REPORT

Assessing Outcomes Relevant for Patient-Centered Outcomes Research Among Adults Aged 18–64 with Disabilities and Federal Data Infrastructure Opportunities

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health and Human Services

by
NORC at the University of Chicago

August 2023

Office Of The Assistant Secretary For Planning And Evaluation

The Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of the U.S. Department of Health and Human Services (HHS) on policy development in health, disability, human services, data, and science; and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

The Office Of Health Policy

The Office of Health Policy (HP) provides a cross-cutting policy perspective that bridges Departmental programs, public and private sector activities, and the research community, in order to develop, analyze, coordinate and provide leadership on health policy issues for the Secretary. HP carries out this mission by conducting policy, economic and budget analyses, assisting in the development and review of regulations, assisting in the development and formulation of budgets and legislation, and assisting in survey design efforts, as well as conducting and coordinating research, evaluation, and information dissemination on issues relating to health policy.

The Office of Behavioral Health, Disability, and Aging Policy

The Office of Behavioral Health, Disability, and Aging Policy (BHDAP) focuses on policies and programs that support the independence, productivity, health and well-being, and long-term care needs of people with disabilities, older adults, and people with mental and substance use disorders. The Division of Disability and Aging Policy, within BHDAP, is responsible for policy and data development, coordination, research and evaluation of policies and programs focused on the functioning and well-being of persons with disabilities and older adults. The Division is the focal point for cross-cutting disability and aging collaboration within the Department and across other federal agencies. Alzheimer's disease and related dementias and intellectual and developmental disabilities, including autism spectrum disorder, are notable areas of engagement and expertise.

Office Of The Secretary – Patient-Centered Outcomes Research Trust Fund

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) was established as part of the 2010 Patient Protection and Affordable Care Act and is charged to build data capacity for patient-centered outcomes research. Coordinated by ASPE on behalf of the Department, OS-PCORTF has funded a rich portfolio of projects to meet emerging U.S. Department of Health and Human Services policy priorities and fill gaps in data infrastructure to enhance capabilities to collect, link, and analyze data for patient-centered outcomes research. For more information, visit https://aspe.hhs.gov/collaborations-committees-advisory-groups/os-pcortf

necessarily represent the views of HHS, ASPE, or NORC. Readers should not interpret any statement in this product as an official position of ASPE or of HHS.

CONTRIBUTING AUTHORS

Mithuna Srinivasan, PhD, Principal Research Scientist, NORC
Frances Jiménez, MPH, Senior Research Associate II, NORC
Avantika Shah, MPH, Research Scientist, NORC
Rachel Kane, BS, Senior Research Associate I, NORC
Madjid Karimi, PhD, CPH, Health Science Analyst, ASPE
Prashila Dullabh, MD, Vice President and Senior Fellow, NORC

PROJECT OFFICERS AND PROJECT LEADERSHIP

Sara Wei (ASPE)
Susan Lumsden (ASPE)
Madjid Karimi (ASPE)
William Marton (ASPE)
Prashila Dullabh (NORC)
Rina Dhopeshwarkar (NORC)
Mithuna Srinivasan (NORC)

Table of Contents

Table of Exhibits

Executive Summary

Background. This review identifies individual-level measures for conducting patient-centered outcomes research (PCOR) relevant to adults with disabilities, aged 18–64 years. The review assesses gaps in the outcome measures that can inform opportunities and priorities to enhance the related federal data infrastructure (that is, expanding national data collection programs, tools, or existing measures to systematically measure and track outcomes important to individuals with disabilities, through standardized data capture, data linkage, and measure development). Our work builds on prior ASPE reports that describe: (1) the current landscape of available federal data, and (2) data infrastructure available for conducting PCOR related to people with intellectual and development disabilities (ID/DD). The current review is not limited to individuals with ID/DD, since most outcome measures are relevant for many types of disability.

Objective of the Study. To facilitate PCOR on individual-level outcomes of adults with disabilities, aged 18–64 years, by reviewing the literature on the outcomes as well as related data considerations.

Methods. We performed a targeted web-based environmental scan of peer-reviewed and gray literature to identify articles that describe outcome measures potentially suitable for PCOR among adults with disabilities aged 18–64. First, we searched PubMed and Google Scholar for PCOR scientific and gray literature using pre-specified search terms. We identified additional gray literature by searching selected agency websites under the U.S. Department of Health and Human Services and the websites of other organizations contributing to PCOR measure development or validation. Second, we performed a two-step article screening process that involved a title/abstract review, followed by full-text screening of the retained articles according to pre-specified inclusion/exclusion criteria. Finally, we conducted backward searching of the references of included articles, to include any additional relevant articles. Information from included articles was abstracted into a spreadsheet inventory. We identified a total of 43 articles (33 peer-reviewed and 10 gray literature) that described potential person-centered outcome measures for the population of interest.

Results. We identified six broad outcome domains relevant to PCOR for adults with disabilities from prior research, including: (1) social and community engagement; (2) choice and control; (3) employment and self-sufficiency; (4) privacy, rights, and human security; (5) health-related social needs; and (6) health and wellbeing. We identified 32 sources of measures across the domains that included standardized tools/instruments, routinely fielded surveys, and administrative datasets. Four data tools (Personal Outcomes Measures, the National Core Indicators-Intellectual and Development Disabilities Survey, the National Core Indicators Aging and Disability Survey, and the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Survey) included at least one measure within each domain.

Conclusion. A wide range of outcome measures and data sources relevant to PCOR for adults with disabilities currently exist; however, important gaps remain. Gaps include: (1) a shortage of standardized measures (and standardized data collection tools); (2) methodological concerns about the reliability and validity of existing measures; (3) infrequent inclusion of personal preferences in outcome measures; and (4) a general lack of capture for multiple outcome domains in existing data sources. Federal interagency collaborations can play an important role in enhancing the available data infrastructure by facilitating longitudinal data linkages and outcomes assessment across a person's lifespan.

Introduction

Since 2010, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) has managed the Office of the Secretary's Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) on behalf of the United States (U.S.) Department of Health and Human Services (HHS). The OS-PCORTF aims to strengthen capacity for the collection, linkage, and analysis of high-quality data for conducting rigorous patient-centered outcomes research (PCOR). In 2019, Congress reauthorized the OS-PCORTF for 10 additional years and identified improving health for individuals with intellectual and developmental disabilities (ID/DD) as a priority area.[1]

Under the ID/DD PCOR priority area, ASPE published two reports (in 2021[2] and 2022[3]) to identify opportunities to advance data infrastructure that enables PCOR for people with ID/DD. The first report reviewed the current landscape of federal data available to advance PCOR that addresses the needs of the ID/DD population and identified 23 short- and long-term opportunities to build data capacity in the field. The second report built on the first report's findings by collecting input from a wide range of stakeholders to prioritize the short-term opportunities previously identified and noting corresponding activities for OS-PCORTF to pursue. In the second report, an identified priority was to improve the capture and collection of standardized person-centered outcome measures important to people with ID/DD. Stakeholders described four domains in which standardization, improved linkage, and measure development are especially needed: (1) abuse, neglect, harm, and exploitation; (2) justice involvement; (3) quality of life and wellbeing; and (4) employment and self-sufficiency. Our report extends ASPE's work further by comprehensively exploring outcome domains deemed important to adults aged 18-64 with disabilities, as well as identifying gaps in outcome measures. The results of our environmental scan are intended to inform ASPE's data infrastructure development strategy that enables PCOR for the population with disabilities.

Patient-centered outcome measures have been defined as outcome measures that "matter most to individual patients in their day-to-day lives";[4,5] that "represent how patients feel, or function, or how they view their [quality of life] QOL"; and that are "ideally designed and chosen with patient engagement to ensure they reflect and encompass patients' priorities, preferences, beliefs, values, hopes, and needs."[4] However, our use of the term PCOR extends beyond conceptualizing an individual solely as a patient—as people with disabilities often have lifelong habilitative support to facilitate community, social, and employment integration that goes beyond the clinical supports of persons referred to as patients.[6,7] In this report, we explore measures that might prove to be relevant to PCOR that encompasses the whole person; that is, individual-level measures that might be relevant for person-centered care, that embody people as unique individuals with their own desires, needs, and preferences and that recognize the impact of "social, mental, emotional, and spiritual needs."[6] Person-centered outcome measures are based on the belief that "the person has the great understanding of themselves" and for this reason assess whether "the individual's desired outcomes and personal needs" are met.[8] Such measures capture "value-based"[9] outcomes defined by the individual as important to achieving their own goals.[8]

Building on the findings from ASPE's two prior reports,[2,3] this report summarizes the results from an environmental scan that identified: (1) outcome measures potentially relevant to answer PCOR questions about the needs of adults with disabilities aged 18–64 (adults with disabilities); and (2) gaps in these measures that can inform opportunities and priorities to enhance the standardization, linkage,

and collection of related data at the federal level. Our report focuses more broadly than on ID/DD alone, as most individual-level outcome measures are relevant to many types of disabilities.

