



NCAPPS

Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Indicators

Prepared by the Human Services Research Institute
as part of NCAPPS technical assistance

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Introduction

To guide the technical assistance provided as part of the National Center on Advancing Person-Centered Practices and Systems (NCAPPS), the Human Services Research Institute conducted a national review of indicators¹ that may be used to assess person-centered principles in aging and disability systems, including mental health systems. This document was prepared to support one State's effort to evaluate person-centered practice across systems.

To ensure that person-centered principles are present in both service planning and the provision of supports across public human service systems, we need a set of indicators to gauge the degree to which these principles are being implemented. To create these indicators, we first identified the definitions of person-centered practice: In the *Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles* report, developed by NCAPPS staff, we provided an overview of criteria and definitions of person-centered thinking, planning, and practice within human service systems and organizations. Here, we present current measures and tools with indicators that align with those criteria and definitions.

At the outset, it was important to separate “person-centeredness” from basic compliance measures. Some important indicators of service quality reflect basic expectations—such as whether staff perform required tasks or address health and safety issues, or whether a case manager responds to requests in a timely fashion. In contrast, person-centered principles and practices involve expectations that focus on the person's experience and the extent to which services and supports are responsive to the person's needs, goals, and unique circumstances.

This document may serve as a useful tool for other States, Tribes, and Territories that are seeking to develop measures of person-centered thinking, planning, and/or practice based on nationally utilized tools and measures.

Process for Conducting the Scan

To generate indicators of person-centered practices, we reviewed surveys that are widely administered in human services systems, focusing on those that addressed the main principles of person-centered thinking, planning and practice as outlined in the first NCAPPS environmental scan. We did not document the psychometric properties (including the reliability and validity) of the instruments or specific indicators, as

¹ Note on terminology: This scan uses the terms “indicator” and “measure” broadly to describe a measurement of a specific concept. Survey tools highlighted in this scan may define “indicator” slightly differently. For some tools in this scan, specific questions rather than indicators are shown.

other, separate scans have reviewed available psychometric properties (e.g., <https://rtcom.umn.edu/database>).

Indicators and questions from tools included in this scan are either systems-level (used to measure of overall system performance in a specific area of concern) or individual-level (may be used to assess and/or address a person’s experiences of services and supports). Importantly, indicators included in this document are measured from the perspective of the person receiving services and/or a family member or guardian (or other who may serve as a proxy for the person where proxies are allowed).

As noted, this scan prioritized indicators specific to person-centered practices over measures of compliance. The following are the categories of indicators that *are not* included in this scan:

- **Health, safety, and security.** People have access to needed healthcare and are safe from harm.
- **Satisfaction.** People like where they live, work, and what they do during the day.
- **Support workers’ timeliness.** Support workers are present when they are supposed to be.
- **Daily Activities.** People are employed, volunteer, and/or take part in other regular daily activities.

Summary of Findings

To organize the indicators, we refined and used the seven common principles of person-centered practices to create “Domains,” as shown in Table 1.

Table 1. Domains and Indicators of Person-Centered Practices

Domain	Indicators
Focus on the person <i>There is a holistic approach to the planning process in which the person is the central focus. The person’s desires are heard, respected, valued and reflected in the services received.</i>	<ul style="list-style-type: none">• People are active members in planning services• People take part in setting and refining goals• Services and supports reflect the individual wishes and desires of people• People who are important in the lives of people receiving services are supported to be a part of their lives• People who support people receiving services are knowledgeable about the strengths and abilities of the people receiving services

