-system for the health and care sector. This system is supposed to provide more possibilities, but so far, the extent to which this includes measurement of user outcomes remains unclear.

The two general "principles" do not tell the full story. There is choice involved in what is generated from the administrative systems, and this type of data includes "feed-back mechanisms" such as registration of complains or other types of non-conformances (e.g., accidents, deviation from expected delivery according to individual plans/statements). Some municipalities publish this type of data as part of a transparency policy, while for others, the data is part of internal quality assessments. Furthermore, both user and employee surveys are common tools among performance measurements.

The larger municipalities tend to have a more systematic and elaborate approach to performance measurement than the small municipalities where the system is more "trust-based." The larger municipalities participating in the ASSS-collaboration tend, on a regular basis, to discuss what measurements to include in which service sector. People from different service sectors participate in working groups that outline the indicators that could be compared between municipalities. The interviewees express a reasonable level of influence on choice of ASSS-indicators, but they also argue that indicators of user outcomes are difficult to establish. The main body of indicators are thus centered on input and process variables, such as expenditures, expenditures per user, number of recipients, number of recipients with intellectual disability, proportion of staff with relevant education, and sick-leave statistics. In short, they are performance measurements strongly linked to the "management of resources" logic. Such indicators appear to be viewed as vital for top management and the municipal councils. This is because they are struggling with limited budgets and fiscal problems. Furthermore, top management appear to be fully aware that these are resource management indicators rather than indicators of quality for users. However, the indicators are still frequently referred to as quality indicators.

At the local authority level, the ASSS-indicators are used, but municipalities also tend to have a more elaborate set of indicators. There is, however, variation between service sectors, and community care appears to lag behind. One large municipality is currently working on a quality report system for services for adults with intellectual disabilities inspired by the current system in nursing homes. This system includes measurement of user satisfaction, staff formal qualifications, the proportion of part-time staff, medication, incidences of non-conformance, nutrition, and waiting lists. The intention is to measure quality of service provision, not outcomes for users, as user outcomes are believed to be too difficult to measure and strongly dependent on individual preferences. The type of measurements included in these reports are less about "management of resources" and more related to structural dimensions that may impact quality. So far, such reports are in the emergence state in services for disabled people.

Another source of information about current indicators at the municipal and/or service levels is the interviews with unit managers. When first asked about existing quality indicators, the unit managers (with a few exceptions) were rather reluctant to answer and even evasive. They felt that they should do quality measuring but had no system in operation. However, when we changed the question to what their unit has to report on and are measured by, the response tended to be: "Everything".

> *We report on sick leave, use of restraint – there is frequent auditing on use of restraint – user surveys, staff surveys every other year, economy of course. We must report on almost everything; thus, we are measured in a large number of areas.* (Unit manager)

Disregarding details, the issues that are frequently mentioned by unit managers can be grouped into four categories: (1) budget and economy, (2) human resources, (3) employer policy, and (4) compliance with procedures. Human resources are indicators such as sick-leave, part-time work, proportion with relevant education, turnover, etc. Employer policy is concerned with reducing part-time employment, the number of staff members with minority backgrounds, climate footprint, and whether the employer is viewed as attractive. Compliance with procedures includes the number of employee development interviews, checklists for completion of activities listed in the users' daily schedule, checklists of performed administrative tasks, counting instances of non-conformance, and deviations in medication handling (in brief, ticking of boxes about whether a procedure was complied with or not). However, when it boils down to what is most important, the rather uniform answer from unit managers is versions of this:

> *If I should rank the ten most important things the unit is measured on, it is budget and economy from number one to ten.* (Unit manager)

This does not mean that unit managers oppose performance measurements or that they are stuck with an unsatisfactory measurement system. Their attitude to measurement is ambivalent; they want it but cannot quite grasp how to measure or quantify issues of importance. They also feel that they can influence what is measured, for instance through the dialogues with top management on strategy, aims and measurement. Some are invited into working groups proposing indicators which should be possible to retrieve from the new administrative IT-system. The main problems from the perspective of unit managers appear to be two, (i) that they cannot grasp how to measure or quantify the issues of importance (i.e., the quality of care for users) and (ii) that they hardly get any feedback on what they report to superior levels of the organization. This means that there are not many efforts to establish performance measurements at the service level and that local authority and service levels are not easily distinguished regarding choice of indicators. The local indicators tend to be chosen by the top administration of the local authority for the purpose of governance. This does not mean that unit managers have little involvement in quality assessment and development, but the activities in the service unit are based on qualitative assessments and discussions among staff, rather than quantification and performance measurement.

In brief, with respect to the choice of performance indicators, data clearly supports the hypothesis of a process bias as well as a bias toward measurements of importance for the management of resources rather than outcomes for users. So far, we conclude that there is an obvious risk of goal displacement, i.e., that measurement of quality is transformed into governance data. Thus, the national recommendation about stronger focus on measurement of outcome for users appears timely.

The "Doing" of Measurements

Our data does not provide the opportunity to identify clear impacts of performance measurements on services, and it is likely that these types of measurements do not in themselves have dramatic effects. The point is rather how they interact with or strengthen other mechanisms. Thus, our analytical strategy was to identify clues in the interviews that are likely to impact on services together with other mechanisms, with special attention paid to unintended or potentially aversive effects. With respect to intended effects, interviewees did not talk about actual experiences but rather emphasized what they hoped for, and their hopes aligned with the motivation for wanting performance measurements. In this section, we will only address the local and service levels because the main issue at the national level is monitoring and policy rather than "doing."

Local Level—Performance Measurement as a Tool in a "Race to the Bottom"?

Performance measurements at the local level primarily center on resource management, sector governance, and input/process indicators. The doing of such indicators appears to be related mainly to the monitoring of how the municipality compares with other municipalities. The logic of this type of benchmarking is to look to others to learn, and it is the political context of benchmarking, rather than the benchmarking as such, that is likely to impact services since the benchmark can be used both for increasing and decreasing ambitions. For instance, in the 1990s, Norwegian municipalities looked to Sweden and argued that "we should do at least as good as them" (25). The point was to learn from someone that presumably offered quality services. The same reasoning applies when municipalities compare the proportion of staff with relevant formal education. If the proportion is low, this is an incentive to recruit more people that have completed higher levels of education. However, according to unit managers, the main current issue is the costs. The local authorities experience fiscal strain, and there is a constant search for cost-cutting opportunities. If a sector spends more than the same sector in other municipalities, it is treated a candidate for cost-cutting initiatives. Thus, one learns from those who spend less on the sector. Several Norwegian municipalities that look for such possibilities have engaged consultancy companies that specialize in analyzing variation in expenditures across municipalities, and the result is frequently cost-cutting proposals (26).

This result is not in itself a consequence of measurements, benchmarking, or learning from others, but in the context of a search for cost-cutting, the outcome resembles what economists term "the race to the bottom." This refers to countries or companies that cut wages, taxes, labor standards, or social security to improve their competitiveness, and those cutting most will lead the development. In the case of benchmarking of costs for community care for disabled people, municipalities learn from those who spend the least. This is not caused by performance measurements, but the measurements provide facts and arguments for cost-cutting efforts. One consequence is that the main "ten issues" that emerge in the development talks between top management and unit leaders center on budget and costs. At the dialogue conference, representatives from user organizations also claimed that "quality indicators" end up in being used as cost-cutting instruments.

As suggested above, one motivation for the use of performance measurement is the management of expectations. We see no clear cases of such "doing" in our data, but the phenomenon can be observed in local newspapers when they publish criticisms from users, family, or disability organizations that tend to be illustrated by the situation of a specific individual. A typical response from the local authorities is that they cannot comment on the specific case; instead, they refer to statistics showing that they spend as much money as other municipalities or they point to user surveys that show reasonable levels of satisfaction. Thus, the performance measurements are not directly used to manage expectations but rather to defend the current level and quality of services against criticisms.

These results point to adverse effects of performance measurement. This does not mean that local authorities only use performance measurement for "bad" purposes. Measurements are also used for identification of problems or service units that need to improve and above all monitoring for the purpose of planning and resource management within the sector. However, this monitoring goes on in the central administration and primarily affects service delivery in the form of budget decisions. According to unit managers who attended the dialogue conference, there is limited communication across organizational levels about performance measurement results.

Service Level—The Impact of a Process Bias

The issues that unit managers report on, excepting budget, staff, and costs, concerns compliance with procedures (i.e., ticking boxes to show whether a task is done or not). The logic of this as part of quality assurance, is that it safe-guards that expected activities or tasks are performed. These tasks could be related to resident activities or different types of staff documentation, such as completing an annual review of a user service plan, organizing meetings with families, reporting instances of non-compliance, etc. The documentation of performed resident activities is important in services that involve a number of part-time staff and extensive use of substitutes. Parts of the reporting is supposed to function as milestones where one reflects on how things are going and possible needs for change. This is, for example, the purpose of the annual review of the user service plan. Ticking procedural boxes is thus unlikely to have any adverse impacts on services because this process is meant to ensure that certain activities are completed. None of the interviewees were skeptical about this, but they did recognize that checking whether a report was delivered or not was an incomplete method of quality assurance. They saw the need to address the content of the report to assess whether it was really used as a milestone. Presently, this did not usually occur unless unit managers received other types of information that suggested a need for action.

Our critical analysis at this point is based on focus group interviews with direct care staff from the earlier study that examined extensive services in other peoples' home. When describing their work, the direct care staff present it as predetermined by the daily schedule for each user and that they have established a set of routines and must-do-tasks that ensures that expected tasks are done. When asked about the reason behind these routines, the typical answer was a variation of the following statement:

> *I do not know. They were here before I started to work here. I do not know who has written them. But we need them. There is a lot of people working here, and if we do not follow strict routines, things may be forgotten.* (19, p. 170)

The professional discretion and reasoning that this type of documentation is meant to ensure, slips into routinization and an unreflective performance of required tasks. This is similar to the criticism of performance measurement raised by those who point to the risk of "indicators replacing goals", with professional discretion and individual tailoring losing ground. Some informants suggested that they are trapped in certain ways of doing things: "*and we have done so for 20 years*" (19, p. 170). The intention of some of the process measurements, such as ticking off that "review of individual plan is finalized," is intended to counteract the possibility of being caught in these types of traps. However, the totality of ticking off boxes runs the risk of reinforcing this routinization trap, because what is measured is what's scheduled. The documentation is just another administrative task to be completed, more than a milestone, and most unit managers were fully aware of this risk.

There are, of course, some reservations to this rather depressing image. First, there is variation across services with respect to whether the "milestone procedures" are simply routine (19). Some services use such milestones to actively to reflect on the current service. Second, there is a distinction between short-term services for people with mental health issues and long-term services for people with intellectual disabilities. To a large extent, the unit managers involved in mental health services did use the milestone procedures as intended; that is, for goalsetting, evaluation, reflection, and, if needed, for change.

DISCUSSION

This article has addressed i) the motivation behind the introduction of performance measurement in community services for disabled people, ii) the choice of indicators in actual use, and iii) the possible impact on services. In the empirical context of Norway, indicators of outcome quality for users are a subset of a wider movement toward performance measurement, and one question has been to what extent measurement of service quality slips into the measurement of service production factors.

The findings show that one can identify multiple motivations for the introduction of performance measurement. At the national level, policy documents explicitly refer to the need for a facts-based and transparent governance, tools for quality assurance, and to provide local and national authorities information needed for the management and planning of the sector (24, p. 22). Measurements are expected to be sensitive to user needs and quality outcome for users. To improve the quality of outcomes for users is also a motivation at the local authority level, but this appears to be overshadowed by needs concerning the management of the sector. At the service unit level, the motivation for performance measurements is foremost as a tool for the development of service quality. Unit managers welcome more use of performance measurements, but they cannot really grasp how the important issues (i.e., quality outcomes for users) can be measured or quantified. Their attitude can be summarized as ambivalent, including a call for better measurement of outcome quality for users.

In practice, local authorities chose which measurements are in operation at the service level. The national government offers some guidance, but in the context of community care, even guidance is underdeveloped. The national authorities do, however, require that local authorities report on a set of measurements relevant to national monitoring and planning. Regarding community services for disabled people, this reporting is basically statistics on service provision (i.e., the number of users and expenditures), whereas for other parts of the health and care system, the reporting also comprises quality indicators, such as regularity of medical checks in nursing homes. At the local authority level, the main driver of choice of measurements is practical—the measurements are what can be retrieved from administrative systems. These measurements are mainly input and process factors, and the most attended indicators appear to be related to expenditures, followed by other information of relevance for the management of the sector. Service units also report on a set of process factors, some of which have potential utility for service quality. This includes reporting on milestones, such as annual reviews of individual service plans, and non-conformance. This reporting is potential tools to uncover shortcomings that need to be acted upon. Many local authorities also conduct user surveys.

As for the "doing" of performance measurements, our data suggests a clear distinction between "up-stream" and "down-stream" information. The up-stream model means that lower levels are providing governance information to higher levels (from local authorities to the national level and from service units to the municipal administration). This information is used for planning, budgeting, management of the sector, and for reporting to political bodies. In community care for disabled people, less information appears to be going "down-stream" to the practical delivery of services. The role of performance measurements in the development of service quality appears to be limited. We do, however, see some indirect impact that is partly related to the local authorities' use of expenditure data and partly related to practices of documentation. The local authorities operate in a context with fiscal strain and have strong incentives to look for cost-cutting strategies. Thus, when comparing themselves with other municipalities, local authorities search for sectors where they spend more than average to identify candidates for cost-cutting. This mechanism resembles the so-called "race to the bottom" and is, at the service level, likely to be experienced as budget cuts. We have also identified a mechanism where routinised reporting on process indicators may turn out to be, not a milestone for evaluation and reflection, but rather part of a general routinization of the service at the expense of professional discretion and individual tailoring. However, this finding is uncertain and may easily be counteracted by a more active practice in the use of such reporting.

The most common user-oriented quality tool is user surveys where reasonable levels of satisfaction tend to be used by local authorities as defense against criticisms. There is, however, reason to ask whether this is a valid and reliable measure. Unit managers comment that they do not trust these measurements because users frequently do not respond independently, many respondents are reluctant to criticize services that they are dependent on, and response rates are very low. This comes in addition to the general homeostatic effects on responses to satisfaction surveys (27), that is, one adapts expectations to the factual situation. The consequence is that, in general, such surveys end up with satisfactions rates of 70–80%, irrespective of the actual situation. Measurement of user satisfaction by surveys thus runs the risk of being insensitive to the quality of care (and that is maybe why they are so popular?).

This study set out to analyze how performance measurement was used in the quality assurance of community services for disabled people. It was inspired in part by studies of the Norwegian Work and Welfare Administration that show there is no correlation between doing well on service quality indicators and success regarding the real goal—to support people into employment (28). This appeared to be a typical case of "indicators replacing goals" due to the strategic behavior of staff. We thus searched for clues about whether the points referred to in the critical literature on performance measurement were in operation and whether the intended benefits were present. We can clearly identify motivations related to transparency, accountability, and benchmarking, and these types of mechanisms also appear to be present in the "up-stream" part of the "doing." As such, this resembles another key point in New Public Management: managerialism. From the point of view of the national government, the performance measurement provides hard facts input to the monitoring and planning of the sector, and for the local authorities, the data is useful tools in budgeting and planning processes. From the perspective of users, however, this is hardly beneficial.

As for the main critical points, such as tunnel vision or target fixation, we have observed few signs of strategic behavior from staff that may lead to this. This may be because the art of performance measurement is underdeveloped in community services for disabled people in Norway and is generally not used at the staff-member level. Our lack of findings should thus not be seen as evidence for the non-existence of such mechanisms. What is evident in our data, however, is the process bias—that one uses indicators that are easily retrievable from administrative systems and that such indicators tend to be input and process factors rather than outcomes for users.

One should note (i) that there appears to be differences depending on the size of the municipality, as smaller municipalities measure less and operate more qualitatively, and (ii) that some of the dubious effects appear to be more evident in long-term services for people with intellectual disabilities, and that the employment of outcome indicators are more used and more useful in short-term services for people with mental health problems. Furthermore, it is essential to highlight that the findings of this study hardly are effects of performance measurement per se, but rather dependent on the context, practical use, and orientation of the indicators in use. The dominance of production indicators does something to the "doing" of indicators. In keeping with this, unit managers tend to expect clear benefits if the measurement of outcome quality for users is introduced. This is among others because such measurements can be used by unit managers to balance the current focus on budget issues in their annual reviews with top management, and possibly also have an impact in budget discussions in the municipal council. They also see potential use in internal quality development efforts.

Our preliminary conclusion is not that one should refrain from performance measurement, but that there is an urgent need to help unit managers with the tools they need to introduce better and more useful indicators of outcomes for users. We do, however, also want to issue a warning that in real-life contexts where quality development meets the economic worries of local authorities, a transformation of well-intended measurements is not unlikely. As a managerial tool, the impact of performance measurements is likely to be context dependent and ambiguous. It is tempting to argue the case of a more qualitative approach to quality development based on user involvement and co-production, professional discretion, and managerial leadership. In principle, this will be a return to the use of Deming's cycle (16). However, performance measurements appear to have gained an irreversible position in the management of health and care services, and the dominance of measurements related to governance information needs to be balanced by more user-oriented measurements. However, at the service level, this should be a supplement rather than a replacement of professional discretion and individual tailoring, and employed as a part of a qualitatively oriented quality cycle.

Finally, one should note a set of reservations about the results presented in this article. First, our study is based on a limited set of interviews with informants, and the narratives from people in the same position were unusually varied. Second, our data primarily comes from documents and interviews at the management level, not hands-on staff or users/user representatives. The missing user perspective is a clear limitation. It is, however, not likely that users or their family have much insight into the current use of performance measurement, but representatives from user associations could add to the current data like they did during the dialogue conference. First-line staff could also contribute to perspectives on their reporting, and to what extent they experience that the reporting affects their doing or is fed back as part of the efforts to identify areas in need of development. To include user and first-line staff perspectives would be a task for future research. Lastly, this study was conducted in a system that is still in the making, as the use of performance measurements are underdeveloped in community care for disabled people. This means (i) that uncovering unintended consequences due to strategic behavior of staff or unit management was less likely than in a more established and elaborated system and (ii) that existing measurements are dominated by administrative indicators that can potentially be applied in any sector, whereas sector-specific measurements play a minor role or no role at all. Thus, the potential of user-oriented measurements to balance the impact of the dominant production-oriented measures has not been studied.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

JT has been lead author and there are equal contributions to data gathering and analyses. All authors have contributed to the data gathering, analysis, and writing of the manuscript. All authors contributed to the article and approved the submitted version.

FUNDING

Funded by the Research Council of Norway (grant number 302878/H40), only role is as funding agency.

REFERENCES

1. Beadle-Brown J, Hutchinson A, Mansell J. Care standards in homes for people with intellectual disabilities. *J Appl Res Intellect Disabil.* (2008) 21:210–8. doi: 10.1111/j.1468-3148.2007.00400.x
2. McEwen J, Bigby C, Douglas J. What are Victoria's disability service standards really measuring? *Res Pract.* (2014) 1:148–59. doi: 10.1080/23297018.2014.956385
3. Schalock RL, Baker A, Claes C, Gonzalez J, Malatest R, van Loon J, et al. The use of quality of life scores for monitoring and reporting, quality improvement, and research. *J Policy Pract Intellect Disabil.* (2018) 15:176–82. doi: 10.1111/jppi.12250
4. Siska J, Beadle-Brown J. Definitions of quality and the importance of measuring and focusing on service quality. In: Siska J, Beadle-Brown J, editors. *The Development, Conceptualisation and Implementation of Quality in Disability Support Services*. Prague: Karolinum Press (2021). p. 137-148.
5. O'Keeffe P, David C. Discursive constructions of consumer choice, performance measurement and the marketisation of disability services and aged care in Australia. *Aust J Soc Issues.* (2020). doi: 10.1002/ajs4.139. [Epub ahead of print].
6. Christensen T, Lægreid P, editors. *The Ashgate Research Companion to New Public Management*. Aldershot: Ashgate Publishing (2011).
7. Pollitt C. The logics of performance management. *Evaluation*. (2013) 19:346–63. doi: 10.1177/1356389013505040
8. Hood C. A public management for all seasons. *Public Admin*. (1991) 69:3–19. doi: 10.1111/j.1467-9299.1991.tb00779.x
9. Boston J. Basic NPM Ideas and their development. In: Christensen T, Lægreid P, editors. *The Ashgate Research Companion to New Public Management*. Aldershot: Ashgate Publishing (2011). p. 17–32.
10. Jantz B, Christensen T, Lægreid P. Performance management and accountability. *Int J Public Admin.* (2015) 38:947–59. doi: 10.1080/01900692.2015.1069838
11. Møller MØ, Iversen K, Andersen VN. *Review af Resultatbaseret Styring. [Review of Management by Performance Measurement]*. Copenhagen: Det nationale institut for kommuners og regioners analyse og forskning (2016).
12. Mansell J. Deinstitutionalisation and community living. *J Intellect Dev Disabil.* (2006) 31:65–76. doi: 10.1080/13668250600686726
13. Eika, K. Hva med de sosiale dimensjonene? [What about the social dimensions]. *Tidsskrift for velferdsforskning.* (2016) 19:359–65. doi: 10.18261/issn.2464-3076-2016-04-05
14. Tøssebro J. Bakteppet – politiske idealer og utviklingslinjer [Background – policy ideals and developments]. In: Tøssebro J, editor. *Hverdag i velferdsstatens bofellesskap [Everyday life in welfare state group homes]*. Oslo: Universitetsforlaget (2019). p. 25–44.
15. Helsetilsynet [Norwegian Board of Health Supervision]. *Nasjonal strategi for kvalitetsutvikling i helsetjenesten [National Strategy for Quality Development in the Health Sector]*. Oslo: Statens helsetilsyn (1995).
16. Deming WE. *Out of Crisis*. Cambridge, MA: MIT (1986).
17. Stortingsmelding [White paper] nr. 25 (2005-2006). *Mestring, muligheter og mening: Framtidas omsorgsutfordringer [Mastery, Possibilities and Meaning: The Care Challenges in the Future]*. Oslo: Helse- og omsorgsdepartementet (2006).
18. Agenda Kaupang. *Kartlegging og bruk av objektive kvalitetsindikatorer i norske kommuner. [Mapping the use of Objective Quality Indicators in Norwegian Municipalities]*. Oslo: KS (2014).
19. Johansen O, Mjøen OM. Profesjonell yrkesutøvelse – styrt av dags- og ukeplaner? [Professional practice – ruled by daily and weekly schedules?] In: Tøssebro J, editor. *Hverdag i velferdsstatens bofellesskap [Everyday Life in Welfare State Group Homes]*. Oslo: Universitetsforlaget (2019). p. 158-178.
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* (2006) 3:77–101. doi: 10.1191/1478088706qp063oa
21. Stortingsmelding [White paper] nr. 28 (1999-2000). *Innhald og kvalitet i omsorgstenestene [The Quality of Care Services]*. Oslo: Sosial- og helsedepartementet (2000).
22. Prop. [Law proposition] 91L (2010-2011). *Lov om kommunale helse- og omsorgstjenester m.m. [Health and Care Services Act]*. Oslo: Helse- og omsorgsdepartementet (2011).
23. Stortingsmelding [White paper] nr. 10 (2012-2013). *God kvalitet – trygge tjenester – Kvalitet og pasientsikkerhet i helse- og omsorgstjenester [Good Quality – Safe Services. Quality and Patient Safety in Health and Care Services]*. Oslo: Helse- og omsorgsdepartementet (2012).
24. Stortingsmelding [White Paper] nr. 9 (2019-2020). *Kvalitet og pasientsikkerhet 2018. [Quality and Patient Safety 2018]*. Oslo: Helse- og omsorgsdepartementet (2019).
25. Tøssebro J, Bonfils I, Teittinen A, Tideman M, Traustadottir R, Vesela H. Normalization fifty years beyond – current trends in the Nordic countries. *J Policy Pract Intellect Disabil.* (2012) 9:134–46. doi: 10.1111/j.1741-1130.2012.00340.x
26. Devold AS. (ltd). *Molde kommune Tjenester for funksjonshemmede Drifts- og ressursanalyse [Molde municipality, services for disabled people Analysis of operations and resource use]*. Molde: Molde Municipality (2018).
27. Cummins R. Normative life satisfaction: measurement issues and a homeostatic model. *Soc Indic Res.* (2003) 64:225–56. doi: 10.1023/A:1024712527648
28. Roaldsnes A. Mål og resultatsyring i Nav [Goals and performance measurement in the Work and Welfare Administration]. *Arbeid og velferd.* (2018) 1:57–80. Available online at: https://arbeidogvelferd.nav.no/journal/2018/1/p-1878/M%C3%A5l_og_resultatstyring_i_Nav_%E2%80%93_kan_det_bidra_til_%C3%A5_f%C3%A5_flere_med_nedsatt_arbeidsevne_i_arbeid?

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Rehabilitation Sciences

POLICY AND PRACTICE REVIEWS
published: 11 May 2022
doi: 10.3389/fresc.2022.873568

Linking Process and Outcome Measures to Improve Employment Support Programs for Individuals With the Most Significant Disabilities

Tim Riesen, Corban Remund and Aubrey Snyder*

Institute for Disability Research, Policy and Practice, Utah State University, Logan, UT, United States

Employment agencies and funding systems commonly use distal outcome measures such as employed or not employed, full-time or part-time, and continuous measures such as wage, hours worked, and type of job to document the employment status of individuals with disabilities. These measures continue to demonstrate that individuals with disabilities fall behind individuals without disabilities in all employment outcomes. While there is utility in distal outcome measures, it is difficult to determine what intervention or program variables were responsible for a specific outcome. Moreover, outcome measures do not provide sufficient information about the quality of employment supports and services an individual with disabilities receives. One way to improve accountability in employment support programs is to link outcomes to specific processes for obtaining and maintaining employment. The purpose of this manuscript is to describe how employment programs can link short-term (proximal) and long term (distal) outcomes measures to specific processes for employment. A customized employment framework is used to illustrate how systematically linking outcomes and processes improves accountability in programs that support job seekers with most significant disabilities.

Keywords: competitive integrated employment, most significant disabilities, process measures, outcome measures, accountability

Edited by:
Jan Šiška,
Charles University, Czechia

Reviewed by:
Jacqueline Moodley,
University of Johannesburg,
South Africa
Julie Beadle-Brown,
University of Kent, United Kingdom

***Correspondence:**
Tim Riesen
tim.riesen@usu.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *10 February 2022*
Accepted: *19 April 2022*
Published: *11 May 2022*

Citation:
Riesen T, Remund C and Snyder A (2022) Linking Process and Outcome Measures to Improve Employment Support Programs for Individuals With the Most Significant Disabilities. Front. Rehabilit. Sci. 3:873568. doi: 10.3389/fresc.2022.873568

INTRODUCTION

The health of economies is often measured by the number of individuals who are attached to the workforce and who are actively employed. An examination of current economic outcome measures in the United States suggest that the U.S. is currently in a changing and robust labor market with unemployment hovering around 3.5% at the end of 2021 (1). Unfortunately, employment outcome measures indicate that the economic and employment realities for individuals with disabilities is quite different. The unemployment rate for individuals with disabilities is two times that of individuals without disabilities (7.9%) (1) while the American Community Survey (ASC) reports that only 37.8% of non-institutionalized individuals with disabilities between the ages of 21–64 are employed (2). When outcome data are drilled down by disability, individuals with the most significant disabilities (MSD) are even less likely to be employed. In fact, only 21.1% of individuals receiving day supports from state intellectual and developmental disability agencies are employed in competitive integrated employment (3).

These data are discouraging because research consistently demonstrates that when individuals with disabilities are engaged in competitive integrated employment (CIE), they experience improved outcomes in economic, psychological, and physical health factors (4). For example, individuals who participate in CIE earn more money (5, 6), tend to work more hours than their counterparts in sheltered work or group integrated work settings (7), and have more personal independence and self-determination (8, 9). Given what we know about the benefits of CIE, there has been a U.S. federal priority to increase high-quality job and career opportunities for individuals with significant barriers to employment, which includes individuals with MSD [e.g., (10–12)]. Despite these amendments, rules, and corresponding funding provisions to support individuals with MSD to find and maintain CIE, changes in employment outcomes remain slow and, in some cases, stagnate. Agencies and programs typically use distal employment outcome measures (i.e., employed or not employed, full-time or part-time, and continuous measures such as wage, hours worked, and type of job) to determine the success of employment programs and supports for individuals with disabilities. Unfortunately, relying exclusively on employment outcome measures does not provide sufficient information about what variables positively or negatively effect valued employment outcomes. Researchers, policy makers, and practitioners must adopt robust measurement strategies to ensure employment programs who support individuals with MSD formally link the taxonomy of an intervention or program to short-term (proximal) outcomes and long term (distal) outcomes. Ongoing adjustments to employment programs or interventions should be made based on evaluation of the process which in turn ensure practitioners are using validated strategies that help job seekers with MSD obtain and maintain meaningful work. The purpose of this article is to describe how employment programs can link proximal and distal outcomes to specific processes for employment. A customized employment framework will be used to illustrate how systematically linking outcomes and processes improves accountability in programs that support job seekers with MSD.

DESCRIPTION OF CURRENT OUTCOME MEASURES

Both proximal and distal outcome measures are used to determine the impact of a program or intervention. Both measures attempt to answer, "what happened" after an intervention or program is implemented. Proximal outcome measures include data that is collected during program implementation and provide information about the most immediate and observable outcome of a program or intervention. Distal outcome measures include data that is collected after program or intervention implemented and are designed to determine the outcomes the program or intervention was intended to achieve (13). Policy makers, researchers, agencies commonly use distal outcome measures such as employed or not employed, type of job, benefited or not benefitted, hourly wage, monthly income, and hours worked per week to determine the success of an employment program.

The American Community Survey (ACS) is an example of a distal outcome measure that is used to inform policy. The ACS is an annual supplement to the U.S. Census and provides large-scale, aggregate distal outcome measures. The ACS provides information about demographics and social and economic statistics that serve as a base for the administration and evaluation of U.S. government programs (14). For disability related demographics, the ACS compiles data on six disability areas related to functional limitations in hearing, vision, cognition, ambulation, self-care, and independent living. For employment measures, the ACS examines employment status, number of weeks worked, and number of hours worked per week. According to Erickson (14), an individual is considered employed if one of two conditions are met. First, the individual works as a paid employee, works in his or her own business, works on his or her farm, or works 15 or more hours as an unpaid worker on a family farm or business. Second, the individual has a job but is not at work during the reference period (i.e., the individual was not working because of illness, bad weather, vacation, or other personal reasons). The ACS defines the reference period as the week prior to the ACS questionnaire being completed. The ACS also measures full-time/full-year employment. Full-time employment is defined as working 50–52 weeks in the previous 12 months and at least 35-h per week.

The Rehabilitation Services Administration (RSA) 911 data is an example of an agency specific distal outcome measure. The RSA-911 data is mandated by the Rehabilitation Act as amended by the Workforce Innovation and Opportunity Act (10) and is used to describe the performance of the vocational rehabilitation (VR) and supported employment (SE) programs in the annual report to the U.S. Congress (15). State VR agencies are required to submit RSA-911 data on a quarterly reporting period. RSA-911data submitted by each state VR agency is aggregated employment outcome data based on VR service recipient outcomes. Among many items, states report on demographics, service interventions (i.e., supported employment, customized employment), the hourly wage at the time an individual exits the program, hours worked, employment status (i.e., employed, not employed, registered apprenticeship), benefits received, and primary occupation using the Standard Occupational Classification.

PROCESS MEASURES

Process measures attempt to answer and document "how something happened" and provide a robust assessment of how well or the fidelity to which practitioners implement a program or intervention (16). The early use of process measures can be traced to improving manufacturing during World War I to monitor the quality of the manufacturing process (17) and the measurement construct has been adopted and is commonly used in the medical field to measure quality in specific medical procedures and treatments (18). Process measures help practitioners obtain actionable information to understand (a) what was done, (b) whether the action was done well (to fidelity), and (c) whether that action was implemented in a timely fashion (17). Using process measures requires systematic analysis of each process for a program or intervention and should be developed using empirical information rather than anecdotal observations of a specific process. Process measures should have demonstrated reliability and validity before they can be used as measures to improve performance and they should be connected and applied to both proximal and distal outcomes (19). Process measures may include information about what services the individual received, the fidelity to which the provider implemented a specific intervention or service, and whether the intervention or service aligns with validated practices. These measures do not guarantee change in outcomes, but they allow programs and practitioners to determine how a program or intervention is directly impacting proximal and distal outcomes. Systematically gathering process data allows programs to make meaningful adjustments to individualized employment programs and interventions that will increase overall distal outcomes. Unfortunately, the use of process measures in human services and rehabilitation fields is limited.

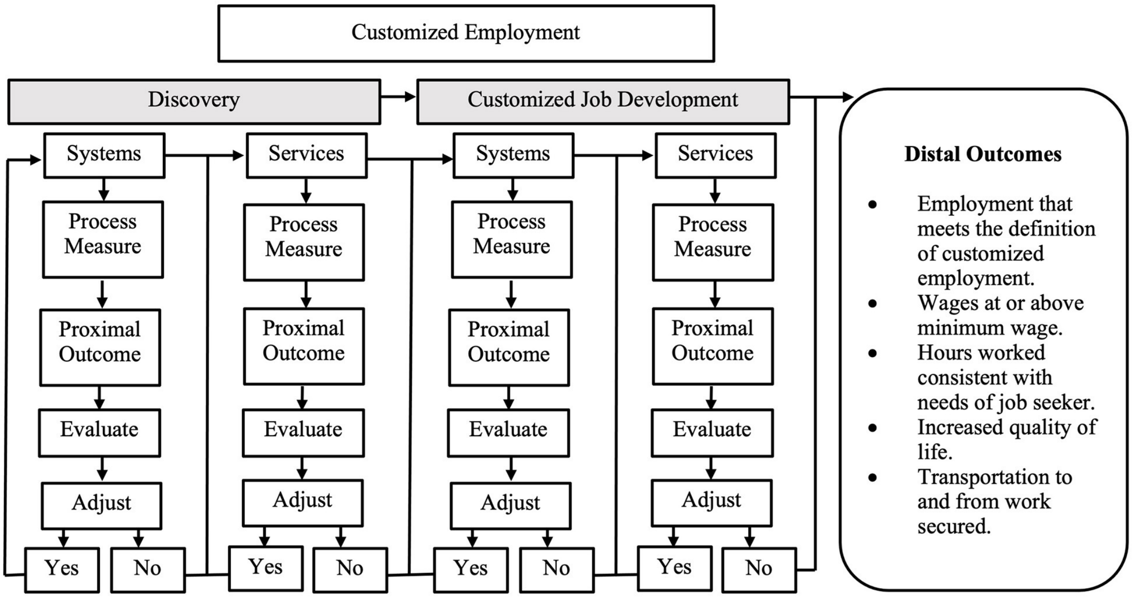
ACTIONABLE RECOMMENDATION: APPLICATION FOR JOB SEEKERS WITH MSD

For most working-age adults, the pathway to meaningful employment occurs over the lifespan (20), is based on a congruence between personality types and work environments (21), and is based on mutual interaction between the individual and the work environment (22). Finding and maintaining meaningful work is based on experiences and unfortunately, individuals with disabilities, especially those with MSD are more isolated and segregated (3, 23, 24) and are engaged in activities and supports that do not represent the demands of integrated community environments (25). As a result, individuals with MSD do not always engage in the full range of experiences that we know help build career identities and pathways and they need individually tailored interventions and supports to navigate, find, and maintain CIE (26). When employment programs measure distal outcomes only, they cannot be sure if changes in practices occurred and that job seekers with MSD are engaged in validated activities lead to CIE. Therefore, employment programs can ensure consistent and validated employment supports are implemented by adapting Donabedian's (27) approach to quality evaluation. Donabedian suggested that improvements in outcomes are made when a combination of measures including structure, process, and outcome measures are used to measure the quality of care. Using both process and outcome measures is important because they help connect a program or intervention to a specific outcome. Employment support programs can ensure program success by measuring and formally linking employment process measures to proximal and distal employment outcome and related measures.

