

Article Inventory: Outcome Measures Relevant for Patient-Centered Outcomes Research Among Adults Aged 18–64 with Disabilities

This inventory includes the 43 peer-reviewed and gray literature articles that describe individual-level outcome measures potentially suitable for patient-centered outcomes research (PCOR) among adults with disabilities aged 18–64, related data infrastructure considerations, or both. This inventory accompanies an ASPE report entitled “Assessing Outcomes Relevant for Patient-Centered Outcomes Research Among Adults Aged 18–64 with Disabilities and Federal Data Infrastructure Opportunities”, which is available on: <https://aspe.hhs.gov/>. The inventory below lists each article (hyperlinked) and for each, summarizes the type of disability assessed, outcome domains and measures identified, and information available within federal data sources regarding outcome measures. Further details about the inventory are described in the report referenced above.

August 2023

PCOR-Relevant Outcome Measures within Each Reviewed Article

Article Name	Type of Disability Assessed in the Article	Outcome Domains Identified in the Article	Outcome Measures Identified in the Article	Federal Data Sources with Information on the Measure(s) Identified in the Article
A Person-Centered Approach to Home and Community-Based Services Outcome Measurement	<ul style="list-style-type: none"> ID/DD Physical disabilities 	<ul style="list-style-type: none"> Social and Community Engagement Choice and Control Employment and Self-Sufficiency Privacy, Rights and Human Security Health-Related Social Needs Health and Wellbeing 	Not mentioned	Not mentioned
Comparing Self-Reported vs. Parent/Caregiver Reported Levels of Social Participation for Young Adults with Intellectual Disabilities: A Pilot Study	ID/DD	Social and Community Engagement	<ol style="list-style-type: none"> Patient-Reported Outcomes Measurement Information System Satisfaction with Participation in Discretionary Social Activities—Calibrated Items (PROMIS SF—Social Sat DSA) Satisfaction with Social Roles and Activities—Short Form (PROMIS Neuro-QoL SF) 	PROMIS
Development and Validation of the FSIQ-RMS: A New Patient-Reported Questionnaire to Assess Symptoms and Impacts of Fatigue in Relapsing Multiple Sclerosis	Multiple Sclerosis	<ul style="list-style-type: none"> Health and Wellbeing Social and Community Engagement 	Fatigue Symptoms and Impacts Questionnaire - Relapsing Multiple Sclerosis (FSIQ-RMS)	Not mentioned
Effects of Person-Centered 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	ID/DD	<ul style="list-style-type: none"> Social and Community Engagement Choice and Control Health and Wellbeing 	<ol style="list-style-type: none"> National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) In-Person Survey (IPS) Life Decisions Scale: Who chose (or picked) the place where you live? (Did you help pick where you live?); Did you choose (or pick) the people you live with (or did you choose to live by yourself)? (Did anyone ask who you'd like to live with? Were you given choices? Did you get to interview people?); Do you choose (or pick) your staff? (Do you get to interview them? Did you get to meet different people or was someone assigned to you? Could you ask to change to someone different?); Who chose (or picked) the place you work? (Did you help make the choice?); Who chose (or picked) your day program or workshop? (Did you help make the choice?) NCI-IDD IPS Everyday Choices Scale: Do you choose what you buy with your spending money? Do not include things like rent or groceries. ; Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?; Who decides how you spend your free time (when you are not working, in school or at the day programs)? NCI-IDD IPS Satisfaction with Community Inclusion Scale: Think about how often you went shopping in the past month. Would you like to go shopping more, less or the same amount as now? ; Think about how often you went out for entertainment in the past month. Would you like to go out for entertainment more, less or the same amount as now? ; Think about how often you went to a restaurant or coffee shop in the past month. Would you like to go out to a restaurant or coffee shop more, less or the same amount as now? ; Think about how often you went to a religious service or spiritual practice in the past month. Would you like to go to religious services or 	Not mentioned