Domain	Indicators
<p>Choice and self-determination</p> <p><i>People make choices about services and supports as well as their own health, well-being and life goals.</i></p>	<ul style="list-style-type: none"> • People are involved in making decisions about their services and supports • People are involved in making decisions about the people who help them • People are involved in making choices in their everyday lives
<p>Community participation</p> <p><i>People have support to participate in and to be members of their communities and are treated as equal members in their communities.</i></p>	<ul style="list-style-type: none"> • People take part in community activities • People do not experience barriers to taking part in activities in their community • People are treated equally and with respect in their communities
<p>Availability of services and supports</p> <p><i>People have access to an array of individualized services that meet their particular needs.</i></p>	<ul style="list-style-type: none"> • People have access to needed services
<p>Accessible Information</p> <p><i>Information is readily available and provided in a clear and meaningful way in order for people to understand options and make informed decisions.</i></p>	<ul style="list-style-type: none"> • People are provided information about services and natural supports that are available • People receive enough information to make informed choices about their services and supports • Information is presented in a way people understand (using people's preferred language and using words people understand) • Support workers speak in a way people understand
<p>Skills, knowledge and training</p> <p><i>Support workers have the right skills, knowledge and training to support the people based on their unique needs.</i></p>	<ul style="list-style-type: none"> • Support workers treat people with respect • Support workers have the right knowledge and training to meet people's unique needs • Support workers are responsive • Services are provided in a way that is respectful to the person's culture
<p>Positive expectations</p> <p><i>There is a belief that people are continuously able to grow and learn new things.</i></p>	<ul style="list-style-type: none"> • Staff believe that the person can grow and learn new things • Staff support the person to grow and learn new things

Common Themes

This scan found some common themes that were present in most or all of the tools reviewed. The most common indicators were measures of choice and self-determination, including measures of a person's ability to choose services and what to do during the day. Items related to support workers' skills, knowledge, and training were also common (e.g., whether staff are respectful and responsive to the person). Indicators of positive expectations, particularly positive expectations held and promoted by support staff, were most commonly present in tools used to survey participants receiving mental health services.

Additional indicators used primarily with aging and mental health populations were found. In aging, a common subset of indicators measured the person's degree of independence and satisfaction with their life. Mental health had a strong focus on recovery, including measures such as: the person believes they can recover, and the person is better able to take care of their own needs. For the purpose of this scan, measures of control and independence are grouped with "choice and self-determination"; recovery-focused items are grouped with "focus on the person" or "positive expectations," depending on the specific measure.

Gaps

This scan also revealed significant gap areas, including in indicators that measure aspects of the planning process, the availability of information, and the continuity of service delivery when the individual is dependent on multiple providers.

Planning Process

This scan found a number of indicators that measure the outcomes of person-centered practices (e.g., ability to make choices in one's life, receiving information in a way that is easy to understand, access to needed individualized services). However, very few tools also included indicators specific to the person-centered planning process beyond items indicating the person was able to choose his or her own goals and/or services. While outcomes are crucial to assessing the overall impact of person-centered practices, it is important to understand whether the person has an active and valued role in determining goals, deciding what is important in his/her life and are able to include people who are meaningful in making those determinations.

Accessible Information

Several tools included questions relating to whether staff spoke to people in a way they understand. Few, however, included additional measures that went beyond the nature of staff interaction. Ease of accessing information about services and supports and getting information in a way that is easy to understand are important aspects of a person-centered system that encourages choice and self-determination.

Continuity of Supports

A notable area where indicators are lacking is whether services and supports are delivered in a coordinated way. Indicators that may be most closely connected to this concept frequently focused on access or satisfaction within a distinct aspect of the service delivery system (e.g., whether the person has adequate transportation, if staff do things the way the person wants them done). Integrated and coordinated supports are important in order to understand the person-centeredness of service delivery in addition to overall satisfaction.

Additional Gaps

Indicators of choice and self-determination were prevalent in nearly all tools reviewed for this scan; however, few measured the impact of the presence of a guardian or conservator. This may be an area to explore given that guardians and conservators may hinder a person's ability to make important life choices.

Items measuring positive expectations were readily seen in tools for mental health service planning; however, such indicators were scant in tools used to understand the experience of people with age-related or other support needs. Positive expectations for growth and belief in each person's capacity, talents, and gifts are important qualities of person-centered thinking and are necessary to encourage people to reach their goals.