The environmental scan explored three overarching key questions:

- What available individual-level outcome measures could advance PCOR for adults with disabilities; are standardized (that is, could be operationally defined consistently across studies and settings or estimated from data that could be collected using standardized instruments); and are used to track outcomes longitudinally (from the point of care through the person's lifespan)?
- What are the current gaps in individual-level outcome measures for PCOR among adults with disabilities?
- What gaps in the federal data infrastructure (for example, standardized data collection, data linkages, and measure development) need to be addressed to advance PCOR for this population?
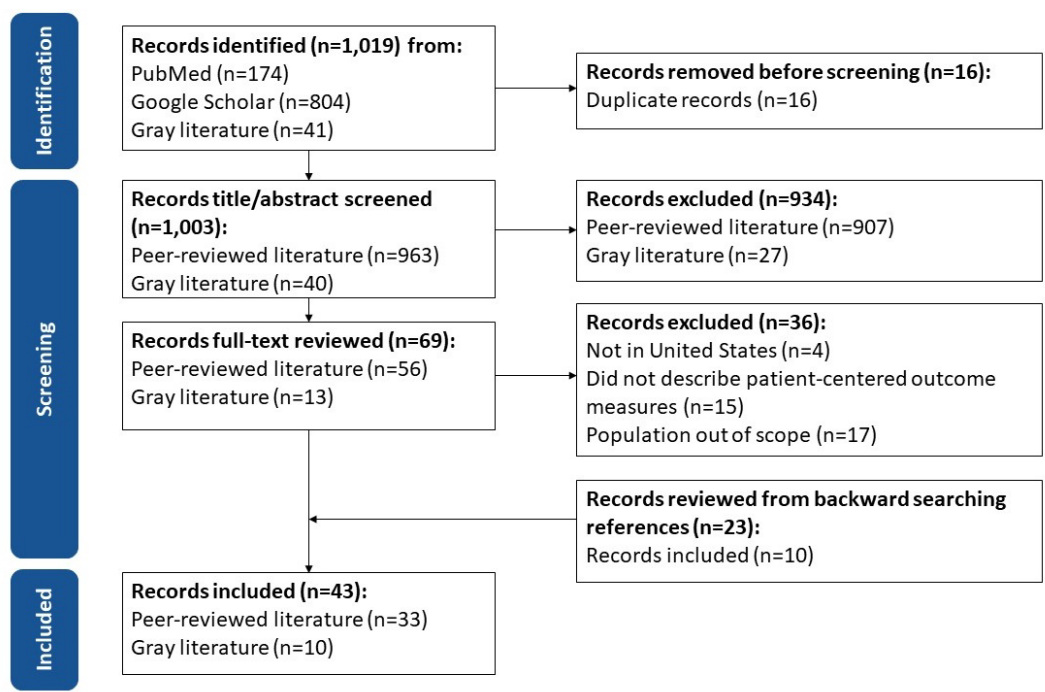
Methods

We performed a targeted web-based scan of peer-reviewed and gray literature to identify PCOR articles that: (1) describe individual-level outcome measures important to understand the health and wellbeing of adults with disabilities; and (2) identify federal data infrastructure issues. First, we used pre-specified search terms to search PubMed and Google Scholar for PCOR studies. Gray literature was identified by searching select HHS agency websites—including the Administration for Community Living (ACL), Office of the National Coordinator for Health Information Technology (ONC), National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ), Centers for Medicare & Medicaid Services (CMS), and the Centers for Disease Control and Prevention (CDC). We also searched the websites of select federal agencies and other organizations that contribute to PCOR measure development or validation—including National Core Indicators® (NCI); National Committee for Quality Assurance (NCQA); National Academies of Sciences, Engineering, and Medicine (NAM); Patient-Centered Outcomes Research Institute (PCORI); StateData.info; the National Council on Disability (NCD); and the Institute of Community Integration (ICI) at the University of Minnesota.

Our two-step article screening process involved a title/abstract review, followed by full-text screening of articles retained according to pre-specified inclusion/exclusion criteria. (For details on search terms and inclusion/exclusion criteria, please see **Appendix A**.) Then, we searched backward through the reference list of the selected articles to add any additional relevant articles. We abstracted data from the included articles and recorded the data on a spreadsheet, to describe the types and attributes of outcome measures and any information on federal data infrastructure tools and strategies available to capture such measures. The article inventory is available on https://aspe.hhs.gov/.

Exhibit 1 shows the article selection process. A total of 1,019 articles were identified initially in the search, of which 16 were dropped because of duplicates across article databases. The titles and abstracts of the remaining 1,003 articles were reviewed based on the inclusion/exclusion criteria, yielding 69 records to be retained. Articles excluded in this stage were out of scope, either because they did not have an outcome assessment focus or if they did, the articles did not focus on individual-level outcomes. Finally, we reviewed the full text of the 69 records, to yield a total of 43 articles (33 peer-reviewed, 10 gray literature).

Exhibit 1. Article Selection Process

Identification

Records identified (n=1,019) from:
PubMed (n=174)
Google Scholar (n=804)
Gray literature (n=41)

Records removed before screening (n=16):
Duplicate records (n=16)

Screening

Records title/abstract screened (n=1,003):
Peer-reviewed literature (n=963)
Gray literature (n=40)

Records excluded (n=934):
Peer-reviewed literature (n=907)
Gray literature (n=27)

Records full-text reviewed (n=69):
Peer-reviewed literature (n=56)
Gray literature (n=13)

Records excluded (n=36):
Not in United States (n=4)
Did not describe patient-centered outcome measures (n=15)
Population out of scope (n=17)

Records reviewed from backward searching references (n=23):
Records included (n=10)

Included

Records included (n=43):
Peer-reviewed literature (n=33)
Gray literature (n=10)

Findings

Below, we describe the key findings from the environmental scan as they relate to identified outcome domains, measures, and related gaps for use in PCOR among adults with disabilities.

PCOR-Relevant Outcome Domains Salient for Adults with Disabilities

Disability has been conceptualized through multiple frameworks.[10] The traditional medical model of disability focuses on treating the disability. The newer socioecological model of disability assumes the environment and society should be designed to enable people with disabilities to participate as equal members of society.[9] An even more integrative framework, the biopsychosocial model of disability, conceptualizes disability as an interaction between impairment and the physical and psychosocial environment.[10] Some researchers have suggested that the type and use of person-centered outcome measures for adults with disabilities seem to be driven by the overarching shift in conceptual framework within the field.[9]

We identified several individual-level outcome measures that may be relevant to conducting PCOR among adults with disabilities. For the purposes of this report, we classified these measures into **six outcome domains**, using an inductive approach**.** The six broad outcome domains encompass several sub-domains and measures previously identified in ASPE's reports[2,3] as important for improving PCOR, specifically for persons with ID/DD. Outcome measures identified in our report focus mostly on incentivizing equitable care based on the preferences of adults with disabilities and as such, may be relevant for person-centered care. Our literature review also identified several measurement frameworks—such as the National Quality Forum (NQF)'s guidance to HHS for assessing the quality of

home- and community-based services (HCBS) in a standardized way[11] and the National Core Indicators-Intellectual and Development Disabilities (NCI-IDD) In-Person Survey[12]—that inform our understanding of the outcome domains important to adults with disabilities. Exhibit 2 displays the six identified outcome domains, example measures, and example data sources under each domain. (See **Appendix B** for all 32 measure sources identified and the outcome domains represented within each.)

For each of the six identified outcome domains, there are measures/sub-domains and relevant data sources, as follows:

Outcome Domain 1: Social and Community Engagement. **The domain includes identified measures that assess the level at which an individual is integrated into the social fabric of the community, which is known to affect overall quality of life.** Indicators within the domain cover measure constructs such as social connectedness and relationships, participation in community activities the person finds meaningful, and a sense of belonging or inclusiveness within a community or group. Several tools exist to collect data for the domain among adults with disabilities, including: the Communicative Participation Item Bank (CPIB),[13] Patient-Reported Outcomes Measurement Information System (PROMIS) Satisfaction with Participation in Discretionary Social Activities-Calibrated Items (PROMIS SF-Social Sat DSA),[14] and the Satisfaction with Social Roles and Activities-Short Form (Neuro-QoL SF).[14] The PROMIS SF-Social Sat DSA, for example, measures individuals' satisfaction with their own social roles and participation in discretionary activities.

Broader data collection tools—such as the Personal Outcome Measures (POM),[15] NCI-IDD,[12] National Core Indicators-Aging and Disabilities (NCI-AD) Survey,[16] Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS) Survey,[17] and Participant Experience Survey (PES)[18]—also include measures related to social and community participation. The POM, for example, includes indicators on the individuals the person considers as their confidants, and if the person lives in integrated communities, by asking questions such as: "Is there someone with whom you share your personal thoughts or feelings?" or "Do you spend time in other places used by people in your community?" The HCBS CAHPS Survey and the National Core Indicators surveys include indicators on whether and how often the person gets together with family or friends.

Outcome Domain 2: Choice and Control. **The domain includes identified measures that assess the degree to which individuals (with or without support systems) have an opportunity to exercise independent decision-making, to choose and control how they satisfy their basic social and health needs, and to receive service types and levels according to their needs and preferences.** In a recent article, Isvan and colleagues utilized two NQF-endorsed scales from the NCI-IDD and NCI-AD surveys (the Life Decisions Scale and the Everyday Choices Scale) to study choice outcomes.[19] The Life Decisions Scale, for example, has questions on whether the person chose where they live or with whom.