A Customized Employment Framework for Linking Process and Outcome Measures

Customized Employment (CE) represents a departure from traditional employment support methods and is designed to support individuals with MSD to find and maintain competitive integrated employment. CE is a sequential, cumulative process consisting of discovery, customized job development, and ongoing training and support. CE begins with discovery, which is psychosocial rehabilitation process used to determine an individual's strengths, interests, skills, and support needs to obtain and maintain customized employment (28). The discovery process includes interviews, observations, documentation review, and interactions with the job seeker (29). Discovery also uses observations of the employment seeker engaged in familiar and less familiar activities and requires interviews with family members and other influential persons in the job seeker's life. This information is used to develop well-coordinated customized job development activities. Customized job development activities use an informational interview framework to learn more about employers, working conditions, and other potential employers who engage in similar work. Jobs are then negotiated based on an employment proposal that accounts for the job seeker's unique skills and interest and the qualified employment specialist creates a job site analysis and plan.

Effective implementation of CE requires the qualified employment specialist to understand each component process of the discovery and customized job development. While it appears that qualified employment specialists are trained to implement critical components of CE, they are not implementing the components to fidelity (30). Integrating process measures with proximal and distal outcome measures can be used to ensure fidelity to intervention, evaluation, and adjusting components of the CE process. One way to measure the CE process is by using validated fidelity scales that have operationalized descriptions of what constitutes high-quality implementation for each element of the CE process. The Discovery Fidelity Scale (DFS) (31) and Job Development Fidelity Scales *(JDFS)* (32) are designed to operationalize the process for CE. The DFS was designed to measure fidelity to CE discovery best practices at both the systems and services levels. The systems fidelity measure examines processes for authorization and access, financing, and qualification of providers while the services fidelity measure examines the alignment of CE best practice to service implementation such as home and community observations, discovery activities, informational interviews, vocational profiles, and plans. The DFS has undergone several validation studies. First, Riesen et al. (33) used a three round, modified Delphi process to generate consensus about what experts believe are acceptable and not acceptable tenets of the DFS. The Delphi panel reviewed and rated the fidelity descriptors for discovery systems and services. The information obtained from the Delphi study was used to further refine the scale and Riesen et al. (28) conducted a study to determine the internal consistency of items on the DFS and the respective constructs. Results suggest that both the systems and services constructs have acceptable



Distal Outcomes

- Employment that meets the definition of customized employment.
- Wages at or above minimum wage.
- Hours worked consistent with needs of job seeker.
- Increased quality of life.
- Transportation to and from work secured.

FIGURE 1 | A conceptualization for integrating and linking processes and corresponding proximal and distal outcomes for CE.

internal consistency. The final DFS consists of two subsections: discovery systems fidelity and discovery services fidelity. The systems section consists of five discovery system tenets and corresponding scaled fidelity descriptors. The services section consists of ten discovery services tenets and corresponding scaled fidelity descriptors. The scaled fidelity descriptors for each of the systems and services tenets represent levels of fidelity to the discovery process for each respective tenet.

The JDFS was designed to measure how to engage businesses that align with the job seeker's strengths and vocational interests. The JDFS consists of two sections: job development systems fidelity and job development services fidelity. Systems fidelity tenets cover the foundation for customized job development referrals; the incorporation of information gathered during discovery in the job development plans; and elements related to customized job development personnel, provider responsibilities, and transportation. Services fidelity tenets include building job-development plans based on discovery findings; using an informational interview approach to contact businesses; analyzing workplace cultures to ensure ecological fit; negotiating mutually beneficial and customized employment opportunities, including job creation through resource ownership or self-employment as appropriate; and maximizing opportunities for long-term career development and growth. Riesen et al. (34) used the Delphi method to build consensus among CE professionals about items on the JDFS and found that customized employment experts believed the fidelity descriptors had value when measuring fidelity to customized job development practice.

A conceptualization for integrating and linking processes and corresponding proximal and distal outcomes for CE discovery and job development are outlined in **Figure 1** and specific descriptions for the processes, process measures, and proximal and distal outcomes are in **Table 1**. As illustrated in the figure, discovery is the initial CE process with two components: systems and services. The systems processes ensure that discovery is appropriately authorized and financed while the services process ensures that discovery is appropriately implemented by a qualified employment specialist, the critical components of the discovery are followed, and the process accurately determines an individual's strengths, interests, skills, and support needs to obtain and maintain customized employment. For example, a critical discovery services process is to conduct home and neighborhood observations and observe the job seeker engaged in task-based activities. From the information gathered during these observations, the qualified employment specialist and the job seeker identify emerging vocational themes (i.e., career identity). Once themes are identified, the qualified employment specialist develops a list of potential employers that align with the identified vocational themes. Informational interviews are subsequently conducted with several employers to confirm if the type of work performed at the workplace aligns with the job seeker's interest and needs. The proximal outcome for this process is a fully developed vocational profile with an operational plan for customized job development. Linking process measures to proximal outcomes for both systems and service level discovery provides the necessary information to evaluate each process to determine whether specific adjustments to the process need to be made. If the process did not produce the desired proximal outcomes, adjustments are made to the process until the desired proximal outcome is achieved. If adjustments are not needed, the next service level process is implemented, evaluated, and adjusted.

After the discovery process is completed, a job seeker begins the process of customized job development. There are two

TABLE 1 | Process, process measures, and proximal and distal outcomes for CE discovery.

Program	**Process** (31)	**Process measures**
Customized Employment Discovery *(Systems)*	• Discovery is an alternative to vocational assessments and evaluations for persons eligible for CE and SE. • Discovery is part of CE or SE. • Discovery is accurately financed. • Providers give all eligible job seekers access to discovery, SE and CE. • The employment specialist provides all integrated employment phases.	• Number of authorizations for discovery for CE and SE eligible individuals. • Number of qualified agencies providing discovery. • Amount of funding allocated to discovery. • Percentage of job seekers engaged in discovery. • Percentage of employment specialists engaged in all employment phase. • Time engaged in discovery.
Customized Employment Discovery (*Services)*	• Begins discovery with an interview in the job seekers home or a mutually acceptable place in the community. • Observe and learn about the job seeker's personal spaces during interviews and visits to the job seeker's home • The employment specialist becomes familiar with the job seeker's neighborhood and surrounding area. • The employment specialist along with others observes the job seeker completing familiar activities, assisting if necessary. • The employment specialist and/or others assist the job seeker to complete several activities in unfamiliar places based on a determination of his or her vocational preferences and emerging vocational themes. • The employment specialist and the job seeker, to the extent possible, completes informational interviews with several businesses that align with the job seeker's, skills, tasks, interests, and vocational themes. • Review information collected to date, revisiting and/or including additional discovery information as needed, to develop the vocational profile. • A vocational profile narrative that completely describes the job seeker's discovery process, one that accurately reflects the job seeker, and answers: Who is this person? • The Employment specialist and the job seeker, along with other members of the job seeker's team, hold a discovery planning meeting to create an employment plan that contains businesses to contact for job development.	• Number of interviews conducted. • Summary of conversations. • Number and types of home observations. • Number and types of neighborhood observations. • Number and types of activity observations. • Number of activities related to employment. • Number and types of informational interviews. • Time to complete reviews. • Vocational profile is completed.

Proximal outcomes

Increased number of consumers engaged in CE job development.

Increased number of agencies who provide discovery.

Completion of task-based discovery activities in the home or community location.

Documented narrative descriptions of emerging patterns in employment.

Completion of informational interviews with businesses that align with emerging vocational themes.

Fully developed vocational profile outlining strengths, interests, and needs relate to employment.

Fully develop plan for customized job development with information about potential employers.

Schedule and hold an employment planning meeting to review vocational profile and job development plan to employment team.

Benefits plan created.

Accommodations and supports identified.

TABLE 2 | Process, process measures, and proximal and distal outcomes for CE job development.

Program	**Process** (32)	**Process measures**
Customized Employment Job Development *(Systems)*	• Customized job development is based on the vocational profile. • Customized job development is based on dedicated financing to provide different services than traditional job development services. • The qualified employment specialist or a qualified person provides Customized job development. • The agency delivering Customized job development services ensures relationships, based on the discovery plan, between the job seeker and community members • The job seeker, utilizing customized job development services, has accessible and reliable transportation services and financing	• Number of qualified agencies providing customized job development. • Amount of funding allocated to customized job development. • Number of community partnerships. • Type of job seeker information presented to employer. • Type of financial planning available to job seeker. • Number of meetings with business that align with strengths, interest, and needs. • Time engaged in job development. • Types of worksite analysis.
Customized Employment Job Development (*Services)*	• The qualified employment specialist and the job seeker decide which of the positive skills, assets, supports, information, pictures or videos, learned or developed during discovery, will be shared with employers and, if applicable, used to develop small business ownership. • The qualified employment specialist assists the job seeker to develop employment that meets the expectations of the financial plan developed during discovery that includes goals and resources, information from a benefits planner, and if applicable, plans to ensure the financial success of job seeker's own business. • The qualified employment specialist and the job seeker work together developing employment that meets the ideal number of hours of work each week and the number of hours of non-work services and supports. • The qualified employment specialist and the job seeker meet with businesses to identify a fit between the workplace culture, tasks, skills, and the job seeker's ideal conditions for employment. • The qualified employment specialist, always with the job seeker when possible, conduct informational interviews with businesses. • The qualified employment specialist completes formal analyses of job tasks, skills, coworker supports, and employee training. • The qualified employment specialist negotiates a mutually beneficial economic win-win proposal, between the job seeker and the business, or when applicable, a self-employment proposal. • The qualified employment specialist creates a job site training plan, detailing job tasks, required skills, new skill development, training, and support strategies for the employer.	• Number of interviews conducted. • Summary of conversations. • Number and types of home observations. • Number and types of neighborhood observations. • Number and types of activity observations. • Number of activities related to employment. • Number and types of informational interviews. • Time to complete reviews. • Vocational profile is completed.
Proximal outcomes		
Fully funded customized job development activities.		
Adequate transportation commensurate with day service transportation.		
Community partners identified.		
Documentation that identifies job seekers ideal conditions of employment and business.		
Completed worksite and job task analysis.		
Completed proposal for a customized job at the job seekers ideal place of employment.		
Fully developed job site training plan.		
Distal outcomes		
Employment that meets the definition of customized employment.		
Improved Quality of Life measures.		
Employment that aligns with the job seeker's career identity.		
Wages at or above minimum wage.		
Hours worked consistent with needs of job seeker.		
Transportation to and from work secured.		
Long-term supports secured.		
Natural supports secured.		

components involved in the customized job development process: systems and services job development. **Table 2** outlines the measures for customized job development. The job development systems process components ensure that customized job development is accurately funded, community partners necessary for successful employment are identified, and the jobseeker has access to adequate transportation at the same rate as other services provided. The services process and measures ensure that customized job development activities align with the job seeker's ideal conditions of employment and career identity. They also ensure that the employment specialist and job seeker are engaging meaningfully with businesses and documenting the types of tasks and activities performed at the business. The proximal outcomes for customized job development are a completed worksite and job task analysis, developed proposal for a customized job, and a fully developed job site training plan. Finally, distal outcome data is collected and examined to determine the overall efficacy of the CE process.

DISCUSSION

The perennially low employment rates for individuals with MSD underscore the importance of expanding, connecting, and balancing measures used to determine the quality and success of employment programs for individuals with MSD. The most common framework for determining success of employment programs relies on distal outcome measures. Unfortunately, relying only on distal employment outcomes as an indicator of program success is problematic because distal outcomes are often influenced by other non-intervention/program factors (16, 35). Without objectively measuring fidelity to the process and linking the process to proximal and distal outcomes, we run the risk of agencies and practitioners believing they are implementing effective programs when they are not. Therefore, as researchers, policy makers, funding agencies, and practitioners examine how to improve outcomes for individuals with MSD, they should adopt more balanced measures to determine the efficacy of employment support programs and interventions. From a research and policy prospective, using both process and outcome measures ensures that employment support practices are operationalized and replicable. From a funding perspective, a balance set of process and outcome measures provides funding agencies a mechanism to continually evaluate the efficacy of the programs and invest in programs that demonstrate positive process and outcome measures for individuals with MSD. Finally, from a practitioner perspective, linking process and outcome measures allows practitioners to continually assess the program or intervention so that meaningful adjustments can be made.

AUTHOR CONTRIBUTIONS

CR and AS contributed to the manuscript by conceptualizing and writing specific sections. All authors contributed to the article and approved the submitted version.

REFERENCES

1. US Bureau of Labor Statistics. *News Release*. (2022). Available online at: https://www.bls.gov/news.release/pdf/empsit.pdf
2. Erickson W, Lee C, von Schrader S. *Disability Statistics from the American Community Survey (ACS)*. Ithaca, NY: Cornell University Yang-Tan Institute (YTI) (2017). Available online at: www.disabilitystatistics.org
3. Winsor J, Timmons J, Butterworth J, Migliore A, Domin D, Zalewska A, et al. *StateData: The National Report on Employment Services and Outcomes Through 2018*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion (2021).
4. Taylor J, Avellone L, Brooke V, Wehman P, Inge K, Schall C, et al. The impact of competitive integrated employment on economic, psychological, and physical health outcomes for individuals with intellectual and developmental disabilities. *J Appl Res Intellect Disabil.* (2022) 35:448–59. doi: 10.1111/jar.12974
5. Blick RN, Litz KS, Thornhill MG, Goreczny AJ. Do inclusive work environments matter? Effects of community-integrated employment on quality of life for individuals with intellectual disabilities. *Res Dev Disabil.* (2016) 53–4:358–66. doi: 10.1016/j.ridd.2016.02.015
6. Butterworth J, Hiersteiner D, Engler J, Bershadsky J, Bradley V. National Core Indicators©: Data on the current state of employment of adults with IDD and suggestions for policy development. *J Vocat Rehabil.* (2015) 42:209–20. doi: 10.3233/JVR-150741
7. Cimera RE. Does being in sheltered workshops improve the employment outcomes of supported employees with intellectual disabilities? *J Vocat Rehabil.* (2011) 35:21–7. doi: 10.3233/JVR-2011-550
8. Schall C, Sima AP, Avellone L, Wehman P, McDonough J, Brown A. The effect of business internships model and employment on enhancing the independence of young adults with significant impact from autism. *Intellect Dev Disabil.* (2020) 58:301–13. doi: 10.1352/1934-9556-58.4.301
9. Shogren K, Weymeyer ML, Palmer SB, Rifenbark GG, Little TD. Relationship between self-determination and post-school outcomes for youth with disabilities. *J Spec Educ.* (2015) 48:256–67. doi: 10.1177/0022466913489733
10. *Workforce Innovation and Opportunity Act of 2014. No. 113–128 U.S. Congress*. (2014). Available online at: https://www.govinfo.gov/app/details/PLAW-113publ128
11. *Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. §1400*. (2004). Available online at: https://sites.ed.gov/idea/statute-chapter-33/subchapter-i/1400
12. *Home and Community Based Servicers Final Settings Rule 79 FR §2947.* Office of the Federal Register, National Archives and Records Administration (2014).
13. Lewis CC, Boyd MR, Walsh-Bailey C, Lyon AR, Beidas R, Mittman B, et al. A systematic review of empirical studies examining mechanisms of implementation in health. *Implement Sci.* (2020) 15:1–25. doi: 10.1186/s13012-020-00983-3
14. Erickson W. *A Guide to Disability Statistics From the American community Survey (2008 forward)*. (2012). Available online at: https://ecommons.cornell.edu/bitstream/handle/1813/90090/DE141_PDF2.pdf?sequence=1andisAllowed=y
15. US Department of Education. *Office of Special and Rehabilitation Services. Policy Directive 19-03*. (2019). Available online at: https://rsa.ed.gov/sites/default/files/subregulatory/pd-19-03.pdf
16. Kessell E, Pegany V, Keolanui B, Fulton BD, Scheffler RM, Shortell SM. Review of Medicare, Medicaid, and commercial quality of care measures: considerations for assessing accountable care organizations. *J Health Polit Policy Law.* (2015) 40:761–96. doi: 10.1215/03616878-3150050
17. Crombie IK, Davies HTO. Beyond health outcomes: the advantages of measuring process. *J Eval Clin Pract.* (1997) 4:31–8. doi: 10.1046/j.1365-2753.1998.t01-1-00003.x
18. Leeds IL, Ladd MR, Sundel MH, Fannon ML, George JA, Boss EF, et al. Process measures facilitate maturation of pediatric enhanced recovery protocols. *J Pediatr Surg.* (2018) 53:2266–72. doi: 10.1016/j.jpedsurg.2018.04.037

19. Watkins KE, Paddock SM, Hudson TJ, Ounpraseuth S, Schrader AM, Hepner KA, et al. Association between process measures and mortality in individuals with opioid use disorders. *Drug Alcohol Depend.* (2017) 177:307–14. doi: 10.1016/j.drugalcdep.2017.03.033
20. Super DE. A life-spa approach to career development. *J Vocat Behav.* (1980) 16:282–98.
21. Holland JL. Exploring careers with typology: What we have learned and some new directions. *Am Psychol.* (1996) 51:397–406. doi: 10.1037/0003-066X.51.4.397
22. Dawis RV, Lofquist LH. *A psychological theory of work adjustment: An individual difference model and its application*. Minneapolis, MN: University of Minnesota (1984).
23. Bates-Harris C. Segregated and exploited: The failure of the disability service system to provide quality work. *J Vocat Rehabil.* (2012) 36:39–64. doi: 10.3233/JVR-2012-0581
24. Merrels J, Buchanan A, Waters R. "We feel left out": experiences of social inclusion for the perspective of young adults with intellectual disabilities. *J Intellect Dev Disabil*. (2019) 44:13–22. doi: 10.3109/13668250.2017.1310822
25. Thibedeau Boyd JM, Beckman CJ. Stop Making It Weird 2.0: Imagining a less-weird world. *J Vocat Rehabil.* (2019) 50:301–5. doi: 10.3233/J.V.R.-191011
26. Wehman P, Taylor J, Brooke V, Avellone L, Whittenburg H, Ham W, et al. Toward competitive employment for persons with intellectual and developmental disabilities: What progress have we made and where do we need to go. *Res Pract Pers Sev Disabil.* (2018) 43:131–44. doi: 10.1177/1540796918777730
27. Donabedian A. Evaluating the quality of medical care. *Milbank Q.* (2005) 83:691–729. doi: 10.1111/j.1468-0009.2005.00397.x
28. Riesen T, Hall S, Keeton B, Snyder A. Internal consistency of the customized employment discovery fidelity scale: a preliminary study. *Rehabil Couns Bull*. (2021) 43:183–93. doi: 10.1177/00343552211043259
29. WINTAC. *The essential elements of customized employment for universal application. Workforce Innovation Technical Assistance Center*. (2017). Available online at: https://leadcenter.org/wp-content/uploads/2017/07/The-Essential-Elements-of-Customized.pdf
30. Inge K, Sima AP, Riesen T, Wehman P, Brookes-Lane N. *A Gap Analysis Of Practitioner Knowledge Of Customized Employment Practices*. Rehabilitation Counseling Bulletin (in press).
31. Hall S, Keeton B, Cassidy P, Iovannone R, Griffin C. *Discovery Fidelity Scale*. Atlanta, GA: Center for Social Capital. Available online at: https://www.griffinhammis.com/wp-content/uploads/2020/10/DFS-December-2018-4-2.pdf
32. Hall SR, Keeton B. *Job Development Fidelity Scale*. Griffin-Hammis Associates (2019).
33. Riesen T, Hall S, Keeton B, Jones K. Customized employment discovery fidelity: Developing consensus among experts. *J Vocat Rehabil.* (2019) 50:23–37. doi: 10.3233/JVR-180985
34. Riesen T, Hall S, Keeton B, Snyder A. Building consensus among experts regarding customized job development fidelity descriptors: a delphi study. *J Rehabil.* (2021) 87:22–30.
35. Brenner MH, Curbow B, Legro MW. The proximal-distal continuum of multiple health outcome measures: the case of cataract surgery. *Med. Care.* (1995) 33:AS236–44.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Rehabilitation Sciences

POLICY BRIEF
published: 02 June 2022
doi: 10.3389/fresc.2022.876871

Advancing Policy and Practice in Medicaid Home and Community-Based Services Quality

Joseph Caldwell[1]* *and David Machledt*[2]

[1] *The Lurie Institute for Disability Policy, Brandeis University, Waltham, MA, United States,* [2] *National Health Law Program, Washington, DC, United States*

This policy brief highlights recent developments and future directions in the Medicaid Home and Community Based Services (HCBS) quality policy and practice within the US. Background is provided about the structure of Medicaid HCBS within the US, the changing landscape of payment and service delivery, and implications for HCBS quality measurement and use. An overview of a HCBS quality framework is provided that was developed with stakeholder input. Frequently used survey tools, existing quality measures, and measure development are discussed. Actionable recommendations are made, including establishment of stakeholder input mechanisms, enhanced federal guidance on a core set of measures, improved data collection and stratification to address equity, multiple mechanisms to assess quality, and increased federal investment in HCBS quality infrastructure.

Keywords: Medicaid, quality, United States, long-term services and supports (LTSS), home and community-based services (HCBS)

OPEN ACCESS

Edited by:
Jan Šiška,
Charles University, Czechia

Reviewed by:
Zhuoying Qiu,
China Rehabilitation Research Center, China
Charlie Lakin,
University of Minnesota, United States

****Correspondence:***
Joseph Caldwell
joecaldwell@brandeis.edu

Specialty section:
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

Received: *15 February 2022*
Accepted: *09 May 2022*
Published: *02 June 2022*

Citation:
Caldwell J and Machledt D (2022) Advancing Policy and Practice in Medicaid Home and Community-Based Services Quality. Front. Rehabilit. Sci. 3:876871. doi: 10.3389/fresc.2022.876871

BACKGROUND

Long-term services and supports (LTSS) refers to a wide range of health and social services provided to individuals who need help with personal care tasks or activities of daily living, such as eating, bathing, and dressing, or with instrumental tasks, such as medication management, meal preparation, and supports for community participation and employment (1). The US lacks a coordinated and comprehensive finance and delivery system for Long Term Supports and Services (LTSS). Though an estimated 14 million US residents need LTSS, the vast majority do not receive paid services and supports (2, 3). Most rely on unpaid supports from family and friends. Among individuals with LTSS needs residing in the community, only approximately 13% receive any form of paid assistance (3).

Medicaid is the primary funder of formal LTSS in the US (4, 5). It is a joint federal (national) and state medical assistance program for low income individuals. Medicaid has strict income and asset eligibility limits. Many people with disabilities have to limit their income or spend down assets just to obtain needed services and supports. Moreover, because the program is a federal-state partnership, eligibility and benefits covered vary considerably across states.

Historically, Medicaid's structure generated an institutional bias for LTSS. Institutional care was the first type of LTSS that Medicaid covered and remains mandatory for states to provide. Over the decades, Medicaid has been a major source of funding for innovations that provide services in homes and other community-based settings. People with disabilities and older adults almost universally prefer Home and Community-Based Services (HCBS) to institutional LTSS, and they are also typically cheaper to provide and lead to better outcomes. But they remain optional Medicaid services.

Moreover, the principal authority states use to design their HCBS programs – the 1915(c) HCBS waiver – permits states to impose enrollment and budget caps that other optional Medicaid services do not have. Section 1915(c) allows states to "waive" certain general Medicaid requirements to target HCBS toward specific populations, so long as beneficiaries have an institutional level of care need. Also, unlike other Medicaid eligibility categories, 1915(c) also allows states to cap enrollment and cap individual service budgets. State governments like these features because they make it easier to manage Medicaid costs, though that may come at the expense of providing access to needed services for all their residents. Some states maintain long waiting lists for these programs, meaning that some people with disabilities and older adults must wait years to access HCBS even though they could enter a nursing facility immediately (6).

Over time the share of Medicaid LTSS expenditures spent on HCBS has increased. HCBS expenditures exceeded institutional expenditures in 2013 and reached 59 percent in 2019 (4). Despite significant expansion and innovation in Medicaid HCBS over the past several decades–from promoting self-directed services, where individuals can hire and train their own care workers, to supporting competitive-integrated employment–access to HCBS for people with disabilities varies widely between states and across populations. As a joint federal-state program, Medicaid allows states substantial discretion to define their LTSS programs (6). States typically operate multiple HCBS programs targeted at different populations (e.g., developmental disabilities, acquired brain injury, physical disabilities and older adults) through a patchwork of different Medicaid authorities that each have different requirements. States utilize different delivery systems and cover different services (7). Even among those already receiving HCBS, substantial unmet needs remain common (8).

BUILDING QUALITY INTO MEDICAID HCBS PROGRAMS

Medicaid's federal-state partnership and historical institutional bias have also shaped approaches to measuring and monitoring quality within Medicaid HCBS programs. The federal government has long regulated nursing facilities and has created a fairly robust national system for reporting on health and safety, staffing hours, and quality metrics (9). But the infrastructure around Medicaid HCBS quality has received far fewer resources and, consequently, is much less developed. Though the Centers for Medicare and Medicaid Services (CMS) has issued federal regulations and guidance, states still largely determine how they approach quality within their HCBS programs. The resulting variability complicates the creation of a coordinated federal approach to HCBS quality.

Quality oversight in 1915(c) waivers amounts to states attesting to six broad assurances in their waiver application, three of which relate to care quality:

1. The state ensures that all waiver services are provided by qualified providers (through licensure or certification standards, monitoring, and oversight over training methodologies).
2. The state shows it has an effective system for reviewing the adequacy of participants' service plans (including choice of providers, regular updates, comprehensiveness).
3. The state shows it has an effective system for assuring participant health and welfare with mechanisms to prevent abuse and neglect, regulate use of restrictive interventions, manage critical incidents, and establish overall health care standards (10).

Since these assurances were added to the 1915(c) waiver approvals in 2004, states have managed their own oversight systems for 1915(c) HCBS programs, with CMS stepping in occasionally to implement corrective action plans if the state has not met its assurances. Most of the state-reported measures focus on whether appropriate processes are in place. CMS reviews the state systems during waiver renewals or applications, and asks its regional offices to conduct onsite reviews at least once over the course of each 3–5-year waiver period. Prior reports and investigations from the Government Accountability Office (GAO) have found that even CMS's limited quality reviews showed that many states did not have adequate systems to meet all three quality assurances, and some received reapprovals despite failures to correct the problems CMS identified (11). More recent GAO studies found similar shortcomings in HCBS quality in capitated managed care (see below) (12).

Other HCBS covered outside 1915(c) programs receive even less scrutiny. While acute care and preventive services like emergency room care, immunizations, and diabetes control are well represented in Medicaid's core measure sets for children and adults, HCBS long lacked any nationally-reported measures. Until 2014, there was not even a meaningful federal Medicaid definition of what can qualify as home or community-based setting.

QUALITY AND ACCOUNTABILITY IN MANAGED LONG-TERM SERVICES AND SUPPORTS

The landscape of HCBS has rapidly changed over the past two decades. Many states have shifted away from fee-for-service (FFS) payment models to new LTSS delivery systems. The FFS system pays providers for each service provided, and has been criticized for rewarding duplicative or unnecessary services. Managed care claims to deliver care more efficiently by improving coordination and information management and restricting provider networks. The most common managed care delivery system replaces FFS with a risk-based, capitated model, where managed care organizations (MCOs) receive a fixed per member/per month payment. This incentive structure financially rewards managed care plans that spend *less* on care (at least in the short term). If a plan's health care expenditures are lower than the fixed monthly payment, the MCO keeps the remainder as profit. Importantly, without effective mechanisms to monitor and evaluate care quality and access, capitated managed care replaces the perceived fiscal excess of FFS with a system that could encourage plans to denying or delaying medically necessary care to save money.

The managed Long-Term Services and Supports (MLTSS) model has grown rapidly in the US (13). In 2004, only eight states had any MLTSS program, and enrollment of MLTSS users barely exceeded 100,000 individuals nationwide (14). By July 2019, 24 states had implemented capitated MLTSS programs, with several pending (15). Total enrollment has surpassed 1.8 million individuals (16). The most common populations served in MLTSS programs have been older adults and adults with physical disabilities. However, more recently some states have incorporated individuals with intellectual and developmental disabilities (I/DD) in statewide MLTSS or developed MLTSS programs specifically for this population (13, 17).

The growth of MLTSS has fueled renewed interest in HCBS quality measurement. With proper design and oversight, states and advocates can use quality and performance measures as one tool to achieve desired outcomes. Contracts increasingly include payment incentives tied to quality outcomes. For example, some states withhold a portion of the capitated rate contingent upon an MCO meeting certain performance metrics. Many states have incentivized shifting expenditures from institutional LTSS to HCBS through MLTSS programs (18, 19). Others have attempted to incentivize community employment outcomes through MLTSS (17). But effectiveness of these “pay for performance” incentives is contingent on valid and reliable HCBS quality measures. Moreover, these approaches alone are insufficient to ensure consistent access to high quality care.

The 2016 CMS Managed Care Rule–the first major update of Medicaid managed care regulations since 2002–issued new requirements for states and MCOs in the area of quality. This included new requirements to validate provider network adequacy annually, to describe the state’s plan to reduce health inequities, and to create a new Quality Rating System for Medicaid managed care plans. The update also incorporated new protections specific to MLTSS. As of July 2017, states with MLTSS programs are required at a minimum to report measures related to quality of life, shifting expenditures from institutional to HCBS, community integration activities, and whether beneficiaries receive the services and supports set forth in their care plans.

Unfortunately, many of the 2016 regulations have taken years to implement. The proposed Quality Rating System has not yet been released for public review and comment. States still await CMS guidance on how to implement network adequacy validations, and so have not been required to do it. Annual reports of each managed care plan, including MLTSS plans, that will detail grievances, financial performance, and other metrics will only finally be required beginning after July 2022 (20). So while the regulations have taken steps to advance quality reporting and accountability for Medicaid HCBS, many gaps remain (21).

HCBS QUALITY FRAMEWORK

As more states shifted to MLTSS, advocates expressed concerns about the MCOs’ frequent poor understanding of the person-centered, non-medical nature of HCBS (22). Moreover, the field of HCBS quality measurement lagged far behind measure development and implementation for acute care and medical settings. By 2015, the National Quality Forum (NQF) – an independent organization that brings stakeholders together to review and endorse performance measures used by the government, states, and private-sector organizations–had endorsed at most a handful of quality measures specific to HCBS.

In response to these concerns, the Administration for Community Living (ACL) and CMS sponsored NQF to convene a multi-stakeholder workgroup to develop a HCBS quality framework, identify gaps, and make recommendations for new measure development. Twenty-two participants, including individuals with disabilities, aging and disability advocates, researchers, and representatives from providers, states, and health plans routinely met for over a year and developed an operational definition of HCBS and a quality framework consisting of 11 domains and forty subdomains (23). The University of Minnesota then conducted follow-up focus groups with 320 participants to assess the framework, including perspectives from across the disability community (24, 25). They generally validated the NQF framework and recommended inclusion of some additional subdomains (See **Figure 1**).

In addition to the HCBS quality framework, the NQF Committee identified potential measure concepts within each domain and made recommendations for measure development. This spurred additional federal investments through ACL and CMS. While the HCBS quality framework is specific to the US system, many domains are in alignment with the core components of the World Health Organization Building Blocks for health systems, particularly the areas of service delivery and workforce (26).

STATE OF HCBS SURVEY INSTRUMENTS AND MEASURES

The Rehabilitation Research and Training Center on HCBS Outcome Measures (RTCOM) at the University of Minnesota developed a database of over 130 instruments that have been used to measure HCBS outcomes (https://rtcom.umn.edu/database). The database was organized around the NQF domains. Most of the instruments are survey tools that cover a wide range of domains. Four of the most frequently used instruments that measure experience and person-reported outcomes are detailed in **Table 1**. Each has advantages and disadvantages: they differ in target populations, rules for use of proxy responses, survey administration method, and response rates.

Despite these differences, some factors affecting quality measurement apply across instruments. For example, in-person interviews require more resources than measures using administrative or claims data. This can deeply influence the extent to which states use these instruments to improve quality. For example, NCI and NCI-AD (the most frequently used instruments) have typically been implemented with small sample sizes, around 400 individuals. This can flag general areas of strength or concern at a state or systems level, but may not provide the state with detailed data to inform corrective actions

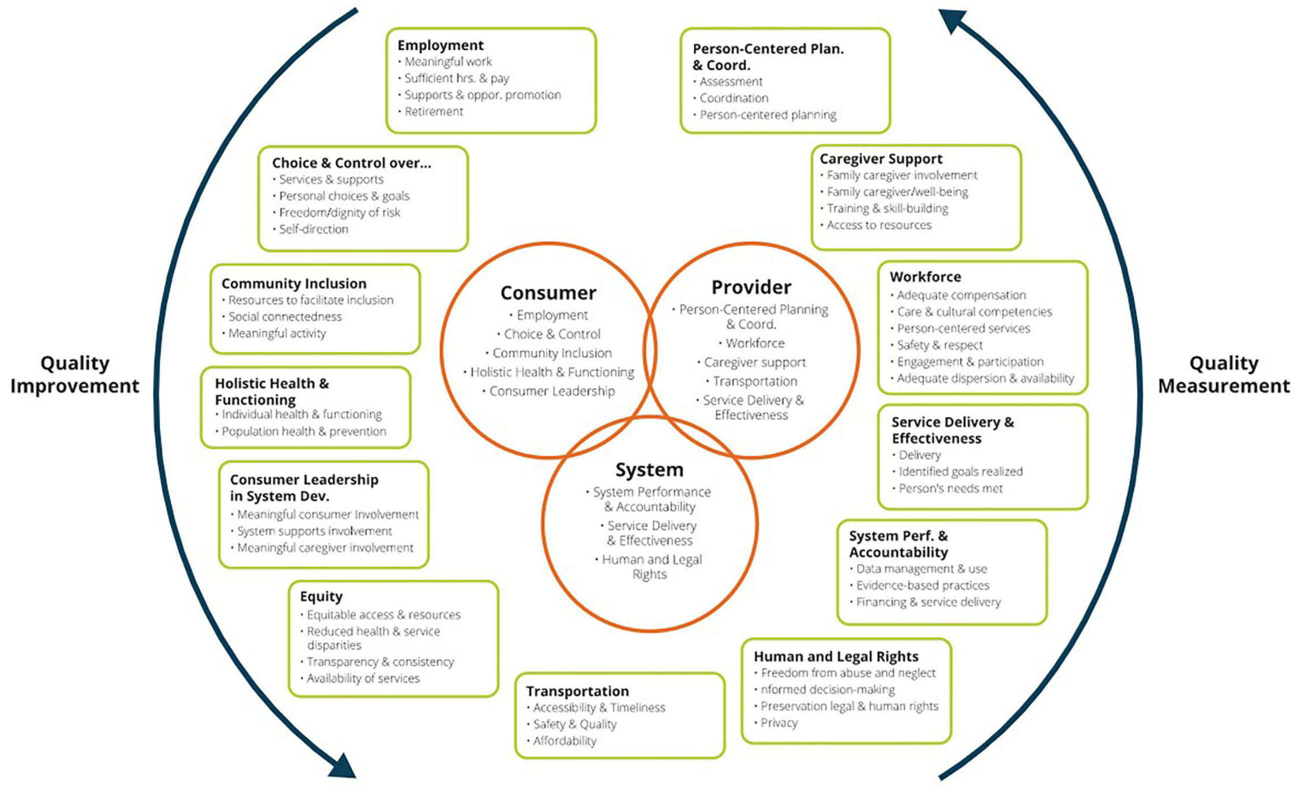


FIGURE 1 | National Quality Forum Framework on HCBS Quality (25).

or to identify inadequate service quality for individuals or subpopulations of interest.