Finally, this scan sought to include tools that measured the transition into services and supports. For youth in particular, the transition from school to adult services is an important period during which young people begin to plan for their futures as adults. For youth with disabilities, indicators included in this scan most frequently measured items around choice and self-determination prior to the transition to adult services. With the exception of the National Longitudinal Transition Study-2 (NLTS2, which ended in 2009), this scan did not identify indicators relating to individuals who are transitioning or have recently transitioned from school to adult services.

Additionally, the scan did not find tools that measure the transition of older adults into the public service system. Assessing person-centered practices at the "intake" stage is important to ensuring that each person's unique needs are met at critical life stages and that people establish expectations of person-centered approaches in the delivery of services.

Environmental Scan

Presentation of Indicators

For ease of review, this document presents the same set of indicators in two ways. First, a summary table is provided with indicators organized by primary population. That table includes:

- **Source.** The tool that was reviewed for indicators. The name of the source includes a hyperlink to a website where the tool and/or a summary of the indicators can be found. (Only publicly available information is included in this scan.)
- **Primary population.** A description of the population from which indicators are assessed. Groupings are: those that focus on more than one population (All), those that focus on aging (Aging), those that focus on intellectual and developmental disability (IDD), and those that focus on mental health (MH).
- **Method of data collection.** A description of how information is collected (interview, mail, self-assessment).
- **Level of measurement.** Identifying the level at which items are measured (system level or individual level) and whether items are an indicator (which may group several questions) or discrete questions.
- **Assessed domain.** The last seven columns of the table indicate which of the domains are assessed. The number of indicators or questions associated with that domain are given in parentheses.

Following the matrix, the same information is presented in a narrative format alphabetically by source, with additional detail regarding the source and specific indicators or questions listed and sorted by domain.

Source	Primary Population	Method of Data Collection	Level of Measurement, Includes Indicators or Questions	Focus on the Person	Choice & Self-determination	Community Participation	Availability of Services & Supports	Accessible Information	Support Worker Skills, Knowledge & Training	Continuity of Supports	Positive Expectations
The American Institutes for Research (AIR) Self-Determination Assessments AIR	All	Self-Assessment	Individual, Questions	X (5)	X (2)				X (4)		X (1)
The Arc's Self-Determination Scale Procedural Guidelines Youth Version Adult Version	All	Self-Assessment	Individual, Questions	X (1)	X (6)	X (2)					
The Council on Quality and Leadership COL	All	Interview	Individual, Indicators	X (1)	X (5)	X (5)	X (1)		X (2)		
Personal Experience Outcomes for Adults with Developmental or Physical Disabilities and Frail Elders PEONIES	All	Interview	Individual and System, Questions		X (4)	X (1)			X (1)		
Empowering Arizona's Individuals with Developmental Disabilities EAZI	All	Interview	Individual, Questions					X (1)	X (3)		

Source	Primary Population	Method of Data Collection	Level of Measurement, Includes Indicators or Questions	Focus on the Person	Choice & Self-determination	Community Participation	Availability of Services & Supports	Accessible Information	Support Worker Skills, Knowledge & Training	Continuity of Supports	Positive Expectations
Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems Survey HCBS CAHPS	All	Interview	System, Questions	X (2)	X (2)	X (1)	X (2)	X (1)	X (5)		X (2)
Oregon Individual Experience Survey ORIES	All	Interview	System, Questions		X (3)	X (2)					
Healthy and Positive Ageing Intellectual Disability POSITIVE AGEING INDICATORS -IDD	Aging (with IDD)	Interview	System, Indicators		X (2)	X (6)	X (3)				
National Core Indicators – Aging and Disability NCI-AD	Aging	Interview	System, Indicators	X (5)	X (4)	X (1)	X (5)	X (2)	X (2)		
The World Health Organization Quality of Life WHOQOL – OLD	Aging	Interview	System, Questions	X (2)	X (4)	X (1)					
National Core Indicators – In-person Survey NCHPS	IDD	Interview	System, Indicators	X (10)	X (9)	X (7)	X (2)	X (2)	X (4)		
National Core Indicators – Family Surveys NCI-Family Surveys	IDD	Mail-out	System, Indicators		X (1)	X (2)	X (1)	X (1)	X (1)		
The World Health Organization Quality of Life WHOQOL – Intellectual Disabilities	IDD	Interview	System, Questions		X (3)	X (1)		X (2)	X (2)		X (1)