Other standardized tools (such as the Self-Determination Inventory: Adult Report)[20] ask respondents to select their degree of agreement with statements such as: "I set my own goals" or "I make choices that are important to me." The POM and PES surveys also include measures that assess choice and control in the context of the person's personal life or that relate to the support they receive from paid staff. The

POM, for example, includes "my choices" and "my goals" as two separate factors for questions on how the person chose where to live, where to work, the services they receive, and what accomplishments please them the most.[21] The PES was developed to monitor quality in waiver programs and includes a few questions related to choice in type of staff and services a person receives, such as "Do you help pick the people paid to help you?" or "Did you know you can change the people who are paid to help you if you want to?"[18] The NCI-IDD captures documentation of guardianship status.[22]

[Outcome Domain 3: Privacy, Rights, and Human Security.](#) The domain includes identified measures that assess a person's privacy; human and civil rights; freedom from abuse, neglect, and discrimination; and involvement with the criminal justice system. We identified five standardized surveys that include measures related to the domain. The NCI-IDD survey, for example, includes privacy, safety, and human rights–related measures (such as having a key to their residence or ability to lock their door, report about feeling afraid, and report about having an opportunity to vote).[12] The POM tool also includes human security and rights (such as feeling safe, being free from abuse and neglect, being treated fairly, being respected, experiencing continuity and security, and exercising individual human rights).[21] The Persons with Disabilities Quality Survey (PDQ-S)[23] and the PES[18] include questions relevant in the context of receiving care. The PDQ-S includes questions such as if the primary care provider showed respect for the person's opinions and decisions or said or did things to make the person feel physically unsafe.[23] To give another example, the PES asks the person if their paid caregivers treated them with respect or injured them in any way.[18]

Outcome measures such as admissions and discharge from correctional facilities were also identified as important within the domain. A recent policy brief, for example, highlights the overrepresentation of people with disabilities in the criminal justice system.[24] An annual survey of state ID/DD agencies collected through the Residential Information Systems Project (RISP) currently provides this information for people with ID/DD.[24]

[Outcome Domain 4: Employment and Self-Sufficiency.](#) The domain includes identified measures that relate to understanding the current status of employment for people with disabilities, as well as other employment-related indicators that promote competitive employment opportunities for this population within community-based businesses. Measures within the domain reflect the U.S. Department of Labor Office of Disability Employment Policy's "Employment First" movement—a "national systems-change framework" based on the principle that "all individuals, including those with the most significant disabilities, are capable of full participation in competitive integrated employment and community life."[25,26]

The literature revealed a mix of self-reported employment measures and measures in administrative datasets. The NCI-IDD survey includes measures such as whether the person is seeking a paid job or has a competitive paid job within a community-based business, is expanding their skillset, or is currently satisfied with their job (if employed).[12] Winsor and colleagues assessed national trends in employment outcomes for people with ID/DD using four data sources—the National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services, the American Community Survey (ACS), the Rehabilitation Services Administration's Case Service Report (RSA-911), and the Social Security Administration Supplemental Security Income (SSI) Annual Statistical Report.[27] These data sources provide information on employment measures for this population, such as type of employment, weekly

hours worked, wages earned, enrollment and exit from vocational rehabilitation program, and receipt of SSI.

Outcome Domain 5: Health-Related Social Needs. The domain includes identified measures that assess immediate non-medical needs at the individual or family level (such as education, food security, housing stability, and access to reliable transportation and utilities). Articles identified a few tools and surveys that can be used to assess measures in the domain for the population of interest. Ellis and colleagues described the Accountable Health Communities Health-Related Social Needs (AHC HRSN) Screening tool—designed to be delivered in point-of-care settings by clinicians, to inform treatment plans and to make referrals to community services (with indicators for safe and stable housing, food security, access to reliable transportation, and utilities).[28] The AHC HRSN tool, for example, asks participants to validate statements regarding being worried about running out of food or money to buy food, or if the utility companies had threatened to shut off services within the last 12 months.

The NCI-IDD and NCI-AD surveys have indicators such as percentage of people who have adequate transportation to do the things they want outside their home or access to stable and reliable internet.[12,16] The HCBS CAHPS Survey includes a set of questions regarding having adequate transportation for medical appointments and use of transportation services (for example, ease of getting in and out of a ride and how often the ride arrived on time).[17]

Outcome Domain 6: Health and Wellbeing. The domain includes identified measures that represent self-reported assessments of overall health-related quality of life and wellbeing, as well as measures related to specific symptoms, functional status, communication capacity, and access to care. Randall and colleagues[29] recently used the Comprehensive Quality of Life Scale-Intellectual/Cognitive Disability, fifth edition (ComQol-I5) and the Personal Wellbeing Index-Intellectual Disability (PWD-ID) tools to assess quality of life and subjective wellbeing outcomes, respectively. Regarding specific symptoms, a 2017 study by Edwards and colleagues[30] also used standardized measures from PROMIS to assess resilience, fatigue, and sleep quality. Instruments used to assess functional status for this population include the Washington Group Short Set on Functioning (WG-SS)[31] and the 32-item Motor Function Measure (MFM32).[32] Our review also identified a small number of instruments related to communication capacity—such as the Communication and Language Assessment questionnaire for persons with Multiple Sclerosis (CLAMS), which assesses symptoms like word-finding difficulty, memory deficits in the verbal modality, and poor discourse structure.[33]

Standardized surveys—such as the NCI-IDD and NCI-AD, PDQ-S, HCBS CAHPS, and PES—include several measures related to overall health or access to care.[12,16–18,23] The NCI-IDD, for example, includes health and wellbeing indicators (such as report of being in a healthy weight range or of being in poor health).[12] The HCBS CAHPS has questions on overall mental and emotional health.[17] Regarding examples of outcomes on access to care, the PES includes questions about having help for activities of daily living such as bathing and dressing.[18]

Exhibit 2. PCOR-Relevant Outcome Domains, Example Measures, and Example Data Sources for Adults with Disabilities

Measure Sub-Domain/Concept	Example Outcome Measures	Example Data Sources
Outcome Domain 1: Social and Community Engagement		
Relationships	Being able to meet up with friends in person when they want	NCI-IDD[12] and NCI-AD[16]
	Frequency of getting together with family or friends who live nearby (in the last three months)	HCBS CAHPS[17]
	Having someone with whom they can share their personal thoughts or feelings	POM[21]
Community Participation	Satisfaction with participation in social roles and participation in discretionary social activities	PROMIS SF-Social Sat DSA[34]
	Report of spending time in other places used by people in their community	POM[21]
	Frequency of doing things in the community that they like	HCBS CAHPS[17]
Outcome Domain 2: Choice and Control		
Goal Setting	Report of setting their own goals	Self-Determination Inventory: Adult Report[20]
	Report of accomplishments that please them the most	POM[21]
Choices and Participation in Life Decisions	Report of making choices that are important to them	Self-Determination Inventory: Adult Report[20]
	Report of picking the place where they live	Life Decisions Scale[12]
	Report of picking the people who are paid to help them	PES[18]
	Report of perceiving that personal assistance/behavioral health staff knew (in the last 3 months) what's on their [program-specific term for "service plan"], including the things that are important to them	HCBS CAHPS[17]
Guardianship	Partial or limited guardianship	NCI-IDD[12]
Outcome Domain 3: Employment and Self-Sufficiency		
Self-Reported Employment-Related Measures	Report of taking part in activities to gain skills to expand their job opportunities	NCI-IDD[12]
	Job satisfaction	NCI-IDD[12]
Objective Employment Data	Type of employment—integrated employment, community-based non-work, and facility-based services	ICI National Survey[25]
	Hours worked and wages earned	RSA-911[25]
	Enrollment in Vocational Rehabilitation Programs	RSA-911[25]

Measure Sub-Domain/Concept	Example Outcome Measures	Example Data Sources
Outcome Domain 4: Privacy, Rights, and Human Security		
Respect	Being treated respectfully by the people paid to help them	PES[18]
Privacy and Safety	Report of feeling afraid in their home, neighborhood, transport, workplace, day program/ at other daily activity and/or other places	NCI-IDD[12]
	Report of having a key to their home	
Rights	Report of having voted or given an opportunity to vote	NCI-IDD[12]
Justice	Admissions and discharge from correctional facilities	RISP[24]
Outcome Domain 5: Health-Related Social Needs		
Housing Stability	Current living situation	AHC HRSN Screening Tool[28]
Food Security	Report of being worried (in the past year) that food would run out before they had money to buy more	AHC HRSN Screening Tool[28]
Reliable Access to Utilities	Report of having electric, gas, oil, or water company threatening to shut off services in their home (in the past year)	AHC HRSN Screening Tool[28]
Transportation	Report of not having reliable transportation to go to medical appointments, meetings, work or from getting things needed for daily living (in the past year)	AHC HRSN Screening Tool[28]
	Use of a van or transportation service (in the past 3 months)	HCBS CAHPS[17]
	Report that they have a way to get to places when they want to do something outside of the home	NCI-IDD[12] and NCI-AD[16]
Outcome Domain 6: Health and Wellbeing		
Overall Health and Wellbeing	Number of days during the past 30 days that they rated their mental health as "not good"	HR-QoL[35]
	Rating of how happy they are with their health	PWD-ID[29]
Specific Symptoms	Rating of severity of fatigue over the past week	PROMIS[34]
	Rating of quality of sleep in the past week	
Functional Status	Difficulty in basic functions such as seeing, hearing, walking	WG-SS[31]
Access to Care	Help with activities of daily living	PES[18]
Communication Capacity	Difficult thinking (in the past 4 weeks) of the particular word they want when talking to others	CLAMS[33]

Gaps in PCOR-Relevant Outcome Measures and Measurement Approaches for Adults with Disabilities

A wide range of outcome measures (and data sources) currently exist for adults with disabilities that may be relevant to PCOR and person-centered care; however, important gaps remain. We identified **five salient gaps**, listed in Exhibit 3, including: (1) a shortage of standardized measures; (2) methodological concerns about reliability and validity of existing measures; (3) infrequent inclusion of personal preferences in outcome measures; (4) a general lack of capture of multiple outcome domains; and (5) limited availability of standardized data collection tools capturing outcomes meaningful to this population across groups within the disability community.