Some states MLTSS programs have used these survey tools and HCBS CAHPS with larger samples to enable valid analysis at the MCO level. Minnesota, for example, conducted over 2100 surveys of roughly 20,000 HCBS recipients with developmental disabilities for its last in-person data collection in 2019 (37). The CQL POMs instrument, on the other hand, has mostly focused on the provider level. This can provide very actionable data, but may not generate a representative sample to learn about trends or problems at the plan or state level. Either way, the cost and time involved in conducting surveys has definitely limited some of the impact of these early HCBS measures.

The federal government has funded additional measure development to fill gaps identified by the NQF Committee. CMS contracted to develop eight measures that include LTSS assessment, care planning, falls prevention, and rebalancing (reducing admissions to institutions, minimizing length of stay, and transitions from institutions to the community) (10). Several of these measures have now been formally endorsed by NQF and included in CMS's proposed HCBS Recommended Core Set. Some are now being used by the National Committee for Quality Assurance (NCQA) in their accreditation of MCOs providing MLTSS (32). CMS is currently contracting to re-specify some of these measures for broader application and develop additional measures in other domains where there are gaps, such as workforce and caregiver support. The RTCOM, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) within ACL, is also developing new person-reported measures in areas including employment, meaningful activity, transportation, social connectedness, and choice and control.

POLICY AND PRACTICE RECOMMENDATIONS

While substantial progress has occurred over the past decade in HCBS quality measurement, there is still a long way to go. While maintaining the federal-state partnership that promotes innovation, we call for a stronger federal role in reporting, oversight, transparency and investment in meaningful use of measures to enhance quality and address equity.

Establish Regular Stakeholder Input Mechanisms for HCBS Quality at the Federal and State Levels

At the federal level, the Secretary of Health and Human Services should establish a multi-stakeholder HCBS Quality Committee that centers representation on the diverse array of people receiving, or in need of Medicaid HCBS and representatives of aging and disability advocacy organizations. Other stakeholders

TABLE 1 | Most frequently used HCBS instruments.

National core indicators (NCI)
NCI is a collaboration between the Human Services Research Institute (HSRI), National Association of State Developmental Disabilities Directors (NASDDDS), and participating states (27). Started in 1997, 46 states and the District of Columbia have participated. The in-person survey of adults with developmental disabilities receiving Medicaid HCBS includes approximately 100 indicators across five domains. In 2019, CMS incorporated NCI into its overall Adult Core Set. In 2021, NQF endorsed a subset of measures from NCI.
National core indicators -aging and disabilities (NCI-AD)
In 2012, HSRI, ADvancing States, and participating states began adapt NCI to help evaluate quality for people with physical disabilities and older adults receiving HCBS (28). The resulting instrument, NCI-AD, began its first round of data collection in 2015-16. Twenty-nine states have participated to date. The in-person survey consists of approximately 50 core indicators across 18 domains.
HCBS consumer assessment of healthcare providers and systems (CAHPS) survey
CMS developed the HCBS CAHPS survey for use by states in fee-for-service and MLTSS (29). It consists of 69 core items that ask beneficiaries to report on their service experience, including getting needed services, communication with providers, case management, community inclusion and empowerment and choice of services. There is also a supplemental employment module. The survey is conducted in-person or over the telephone. In November 2016, NQF endorsed 19 measures from the instrument. To date, only a handful of states have used the HCBS CAHPS, but CMS is promoting greater adoption through a learning collaborative and technical assistance.
Council on quality and leadership (CQL) personal outcome measures (POMs)
The Council for Quality and Leadership (CQL) developed the POM tool in 1992 (30, 31). The POMs is an individual-level discovery tool used to determine what is important to the person receiving supports. It includes 21 indicators across 5 factors (My Human Security, My Relationships, My Community, My Choices, My Goals). CQL–trained interviewers conduct each in person interview. The POMs tool has primarily been used at the provider level, mostly with providers providing services to individuals with intellectual and developmental disabilities, as part of an accreditation process.

should include the major players in quality measurement, such as health plans, measure developers, measure steward organizations, provider representatives, and states and relevant national associations representing state officials. The quality committee could help define and regularly update a core HCBS quality measure set (discussed below), inform measure development to fill gaps in measures, and act as an advisory body for other elements of HCBS quality at the national level.

States should also be required to establish their own HCBS Quality Committees based on a similar structure as the federal committee. A handful of states have already established such entities indicating feasibility. States would have flexibility to build upon existing committees and coordinate with other requirements, such as those in the managed care regulations. For example, every state has a Medicaid Medical Care Advisory Committee (MCAC) that includes beneficiaries, advocates, providers, and state officials that could be a basis for an HCBS Quality committee. Alternatively, in MLTSS programs, each plan is required to establish and maintain a member advisory committee with a representative sample of the LTSS population that could be a source for a state quality committee. Of course, the existence of quality committees should not supplant opportunities for public comment on selecting reportable measures, developing quality strategy priorities, and so forth. However, this structure would allow states and health plans to benefit from sharing the lived experience of people who use the HCBS system, while improving transparency and allowing beneficiaries to build up expertise in a technical field that plays a vital oversight role in HCBS quality.

Establish a Core Set of HCBS Quality Measures and Require Transparent Public Reporting

The federal government should issue guidance on a core and supplemental set of HCBS quality measures. CMS began work on this in 2020 through issuing a public request for information (33); additional work is needed to finalize and incentivize rapid state implementation of both core and supplemental sets. Ultimately, states should be required to publicly post annual reports on all the core measures. Recent legislation has already mandated reporting on Medicaid and CHIP core sets for children (34) and for behavioral health measures (35) starting in 2024. Required core measures should set a federal minimum for quality oversight of HCBS to facilitate the creation of national benchmarks and apples-to-apples comparisons across states. However, CMS should continue to support state innovation to develop and use additional HCBS measures that fill gaps or allow for easier administrative reporting.

States should also publicly report HCBS quality data in ways that allow beneficiaries to compare quality across HCBS programs, managed care plans, and even providers. Public reporting on HCBS quality at the plan (and eventually provider) level could help individuals and families to make informed choices to suit their care needs.

Improve Data Collection and Require Stratification to Address Equity in HCBS Quality

The COVID-19 pandemic has reemphasized the longstanding structural inequities in the US healthcare system. Moreover, the pandemic has exposed major holes in our data systems that make it hard to even identify health disparities, let alone inform effective remediation. The pandemic has reenergized a push to build data systems that can collect, report, and verify data stratified by key demographic factors including by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, rural/urban environment, and service setting. The systems must permit analysis across multiple demographic categories, such as race and disability, so we can track compound disparities and then focus resources on improving them. Stratification should not only apply to HCBS core measures, but also allow us to know more about disparities people with disabilities may experience accessing preventive and acute care services, such as diabetes-control or vaccinations.

Enhance Oversight and Accountability Through a Multi-Faceted Quality System

An effective quality control system for HCBS systems must include multiple pathways to evaluate services. Though performance measures provide important insights about HCBS quality and access, they cannot provide a complete picture across the range of services and providers covered. Survey samples may not be big enough, or the time lag from data collection to reporting may be too great to catch incipient problems. For this reason, HCBS quality systems must include other accountability mechanisms that use different methods, For example, each state should designate an HCBS Ombuds office charged with both helping beneficiaries troubleshoot problems using the HCBS program and with rapidly identifying and publicly reporting common problems to direct system improvements. States and plans could also track and report data on grievances and appeals to flag potential problems that may not be reported in the array of performance measures. A similar approach has already been piloted in multiple states that participated in a Medicare/Medicaid integration demonstration focused on older adults and people with disabilities (36).

Increase Federal Investment to Improve HCBS Quality Infrastructure

The growth of MLTSS only sharpens the urgency for Congress to significantly increase the federal funding for administrative activities related to adoption of HCBS quality activities. This includes consumer and other stakeholder engagement, data and quality infrastructure, expanding the sample size for beneficiary experience surveys, and facilitating public, stratified reporting of quality measures. Additional federal funding, such as an enhanced federal match for expenditures related to HCBS quality improvement, could accelerate development of new quality measures to fill gaps, such as workforce and employment metrics, that could help to overcome the institutional bias in Medicaid quality measurement. CMS must provide ongoing technical assistance activities to states in meaningful use of measures to improve community living and health outcomes for recipients of HCBS.

CONCLUSION

The US may still be a long way from reckoning with the need for a comprehensive, well-funded system to provide LTSS. But as the population quickly ages and the pandemic creates millions more people who need LTSS and cannot rely on family members to fill in the gaps, there is an urgent need and opportunity to strengthen the piecemeal systems already in place. Medicaid HCBS continue to expand and evolve, and the need for a robust, multi-layered, beneficiary-centered oversight and accountability system has never been greater. Many new tools are just coming on line to vastly improve states' ability to evaluate HCBS quality, but states need resources and impetus from the federal government to make meaningful use of these measures to enhance the quality of HCBS for individuals with disabilities and older adults.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

FUNDING

This study was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90TRCP0004. NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS).

REFERENCES

1. U. S. Senate Commission on Long-Term Care. *U. S. Senate Commission on Long-Term Care: Report to the Congress*. Washington, DC: U.S. Senate (2013).
2. Hado E, Komisar H. *Fact Sheet: Long-Term Services and Supports*. Washington, DC: AARP Public Policy Institute. (2019).
3. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who pays, and how much? *Health Aff*. (2010) 29:11–21. doi: 10.1377/hlthaff.2009.0535
4. Murray C, Tourtellotte A, Lipson D, Wysocki A. *Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2019*. Chicago, IL: Mathematica, prepared for the Centers for Medicare and Medicaid Services (2021).
5. Reaves EL, Musumeci M. *Medicaid and Long-Term Services and Supports: A Primer*. Washington, DC: Kaiser Family Foundation (2015).
6. Musumeci M, O'Malley Watts M, Chidambaram P. *Key State Policy Choices About Medicaid Home and Community-Based Services*. Washington, DC: Kaiser Family Foundation (2020).
7. O'Malley Watts M, Musumeci M, Chidambaram P. *Medicaid Home and Community-Based Services Enrollment and Spending*. Washington: DC: Kaiser Family Foundation (2020).
8. Chong N, Akobirshoev I, Caldwell J, Kaye HS, Mitra M. The relationship between unmet need for home and community-based services and health and community living outcomes. *Disabil Health J*. (2022) 15:101222. doi: 10.1016/j.dhjo.2021.101222
9. Centers for Medicare and Medicaid Services (CMS). *Medicare.gov – Care Compare*. (2022). Available online at: https://www.medicare.gov/care-compare/ (accessed May 20, 2022).
10. Centers for Medicare and Medicaid Services (CMS). *Application for a § 1915(c) Home and Community-Based Waiver Instructions, Technical Guide, and Review Criteria Version 3.6, 10-11*. Baltimore, MD: CMS (2019).
11. Government Accountability Office (GAO). *Oversight of Quality of Care in Medicaid Home and Community-Based Services Waiver Programs*. (2012). Available online at: https://oig.hhs.gov/oei/reports/oei-02-08-00170.pdf (accessed May 20, 2022).
12. Government Accountability Office (GAO). *Medicaid Managed Care: CMS Should Improve Oversight of Access and Quality in States' Long-Term Services and Supports Programs, GAO-17-632*. (2017). Available onlineat: https://www.gao.gov/products/gao-17-632 (accessed May 20, 2022).
13. Medicaid and CHIP Payment and Access Commission (MACPAC). *Tailoring MLTSS Programs for Individuals with Intellectual and Developmental Disabilities*. Washington, DC: MACPAC (2018).
14. Saucier P, Kasten J, Burwell B, Gold L. *Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 Update, 9. Truven Health Analytics,*

prepared for the Centers for Medicare and Medicaid Services. Baltimore, MD: CMS (2012).

15. Gifford K, Ellis E, Lashbrook A, Nardone M, Hinton E, Rudowitz R, et al. *A View from the States: Key Medicaid Policy Changes: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2019 and 2020*. Washington, DC; Kaiser Family Foundation (2019).
16. Lewis E, Eiken S, Amos A, Saucier P. *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update, 4 (Jan. 2018). Truven Health Analytics Prepared for Prepared for the Centers for Medicare and Medicaid Services*. Baltimore, MD: CMS (2018).
17. Dobson C, Ne'eman A, Sowers MP, Vega L. *MLTSS for People with Intellectual and Developmental Disabilities*. Washington, DC: National Association of States United for Aging and Disabilities (now Advancing States) (2018).
18. Kaye HS. *Managed Long-Term Services and Supports: Using Capitation To Promote Home and Community-Based Services*. San Francisco, CA: Community Living Policy Center (2017).
19. Ne'eman A. *Managed Long-Term Services and Supports: Contract Provisions Related to Transition and Diversion from Institutional Placement*. San Francisco, CA: Community Living Policy Center, University of California, San Francisco (2018).
20. Centers for Medicare and Medicaid Services (CMS). *Technical Assistance Guide for Administration of the Consumer Assessment of Healthcare Providers and Systems Home and Community Based Services (HCBS CAHPS®) Survey*. Baltimore, MD: CMS (2021).
21. Government Accountability Office (GAO). *Medicaid Long-Term Services and Supports: Access and Quality Problems in Managed Care Demand Improved Oversight*. (2020). Washington, DC: GAO. Available online at: https://www.gao.gov/products/gao-21-49 (accessed May 20 2022).
22. National Council on Disability. *Medicaid Managed Care Community Forums: Final Report*. Washington, DC: NCD (2016).
23. National Quality Forum. *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement*. Washington, DC: National Quality Forum (2016).
24. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTCOM). *Stakeholder Input: Identifying Critical Domains and Subdomains of HCBS Outcomes*. (2016). Available onlineat: https://rtcom.umn.edu/phases/phase-1-stakeholder-input (accessed May 20, 2022).
25. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTCOM). *Brief 3: Development of HCBS Outcome Measures*. (2020). Available online at: https://publications.ici.umn.edu/rtcom/briefs/brief-three-development-of-hcbs-outcome-measures (accessed May 20, 2022).
26. World Health Organization. *Everybody's Business – Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action*. Geneva, Switzerland: World Health Organization (2007). Available online at: https://apps.who.int/iris/handle/10665/43918 (accessed May 20, 2022).
27. National Core Indicators (NCI). *About National Core Indicators*. (2022). Available online at: https://www.nationalcoreindicators.org/about/ (accessed May 20, 2022).
28. National Core Indicators for Aging and Disabilities (NCI-AD). *About National Core Indicators for Aging and Disabilities*. (2022). Available online at: https://nci-ad.org/about/ (accessed May 20, 2022).
29. Centers for Medicare and Medicaid Services (CMS). *Medicaid and CHIP Managed Care Monitoring and Oversight Tools*. Baltimore, MD. (2021). Available online at: https://www.medicaid.gov/federal-policy-guidance/downloads/cib06282021.pdf (accessed May 20, 2022).
30. Gardner J, Carran DT, Nudler S. Measuring quality of life and quality of services through personal outcome measures: Implications for public policy. *Int Rev Res Ment Retard*. (2001) 24:75–100. doi: 10.1016/S0074-7750(01)80006-9
31. The Council for Quality and Leadership (CQL). *Personal Outcome Measures*. (2022). Available online at: https://www.c-q-l.org/tools/personal-outcome-measures/ (accessed May 20, 2022).
32. National Committee for Quality Assurance. *Long-Term Services and Supports Programs*. (2022). Available online at: https://www.ncqa.org/programs/health-plans/long-term-services-and-supports/ (accessed May 20, 2022).
33. Centers for Medicare and Medicaid Services (CMS). *Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services. Baltimore, MD*. (2020). Available online at: https://www.medicaid.gov/medicaid/quality-of-care/downloads/rfi-hcbs-recommended-measure-set.pdf (accessed May 20, 2022).
34. Bipartisan Budget Act of 2018. Pub. L. 115-123, § 50102, 132 Stat. 175 [Amending 42 U.S.C. § 1320b-9a to mandate that states report annually on the child core measure set](2018).
35. Substance Use-Disorder Prevention That Promotes Opioid Recover and Treatment for Patients and Communities Act. Pub. L. 115-271, § 5001, 132 Stat. 3961 [requiring states to report annually on all adult behavioral health core measures by, 2024] (2018).
36. Archibald N, Perra D, Tourtellotte A, Lim K. (2021). *State Approaches to Developing and Operating Ombudsman Programs for Demonstrations under the Financial Alignment Initiative*. Washington, DC: Integrated Care Resource Center. Available online at: https://www.integratedcareresourcecenter.com/sites/default/files/Ombudsman%20Programs%20brief.pdf (accessed May 20, 2022).
37. National Core Indicators (NCI). *In Person Survey (IPS) State Report 2018-2019: Minnesota*. (2019). Available online at: https://www.nationalcoreindicators.org/upload/core-indicators/MN_IPS_state_508.pdf (accessed May 20, 2022).

Author Disclaimer: Contents reflect the views of the authors and not the National Institute on Disability, Independent Living, and Rehabilitation Research.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Rehabilitation Sciences

TYPE Policy and Practice Reviews
PUBLISHED 23 August 2022
DOI 10.3389/fresc.2022.960996

OPEN ACCESS

EDITED BY
Jan Šiška,
Charles University, Czechia

REVIEWED BY
Julie Beadle-Brown,
University of Kent, United Kingdom
Zhuoying QIU,
China Rehabilitation Research Center/WHO Collaborating Center for Family International Classifications, China

*CORRESPONDENCE
Dorothy Hiersteiner
dhiersteiner@hsri.org

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 03 June 2022
ACCEPTED 25 July 2022
PUBLISHED 23 August 2022

CITATION
Bradley V and Hiersteiner D (2022) Quality monitoring of intellectual and developmental disabilities systems in the US: Assessing the utility and applicability of selected National Core Indicators to national and state priorities.
Front. Rehabilit. Sci. 3:960996.
doi: 10.3389/fresc.2022.960996

Quality monitoring of intellectual and developmental disabilities systems in the US: Assessing the utility and applicability of selected National Core Indicators to national and state priorities

Valerie Bradley[1] and Dorothy Hiersteiner[2]*

[1]President Emerita, Human Services Research Institute, Cambridge, MA, United States, [2]Co-Director of National Core Indicators®, Human Services Research Institute, Cambridge, MA, United States

This article provides historical context on the evolution of performance measures for system improvement, examines the perspectives and insights of state public managers on the use and utility of NQF-endorsed outcome measures from the NCI®-IDD In-Person Survey (IPS) for quality improvement, and discusses the necessity of ensuring that outcome measures align with public policy goals.

KEYWORDS

intellectual and developmental disability, disability, performance measurement, quality of life

Introduction

There is a growing understanding among public administrators of services and supports to people with intellectual and developmental disabilities (IDD) that the best way to assess quality is to ask service participants about their experience. As a result, surveys assessing quality of life and service outcomes based on participant report are increasingly being used to analyze service quality and system performance. The purpose of this article is to explore the use and utility of 14 National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD) measures to the promotion of contemporary public policy goals based on the rankings of state public IDD managers in states across the United States.

In addition to methodological and psychometric evaluation, reviews of the attributes of outcome measurement systems should also include an analysis of the utility of data collection to inform system improvement. Because policy goals change over time, it is also necessary to periodically review measures to determine their alignment with current policy evaluation needs, research findings, priorities, and aspirations (1).

This article provides historical context for the evolution of performance measurement for system improvement in the United States, examines the perspectives and insights of state public managers on the use and utility of National Quality Forum (NQF)-endorsed outcome measures from the NCI®-IDD In-Person Survey

(IPS), and discusses the necessity of ensuring that outcome measures align with public policy goals. While the discussion relies primarily on experiences and practices in the United States, it is hoped that the findings will bolster efforts internationally to ensure that outcome measure remains dynamic and responsive to changing priorities.

Historical perspective

Process standards

To understand the prominence of outcome measurement in the performance of systems of support for people with IDD, it is necessary to reflect on the evolution of quality monitoring in recent decades. As community-based systems expanded in the 1980s and 1990s, public managers developed highly specific process standards intended to embed promising clinical and practice developments into routine practice. This change appeared in state standards for individual habilitation plans, the composition of planning teams, and means to measure progress toward identified goals. Thus, evaluation and monitoring of these standards involved assessing whether certain strategies, steps, processes, and practices were implemented, and did *not* focus on outcomes experienced by the individual or measurement of progress towards individual goals. The concentration on treatment strategies and planning were especially evident in the design of original regulations governing Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).

Critique of process standards

As providers became more sophisticated, services and supports less facility-based, and residential arrangements more varied, critics in the field began to chafe under the constraints of rigid and prescriptive process standards. Frustration with ICF/MR standards persisted well into the 1990s (2–6). Researcher Tecla Jaskulski summarized these concerns in a report to the Health Care Finance Administration (7):

- Compliance does not equate with quality
- Standards are not focused on outcomes
- Processes that are reviewed are not sufficiently linked to desired outcomes
- Yes/no dichotomy (i.e., in or out of compliance) ignores individual differences
- Adversarial approach of the survey creates an atmosphere of fault-finding
- There is no focus on continuous quality improvement
- Survey process itself is intrusive in the lives of people with mental retardation

Dissatisfaction with prescriptive process standards led to an exploration of ways to incorporate outcomes into quality assurance assessments. An early examination of the multiple facets of quality monitoring (8) noted that, "Outcome measures are generally seen as the most telling measures to use and as the ultimate basis for legitimizing other approaches to measuring service quality" (p. 17). Authors went on to state, "… in our analysis of 22 quality assurance systems … few concentrated on outcome measures, and some have not client outcome measures at all" (p. 90).

Clinical/functional outcomes

Initial models to better incorporate client or consumer outcomes focused primarily on the extent to which individuals acquired skills or achieved goals, relying on functional scales such as the Scales of Independent Behavior (9) and the Vineland Adaptive Behavior Scales (10). This form of "outcome measurement" was informed by objectives set in individual plans, which in turn reflected expectations of professional providers or caregivers. By the early 1990s, the emphasis again shifted to individual goals such as choice-making, satisfaction, quality of life, and empowerment, moving the locus of assessment from the team to the individual. Rather than focusing primarily on improvement in adaptive skills (or reduction in maladaptive behavior), criteria for the effectiveness of services and supports underscored those outcomes most valued by the individual (11).

Emergence of quality-of-life outcomes

Early initiatives in the United States

A factor that shaped the emerging emphasis of quality-of-life outcomes was the changed expectations and aspirations of people with IDD and their families. These changes could be seen in the advent of self-determination and consumer-directed services in the 1990s. An evaluation of self-determination projects under the Robert Wood Johnson Foundation (12) explored how self-advocates felt about the importance of autonomy in their lives. Self-advocates cited the following key factors enhancing quality of life:

- I am a person like all people: my life is my own.
- I speak for myself. I speak up. I stick up for myself.
- I make my own choices.
- I am the boss of my own life.
- I make my decisions in my own life.
- I do for myself … and not depend on others so much. (p. 4)

These statements reveal that quality of life is a construct that is best understood from the perspective of people receiving services and supports and their family and friends.

An example of this shift from reliance on process and functional outcomes to quality-of-life measures can be seen in the revamped standards published by the Accreditation Council on Services for People with Disabilities (13). Instead of 817 process standards (14) (e.g., advocacy, information and referral, individual records, and plan coordination), the Council proposed a set of ten outcome measures for people and four performance indicators for organizations. Consumer outcomes were (ACDD, 1993, p. 11):

- Personal goals
- Choice
- Social inclusion
- Relationships
- Rights
- Dignity and respect
- Health
- Environment
- Security
- Satisfaction

Emergence of National Core Indicators

By the late 1990s, tying performance to outcomes experienced by system participants was widely accepted among advocates, stakeholders, and public managers in the U.S.. What was missing, however, was a common standard tool to canvass participant experiences in a valid and reliable way. Several factors led to the realization of such a tool. First, at the helm of increasingly complex community systems, public managers in IDD sought ways to assess the conduct and impact of supports without actual field observation. Second, improvements in computer capacity made it possible to aggregate and analyze large datasets. Third, state IDD budgets had swelled as the community system expanded, and thus expenditures needed to be justified through results. Finally, an emerging consensus in the field regarding the importance of listening directly to the perspectives and opinions of people receiving supports opened the door for the use of a face-to-face survey administered directly with people receiving services. These factors resulted in the formation of the National Core Indicators® (NCI®) system performance initiative.

In 1997, representatives of 13 state IDD agencies launched an unprecedented effort to create an interstate collaborative for the creation, collection, and analysis of uniform key performance indicators. Since its founding, NCI® has expanded to 48 states, the District of Columbia, and 21 regional developmental disabilities centers in California. NCI® has also grown in its capacity to develop and administer surveys to measure performance of state aging and physical disability systems, measure outcomes experienced by families of people receiving IDD system services and assess the stability and quality of the workforce of direct support professionals. NCI® data make it possible for participating states to track changes in performance, compare outcomes across states, and monitor national trends.

NCI® performance indicators used to measure IDD system performance (heretofore called NCI-IDD) provide a macro-level view of system performance to gauge trends and identify potential gaps. They are intended for use in tandem with other state-administered quality assurance processes under broader quality management systems (e.g., critical incident and reporting systems, risk assessments, provider monitoring, etc.).

To establish the core indicators, state developmental disabilities policymakers identified key criteria to accomplish vital program outcomes. These were designed to: (1) be directly relevant to major organizational or systemic goals; (2) reflect activities that can be influenced by the organization or system; (3) have face validity and should be relevant to the major constituencies served by the organization or system; (4) have directional qualities to reflect changes over time; (5) be expressed as rates or proportions; and (6) include a standard or goal for the desired level of attainment of each outcome (11).

Domains and subdomains within which the indicators are organized reflect major areas of outcomes that affect the mission of public developmental disabilities systems. They include:

Domains and Subdomains:

- Individual outcomes
    - o Employment, Community Inclusions and Belonging, Community Participation, Choice and Decision-Making, Relationships, Satisfaction
- System performance
    - o Self-Direction, Service Coordination, Workforce, Access
- Health, wellness, and rights
    - o Safety, Health, Medication, Rights and Respect
- Family experience
    - o Information and Planning, Access and Support Delivery, Workforce, Choice and Decision-Making, Community Connections, Health, Welfare and Safety

As outcome measurement has become an integral component of oversight in public state IDD systems, outcome measures have increasing been accepted as national benchmarks. The Centers for Medicare and Medicaid (CMS) Adult Core Measure Set and the CMS Medicaid and CHIP Scorecard both reflect this important approach (15). The challenge going forward is the extent to which this rich information about participant experience reflects information needed to evaluate the impact of public and in turn is used for both quality improvement and to evaluate the impact of public policy.

What's next

The previous review of the historical context for the evolution of performance measurement in IDD systems underscores the importance and prominence of quality-of-life measures in conducting oversight of public services and supports for people with IDD. The challenge going forward is to find ways to ensure that measures such as NCI-IDD continue to align with the immediate policy aims of public IDD systems and that they are consistent with the changing context of the provision of services. Lombardi et al. (16) have argued that while the overarching principles that should govern service provision have remained constant over many years, the context within which services operate changes over time as more is learned about best practice and the policies need to achieve those larger system aspirations. Measures therefore need to be reassessed periodically to determine whether they are capturing important contextual elements.

Further, Shogren et al. (17) have described public policy goals as inputs to systems of services and supports, and outcomes as the outputs. According to the authors, this framework (or logic model), allows public managers "to identify core processes that reengineering, quality improvement, and enhanced performance can improve." Because outcomes or outputs shed light on the efficacy of public policy, it is important to periodically assess whether those results continue to align with public policy goals, as well as whether they are incorporated in the process of quality improvement.

Method

NCI®-IDD In Person Survey (IPS) measures endorsed by the National Quality Forum

In 1999, the U.S. government created the National Quality Forum (NQF) to advance accountability, patient protection, and quality of care using a variety of measurements and public data reporting. The federal government relies on NQF to review, study, and endorse healthcare-related measures and processes to define government-backed performance and quality measurement strategies. The process for NQF endorsement is rigorous and comprehensive, and measures that achieve endorsement can be relied on to demonstrate strong psychometric properties.

In 2016, NQF released the report, "Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement," calling for increased attention to measures to assess the quality of home and community-based services (HCBS). In the report, NQF defined a measurement framework that included 11 domains and 40 subdomains as areas for quality measurement within HCBS.

In January 2022, NQF approved 14 NCI®-IDD measures following meticulous review of scientific methods, consensus panel analysis, and a public comment period. NQF recognized the high demand for quality measures in home and community-based services, acknowledging the compelling evidence underlying NCI®-IDD measures. The 14 measures are:

Domain: Person-Centered Planning (PCP) and Coordination

- The proportion of people who express they want a job who have a related goal in their service plan
- The proportion of people who report their service plan includes things that are important to them
- The proportion of people who express they want to increase independence in functional skills (ADLs) who have a related goal in their service plan
- The proportion of people who report they are supported to learn new things
- The proportion of people who report satisfaction with the level of participation in community inclusion activities

Domain: Community Inclusion

- The proportion of people who reported that they do not feel lonely often
- The proportion of people who reported that they have friends who are not staff or family members
- The proportion of people who report adequate transportation
- The proportion of people who engage in activities outside the home

Domain: Choice and Control

- The proportion of people who reported they chose or were aware they could request to change their staff
- The proportion of people who reported they could change their case manager/service coordinator
- The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere
- The proportion of people who report making choices (independently or with help) in life decisions

Domain: Human and Legal Rights

- The proportion of people who report that their personal space is respected in the home

The 14 measures are part of the NCI-IDD In-Person Survey (IPS) which assesses participant outcomes. The survey has three parts. The background section includes sociodemographic, health, employment, and other information that is collected directly from existing administrative records. Section 1 covers more subjective, opinion-based questions that can only be answered by the participant (e.g., Do you like your job? Do you like where you live?). Section 2 contains questions that can be answered by a proxy if the individual is unwilling or unable to respond. This final section relates to more concrete, objective facts, such as the number of times a person went shopping in the community in the past month. In the more than two decades that the survey has been used, approximately two-thirds of respondents have been capable of answering questions without the assistance of a proxy.

The IPS has undergone a number validity and reliability tests and is accompanied by a comprehensive training package. The survey process also includes protocols to detect acquiescent response or "social desirability" including training surveyors to understand whether people are "acquiescing" and if so to rephrase the question in different ways to gather more accurate information. In addition, there is a "proxy determination" section that is designed (and tested) to help surveyors assess whether a proxy is needed (and whether section I should be skipped). This section guides the surveyor to ask non-service-related questions to ascertain the respondent's comprehension and ability to respond accurately.

Each state collects information on and completes a survey with a random sample of individuals that reaches the 5%

margin of error and 95% confidence level, based on the total eligible addition population in the state. Individuals are eligible if they receive at least one service from the DD system in in addition to case management. To compare results from state to state, some data are risk-adjusted based on the functional characteristics of individuals served to reduce the impact on aggregate results of differences by state. In addition to recent endorsement by NQF, measures from the IPS have been included in the Medicaid and Children's Health Insurance Program (CHIP) Scorecard and are included in the Medicaid Adult Health Care Quality Measures Core Set (18).

Survey of public managers

The authors designed a survey to be completed by state public managers to assess their perspectives on the utility and applicability of the NCI®-IDD 14 IPS measures endorsed by NQF. The survey was sent to state DD systems staff who were the state-designated NCI®-IDD liaisons, with instructions suggesting that the initial respondent could consult with other staff in the IDD agency or elsewhere to arrive at the rankings and determine whether the measure was being used for quality improvement.

The survey asked respondents to apply two of the "Criteria for Evaluation" used by NQF (19) for measure endorsement to the 14 endorsed measures. The two criteria were "importance to measure" and "usability and use" and respondents were directed to rank each statement on a five-point Likert scale: 1 = very important, 2 = important, 3 = somewhat important, 4 = not very important, 5 = not important. The survey instructions included definitions of the rating criteria:

- Importance to Measure and Report: Extent to which the specific measure focus is consistent with best practice in the IDD field, is necessary for significant gains in the quality of home and community-based services and improves the quality-of-life outcomes for a specific high-priority aspect of the IDD system where there is variation in or less-than-optimal performance.
- Usability and Use: Extent to which potential audiences (e.g., consumers, purchasers, providers, policymakers) use or could use performance results for accountability and performance improvement to achieve the goal of high-quality, efficient, home and community-based services for people with IDD.

Respondents were then asked, "Is the measure used or planned to be used for quality improvement? If not, why?"

Results

Twenty-seven (27) responses were received by the close of the survey on April 15, 2022. Of those, two were incomplete, and two were from one state. Respondents to the survey listed a variety of positions and departments, including quality assurance, waiver management, IDD program management, NCI®-IDD liaison, quality improvement, strategic planning, and health planning. State staff that responded to the survey included state home and community-based waiver managers, quality assurance staff, NCI® liaisons, strategic planners, and IDD program consultants.

Table 1 shows results by measure and domain. Measures within domains are ranked based on the proportion of respondents who scored the indicator "very important" or "somewhat important."

Important to measure

At least three-fourths of respondents rated all measures as very or somewhat important and four measures were rated very or somewhat important by all respondents. This suggests that public managers believe this subset of measures in the IPS aligns with public policy goals and can be used to assess the performance of services.

Usability and use

With few exceptions, scores for the usability and use of each measure were likewise fairly high but were lower than the initial rating of importance to measure. Several reasons for this differential may include:

- Current wording of the measure does not adequately reflect the service context
- Results of the measure are not seen as immediately actionable
- Results are not as important to key constituencies

Measure is used or is planned to be used for quality improvement

While respondents rated the importance of the measures highly, a number indicated that some measures were not currently being used for planning and enhancement, nor were there plans to use the results from that measure in the future. This does not necessarily undermine the measure's potential utility, but rather indicates a need for more intentionality in public systems regarding how to use outcome data to shed light on the achievement of policy goals and to identify elements of service that influence or can influence performance.