Source	Primary Population	Method of Data Collection	Level of Measurement, Includes Indicators or Questions	Focus on the Person	Choice & Self-determination	Community Participation	Availability of Services & Supports	Accessible Information	Support Worker Skills, Knowledge & Training	Continuity of Supports	Positive Expectations
Recovery Oriented Systems Indicators Measure ROSI	MH	Self-assessment	System, Questions	X (6)	X (2)		X (2)	X (3)	X (2)		X (4)
Mental Health Statistics Improvement Plan MHSIP	MH	Mail-out, interview	System, Questions	X (4)	X (1)	X (1)	X (4)	X (1)	X (3)		X (1)
Mental Health Statistics Improvement Plan – Youth MHSIP Youth	MH	Mail-out, interview	System, Questions	X (2)	X (3)		X (1)		X (4)		
Yale Program for Recovery and Community Health The Recovery Self-Assessment RSA	MH	Self-assessment	Individual, Questions	X (9)	X (4)	X (1)			X (8)		X (4)

Sources

The American Institutes for Research (AIR) Self-Determination Assessments

AIR in collaboration with Teachers College, Columbia University in New York City, developed the student, parent, and educator versions of the AIR Self-Determination Assessments with funding from the U.S. Department of Education, Office of Special Education Programs. The AIR Self-Determination scale:

- Produces a profile of the student's level of self-determination
- Identifies areas of strength and areas needing improvement
- Identifies specific educational goals that can be incorporated into the student's IEP

The AIR Assessments measure two broad self-determination components. Capacity refers to the student's knowledge, abilities, and perceptions that enable them to be self-determined. Opportunity refers to the student's chances to use their knowledge and abilities.

Website/Citation:

<http://www.ou.edu/content/dam/Education/documents/miscellaneous/air-self-determination-scale-student-form.pdf>

Primary population: All

Method of data collection: Self-assessment (or completed by parent)

Level of measurement: Individual

Questions or Indicators:

Focus on the person

- I know what I need, what I like, and what I'm good at.
- I figure out how to meet my goals. I make plans and decide what I should do.
- I check how I'm doing when I'm working on my plan. If I need to, I ask others what they think of how I'm doing.
- If my plan doesn't work, I try another one to meet my goals.
- I feel good about what I like, what I want, and what I need to do.

Choice and Self-determination

- I set goals to get what I want or need. I think about what I am good at when I do this.
- I believe that I can set goals to get what I want.

Support Worker Skills, Knowledge and Training

- At school/At home, I have learned how to make plans to meet my goals and to feel good about them.
- I have someone at school/at home who can tell me if I am meeting my goals.
- People at school/ People at home listen to me when I talk about what I want, what I need, or what I'm good at.
- People at school/at home understand when I have to change my plan to meet my goals. They offer advice and encourage me when I'm doing this.

Positive Expectations

- People at school/ People at home let me know that I can set my own goals to get what I want or need.

The Arc's Self-Determination Scale Procedural Guidelines

The Arc's Self-Determination Scale (Adult Version) is a self-report measure of self-determination designed and validated primarily for use by adults with cognitive and developmental disabilities. The scale has two primary purposes:

- To provide a tool that assists in identifying individual strengths and areas of support need in self-determination; and
- To provide a research tool to examine the relationship between and among self-determination and factors that promote/inhibit self-determined behavior, to evaluate the efficacy of interventions to promote self-determination, and for use with related research activities.

Website/Citation:

<https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/Adult%20Version%20of%20The%20Arc%27s%20Self-Determination%20Scale.pdf> (Adult Version)

https://www.researchgate.net/publication/281439481_The_Arc's_Self-Determination_Scale_Adolescent_Version_Assessment_Form (Youth Version)

Primary population: All

Method of data collection: Self-assessment

Level of measurement: Individual

Questions or Indicators:

Focus on the Person

- I volunteer in things that I am interested in.