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			<p>spiritual practices more, less or the same amount as now?; Do you want to be a part of more groups in your community?</p> <p>4. NCI-IDD IPS Living a Good Life: 'Are services and supports helping you to live a good life?'</p> <p>5. NCI-IDD IPS Subjective Health Status: 'Overall, how would you describe your health?'</p> <p>6. NCI-IDD IPS Self-reported measures of Person-Centered Planning: 'Does your case manager/service coordinator ask what you want? (Does your case manager/service coordinator ask what is important to you?); 'Are you able to contact your case manager/service coordinator when you want to? (Can you talk to your case manager/service coordinator when you want to?); 'Were you able to choose the services that you get as part of your service plan?'; 'Does your service plan include things that are important to you?'</p>	
Fair-Wages for People With Disabilities: Barriers and Facilitators	ID/DD	Employment	The Personal Outcome Measures® indicator that asks if participants have access to fair-wages. Fair-wages was defined as at least minimum wage. The DV was coded as a dichotomous response (no = 0 or yes = 1).	Not mentioned
An Examination of Support Needs, Supports, and Outcomes for People With Intellectual and Developmental Disabilities	ID/DD	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Privacy, Rights, and Human Security 	<p>The NCI-IDD IPS was used to construct three outcome measures using previously validated scales for (a) privacy rights, (b) everyday choice making, and (c) community participation, each aligning with NQF domains:</p> <ol style="list-style-type: none"> 1. Privacy rights: a factor constructed from two items that assessed whether a person had a key to their residence and if they had the right to lock their bedroom door. 2. Everyday choice: opportunities to make key decisions about how they schedule daily activities and leisure or even how they spend their money. 3. Community participation was tracked by items measuring the frequency of participation in four community activities: shopping, errands, entertainment, and eating out at coffee shops and restaurants. 	Not mentioned
Self-Determination Assessment in Adults With and Without Intellectual Disability	ID	Choice and Control	Self-Determination Inventory System: Adult Report (> 21 constructs assess three domains: volitional action, agentic action, action-control beliefs)	Not mentioned
Promising Practices in the Frontiers of Quality Outcome Measurement for Intellectual and Developmental Disability Services	ID/DD	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Employment and Self-Sufficiency • Privacy, Rights and Human Security • Health-Related Social Needs • Health and Wellbeing 	Not mentioned	Not mentioned
The Communicative Participation Item Bank: Evaluating, and Reevaluating, Its Use across Communication Disorders in Adults	Communication disorders	Social and Community Engagement	The Communicative Participation Item Bank (CPIB) is a 46-item bank addressing verbal conversational situations.	PROMIS

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The Personal Outcome Measures(®)	Not specified	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Employment and Self-Sufficiency • Privacy, Rights and Human Security • Health-Related Social Needs • Health and Wellbeing 	<p>POM</p> <ol style="list-style-type: none"> 1. My human security includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people are treated fairly; people are respected; people experience continuity and security; and, people exercise rights. 2. My community includes the following indicators: people interact with other members of the community; people live in integrated environments; people participate in the life of the community; and people use their environments. 3. My relationships include the following indicators: people have intimate relationships; people have friends; people are connected to natural support networks; people decide when to share personal information; and, people perform social roles. 4. My choices includes the following indicators: people choose where and with whom to live; people choose services; and, people choose where they work. 5. My goals includes the following indicators: people realize personal goals; and, people choose personal goals. 	Not mentioned
The Social Determinants of Health Index	<ul style="list-style-type: none"> • ID/DD • Mental illness • Neurological disabilities • Cerebral palsy • Autism spectrum disorder • Personality/psychotic disorder • Impulse-control disorder • Down syndrome • Physical disabilities • Brain injury • Alzheimer’s disease or other dementia 	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Health and Wellbeing 	<p>Social Determinant of Health Index (POM)</p> <p>Choice and Engagement includes:</p> <ol style="list-style-type: none"> 1. Interact with other members of the community 2. Participate in the life of the community 3. Different social roles 4. Choose where they work 5. Choose where and with whom to live. <p>Person-Centeredness includes:</p> <ol style="list-style-type: none"> 6. Exercise rights 7. Treated fairly 8. Respected 9. Continuity and security. <p>Health and Safety includes:</p> <ol style="list-style-type: none"> 10. Best possible health 11. Safe 	Not mentioned
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	Spinal Muscular Atrophy (SMA)	Health and Wellbeing	<p>32-item Motor Function Measure (MFM32)</p> <p>Standing and transfers (13 items), axial and proximal motor function (12 items) and distal motor function (7 items)</p>	Not mentioned
Harmonizing Disability Data To Improve Disability Research And Policy	Not specified	Health and Wellbeing	<ol style="list-style-type: none"> 1. The Washington Group Short Set on Functioning (WG-SS) Basic: seeing, hearing, walking or climbing steps, remembering or concentrating, washing all over or dressing, and communicating 2. The Washington Group Extended Set on Functioning (WG-ES): psychosocial difficulties, upper body mobility, pain, fatigue, and information on the use of assistive devices 	Not mentioned