Gap 1: Shortage of Standardized Measures within Certain Outcome Domains. We documented a few standardized measures and tools for each

> **Exhibit 3. Gaps in PCOR-Relevant Outcomes for Adults with Disabilities**
>
> **GAPS RELATED TO MEASURES**
>
> 1. Shortage of standardized measures within certain outcome domains
> 2. Methodological concerns about the reliability and validity of existing measures
> 3. Infrequent inclusion of personal preferences in outcome measures
>
> **GAPS RELATED TO DATA SOURCES**
>
> 4. Existing data sources cover limited number of outcome domains
> 5. Lack of standardized, individual-level, and longitudinal measurement tools for use across groups within the disability community

outcome domain of interest among adults with disabilities. However, **most measures either were not in widespread use in the literature or were validated only for use with a specific population within the disability community (that is, a specific condition, type of disability, or service population).** Many of the scales designed to assess a specific outcome or concept—such as the CPIB (a measure of community participation); Desired Life Outcomes Assessment Tool (DLAST, measuring HCBS toward achieving outcomes important to people with disabilities)[36]; or Connor-Davidson Resilience Scale (CD-RISC, measure of stress coping ability)—were only cited in one source article included in our review. Furthermore, researchers noted that existing tools may not capture the full range of outcomes important to adults with disabilities. Dinora and colleagues (2023) noted that measure scales for privacy rights, everyday choice, and community participation derived from the NCI-IDD Survey do not represent a comprehensive set of outcome measures potentially meaningful to people with ID/DD. Additional measures are needed.[37]

Potential improvements in transportation-related measures: Researchers have noted that measures under development and testing by the NQF HCBS Outcome Measure Framework team will assess person-centered aspects of transportation-related outcomes,[13,28] including whether their transportation meets their needs.[29]

In two areas, we observed limited measurement of individual-level standardized outcomes: (1) transportation, within the health-related social needs domain; and (2) guardianship and supported decision-making, within the choice and control domain. The NCI-IDD and NCI-AD Surveys and the HCBS CAHPS Survey ask about transportation access. But the HCBS CAHPS Survey only probes about transportation to medical appointments[17]; and the NCI Surveys ask only about having transportation access when the respondent wants or needs it.[12,16] Researchers have also called for improved

data collection of measures on the "outcomes of guardianship, supported decision-making, and other protective arrangements and alternatives."[38] The NCI-IDD survey does include questions about guardianship status, but the survey has been critiqued for not providing "a complete picture of guardianship for people with ID/DD in all states."[22] In addition, Swenson called for greater study of unintended consequences of services and programs in outcomes meaningful to people with disabilities (for example, outcomes that directly impact the person's human rights).[39]

Gap 2: Methodological Concerns about the Reliability and Validity of Existing Measures. The literature revealed several issues regarding how certain measures have been tested for reliability and validity. Bogenschutz and colleagues (2022) highlighted the dearth of high-quality psychometric measurement tools available for adults with disabilities and with ID/DD in particular.[40] Tichá (2021) also cautioned that **many measurement initiatives in the U.S. lack robust psychometric data to support use.**[36] Many existing quality of life assessment tools (for example, the Supports Intensity Scale–Adult Version) either have not been validated beyond the initial developers or have not been validated with multiple groups of people with disabilities of varying complexity.[40] In particular, HCBS CAHPS measures have been critiqued for their low validity and reliability ratings and for their lack of representative samples used in psychometric testing.[9] Researchers have also noted the cognitive bias of some scales—particularly in the assessment of self-reported health and quality of life outcomes that switch between affirmative and negatively worded language or describe nuanced concepts—making the scales less reliable measures for people with greater cognitive impairment.[14,41] A final challenge to developing measures for outcomes meaningful to adults with disabilities is how to properly operationalize complex concepts (such as self-determination, care, and community participation) that are inherently subjective.[20,42] Experts have noted the need for measures that account for varying capacities to comprehend abstract and complex outcomes.[42]

Gap 3: Infrequent Inclusion of Personal Preferences in Outcome Measures. Researchers called for further development of measurement approaches and tools to assess individuals' preferences and progress toward personal goals.[25,36,43] Several frequently used instruments (for example, NCI-IDD, NCI-ADD, POM) collect information on individual-level outcomes in several meaningful domains; however, **their measures often lack a person-driven focus (that is, failure to take into account a person's preferences and desires or whether the person has control over the activities in question).**[25,36,43]

Lack of person-driven focus in outcome measures: For example, NCI measures have been noted to ask about frequency of social participation but not to assess an individual's desired levels of participation in social activities.[15]

The Goal Attainment Scaling (GAS) tool promises to improve documentation and assessment of individuals' service- and care-related preferences and outcomes. Work is underway to use the GAS as an individual-level outcome measure to quantify progress in achieving desired goals for individuals with disabilities. In GAS, individuals identify personal goals for themselves. The tradeoff with such a personalized scale is a limit to comparability of goals between individuals and across populations.[9,44] **However, research is being conducted to improve the reliability and validity of the GAS as an outcome measure, so it can be used across settings to assess individualized outcome measures in a more standardized way**. Under the new GAS–Community-Based (GAS-CB) framework, the GAS outcome measure would assess individuals' goal attainment in five domains: employment and postsecondary

education, daily living, healthy living, social and spiritual, and safety and security. The measure would use an 80-item goal bank to create a more standardized approach to using the GAS. From the goal bank, individuals could customize goals to fit their needs and preferences.[45] Additional research is needed to better understand how to use the GAS in concert with existing standardized measures.[44]

When adults with disabilities are unavailable (for example, when hospitalized) or unable (for example, because of cognitive or functional impairments) to communicate for themselves, proxy-reporting is used.[9] However, **proxy responses often fail to accurately reflect the preferences and opinions of people with disabilities**.[9,20] The discrepancy is especially pronounced in outcomes that are more subjective and satisfaction-focused, such as self-determination,[20] quality of life,[9] social participation,[14] and health status.[41]

Use of proxy reporting: Measures derived from administrative datasets (for example, RSA-911), often include observer- or proxy-reported data. Similarly, instruments such as the HCBS CAHPS can be used with proxies if the respondent is unable to respond accurately to the questions. Other tools (for example, NCI-IDD, NCI-AD, and POM) include specific sections that contain "objective" observable measures that can be completed by a proxy or observer.

Gap 4: Existing Data Sources Cover Limited Number of Outcome Domains. Of the 32 sources of outcome measures that our review identified, **only four include at least one outcome measure within each of the six identified outcome domains.** These were the NCI-IDD and NCI-AD Surveys, POM, and the HCBS CAHPS Survey (see **Appendix B**). Almost half of the data sources (n=15) capture only outcomes for a single domain. A narrow focus on domains within a given data source limits the ability of PCOR researchers to assess a host of important outcomes across people's lifespans unless there are linkages to other data sources. Direct access to data that capture outcomes across a range of domains is important to produce more robust evidence on the impact of services, programs, or interventions for individuals with disabilities, including on outcomes relevant across the lifespan.[46,47]

Gap 5: Lack of Standardized, Individual-Level, Longitudinal Measurement Tools for Use Within the Disability Community. Given limited standardization in outcome measures, there is considerable heterogeneity in the tools used to collect data on outcome measures for adults with disabilities. **Most tools are designed and validated for use with groups of people with disabilities who are part of a specific program or who receive specific services.** In our literature search, the most frequently used data sources for secondary analyses of outcome measures (including the NCI-IDD and NCI-AD, POMs, and HCBS CAHPS) are designed to assess the quality and person-centeredness of services the HCBS population receives. Because the intended use of such measures is to understand the degree to which HCBS recipients' needs or wants are met, or if they receive supports aligned with their goals, there is limited applicability of the data beyond the HCBS population.[36]

There is limited availability of national data on individual-level outcome measures for adults with disabilities, as most national datasets aggregate measures to the state level or assess program- or system-level outcomes (for example, RSA-911, ACS, NCI-IDD and NCI-AD, ICI National Survey).[25] Additionally, **few measures captured at the national level have been used longitudinally to track individual outcomes across a person's lifespan**. Two of the most prominent national data collection tools for PCOR-relevant outcome measures for populations with disabilities—the NCI-IDD and NCI-AD— are cross-sectional surveys, so they cannot be used to track individuals' outcomes over time.[9] For

measures that can be used longitudinally—such as those derived from the POM and HCBS CAHPS—evidence is needed to demonstrate that the measures are sensitive enough to assess outcome changes over time.[9] Measures being developed under the NQF HCBS Outcome Measurement Framework are currently being tested for longitudinal use, with results forthcoming in 2023.[9]

Discussion

For the purposes of this report, we derived six outcome domains by grouping the outcomes measures that have been most commonly used or analyzed in the peer-reviewed and gray literature for adults with disabilities aged 18–64: (1) social and community engagement; (2) choice and control; (3) employment and self-sufficiency; (4) privacy, rights, and human security; (5) health-related social needs; and (6) health and wellbeing. Our review of the literature identified data infrastructure considerations that researchers have suggested to improve the development and use of standardized outcome measures for adults with disabilities and that may be suitable for PCOR studies. Such considerations fall into two categories: (1) development and use of data standards to facilitate measure standardization and harmonization across data sources; and (2) improvement of data collection systems and linkages to produce more comprehensive outcomes data that can support rigorous PCOR for adults with disabilities.