Choice and Self-determination

- I do free time activities based on my interests.
- I plan weekend activities that I like to do.
- My friends and I choose activities that we want to do.
- I choose my clothes and the personal items I use every day.
- I decorate my own room.
- I choose how to spend my personal money.

Community Participation

- I am involved in community activities.
- I go to restaurants that I like.

The Council on Quality and Leadership (CQL)

Personal Outcome Measures® are a powerful tool to ensure supports and services are truly person-centered. In a Personal Outcome Measures® interview, 21 indicators are used to understand the presence, importance and achievement of outcomes involving choice, health, safety, social capital, relationships, rights, goals, dreams, employment and more. The insight gained during a Personal Outcome Measures® interview can then be used to inform a person-centered plan, and at an aggregate level, influence an organization's strategic plan. For decades, they have been an effective data set for valid and reliable measurement of individual quality of life.

Website/Citation:

<https://www.c-q-l.org/>

Primary population: All

Method of data collection: Interview (in-person)

Level of measurement: Individual

Indicators (or summary of):

Focus on the Person

- People realize personal goals

Choice and Self-determination

- People decide when to share personal information
- People choose where and with whom they live
- People choose where they work
- People choose services

- People choose personal goals

Community Participation

- People use their environments
- People live in integrated environments
- People interact with other members of the community
- People participate in the life of the community
- People perform different social roles

Availability of Services and Supports

- People are connected to natural support networks

Support Worker Skills, Knowledge and Training

- People are treated fairly
- People are respected

Personal Experience Outcomes for Adults with Developmental or Physical Disabilities and Frail Elders in Wisconsin's Medicaid-Funded HCBS and Managed Long-Term Care Programs (PEONIES)

This project is funded by the Wisconsin Department of Health and Family Services. Its purpose is to develop a way of measuring and using Personal Experience Outcomes for people receiving long-term care services in the community. The intent of the project is to develop ways of interviewing people to learn about the outcomes they want in their lives. This information can be used for many purposes. Some of these purposes are:

- Help Care Managers and Consumers work together to make sure services are supporting the things that are most important to the Consumer.
- Help Long-Term Care Programs (COP, CIP, Family Care, Partnership Program, other managed long-term care programs) monitor and improve quality.
- Help DHFS ensure that the programs they fund are helping people achieve the quality of life they desire.

Website/Citation:

<https://www.chsra.wisc.edu/peonies/personal-experience-outcomes.htm>

Primary population: All

Method of data collection: Interview (in-person)

Level of measurement: Individual, system

Questions or Indicators:

Choice and Self-determination

- I decide where and with whom I live.
- I make decisions regarding my supports and services.
- I decide how I spend my day.
- I do things that are important to me.

Community Participation

- I am involved in my community.

Support Worker Skills, Knowledge and Training

- I have privacy.

Empowering Arizona's Individuals with Developmental Disabilities (EAZI)

These quality surveys were developed to be administered by consumers to other consumers and their families. They measure in-home attendant care, habilitation, and respite services delivered. In addition to surveys are materials used to train the interviewers, survey response thresholds, and a presentation outlining survey findings.

Website/Citation:

<http://www.nasuad.org/hcbs/article/quality-improvement-surveys-and-training-materials-arizona>

Primary population: All

Method of data collection: Interview (in-person)

Level of measurement: Individual

Questions or Indicators:

Accessible Information

- Providers listen to you, acknowledge your comments, and keep you informed in a way that you can understand.

Support Worker Skills, Knowledge and Training

- Providers are willing to help you; they respond promptly to your questions and/or needs.
- The provider has the skills and knowledge they need to provide the service. *(includes items on cultural competence)*
- The provider helps you advocate for quality services.

Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems Survey (HCBS CAHPS)

The HCBS CAHPS Survey is a questionnaire with a maximum of 69 core items developed for measuring beneficiary experience with the Medicaid home and community-based services and supports delivered by providers. Core questions cover topics such as: getting needed services, communication with providers, case managers, choice of services, medical transportation, and personal safety, as well as community participation and empowerment.