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Job Satisfaction, Quality of Work Life and Work Motivation in Employees with Intellectual Disability: A Systematic Review	ID/DD	Employment and Self-Sufficiency	<p>Measures related to Job satisfaction, Quality of Work Life, Work Motivation</p> <ol style="list-style-type: none"> Newly devised and adopted questionnaire: Occurrence of comorbid condition, education, motivation, self-esteem, self-knowledge, expectation regarding future work level, living situation, perceived support from, parents and in general, attitude of parents and social environment regarding work Unpublished online survey designed by the authors, informant based: Employment rates, type of employment, job training, job setting, job schedules and job satisfaction 	Not mentioned
Friendship, Quality of Life, and People with Intellectual and Developmental Disabilities	ID/DD	Social and Community Engagement	<ol style="list-style-type: none"> Friends Outcomes Present (POM): How do you define friendship? Who are your friends?; With whom do you like to spend time? ; What do you like to do with friends?; How often do you see your friends? ; Do you spend enough time with them?; Besides seeing your friends, what other kinds of things do you do to stay in contact? ; Do you have enough friends? Would you like more? People Have Friends (POM): With whom does the person choose to spend time?; Who are the person's friends? How do you know?; What contact does the person have with his or her friends?; Are the interactions and contacts the person has with friends similar to typical friendships that you or people you know have? Are they voluntary, mutual, and interactive?; How do you determine the importance of friendship to the person?; How do you know if the person needs support to develop or maintain friendships?; How do you determine satisfaction with the extent and frequency of contact?; Are there any barriers that affect the outcome for the person? ; How do you assist the person to overcome barriers to this outcome?; What organizational practices, values, and activities support this outcome for the person? 	Not mentioned
Development and Validation of the Communication and Language Assessment Questionnaire for Persons with Multiple Sclerosis (CLAMS)	Multiple Sclerosis	Health and Wellbeing	<p>Communication and Language Assessment Questionnaire for persons with Multiple Sclerosis (CLAMS)</p> <p>Word finding difficulty, non-specific vocabulary, memory deficits in the verbal modality, insufficient information at discourse level, distractibility in conversation, linguistic non-fluency, and poor discourse structure</p>	Not mentioned
Identifying Predictors for Enhanced Outcomes for People With Intellectual and Developmental Disabilities	ID/DD	<ul style="list-style-type: none"> Social and Community Engagement Choice and Control Privacy, Rights, and Human Security 	<ol style="list-style-type: none"> National Core Indicators-Intellectual and Development Disabilities In-Person Survey (NCI-IDD IPS) <ul style="list-style-type: none"> Community inclusion: summing four items from the NCI, each representing the number of times the respondent did the following activities in the previous month: went shopping, did errands, went out for entertainment, or went out to eat. Social participation: whether the person went shopping in the previous month, (b) whether they did errands in the previous month, (c) whether they went out for entertainment in the previous month, (d) whether they went out to eat in the previous month, (e) Whether they took a vacation in the previous year, (f) whether they have friends other than staff or family, and (g) whether they have a best friend Everyday choices: how much choice a person has to determine their daily schedule, how much choice they have in determining how to use their personal spending money, and how much choice they have to determine how to use their free time 	Not mentioned