Development and Use of Data Standards to Facilitate Measure Standardization and Harmonization across Data Sources

Promoting greater consistency in operational definitions of outcome measures will promote data collection and harmonization efforts which is necessary for advancing the development of robust, national-level datasets. Standardization will greatly improve the representation of the populations studied, as well the usefulness of the data for PCOR. To support use of state-derived data for outcome assessment across states, experts recommended examining measures of health and risk factors across available data platforms to determine which can best be standardized. Future efforts would do well to expand on the strategies identified in a CDC-funded cross-state Medicaid data project. The project's goal is to harmonize data from administrative Medicaid records, all-payer claims, and state-funded service data across 10 states, using a diagnostic-based identifier for ID/DD.[48,49]

Researchers highlighted the need for measure harmonization among: (1) national surveys and surveillance systems, (2) state agency and service system data, and (3) administrative and patient-reported data.

In addition, experts identified where **new standardized outcomes measures are needed, including in employment,**[50] **transportation, and guardianship and decision-making,**[22,38] as well as more broadly to account for individuals' preferences and desired outcomes.[25,36,43] Researchers have highlighted the need to develop condition-agnostic, person-reported outcome measures to allow for outcome comparability across specific conditions.[51]

Improvements to Data Collection Systems and Linkages to Produce More Comprehensive Outcomes Data to Support Rigorous PCOR

Researchers noted that **interagency collaboration is needed to develop comprehensive data collection programs in the outcome areas of employment and guardianship.**[38,50] As noted in a 2019 report, there

is little to no collection of state and national data on guardianship status and associated outcomes, and most states lack a centralized data collection or tracking system for such outcomes.[22,38] Other researchers have called for improved systems to track and support outcomes related to competitive integrated employment for individuals with ID/DD.[50]

Experts have called for development of interagency partnerships to support longitudinal data collection and the study of outcomes for people with disabilities.[36,48] Researchers identified development of longitudinal datasets within each state that capture individual-level outcomes for all disability groups eligible for HCBS, noting this approach as the most effective strategy to increase availability of longitudinal data for HCBS recipients. In addition, experts have called for a national-level longitudinal dataset for people with disabilities who receive HCBS.[36] Such data development must be extended to people with disabilities more generally, as well as to those with specific conditions.

As noted by stakeholders, linkages need to be established across multiple datasets to capture administrative data, person-reported outcome measures, claims and service utilization, and clinical records. Researchers noted that the lack of linkages between system- and individual-level outcome metrics poses fundamental challenges to understanding the relationship between service/program participation and individual outcomes. Experts have cited several datasets that, when linked with other datasets, would provide a more comprehensive view of outcomes for adults with disabilities—including state ID/DD service agency administrative data; educational programs (for example, the Individuals with Disabilities Education Act [IDEA] database); Temporary Assistance for Needy Families (TANF); RSA-911; Medicaid and Medicare administrative data; Social Security Administration's Disability Analysis File; state All-Payer Claims Databases (APCD); NCI-IDD and NCI-AD survey data; CAHPS HCBS survey data; Behavioral Risk Factor Surveillance System (BRFSS) data; Supports Intensity Scale (SIS) data; incident reporting datasets

In comparison to using one data source alone, linking individual-level measures within surveys with administrative data allows researchers to study unique associations and control for multiple confounders.[16]

(for example, death or serious injury); Medicare Current Beneficiary Survey (MCBS); and the National Health Interview Survey (NHIS).[40,47,48,52] However, some researchers have cautioned that significant work is needed to make the data accessible to researchers, before linked datasets can be useful to researchers.[40]

Harmonized operational definitions to identify people with disabilities consistently across sources are needed to ensure accurate and complete linkages.[40,48,53] Mont and colleagues (2022) recommended identifying existing administrative data sources that capture individual-level outcome measures meaningful to this population and adding a standardized set of questions to identify people with disabilities.[53] The Washington Group Short Set on Functioning (WG-SS) is a good example of a standardized response scale that is widely used to identify people with functional limitations, one that is not specific to a certain type of disability.[31] Efforts to develop more standardized methods to identify people with disabilities will facilitate data linkages and may also help to reduce the underrepresentation of people with disabilities in studies that use administrative and clinical data.[48,53]

Stakeholders identify several key success factors to implement the improvements noted above, including building trust and relationships with key stakeholders, creating representative datasets to better understand health disparities, and addressing resource barriers. Transparent relationships

(among persons with disabilities, state and federal agencies, and researchers) are foundational to the development of ethical data linkages with stakeholders[40]—and an important activity to address the privacy and data security concerns of those providing data.[3] One such mechanism to build trust is to use research teams that include people with disabilities as research partners in the design and development of outcome measures, as well as in the actual PCOR studies.[40] In addition, experts have called for greater investment in data collection, measurement, and analysis of disparities for Black, indigenous, and people of color (BIPOC) populations within the community of people with disabilities. These groups, which have often been overlooked and underrepresented in outcomes studies, face greater health inequities compared with their White counterparts.[37,54] In recent years, PCORI has funded several projects to build capacity to include people with disabilities in research—such as Project CONNECT[55] and an Engagement and Compensation Guide for including autistic individuals throughout the research lifecycle.[56] Building trust and transparency is a time- and resource-intensive undertaking. Limited funding and personnel are often a barrier to collaboration; such barriers must be acknowledged and addressed.

Current OS-PCORTF Projects Aimed at Advancing Data Capacity for ID/DD PCOR

The OS-PCORTF is working to advance data capacity for ID/DD PCOR by funding projects that address the priorities and gaps identified through our research and in prior ASPE reports.[2,3] Two current projects are aimed at improving the visibility of people with ID/DD in datasets that can be used for PCOR, as well as the utility of outcomes data for PCOR studies:

- [Integrated Dataset on Intellectual and Developmental Disabilities (iDIDD): Linking Data to Enhance Person-Centered Outcomes Research](#) will create a publicly accessible, de-identified dataset linking several state-level sources to analyze service eligibility, utilization, and person-centered outcomes.[57]
- [Engaging People with ID/DD to Enhance Functional Disability Representation in Point of Care Settings](#) is taking the necessary first step to improve the identification of people with ID/DD in electronic health record (EHR)-derived datasets, by creating a standardized definition of functional disability to collect disability status in provider settings.

Limitations of This Study

This report is restricted to outcome measures designed for PCOR among the adult population with disabilities, aged 18–64 years. As such, the information may not have captured outcomes more relevant to other groups within the disability community (for example, older adults or youth). In addition, even within our well-defined scope, we may have missed certain data sources or measures that could be relevant to PCOR relevant to adults with disabilities. Finally, the report is based on an environmental scan of relevant peer-reviewed literature and gray literature from HHS agencies and the websites of other organizations contributing to PCOR measure development or validation. The findings were not informed by, or supplemented with, input from people with disabilities. The report serves as a starting point to identify potential data gaps or initial courses of action that can be reviewed by partners in the disability community; in turn, partners can offer additional feedback before any of the findings or data infrastructure considerations presented here are operationalized.

Conclusion

This report summarizes the current state of the literature on PCOR-relevant outcome measures for adults with disabilities and identifies six common outcome domains tracked by disability researchers. The use of person-centered outcome measures within the field of disability studies remains a relatively new concept. Several promising opportunities exist to increase adoption and use of individual-level, standardized outcome measures to study outcomes across the lifespans of people with disabilities. To ensure adoption and use of such measures, relevant stakeholders should prioritize data improvement activities related to outcomes that: (1) clinicians are able to impact,[9,28] (2) payers and regulators can support,[40] and (3) can be integrated into delivery systems.[18,36]

Our environmental scan revealed promising areas for future study. Researchers described a need for robust reliability and validity testing of existing instruments to ensure that measures used are both psychometrically valid across populations within the disability community and that assess their stated purpose.[40,58] In future research, it will be valuable to investigate specific strategies that states have used or are currently using to enhance linkage and harmonization of HCBS programmatic outcome data with other state and federal data sources. Linkage and harmonization will help identify state-level strategies that could be replicated at the federal level; federal stakeholders can then encourage access and linkage to patient-reported outcomes data for people with disabilities. Opportunities also likely exist for future collaboration with non-government entities (like the Rehabilitation Research and Training Center on HCBS Outcome Measurement) that are working to comprehensively map existing measures to NQF outcome domains.[59] Finally, as person-centered outcomes measurement for people with disabilities continues to develop, it will be valuable to promote research strategies that reduce inappropriate use of proxy-reporting for person-centered outcomes. Promising areas of future inquiry include: (1) ascertaining best practices for accessible instrument design to reduce reliance on proxy-reporting for people with cognitive or communication disabilities;[9] and (2) developing frameworks to determine clearly when proxy-reporting, rather than self-reporting, is truly merited.[41]

Appendix A. Additional Detail on Methods

Exhibit A1. Search Terms

Search Term Category	Example Terms
Patient-Centered Outcomes or Healthcare Research	"patient-centered"; "person-centered" "lived experience"; "clinical effectiveness research"; "human-centered"; "healthcare research"; equity; "patient-centered outcomes research"; "PCOR"; "person-centered outcomes research"
Disability Population	"disabled persons"[Mesh]; "disabilit*"; ID/DD; IDD; "functional limitation"; "activities of daily living"[Mesh]; NOT injury
Outcome Measures	"outcome measure"; "outcome domain"; self report*; "proxy"; "metric"; quality indicators, health care"[Mesh]
Gaps/Opportunities	"data variability"; "data heterogeneity"; "data limitations"; "data challenges"; "data linkages"; "data accuracy"[Mesh]
Data Infrastructure	"data infrastructure"; "federal data infrastructure"