If respondents reported that the measure was not being used for quality improvement in their state, respondents were asked to explain why. The following reasons were given:

TABLE 1 Survey responses.

	Importance to measure and report: Very important or important ($N = 24$)	Usability and use: Very usable or usable ($N = 24$)	Is the measure used or planned to be used for quality improvement in your state?: Yes ($N = 23$)
NQF domain: Person centered planning and coordination			
Indicator: The proportion of people who report satisfaction with the level of participation in community inclusion activities	100%	87.5%	82.6%
Indicator: The proportion of people who express they want a job who have a related goal in their service plan	100.0%	83.3%	87.5%
Indicator: The proportion of people who report their service plan includes things that are important to them	91.7%	75.0%	73.9%
Indicator: The proportion of people who express they want to increase independence in functional skills who have a related goal in their service plan	75.0%	75.0%	56.5%
Indicator: The proportion of people who report they are supported to learn new things	75.0%	62.5%	47.8%
NQF domain: Community inclusion			
Indicator: The proportion of people who reported that they have friends who are not staff or family members	87.5%	79.2%	60.9%
Indicator: The proportion of people who engage in activities outside the home	87.5%	83.3%	60.9%
Indicator: The proportion of people who reported that they do not feel lonely often	83.3%	62.5%	40.9% ($n = 22$)
NQF domain: Choice and control			
Indicator: The proportion of people who report making choices (independently or with help) in life decisions	100.0%	100.0%	65.2%
Indicator: The proportion of people who reported they chose or were aware they could request to change their staff	95.8%	87.5%	60.9%
Indicator: The proportion of people who reported they could change their case manager/service coordinator	95.8%	83.3%	65.2%
Indicator: The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere	79.2%	83.3%	47.8%
NQF domain: Human and legal rights			
Indicator: The proportion of people who report that their personal space is respected in the home	100%	100.0%	60.9%

- New staff were unsure how to use data
- Have not concentrated on that aspect of a particular subdomain
  - o "We [use] several questions about level of participation in community inclusion activities, however we do not specifically [use this measure] about satisfaction [with community inclusion]."
- Considering use of the measure in the future
- Has been used inconsistently in the past
  - o "[This measure] has been used for QI initiatives but is not consistently used year over year."
- Measure is of value but not a high priority for strategic planning or quality improvement
- Only so many initiatives that can be managed
- Getting the information from other sources
  - o "We ask many questions related to service plans already in a separate QI process, however we do not use this specific [NCI-IDD measure]."
- Do not think the measure is actionable
  - o "For [State] this is not an actionable question. It is not clear what the measure would tell us or how we would be able to use the data."

- Does not reflect what people want
- Do not know how to address, there are other ways of getting at this
- Difficult during COVID (i.e., a measure of the level of engagement in activities out of the home)
- Good for providers and organizations but not for waiver management
    - "[State] HCBS feels that this measure will be useful for providers and organizations in the state, but it won't be useful for HCBS at the state level."
- Do not use because ratings are high
- Difficult to implement given staff shortage
- Measure is not relevant to state practice
    - "[State] does not focus on this."
- Could be helpful for settings rule verification

These responses indicate that more general explanations for not actively using particular measures were due to a measure not reflecting state priorities, limited capacity for utilization, and/or COVID-related obstacles to use or relevance. Some respondents also noted that measures were being considered for future analysis, and still others commented on the actionability of the measure, limited avenues for remediating poor results, and lack of alignment with individual goals. It will be important to determine whether these are idiosyncratic problems or serve as a broader critique of the measure and/or its applicability to state quality improvement processes.

Discussion

Implications

The results of this preliminary survey suggest that the subset of NCI®-IDD IPS measures endorsed by NQF are seen by public managers as important to measure and, to a slightly lesser extent, are seen to have utility. Fewer respondents, however, note that the measures are actively being used for quality improvement. Obviously, there are only so many measures that can be intentionally tracked and analyzed given limited time and resources. Further, each state's system context may give rise to different priorities. However, some respondents suggested that certain measures do not reflect state practice/policies or there are not realistic ways of remediating negative performance based on the measure.

This survey of state public managers is a first step in a periodic "audit" to determine the viability of outcome measures and their utility to performance and quality measurement. A next step would be an analysis of reasons why some measures were rated lower than others in order to understand the differences in utility, as well as to understand the possible need for more technical assistance to aid public managers in applying survey outcomes to quality enhancement.

Limitations

This study should be viewed as a qualitative rather than a quantitative examination of the alignment between quality-of-life outcome measures and the current service and policy context. It is meant to start a serious discussion about how to conduct periodic reviews of quality-of-life indicators regarding their useful life and to justify the resources invested in the multi-faceted process of conducting individual interviews. More comprehensive studies of the connections between context and policy on the one hand and outcome indicators on the other will be necessary to avoid measurement for its own sake delinked from public purpose.

Conclusion

Though Peter Drucker may have never said, "What gets measured gets done" or, alternatively, "What gets measured gets managed," there is still wisdom in the statement. The outcomes that get measured in the IDD system signal to the field that those outcomes reflect of the values of the system. However, measurement of outcomes should not just signal policy priorities but should be used to evaluate the success of current policies and the need for future policy reform. Outcome measurement should be part of an iterative process that reveals the impact of policies plus the efficacy of elements of the system context – an aspect of the system that Shogren et al. (17) term "influencing factors." Therefore, it is important for public managers to periodically review whether there is continuity between policy goals and outcomes measurement as well as a collateral review of the processes and practices that are in place to implement those goals. Additionally, it is critical for measure developers to ensure that measures align with policy priorities and are usable.

The challenges highlighted by these results are first, there is a need to work with states to suggest ways to integrate outcome measures into systemic evaluations of state system performance. Secondly, periodic review of outcome measures is important to ensure that they continue to reflect the desired outputs of policy initiatives. Third, negative performance should be accompanied by a more in-depth examination of the system context and the presence or absence of known best practices or "influencing factors." Shogren et al. (17) use the phrase "outcomes-driven policy" to describe a more comprehensive and robust measurement structure. To ensure the continuing relevance of outcome measurement, it is time to strive for "policy-driven outcomes."

Author contributions

VJB created the overall conceptual framework for the article and did most of the writing. DH contributed to the survey of public managers, analyzed the responses, created the table of responses, and edited the final manuscript. All authors contributed to the article and approved the submitted version.

Acknowledgments

The authors want to thank the state public managers that responded to the outcomes survey and therefore made this article possible.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Pew Trusts. The role of outcome monitoring in evidence-based policymaking. Available at: https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2018/08/the-role-of-outcome-monitoring-in-evidence-based-policymaking (Accessed July 21, 2022).

2. Boggs E. Getting into the jet stream. *Ment Retard.* (1992) 30(3):178–180.

3. Kennedy M. What quality assurance means to me: Expectations of consumers. In: Bradley V, Bersani H, editors. *Quality assurance for individuals with developmental disabilities: Its everybody's business.* Baltimore: Paul H. Brookes (1990).

4. Holburn S. Rhetoric and realities in today's ICF/MR: Control out of control. *Ment Retard.* (1992) 30(3):133–137.

5. Shea J. From standards to compliance, to good services, to quality lives: Is this how it works? *Ment Retard.* (1992) 30(3):143–147.

6. Taylor S. The paradox of regulations: A commentary. *Ment Retard.* (1992) 30 (3):185–186.

7. Jaskulski T. *Analysis of the application of the active treatment definition (unpublished report).* Cambridge, MA: Human Services Research Institute (1996).

8. Ashbaugh J, Bradley V, Allard M, Reday M, Stoddard S, Collignon F. *Assuring the quality of human services: A conceptual analysis.* Washington, DC: Human Services Research Institute; Berkeley: Berkeley Planning Associates (1980).

9. Bruininks R, Woodcock R, Weatherman F, Hill BK. *Scales of independent Behavior.* Allen, TX: DLM/Teaching Resources (1984).

10. Sparrow S, Balla D, Cichetti D. *Vineland adaptive behavior scales.* Circle Pines, MN: American Guidance Service (1984).

11. Bradley V. Evolution of a new service paradigm. In: Bradley V, Ashbaugh J, Blaney B, editors. *Creating individual supports for people with developmental disabilities: A mandate for change at many levels.* Baltimore: Paul H. Brookes (1994).

12. Agosta J, Silver J, Heaviland M, Bradley V. *Year two impact assessment report: Focus on self-advocate perspectives.* Cambridge, MA: Human Services Research Institute (2000).

13. The Accreditation Council on Services for People With Disabilities. *Outcome based performance measures.* Towson, MD (1993).

14. The Accreditation Council on Services for People with Developmental Disabilities. *Standards and interpretation guidelines for services for people with developmental disabilities.* Landover, MD: National Quality Enhancement Program (1990).

15. Medicaid.gov. Medicaid & chip scorecard. Available at: https://www.medicaid.gov/state-overviews/scorecard/index.html (Accessed July 21, 2022).

16. Lombardi M, Claes C, Bradley V, Schalock R. *The influence of context on the conceptualization, measurement, and application of the concept of quality of life.* Submitted to *J Policy Pract Intellect Disabil.* (2022).

17. Shogren K, Luckasson R, Schalock R. Using context as an integrative framework to align policy goals, supports, and outcomes in intellectual disability. *Intellect Dev Disabil.* (2015) 53(5):367–376.

18. Medicaid.gov. Adult health care quality measures. Available at: https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/adult-health-care-quality-measures/index.html (Accessed July 21, 2022).

19. National Quality Forum. *Measure evaluation criteria and guidance for evaluating measures for endorsement.* Washington, DC (2021). Available at: https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=88439 (Accessed July 21, 2022).

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 26 August 2022
DOI 10.3389/fresc.2022.890822

OPEN ACCESS

EDITED BY
Renata Ticha,
University of Minnesota Twin Cities,
United States

REVIEWED BY
Daniel Mont,
Center for Inclusive Policy, United States
Masauso Chirwa,
University of Zambia, Zambia

*CORRESPONDENCE
Johannes Schaedler
schaedler@zpe.uni-siegen.de

†These authors have contributed equally to this work.

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 06 March 2022
ACCEPTED 01 August 2022
PUBLISHED 26 August 2022

CITATION
Rohrmann A and Schaedler J (2022) Quality assessment, inclusive community development, and collective learning: An institutional perspective from Germany.
Front. Rehabilit. Sci. 3:890822.
doi: 10.3389/fresc.2022.890822

Quality assessment, inclusive community development, and collective learning: An institutional perspective from Germany

Albrecht Rohrmann[†] and Johannes Schaedler*[†]

Center for Planning and Evaluation of Social Services (ZPE), University Siegen, Siegen, Germany

This article reviews the German discourse on quality of life, quality assurance, and outcome measurement in services for persons with intellectual disabilities. Following institutional assumptions of path dependencies in organizational development, it is argued that concepts such as quality assurance must be understood in the context of the national support system development. For the Federal Republic of Germany, it can be noted that previous approaches to quality assurance of services based on measurement and evaluation tools have not been the drivers of innovation for inclusion. The driving forces behind reforms in the field of disability originated from the three angles of the social service structure (people with disabilities, statutory welfare agencies, and service providers). Policies of key actors were not part of a consistent reform strategy. However, the main elements of the inclusive philosophies of the disability rights movement became hegemonial and led to national legislation that prioritizes person-centered support arrangements in inclusive settings. With regard to governance arrangements in Germany and the idiosyncrasies of local disability fields, it is suggested that there should be a conceptualization of quality assurance in a multilevel approach as "local quality dialogues for collective learning."

KEYWORDS

intellectual disability services in Germany, quality assurance, inclusion, path, drivers for innovation, quality dialogue, local planning, collective learning

Introduction

Quality development measures are often expected to provide strong impulses for improving the life conditions of people with disabilities, especially for people with intellectual disabilities. In this context, the focus of attention is exclusively directed to the quality of support practices within single-service organizations. The UN Convention on the Rights of Persons with Disabilities (CRPD), particularly the requirements of Article 19, has provided an effective international impulse for many countries toward political and professional measures to promote independent living. Nevertheless, its implementation in each national context is based on the respective developmental paths of social welfare systems and differ from country to country.

This ground must be understood in the international discourse on concept development for improving the quality of life of people with disabilities.

The development in the Federal Republic of Germany is characterized by the fact that there is a legal entitlement to social benefits for people with disabilities. This is regulated at the federal level and services are financed by governmental agencies. But, in the field of service provision, non-governmental associations, such as those of churches, dominate. They are called intermediary organizations because they combine the characteristics of state organizations, of enterprises, and of organizations of the voluntary sector. They are granted a high degree of autonomy in the design of assistance and traditionally have a strong influence on how society deals with the target group they support. They often claim to represent the rights of people with disabilities in an advocatory manner.

Regardless of the federal legal basis, there are very large regional differences in the infrastructure of support services for people with disabilities. This is related, for example, to the tradition of large institutions, the regionally varying activities of lobby groups for inclusion, and the policy of municipalities and other regional stakeholders.

The example of the development in the Federal Republic of Germany shows that an isolated discussion of quality in service organizations in general cannot make a substantial contribution to improving the quality of life for people with disabilities. Such a perspective would focus on only on the interaction between professionals and beneficiaries and would ignore the context of this relationship. If, on the other hand, looking at the drivers of innovation to comply with the requirements of the UN CRPD, albeit hesitantly and sometimes contradictorily, it becomes apparent that the structures of the support system become crucial for change. The structures refer to the financing of services, the management of services in individual cases, the rights of the beneficiaries, and the integration of support services into the regional community. Reviewing the development of the support system in Germany, therefore, is to contribute to the understanding of the structural dimension in the quality debate.

The governance context of the German service system for persons with intellectual disabilities

In order to understand how the discourse on "quality of life" and "quality of services" and "outcome measurement" has been received in the field of services for people with intellectual disabilities in Germany, it is necessary to look at the governance system in this field and its developmental paths until today. When speaking of "fields," we relate to neo-institutional approaches in organizational analysis (1–3). An organizational field can be defined as "those organizations that, in the aggregate, constitute a recognized area of institutional life: key suppliers, resource and product consumers, regulatory agencies, and other organizations that produce similar services or products" (4, p. 64). On this basis, it can be assumed that single disability services are interconnected with other disability service organizations in their region and thus form a field. Such fields share conceptual assumptions, knowledge, have specific forms of interaction, power structures, and are aware of a common purpose. With regard to the developmental paths of organizations and their fields, it seems plausible that history matters, i.e., "initial choices preclude future options, including those that would have been more effective in the long run (…) Altering institutional rules always involves high switching costs, thus a host of political, financial and cognitive considerations mitigate against making such changes" (5). Recognizing path dependency can explain why paradigmatic changes of given institutional practices in disability services are so hard to realize in practice.

Therefore, in the following, key aspects of the development of services for people with intellectual disabilities in Germany will be summarized.

Intellectual disability services that Germany developed in the 19th century in the framework of religious organizations that rather early formed umbrella organizations: the protestant actors established the "Innere Mission" (1848), which later became the "Diakonie," and on the catholic side in 1898, the "Caritas" was founded as a joint association of catholic initiatives (for the deeper political context, see ref. 3, pp. 21–94). At the turn of the 19th to the 20th century, there were approximately 80 religiously run "imbecile institutions" in Germany, each one often caring for more than 1,000 people (6). The running of the large facilities was mostly supported by order sister and brothers, i.e., voluntary and unpaid workforce of unmarried women and men who acted with a strong religious orientation focusing on physical care, work, and religious education.[1] In the early 1920s after WW I, the political system in Germany changed from monarchy to republic and the religious welfare organizations were joined with other welfare organizations from the labor movement (*Arbeiterwohlfahrt*, Workers' Welfare Association) *Deutsches Rotes Kreuz*, Red Cross, the *Paritätische Wohlfahrtsverband*, Independent Welfare Association, and the *Zentralwohlfahrtsstelle der Juden*, Jewish Welfare Organization)[2] to form a powerful

---

[1] During the Nazi regime, they failed to counter the eugenic movement and the euthanasia crimes (7).

[2] After having been dissolved like the other welfare umbrellas by the Nazi regime, the Jewish Welfare Association had already been reestablished in 1951, and today, it has a nationwide network again (see https://zwst.org/de).

overall third sector umbrella organization "*Liga der Freie Wohlfahrtspflege*" ("League of non-statutory welfare").

Since then, the relation between the state and the non-statutory welfare organizations is defined by the so-called "principle of subsidiarity," which in simple terms means that whatever the individual, family, group, or organizational body can do for themselves is not to be left to the responsibility of the government. This principle became a structural element of later German social legislation with far-reaching consequences. Until today, it obligates the German government agencies to leave the provision of all kinds of social services to the non-statutory, free voluntary welfare organizations, while the state remained responsible for meeting relevant costs. All service (8) providers at the local level were expected to be a member of one of the six welfare associations listed above. As a result, the provision structures in social work in general are shaped by non-governmental associations that run most[3] of the various services, whereas the main role of governments is that of the funder. Moreover, the non-statutory welfare sector still has a legally guaranteed conceptual autonomy on how to provide services as long as this remains within the framework of the legal prescriptions of the Social Code Book (SGB).

The field of intellectual disabilities is structured just like this, whereby the religious organizations nationwide are still the biggest players in disability service provision, followed by parents' organizations and others. Which provider association is dominant in a certain region differs according to given local developmental paths with origins in local social milieus and religious traditions. Despite marketization policies that had started in the mid-1990s, in the field of intellectual disability, there are almost no private service providers with a for-profit orientation (8).

For the context of this article, it is important to note that governance structures and financing of services for persons with intellectual disabilities in Germany are shaped in a triangular relationship between the individual persons as the beneficiaries, the state, and the service providers. The national government regulates eligibility conditions of beneficiaries for the different service areas through the national Social Code Book IX that have to be implemented by the sixteen federal states and by local governments. In order to receive the services they are legally entitled for, people with intellectual disabilities have to go through an application procedure that is based on the assessment of their individual needs. This application procedure leads to a legal claim of a beneficiary against the government to pay for eligible services provided by non-governmental welfare organizations. Healthcare and long-term care needs of people with intellectual disabilities are covered by social insurance schemes and are part of the general social protection system. Most other services for persons with intellectual disabilities that offer support, e.g., in day-to-day living, employment, or leisure time are part of the social assistance system under the "Integration Act" and therefore means-tested; in reality, private funding or out-of-pocket payment plays only a marginal role.

When in the 1970s the debate on deinstitutionalization in mental health services received high public attention, also the large care institutions for persons with intellectual disabilities came under growing critique. With some delay, the Scandinavian principle of normalization as conceptualized by Bank–Mikkelsen, Grunewald, or Nirje (see all their contributions in 9) was intensively discussed in the 1980s. However, in practice, it affected the German service system for people with intellectual disabilities only in a "moderate" way, i.e., primarily as a professional guideline, thus widely ignoring both its dimension of citizen rights and its sociopolitical ambition to improve the living conditions of persons with disabilities. Roughly speaking, the appropriateness of segregating facilities such as special kindergartens, special schools, residential homes, or sheltered workshops was not generally questioned. Instead, contradictions between concepts and institutional practice in the field were often summoned under unprecise normalization wordings, i.e., that services should allow persons with disabilities "obtain an existence *as close to* the normal as possible" (Bank–Mikkelsen). Still, especially parents' associations all over Western Germany, felt supported by the principle of normalization and engaged successfully in establishing group homes (with mostly 24 places in three groups) as an alternative to large institutions. As a result, gradually more of such residential homes for persons with intellectual disabilities were added to the traditional institutional system, but often based on the assumption that people with severe and profound disabilities were better off in large institutions.

While as in other Western countries, also in Germany, the disability rights movement became stronger and conceptual critique on large institutions and the segregating support system for people with disabilities also became more influential. However, the high autonomy of voluntary welfare organizations from governmental influence was still unanimously defended by most relevant actors from across the voluntary welfare sector. For principal reasons, it was requested that the state should remain in the role as a funder for social welfare and governments should not interfere in conceptual issues such as service models. Moreover, approaches of governments to make providers to report on the quality of their services were branded as an illegitimate element in the legal system (10). Even though when pressure

---

[3] The exemption is the field of long-time care services for the elderly, where private-for-profit providers count for ca. 50% of services.

on policymakers, e.g., from disabled people's organizations campaigning against segregating institutions and for new inclusive service models had mounted in the early 1990s, many government actors tried to avoid conflicts with the non-governmental service sector. Also because of corporatist structures reflecting the strong influence of the voluntary welfare sector in social politics, there was not much public political interest in substantial reforms for systematic dismantling of large institutions and building a community service system.

Following neoliberal ideas from the US and UK in the 1990s, both government actors and welfare organizations also in the disability sector came under the influence of new public management philosophies. While culture and routines in services became more "managerial" in nature, government actors on different political levels attempted with new legislation to release themselves from the role of the mere funder in order to make the system more cost-effective. According to the slogan "value for money," concrete steps were undertaken by policymakers to implement market elements such as purchasing and commissioning in social service provision and to implement a financing system based on contracts with service providers (11). As part of the contract conditions of the new funding system for the disability services of 1994, service providers were expected to provide high-quality services and to document these by establishing internal quality assurance schemes.

It was a widespread assumption of bureaucrats in the welfare administration and among service providers that such instruments for quality assurance would have the potential to function as motors for modernizing the institutionalized system of services for persons with intellectual disabilities. In search of orientation on how to conceptualize the quality assurance in disability services, two main routes were taken:

The direction of one route led to an international discourse on quality of life (QoL) and quality of services (QoS) that had reached the German intellectual disability field *via* publications of the International League of Parents Organizations (ILSMH).[4] Approaches to measure QoL were rather regarded as a contribution to the value base of service providers and were conducted with a strong ceremonial interest but not for systematic development of the service organizations. The issue "quality of services" was received in the tradition of Wolfensberger's instruments PASS or PASSING (12), which claimed to measure "how normalizing are current human services" (13). With some adaptions, comprehensive instruments for large institutions[5] were developed by German provider organizations, often with a strong focus on staffing issues (14). These instruments were mostly regarded as part of a strategy to improve the position of service providers in the funding negotiations with the government (11).

An exception was the so-called "LEWO- instrument," which became widely used as a method to develop the quality of services in group homes (15). It followed the idea of guided self-evaluation, providing professional standards for good support and management of services that were to be matched in a multistakeholder evaluation team with given practices in order to come to internal recommendations for developing the quality of life of users.

The other direction, in which actors look for conceptual orientation on how to assure the quality of services for persons with disabilities, was led by quality management systems. These approaches were inspired either from quality assurance schemes in the industrial sector or from corresponding models in other fields of human service delivery, mainly healthcare in hospitals. In the context of upcoming managerialism in services for people with disabilities, approaches such as "Total Quality Management" (TQM) were used to install quality management systems in many service organizations. These QM systems were based on a "quality-handbook" in which key processes of service provision were described as a compulsory orientation for staff. Services were expected to perform with better quality and higher cost-efficiency when establishing such QM systems with regular audits and certification according to industrial norms. In the same context, Donabedian's model of assessing of service quality (16) obtained a leading function also in the field of intellectual disability services. The model was originally developed for rating and ranking the quality of US hospitals and discriminates between "structure," "process," and "outcomes":

> *Structure* refers to the resources used in the provision of care, and to more stable arrangements under which care is produced; *process* refers to the activities that constitute care; and the *outcomes* are the consequences to health that were referred to in the proceeding section. (16, p. 6)

Donabedian's dimensions are still of use when it comes to describing and analyzing services for people with intellectual disabilities in Germany. Also, in some disability services, QM systems are still existing. But in practice, both approaches have lost relevance and generally speaking, often led to rather

---

[4] Later, its name was changed to *Inclusion International*.

[5] For an overview see (17) SYLQUE (System zur Entwicklung von Lebensqualität in Einrichtungen für Behinderte) or GBM (Gestaltung der Betreuung von Menschen mit Behinderungen) see (17).

technical approaches. This was due to the fact that the implementation of quality assurance schemes could not effectively support the claims of service providers for better staffing in negotiations with governments. Also, the QM approaches failed to be consistent with regard to quality standards for structures. While focusing on processes in services, they tended to ignore the crucial meaning of the institutional setting itself for people with intellectual disabilities being at risk of institutional discrimination. Thus, quality assurance concepts as such could not contribute to substantially transforming the widely specialized residential care system for persons with intellectual disabilities into service models that comply with the inclusive paradigm.

This does not mean that during this period no progress toward inclusive services models was achieved. Indeed, in the early 2000s, new service models based on individual support arrangements for persons with intellectual disabilities living alone or with a mate in their own apartments were initiated by innovative service providers all over the country. This process contributed to the development of a parallel system of institution-based care and community care. It followed the logic of an additive pattern of change, i.e., more and more inclusive services were established, while residential homes and institutions widely remained as they were, which seems to be typical for reforms in corporatist governance arrangements such as in Germany.[6]

Reformers again were rather optimistic when policymakers introduced concepts like “self-determination” and “equal participation” of people with disabilities in the national Rehabilitation Law 2001. Also, new funding options for services for persons with disabilities such as “personal budgets” were established in order to give beneficiaries more choice and strengthen their position as service users. However, the expected effect, that people with disabilities in great numbers would vote with their feet, i.e., against care in larger institutions and go for self-directed care arrangements, has not been realized. This can be attributed to bureaucratic hurdles to utilization and restraint on the part of provider organizations, but also raises the question of whether market control can replace the systematic planning and development of services (18, p. 136 f.).

Progress for more inclusive service models was achieved through local initiatives from the disability rights movement who took the impulses from the UN CRPD after its German ratification 2009 and campaigned against discrimination and for new inclusive service models also for persons with intellectual disabilities. The Federal Participation Act (Bundesteilhabegesetz, BTHG) that came into force in 2017 can be seen as another political effort to reform the services and assistance provided for persons with disabilities. The Participation Act has been constructed “in the light of UN-CRPD” and aims at putting the beneficiary at the center of service provision. It intends to overcome the parallel system of institutional and community care by prioritizing the development of inclusive services across the lifespan, e.g., for family support, for inclusive education, for supported living, or for supported employment. At the same time, the Participation Act again wants to increase the possibilities of government actors to steer service delivery processes and strengthen the position of governments in the triangular system of service provision.

Summarizing the documented reform efforts, it can be stated for Germany that the institutional cornerstones of the triangular governance structure of services for people with intellectual disabilities have remained stable over time. The inherent institutional persistence of the corporatist setting has made modernization policies difficult but has also protected the sector from neoliberal austerity policies that could have led to major cuts in the funding of services. Still, existing large institutions find themselves under continuing critique and are trying to compensate their massive legitimation deficits with various organizational strategies. However, in the last few decades, inclusive services offering support in inclusive education, supported living, supported employment, various forms of personal assistance for independent living, etc., have been established all over the country serving people with all kinds and degrees of impairments.

As has been shown, approaches for quality assurance in services based on measurement and assessment instruments have not been the motors of this overall development toward inclusion. But then, what have been its drivers and what relevance could fall on quality development approaches?

Drivers of innovations

As has been explained, the governance structure in the field of services for people with intellectual disabilities in Germany is characterized by a remarkable persistence against institutional change toward inclusive models. However, in addition to institutional care in large and small residential facilities over time, new service models have been implemented across the country that allow people with intellectual disabilities to live independently and be included in their communities. The driving forces behind this development have been very different and are not part of a consistent reform strategy. They rather result from activities in all the three angles of the social service triangle (beneficiaries, statutory welfare agencies, and service providers) with very different motivations and

---

[6] On the other hand, as being persistent against institutional change, the corporatist settings did not allow the implementation of neoliberal austerity policies that have led to major cuts in funding of services in countries with more marketized social sectors.

policies. We think the following "drivers" can be identified, which are only loosely coupled with quality.

Disability rights movement and user control

Despite many setbacks, the disability rights movement has succeeded in gaining public support for a non-discriminative policy. That has been institutionalized step by step, e.g., in a ban on discrimination against people with disabilities in the German constitution and individual entitlements for inclusive services and legal requirements for accessible environments. The disability rights movement has also had a strong impact on the support system for people with disabilities (19). This was achieved on the basis of new rights-based assumptions and philosophies on the purpose of support services with consequences for assessment and measurement of their outcomes:

As has been outlined above, over years, beneficiaries have been demanding more influence in the development and design of services, so that they allow more user control and higher flexibility with maximum self-determination. In many services that were founded in the last two decades by innovative service providers (20, p. 7), the importance of people's own home became the focus and was also developed for people with intellectual disabilities. By separating the rental relationship of a client with disability from the support relationship, the right for privacy was to be realized and maximum user control ensured. This puts structural criteria for the organization of services in the foreground, while professional considerations on quality of services become second in importance. In this perspective, professional concepts for measuring quality of life even with general indicators tend to be viewed critically because they might call the individual autonomy of persons with disabilities into question. It is believed that in weighing user control against the limitations of organizational practices, services should respect people's rights for participation and support individual lifestyles even when considered as undesirable or even risky by experts.

According to the new Participation Act, all services should enable independent living. This also sets a new orientation for the discussion on quality standards. Positive outcomes of support are not primarily to be measured by the quality of the work processes in facilities but by the facilitation of participation and independent living of persons with intellectual disabilities. Thus, the structural features of support services such as flexibility, local availability, and avoidance of dependency become more important. Moreover, when reflecting about standards, the safeguarding of user control and self-determination also become most relevant.

The conceptual assumptions of inclusive services, however, are based on individual rights but do not agree with mere market philosophies. The latter do not adequately understand the fact that services cannot be established only when an individual need is articulated, but in a welfare state, arrangements must be available as part of a public social infrastructure. This shifts the focus of the quality discussion away from the individual service organization to the development of a local service system with different services and support offers.

Government's steering by contract management and individual service planning

With all inherent contradictions, it can be stated that government welfare agencies have successfully claimed more influence and control on the provision of services in the field of intellectual disability in Germany. This development can be seen in the context of the economization of the provision of social services, which oriented policymaking toward independent living that constrained the institutional power of large care institutions and their political networks. It also offered incentives for institutional change for traditional service providers and support for new social entrepreneurs with innovative concepts.

Government actors have chosen two different approaches for this: (a) contracts with service providers and (b) individual planning procedures with beneficiaries.

Ad (a): In 1994, the national government changed the funding basis of social services supporting people with disabilities. Earlier, service providers could bill the government welfare agency for their costs after providing services, whereas since then, they must enter into a contract for a future period. The contract also contains an agreement on quality assurance measures. However, no inspection requirements were placed on the measures, and control effects remained limited. Nevertheless, it can be assumed that the use of instruments for contracting and quality assurance has contributed to increasing the transparency of the service provision.

Ad (b): Governments have started to exercise more control on the assessment of individual needs as part of the application procedure of beneficiaries for services. The aim is to ensure that person-centered assistance is granted rather than standardized care packages, e.g., a place in a group home. For this purpose, welfare agencies have developed instruments for individual service planning and such "planning procedure" (§ 117 SGB IX) has to be carried out as a compulsory part of each application procedure. For the planning procedure, an impressive list of quality criteria was specified by the legislator: accordingly, the procedure must be transparent, interagency, interdisciplinary, consensus-oriented, individual, lifeworld-oriented, social space–oriented, and oriented to individual goals.

Only the beneficiaries and statutory welfare agencies are to be involved in this process of needs assessment and service planning, while service providers are not to participate in order to avoid conflicts of interests. However, the beneficiaries can consult a person they trust, so service providers might have access to the process this way. In the case of children and adolescents, the public youth welfare agency is tob be involvedand in the case of long-term care needs the long-term insurance agency is to be involved. At the center of the procedure is a systematic needs assessment, which refers to all nine domains of life of the International Classification of Functioning, Disability and Health (ICF). On this basis, needs are identified and a plan is drawn up that is binding on service providers. In their service agreement, the services commit to aligning their support with the support plan. The implementation of the plan is monitored and updated *via* the agreed objectives.

At the time of writing, the new individual planning process has not yet been fully implemented. Many statutory welfare agencies lack qualified staff to carry out this challenging task. In practice, therefore, individual planning is often re-delegated to service providers. Also, as before the reform, service contracts with service providers are still based on standardized service packages, which often are not related to individual goals. Notwithstanding these difficulties, the implementation of the new procedures for service agreement and individual support planning has already had a significant impact on the quality discussion. Procedural questions of correctly assessing needs, setting appropriate goals, and negotiating appropriate services have become main challenges.

With regard to measuring the effectiveness of support, the individual support plan and its objectives to improve participation become the key document. The monitoring of individual objectives for equal participation implies a conceptual departure from measurable indicators of quality of life. Following assumptions of what is called the "the capability approach" (21), the purpose of reflection, given service practices, is about enabling participation in different areas of social life. It should be noted, however, that the possibilities of equal participation cannot be achieved through quality support of one service alone. Participation is possible only if the structures of the housing market, the education, and the socioeconomic system offer opportunities for equal participation at the local level.

Development of services and isomorph processes

The traditional providers of services have also taken up the reform impulses from professional debates and diversified their service structures. Almost all have now added counseling and supported living services to their portfolio. They have modernized their profile from charity organizations to social enterprises. How come? One explanation can be found in the fact that the providers of service providing organizations depend on resources from their external environment. In order to ensure that resources are continuously provided on a safe basis, service organizations are interested in meeting the expectations of other relevant actors. Such legitimation, of course, must come from government funding agencies but also from other stakeholders of the field and from the general public. As Richard Scott from the perspective of organizational sociology put it: "In institutional environments organizations are rewarded for establishing correct structures and not for the quantity and quality of their outputs" (2, p. 167). Therefore, service organizations must make sure that they are "acting on collectively valued purposes in a proper an adequate manner" (5, p. 185) which makes them sensitive for changing expectations in their environment concerning how modern services for people with intellectual disabilities should operate. Certainly, traditional care organizations will be interested in stability, in maintaining their internal power structure, and in avoiding transition cost and therefore use their autonomy to avoid change. However, when service organizations become aware that other service organizations in their field offering inclusive models gain positive attention and public recognition for reasons of legitimation, they will tend to go with their practices isomorphic in the same direction as the "successful others."

To sum up the argument, the more the inclusive paradigm in providing services for people with intellectual disabilities became hegemonial, the more even very conservative service providers were forced to change their service models. This process supported the diffusion of innovative service models, and today, it can be observed that some forms of segregating institutional facilities, i.e., large institutions or group homes, are being retained. Service providers also offer apartments for small groups of people with disabilities, for couples or individuals, where the tenancy is linked to the provider. This development must be viewed critically with regard to the requirements of the UN CRPD, especially with regard to Article 19 and its interpretation by the Committee for disabled persons of the United Nations (22). However, an altogether developmental dynamic toward decentralized flexible support services can be seen.

With regard to the quality discussion, it is significant that again the dimension of structural criteria (16) is gaining importance. Smaller units with rules that are conceptually oriented to private housing are supposed produce higher quality of services. With the shift from focusing on structures and not on processes of client–staff interaction, an improvement in the quality of life of the users is expected.

These developments, which focus in different ways on the position of users, government agencies, and service providers, are by no means free of tension to one another. What they have in common is that they shift the focus away from services as self-containing units to service systems and accessible environments. This seems to require a redefinition of what exactly should be the subject of quality assessment. When services are seen in the perspective of the UN CPRD as a part of "appropriate measures" for people with intellectual disabilities to enable participation and inclusion on an equal basis with others, the focus of assessing and developing outcomes should be widened from the single service organization to local service fields and community infrastructure. Approaches to this will be outlined in the following.