Website/Citation:

<https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html>

Primary population: All

Method of data collection: Interview (phone or in-person)

Level of measurement: System

Questions or Indicators:

Focus on the Person

- In the last 3 months, how often did {personal assistance/behavioral health staff/homemakers} treat you the way you wanted them to?
- In the last 3 months, how often did {personal assistance/behavioral health staff/homemakers} listen carefully to you?

Choice and Self-determination

- In the last 3 months, did you take part in deciding what you do with your time each day?
- In the last 3 months, did you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?

Community Participation

- In the last 3 months, when you wanted to, how often could you do things in the community that you like?

Availability of Services and Supports

- In the last 3 months, did you get help from {program specific term for case manager services} to help make sure that you had all the services you needed?
- In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what's on your [program-specific term for "service plan"], including the things that are important to you?

Accessible Information

- In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand?

Support Worker Skills, Knowledge and Training

- In the last 3 months, how often did {personal assistance/behavioral health staff/homemakers} treat you with courtesy and respect?
- In the last 3 months, did you feel {personal assistance/behavioral health staff/homemakers} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
- In the last 3 months, did this {case manager} work with you when you asked for help with getting or fixing equipment?
- In the last 3 months, did this {case manager} work with you when you asked for help with getting other changes to your services?
- In the last 3 months, could you contact this {case manager} when you needed to?

Positive Expectations

- In the last 3 months, did {personal assistance/behavioral health staff} encourage you to do things for yourself if you could?
- In the last 3 months, did your [program-specific term for “service plan”] include... [none, some, most, all of the things that are important to you]

Oregon Individual Experience Survey (ORIES)

In consultation with Stakeholders, the Oregon Department of Human Services (DHS) and Oregon Health Authority (OHA) developed and conducted the Individual Experience Assessment (IEA) for individuals receiving Medicaid-funded HCBS services in provider-owned, controlled, or operated residential settings and non-residential settings. In addition to questions about residential settings, the IEA contained questions specifically related to employment and day services. The IEA focused primarily on whether the individual feels his or her service experiences align with what is required in the settings requirements.

Website/Citation:

<https://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCBS/Resources/Adult%20Individual%20Experience%20Survey.pdf>

<https://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCBS/TransitionPlan/Oregons-Approved-Transition-Plan-Feb-2019.pdf>

Primary population: All

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Choice and Self-determination

- Before I moved to where I live now, I was told about or able to visit other places to live.
- I was offered the choice to live in a place that is not only for people who have disabilities.
- If I live in a shared room, I was offered the choice of a private bedroom or living unit.
- I have a choice in who my roommate is.
- Where I live supports my independence and making life choices.
- I am supported where I live to make my own scheduling decisions.

Community Participation

- Where I live makes it EASY[/HARD] for me to be part of the community where I am located.
- Where I live makes it easy for me to participate in community activities.
- Where I live makes it easy for me to get around in the community as I desire.
- I have regular opportunities be part of the broader community.

Healthy and Positive Ageing Initiative Positive Ageing Indicators – Intellectual Disability 2018

The Healthy and Positive Ageing Initiative (HaPAI) was established to play a key role in the implementation of Goal 4 of the National Positive Ageing Strategy (NPAS): Support and use research about people as they age to better inform policy responses to population ageing in Ireland. HaPAI is a joint national programme led by the Department of Health with The Atlantic Philanthropies, the Health Service Executive (HSE) and the Age Friendly Ireland Programme. A commitment to monitoring progress is part of both the NPAS and Healthy Ireland, and HaPAI has developed the Positive Ageing Indicators to fulfil this commitment and to support good planning and policy development for older people in Ireland, now and into the future.