Exhibit A2. Environmental Scan Inclusion and Exclusion Criteria

Category	Inclusion Criteria	Exclusion Criteria
Publication Year	2018 - present (last 5 years) for peer-reviewed research studies and gray literature in the United States (U.S.) 2013 – present (last 10 years) for systematic reviews or meta-analyses in the U.S.	Prior to 2018, if not systematic review/meta-analysis Prior to 2013, if systematic review/meta-analysis
Document Type	**Gray literature**: Reports, working papers, evaluation studies, white papers, conference proceedings, presentations, case studies, fact sheets, issue briefs, and government documents **Peer-reviewed journal articles**: Theoretical articles, primary and secondary data analyses, scoping review, meta-analyses/systematic reviews	**Gray literature**: Opinion pieces
Language	English	Non-English
Sources	Academic, expert, evaluator	News outlet
Population	Adults ages 18-64 years with disabilities	Individuals without disabilities, and individuals with disabilities who fall outside of the 18-64 age range
Focus	Research with or concerning a study for the specified population and defined (standardized) outcome measures	No discussion of (standardized) outcome measures for the specified population

Category	Inclusion Criteria	Exclusion Criteria
	Specific focus on capturing studies that represent the lived experiences of the specified population	Biomedical or genetic research; study populations defined based on clinical health records data Only a mental/behavioral health component is addressed

Exhibit A3. Peer-Reviewed Literature Searches Conducted

Search	Database	Exact Search String	Filters Applied
#1	PubMed	("Patient-centered"[All Fields] OR "lived experience"[All Fields] OR "clinical effectiveness research"[All Fields] OR "human-centered"[All Fields] OR "person-centered"[All Fields] OR "patient-centered outcomes"[All Fields] OR "patient-centered outcomes research"[All Fields] OR "person-centered outcomes research"[All Fields] OR "PCOR"[All Fields]) AND ("outcome assessment, health care"[MeSH Terms] OR ("outcome"[All Fields] AND "assessment"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "health care outcome assessment"[All Fields] OR ("outcome"[All Fields] AND "measure"[All Fields]) OR "self report*"[All Fields] OR "proxy"[All Fields] OR "metric"[All Fields] OR "quality indicators, health care"[MeSH Terms] OR "indicator"[All Fields]) AND ("ID/DD"[All Fields] OR "IDD"[All Fields] OR "disabilit*"[All Fields] OR "disabled persons"[Majr] OR "functional limitation"[All Fields] OR "activities of daily living"[MeSH Terms]) NOT ("injury"[All Fields])	2018-2023 English middle-aged, adults
#2	PubMed	("Patient-centered"[All Fields] OR "lived experience"[All Fields] OR "clinical effectiveness research"[All Fields] OR "human-centered"[All Fields] OR "person-centered"[All Fields] OR "patient-centered outcomes"[All Fields] OR "patient-centered outcomes research"[All Fields] OR "person-centered outcomes research"[All Fields] OR "PCOR"[All Fields]) AND ("outcome assessment, health care"[MeSH Terms] OR ("outcome"[All Fields] AND "assessment"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "health care outcome assessment"[All Fields] OR ("outcome"[All Fields] AND "measure"[All Fields]) OR "self report*"[All Fields] OR "proxy"[All Fields] OR "metric"[All Fields] OR "quality indicators, health care"[MeSH Terms] OR "indicator"[All Fields]) AND ("ID/DD"[All Fields] OR "IDD"[All Fields] OR "disabilit*"[All Fields] OR "disabled persons"[Majr] OR "functional limitation"[All Fields] OR "activities of daily living"[MeSH Terms]) NOT ("injury"[All Fields])	systematic reviews 2013-2023 English middle-aged, adults
#3	Google Scholar	("intellectual disability" OR "intellectual disabilities" OR "developmental disability" OR "developmental disabilities" OR "intellectual and developmental disabilities") AND "outcome measure" AND ("patient-centered outcomes research" OR "patient-centered")	Date: 2018-2023
#4	Google Scholar	(disability OR disabilities OR "people with disabilities") AND ("patient-centered outcomes research" OR PCOR OR "person-centered") AND (("data infrastructure") OR (data AND gap) AND federal) -child	Date: 2018-2023

Search	Database	Exact Search String	Filters Applied
#5	Google Scholar	(disability OR "people with disabilities") AND ("patient-centered outcomes research" OR PCOR OR "person-centered") AND (("data infrastructure") OR ("federal data")) -child	Date: 2018-2023
#6*	PubMed	("Patient-centered"[All Fields] OR "lived experience"[All Fields] OR "clinical effectiveness research"[All Fields] OR "human-centered"[All Fields] OR "person-centered"[All Fields] OR "patient-centered outcomes"[All Fields] OR "patient-centered outcomes research"[All Fields] OR "person-centered outcomes research"[All Fields] OR "PCOR"[All Fields]) AND "data infrastructure"[All Fields] AND ("ID/DD"[All Fields] OR "IDD"[All Fields] OR "disabilit*"[All Fields] OR "disabled persons"[MeSH Major Topic] OR "functional limitation"[All Fields] OR "activities of daily living"[MeSH Terms])) NOT "injury"[All Fields]	Date: 2018-2023

Search yielded zero results.

Appendix B. Outcome Domain and Outcome Measure Source Crosswalk

Outcome Measure Source	Outcome Domain Captured					
	Social and Community Engagement	Choice and Control	Employment and Self-Sufficiency	Privacy, Rights, and Human Security	Health-Related Social Needs	Health and Wellbeing
Standardized Measure Tools/Instruments						
Personal Outcome Measures®[21]	X	X	X	X	X	X
Fatigue Symptoms and Impacts Questionnaire - Relapsing Multiple Sclerosis (FSIQ-RMS)[60]	X					X
Connor-Davidson Resilience Scale[61]						X
PROMIS Scales[34]	X					X
Patient Health Questionnaire-9[62]						X
Accountable Health Communities Health-Related Social Needs (AHC HRSN) Screening Tool[28]			X	X	X	X
Supports Intensity Scale-Adult Version[37]						X
Self-Determination Inventory System: Adult Report[20]		X				
Communication Participation Item Bank (CPIB)[63]	X					
Washington Group Short Set on Functioning Basic Version (WG-SS)[31] and Enhanced Version (WG-ES)[64]						X
Desired Life Outcomes Assessment Tool (DLAST)[36]		X				X
Neuro-QoL[65]	X					X
32-Item Motor Function Measure (MFM 32)[32]						X
Communication and Language Assessment Questionnaire for Persons with Multiple Sclerosis (CLAMS)[33]						X
Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability edition (ComQoL 15)[29]	X					X
Personal Wellbeing Index – Intellectual Disability (PWD)[29]	X					X

Outcome Measure Source	Outcome Domain Captured					
	Social and Community Engagement	Choice and Control	Employment and Self-Sufficiency	Privacy, Rights, and Human Security	Health-Related Social Needs	Health and Wellbeing
Surveys						
Home and Community-Based Services Consumer Assessment of Healthcare Providers & Systems (HCBS CAHPS)[17]	X	X	X*	X	X	X
Patient Experience Survey, Elderly/Disabled Version (PES E/D)[18]	X	X		X		X
National Core Indicators-Intellectual and Development Disabilities In-Person Survey (NCI-IDD IPS)[12]	X	X	X	X	X	X
National Core Indicators Aging and Disability (NCI-AD) Survey[16]	X	X	X	X	X	X
Persons with Disability Quality Survey (PDQ-S)[23]	X	X		X	X	X
Behavioral Risk Factor Surveillance System (BRFSS)[66]					X	X
Nationwide Adult Medicaid CAHPS[67]						X
ICI's IDD Agency National Survey of Day and Employment Services (ICI National Survey)[25]			X			
National Health Interview Survey (NHIS)[68]					X	X
National Health and Nutrition Examination Survey (NHANES)[69]			X		X	X
Medicare Current Beneficiary Survey (MCBS) [52]						X
American Community Survey (ACS) (linkage)[25]			X			
Medical Expenditures Panel Survey (MEPS)[70]						X
Administrative Datasets						
Rehabilitation Services Administration Case Service Report (RSA-911)[25]			X			
Residential Information Systems Project (RISP) Survey of State ID/DD Agencies[24]				X	X	
Social Security Administration (SSA) Disability Analysis File[71]			X			