Measuring and assessing quality in a community development perspective

It can be assumed that the purpose of quality development is to improve the living conditions of people with intellectual disabilities and to further develop the day-to-day routines of service provision in a given local region. Thus, the main function of measuring the outcome of given practices is to allow a reflection on their strengths and weaknesses in order to identify steps for improvement. This needs suitable methodologies for assessment of services and of the living conditions of their clients, but it also has implications on which actors should be involved in what formats. With regard to the highly structured governance arrangements and the idiosyncrasies of local disability fields, we suggest a conceptualization of such processes as "local quality dialogues for collective learning."

In the following, three levels will be distinguished at which a new impulse for quality development can start: the individual level of enabling self-determination and independent living, the level of quality management in services, and the level of local networks and infrastructure for enabling participation. We feel that on each level such quality dialogues should be based on quality standards and indicators that allow assessment, and this assessment should be done in multistakeholder settings in which people with disabilities have a strong voice. Furthermore, quality standards and assessment procedures on the different levels should be closely coupled with mechanisms to translate recommendations into practice. Moreover, altogether, they should follow a consistent policy of raising the living conditions of people with disabilities, a policy that is coordinated by local governments.

The individual level

The quality of services for people with intellectual disabilities is determined in particular by the extent to which they allow independent living. In the German welfare state system, beneficiaries must apply for legal entitlements in order to gain access to services. While earlier the application procedure was about finding a place in an institution, the procedure now starts with assessing the will, wishes, and needs of a person. This leads to an individual support plan that forms the basis for both public financing of the service arrangement and the measurement and monitoring of its effectiveness with regard to the given objectives.

Such individual assessment procedures are very complex endeavors and need high professional expertise. Particularly when connected with diagnoses, they can cause shaming and stigmatization of people with disabilities seeking assistance. Therefore, quality criteria are needed to define how the procedures for needs assessment can be carried out in a non-discriminatory manner. Following the UN CRPD, disability can be understood as a result of interaction between people with impairments and barriers in the environment. The assessment of support needs can, therefore, no longer be based on the characteristics of a person with impairments only. It also must also consider the context factors in the environment of the person that hinder or promote active participation in all domains of day-to-day life. Therefore, quality standards and indicators are needed to relate to such procedural requirements. They should also create a basis for the joint evaluation of the given support arrangement. Furthermore, it seems necessary for improving the quality of the service provision to establish an institutional link between individual planning procedures for a person with disabilities and the development of an inclusive social environment in the given community.

The level of services

From what has been said, we argue that quality development at the level of service organizations should be based on professional standards that comply with the human rights model of disability and the prescriptions of the UN CRPD. These standards should be discussed and negotiated in a participatory manner with all relevant actors to promote ownership on compliance with the standards in use. This should also include a reflection on needs for further development of the residential service organizations themselves. For the development of suitable standards and criteria it is possible to use existing concepts and approaches (see contributions in ref. 23).

The formation of user interest groups has widely become a standard in housing services that is increasingly safeguarded by corresponding legal requirements. When establishing quality circles or evaluation teams for quality development in service organizations, the participation of users should become a standard. The assessment of practices should not be limited to internal processes within the service organization. Of course, strategic decision-making, e.g., about the future profile of the organization, will remain the preserve of management and supervisory bodies. However, participation practices and even peer evaluation by users can contribute to reproducing a segregating framework of institutions if they do not reach the level of service development.

The UN's Committee for Disabled people recommends "a strategy and a concrete plan of action for deinstitutionalization" (22, p. 11) for the development of service organizations in the direction given by Article 19 UN CRPD. Such action plans for continuous inclusive development of services are to be developed in a participatory way. This can become a part of structural quality management of services. This would shift the focus of quality assurance to overcoming segregating practices in residential facilities for persons with disabilities. Experiences show that quality measurement activities focusing only on single services probably soon reach their limits. The main quality criteria are, when single services understand themselves as part of a regional network of support services and locate their activities in the context of a coordinated effort to develop inclusive communities. In the US context, some decades ago, similar ideas were discussed under the term "communitization" (24).

The level of local support networks and infrastructure

A self-determined life is realized in social relationships. The accessibility and usability of the local social environment is of particular importance when people have to cope with disabilities and major social dependencies. Their locality with its very concrete conditions is where participation in everyday life, in education, in leisure time, or in employment is realized. This is also true even when decisions about, e.g., education systems or inclusive labor markets are made at other levels. Since some time, it can be observed that the use of digital media and assistive technology is becoming increasingly important for social participation. Gaps in digital participation lead to new social divisions with high risks for people with intellectual disabilities (25).

In Germany, there is a widely developed legislation regulating support services for people with disabilities in the form of Social Code Book IX. However, these contain only weak specifications for the planning of service systems at the local level. While in many municipalities and districts local action plans exist to develop accessibility and inclusive infrastructure, this is still not well linked to the field of disability services. However, both the accessibility and usability of the physical infrastructure and the accessibility of digital technology are critical for inclusion and full participation of people with disabilities. Quality standards for a local infrastructure that enables people with disabilities to live self-determined lives should relate to the following aspects:

- Appropriate housing, educational and employment opportunities, and recreational activities to meet diverse needs without discrimination.
- The accessibility of public space for all.
- Self-advocacy and support groups to represent interests in the community.
- Counseling services, including peer counseling, to assist in organizing an independent living in all areas of life.
- Decentral organized services for support in everyday life.

With these standards, the focus of quality discourse changes. It is not only the quality of a single service that is relevant for opportunities to live a self-determined life included in society but the structures and living conditions in the community. This brings local governments in an important position as they represent the political level closest to the citizen and are responsible for providing quality services and inclusive infrastructure in their territory. Systematic planning processes at the community level that are coordinated by local governments become a central quality requirement for the implementation of a rights-based approach for disability services. This also refers to the United Nations' Sustainable Development Goals where Goal 11 calls to "Make cities and human settlements inclusive, safe, resilient and sustainable" (https://sdgs.un.org/goals/goal11).

There is already knowledge and practical experience on the methodologies that can be used to assess and develop the quality of services and local infrastructure in the context of inclusive community planning (26, 27).

Conclusion

As we have shown, the governance structure in the field of services for people with intellectual disabilities in Germany is characterized by a remarkable persistence against institutional change toward inclusive models. However, in addition to institutional care in large residential facilities, over time, new service models have been successfully implemented across the country that allow people with intellectual disabilities to live independently and be included in their communities. Approaches for quality assurance in services based on measurement and assessment instruments have not been the motors of this development toward inclusion. Rather, the driving forces behind this development stem from activities in all the three angles of the social service triangle (beneficiaries, statutory welfare agencies, and service providers), but they were not part of a consistent reform strategy. This does not mean that approaches for quality assessment are generally regarded as ineffective, but we suggest a widening of their focus from single services to local service fields and inclusive infrastructure. With regard to the highly structured governance arrangements in Germany and the idiosyncrasies of local disability fields, we also suggest a conceptualization of quality assessment as "local quality dialogues for collective learning." These local dialogues should be initiated on three levels: (a) the individual level of enabling self-determination and independent living, (b) the level of quality management in services, and (c) the level of local networks and infrastructure for enabling participation. When developing standards and indicators for assessing the quality of a given local situation, we argue that with reference to Donabedian's model, the dimension of "structures" is crucial if person-centered support arrangements are to be realized.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, Further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for this study in accordance with the local legislation and institutional requirements.

Author contributions

All authors contributed to the article and approved the submitted version.

Funding

The publication fee will be covered by the University of Minnesota.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Powell WW, DiMaggio Paul J. *The new institutionalism in organizational analysis*. Chicago: Univ. of Chicago Press (1991). 478 p.

2. Scott RW. Unpacking institutional arguments. In: WW Powell, J DiMaggio Paul, editors. *The new institutionalism in organizational analysis*. Chicago: Univ. of Chicago Press (1991). p. 164–82.

3. Schädler J. *Stagnation oder Entwicklung in der Behindertenhilfe? Chancen eines Paradigmenwechsels unter Bedingungen institutioneller Beharrlichkeit*. Hamburg: Kovac (2003).

4. DiMaggio PJ, Powell WW. The iron cage revisited: institutional isomorphismus ans collective rationality in organization fields. In: WW Powell, J DiMaggio Paul, editors. *The new institutionalism in organizational analysis*. Chicago: Univ. of Chicago Press (1991). p. 63–82.

5. Powell WW. Expanding the scope of instituional analysis. In: WW Powell, J DiMaggio Paul, editors. *The new institutionalism in organizational analysis*. Chicago: Univ. of Chicago Press (1991). p. 183–203.

6. Bradl C. Anfänge der Anstaltsfürsorge für Menschen mit geistiger Behinderung ("Idiotenanstaltswesen"): Ein Beitrag zur Sozial- und Ideengeschichte des Behindertenbetreuungswesens am Beispiel des Rheinlands im 19. Jahrhundert. Frankfurt/M (1991).

7. Klee E. *"Euthansie" im NS-Staat: die "Vernichtung Lebensunwerten Lebens"*. Frankfurt a.M.: Fischer (1985).

8. Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege (BAGFW). Einrichtungen und Dienste der Freien Wohlfahrtspflege: Gesamtstatistik 2016. Berlin (2018).

9. Kugel RB, Wolfensberger W, editors. *Changing patterns in residential services for the mentally retarded*. Washington, DC: University of Nebarask College of Medicine (1969).

10. Cremer G, Fink F. Bundesteilhabegesetz: stehen wir vor einer ordnungspolitischen wende. *Nachrichtendienst des Deutschen Vereins*. (2015) 95:353–7.

11. Schädler J. Qualitätsentwicklung und Qualitätssicherung - Plädoyer für ein professionsnahes Konzept in der Sozialen Arbeit. In: J Schädler, N Schwarte, A Trube, editors. *Der Stand der Kunst: Qualitätsmanagement sozialer Dienste: Von grundsätzlichen Überlegungen zu praktischen Ansätzen eines fach- und adressatenorientierten Instrumentensets*. Münster: Votum (2001). p. 13–38.

12. Wolfensberger W, Thomas S. *PASSING a tool for analyzing service quality according to social role valorization criteria. Ratings manual*. Syracuse, NY: Training Institute for Human Service Planning (2007).

13. Flynn R. Normalization, PASS and service quality assessment. In: R Flynn, editors. *Normalization, social integration, and community services*. Baltimore: University Park Press (1980). p. 323–62.

14. Gromann P, Niehoff U. Selbstbestimmung und qualitätssicherung. *Geistige Behinderung*. (1999) 39:156–67.

15. Schwarte N, Oberste-Ufer R. *LEWO II: Lebensqualität in Wohnstätten für erwachsene Menschen mit geistiger Behinderung - ein Instrument für fachliches Qualitätsmanagement*. Marburg: Lebenshilfe-Verl. (2001). 524.

16. Donabedian A. *The definition of quality and approaches to its assessment*. Ann Arbor, Mich.: Health Administration Press (1980). 163.

17. Schädler J. *Qualitätssicherung und Organisationsentwicklung in Einrichtungen und Diensten für Menschen mit geistiger Behinderung*. Marburg: Lebenshilfe - Verlag (1999).

18. Bundesarbeitsgemeinschaft für Rehabilitation (BAR). Trägerübergreifende Ausgabenstatistik der BAR. Reha-Info (2021).

19. Köbsell S. Towards self-determination and equalization: a short history of the German disability rights movement. *Disabil Stud Q*. (2006) 26. doi: 10.18061/dsq.v26i2.692

20. Degener T. *Personal Assistent Service Programs in Germany, Sweden and the USA* (1992). 63 p. https://files.eric.ed.gov/fulltext/ED347720.pdf

21. Nussbaum MC. *Frontiers of justice: disability, nationality, species membership*. Cambridge, Mass: Belknap Press of Harvard Univ. Press (2007). 487 p.

22. UN-Committee on the Rights of Persons with Disabilities. General comment No. 5 (2017) on living independently and being included in the community. Geneva (2017). Available at: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx (Accessed Apr 13, 2019).

23. Siska J, Beadle-Brown J. *The development, conceptualisation and implementation of quality in disability support services*. Prague: Karolinum Press (2021). 344.

24. Hogan MF. Normalization and communitization. Implementation of a regional, community integrated service system. In: RJ Flynn, KE Nitsch, editors. *Normalization, social integration, and community services*. Baltimore: University Park Press (1980). p. 283–99.

25. Lussier-Desrochers D, Normand CL, Romero-Torres A, Lachapelle Y, Godin-Tremblay V, Dupont M-È, et al. Bridging the digital divide for people with intellectual disability. *Cyberpsychology*. (2017) 11. doi: 10.5817/CP2017-1-1

26. Rohrmann A, Schädler J, Kempf M, Konieczny E, Windisch M. *Inklusive gemeinwesen planen*. Düsseldorf: Eine Arbeitshilfe (2014).

27. Schädler J, Wissenbach L. The role of local planning in the implementation of the UNCRPD. In: J Siska, J Beadle-Brown, editors. *The development, conceptualisation and implementation of quality in disability support services*. Prague: Karolinum Press (2021). p. 313–28.

Frontiers in Rehabilitation Sciences

TYPE Review
PUBLISHED 01 February 2023
DOI 10.3389/fresc.2023.1056530

OPEN ACCESS

EDITED BY
Brendan McCormack,
The University of Sydney, Australia

REVIEWED BY
V TY,
Queen Margaret University, United Kingdom
Di Yan,
University of Rochester Medical Center,
United States
Parthenia Dinora,
Virginia Commonwealth University,
United States

*CORRESPONDENCE
Matthew A. Roberts
✉ robe0290@umn.edu

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 28 September 2022
ACCEPTED 10 January 2023
PUBLISHED 01 February 2023

CITATION
Roberts MA and Abery BH (2023) A person-centered approach to home and community-based services outcome measurement.
Front. Rehabil. Sci. 4:1056530.
doi: 10.3389/fresc.2023.1056530

A person-centered approach to home and community-based services outcome measurement

Matthew A. Roberts* and Brian H. Abery

Institute on Community Integration, Rehabilitation Research and Training Center on HCBS Outcome Measurement, University of Minnesota, Minneapolis, United States

In the United States, over 2.5 million people with disabilities are recipients of supports through the Center for Medicare and Medicaid Services (CMS) Home and Community-Based Services (HCBS) program. Recent decades have seen a growing focus on providing HCBS in a person-centered manner thereby supporting outcomes that are both important *for* and *to* the person. HCBS outcome measurement, however, has not kept pace with advancements in person-centered thinking as it relates to providing supports to people with disabilities. The concept of person-centered outcome measurement has been inadequately defined and is frequently misunderstood including by those in the measurement field. The authors first operationally define person-centered measurement and establish its importance within the context of HCBS and the recent CMS's Final Settings Rule. The important role that person-centered measurement has to play in quality improvement efforts in this area is then explored. A discussion is subsequently provided as to the challenges that are faced in person-centered measurement specific to the disability field. In addition to further conceptualizing and defining this form of measurement, recommendations are provided for moving the field forward.

KEYWORDS

HCBS, outcome measurement, measure development, person-centered analysis/approach, person-reported outcome, home and community-based services, person-centered measurement

Introduction

Over 2.5 million people with disabilities in the United States receive Home and Community-Based Services (HCBS) through the Centers for Medicare and Medicaid Services (CMS) Long-Term Services and Supports (LTSS) program (1). The program is intended to support people with disabilities living in more inclusive settings that offer greater access to and integration within the community. Enrollment and HCBS program spending has increased significantly over recent decades as more people with disabilities prefer receiving support in their community in place of institutional settings (1). Unfortunately, in far too many cases HCBS results in a person living physically within the community but failing to experience being part of the community in a psychological and social sense [e.g. (2–4),].

The Medicaid program, including HCBS is jointly funded by the federal government and states. The federal government provides approximately fifty-six cents for every Medicaid dollar spent with states providing the balance (5). Because states are required to partially fund HCBS, they are allowed a significant amount of flexibility in how they design and administer HCBS programs. This includes the capacity to determine, (1) *who* to cover (i.e., target populations, eligibility criteria), (2) *what* to cover (a variety of waiver benefit packages), (3) *how services are delivered* (e.g., self-directed supports, through Managed Care Organizations (MCOs), and (4) *how providers are reimbursed*. Unlike Medicaid, HCBS waivers allow states to both choose and limit how many people are served under each waiver and which services are covered for which populations. Although HCBS programs vary significantly between states, some of the most common populations eligible for services include people with intellectual and developmental disabilities (IDD), physical disabilities (PD), psychiatric disabilities (psychD), traumatic and acquired brain injury (TBI/ABI), and age-related disabilities (ARD). The ability of states to limit HCBS waiver enrollment has resulted in extremely long waiting lists in most of the country because the number of people seeking services far exceeds the number of waiver slots available (6). Home and Community-Based Services are further complicated because of the extremely diverse and varied support needs of HCBS recipients. Supports range from those that are limited to periods of transition or a single context to services needed on a continuous basis. This has led states to develop and implement a wide variety of programs, services, and supports, aimed at meeting the unique support and service needs of the populations served.

As a result of the variety of programs and diversity of recipients, measurement of the quality of supports that the recipients of HCBS receive and the outcomes these individuals experience is far from a simple process. A nuanced approach needs to be taken that is responsive to a wide variety of personal and contextual factors. This process needs to be decidedly different than that currently used in medical/healthcare contexts due to the dissimilarities in the constructs measured. Unlike many outcome measures related to health (e.g., the number of urinary tract infections or falls experienced by a person, blood pressure, etc.) outcomes associated with HCBS (e.g., the extent to which people with disabilities experience a sense of social connectedness) are both more complex and difficult to assess. A second set of critical contextual factors for which one needs to account are the policies and regulations under which HCBS is implemented which vary significantly between states in the U.S.

In 2014 CMS published the Final Settings Rule for HCBS; thereby, establishing a set of requirements for the qualities that needed to be in place for HCBS settings to be eligible for reimbursement through CMS under sections 1915(c), 1915(i) and 1915(k). The provisions established an outcome-oriented definition of home and community-based services that firmly supports the self-determination and choice of recipients. Through their emphasis on person-centered services and supports, as well as service plans developed through a person-centered approach, the regulations require that planning processes reflect individually identified needs, goals, and preferences. Additionally, it strongly supports the achievement of the unique desired life outcomes of each HCBS recipient. Since its initial publication eight-years ago, states have been granted a number of extensions with respect to the date when they are required to be in compliance with the Final Settings rule. At this time, the deadline has been established as March 17, 2023. After this point, federal reimbursement for HCBS providers will be contingent on their compliance with the Settings Rule and the provision of services in a truly person-centered manner.

Long before implementation of the Final Settings Rule (7), the focus of home and community-based services had begun to move away from custodial-like care to the provision of supports that reflect the uniqueness and desired life outcomes of the recipients of support. No longer is it sufficient to focus services on what's important *for* the person. Rather, supports must reflect *both* what is important *for* and what is important *to* the person (8). For decades, states and providers have been increasing efforts to design services to be more person-centered. The State of Minnesota (U.S.) Department of Human Services, for example, has over the past 5-years funded a program of "person-centered thinking and planning" education for HCBS providers from across the state. The goal of this program is to equip provider agencies with the knowledge and tools necessary to plan and provide services in a person-centered manner while meeting the requirements of the Final Settings Rule.

In addition to the CMS/HCBS system's move toward person-centered service provision, there are legal and compliance motivations within the HCBS environment that support the need for measurement that is person-centered. In 1999 the U.S. Supreme Court ruled in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constituted discrimination and was in direct violation of title II of the Americans with Disabilities Act. Under the Olmstead decision (9), states in the U.S. are now obligated to provide services for people with disabilities in the most inclusive community settings possible as well as support them to achieve desired life outcomes. In many states, obligations under the Olmstead decision continue to be monitored by court-appointed staff to ensure that progress is being made with respect to outcomes. To fully measure the effectiveness of programs that provide services and supports in meeting Olmstead requirements, a person-centered approach to measurement is needed. The approach needs to emphasize the degree to which the outcomes experienced by HCBS recipients match their needs and preferences and move them forward in achieving desired life outcomes.

This article is intended to correct misconceptions that many professionals in community living have about person-centered measurement, discuss the need for a person-centered approach to measurement in this area, and review the strengths and limitations of existing as well as person-centered approaches to measurement in the field of home and community-based services. Information regarding the development process that staff at the RTC/OM are using is provided to supplement the discussion and provide readers with a general idea as to a process that could be used to move in this direction.

The need for new approaches to HCBS outcome measurement

There has been great interest in assessing the outcomes of HCBS recipients over the past twenty-years. During this period, The Human Services Research Institute's *National Core Indicators*, the Center for Quality Leadership's *Personal Outcome Measures*, and the CAHPS Home and Community-Based Services Survey have all been developed and are being used by both states and support providers as one means through which to demonstrate compliance with CMS regulations. Each of these approaches has its strengths. However, all have significant limitations that lead to the need to develop new measurement approaches that address these shortcomings.

The *National Core Indicators (NCI and NCI-AD)* is currently the most widely used tool in the U.S. for the assessment of outcomes associated with the receipt of home and community-based services. The instrument was developed and validated as a state-level compliance measure and not intended to be used at the provider or individual level for quality improvement, service plan development, and/or outcome assessment. Although the NCI includes indicators in a variety of areas, it is intended to be administered (and was validated) at the instrument level as opposed to on an indicator-by-indicator basis. Users are therefore required to administer items related to all indicators as opposed to only those in which there is a specific interest. It should also be noted that although NCI and NCI-AD have been used with populations beyond those for which they were intended (i.e., people with IDD, physical, and age-related disabilities) these tools have only been validated for use with the limited disability groups noted. In addition, research has indicated that while some NCI indicators hold together well psychometrically (10), others do not (11).

CQL's *Personal Outcome Measures* (12) although one of the better developed and validated HCBS Outcome tools is part of a commercially available system of assessment and quality improvement. It has been validated with a much wider variety of people with disabilities than the NCI and possesses good psychometric properties. However, the instrument is time-consuming with respect to administration (715 items; 12) limiting its feasibility for many providers. In addition, the CQL-POM, as part of a quality improvement package, is quite expensive to use with onsite administration training alone costing $7,000.

A third approach to outcome assessment in the human services field that has recently been championed by the Center for Medicaid and Medicare Services is the *HCBS CAHPS Survey*. This CAHPS is a questionnaire with 69 core items developed for measuring the experiences of people with disabilities who are HCBS recipients. The CAHPS, unfortunately, currently has limited data available with respect to its validity or reliability. Internal consistency reliabilities for seventeen of its nineteen measures fail to meet even the most basic criteria for psychometric acceptability, there are serious questions about the representativeness of the sample used for the field study as well as the evidence presented to support validity, and in a number of indicator areas, there appears to be a ceiling effect with the overwhelming majority of respondents indicating the highest possible level of service quality or personal outcomes (13).

In addition to the individual shortcomings of the most widely used HCBS outcome measures, there are three additional limitations that cut across the instruments noted above as well as other outcome assessment tools that contribute to the need for development of new measurement approaches. The first of these entails the relatively small percentage of items included in most HCBS outcome measurement instruments that meet the criteria for person-centeredness. A recent study of 140 outcome measures used with HCBS populations (14) found that only 36% of the items included in these tools were person-centered in nature. Although some outcome measures (e.g., the CQL-POM) are more person-centered than others, the overall results of this study clearly indicate the need for approaches to assessment that place greater priority of assessing outcomes within the context of what is most important to individual persons with disabilities. Overall, measurement of the extent to which HCBS recipients experience *person-centered outcomes*—outcomes that go beyond compliance and include assessment of what is important to the person, has lagged far behind the push for person-centered services. Providing person-centered services, however, is incompatible with measurement that does not consider an individual's desired life outcomes.

A second shortcoming that cuts across tools is the lack of evidence that they are sufficiently sensitive to change over time that they can be used in a longitudinal manner. Some developers, such as HSRI (NCI) explicitly state that their measures are not intended to be used longitudinally. Others (e.g., CQL, CAHPS) have yet to provide evidence that, when used in a longitudinal manner, their measures are sufficiently sensitive to change that they can be used as evidence of the effectiveness/efficacy of quality improvement efforts or changes that take place in a HCBS recipient's life. A third reason to think about the development of new approaches to outcome measurement in HCBS emanates from the resources needed to administer measures at a time when the human services field is experiencing serious workforce shortages. All of the tools referenced above are intended to be administered in their entirety as full instruments. They are neither modular in format allowing for administration focused on only one or a few indicators, nor tiered and able to provide both a quick general overview of indicators as well as a more in-depth assessment.

The Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM) at the University of Minnesota, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), was created for the purpose of improving HCBS outcome measurement in the United States. The center has conducted its work in multiple phases beginning with the selection and conceptualization of several measurement domains for the development of person-centered measures and, in later phases, the testing and validation of those measures. A key part of the process in completing the RTC/OM phases has been defining person-centered measurement and executing a process for developing and validating person-centered measurement tools.

Person-centered HCBS outcome measurement tools are essential for acquiring valid information regarding both the extent to which the services provided to people with disabilities are truly person-centered *and* the extent to which these supports foster the achievement of person-centered goals. When this form of measurement is not used, the information collected yields data solely with respect to the extent to which the person's experiences are aligned with benchmarks defined by someone other than the individual with a disability. This form of "non-person-centered measurement" and the benchmarks on which it is based assumes that, unlike the general population, all people with disabilities desire the same life outcomes with respect to employment, education, housing, and social relationships. This assumption must be argued to hold regardless of differences in the cultural, racial/ethnic, and gender make-up of the people in question as well as variation in the types of disability they experience or their level of support needs. Previous research, however, suggests that these assumptions are not supported and that future aspirations as well as how people define their quality of life are as varied as within the general population (15–18). A number of researchers (16, 19–

21) therefore suggested some time ago that tools need to be developed that rely less on generalized outcome measures and consider both the unique profiles of people with disabilities and the social and environmental factors that influence the outcomes they both desire and experience.

Much of today's focus on outcome measurement is driven by the need of program administrators and federal and state agencies to have evidence of the impact of HCBS on the outcomes that the recipients of services experience. This is to both demonstrate compliance with current regulations and support continued congressional funding of HCBS programs. Given the Final Settings Rule (7) it is critical to collect and share data with funding agencies that demonstrate the extent to which HCBS are supporting person-centered outcomes associated with the full inclusion in the community. It is also essential that measures are available to track how policy changes, as well as efforts at quality improvement, assess the extent to which services are provided in the manner intended (e.g., program fidelity) and produce better outcomes. In the remainder of this article, we explore the concept of person-centered measurement within the context of HCBS, how it can be operationalized, the challenges with using this approach, and strategies that can be used to develop measures that achieve this measurement pre-requisite.

The concept of person-centeredness

The concept of person-centeredness has existed for decades and can be traced back to Carl Rogers [e.g., (22, 23)]. Fundamentally, person-centeredness posits that the person has the greatest understanding of themselves, and a full appreciation and involvement of the person is necessary to achieve successful outcomes (23). Over the past forty-years the field of disability services has evolved to include person-centeredness in the areas of planning, service delivery and coordination, outcomes, and assessment. Person-centered practice emerged in the United States during the early 1980s as people with IDD transitioned from institutional to community-living. With this came the need for individualized service plans to fit the needs of each person living within the community based upon their preferences and desired life outcomes (24, 25). Recent decades have also seen the parallel development of patient-centered models in health care [e.g., (26–28)]. CMS has pivoted to support the incorporation of person-centered planning and practices into disability support systems (i.e., HCBS, LTSS) including recent efforts by a national stakeholder committee to further define person-centered planning and practices, generate core service delivery competencies in the area, and develop compatible measurement frameworks (29). As the sophistication of person-centered practices have increased, even more attention is needed toward measuring whether the services result in the outcomes that are important to individuals.

Person-centeredness as we define it is essential to treating people with disabilities with fairness and equity. The Convention on the Rights of Persons with Disabilities (30) asserts the right of every person with a disability to live and enjoy their life on an "equal basis with others" (article 10) as fully included participants in society. This includes the right to personal self-determination. In the United States, the HCBS Settings Rule (7) requires that people with disabilities receives support and services that are provided in ways that are based on their personal preferences and assist them in achieving desired life outcomes. This includes the right to choose where one will live and with whom; if and in what type of job one will work, as well as the types and limits of the supports one receives. Environments and the professionals providing supports must promote the individuals having control over day-to-day choices including the kinds of support they will receive (31). The purpose of this rule is to ensure HCBS are provided in a manner that promotes both community inclusion and self-determination and is delivered based on what is important to each individual, rather than asking people to adapt or compromise based on what is most convenient or available within the system. This focus on ensuring that each person has opportunities to make meaningful choices about support to be received and about his/her life, is in keeping with both the CRPD (30) and the rallying call of people with disabilities who have for years been stating, "nothing about us, without us."

The changes noted above are grounded in a paradigm shift in the field of disability services from a *medical model*, which focuses on somehow changing or "fixing" people with disabilities so that they will better fit into the existing society, to a *social-ecological model* of disability, which shifts the onus to creating environments that best accommodate people with disabilities with the intent that they experience life as full members of the community. This paradigm shift requires that HCBS be individualized to address what is important both *to* and *for* each person with a disability, rather than designing service systems that assume that all people with disabilities desire to experience the same or similar life outcomes. This paradigm shift demands that tools designed to measure the effectiveness or quality of HCBS must be person-centered and based on the needs and preferences of each individual serving as the benchmark to which we compare experienced outcomes. For example, the idea that all people with disabilities desire to have a large number of friends and that more friends is a *better* outcome than fewer friends may reflect the preferences of some but certainly not all, people with as well as without disabilities. Some people may feel socially connected to their communities if they have a few close friends. For others, however, a larger number of social relationships will be necessary. Person-centeredness is paramount to ensure both equality and equity with respect to outcomes whether one is considering national or international policy and regulations.

Delivering supports in a person-centered manner requires a responsive service system. It changes the way services are delivered from a top-down approach in which the consumer receives supports according to parameters defined by state and federal agencies funding those supports, to a more bottom-up approach in which the parameters are more flexible and based on the individual needs and preferences of people with disabilities. This process begins with people with disabilities effectively communicating their desired life outcomes and subsequently advocating for supports designed to help them achieve these ends. At a second level, it entails staff or caregivers who directly work with the recipients of services and understand their needs and desires ensuring that service plans and day-to-day supports are directed at facilitating people with disabilities achieving these outcomes. Beyond this, it extends to the leadership of service provider's and the extent to which they support and enable staff to provide person-centered supports. At the uppermost level it extends to government systems that regulate and fund the provider agencies. A similar paradigm shift has taken place in the United States educational system in which there has been a move away from schools dictating educational plans for students with disabilities in favor of the student, family, and school becoming partners in creating an educational plan and determining the best supports for the student.

The concept of person-centered supports is not focused on each person experiencing every outcome they desire. Rather, it focuses on the extent to which a person's desired life outcomes are heard and acknowledged by their planning team, included in their service plan, and efforts made to make progress toward them. Making supports truly person-centered also requires ongoing assessment of the support recipient's preferences, personal goals, needs, and progress/outcomes since these are likely to change over time, as well as a willingness at the provider level to change policies when necessary and adjust services to support the individual in pursuit of their personal goals.

Person-centered measurement

Despite decades of research defining the person-centered concepts, the concept of *person-centered measurement* has not been well defined or understood. Consequently, measure developers have struggled with identifying exactly what makes a measure or item person-centered. Historically, at least in western cultures, measurement has focused on comparing the performance or experiences of a target person to benchmarks or the performance or outcomes experienced by other people (i.e., the norming group). This approach makes sense and works well when one is measuring outcomes against which there is a known performance criteria or standard that one desires to see a person attain (a benchmark) or it is important to determine an individual's performance relative to a larger group (norm-referenced). For example, in the healthcare field, person-centered practice frameworks [e.g., (27, 28, 32)] have established standards that can be used to compare achieved outcomes against.

In some cases, however, there are no real standards against which to measure a person's outcomes or performance other than the extent to which they meet the individual's desired outcomes and personal needs. We argue that this is the case when one's focus is on measuring the outcomes people with disabilities who receive home and community-based services experience. In these instances, the "standard" against which to compare outcomes or experiences needs to be based on the service recipient's personally defined preferences or goals—not those that other people or the service system sets for them.

In the context of measuring outcomes associated with people who receive HCBS, we contend that for measures to truly be person-centered they meet a number of specific criteria. This is not intended to imply that all HCBS quality measures need to be person-centered. For example, some indicators of workforce characteristics would not make sense to design in a person-centered manner. Rather, we believe that attention in this area needs to be focused on measures of the personal outcomes that people with disabilities desire to experience when they are recipients of HCBS.

From their conceptualization, person-centered HCBS outcome measures need to be designed with the intent that they will be responded to by people with disabilities themselves. Although informed respondents can often provide valuable information with respect to another person's experiences, being able to accurately articulate what another individual believes they need, outcomes they desire to experience, and/or the degree to which they view themselves as making progress toward achieving those outcomes is a difficult task. Previous research indicates that most people have a difficult time understanding how others experience their world, what they desire, or when they are satisfied with the outcomes they experience [e.g., (33–37)]. Designing measures so that they can be directly responded to by people with disabilities themselves places a heavy responsibility on developers that measures are designed so that they (a) are clearly understood by the intended respondents; (b) based upon a time frame that respondent can conceptualize; (c) provide response options that accurately reflect an individual's experiences; and (d) are able to be responded to in a manner that permits people to indicate the extent to which the outcomes they are experiencing align with their desired level of the outcome or indicate progress. For example, although an item that asks a respondent how many hours per-week they work provides some useful data, asking that question and following-up with, "To what extent are you working the number of hours you desire to work?" has the potential to provide more person-centered information.