HaPAI commenced in 2015 with the purpose of completing research activity in three areas:

- Development of national indicators of older people's health and wellbeing, leading to the publication of a biennial report on the health and wellbeing of older people in Ireland;

- Establishment of a research fund to commission targeted additional research to fill identified data gaps required to cover all indicators, relevant to the design or configuration of future services and supports for older people; and
- At a local level, developing indicators using either national data broken down to the county level where possible, or additional data collected locally and published in a series of county reports in selected counties.

Website/Citation:

<https://health.gov.ie/wp-content/uploads/2019/05/IDS-TILDA-indicator-report-2018.pdf>

Primary population: Aging with IDD

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Choice and Self-determination

- Percentage of people with an intellectual disability aged 40+ with choice in day-to-day activities
- Percentage of people with an intellectual disability aged 40+ with choice in major life decisions

Community Participation

- Percentage of people aged 50+ who engage in one or more social leisure activity at least once a week
- Percentage of people with an intellectual disability aged 40+ who engaged in political activities in the past twelve months
- Percentage of people with an intellectual disability aged 40+ who engage in one or more social leisure activity at least once a week
- Percentage of people with an intellectual disability aged 40+ who participated in social or cultural activities in the past twelve months
- Percentage of people with an intellectual disability aged 40+ who feel part of their community
- Percentage of people with an intellectual disability aged 40+ who report barriers to participation

Availability of Services

- Percentage of people with an intellectual disability aged 40+ who report lack of access to transport has affected social participation
- Percentage of people with an intellectual disability aged 40+ with access to an advocacy service

- Percentage of people aged 50+ who experience difficulty accessing essential services

National Core Indicators – Aging and Disability

NCI-AD™ is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance.

The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including service planning, rights, community participation, choice, health and care coordination, safety and relationships.

Website/Citation:

<https://nci-ad.org>

Primary population: Aging

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Focus on the Person

- Proportion of people whose service planning meetings take place when, where and with whom they want
- Proportion of people whose preferences and needs are discussed in their service planning meetings
- Proportion of people who receive a copy of their service plan after their service planning meetings
- Proportion of people whose service plan reflects what is discussed during their service plan meetings
- Proportion of people whose service plan includes their preferences and choices

Choice and Self-determination

- Proportion of people who are involved in making decisions about their everyday lives
- Proportion of people who can choose or change the kind of services they receive and who provides them
- Proportion of people who feel in control of their life
- Proportion of people who are involved in making decisions about their service plan

Community Participation

- Proportion of people who are able to participate in preferred community activities

Availability of Services and Supports

- Proportion of people who receive the services that they need
- Proportion of people whose case manager talks to them about their unmet needs
- Proportion of people who want help planning for their future service needs
- Proportion of people who get needed home modifications, equipment, and assistive devices
- Proportion of people who have adequate transportation

Accessible Information

- Proportion of people who have access to information about services in their preferred language
- Proportion of people who know whom to contact with a complaint or question about their services

Support Worker Skills, Knowledge and Training

- Proportion of people who can get in contact with their case manager when they need to
- Proportion of people whose paid support staff treat them with respect

The World Health Organization Quality of Life (WHOQOL) – OLD

The WHOQOL is a quality of life assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally.

Website/Citation:

https://www.who.int/mental_health/evidence/WHOQOL_OLD.PDF?ua=1

Primary population: Aging

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Focus on the Person

- To what extent are you able to do the things you'd like to do?

- To what extent are you satisfied with your opportunities to continue achieving in life?

Choice and Self-determination

- How much freedom do you have to make your own decisions?
- To what extent do you feel in control of your future?
- To what extent do you feel that you have enough to do each day?
- How satisfied are you with the way you use your time?

Community Participation

- How satisfied are you with your opportunity to participate in community activities?

National Core Indicators – In-Person Survey

National Core Indicators (NCI)TM is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community participation, choice, and health and safety.