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			<ul style="list-style-type: none"> - Rights: whether someone else could open the person’s mail, whether the person can use the phone when desired , and whether the person can be alone when desired <p>2. Supports Intensity Scale (SIS)</p> <ul style="list-style-type: none"> - Supports required by an individual in 57 life activities in the areas of home living; community living; life-long learning; employment; health and safety; social interaction; and protection and advocacy. Each activity is evaluated according to the frequency, daily support time, and type of support required by the person to participate in the activity. - 15 exceptional medical needs and 13 behavioral support needs of the individual being tested 	
Testing a Wellness Indicators Measure for People with Intellectual and Developmental Disabilities	ID/DD	Health and Wellbeing	<p>Wellness model was constructed from three clusters of NCI-IDD IPS variables:</p> <ul style="list-style-type: none"> • Mental Health: Four variables were selected for inclusion in the mental health factor: (1) presence of mood disorder (e.g., depression, bipolar disorder, etc.), (2) presence of an anxiety disorder (e.g., obsessive disorders, panic disorders, etc.), (3) presence of a psychotic disorder (e.g., schizophrenia, etc.), and (4) presence of another mental illness or psychiatric diagnosis. • Cardiovascular Health: Variables that we used were: (a) presence of cardiovascular disease (e.g., coronary heart disease, angina), (b) presence of diabetes, including Type 1 and Type 2, (c) presence of high blood pressure, and (d) presence of high cholesterol. • Behavioral Wellness: There were six variables in this subscale: (1) noted behavioral challenges (e.g., aggression, self-injurious behaviors, pica, etc.); (2) whether the person has been prescribed medication for a behavior modification purpose (e.g., stimulant, sedative, or beta-blocker to treat ADHD, aggression, self-injurious behavior, etc.); (3) whether the individual has a current behavior plan; (4) support needs for self-injurious behavior; (5) support needs for disruptive behavior; and (6) support needs for destructive behavior. All of these variables could be addressed through the NCI-IDD IPS background section. 	Not mentioned
An Item Bank to Measure Systems, Services, and Policies: Environmental Factors Affecting People With Disabilities	Neurologic disabilities	Social and Community Engagement	<ol style="list-style-type: none"> 1. Health services 2. Community living 3. Community participation resources 	Not mentioned
Using the ICF’s Environmental Factors Framework to Develop an Item Bank Measuring Built and Natural Environmental Features Affecting Persons with Disabilities	Neurologic disabilities	Health-Related Social Needs	<p>Built and Natural Environmental (BNE) Barriers Item Bank: (1) architectural features of buildings; (2) land development such as sidewalks and roadways; (3) environmental features such as noise, crowds, and indoor air quality; and (4) cognitive and sensory cues.</p>	Not mentioned

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Changes in Resilience Predict Function in Adults With Physical Disabilities: A Longitudinal Study	Physical disabilities (including multiple sclerosis, muscular dystrophy, spinal cord injury, or post-polio syndrome)	Health and Wellbeing	<ol style="list-style-type: none"> 1. Resilience (Connor-Davidson Resilience Scale): 10-item scale of: able to adapt to change, can achieve goals despite obstacles, and can handle strong feelings 2. Depression (Patient Health Questionnaire-9) 3. Fatigue (PROMIS Fatigue Short Form): assesses fatigue severity, which asked subjects to rate the severity of their fatigue over the past week using a 5-point Likert scale. Items included the following: how often did you feel tired?; how often did you run out of energy?; and how often were you too tired to bathe or shower? 4. Sleep Quality (PROMIS Sleep Disturbance): asks subjects to rate the quality of sleep they had gotten in the past week on a 5-point Likert scale. Items included the following: I had difficulty falling asleep, my sleep was restless, and I had trouble sleeping. 5. Physical Function (8-item PROMIS Physical Functioning): which asks subjects to rate how well they are able to complete certain physical tasks on a 5-point Likert scale. Items include the following: are you able to carry a bag of groceries a short distance?; and are you able to do vigorous activities, such as playing sports? 	Not mentioned
Care Plans, Care Teams, and Quality of Life for People with Disabilities	<ul style="list-style-type: none"> • Physical disabilities • Behavioral disabilities • Developmental disabilities 	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Health and Wellbeing • Health-Related Social Needs 	<p>Persons with Disability Quality Survey (PDQ-S)</p> <ol style="list-style-type: none"> 1. "I am able to get together, talk with, or chat online with other people each day." 2. "I feel free to take risks when I want to, even if some people do not agree with my choices." 3. "I do things that make me feel good about myself - such as work, school, volunteer activities, or creative projects." 4. "I decide for myself what I will do each day and when I will do it—for example, when I wake up, eat, or go to bed and what I do for fun at home or in my community." 5. "I believe my quality of life will get better in the future." 6. "I worry about keeping my housing or having a place to live." 	Not mentioned
Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics — United States, 2018	<ul style="list-style-type: none"> • Cognitive disabilities • Independent living disabilities • Mobility disabilities • Self-care disabilities • Vision disabilities • Hearing disabilities 	Health and Wellbeing	Frequent mental distress: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" (Health Related-Quality of Life Scale)	Behavioral Risk Factor Surveillance Survey (BRFSS)