A second critical aspect of person-centered measurement is its focus on outcomes that are *both important for* and *important to* HCBS recipients. Six years ago, the National Quality Forum utilized an expert panel to develop recommendations for the inclusion and prioritization of domains to address performance measure gaps in HCBS outcome measurement (38). On the basis of their work, the NQF developed a framework of eleven core domains each of which included 4–7 subdomains reflecting HCBS quality. As part of a multi-year center, the University of Minnesota's Rehabilitation Research and Training Center on Home and Community-Based Services Outcome Measurement (RTC/OM) undertook a national validation study of the framework with stakeholders representing multiple groups including people with a variety of disabilities (IDD, PD, TBI/ABI, PsychD, Age-Related), family members, HCBS providers, and state and national level program administrators. Results indicated strong support for the framework as well as some needed refinements (39). This refined framework (see **Figure 1**) includes a myriad of outcomes that require measurement at a person-centered level. However, the developers of new measures as well as the majority of currently available HCBS outcome measures all too often assume that achieving desired life outcomes in all domains and subdomains are of equal importance to people receiving supports. Given differences in people's preferences and the limited resources available within the HCBS system, an approach which weights outcomes with respect to their *importance to the individual* needs to be incorporated if we are to achieve truly person-centered

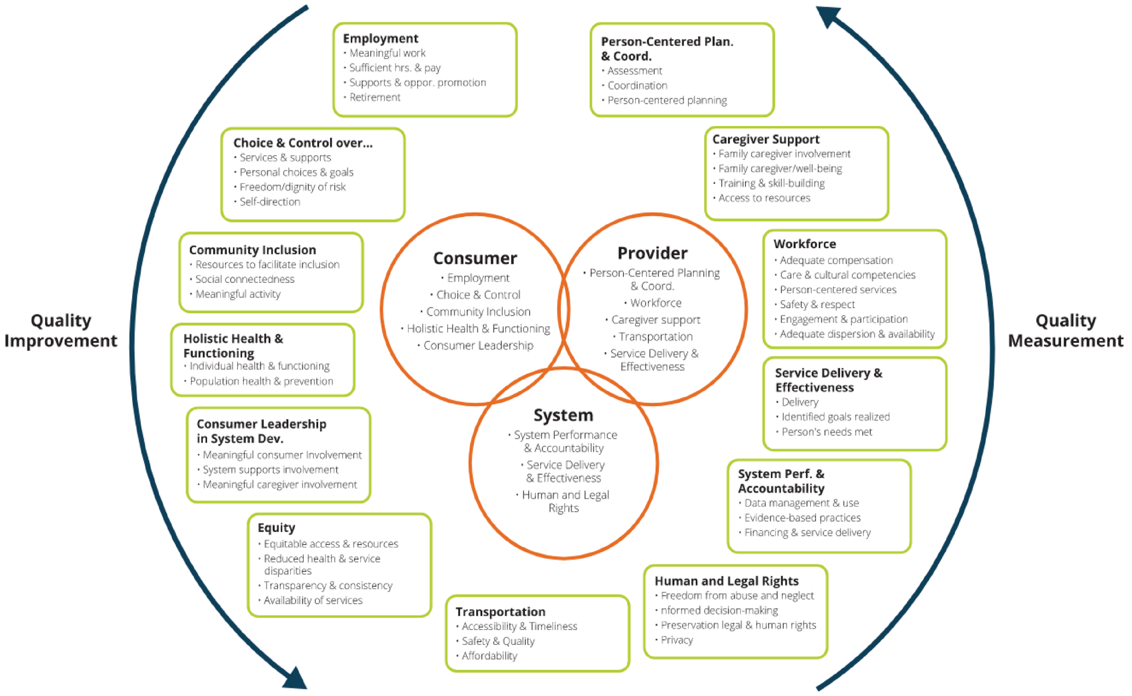


FIGURE 1
Revised national quality forum HCBS outcome measurement framework training and training center on home and community-based services outcome measurement (RTC/OM), a systematic search of HCBS outcome measures was undertaken and over 200 instruments reviewed for inclusion into a database of HCBS outcome measures. The items for each instrument were coded into the domains and subdomains included in the NQF framework and for a number of other characteristics including whether they met the criteria for being person-centered. To be coded as "person-centered" an item needed to meet two simple criteria: (a) be designed to be responded to by the person with a disability or when a direct response was impossible, a proxy; (b) enable the responding person to express a preference, desire, need, want, or the extent to which these have been met (see https://rtcom.umn.edu/database). Table 1 summarizes the percentage of items coded as "person-centered" for relevant NQF domains.

measurement based upon the unique needs and desired life outcomes of each individual.

A third criteria that we believe is essential for person-centered systems of measurement are their capacity to be used in a longitudinal manner. Given that such systems would be developed with the intent to focus on measuring the extent to which HCBS recipients are progressing toward or achieving their desired life outcomes, suitability for longitudinal use and sensitivity to change over time will be critical characteristics of the system. Current approaches to HCBS outcome measurement are primarily cross-sectional (i.e., the outcomes/experiences of a different set of respondents are assessed every year). As a result, one needs to make many assumptions with respect to the year-to-year representativeness and comparability of samples in order to interpret results. As a result, interpretations of improvement/progress toward outcomes on the part of individuals are not possible and systems improvement is only able to be made in an indirect manner. Although measurement systems of this type do provide important information (e.g., compliance with state and federal regulations) they leave much to be desired as instruments of quality improvement.

Given the criteria specified, what is the extent to which measures currently used to assess the outcomes of HCBS recipients are person-centered? As part of the Rehabilitation Research.

The table indicates that the majority of items that could be coded into an HCBS outcome domain did not meet the established criteria for being person-centered. To illustrate, one recently developed tool is the CAHPS Home and Community-Based Services Survey (40). A total of 87 items were coded into various domains of the NQF framework, but only 10 of these items were coded as person-centered (41). During a follow-up effort, seven states were identified as using this tool for outcome measurement in HCBS programs (42).

TABLE 1 Percentage of items coded as person-centered by NQF domain.

NQF domain	Items coded	% PC
Choice and Control	1,144	49.7%
Community Inclusion	1,757	31.8%
Equity	86	30.2%
Holistic Health and Functioning	1,129	34.1%
Human and Legal Rights	543	23.8%
Person-Centered Planning and Coordination	524	47.3%
Service Delivery and Effectiveness	784	32.4%
Across all Domains[a]	*5,275*	*34.6%*

[a] Overall sum and percentage exclude items coded into two or more domains.

In addition to people with disabilities, there are several other stakeholder groups that would benefit from the expansion of person-centered HCBS outcome measurement. Families, together with their member with a disability could use this information to better determine which provider organizations they desire to provide supports as well as to ascertain whether the services their member with a disability receives are facilitating progress toward or the achievement of desired life outcomes. Service providers would also profit from this information utilizing it to help determine if programmatic and policy changes intended to improve service quality have been successful and to assess whether supports are meeting recipients' needs. Managed Care Organizations (MCOS) which are increasingly administering HCBS in the U.S. are another stakeholder group that would benefit from access to psychometrically sound person-centered measures. Such measures would be useful for providing information about the extent to which individual providers within the MCO network are delivering services that result in person-centered outcomes and use this information to both select additional HCBS provider agencies and potentially incentivize those that are facilitating personal outcomes of HCBS recipients that are consistent with the Centers for Medicaid and Medicare Services Final Settings Rule (7).

Person-centered measurement and goal attainment scaling

It is our belief that HCBS outcome measurement should have a prime focus on quality improvement. Therefore, the ability to track the extent to which the services HCBS recipients receive support their making progress toward achieving desired life outcomes over time is essential. This requires measures that can be used on multiple occasions with the same respondents. Such measures need to be sufficiently sensitive to change across time that they are able to detect meaningful differences in a person's experiences, outcomes, and goal attainment within relatively short periods (e.g., 6–12 months). To achieve this level of measurement, developers need to be sensitive both to the manner in which items are worded and the response options that respondents are provided. The former corresponds to developing items that are sufficiently specific so that change can be detected over short periods. The latter focuses on providing those with whom measures are being used with options for responding that allow them to indicate meaningful change in their lives. One approach that we believe responds to this need is the use of *Goal Attainment Scaling* (GAS).

Goal Attainment Scaling (GAS) is a method for writing personalized evaluation scales (43) in order to quantify progress toward defined goals. Developed over 50-years ago, this approach to measurement is attracting growing interest, especially within the context of intervention and clinical research because it permits the efficacy of treatments to be assessed with respect to goals set by the clients themselves. Although GAS was initially used primarily within the health-related rehabilitation fields for people with physical disabilities and in rehabilitation psychology (44, 45), recent years have found it increasingly used as an outcome measure for people of all ages with a wide variety of functional limitations including adults (46–52), aging adults (53, 54) children in clinical and special education settings (55–62), infants (63) and with parents of children with disabilities (64).

Most recently, Shogren and colleagues (65) have made the case for the use of Goal Attainment Scaling in research focused on determining the efficacy of interventions for people with intellectual and developmental disabilities. She and her colleagues contend that the use of this approach: (a) supports the need for valid and reliable processes to quantify the progress individuals make toward achieving or making progress toward personal goals, (b) allows for the aggregation of data across individuals to determine group effects, and (c) is consistent with the movement toward person-centered services and the support of the self-determination among people with IDD. Within the context of HCBS outcomes measurement, Shogren and her group make the case that traditionally used non-GAS measures while providing information with respect to outcomes, fail to provide a holistic representation of the degree to which the outcomes of programs are truly a function of the supports people receive and the relationship of individuals with disabilities achieving personal goals and longer-term outcomes. Several literature reviews on GAS have been published (54, 66–70) and together with studies that specifically addressed the psychometric qualities of GAS (71–74) these publications suggest that this approach has more than sufficient evidence to support its use in a wide variety of measurement contexts.

How is the process of goal attainment scaling implemented? The first step in GAS is to identify an individualized goal of interest. In the context of HCBS measurement, this could be a desired life outcome either associated with a specific domain of NQF HCBS Outcome Measurement Framework (38) or external to it. The individual with a disability him/herself, with support from others when needed, must be the person on which this phase of GAS centers. The second phase of GAS entails determining what outcomes or behavior will reflect varying degrees of goal attainment in relation to those outcomes of interest. Once again, this step needs to be driven by the perspective of the HCBS recipient as opposed to others. A third step in developing a GAS approach to outcome measurement entails the development of five-point rating scales that operationalize expected outcomes. Typically, these range from −2 (much less than expected) through 0 (expected) to +2 (much more than expected). An alternative approach that has been used entails levels ranging from a −2 (no change) to a +2 (much better than expected) outcome or attainment of the desired outcome or goal. As a next step in the process, a specific time interval for evaluation of progress needs to be set. Depending on the goals or desired outcomes in question this can be anywhere from a few weeks to a full year. The final step in the GAS process is to rate goal attainment after the specified period, using the established GAS rubric and calculate the overall attainment score for the individual's goals.

A number of diverse ways of analyzing the results of GAS can be found in the literature. Scoring each and every goal between −2 and +2 provides a direct indication of the degree to which each goal has been achieved (45). This approach is likely to be easily understood by both HCBS recipients and providers and can be used at the individual level. However, it makes it difficult to undertake aggregated statistical analysis. A second approach is to transform raw GAS scores into T-scores enabling normalization and analysis using a variety of parametric statistics. This is the approach recommended by Kiresuk (43, 75) and covered in depth by Krasny-Pacini and colleagues (44). The mean of raw scores (76) as well as the sum of the differences between the baseline and the level of goal attainment for each person's goals have also been approaches (77). The T-score is the most frequently used method allowing for the reporting of results as a single standardized value.

GAS is a valuable, but certainly not the only strategy to use in order to move toward more person-centered measurement. In some cases, those undertaking program evaluation are interested in aspects of an individual's experience unrelated to the specific goals or outcomes they set for themselves. In other contexts (e.g., freedom from abuse and neglect) personal goals are subservient to state and federal legislation that fully prohibits these negative outcomes. In these instances, ensuring that measure items meet the criteria noted above and are responded to directly by persons with disabilities, solicit a preference, desire, want, need or emotional state from respondents, and provide a chance for people to indicate the degree to which those preferences, needs, etc. are being met provide what we consider to be person-centered data.

Challenges to using person-centered measurement and goal attainment scaling

The GAS process is highly adaptable and has great potential to be used as a person-centered outcome measure to establish the impact of supports received by HCBS recipients regardless of differences in desired outcomes or goals [see (44, 65, 78)]. It is not, however, without its challenges. As Shogren and colleagues (65) point out individualization of goals though desired in practice (79), can change the nature of goals. Goals lacking in precision also have implications for the accuracy of measurement. Shogren also points out that, in many cases, goals identified in one context (e.g., transition planning) are specific to other environments (e.g., work) increasing the challenge of meaningful and reliable GAS rating scales.

Additional challenges to using goal attainment scaling and person-centered approaches within the context of HCBS outcome measurement are related to (a) accounting for differences in the *importance* (to the person with a disability in question) of specific goals and outcomes, (b) the *challenges* a person is likely to face in making progress toward or achieving desired life outcomes, (c) the *time* it is likely to take to achieve sufficient progress to goals for change to be measurable, and (d) the *motivation* an HCBS recipient has with respect to working toward specific desired outcomes.

When attempting to measure the overall quality of outcomes a person experiences, it is critical to account for the fact that, for most people, some goals/desired life outcomes are significantly more important to achieve than others. Achieving a desired life outcome of a low level of importance is not the same as realizing one that ranks at the top of one's list of important outcomes. GAS is able address this challenge through the weighting of T-scores, giving more weight to certain outcomes/goals and their corresponding scales than others based on an individual's importance weightings. A similar situation exists with respect to the level of challenge or difficulty one is likely to encounter to achieve a specific goal. Some goals (e.g., moving from one occupation to a new one that will require extensive additional training) will require an individual to navigate significantly greater obstacles than other outcomes (e.g., acquiring a bicycle). Various weighting methods have been suggested in the literature as a function of the difficulty (80) and the probability of attaining the goal (81) that when employed properly allow one to take these factors into consideration.

A third challenge that must be confronted when using person-centered and GAS-based measures within an HCBS context relates to time. More specifically, how much time will be necessary in order for individuals to make sufficient progress toward their goals and desired outcomes so that change is detectable? This will likely vary significantly based upon the nature of a person's goals as well as the quality and specificity of the goals that have been developed. In addition, it will be affected by how organizations undertaking measurement/evaluation use the data collected. Regarding the latter, it is important to differentiate between whether the intent of measurement is as part of a formative or summative evaluation process. When the intent is the former, the idea is to monitor progress, ensure that recipients of services are on the right track to eventually achieve desired goals and make needed changes when initial strategies are not working. This approach requires goals to be specified in a fine-toothed manner and likely requires the breaking down of large/long-term goals into subgoals that are measurable over a shorter period of time. If the intent of measurement is summative, or primarily focused on the achievement of a standard after a person has been exposed to a program of supports and services, goals and the measures used to assess them are unlikely to need to be as fine-grained as those employed for assessment of a formative nature.

A final critical challenge to overcome if person-centered approaches to measurement are to be used within the context of HCBS is the necessity of obtaining responses directly from people with disabilities. Minimizing the use of administrative data sets and proxy respondents as a source of data is essential given that in many cases, the questions being asked can best or in some cases only be answered in a valid manner by the people in question themselves. HCBS recipients, however, vary greatly with respect to the nature of their disabilities, intensity of supports they need, and their capacities. This includes the ability to communicate their thoughts and feelings in a valid and reliable manner. Some individuals may not possess or may have lost the capacity for functional communication. The extent to which people who experience disabilities that have a cognitive component can provide valid self-report responses data needs to be carefully considered (82). Some individuals with intellectual and developmental disabilities, psychiatric disabilities, and TBI/ABI experience limitations with respect to understanding the meaning of questions, being able to accurately recall information, determine the order in which events took place, or make comparisons. Others may have great difficulty expressing their thoughts and feelings (83).

The language and cognitive demands of items as well as the response formats provided whether in the form of a survey or interview can present challenges to the reliability and validity of data collected. Items phrased negatively have been found more difficult for individuals with cognitive limitations to comprehend (83). Additionally, research indicates that questions about frequency, time, or abstract concepts (e.g., how inclusive do you feel when in the community?) can also be problematic (82, 84, 85). Fang and colleagues reported that complex rating scales are often quite difficult for people with cognitive limitations to comprehend (86). For some years now it has been known that people with intellectual disabilities may be prone to response bias including a tendency to select positive/agreeable response options (87–89) and both acquiescence and recency bias (84, 90) irrespective of one's true opinion). Additional research indicates that the higher the cognitive demand of a question/item, the more likely it is that a person will provide a biased response (91).

In spite of the challenges, a number of approaches have been shown to reduce the difficulties most people with intellectual disabilities experience in responding to self-report interview questions. These include tools to engage people with IDD such as participatory photographic research methods (92) or visual and metaphorical devices (93). Hollomotz (94) found that when questions were posed in plain language and accompanied by concrete reference tools, including picture cards and photo-story vignettes people with IDD were able to respond to a range of questions about sensitive topics including sex, risk, and their social and leisure lives. Cognitive and language limitations have been shown to be able to be minimized through the use of simplified question wording and response formats (84, 95, 96). Limitations in the ability of interviewees to respond to questions have been avoided through the use of response formats that require no more than a pointing response to emojis/icons or pictures. Simple response scales (e.g., yes, sometimes, no) have also been successfully used. Difficulties responding to questions regarding time have been minimized through the use of reference points with which an individual is likely to be familiar (e.g., birthdays or holidays). Adjusting the depth of questioning in line with what a respondent wants to or can offer has also been found to enhance the quality of data obtained as has a simplified conversational approach (97–100).

The strategies noted above have been shown to increase the capacity of people with a variety of disabilities to respond in a reliable and valid manner to self-report measures. There are still some individuals, however, who in spite of these approaches are unable to report accurately on the outcomes they experience. In these cases, a proxy respondent may be needed. In addition to the obvious person-centeredness limitations of not obtaining a direct response from the person, there are other difficulties associated with proxy responding that need to be considered. There may not be a proxy who truly knows the person well enough to provide a valid response. Moreover, evidence suggests that the validity of proxy responses decreases when the judgment/response made on behalf of the person is more subjective (101).

This does not mean however proxy responses do not provide a viable and important alternative when there is no other way to solicit information. For the past twenty-years, research has been undertaken in an attempt to better understand how proxy data can be used and its limitations. Stancliffe (102) and McVilly and colleagues (103) both found that in contrast to earlier research utilizing non-standardized approaches to assess quality of life, use of the Quality of Life Questionnaire (QOL-Q) resulted in a high degree of concordance between people with IDD and proxy respondents. More recently, Simões & Santos (104) as well as a host of other researchers [e.g., (105–107)] who have compared the points of view of clients with IDD and independent ratings of family members and staff, have found moderate to strong correlations (.69–.89) between persons with disabilities and knowledgeable caregivers when comparing various aspects of quality of life on both the QOL-Q and the WHOQOL-BREF. This does not mean that differences in perspectives do not exist. As might be expected, agreement is higher in some areas than others with higher levels of concordance with respect to more objective assessments of conditions of life and lower when the focus is on perceptions of satisfaction [e.g., (108)]. With respect to the latter, most findings indicate that the ratings of people with IDD are higher than those of family and staff (104, 105, 107). As Perkins (109) concluded, overall, proxy reports can be useful in determining a variety of aspects of well-being of people with disabilities as long as those using measures keep in mind that variety of factors that have the capacity to enhance (e.g., experiences/abilities that are more objectively assessed, and attention to question format) or diminish (e.g., experiences/abilities that are more subjectively assessed, severity of dementia, and level of ID) the quality of information obtained.

Alternative methods of using a proxy have also been put forth. Kaye (110) proposed that using a proxy-assisted approach can sometimes be effective as a compromise between proxy-only and self-reported responding methods. Using this method, the proxy responds with the person who has difficulty responding for themselves to assist with choosing a response. In an application of this approach to healthcare experiences, Elliot et al. (111) found a reduction in the level of bias compared to a proxy-only approach, but the proxy-assisted responses were still found to have a greater potential for bias than self-reports. Rand and colleagues (112) proposed a novel method of obtaining responses from a proxy. They posited that the proxy needed to first provide their *own* opinion on the outcome experienced by the person they are responding for prior to providing a response on how they think the person with a disability might respond. They suggest that this may reduce some of the response bias related to the proxy's own opinion. This method was utilized by the RTC/OM to develop proxy measures that include a reduced set of items that proxy respondents reported as both understandable and answerable during cognitive testing. This approach has the added benefit of providing two unique pieces of information for each item answered: (1) the opinion of someone who knows the person well and; (2) the proxy's best guess as to how the person with a disability would respond if they could. Further research is needed on this approach as to whether the proxy can sufficiently separate these distinct types of information when responding.

A final challenge to the use of person-centered measurement in the HCBS field results from the limited financial resources available to providers to undertake such evaluation and the workforce shortages endemic to the field. However, any type of assessment or progress monitoring, including alternative approaches, is going to require resources. Some (e.g., administrative data sets) might be less expensive than securing the information from persons with disabilities themselves. However, these alternatives would certainly: (a) not be person-centered and (b) be significantly less likely to provide *actionable* data that would lead to improved individual outcomes and/or enhanced supports and services. Although desired life outcomes/goals as well as their importance to an individual are in fact likely to change over time, the approach we advocate can be effectively used as a progress monitoring tool to detect these changes and allow for modifications in both supports and outcome measurement related to an individual's current desired life outcomes. In conjunction with person-centered approaches to planning, assessment, and services/supports this approach possesses the potential to more effectively ensure that the support received by an HCBS recipient actually address outcomes relevant to the lives they desire to lead. The approach for which we are advocating is broader than merely assessing the extent to which people with disabilities are making progress or achieving their goals. It includes an assessment of outcome domains and subdomains laid out in the National Quality Forum's HCBS Outcome Measurement Framework. This approach is needed by providers to assure both state and federal funding agencies that services and supports as well as the outcomes experienced by HCBS recipients and in concordance with the Final Settings Rule (7).

The need for a person-centered measure development framework

As Lipson (113) notes, there has been a significant amount of research and development in the area of *person-reported* measurement as it relates to people with disabilities. Unfortunately, there appears to be a mistaken belief that *person-reported* measures are equivalent to *person-centered* measures. As noted previously, this is not the case. Both CMS and the National Quality Forum (NQF) have provided extensive guidance on measure development (see CMS MMS Blueprint, 5 & HCBS Outcome Measurement Framework, 38) in addition to guidance on developing person-reported measures. Yet, there is little guidance on how to develop measures that are person-centered.

Person-centered measurement infuses person-centeredness into the measurement tool, items, and the information obtained from the tool from the initiation to the end of the development process. What is measured, how it is measured, and the manner in which people are able to respond to questions all need to be informed through input from people with disabilities. What is measured needs to be *important to* them as well as important *for* them so that measurement informs us of the degree to which HCBS supports people with disabilities to achieve personally defined desired life outcomes. Given the relative lack of person-centered measures, further development of a framework and process for developing such measurement tools is warranted. In the following sections, we will describe the process used by the RTC/OM to develop person-centered measures.

A person-centered measure development process

The Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM), funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) was tasked with developing person-centered HCBS quality and outcome measures. The measures, based on the National Quality Forum's (NQF) HCBS Measurement Outcome Framework, were developed based on input from over 350 stakeholders who took part in a series of national participatory planning and decision-making (PPDM) groups. Groups included persons with a variety of disabilities, family members, HCBS providers, and state program administrators. These groups reviewed the NQF Framework to determine the relative importance of each domain and subdomain in the NQF framework. These importance data were used, in conjunction with a gap analysis of existing measures, to prioritize the development of multiple person-centered measures. The PPDM format allowed stakeholders to weigh the importance of potential measure domains and subdomains, add or subtract from the NQF model and move toward consensus as to which were most important to measure.

Much of what has been discussed thus far has focused on person-centered measurement at a broad measure/instrument level. However, the items of which measures are composed are fundamental to person-centered measurement and unfortunately this aspect of measurement has often been neglected. As noted previously, in order to meet the criteria for person-centeredness an item must: (a) be responded to by the person, (b) solicit from the respondent a preference, desire, want, need or emotional state; and (c) provide a chance for the individual to indicate the degree to which those preferences, needs, etc. are being met. It should also be noted that individual should have the opportunity to either indicate the level of importance they place on the content included in the item and/or have the prospect of creating desired life outcomes of their own if items do not correspond well to **Table 2** provides examples of items in several NQF domains that are not person-centered as well as items from RTC/OM measures that meet person-centered criteria.

The RTC/OM has used an iterative, multi-phased process for developing measures based on extensive stakeholder feedback. This approach is based not only on the belief that measures need to be person-centered but that they should also have strong evidence of their reliability and validity prior to being used. Following the completion of draft items for each measure concept, a technical

TABLE 2 Examples of person-centered measurement.

NQF Domain	Not Person-Centered	Person-Centered
Social Connectedness	How many times in the last month have you visited with your family members.	I am able to keep in contact with my friends and family members as much as I want.
Choice & Control	How much control do you have over your daily schedule?	I have the amount of control I want/desire over the supports I receive.
Transportation	Logs of community outings	The transportation I use for my leisure and social activities meets my needs.
Meaningful Activity	Frequency counts of community outings over a specified period (e.g., times shopping, out to eat, etc.).	I take part in social activities that I enjoy as much as I want?

expert panel (TEP) consisting of people with disabilities, family members, content and measurement experts in each concept area, and HCBS program administrators was convened to review and rate each item that was part of a measure. Reviewers rated items on four-point scales with respect to their importance to the construct, understandability, utility, and feasibility of administration. When items received low scores, reviewers responded to open-ended questions to provide specific feedback related to that item. TEPs also provided feedback on the appropriateness of the response options for each item with respect to their understandability, completeness, and potential ability to accurately convey the experiences of people with disabilities. TEP ratings and feedback were used to revise and, in some cases, remove or replace items that stakeholders indicated did not adequately measure a concept.

An innovative strategy taken during measure concept development was to design the measures under development to be modular as opposed to intended to be used as an instrument. This will allow users interested in better understanding the outcomes experience by HCBS recipients in specific areas to avoid having to administer an entire interest. In addition, each measure has been developed as consisting of two tiers. Four to five Tier-1 items can be used to provide an overall picture of outcomes within a specific domain or across all domains. Tier-2 items which number from 12 to 20 for each measure provide more detailed information with respect to the outcomes experienced by respondents and are intended to support measure users to collect actionable data.

A second step in the measure development process included extensive cognitive testing (CT) of items using the *Cognitive Aspects of Survey Methodology* (CASM) framework (114, 115) and receiving direct input from individuals with disabilities. This process is necessary to confirm items are understood as intended (116, 117) and response options provide respondents with the opportunity to respond in a manner that accurately reflects their thoughts and feelings (118). This form of stakeholder involvement was essential given the intended use of measures with people with a wide variety of disabilities who receive a variety of HCBS.

Following revisions to items based on the results of cognitive testing, all measures were pilot tested with members of each disability population with which they were intended to be used to determine their reliability (internal consistency, test-retest, and inter-interviewer) and the extent to which they were feasible and usable for their intended purpose. Piloting with a diverse sample of adults with disabilities with varying support needs provided measure developers with a more robust set of data related not only with respect to measures and measure items but information about the extent to which the measures developed were suitable for use with HCBS recipients with a variety of disabilities and support needs. Results of the pilot-testing of thirteen person-centered measures spanning seven domains of the NQF HCBS Outcome Measurement Framework (38) have been extremely encouraging with internal consistency (.63–.94; Mean = .81), test-retest (.72–.99; Mean = .85) and inter-rater (.89–.98; Mean = .92) reliabilities on all but one measure found to be at more than acceptable levels. Administration time indicated that most individuals could complete a full measure in no more than 10–15 min and had little difficulty understanding or responding to items indicating a high degree of feasibility with respect to administration.

At the present time, Center staff are in the midst of a national field study being conducted to gather additional information with respect to the psychometric characteristics of the measures that have been developed. Due to the manner in which measures are intended to be used, recruitment is taking place at the provider organization level with multiple participants being recruited from each organization. Participant recruitment has focused on developing a sample of up to 1,000 HCBS recipients with intellectual and developmental disabilities, physical disabilities, traumatic/acquired brain injury, and both psychiatric and age-related disabilities of vary degrees of severity and with a wide range of support needs. Data is being collected over three points approximately 6-months apart with the goal of being able to provide estimates of the degree to which measures are sensitive to change over time. Given that some people with disabilities across all groups of interest may not be able to effectively communicate their experiences as HCBS recipients, a truncated set of proxy measures is also being tested as part of the study.

A final goal of the national field study centers on developing benchmarks against which to compare the outcomes people without disabilities experience in those areas covered by the National Quality Forum's HCBS Outcome Measurement Framework (38). As part of this effort, a national sample of 400 people without disabilities is being surveyed as to the outcomes they experience with respect to a variety of aspects of self-determination/choice and control, social connectedness, meaningful community activity, employment, and transportation. It is hoped that this data will provide an initial set of outcome benchmarks toward which provider organizations can work in an effort to provide people with disabilities with an enhanced degree of equity with respect to outcomes related to a wide variety of aspects of quality of life.

Conclusion

In this article, we first reviewed the need for HCBS outcome measurement to move beyond its current focus on enumerating the extent to which people with disabilities achieve a predefined set of outcomes (what is important *for* them). We contend that it is just as important to take into consideration an individual's personal needs, preferences, desires, and context (what is important *to* them). If the overall goal of HCBS is to support people with disabilities to lead the lives they desire within inclusive communities, it is imperative that the field move beyond its current focus toward an approach to measurement that is person-centered. This approach is consistent with the HCBS final settings rule (7) in the U.S. and the basic tenets of the Conference on the Rights of People with Disabilities (30) as well as grounded in a paradigm shift in the field of disability services from a *medical* to a *social-ecological model* of disability. We assert that person-centered measurement, which includes a focus on *both* what is important *for* and *to* people with disabilities, is consistent with the National Quality Forum's Framework for HCBS Outcome Measurement (38) and is a key element to fully understanding the effectiveness (or lack thereof) of the supports provided to people receiving community-based services and the quality of outcomes such individuals experience.

The concept of person-centeredness was next explored with a focus on how programs of measurement can move toward a more person-centered approach. This will require a change in focus in many western cultures from measurement focused on comparing the experiences of a target person to benchmarks or outcomes experienced by others to a measurement system in which the "standard" is based on the service recipient's personally defined preferences or goals—not those that other people or the service system sets for them. In the context of measuring outcomes associated with people who receive HCBS, we contend that for measures to truly be person-centered they must be (a) designed with the intent that they will be responded to by people with disabilities themselves; (b) focus on outcomes that are both *important for* and *important to* the recipients of supports; (c) allow people to accurately articulate what they need, outcomes they desire to experience, and the degree to which they view themselves as making progress toward achieving those outcomes; (d) possess the capacity to be used in a longitudinal manner; and (e) permit the individual to indicate the extent to which specific outcomes are of importance to them. As part of this discussion, Goal Attainment Scaling (GAS) was explored as one, but certainly not the only, method for moving toward more person-centered measurement as it potentially allows individuals with disabilities who are receiving supports to quantify the progress they see themselves as making toward personally desired life outcomes or goals. Although the use of this approach does require one to overcome some challenges, evidence of its reliability and validity when used within the rehabilitation sciences is quite encouraging. In addition, in the approach that we advocate, it is the recipients of HCBS supports who identify the desired life outcomes most important to them which then serve as the basis of measurement thus increasing the likelihood that measures are culturally relevant and appropriate.

Given the current state of HCBS outcome measurement, it is clear to us that a framework for the development and validation of person-centered community-based measures would be useful. As an initial step in this direction, we offer the approach to measure concept development that has been used by the University of Minnesota's Research and Training Center on HCBS Outcome Measurement. This approach which is consistent with the NQF's Framework for HCBS outcome Measurement (38) was initiated on the basis of what people with disabilities themselves indicated was most important to measure. It involved a structured, iterative process of item and measure concept development grounded in existing research and theory with respect to the domains of measurement. The iterative process employed allowed a variety of stakeholder groups including people with a variety of disabilities, family members, content area experts, community support providers, and state program administrators to weigh in on the measures under development. Although the process is not yet complete with measures undergoing national field-testing, the results of extensive cognitive testing, and piloting of the measures are quite promising and suggest that this may be an approach to measure development that has potential utility for much needed future efforts in this area.

Author contributions

MAR contributed to the original conceptualization of the manuscript, the development of the first draft, and the editing of the final draft. BHA contributed to the initial conceptualization and made significant additions and revisions toward the formulation of the final draft. All authors contributed to the article and approved the submitted version.

Funding

The development of this manuscript was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), federal grant # 90RT5039.

Acknowledgments

John Smith, MSW, Jean-Baptiste Quillien, Ph.D., and Adele Dimian, Ph.D. each assisted with the original conceptualization of the manuscript.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Watts MO, Musumeci M, Chidambaram P. Medicaid home and community-based services enrollment and spending. *Kaiser Fam Found.* (2020) 1–22.

2. Chong N, Akobirshoev I, Caldwell J, Stephen Kaye H, Mitra M. The relationship between unmet need for home and community-based services and health and community living outcomes. *Disabil Health J.* (2022) 15(2):101222. doi: 10.1016/j.dhjo.2021.101222

3. Fabius C, Shugrue N, Robison J. Outcomes associated with home and community-based service type among older money follows the person participants. *Innovation in Aging.* (2018) 2(suppl_1):972–73. doi: 10.1093/geroni/igy031.3602

4. Firsing SL, Dantzler JA, Hackman C, Rush SE, Borkovich RA, Delport J. Exploration of the effects of medicaid home and community-based services waiver services on

outcomes for people with intellectual disability. *Inclusion (Washington, D.C.)*. (2016) 4 (2):120–32. doi: 10.1352/2326-6988-4.2.120

5. Centers for Medicare and Medicaid Services (CMS). *Blueprint for the CMS Measures Management System Version 17.0*. (2021). Available from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Blueprint.pdf

6. Musumeci MB, O'Malley Watts M, Chidambaram P. *Key State Policy Choices About Medicaid Home and Community-Based Services*, Kaiser Family Foundation, February 4, 2020 (2020). Available from: https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/

7. Centers for Medicare & Medicaid Services (CMS), HHS. Medicaid program; state plan home and community-based services, 5-year period for waivers, provider payment reassignment, and home and community-based setting requirements for community first choice and home and community-based services (HCBS) waivers. Final rule. *Fed Regist*. (2014) 79(11):2947–3039.

8. Smull M. Choice and control. *Supported Development Associates*. (2017). Available from: https://www.sdaus.com/_files/ugd/17ee81_1168fc9451614ff58929cb8bf5d63e72.pdf

9. Olmstead vs. L.C. 119 S. Ct. 2176, United States Supreme Court, (1999).

10. Tichá R, Lakin KC, Larson S, Stancliffe R, Taub S, Engler J, et al. Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellect Dev Disabil*. (2012) 50 (6):486–504. doi: 10.1352/1934-9556-50.06.486

11. Tichá R, Stancliffe RJ, Lakin KC, Larson SA, Engler J, Bershadsky J, et al. *Community participation of adults with intellectual and developmental disabilities receiving residential supports in 19 states*. Minneapolis, MN, United States: University of Minnesota – Institute on Community Integration (2015).

12. The Council on Quality and Leadership (CQL). *Personal outcome measures: Measuring personal quality of life*. 3rd ed. Towson, Maryland: The Council on Quality and Leadership (2017).

13. Nyce A, Abery B, Tichá R. An analysis of the HCBS CAHPS survey [Unpublished manuscript]. Institute on Community Integration, University of Minnesota. (2020).

14. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). *HCBS Instrument Database* [Online database]. (2017). Available from: https://rtcom.umn.edu/database

15. Buntinx WH, Schalock RL. Models of disability, quality of life, and individualized supports: implications for professional practice in intellectual disability. *J Policy Pract Intellect Disabil*. (2010) 7(4):283–94. doi: 10.1111/j.1741-1130.2010.00278.x

16. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. (2013) 17(1):103–16. doi: 10.1177/1362361312441266

17. Howlin P, Moss P. Adults with autism spectrum disorders. *Can J Psychiatry*. (2012) 57(5):275–83. doi: 10.1177/070674371205700502

18. Schalock RL, Keith KD, Verdugo MÁ, Gómez LE. Quality of life model development and use in the field of intellectual disability. In: Kober R, editor. *Enhancing the quality of life of people with intellectual disabilities*. Dordrecht: Springer (2010). p. 17–32.

19. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry*. (2004) 45(2):212–29. doi: 10.1111/j.1469-7610.2004.00215.x

20. Renty JO, Roeyers H. Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. *Autism*. (2006) 10(5):511–24. doi: 10.1177/1362361306066604

21. Rodogno R, Krause-Jensen K, Ashcroft RE. "Autism and the good life": a new approach to the study of well-being. *J Med Ethics*. (2016) 42(6):401–8. doi: 10.1136/medethics-2016-103595

22. Rogers CR. *On becoming a person: a therapist's view of psychotherapy*. London: Constable (1961).

23. Rogers CR. The foundations of the person-centered approach. *Education*. (1979) 100(2):98–107. Available from: https://doi.org/10.5840/dialecticshumanism19818123

24. O'Brien CL, O'Brien J. The Origins of Person-Centered Planning: A Community of Practice Perspective. (2000).

25. O'Brien J. A Genealogy of Person-Centered Planning With People With Developmental Disabilities. (2021). Available from: https://inclusion.com/site/wp-content/uploads/2021/10/Geneology-of-person-centered-planning.pdf

26. Mead N, Bower P. Patient-Centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*. (2000) 51(7):1087–110. doi: 10.1016/S0277-9536(00)00098-8

27. McCormack B, McCance TV. Development of a framework for person-centred nursing. *J Adv Nurs*. (2006) 56(5):472–9. doi: 10.1111/j.1365-2648.2006.04042.x

28. McCance T, McCormack B, editors. *Person-centred practice in nursing and health care: theory and practice*. Chichester, West Sussex; Ames, Iowa: John Wiley & Sons (2017).

29. National Quality Forum (NQF). Person-centered practice and planning: Final report. (2020). Available from: https://www.qualityforum.org/Publications/2020/07/Person_Centered_Planning_and_Practice_Final_Report.aspx

30. United Nations. Convention on the rights of people with disabilities (CRPD). (2006). Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

31. Riesen T, Snyder A. *A guide to the home-and community-based services (HCBS) final settings rule*. Logan, UT: Center for Persons with Disabilities Utah State University. (2019). Available from: https://ceiutah. *com/wp*-content/uploads/2020/01/HCBS-Provider-Manual-final. pdf

32. McCormack, Brendan. "A Conceptual Framework for Person-Centred Practice with Older People." *International Journal of Nursing Practice*. (2003) 9(3):202–9. doi: 10.1046/j.1440-172X.2003.00423.x

33. Hutchinson C, Worley A, Khadka J, Milte R, Cleland J, Ratcliffe J. Do we agree or disagree? A systematic review of the application of preference-based instruments in self and proxy reporting of quality of life in older people. *Soc Sci Med*. (2022) 305:115046. doi: 10.1016/j.socscimed.2022.115046

34. Kinghorn P, Afentou N. Proxy responses to ICECAP-A: exploring variation across multiple proxy assessments of capability well-being for the same individuals. *PLoS One*. (2020) 15(7):e0236584. doi: 10.1371/journal.pone.0236584

35. Nicholas M, Jennelle L, Connor LT, Haynes C, Zipse L. Do caregiver proxy reports and congruence of client–proxy activity participation goals relate to quality of life in people with aphasia? *Int J Lang Commun Disord*. (2020) 55(3):373–86. doi: 10.1111/1460-6984.12524

36. Scott HM, Havercamp SM. Comparisons of self and proxy report on health-related factors in people with intellectual disability. *J Appl Res Intellect Disabil*. (2018) 31 (5):927–36. doi: 10.1111/jar.12452

37. van der Vorst A, Zijlstra GA, De Witte N, De Lepeleire J, Kempen GI, Schols JM. Can proxy assessments serve as a first screener for identifying people at risk for multidimensional frailty? *Eur Geriatr Med*. (2018) 9(4):501–7. doi: 10.1007/s41999-018-0067-x

38. National Quality Forum (NQF). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement*. (2016). doi: 10.1111/j.1365-2648.2006.04042.x. Available from: http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_Measurement.aspx

39. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). *Stakeholder Input: Identifying Critical Domains and Subdomains of HCBS Outcomes*. (2016). Available from: https://rtcom.umn.edu/phases/phase-1-stakeholder-input

40. Centers for Medicare and Medicaid Services (CMS). *CAHPS Home- and Community-Base Services Survey Version 1*. (2016). Available from: https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-english.pdf

41. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). *CAHPS Home and Community-based Services Survey EoC* [online database]. (2020a). Available from: https://rtcom.umn.edu/database/instruments/cahps%20hcbs%20eoc

42. Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). *State HCBS Assessment Tools* [Online database]. (2019).

43. Kiresuk TJ, Sherman RE. Goal attainment scaling: a general method for evaluating comprehensive community mental health programs. *Community Ment Health J*. (1968) 4 (6):443–53. doi: 10.1007/BF01530764

44. Krasny-Pacini A, Hiebel J, Pauly F, Godon S, Chevignard M. Goal attainment scaling in rehabilitation: a literature-based update. *Ann Phys Rehabil Med*. (2013) 56 (3):212–30. doi: 10.1016/j.rehab.2013.02.002

45. Steenbeek D, Meester-Delver A, Becher JG, Lankhorst GJ. The effect of botulinum toxin type A treatment of the lower extremity on the level of functional abilities in children with cerebral palsy: evaluation with goal attainment scaling. *Clin Rehabil*. (2005) 19(3):274–82. doi: 10.1191/0269215505cr859oa

46. Ashford S, Turner-Stokes L. Goal attainment for spasticity management using botulinum toxin. *Physiother Res Int*. (2006) 11(1):24–34. doi: 10.1002/pri.36

47. Borg J, Ward AB, Wissel J, Kulkarni J, Ertzgaard P, Åkerlund P, et al. Rationale and design of a multicentre, double-blind, prospective, randomized, European and Canadian study: evaluating patient outcomes and costs of managing adults with post-stroke focal spasticity. *J Rehabil Med*. (2011) 43:15–22. doi: 10.2340/16501977-0663

48. Desloovere K, Schörkhuber V, Fagard K, Van Campenhout A, De Cat J, Pauwels P, et al. Botulinum toxin type A treatment in children with cerebral palsy: evaluation of treatment success or failure by means of goal attainment scaling. *Eur J Paediatr Neurol*. (2012) 16(3):229–36. doi: 10.1016/j.ejpn.2010.09.006

49. Gould KR, Feeney TJ, Hicks AJ, Ponsford JL. Individualized goal attainment scaling during a trial of positive behaviour support in adults with acquired brain injury. *Neuropsychol Rehabil*. (2021) 32:1–19. doi: 10.1080/09602011.2021.2016447

50. Hanssen KT, Beiske AG, Landrø NI, Hofoss D, Hessen E. Cognitive rehabilitation in multiple sclerosis: a randomized controlled trial. *Acta Neurol Scand*. (2016) 133 (1):30–40. doi: 10.1111/ane.12420

51. Turner-Stokes L, Williams H, Johnson J. Goal attainment scaling: does it provide added value as a person-centred measure for evaluation of outcome in neurorehabilitation following acquired brain injury? *J Rehabil Med*. (2009) 41 (7):528–35. doi: 10.2340/16501977-0383

52. Turner-Stokes L, Baguley IJ, De Graaff S, Katrak P, Davies L, McCrory P, et al. Goal attainment scaling in the evaluation of treatment of upper limb spasticity with botulinum

toxin: a secondary analysis from a double-blind placebo-controlled randomized clinical trial. *J Rehabil Med.* (2010) 42(1):81–9. doi: 10.2340/16501977-0474

53. Clare L, Kudlicka A, Oyebode JR, Jones RW, Bayer A, Leroi I, et al. Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: a multicentre randomised controlled trial (the GREAT trial). *Int J Geriatr Psychiatry.* (2019) 34(5):709–21. doi: 10.1002/gps.5076

54. van Seben R, Reichardt L, Smorenburg S, Buurman B. Goal-setting instruments in geriatric rehabilitation: a systematic review. In: *The impact of acute hospitalization on older persons*. Amsterdam: ProefschriftMaken (2017) 107 p.

55. Adair B, Ullenhag A, Keen D, Granlund M, Imms C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Dev Med Child Neurol.* (2015) 57(12):1093–104. doi: 10.1111/dmcn.12809

56. Barton EE, Reichow B, Schnitz A, Smith IC, Sherlock D. A systematic review of sensory-based treatments for children with disabilities. *Res Dev Disabil.* (2015) 37:64–80. doi: 10.1016/j.ridd.2014.11.006

57. Carter EW, Asmus J, Moss CK, Biggs EE, Bolt DM, Born TL, et al. Randomized evaluation of peer support arrangements to support the inclusion of high school students with severe disabilities. *Except Child.* (2016) 82(2):209–33. doi: 10.1177/0014402915598780

58. Case-Smith J, Weaver LL, Fristad MA. A systematic review of sensory processing interventions for children with autism spectrum disorders. *Autism*. (2015) 19(2):133–48. doi: 10.1177/1362361313517762

59. Gaffney E, Gaffney K, Bartleson L, Dodds C. Goal attainment scaling made easy with an app: GOALed. *Pediatr Phys Ther.* (2019) 31(2):225–30. doi: 10.1097/PEP.0000000000000602

60. O'Connor C, Stagnitti K. Play, behaviour, language and social skills: the comparison of a play and a non-play intervention within a specialist school setting. *Res Dev Disabil.* (2011) 32(3):1205–11. doi: 10.1016/j.ridd.2010.12.037

61. Schoen SA, Lane SJ, Mailloux Z, May-Benson T, Dianne Parham L, Roley SS, et al. A systematic review of ayres sensory integration intervention for children with autism. *Autism Res.* (2019) 12(1):6–19. doi: 10.1002/aur.2046

62. Wales D, Skinner L, Hayman M. The efficacy of telehealth-delivered speech and language intervention for primary school-age children: a systematic review. *Int J Telerehabil.* (2017) 9(1):55. doi: 10.5195/ijt.2017.6219

63. Morgan C, Novak I, Dale RC, Badawi N. Optimising motor learning in infants at high risk of cerebral palsy: a pilot study. *BMC Pediatr.* (2015) 15(1):1–11. doi: 10.1186/s12887-015-0347-2

64. Mayson TA, Ward VJ, Harris SR. Parent goals as outcome measures for children receiving treadmill training: a series of case reports. *Dev Neurorehabil.* (2012) 15 (3):219–22. doi: 10.3109/17518423.2011.654282

65. Shogren KA, Dean EE, Burke KM, Raley SK, Taylor JL. Goal attainment scaling: a framework for research and practice in the intellectual and developmental disabilities field. *Intellect Dev Disabil.* (2021) 59(1):7–21. doi: 10.1352/1934-9556-59.1.7

66. Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: a systematic review. *Clin Rehabil.* (2006) 20(9):756–72. doi: 10.1177/0269215506070793

67. Shankar S. *Investigating substantive validity evidence using action-project method for the goal attainment scaling measure* [*Phd diss.*]. University of British Columbia (2019).

68. Shankar S, Marshall SK, Zumbo BD. A systematic review of validation practices for the goal attainment scaling measure. *J Psychoeduc Assess.* (2020) 38(2):236–55. doi: 10.1177/0734282919840948

69. Steenbeek D, Ketelaar M, Galama K, Gorter JW. Goal attainment scaling in paediatric rehabilitation: a critical review of the literature. *Dev Med Child Neurol.* (2007) 49(7):550–6. doi: 10.1111/j.1469-8749.2007.00550.x

70. Vu M, Law AV. Goal-attainment scaling: a review and applications to pharmacy practice. *Res Soc Adm Pharm.* (2012) 8(2):102–21. doi: 10.1016/j.sapharm.2011.01.003

71. Lee CE, Shogren KA, Segal J, Pezzimenti F, Aleman-Tovar J, Taylor JL. Goal attainment scaling—community-based: a method to incorporate personalized outcomes into intervention research with youth and adults on the autism spectrum. *Autism*. (2022) 26(1):178–87. doi: 10.1177/13623613211024492

72. May-Benson TA, Schoen SA, Teasdale A, Koomar J. Inter-rater reliability of goal attainment scaling with children with sensory processing disorder. *Open J Occup Ther.* (2021) 9(1):1–13. doi: 10.15453/2168-6408.1693

73. Urach S, Gaasterland CMW, Posch M, Jilma B, Roes K, Rosenkranz G, et al. Statistical analysis of goal attainment scaling endpoints in randomised trials. *Stat Methods Med Res.* (2019) 28(6):1893–910. doi: 10.1177/0962280218777896

74. van Blijswijk SC, Gussekloo J, Heijmans FM, Wind AW, den Elzen WP, Blom JW. Goal attainment scaling with older people in general practice: a feasibility study. *Int J Nurs Stud Adv.* (2021) 3:100015. doi: 10.1016/j.ijnsa.2020.100015

75. Kiresuk TJ, Lund SH. Implementing goal attainment scaling. In: TJ Kiresuk, A Smith, JE Cardillo, editors. *Goal attainment scaling: applications, theory and measurement*. Hillsdale, NJ: Lawrence Erlbaum Associates (1994) 1–22.

76. Wallen M, Ziviani J, Naylor O, Evans R, Novak I, Herbert RD. Modified constraint-induced therapy for children with hemiplegic cerebral palsy: a randomized trial. *Dev Med Child Neurol.* (2011) 53(12):1091–9. doi: 10.1111/j.1469-8749.2011.04086.x

77. Maloney FP. Goal attainment scaling. *Phys Therapy*. (1993) 73:123. doi: 10.1093/ptj/73.2.123

78. Shogren KA, Burke KM, Antosh A, Wehmeyer ML, LaPlante T, Shaw LA, et al. Impact of the self-determined learning model of instruction on self-determination and goal attainment in adolescents with intellectual disability. *J Disabil Policy Stud.* (2019) 30(1):22–34. doi: 10.1177/1044207318792178

79. Shogren KA, Abery B, Antosh A, Broussard R, Coppens B, Finn C, et al. Recommendations of the self-determination and self-advocacy strand from the national goals 2015 conference. *Inclusion.* (2015) 3(4):205–10. doi: 10.1352/2326-6988-3.4.205

80. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. *Clin Rehabil.* (2009) 23(4):362–70. doi: 10.1177/0269215508101742

81. Khan F, Pallant JF, Turner-Stokes L. Use of goal attainment scaling in inpatient rehabilitation for persons with multiple sclerosis. *Arch Phys Med Rehabil.* (2008) 89 (4):652–9. doi: 10.1016/j.apmr.2007.09.049

82. Fujiura GT, RRTC Expert Panel on Health Measurement. Self-reported health of people with intellectual disability. *Intellect Dev Disabil.* (2012) 50(4):352–69. doi: 10.1352/1934-9556-50.4.352

83. Emerson E, Felce D, Stancliffe RJ. Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellect Dev Disabil.* (2013) 51(5):333–48. doi: 10.1352/1934-9556-51.5.333

84. Finlay WM, Lyons E. Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychol Assess.* (2001) 13(3):319. doi: 10.1037/1040-3590.13.3.319

85. Stancliffe RJ, Tichá R, Larson SA, Hewitt AS, Nord D. Responsiveness to self-report interview questions by adults with intellectual and developmental disability. *Intellect Dev Disabil.* (2015) 53(3):163–81. doi: 10.1352/1934-9556-53.3.163

86. Fang J, Fleck MP, Green A, McVilly K, Hao Y, Tan W, et al. The response scale for the intellectual disability module of the WHOQOL: 5-point or 3-point? *J Intellect Disabil Res.* (2011) 55(6):537–49. doi: 10.1111/j.1365-2788.2011.01401.x

87. Heal LW, Sigelman CK. Response biases in interviews of individuals with limited mental ability. *J Intellect Disabil Res.* (1995) 39(4):331–40. doi: 10.1111/j.1365-2788.1995.tb00525.x

88. Sigelman CK, Budd EC, Spanhel CL, Schoenrock CJ. When in doubt, say yes: acquiescence in interviews with mentally retarded persons. *Ment Retard.* (1981) 19(2):53.

89. Sigelman CK, Budd EC, Spanhel CL, Schoenrock CJ. Asking questions of retarded persons: a comparison of yes-no and either-or formats. *Appl Res Ment Retard.* (1981) 2 (4):347–57. doi: 10.1016/0270-3092(81)90029-1

90. Stancliffe RJ. Proxy respondents and quality of life. *Eval Program Plann.* (2000) 23 (1):89–93. doi: 10.1016/S0149-7189(99)00042-7

91. Krosnick JA. Response strategies for coping with the cognitive demands of attitude measures in surveys. *Appl Cogn Psychol.* (1991) 5(3):213–36. doi: 10.1002/acp.2350050305

92. Aldridge J. Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disabil Soc.* (2007) 22(1):1–17. doi: 10.1080/09687590601056006

93. Nind M, Vinha H. Creative interactions with data: using visual and metaphorical devices in repeated focus groups. *Qual Res.* (2016) 16(1):9–26. doi: 10.1177/1468794114557993

94. Hollomotz A. Successful interviews with people with intellectual disability. *Qual Res.* (2018) 18(2):153–70. doi: 10.1177/1468794117713810

95. Cuthill FM, Espie CA, Cooper S-A. Development and psychometric properties of the Glasgow depression scale for people with a learning disability: individual and carer supplement versions. *Br J Psychiatry.* (2003) 182(4):347–53. doi: 10.1192/bjp.182.4.347

96. Lloyd V, Gatherer A, Kalsy S. Conducting qualitative interview research with people with expressive language difficulties. *Qual Health Res.* (2006) 16(10):1386–404. doi: 10.1177/1049732306293846

97. Antaki C, Richardson E, Stokoe E, Willott S. Can people with intellectual disability resist implications of fault when police question their allegations of sexual assault and rape? *Intellect Dev Disabil.* (2015) 53(5):346–57. doi: 10.1352/1934-9556-53.5.346

98. Cridland EK, Phillipson L, Brennan-Horley C, Swaffer K. Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qual Health Res.* (2016) 26(13):1774–86. doi: 10.1177/1049732316637065

99. Finlay WM, Antaki C. How staff pursue questions to adults with intellectual disabilities. *J Intellect Disabil Res.* (2012) 56(4):361–70. doi: 10.1111/j.1365-2788.2011.01478.x

100. Perry J. Interviewing people with intellectual disabilities. In: Emerson E, Hatton C, Thompson T, Parmenter T, editors. *The international handbook of applied research in intellectual disabilities*. Chichester, West Sussex; Ames, Iowa: John Wiley & Sons, Ltd. (2004). p. 115–32. doi: 10.1002/9780470713198.ch5

101. Hart T, Sherer M, Temkin N, Whyte J, Dikmen S, Heinemann AW, et al. Participant-proxy agreement on objective and subjective aspects of societal participation following traumatic brain injury. *J Head Trauma Rehabil.* (2010) 25 (5):339–48. doi: 10.1097/HTR.0b013e3181c7e60b

102. Stancliffe RJ. Proxy respondents and the reliability of the quality of life questionnaire empowerment factor. *J Intellect Disabil Res.* (1999) 43(3):185–93. doi: 10.1046/j.1365-2788.1999.00194.x

103. McVilly KR, Burton-Smith RM, Davidson JA. Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *J Intell Dev Disabil*. (2000) 25(1):19–39. doi: 10.1080/132697800112767

104. Simões C, Santos S. The quality of life perceptions of people with intellectual disability and their proxies. *J Intellect Dev Disabil*. (2016) 41(4):311–23. doi: 10.3109/13668250.2016.1197385

105. Balboni G, Coscarelli A, Giunti G, Schalock RL. The assessment of the quality of life of adults with intellectual disability: the use of self-report and report of others assessment strategies. *Res Dev Disabil*. (2013) 34(11):4248–54. doi: 10.1016/j.ridd.2013.09.009

106. Claes C, Van Hove G, Vandevelde S, van Loon J, Schalock R. The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Res Dev Disabil*. (2012) 33(1):96–103. doi: 10.1016/j.ridd.2011.08.024

107. Schmidt S, Power M, Green A, Lucas-Carrasco R, Eser E, Dragomirecka E, et al. Self and proxy rating of quality of life in adults with intellectual disabilities: results from the DISQOL study. *Res Dev Disabil*. (2010) 31(5):1015–26. doi: 10.1016/j.ridd.2010.04.013

108. Verdugo MA, Navas P, Gómez LE, Schalock RL. The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *J Intellect Disabil Res*. (2012) 56(11):1036–45. doi: 10.1111/j.1365-2788.2012.01585.x

109. Perkins EA. Self-and proxy reports across three populations: older adults, persons with Alzheimer's disease, and persons with intellectual disabilities. *J Policy Pract Intellect Disabil*. (2007) 4(1):1–10. doi: 10.1111/j.1741-1130.2006.00092.x

110. Kaye HS. NHIS And NHIS-D: non-response, proxy. In: Kroll T, Keer D, Placek P, Cyril J, Hendershot G, editors. *Towards best practices for surveying people with disabilities*. Vol. 1, New York: Nova Science Publishers, Inc. (2007). 105 p.

111. Elliott MN, Beckett MK, Chong K, Hambarsoomians K, Hays RD. How do proxy responses and proxy-assisted responses differ from what medicare beneficiaries might have reported about their health care? *Health Serv Res*. (2008) 43(3):833–48. doi: 10.1111/j.1475-6773.2007.00820.x

112. Rand S, Caiels J, Collins G, Forder J. Developing a proxy version of the adult social care outcome toolkit (ASCOT). *Health Qual Life Outcomes*. (2017) 15(1):108. doi: 10.1186/s12955-017-0682-0

113. Lipson DJ. *Person-reported outcome measures for home and community-based services. HCBS Quality Measures Issue Brief, Mathematica*. (2019). Available from: https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measures-brief-2-person-reported-outcome.pdf

114. Tourangeau R. Cognitive science and survey methods. In: T Jabine, ML Straf, JM Tanur, R Tourangeau, editors. *Cognitive aspects of survey design: Building a bridge between disciplines*. Washington, DC: National Academy Press (1984). p. 73–100.

115. Tourangeau R. The survey response process from a cognitive viewpoint. *Qual Assur Educ*. (2018) 26(2):169–81. doi: 10.1108/QAE-06-2017-0034

116. Kramer JM, Schwartz A. Reducing barriers to patient-reported outcome measures for people with cognitive impairments. *Arch Phys Med Rehabil*. (2017) 98(8):1705–15. doi: 10.1016/j.apmr.2017.03.011

117. Willis GB, Royston P, Bercini D. The use of verbal report methods in the development and testing of survey questionnaires. *Appl Cogn Psychol*. (1991) 5 (3):251–67. doi: 10.1002/acp.2350050307

118. Castillo-Díaz M, Padilla J-L. How cognitive interviewing can provide validity evidence of the response processes to scale items. *Soc Indic Res*. (2013) 114(3):963–75. doi: 10.1007/s11205-012-0184-8

Frontiers in Rehabilitation Sciences

TYPE Review
PUBLISHED 21 February 2023
DOI 10.3389/fresc.2023.1043564

EDITED BY
Jacqueline Moodley,
University of Johannesburg, South Africa

REVIEWED BY
Axel Kaehne,
Edge Hill University, United Kingdom
Ivan Neil Gomez,
University of Santo Tomas, Philippines

*CORRESPONDENCE
Jan Šiška
✉ jan.siska@pedf.cuni.cz

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 13 September 2022
ACCEPTED 17 January 2023
PUBLISHED 21 February 2023

CITATION
Beadle-Brown J, Šiška J and Káňová Š (2023) Mapping frameworks and approaches to measuring the quality of transition support services for young people with intellectual and developmental disabilities.
Front. Rehabil. Sci. 4:1043564.
doi: 10.3389/fresc.2023.1043564

Mapping frameworks and approaches to measuring the quality of transition support services for young people with intellectual and developmental disabilities

Julie Beadle-Brown[1], Jan Šiška[2]* and Šárka Káňová[3]

[1]Tizard Centre, University of Kent, University of West Bohemia in Pilsen, Canterbury, United Kingdom, [2]Faculty of Education, University of West Bohemia in Pilsen, Pilsen and Charles University, Prague, Czech, [3]Faculty of Education, University of West Bohemia in Pilsen, Pilsen, Czech

Transition to adulthood for young people with intellectual disabilities and developmental disabilities (IDD) has been given significant attention in research, policy development and practice. The aim of this paper was to explore how a recently developed theoretical outcomes-based framework for measuring the quality of services for people with disabilities could potentially be useful in conceptualizing and supporting successful transition to adulthood. The theoretical discussion draws on both the scoping review and template analysis that was used to develop the Service Quality Framework and on a separate study synthesizing expert completed country templates and literature review which included models of and research on successful transition to adulthood. Synthesis identified that using a quality of life outcomes focused framework of Service Quality could be mapped onto and extend current thinking on what is seen as successful transition to adulthood by putting the focus on successful transition as people with IDD moving towards having similar opportunities and quality of life as other adults without disabilities living in the same community/society. Implications of a more wide-ranging definition and holistic view for both practice and future research are discussed.

KEYWORDS

intellectual and developmental disabilities, transition, quality of support services, quality of life, education, measurement

1. Introduction

Transition to adulthood for young people with intellectual and developmental disabilities (IDD) has been emphasized as an area of considerable significance. The difficulties this group experiences when moving from school to employment, to higher education and active participation in the community after leaving school, has been highlighted as a major contributor to isolation and exclusion (1). Despite the United Nations Convention for the Rights of Persons with Disabilities (2), young people with IDD and complex needs often transition from special schools to other congregated settings such as to care homes, because of the lack of appropriate alternatives (3, 4).

One key issue is that there is as yet no agreed conceptualization of what constitutes "successful transition" more generally or specifically for young people with IDD. Some of the literature has focused rather narrowly on transition from child to adult health, mental health and/or social care services (5, 6) or on transition predictors in-school activities that positively correlate with postschool success in post-secondary education, employment, and independent living (7). Some conceptualizations of transition have had a broader focus. Wehman (8) conceived of transition as a *period of significant life changes* that naturally occur after leaving school including change in the concept of oneself; body changes; sexuality and partnership; financial and work needs; the need for independence in travel and mobility, etc. Much of the literature focuses on transition as moving into adulthood and "successful transition" equates to achieving indicators of adulthood, such as employment, financial independence, post-secondary education, and engagement in close relationships such as marriage, or parenthood (9). However, some of these role transitions are becoming less reliable indicators of adulthood, as altering economic and social conditions continue to change the traditional path to adulthood for all youth, for example, due to difficulties with finding employment (10). This potentially impacts on whether young people can be financially independent and live independently, meet a wider range of people with whom to form relationships, etc. Factors that hinder and facilitate the participation of persons with IDD in employment are often found in the environment, with personal factors also influencing participation. The presence of negative attitudes and lack of support services were major limiting factors within the environment (11, 12). In addition, definitions of "success in employment" shared by parents of young persons with intellectual disabilities appear to go beyond the constrained criterion of full-time competitive employment. Parents value a range of occupational outcomes that consider their son or daughter's skills and interests, just one of which was competitive employment.

A recent review of policy, guidance and research focusing on four countries related to successful transition of young persons with IDD identified that, although successful transition is conceptualised in different ways in different countries (13), there appear to be five core outcomes or indicators of transition success:

- having a job (employment) and/or financial independence (the U.S., United Kingdom, the Czech Republic, and Australia),
- independent living/moving out of the family home (the U.S., Australia, and United Kingdom),
- further education (the U.S.),
- growing your social networks, relationships and being part of your community; (United Kingdom),
- physical and mental health/well-being (United Kingdom).

Such indicators of "successful" transition have been regarded by some as normative or even harmful, particularly for young disabled people, who often face additional and significant barriers to achieving these indicators (14, 15). For many people with disabilities, support is required through both, the process of transition typically to employment or independent living and into adulthood itself. The higher people's support needs are, the more help people are likely to need. This means that support services of one type or another are likely to be involved in the transition process. Unfortunately, research tells us that quite often services are not structured holistically—across the life span, seeing people across the threshold from child to adult environment (16). Reasons for it could be found for example in rigid fragmentation of support services into specific administration entities such as health, education, social security, and social services. This might result in a gap or risk of people falling through the gaps (17, 18). On the contrary, programs for helping young people with disabilities to develop the skills needed for adulthood only exist in a few countries and the focus of these is primarily on further education. Often, there is a primary focus on transition planning, which is used on a voluntary basis in most countries, although is embedded in federal disability legislation in the U.S.—Individuals with Disabilities Education Act, 2004.

There is also relatively little data on how successful transition programs and support are—both in terms of short term and long-term outcomes and on what might predict successful transition. Although there is some research on models of successful transition to adulthood for young people without disabilities (19) and some predictors of successful transition to adulthood of persons with disabilities have been identified (7, 20), much less is known about the factors that determine successful transition for young people with intellectual and developmental disabilities and how to measure quality of transition support provided with participation of those who use such support. One study from Scotland evaluated a personal budget scheme used in Scotland. The results suggest that giving people a transition related personal budget can be useful, however, having access to funding is only any use if you know what you want to buy and where (15). In other countries there are specific transition support services (sometime called transition programs) to prepare young people for adulthood, but these are frequently segregated rather than integrated or inclusive. In addition, Lindsay et al. (21) reported positive impacts from a range of interventions for young persons with IDD, but there was a gap in research focusing on the types of support that work best, and how young disabled people viewed these.

So, with limited data on the impact of transition programs, no agreed definition of what success looks like and a lack of systematic strategies for assessing impact of transition support, this makes it very difficult to both develop new services and evaluate existing services and support in terms of how well they promote successful transition to adulthood. In this paper, we draw on two separate research studies to discuss a potential theoretical model for thinking about successful transition for young persons with IDD and how this might be implemented and measured. The first study (22) focused on developing a framework that could be potentially used for measuring the quality of disability services across Europe (hereafter referred to the Service Quality Framework). The second study (13) collated research, policy and information on practice and support related to transition of young people with intellectual disabilities in four countries.

2. Methods

2.1. The development of the service quality framework

The development of a theoretical outcomes-focused framework for measuring service quality was commissioned by the European Association of Service Providers for People with Disabilities

(EASPD) as a response to the new European Strategy on the Rights of Persons with Disabilities 2021–2030, which included the aim of developing a European Framework for Social Services of Excellence for Persons with Disabilities. The remit of the research was to develop a framework for measuring the quality of social services for people with disabilities and a set of quality indicators which were (a) in line with the UN CRPD and (b) focused primarily on quality-of-life outcomes. This process was seen as the first phase in an ongoing program of work that would ultimately empirically test the feasibility and reliability of the Service Quality Framework. Although the final version of the commissioned Framework (22) included domains that went beyond outcomes to include indicators of processes and structures (23), for the purposes of this paper we will focus primarily on the sections of the framework that focused on quality of life outcomes.

2.1.1. Introduction to quality of life outcomes

The concept of quality of life has a long and varied history, with varying definitions and conceptualizations used over time. Key developments in the conceptualization of QOL and service-related outcomes that led up to the production of the international consensus on Quality of Life led by Schalock et al. (24) are summarized in Schalock and Verdugo (25) and discussed further in Šiška and Beadle-Brown (22). Although recognizing that there are other frameworks of quality of life such as the ICF framework, Šiška and Beadle-Brown (22, 26) note that the ICF framework is more commonly used with reference to health-related quality of life and is also focused at a much wider systems or societal level more generally. Whilst it is important to acknowledge the interactions between wider societal aspects and individual quality of life, it was felt that, in the context of monitoring the quality of social care services, it was important to have a framework which makes it clear how services can positively influence people's outcomes and reduce the likelihood that services will attribute poorer quality of life outcomes to societal or impairment related factors. Thus, this research used the eight quality of life domains set out in the international consensus of 2002 (24)—physical well-being, emotional well-being, material well-being, social relationships, social inclusion, personal development, self-determination and rights—and drew on the conceptualization most recently summarized in Schalock and Verdugo (25).

2.1.2. The scope and methods of the service quality framework development work

The scope of the commissioned framework included the following:

- any service providing in-home support for living of any type to children or adults with disabilities living in their own home,
- any service providing short term care and support/respite/short breaks (in home or out of home)
- any service providing residential care for people with disabilities
- any service providing day activities, occupation, training for work or independent living, etc.

Services which were primarily providing support in health, education or in employment were not included in the research.

Two primary methods—a scoping review of the published literature (as described in the JBI Manual for Evidence Synthesis (27) and a template syntheses—were used to identify international literature, policy and frameworks related to measuring the outcomes of services.

2.1.3. Scoping review

The scoping review focused on identifying and clarifying how service quality had been defined and measured in the published peer-reviewed and grey international literature.

2.1.3.1. Inclusion criteria

Population—literature (including grey literature) related to people with disabilities (could include all disabilities and mental health problems).

Concept—Service quality—definitions, conceptualization and measurement. Had to include some reference to outcomes for people using services.

Context—literature (including grey literature) which explored quality of services for people with disabilities:

- in any country
- In the following types of services:
    - ○ any service providing in-home support for living of any type to children or adults with disabilities living in their own home,
    - ○ any service providing short term care and support/respite/short breaks (in home or out of home)
    - ○ any service providing residential care for people with disabilities
    - ○ any service providing day activities, occupation, training for work or independent living, etc.

Services which were primarily providing support in health, education or in employment were not included in the research.

Language—published in English.

Years—no limitation although if more than one version of a framework or model weas identified the most rest one was included.

Types of evidence—This was left open within the defined concept and context of the review to allow the findings to be as comprehensive as possible.

2.1.3.2. Search strategy

Evidence was identified through three methods:1. Academic Publication Database search using EBSCO Host, Scopus and Web-of-Science

a. using the following string of search terms: Service quality AND Disab* AND Concept* OR Defin* OR Measur*.
b. Citation searches for "Donabedian"

1. a general Google search using the same search terms to identify sources not published in academic journals such as websites, policy or guidance etc.
2. the authors' existing knowledge, academic networks and the content of a recent book on Quality in Social Services (28).

2.1.3.3. Quality assessment

Quality was not assessed as the review was identifying how service quality was defined and evaluated and we were interested in any frameworks or tools that were being used. As such sources were not exclude on the basis of quality. In reality, only a very small number of the models and frameworks identified had been evaluated empirically.

2.1.3.4. Data extraction

Out of a total of 126 publications identified for the initial review, 40 publications (covering 14 countries) were identified for inclusion in the data extraction process for the scoping review. An additional, 34 publications were used to complete the country templates for the UK, Australia, and USA (see below). Data extraction focused on identifying the frameworks used to conceptualize and measure service quality, indicators of service quality and any domains used to organize these indicators, with a particular focus on outcomes. Please note that in this context the word "indicator" is used to mean something that indicates the state or level of outcomes. These are usually characteristics, artefacts or events that can be observed or that individuals might report in terms of their experiences. It is not used to imply statistical predictability.

2.1.4. Template synthesis

For the template synthesis, a specifically designed template was used to gather and organize information from a range of 14 countries identified to represent different types of social service systems and contexts.. In the case of European countries, this template was initially sent to National Disability Experts for input who were part of European Disability Expertise network (EDE). Where no response was gained from the national experts, other contacts were approached, e.g., through European level umbrella organizations for service providers, social service directors and disabled people's organizations or family-based networks.