*HCBS CAHPS has a supplemental employment module

Appendix C. Glossary of Acronyms

Acronym	Definition
ACS	American Community Survey
AHC	Accountable Health Communities
APCD	All-payer claims database
BNE	Built and natural environmental
BRFSS	Behavioral Risk Factor Surveillance Survey
CAHPS	Consumer Assessment of Healthcare Providers & Systems
CD-RIS	Connor-Davidson Resilience Scale
CLAMS	Communication and Language Assessment questionnaire for persons with Multiple Sclerosis
CPIB	Communicative Participation Item Bank
ComQol-I5	Comprehensive Quality of Life Scale-Intellectual/Cognitive Disability, fifth edition
DLAST	Desired Life Outcomes Assessment Tool
FSIQ-RMS	Fatigue: Fatigue Symptoms and Impacts Questionnaire-Relapsing Multiple Sclerosis
GAS	Goal Attainment Scaling
GAS-CB	Goal Attainment Scaling–Community-Based
HCBS	Home and community-based services
HCBS CAHPS	Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services
HRSN	Health-related social needs
ICI	Institute for Community Integration, University of Minnesota
ICI National Survey	National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services
ID/DD	Intellectual and developmental disabilities
IDEA	Individuals with Disabilities Education Act
MCBS	Medicare Current Beneficiary Survey
MEPS	Medicare Expenditures Panel Survey
MFM32	32-item Motor Function Measure
NCI	National Core Indicators
NCI-AD	National Core Indicators-Aging and Disabilities Survey
NCI-IDD	National Core Indicators-Intellectual and Developmental Disabilities Survey
NCQA	National Committee for Quality Assurance
Neuro-QoL SF	Satisfaction with Social Roles and Activities-Short Form
NHANES	National Health and Nutrition Examination
NHIS	National Health Interviewer Survey
NQF	National Quality Forum
PDQ-S	Persons with Disabilities Quality Survey
PES	Participant Experience Survey
PES E/D	Participant Experience Survey, Elderly/Disabled Version
POM	Personal Outcome Measures®
PROM	Patient-reported outcome measure
PROMIS	Patient-Reported Outcomes Measurement Information System

Acronym	Definition
PROMIS SF-Social Sat DSA	Patient-Reported Outcomes Measurement Information System (PROMIS) Satisfaction with Participation in Discretionary Social Activities–Calibrated Items
PWD	People with disabilities
PWD-ID	Personal Wellbeing Index-Intellectual Disability
QoL	Quality of Life
RISP	Residential Information Systems Project Survey of state ID/DD agencies
RSA-911	Rehabilitation Services Administration's Case Service Report
SDOH	Social determinants of health
SIS	Supports Intensity Scale
SMA	Spinal muscular atrophy
SSA	Social Security Administration
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families
WG-ES	Washington Group Extended Set on Functioning
WG-SS	Washington Group Short Set on Functioning-Basic Version

References

1. *Further Consolidated Appropriates Act, 2020.*; 2019.
   https://www.congress.gov/116/plaws/publ94/PLAW-116publ94.pdf

2. Dhopeshwarkar R, Heaney-Huls K, Hovey L, Leaphart D, Dullabh P. Considerations for Building Federal Data Capacity for Patient-Centered Outcomes Research Related to Intellectual and Developmental Disabilities. Office of the Assistant Secretary for Planning and Evaluation; 2021. Accessed May 16, 2023. https://collections.nlm.nih.gov/catalog/nlm:nlmuid-9918367687806676-pdf

3. Dhopeshwarkar R, Rotondo C, Jimenez F, et al. Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities. Office of the Assistant Secretary for Planning and Evaluation; 2022. Accessed May 16, 2023. https://aspe.hhs.gov/sites/default/files/documents/dab8370bf95a35d678e6968de86f9ecd/idd-opportunities.pdf

4. Aronson KI, Danoff SK, Russell AM, et al. Patient-centered Outcomes Research in Interstitial Lung Disease: An Official American Thoracic Society Research Statement. *Am J Respir Crit Care Med*. 2021;204(2):e3-e23. doi:10.1164/rccm.202105-1193ST

5. Frank L, Basch E, Selby JV. The PCORI Perspective on Patient-Centered Outcomes Research. *JAMA Netw Open*. 2014;312(15):1513-1514. doi:10.1001/jama.2014.11100

6. Kumar R, Chattu VK. What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care! *Journal of Family Medicine and Primary Care*. 2018;7(3):487. doi:10.4103/jfmpc.jfmpc_61_18

7. Starfield B. Is Patient-Centered Care the Same As Person-Focused Care? *The Permanente Journal*. 2011;15(2):63-69. doi:10.7812/TPP/10-148

8. Schalock RL, Luckasson R. Enhancing research practices in intellectual and developmental disabilities through person-centered outcome evaluation. *Res Dev Disabil*. 2021;117:104043. doi:10.1016/j.ridd.2021.104043

9. Roberts MA, Abery BH. A person-centered approach to home and community-based services outcome measurement. *Frontiers in Rehabilitation Sciences*. 2023;4. Accessed April 11, 2023. https://www.frontiersin.org/articles/10.3389/fresc.2023.1056530

10. Petasis A. Discrepancies of the Medical, Social and Biopsychosocial Models of Disability; A Comprehensive Theoretical Framework. *International Journal of Business Management and Technology*. 2019;3(4). https://www.theijbmt.com/archive/0928/1686534688.pdf

11. National Quality Forum. *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement*. National Quality Forum; 2016. Accessed May 16, 2023. https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_Measurement.aspx

12. National Association of State Directors of Developmental Disabilities Services, Human Services Research Institute. NCI IDD Indicators. Published online August 2021. Accessed May 19, 2023. https://legacy.nationalcoreindicators.org/upload/aidd/NCI_IDD_Indicators_FINAL_21-22.pdf

13. Baylor C, Eadie T, Yorkston K. The Communicative Participation Item Bank: Evaluating, and Reevaluating, Its Use across Communication Disorders in Adults. *Semin Speech Lang*. 2021;42(3):225-239. doi:10.1055/s-0041-1729947

14. Espiritu EW, Michaels NN, Schmidt K, et al. Comparing self-reported vs. parent/caregiver reported levels of social participation for young adults with intellectual disabilities: A pilot study. *J Intellect Disabil*. 2022;26(4):885-899. doi:10.1177/17446295211037223

15. Friedman C. The personal outcome measures(®). *Disabil Health J*. 2018;11(3):351-358. doi:10.1016/j.dhjo.2017.12.003

16. National Association of State Directors of Developmental Disabilities Services, Human Services Research Institute. 2021-22 NCI-AD Indicator Crosswalk. Published online September 8, 2021. Accessed May 18, 2023. https://nci-ad.org/images/uploads/NCI-AD_Indicators_w_NCI_and_PCP.pdf

17. Centers for Medicare & Medicaid Services. CAHPS® Home- and Community-Based Services Survey. medicaid.gov. Published January 19, 2017. Accessed May 19, 2023. https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-english.pdf

18. Lipson DJ. Person-Reported Outcome Measures for Home and Community-Based Services. Mathematica; 2019.

19. İsvan N, Bonardi A, Hiersteiner D. Effects of person-centred planning and practices on the health and well-being of adults with intellectual and developmental disabilities: a multilevel analysis of linked administrative and survey data. *Journal of Intellectual Disability Research*. 2023;n/a(n/a). doi:10.1111/jir.13015

20. Shogren KA, Rifenbark GG, Hagiwara M. Self-Determination Assessment in Adults With and Without Intellectual Disability. *Intellectual and Developmental Disabilities*. 2021;59(1):55-69. doi:10.1352/1934-9556-59.1.55

21. The Council on Quality and Leadership. Personal Outcome Measures Factors and Indicators. Council on Quality and Leadership. Published March 2020. Accessed May 19, 2023. https://www.c-q-l.org/wp-content/uploads/2020/03/CQL-Personal-Outcome-Measures-Factors-And-Indicators.pdf

22. National Council on Disability. Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities. National Council on Disability; 2019. www.ncd.gov

23. Donelan K, Chang Y, Matulewicz H, Warsett K, Heaphy D, Iezzoni LI. Care Plans, Care Teams, and Quality of Life for People with Disabilities. *J Gen Intern Med*. 2020;35(8):2274-2280. doi:10.1007/s11606-020-05908-w

24. Neidorf j. *OVERREPRESENTATION OF PEOPLE WITH IDD MOVING BETWEEN LARGE STATE-RUN INSTITUTIONS AND THE CRIMINAL LEGAL SYSTEM*. Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota; 2023. https://ici.umn.edu/series/10

25. Nord D. *A Review of Commonly-Used State Employment Measures in Intellectual and Developmental Disability Services*. Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota; 2012.

26. Office of Disability Employment Policy. Employment First. DOL. Accessed June 21, 2023. http://www.dol.gov/agencies/odep/initiatives/employment-first

27. Winsor J, Timmons J, Butterworth J, et al. *StateData: The National Report on Employment Services and Outcomes Through 2018*. Institute for Community Inclusion (UCEDD), University of Massachusetts Boston; 2021.