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A Guide to Using the Accountable Health Communities Health-Related Social Needs Screening Tool: Promising Practices and Key Insights	Not specified	<ul style="list-style-type: none"> • Social and Community Engagement • Employment and Self-Sufficiency • Privacy, Rights, and Human Security • Health-Related Social Needs • Health and Wellbeing 	<p>Accountable Health Communities Health-Related Social Needs Screening Tool</p> <p>“What is your living situation today?”</p> <p>“Think about the place you live. Do you have problems with any of the following? Pests, mold, lead paint or pipes, lack of heat, oven or stove not working, smoke detectors missing or not working, water leaks”</p> <p>“Within the past 12 months, you worried that your food would run out before you got money to buy more.”</p> <p>“Within the past 12 months, the food you bought just didn’t last, and you didn’t have money to get more.”</p> <p>“In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting to things needed for daily living?”</p> <p>“In the past 12 months, has the electric, gas, oil, or water company threatened to shut off services in your home?”</p> <p>“How often does anyone, including family and friends, physically hurt you?”</p> <p>“How often does anyone, including family and friends, insult or talk down to you?”</p> <p>“How often does anyone, including family and friends, threaten you with harm?”</p> <p>“How often does anyone, including family and friends, scream or curse at you?”</p> <p>“How hard is it for you to pay for the very basics like food, housing, medical care, and heating?”</p> <p>“Do you want help finding or keeping work or a job?”</p> <p>“If for any reason you need help with day-to-day activities such as bathing, preparing meals, shopping, caring for children or dependents, managing finances, etc., do you get the help you need?”</p> <p>“How often do you feel lonely or isolated from those around you?”</p> <p>“Do you speak a language other than English at home?”</p> <p>“Do you want help with school or training? For example, starting or completing job training or getting a high school diploma, GED, or equivalent.”</p> <p>“In the last 30 days, other than the activities you did for work, on average, how many days per week did you engage in moderate exercise (like walking fast, running, jogging, dancing, swimming, biking, or other similar activities)?”</p> <p>“On average, how many minutes did you usually spend exercising at this level on one of those days?”</p> <p>“How many times in the past 12 months have you had 5 or more drinks in a day (males) or 4 or more drinks in a day (females)? One drink is 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of 80-proof spirits.”</p> <p>“How many times in the past 12 months, have you used tobacco products (like cigarettes, cigars, snuff, chew, electronic cigarette)?”</p> <p>“How many times in the past 12 months, have you used prescription drugs for non-medical reasons?”</p> <p>“How many times in the past 12 months, have you used illegal drugs?”</p> <p>“Over the past 2 weeks, how often have you been bothered by any of the following problems: little interest or pleasure in doing things? Feeling down depressed or hopeless?” (PHQ-2)</p> <p>“Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his or her mind is troubled all the time. Do you feel this kind of stress these days?”</p>	Not mentioned

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Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities	ID/DD	Health-Related Social Needs Employment and Self-Sufficiency	<ol style="list-style-type: none"> 1. IDEA Database: Number of children (ages 3-21) who receive special education and related services under IDEA 2. SSA Disability Analysis File: Beneficiaries with disabilities who were between the ages 18 and retirement age and who participated in the SSI and/or SSDI programs at any time between 1996 and the year of the file 	<ul style="list-style-type: none"> • The Consumer Assessment of Healthcare Providers and Systems Home and Community Based Services Survey (CAHPS HCBS) • BRFSS • NCBDDD's Disability and Health Data System (DHDS) • Social Security Administration (SSA) Disability Analysis File • National Health Interview Survey (NHIS) • Current Population Survey (CPS) • Survey of Income Program Participation (SIPP)
A Review of Commonly-Used State Employment Measures in Intellectual and Developmental Disability Services	ID/DD	Employment and Self-Sufficiency	<p>Employment in the community</p> <ol style="list-style-type: none"> 1. NCI Consumer Survey: Percent of recipients with a paid job in a community-based setting; includes supported employment, competitive employment, enclave, or work crew. 2. ICI National Survey: Percent of recipients with competitive, individual supported, group supported, and self-employment. 3. RSA-911: The percent of all recipients with intellectual disabilities with Individualized Employment Plans who were employed at case closure. 4. American Community Survey: The percentage of noninstitutionalized people with a cognitive disability, ages 18-64, in the United States who were employed in 2010 	<ul style="list-style-type: none"> • Rehabilitation Services Administration Case Service Report (RSA-911) • American Community Survey
Overrepresentation of People with IDD Moving Between Large State-Run Institutions and the Criminal Legal System	ID/DD	Privacy, Rights, and Human Security	<ol style="list-style-type: none"> 1. Percent admitted from correctional facility to large state-run institutions 2. Percent discharged to correctional facility from large state-run institutions 	Not mentioned