The country template was available in two formats—a detailed structured form guiding people with a list of questions to answer and a more open, descriptive format, if people felt there was limited information in the structured form, or they did not have sufficient time to complete the detailed version. Information about the project and instructions for completing the template were provided.

The template was designed to collate information on both formal (i.e., embedded in legislation) methods of defining and measuring quality and more informal measures, such as voluntary frameworks used by service providers, or disabled people's organisations.

Some of the country templates were completed by the research team using the information identified in the literature review specific to those countries and publicly available information (such as the DOTCOM EU disability database) and then checked with local experts where possible.

Relatively complete templates from the national experts were gained for eight countries: Germany, UK, Ireland, Romania, USA, Czech Republic, Finland, and Australia. In addition, some less detailed information was available from country experts and in written sources instead of the country templates for Sweden. Norway, Netherlands, Slovenia, and Spain.

The information gathered and organized in the templates was then reviewed and analyzed by the researchers with a focus on how service quality was conceptualized or defined, whether outcomes featured in these conceptualizations and if so, which quality of life domains were featured (even if quality of life was not specifically mentioned). The relationships with the UNCRPD were also explored. In addition, analysis focused on how service quality and outcomes are measured and whether people with disabilities and other stakeholders have been involved in the development of the frameworks and tools. Finally, innovative frameworks and tools that were in line with the objectives of this research were identified and synthesized into a separate datafile to draw out the dimensions of quality and outcomes included and how quality was measured.

2.1.5. Evidence synthesis

The information gathered from both the scoping review and template synthesis was summarized and used to identify frameworks and tools which were used to conceptualize or measure service quality, and which included at least some element that focused on outcomes.

Table 1 Summarizes the literature identified, used and the countries covered by the literature.

The 20 Frameworks identified from this strategy varied in terms of country of origin (USA, Australia, UK, Netherlands, Ireland, Czech Republic, and New Zealand; two were cross European

TABLE 1 Summary of the literature identified by the scoping review and template analysis in the development of the service quality framework.

	Number of papers
Number of peer-reviewed academic papers identified as potentially relevant on title and abstract scan	31
Number of publications identified from other sources (including grey literature)	96
Total identified for possible inclusion	**126**
Number excluded completely on reading full text	35
Number identified as relevant to introduction/background	11
Number only relevant in terms of informing methodology for framework development (i.e., they were not related to social care settings or people with disabilities but looked at methodologies for developing frameworks). Excluded for the purpose of this paper	6
Number used for detailed country templates (UK, Australia and US and not used in the more general review)	14 (UK) 17 (Australia) 5 (USA) 34 Total
Final number of papers, reports and other documents included in the review of literature on quality frameworks and indicators and data extracted	**40**
Countries from which literature on Frameworks and Indicators was included	USA Australia UK Ireland Netherlands Sweden New Zealand Lithuania Europe (generally) Serbia Canada Czechia Spain Romania Greece

measures). These 20 frameworks were then mapped onto the quality-of-life domains identified by the Schalock et al. (24) International consensus on quality of life (QoL). Only two of the identified frameworks used the domains directly. All the remaining frameworks included at least some elements that could be mapped onto at least one of the QoL domains, with some of the identified frameworks mapping to all of the QOL domains, either at the overarching domain level or at the level of individual indicators or standards. For example, on the Home and Community-based Services Outcomes (USA) National Quality Framework, the domain of social connectedness included items that mapped to both the Interpersonal Relationships and Social Inclusion domains of the QOL Framework. On the National standards for Residential services for children and adults with disabilities (Ireland), Standard 3.1 states that "Each person is protected from abuse and neglect and their safety and welfare is promoted"—this individual standard mapped onto the wider QOL domain of physical well-being. At the end of the mapping process, the 2002 QoL conceptualization was found to still be the most comprehensive and holistic framework for thinking about QoL outcomes.

Table 2 summarizes the mapping for the 20 identified frameworks or tools onto the Schalock QoL Domains.

These eight quality of life domains were therefore adopted to structure the outcomes element of Service Quality Framework (22). The potential indicators in each domain were derived from a number of sources: (1) the frameworks identified in the mapping review and template synthesis above; (2) the wider published literature and theory related to quality of life; and (3) what people with disabilities have said is important to them for a good life. Outcome indicators were provided as both subjective indicators (what people would say when asked) and objective indicators ("what you would see or hear"). **Table 3** provides an example of what this looked like for one of the quality of life domains—self-determination. In total there were 47 subjective indicators and 68 objective outcome indicators proposed.

2.1.6. Testing the content and face validity of the service quality framework

The Framework and full set of indicators were consulted on with a wide range of knowledge experts who provided feedback from a

TABLE 2 Mapping of the domains, dimensions, and indicators of each of the framework identified in the research to the schalock et al. (2002) Quality of life domains.

Framework/tool	To which Schalock et al. QoL domains could at least some domains or indicators be mapped?							
	PD	IR	R	SI	SD	MW	PW	EW
Frameworks where whole domains could be mapped								
Bigby et al. (2014, Australia)	✓	✓	✓	✓	✓	✓	✓	✓
The Quality Cube (Netherlands)	✓	✓	✓	✓	✓	✓	✓	✓
ASCOT—Social Care related quality of life (UK and internationally)	✓	✓	✓	✓	✓	✓	✓	✓
Changing our Lives Quality of life Standards (UK)	✓	✓	✓	✓	✓	✓	✓	✓
Social Services Quality Standards (Czechia)	✓	✓	✓	✓	✓	✓	✓	✓
Personal Outcomes Measure (the U.S. and internationally)	[✓]	✓	✓	✓	✓			✓
National Quality Forum framework AND the Home and Community-based Services Outcomes (the U.S.)	✓	✓	✓	✓	✓	[✓]		
National Core Indicators (the U.S.)	✓	✓		✓	✓	[✓]		✓
Quality of life Outcomes Domain Framework (Ireland)	✓	✓	✓	✓	✓	[✓]	✓	✓
Frameworks where individual indicators, standards or parts of domains could be mapped								
National standards for residential services for children and adults with disabilities (Ireland)	✓	✓	✓	✓	✓		✓	✓
EQUASS (Europe)			✓	✓	✓		✓	
Guidance on a Human Rights-based Approach in Health and Social Care Health Services. By Health Information and Quality Authority (Ireland)			✓	✓	✓		✓	
National longitudinal Transition Study (Shrogren et al) the U.S.	✓	✓			✓	✓	✓	✓
Standards New Zealand Health and disability services standard NZS 8134: 2021	✓	✓	✓	✓	✓	✓	✓	✓
Quality of life impact of services tool (QOLIS) (Europe)	✓	✓		✓	✓	[✓]		✓
Šiška et al. (2021, Czech Republic)	✓	✓	✓	✓	✓	✓	✓	✓
National Standards for Disability services (Australia)	✓		✓	✓	✓		✓	
NDIS Practice Standards and Quality Indicators (Australia)		✓	✓		✓	✓	✓	✓
Person-centred advocacy, vision, and education (the U.S.)	✓	✓	[✓]	✓	✓	[✓]	✓	[✓]

SD, self-determination; MW, material well-being; R, rights; PD, personal development (including meaningful occupation); PW, physical well-being; SI, social inclusion; IR, interpersonal relationships; EW, emotional well-being; [✓], link is indirect or related to one indicator only (e.g., employment).

TABLE 3 Example of how the framework was set out, showing one quality of life domain (self-determination) and the corresponding indicators.

QoL domain	Self-reported indicators—what we would like the people in receipt of services to say?	Objective indicators—what would we see and hear?
Self-determination/ autonomy	• I have choice and control over the big things in life—where I live, who I live with, where I work, how I spend my money, who provides my support and what they help me with.	• Individuals are offered the opportunity and supported to express preferences and make choices about day-to-day aspects of their lives. • Staff use appropriate communication to support choice and respect people's decisions. • People's choices and preferences guide what staff do rather than staff preferences and agendas. • People are helped to understand and predict what their day will be like. • Individuals are supported to understand what is involved in bigger life decisions, with information provided in an accessible way. • Where people might find it difficult to make such decisions, services ensure that the person's will and preference, based on experience of supporting the individual over time as well as their previous choices and decisions, is used to guide decisions. • Individuals have access to independent help such as an advocate to ensure their views are heard.
	• I have control over my day-to day life—what I do, where I go, what I eat and drink, when I do things, how I do things.	
	• I am provided information about choices, decisions, or opportunities in a form that I understand.	
	• I have a way to communicate my needs, wishes and decisions that works for me.	
	• People listen when I tell them or show them what I want.	
	• I have help (e.g., an advocate), if I need it, to let others know what I want and need.	
	• I attend meetings about my care and support and am involved in planning my life and my support.	• Individuals are involved in a meaningful way in identifying goals and aspirations during planning processes. • Individuals are supported to be attend and participate in their planning meetings.
	• I get help to achieve the goals I want to achieve.	
	• I am treated as an individual.	• People are treated as individuals rather than being seen as part of a group of "residents" or "service users". They are not "forced" to do things with others because of how the service is organised.

range of different perspectives. Stakeholders included members of the EASPD task force group on disability service quality, other service providers, academics, representatives of disabled peoples' organizations and family members of people with IDD. Stakeholders came from a range of different countries across Europe as well as more widely. Several elements of the Delphi technique were used during the process to arrive at a group opinion. These included an online survey, individual consultation *via* email or in person and discussion or individual feedback *via* the group facilitator following a presentation. The feedback provided by the stakeholders was systematically analyzed and considered during preparation of the final set of proposed indicators. More information on the findings from the consultation and the detailed resulting framework with all indicators can be found in Šiška and Beadle-Brown (22). Identifying the indicators of transition success.

In terms of indicators of transition success, this paper primarily draws on a mapping of literature, policy and practice in four countries (USA, UK, Czech Republic and Australia). This mapping study combined two methods—template syntheses and rapid literature review. The five members of the research team working on this were all researchers with national and international expertise in the field. Each member drew on their existing knowledge of policy, practice and research on transition in their respective countries and conducted a rapid literature search to identify further resources relevant to transition in their country. Search terms to identify both peer reviewed and grey literature were kept broad (for example, disab* and transition). A template to collate and summarize the information gathered was developed collaboratively and completed by each member of the team for the relevant country.

These four templates were then reviewed by one member of the team who extracted key information into an Excel spreadsheet so that it could be synthesized across countries. The elements most relevant to this paper related to: how transition is defined or conceptualized; models that support successful transition; and the focus of research on transition within each country. As part of the extraction process, gaps in information were identified and the experts asked to add missing information specific to the identified gaps.

3. Linking the indicators of transition success to the service quality framework

In this section we will expand and reflect on some of the specific outcomes-based domains and indicators from the Service Quality Framework described above and identify their potential relevance to conceptualizing and supporting successful transition. We will consider how it might be helpful to think about successful transition as the young person moving towards having similar opportunities and QoL as adults without disabilities living in the same community/society. This doesn't mean that everyone's life is the same, but that people have the same opportunities to explore, and then to follow, what is important to them and what they need to do to achieve the things that are important to and for them.

Table 4 provides a summary of the mapping of the transition success indicators identified in the literature and the QoL domain indicators from the Service Quality Framework.

3.1. Transition success indicator: employment and financial independence

Considering first the transition indicator of having a job (employment). Employment is considered important in several ways—it is widely recognized that having meaningful ways to spend your time is good for both *personal development* and *emotional well-being*. Also important for emotional well-being is the structure and routine that having a job often gives. Of course, paid employment is also important for *material well-being*, the ultimate level of which would be financial independence. Finally, paid employment is also considered important in many societies as a way of contributing to society—e.g., by paying taxes, national insurance etc.- thus employment can also be important for people to be seen as active citizens, accessing their *rights* and being *socially included*. This has the unfortunate effect of setting up those who are not able to take up paid employment for health or disability reasons or because of caring responsibilities, in a negative light. There are many barriers to young people with IDD accessing and keeping employed positions, many of which are nothing to do with the needs, skills, and motivation of the individuals themselves (18). Although around two thirds of people with learning disabilities in the UK report that they would like to be in paid employment, Mencap's 2019 survey in the UK found that only 23% percent of people with intellectual disability (aged 18–64) have a paid job and for 62% of those with a paid job, they worked for 16 h a week or less.[1] Although 77% of autistic adults in the UK want paid employment, the Office of National Statistics report on Outcomes for Disabled People in the UK 2020, found that autistic people are the least likely to be in work than any other disabled group with just under 22% in employment. Even in the US where the focus is more on transitioning to employment, only 34% of people with ID (aged 21–64) are employed and approximately half of these work in a sheltered setting rather than in open employment (29).

TABLE 4 Summary of transition success indicators and the QoL domain indicators.

Indicators of transition success	QoL Domains
Having a job (employment) Financial independence	Direct: Personal development (including meaningful occupation). Material well-being, security Indirect: Emotional well-being Social relationships Social inclusion
Independent living/moving out of the family home	Material well-being Rights Self-determination/autonomy
Further education	Personal Development
Growing your social networks, relationships and being part of your community	Social relationships Social inclusion
Physical and mental health/well-being	Physical well-being Emotional well-being *These two effect on people's ability to do some of the things that impact on other elements of QoL.*

Lecerf (30) notes that just over half of people with a disability are employed compared to three quarters of people without disabilities. Women with disabilities, young disabled people and those with high support needs are the most likely to be excluded from the labour market. Vaalavuo (31) commented that an increasing number of Europeans are working part-time. However, for persons with disabilities part-time work might be the only available option due to health issues or/and work-limitations. In addition to decreasing availability, part-time jobs are often of lower quality with lower hourly wages, provide poorer training and career opportunities, and, in the long run, reduce pension entitlements.

Even once they have got a job, retaining that job is often an issue (32). Education and training programs related to employment do not always result in jobs for people (18). In many countries, there is also what is sometimes called the "benefit trap"—where earning a salary can mean people lose their benefits and regaining benefits is extremely difficult to do should someone lose their job or find they cannot cope with the job they took on. These issues have been accentuated by the financial crisis and the COVID pandemic (29, 33). Lack of accessibility of environments, transport, communications in the workplace, lack of structure and guidance can also have negative impact—ensuring people have reasonable accommodation is a key part of the *Rights* domain of QoL.

Another issue that can limit the possibilities for people to access paid work, is the limited range of jobs that are sometimes considered as suitable or accessible for individuals with IDD. Examples of creative approaches we have come across in practice include options such as developing a small business (e.g., a window cleaning, car cleaning business, catering business, gardening services, dog walking business); job sharing (for example a newspaper round) amongst those who live together; being a local rep for a catalogue company; providing office services such as shredding, copying etc.

Whilst supporting young people to access paid employment in a way that ensures their needs are met is clearly desirable, focusing on other ways to ensure personal development, social inclusion and emotional wellbeing whilst looking for paid employment is also really important—voluntary work, helping out neighbors or

---

[1] https://www.mencap.org.uk/about-us/what-we-think/employment-what-we-think

looking after pets, caring for their own home and garden, growing fruit and veg to help save money on shopping, making things like cards, presents, baking for friends, family or charities, taking part in sports and other leisure activities, being part of clubs and groups such as choirs, art groups, dance troupes, theatres, etc.

3.2. Transition success indicator: independent living/moving out of the family home

Living independently doesn't necessarily mean that you are living on your own and without support. It is about, at the same age as most of your peers, moving into a home you consider your own, even if you are sharing with others, with the support you need to have your needs met and to participate in your local community as fully as possible. It is about having choice over where you live and with whom you live and not having your support tied to your place of living so that you can move and take your support with you, or you can change who provides your support without having to change where you live. Of course, the age at which this happens for young people without IDD varies by country, culture, financial status etc. However, those with IDD are more likely to remain living in their family home or to move into congregate settings than even those with other disabilities (34). In terms of choice, there is little research on choice over living situation and support arrangements and most of what there is more than 10 years old. However, the literature that does exist suggests that the majority of people with intellectual disabilities do not experience choice and control over living arrangements or support arrangements (3, 35–37).

In terms of mapping to the QoL outcome domains and indicators, moving out of the family home and living independently in the community, with choice about where and with whom you live and who provides your support, is an indicator of the QoL domains of *personal development*, *material well-being* and *self-determination*.

3.3. Transition success indicator: further education

This element of transition success is most clearly linked to the QoL domain of "*personal development*". It is most commonly associated with formal processes such as attending adult education classes, college or university, but also participating in an internship or apprenticeship. Being able to attend the same further education venues as your peers is an important right but also is associated with barriers in terms of knowledge and attitudes of teachers, accessibility of environments, etc. In addition, personal development can also be achieved through many more informal opportunities to learn and to practice skills you already have so that you develop and experience success. This in turn is related to "*emotional well-being*", in particular self-esteem and confidence.

3.4. Transition success indicator: growing your social networks, relationships and being part of your community

Needing no detailed explanation, these indicators of transition success are clearly linked to the QoL domains of "*social relationships*" and "*social inclusion*". Thinking about these domains as broadly as possible can facilitate people to come into contact with a wider range of people in the community more often, can help change attitudes towards people with IDD when people are seen contributing to society in some way and allow people to show their skills and personalities. This in turn may open doors to opportunities for employment, new relationships, and new ways to be part of society and increase people's sense of belonging and emotional well-being.

However, at an even more basic level, young people need to feel they can trust those who provide support for them especially at this relatively traumatic time. So just ensuring young people are being listened to, respected, and have the freedom and support to make decisions about relationships is a key aspect of becoming an adult.

3.5. Transition success indicator: physical and mental health/well-being

We have identified above several ways that other elements of transition may be connected to emotional well-being. However, it is also important to ensure that people's physical and mental health is being promoted and protected as much as possible in order to ensure they are able to engage with opportunities for occupation, participation, relationships, inclusion etc. If people's health care needs are not being met, then holding down a job is likely to be relatively impossible for them. A key point here, however, is the fact that the process of transition is seen as a very stressful one for both young people and their families (38, 39). This is particularly true for young people who are autistic (40). Putting things in place to make the process as easy as possible for both will ensure people start off on a "good foot" in terms of adult life.

3.6. Additional elements of transition to adulthood—decision making and autonomy

One important element of becoming an adult that is rarely explored in research to date is the issue of supporting independence in decision making, legal capacity, having personal relationships, having a family and how we can prepare young people with IDD for those events and opportunities. For many young people with IDD they may not have very much decision making experience by the time they legally become an adult and they may have little experience of different options for work, living, education, activities, etc. to help them make decisions. When thinking about whether people are becoming self-determined adults, then the QoL Framework gives us some indications of how we would know whether this was happening. It also sensitizes those who provide support to know what they should be aiming to help people achieve and experience (See **Table 2**).

4. Conclusion

This paper set out to discuss the potential application of an outcomes-based Framework focused on the Quality of Services for people with disabilities to the conceptualization and evaluation of successful transition. We have proposed that using a the framework by mapping its indicators onto the QOL domains could potentially provide a more holistic, comprehensive and inclusive way of examining transition success and at the quality of transition services. Whilst indicators such as employment and further education are important, so are people's experiences while accessing these and so are good outcomes in other domains. For example, someone could have a paid job but continue to live in a larger institutional setting with no choice about where they live and who they live with or on what to spend their money. Or someone could go to college and do a course they are interested in but find it very stressful and experience bullying while there. For some people, finding paid jobs in the open market or a place at mainstream college will be much harder and take longer to arrange, more funding to support etc. However, this doesn't mean that they can't experience a wide range of opportunities for meaningful occupation that improve all other QoL domains and may even lead to an income with enough creativity from those who provide support.

If this QOL focused Service Quality framework was to be adopted as a way to judge whether young people have successfully transitioned to adulthood (taking account of cultural differences and individual preferences) or to judge the quality of transition services, then this would have a number of implications.

4.1. Implications for research

Firstly, although the original Schalock et al. (24), Quality of Life framework used to organize and structure the outcomes elements Service Quality Framework used for this theoretical discussion, is a well-established and validated framework, the Šiška and Beadle-Brown (22) Service Quality Framework still needs to be empirically tested. The original development work on the Service Quality Framework explored face and content validity, but establishing the feasibility, reliability and other aspects of validity of the framework to allow service providers, quality assessors and researchers to use it to measure service quality is still needed. Although there are a number of existing subjective measures looking at the QOL outcome domains, there are few tools that allow assessment of the objective indicators. Future research should prioritize establishing the feasibility, useability and reliability of the Service Outcomes framework. Such research could usefully include services supporting young people with IDD leading up to and through the transition from school, allowing the validity of the suggestions made in this discussion paper to be tested empirically.

Secondly, as it would be a more holistic and wider view of transition success, such a framework could potentially allow more people with IDD to be evaluated to be experiencing successful transition to adulthood in more life areas, even if they are not working or attending post-secondary education. However, this would require the use of a wider range of research measures, both subjective and objective, with evidence of validity and reliability. Some elements of the framework are likely to be best evaluated using observational measures, which carries implications in terms of project duration, costs, and potentially ethical approval. However, observational methods are already well established in the field of IDD research and quality evaluation (41) with particular importance when gathering the experiences of people with more severe intellectual disability.

4.2. Implications for practice

The use of such a wide and holistic framework for conceptualizing transition is likely to mean that a greater number of agencies would need to be involved, working in partnership, and over a longer period of time, with a greater focus on starting transition planning and preparation for adulthood at an earlier stage.

Supporting transition to adulthood is an ongoing process and needs to be built up over quite a long time. This would mean that schools and potentially families and children's services would have an even more important role in preparing young people for adult life and would potentially require curriculum and support content to be modified. Families are likely to need support as they rarely have access to the training and other forms of support available to staff in schools and other services. They may also have been led by professionals and others to have low expectations of their son or daughter and may need help to see the potential the person has.

Although there is not a lot of literature focused on the factors that bring about successful transition outcomes, the research that does exist suggests that key factors might include young people having experience of different jobs to help them decide what they might like to do after school (42) and good co-ordination between educational system and the labour marker (18). In transition from child to adult health services, Kerr et al. (43) found validating evidence for three of the eight interventions reviewed—an early start to the transition process, developing adolescent/young adult autonomy and the role of parents/carers. The importance of effective communication between healthcare professionals and the adolescent/young adult and their parents/carers was also highlighted. It is conceivable that these interventions are much more general and not specific to health contexts and this tie into the findings from Garrels and Sigstad (15).

The frequent focus of the literature has been on good transition planning. However, planning on its own is not enough (15). Some literature has suggested that giving people a transition related personal budget can be useful. However, having access to funding is only any use if you know what you want to buy and you have a range of good quality options from which to purchase. Looking at the wider literature in terms of improving people's QoL is helpful here—to improve people's quality of life, we know that the nature of the support provided is key (see, for example 41). Support needs to be enabling and empowering, giving people many opportunities to engage in meaningful activities and interactions in ways that are manageable for them, providing just enough of the right support so that people can gain the experience they need to make choices and decisions, can develop their skills, and can become a full and active citizen. For many people this needs to happen consistently over quite a long period of time.

To ensure young people experience successful outcomes as they transition to adulthood, schools, colleges, and transition support services where they exist would need to be paying attention to all of these things. This may require changes in the training of teachers and staff at transition services. It also may require changes in policy and resource planning and allocation systems. Systems and frameworks used to assess quality may also need to be adapted. However, having a QoL based framework for measuring quality of services supporting young people and for adult support settings, may help to reduce the gap or indeed the steep divide that often exists when young people reach 18 (17). It might also help to reduce the experience of families coming up against a "cliff edge" or of entering a "black hole" (44).

Author contributions

The authors confirm contribution to the paper as follows: study conception and design, data collection: analysis and interpretation of results: JŠ and JB-B; draft manuscript preparation: JŠ, JB-B and ŠK. All authors contributed to the article and approved the submitted version.

Funding

Work on this article was supported by the Czech Science Foundation. The project name: PEDAL, project ID 22-26896S.

Acknowledgments

The authors would like to acknowledge Renáta Tichá and Brian Abery for initiating this special issue.

Conflict of interest

Publisher's note

References

1. Ravenscroft J, Wazny K, Davis JM. Factors associated with successful transition among children with disabilities in eight European countries. *PLoS One*. (2017) 12(6): e0179904. doi: 10.1371/journal.pone.0179904

2. United Nations Convention on the Rights of Persons with Disabilities (December 13, 2006).

3. Šiška J, Beadle-Brown J, Káňová Š, Šumníková P. Social inclusion through community living: current situation, advances and gaps in policy, practice and research. *Social Inclusion*. (2018) 6(1):94–109. doi: 10.17645/si.v6i1.1211

4. Ormston R, Eunson J, McAteer G. Improving outcomes for people with learning disabilities: Opportunities and challenges for housing. Key Findings and Recommendations. Ipsos MORI Scotland (2017). Available at: https://www.scld.org.uk/wp-content/uploads/2017/10/Improving-Outcomes-key-findings.pdf

5. Kaehne A, Kiernan J, Ridley J. Systematic review of study designs and methods in health transition research for young people with intellectual disabilities. *Heliyon*. (2019) 5(11):e02750. doi: 10.1016/j.heliyon.2019.e02750

6. Sullivan WF, Heng J, Abells D, Perry A, Henze M. Supporting adults with intellectual and developmental disabilities to cope and thrive through transitions to later-life phases. *Can Fam Physician*. (2019) 65(Suppl 1):S30–2.

7. Mazzotti VL, Rowe DA, Kwiatek S, Voggt A, Chang W, Fowler C, et al. Secondary transition predictors of postschool success: an update to the research base. *Career Dev Transit Except Individ*. (2021) 44(1):47–64. doi: 10.1177/2165143420959793

8. Wehman P. *Life beyond the classroom: Transition strategies for young people with disabilities*. 3rd edn. Baltimore: Paul H. Brookers Publishing (2001).

9. Wehman P, Schall C, Carr S, Targett P, West M, Cifu G. Transition from school to adulthood for youth with autism Spectrum disorder. *J Disabil Policy Stud*. (2014) 25 (1):30–40. doi: 10.1177/1044207313518071

10. Settersten RA, Ray B. What's going on with young people today? The long and twisting path to adulthood. *Future Child*. (2011) 20:19–41. doi: 10.1353/foc.0.0044

11. Dispenza F. Empowering the career development of persons with disabilities (PWD). *J Career Dev*. (2019) 48(5):670–85. doi: 10.1177/0894845319884636

12. Morwane RE, Dada S, Bornman J. Barriers to and facilitators of employment of persons with disabilities in low- and middle-income countries: a scoping review. *Afr J Disabil*. (2021) 10:833. doi: 10.4102/ajod.v10i0.833

13. Šiška J, Tichá R, Stancliffe R, Beadle-Brown J, Abery B, Káňová Š. Transition to where and to what: mapping the current situation, advances and gaps in policy, practice, and research on transition for students with IDD across four countries. Submittted to the Journal of Policy and Practice in Intellectual Disability.

14. France A, Threadgold S. Youth and political economy: towards a bourdieusian approach. *J Youth Stud*. (2016) 19(5):612–28. doi: 10.1080/13676261.2015.1098779

15. Pearson C, Watson N, Gangneux J, Norberg I. Transition to where and to what? Exploring the experiences of transitions to adulthood for young disabled people. *J Youth Stud*. (2021) 24(10):1291–307. doi: 10.1080/13676261.2020.1820972

16. Bradshaw J. Ensuring quality in practice—person-centred approaches. In: J Šiška, J Beadle-Brown, editors. *The development, conceptualisation and implementation of quality in disability support services*. Prague: Karolinum Press (2021).

17. Maniatopoulos G, Le Couteur A, Vale L, Colver A. Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's To adults' services for young people with long-term health conditions in England. *J Health Serv Res Policy*. (2018) 23(2):107–15. doi: 10.1177/1355819617752744

18. Garrels V, Sigstad HMH. Employment for persons with intellectual disability in the nordic countries: a scoping review. *J Appl Res Intellect Disabil*. (2021) 34:993–1007. doi: 10.1111/jar.12880

19. McNeil B, Reeder N, Rich J. *A framework of outcomes for young people*. UK: The Young Foundation (2012). https://youngfoundation.org/wp-content/uploads/2012/10/Framework-of-outcomes-for-young-people-July-2012.pdf

20. Test DW, Mazzotti VL, Mustian AL, Fowler C, Kortering L, Kohler P. Evidence-Based secondary transition predictors for improving postschool outcomes for students with disabilities. *Career Dev Except Indi*. (2009) 32(3):160–81. doi: 10.1177/0885728809346960

21. Lindsay S, Lamptey D-L, Cagliostro E, Srikanthan D, Mortaji N, Karon L. A systematic review of post-secondary transition interventions for youth with disabilities. *Disabil Rehabil*. (2018) 41(21):2492–505. doi: 10.1080/09638288.2018.1470260

22. Šiška J, Beadle-Brown J. *(Tech.). Innovative frameworks for measuring the quality of services for persons with disabilities*. Brussels, Belgium: EASPD (2021).

23. Donabedian A. *Explorations in quality assessment and monitoring*. Health Administration Press (1980).

24. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. Conceptualization, measurement, and application of QoLfor persons with intellectual disabilities: report of an international panel of experts. *Ment Retard.* (2002) 40 (6):457–70. doi: 10.1352/0047-6765(2002)040<0457:cmaaoq>2.0.co;2

25. Schalock RL, Verdugo MA. Quality of life as a change agent. In: RI Brown, RM Faragher, editors. *Quality of life and intellectual disability: knowledge application to other social and educational challenges*. New York: Nova Science Publishers (2014). p. 19–34.

26. Šiška J, Beadle-Brown J. *Innovative framework for measuring the quality of services for persons with disabilities. EASPD. International conference: quality of life & support services: from words to action*; October 13, 2022; Malta (n.d.).

27. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Chapter 11: scoping reviews (2020 version). In: E Aromataris, Z Munn, editors. *JBI Manual for evidence synthesis*. Prague: JBI (2020). Available at: https://synthesismanual.jbi.global. doi: 10.46658/JBIMES-20-12

28. Šiška J, Beadle-Brown J. *The development, conceptualisation and implementation of quality in disability support services*. Karolinum Press (2021).

29. Siperstein GN, Parker RC, Drascher M. National snapshot of adults with intellectual disabilities in the labor force. *J Vocat Rehabil.* (2013) 39(3):157–65. doi: 10.3233/jvr-130658

30. Lecerf M. Employment and disability in the European Union—European Parliament (n.d.). Available at: https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/651932/EPRS_BRI(2020)651932_EN.pdf (Retrieved April 10, 2022)

31. Vaalavuo M. Part-time work: A divided Europe. Employment, Social Affairs & Inclusion—European Commission (2016). Available at: https://ec.europa.eu/social/main.jsp (Retrieved March 10, 2022)

32. Kocman A, Fischer L, Weber G. The Employers' perspective on barriers and facilitators to employment of people with intellectual disability: a differential mixed-method approach. *J Appl Res Intellect Disabil.* (2018) 31:120–31. doi: 10.1111/jar.12375

33. Linehan C, Birkbeck G, Araten-Bergman T, Baumbusch J, Beadle-Brown J, Bigby C. COVID-19 IDD: findings from a global survey exploring family members' and paid staff's Perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities (IDD) and their caregivers. *HRB Open Res.* (2022) 5:27. doi: 10.12688/hrbopenres.13497.1

34. Šiška J, Beadle-Brown J. Progress on deinstitutionalisation and the development of community living for persons with disabilities in Europe: are we nearly there? *Disabil Soc.* (2022):1–20. doi: 10.1080/09687599.2022.2071676

35. Stancliffe RJ, Lakin KC, Larson S, Engler J, Taub S, Fortune J. Choice of living arrangements. *J Intellect Disabil Res.* (2011) 55:746–62. doi: 10.1111/j.1365-2788.2010.01336.x

36. Hatton C, Watters J. *National personal budgets survey 2013: summary of main findings and next steps.* Lancaster: Lancaster University and In Control (2013).

37. Söderström S, Tøssebro J. *Innfridde mål elelr brudte visjoner [fulfilled ideals or broken promises]*. Trondheim: NTNU Social Research (2011).

38. Codd J, Hewitt O. Having a son or daughter with an intellectual disability transition to adulthood: a parental perspective. *Br J Learn Disabil.* (2020) 49(1):39–51. doi: 10.1111/bld.12327

39. Biswas S, Tickle A, Golijani-Moghaddam N, Almack K. The transition into adulthood for children with a severe intellectual disability: parents' views. *Int J Dev Disabil.* (2016) 63(2):99–109. doi: 10.1080/20473869.2016.1138598

40. Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism Spectrum disorders: review and recommendations. *Focus on Autism Other Dev Disabil.* (2009) 24(2):77–88. doi: 10.1177/1088357608329827

41. Mansell J, Beadle-Brown J. *Active support enabling and empowering people with intellectual disabilities*. Jessica Kingsley Publ (2012).

42. Bigby C, De Losa L. After-school jobs for students with intellectual disabilities. La Trobe. Report (2021). doi: 10.26181/60876b527487b

43. Kerr H, Widger K, Cullen-Dean G, Price J, O'Halloran P. Transition from children's To adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison. *BMC Palliat Care.* (2020) 19(115):1–11. doi: 10.1186/s12904-020-00620-2

44. Broach S, Clements LJ. *Disabled children: a legal handbook*. Legal Action Group (2020).

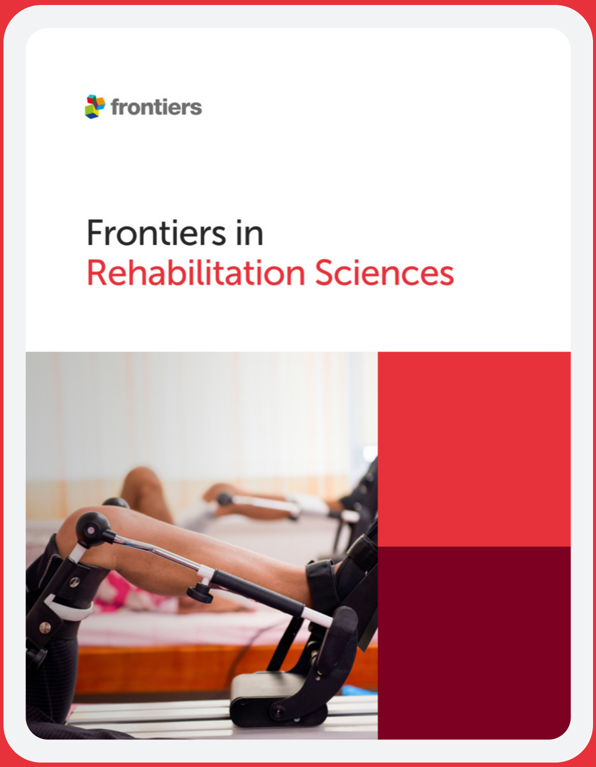
Frontiers in Rehabilitation Sciences

Innovations in optimizing functioning for people who experience disability

An innovative journal which investigates new ways to optimize the functioning and wellbeing of people who experience disability, focusing on rehabilitation as the health strategy of the 21st century.

Discover the latest Research Topics

See more →



frontiers

Frontiers in
Rehabilitation Sciences

Frontiers

Avenue du Tribunal-Fédéral 34
1005 Lausanne, Switzerland
frontiersin.org

Contact us

+41 (0)21 510 17 00
frontiersin.org/about/contact

frontiers | Research Topics