28. Ellis L, Kogan R, Hanson L. A Guide to Using the Accountable Health Communities Health-Related Social Needs Screening Tool: Promising Practices and Key Insights. Centers for Medicare and Medicaid (CMS); 2022. https://innovation.cms.gov/media/document/ahcm-screeningtool-companion

29. Randall KN, Bernard G, Durah L. Association between employment status and quality of life for individuals with intellectual or developmental disability. *J Appl Res Intellect Disabil*. 2023;36(2):270-280. doi:10.1111/jar.13053

30. Edwards KA, Alschuler KA, Ehde DM, Battalio SL, Jensen MP. Changes in Resilience Predict Function in Adults With Physical Disabilities: A Longitudinal Study. *Archives of Physical Medicine and Rehabilitation*. 2017;98(2):329-336. doi:10.1016/j.apmr.2016.09.123

31. Washington Group on Disability Statistics. The Washington Group Short Set on Functioning (WG-SS). Published online October 11, 2022. Accessed May 16, 2023. https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Washington_Group_Questionnaire__1_-_WG_Short_Set_on_Functioning__October_2022_.pdf

32. Duong T, Braid J, Staunton H, et al. Understanding the relationship between the 32-item motor function measure and daily activities from an individual with spinal muscular atrophy and their caregivers' perspective: a two-part study. *BMC Neurol*. 2021;21(1):143. doi:10.1186/s12883-021-02166-z

33. El-Wahsh S, Bogaardt H, Kumfor F, Ballard K. Development and validation of the communication and language assessment questionnaire for persons with multiple sclerosis (CLAMS). *Mult Scler Relat Disord*. 2020;43:102206. doi:10.1016/j.msard.2020.102206

34. HealthMeasures. Available Promis Measures For Adults. HealthMeasures by Northwestern University. Published August 5, 2022. Accessed May 19, 2023. https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures

35. Cree RA. Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics — United States, 2018. *MMWR Morb Mortal Wkly Rep*. 2020;69. doi:10.15585/mmwr.mm6936a2

36. Tichá R, Abery B. Measuring Outcomes of People with Disabilities in the US: Current Challenges and Opportunities. In: Šiška J, Beadle-Brown J, eds. *The Development, Conceptualisation and Implementation of Quality in Disability Support Services*. 1st ed. Charles University in Prague, Karolinum Press; 2021:291-312. Accessed April 17, 2023. https://karolinum.cz/en/books/siska-the-development-conceptualisation-and-implementation-of-quality-in-disability-support-services-25178

37. Dinora P, Prohn SM, Bogenschutz M, Broda MD, Lineberry S, West A. An Examination of Support Needs, Supports, and Outcomes for People With Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities*. 2023;61(1):65-78. doi:10.1352/1934-9556-61.1.65

38. Guardianship and Alternatives: Protection and Empowerment. Published online March 30, 2023:8. Accessed May 19, 2023. https://www.aging.senate.gov/download/testimony_shogren-03302023

39. Swenson S. Don't Look Down: The Limits of Meroscopic Measurement. *Frontiers in Rehabilitation Sciences*. 2022;3. Accessed April 14, 2023. https://www.frontiersin.org/articles/10.3389/fresc.2022.873325

40. Bogenschutz M, Dinora P, Lineberry S, Prohn S, Broda M, West A. Promising Practices in the Frontiers of Quality Outcome Measurement for Intellectual and Developmental Disability Services. *Frontiers in Rehabilitation Sciences*. 2022;3. Accessed April 11, 2023. https://www.frontiersin.org/articles/10.3389/fresc.2022.871178

41. Shogren KA, Bonardi A, Cobranchi C, et al. State of the Field: The Need for Self-Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities. *Policy Practice Intel Disabi*. 2021;18(4):286-295. doi:10.1111/jppi.12386

42. National Disability Authority. *Outcome Measurement in Evaluating the Quality of Disability Services*. National Disability Authority; 2019. https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fnda.ie%2Fuploads%2Fpublications%2Foutcome-measurement-in-evaluating-the-quality-of-disability-services.docx&wdOrigin=BROWSELINK

43. DuBois L, Tennety N, Roiter S, et al. Person-centered measures of Home- and Community-Based Services: Identifying approaches to measuring outcomes, services, and supports. Published online December 24, 2022:2022.12.22.22283875. doi:10.1101/2022.12.22.22283875

44. 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. *Intellectual and Developmental Disabilities*. 2021;59(1):7-21. doi:10.1352/1934-9556-59.1.7

45. Eun Lee C, Shogren KA, Segal J, Pezzimenti F, Aleman-Tovar J, Taylor JL. Goal Attainment Scaling – Community-Based: A new method to incorporate personalized outcomes into intervention research with youth and adults on the autism spectrum. *Autism*. 2022;26(1):178-187. doi:10.1177/13623613211024492

46. National Academies of Sciences E, Sciences D on E and P, Division H and M, et al. *Priority Areas for the PCOR Data Infrastructure*. National Academies Press (US); 2022. Accessed April 11, 2023. https://www.ncbi.nlm.nih.gov/books/NBK584415/

47. Dinora P, Bogenschutz M, Broda M. Identifying Predictors for Enhanced Outcomes for People With Intellectual and Developmental Disabilities. *Intellect Dev Disabil*. 2020;58(2):139-157. doi:10.1352/1934-9556-58.2.139

48. Bonardi A. Enriching Our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities.; 2019. https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

49. McDermott S, Royer J, Cope T, et al. Using Medicaid Data to Characterize Persons With Intellectual and Developmental Disabilities in Five U.S. States. *Am J Intellect Dev Disabil*. 2018;123(4):371-381. doi:10.1352/1944-7558-123.4.371

50. Barth S, Lewis B, Simmons T. Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences. Health Management Associates; 2020.

51. Cohen ML, Hula WD. Patient-Reported Outcomes and Evidence-Based Practice in Speech-Language Pathology. *Am J Speech Lang Pathol*. 2020;29(1):357-370. doi:10.1044/2019_AJSLP-19-00076

52. Centers for Medicare and Medicaid (CMS). *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources*. Centers for Medicare and Medicaid; 2020.

53. Mont D, Madans J, Weeks JD, Ullmann H. Harmonizing Disability Data To Improve Disability Research And Policy. *Health Affairs*. 2022;41(10):1442-1448. doi:10.1377/hlthaff.2022.00479

54. Caldwell J, Machledt D. Advancing Policy and Practice in Medicaid Home and Community-Based Services Quality. *Frontiers in Rehabilitation Sciences*. 2022;3. Accessed April 11, 2023. https://www.frontiersin.org/articles/10.3389/fresc.2022.876871

55. Patient-Centered Outcomes Research Institute. Project CONNECT. Published August 19, 2022. Accessed June 23, 2023. https://www.pcori.org/research-results/2022/project-connect

56. Stephen Shore, Teal Benevides. Autistic Adults and other Stakeholders Engage Together: Engagement & Compensation Guide (Version 2.1). Published December 2018. Accessed June 23, 2023. https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf

57. Office of the Assistant Secretary for Planning and Evaluation. Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research. ASPE. Accessed May 19, 2023. https://aspe.hhs.gov/dataset-intellectual-developmental-disabilities-linking-data-enhance-person-centered-outcomes

58. Heinemann AW, Lai JS, Wong A, et al. Using the ICF's environmental factors framework to develop an item bank measuring built and natural environmental features affecting persons with disabilities. *Qual Life Res*. 2016;25(11):2775-2786. doi:10.1007/s11136-016-1314-6

59. Rehabilitation Research and Training Center on HCBS Outcome Measurement. NQF Outcome Domains. Institute on Community Integration at the University of Minnesota. Accessed May 19, 2023. https://rtcom.umn.edu/database/domains

60. Hudgens S, Schüler R, Stokes J, Eremenco S, Hunsche E, Leist TP. Development and Validation of the FSIQ-RMS: A New Patient-Reported Questionnaire to Assess Symptoms and Impacts of Fatigue in Relapsing Multiple Sclerosis. *Value Health*. 2019;22(4):453-466. doi:10.1016/j.jval.2018.11.007

61. Connor KM, Davidson JRT. Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety*. 2003;18(2):76-82. doi:10.1002/da.10113

62. Spitzer R, Williams J, Kroenke K. Patient Health Questionnaire-9 (PHQ-9). Accessed May 19, 2023. https://www.phqscreeners.com/images/sites/g/files/g10060481/f/201412/PHQ-9_English.pdf

63. Baylor C, Yorkston K, Eadie T, Kim J, Chung H, Amtmann D. The Communicative Participation Item Bank (CPIB): item bank calibration and development of a disorder-generic short form. *J Speech Lang Hear Res*. 2013;56(4):1190-1208. doi:10.1044/1092-4388(2012/12-0140)

64. Washington Group on Disability Statistics. The Washington Group Short Set on Functioning – Enhanced (WG-SS Enhanced). Published online October 11, 2022. Accessed May 19, 2023. https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Washington_Group_Questionnaire__3_-_WG_Short_Set_on_Functioning_-_Enhanced__October_2022_.pdf

65. HealthMeasures by Northwestern University. Available Neuro-QoL Measures for Adult Self-Report. Accessed May 19, 2023. https://www.healthmeasures.net/index.php?option=com_content&view=category&layout=blog&id=227&Itemid=824

66. Centers for Disease Control & Prevention. 2021 BRFSS Questionnaire. Published online June 8, 2022. Accessed May 19, 2023. https://www.cdc.gov/brfss/questionnaires/pdf-ques/2021-BRFSS-Questionnaire-1-19-2022-508.pdf

67. Centers for Medicare & Medicaid Services. Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers & Systems. CMS.gov. Published December 1, 2021. Accessed May 22, 2023. https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/LimitedDataSets/CAHPS

68. National Center for Health Statistics. National Health Interview Survey: NHIS Sample Adult and Child Questionnaires. Published online 2019. Accessed May 19, 2023. https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2019/NHIS-Adult-Child-Questionnaires-brochure-508.pdf

69. National Center for Health Statistics. National Health and Nutrition Examination Survey: 1999–2022 Survey Content Brochure. Accessed May 19, 2023. https://wwwn.cdc.gov/nchs/data/nhanes/survey_contents.pdf

70. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey. Published online 2021. Accessed May 19, 2023. https://meps.ahrq.gov/survey_comp/hc_survey/paper_quest/2021/2021_SAQ.pdf

71. Mathematica. Overview and Documentation of the Social Security Administration's Disability Analysis File (DAF) Public Use File for 2019 (PUF19). Social Security Administration; 2021. https://www.ssa.gov/disabilityresearch/documents/daf_puf/DAF19_Public%20Use%20File%20Documentation.pdf