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Outcome Measurement in Evaluating the Quality of Disability Services	Not specified	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Privacy, Rights, and Human Security • Health and Wellbeing • Health-Related Social Needs 	<ol style="list-style-type: none"> 1. Standardized indicator: Did you choose where you live? Do you choose whom you live with? Do you have a key to your accommodation? Are you happy with your accommodation? 2. Observation: Assess if person has access to all areas in his/her home and garden and can come and go in home and garden as and when he/she appears to want to. Assess if home is adapted to his/her needs in terms of size, design, location, etc., and if person has his/her own possessions around the home. 3. Outcome predictors: Does person have access to transport and to local community facilities and to personal assistants in the community? 4. Open-ended interview questions: Do you want to move house? What are your goals? Have services supported you to attain these goals? How have they done this? 5. Standardized Indicator: Do you get up and go to bed at the time you want to? Can you eat your meals when you want to? Do you decide what activities you do during the week? 6. Observation: Staff are supporting person to express preferences and make choices about day-to-day aspects of his/her lives which mean that a person's preferences guide what staff do. Staff use appropriate communication to support choice and to respect people's decisions 7. Outcome predictor: Staff are using Active Support. The person has access to opportunities and supports to maintain and develop valued social roles in the community, in line with his/her needs and wishes. 8. Open-ended interview questions: What are your most important goals? What have services done to help you attain them? 9. Short Form-36 (SF-36) is a 36-item, person-reported survey of person health. 10. Short Form-12 (SF-12) is a multipurpose short form survey with 12 questions taken from the SF- 36 survey. 11. PROMIS Global Health-10 short form (Patient-Reported Outcomes Measurement Information System), 10 items that assess health and functioning including physical, mental and social health and pain, fatigue and overall perceived quality of life. 12. The Quality of Life Impact of Services tool (QOLIS): 8 variables assessing three domains: 1) Personal development – inter-personal relations and self-determination, 2) Social inclusion – employability, citizenship and rights, 3) Wellbeing – emotional, physical and material. 	Not mentioned
Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities	ID/DD	Choice and Control	Having a full or partial guardian or conservator	Not mentioned

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Person-Reported Outcome Measures for Home and Community-Based Services	<ul style="list-style-type: none"> • ID/DD • Physical disabilities • Severe mental illness 	<ul style="list-style-type: none"> • Social and Community Engagement • Choice and Control • Health-Related Social Needs • Privacy, Rights, and Human Security • Employment and Self-Sufficiency • Health and Wellbeing 	Not mentioned	Not mentioned
StateData: The National Report on Employment Services and Outcomes Through 2018	ID/DD	Employment and Self-Sufficiency	<ol style="list-style-type: none"> 1. ICI National Survey: Core variables include 1) the number of people served (total and by day and employment service categories), 2) number of people on waiting lists, 3) expenditures by service, and 4) total funding by source. All questions focus on community-based day or employment services monitored by the state IDD agency, including services funded by another state agency (such as the Medicaid agency). (State-level outcomes) 2. RSA-911: Successful rehabilitation: Closure with an employment outcome, including integrated employment (including supported employment), self-employment, state-agency-managed business enterprise, homemaker, and unpaid family worker. Rehabilitation rate: The percentage of individuals receiving services who achieve a successful rehabilitation. Calculated as: closures with an employment outcome / closures with an employment outcome + closures without an employment outcome after receiving services. Adjusted hourly wage, weekly work hours, time from application to exit with employment also captured. 3. Supplemental Security Income (SSI) Annual Statistical Report: reports work-incentive participation and the number of individuals receiving SSI who are working. 4. American Community Survey: Employment rate: The percentage of civilian, non-institutionalized working-age (16–64 years old) individuals who have a job. 	<ul style="list-style-type: none"> • The National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services (ICI Survey) • RSA-911 • American Community Survey • SSA Supplement Security Income File
Measuring Outcomes of People with Disabilities in the US: Current Challenges and Opportunities	<ul style="list-style-type: none"> • ID/DD • Physical disabilities • Severe mental illness 	<ul style="list-style-type: none"> • Choice and Control • Health and Wellbeing 	Desired Life Outcomes Assessment Tool (D-LAST)	Not mentioned

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Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources	<ul style="list-style-type: none"> Cognitive disabilities Physical disabilities 	<ul style="list-style-type: none"> Health-Related Social Needs Health and Wellbeing 	<p>Disability: Deafness or serious difficulty hearing • Blindness or difficulty seeing • Difficulty concentrating, remembering, or decision making, particularly due to a physical, mental, or emotional condition • Difficulty walking or climbing stairs • Difficulty dressing or bathing • Difficulty doing errands alone, including visiting a doctor’s office • Activities of daily living (ADLs) • Instrumental activities of daily living (IADLs) • Specific disability types or limitations • Aspects of health status that could relate to or be the result of a disability</p> <p>Access: Usual source of care • Receipt of preventative health services • Preventable hospitalizations • Unmet needs and barriers to care • Care-seeking behaviors • Health insurance coverage • Physical accessibility of a facility or the equipment used in a visit</p> <p>Patient Experience: Satisfaction with care • Ease of communication with providers • Difficulty obtaining needed care (including from specialists) • Wait time for appointments and providers</p> <p>Social Determinants of Health: Limited English Proficiency and language preferences • Transportation barriers • Food insecurity • Housing insecurity • Utility access</p>	<ul style="list-style-type: none"> CAHPS HCBS BRFSS NHIS
Association between Employment Status and Quality of Life for Individuals with Intellectual or Developmental Disability	ID/DD	<ul style="list-style-type: none"> Social and Community Engagement Employment and Self-Sufficiency Health and Wellbeing 	<ol style="list-style-type: none"> Employment Indicators Survey Based on NCI-IPS: Type of paid community job; Bi-weekly hours; Average hourly wage; Length of employment at current job; Receives paid time off at community job; Job industry; Has community employment plan as a goal in service plan; Takes classes, training, or does something to get a job or do better at current job; Attends a day program or workshop; Volunteers; Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability (ComQoL-15) Personal Wellbeing Index-Intellectual Disability (PWD-ID) 	Not mentioned
Person-centered Measures of Home- and Community-Based Services: Identifying Approaches to Measuring Outcomes, Services, and Supports	<ul style="list-style-type: none"> ID/DD Physical disability Psychiatric disability Age-related disability 	<ul style="list-style-type: none"> Social and Community Engagement Choice and Control Health and Wellbeing 	Not mentioned	Not mentioned
Building Data Capacity for Patient-Centered Outcomes Research: Interim Report 1—Looking Ahead at Data Needs	ID/DD	N/A	Not mentioned	Not mentioned
Patient-Reported Outcomes and Evidence-Based Practice in Speech-Language Pathology	Communication disorders	N/A	Not mentioned	Not mentioned
State of the Field: The Need for Self-Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities	ID/DD	N/A	Not mentioned	Not mentioned

Article Name	Type of Disability Assessed in the Article	Outcome Domains Identified in the Article	Outcome Measures Identified in the Article	Federal Data Sources with Information on the Measure(s) Identified in the Article
Don't Look Down: The Limits of Meroscopic Measurement	Not specified	N/A	Not mentioned	Not mentioned
Goal Attainment Scaling – Community-Based: A New Method to Incorporate Personalized Outcomes into Intervention Research with Youth and Adults on the Autism Spectrum	Autism Spectrum Disorder (ASD)	N/A	Not mentioned	Not mentioned
Goal Attainment Scaling: A Framework for Research and Practice in the Intellectual and Developmental Disabilities Field	ID/DD	N/A	Not mentioned	Not mentioned
Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences	<ul style="list-style-type: none"> ID/D Physical disabilities Severe mental illness 	N/A	Not mentioned	Not mentioned
Collaborative Design of a Health Care Experience Survey for Persons with Disability	Not specified	<ul style="list-style-type: none"> Health and Wellbeing Health-Related Social Needs 	<ol style="list-style-type: none"> 1. Person-health care interaction 2. Person factors 3. Health care 4. Physical, environmental, and social policy factors 	Not mentioned