Website/Citation:

www.nationalcoreindicators.org

Primary population: IDD

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Focus on the Person

- The percentage of people who took part in their last service planning meeting (or had the option to take part but chose not to)
- The percentage of people who knew what was being talked about at the last service planning meeting
- The percentage of people whose service planning meeting included people they wanted to be there
- The percentage of people whose service plan included things that are important to them

- The percentage of people who know whom to ask if they want to change services
- The percentage of people who report they are supported to learn new things
- The percentage of people who express they want to increase independence in functional skills (ADLs) who have a related goal in their service plan
- The percentage of people who reported wanting to create, expand and/or maintain friendships whose service plan contained a goal to create, expand, strengthen and/or maintain friendships and relationships
- The percentage of people who express they want a job who have a related goal in their service plan
- The percentage of people who report wanting to increase participation in activities in the community whose service plan contained a goal to increase this person's participation in activities in the community

Choice and Self-determination

- The percentage of people who have input in choices about: where and with whom they live; where they work; the day program/workshop they attend; the staff who help them
- The percentage of people who have input in choices about: their daily schedule; how to spend free time; what to buy with their spending money
- The percentage of people who have enough choice about their daily schedule and what to do in free time
- The percentage of people who can change their service coordinator/case manager if they want to
- The percentage of people who are currently using a self-directed supports option
- The percentage of people who are currently using a self-directed supports option who report that they hire or manage staff
- The percentage of people who are currently using a self-directed supports option who have enough help in deciding how to use their individual budget/services
- The percentage of people who are currently using a self-directed supports option who report that they can make changes to their budget/services if they need to
- The percentage of people who were able to choose what services they got as part of the service plan

Community Participation

- The percentage of people who regularly participate in everyday integrated activities in their communities
- The percentage of people who are able to see their families and friends when they want
- The percentage of people who indicate they would like more help to make or keep in contact with friends
- The percentage of people who have other ways to communicate with friends when cannot see them
- The percentage of people who do things in their communities that they like to do, as often as they want
- The percentage of people who take part in community activities
- The percentage of people who are happy with, or would prefer a different amount of community activities, such as shopping, community group activities, entertainment, going out to eat, and religious service

Availability of Services and Supports

- The percentage of people who report having a way to get places when they want to go somewhere
- The percentage of people who need additional services and supports

Accessible Information

- The percentage of people self-directing who reported they receive information about money that's left in budget
- The percentage of people who are currently using a self-directed supports option who receive information about their budget/services that is easy to understand

Support Worker Skills, Knowledge and Training

- The percentage of people who have met or spoken with their service coordinators
- The percentage of people reporting that service coordinators ask them what they want
- The percentage of people who report that they can contact their case manager/service coordinator when wanted
- The percentage of people indicating that staff treat them with respect

National Core Indicators Family Surveys

National Core Indicators (NCI)TM is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

The family indicators address how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.

Website/Citation:

www.nationalcoreindicators.org

Primary population: IDD

Method of data collection: Mail-out survey or online

Level of measurement: System

Questions or Indicators:

Choice and Self-determination

- Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them

Community Participation

- Families/family members use integrated community services and participate in everyday community activities.
- Families maintain connections with family members not living at home.

Availability of Services and Supports

- Families/family members with disabilities get the services and supports they need.

Accessible Information

- Families/family members with disabilities have the information and support necessary to plan for their services and supports.

Support Worker Skills, Knowledge and Training

- Families/family members with disabilities receive adequate and satisfactory supports.

The World Health Organization Quality of Life (WHOQOL) – Intellectual Disabilities

The WHOQOL is a quality of life assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally.

Website/Citation:

https://www.who.int/mental_health/evidence/WHOQOL_DIS_ID_Intellectual_Disabilities.pdf?ua=1

Primary population: IDD

Method of data collection: Interview (in-person)

Level of measurement: System

Questions or Indicators:

Focus on the Person

- Do you feel in control of your life?
- Do you make your own choices about your day-to-day life?
- Do you get to make the big decisions in your life?

Choice and Self-determination

- Are you satisfied with your ability to do your daily activities?

Community Participation

- Are you satisfied with your chances to be involved in social activities?
- Are you satisfied with your chances to be involved in local activities?

Accessible Information

- Are you able to get the information that you need in your day-to-day life?
- Are you satisfied with your ability to communicate with other people?

Support Worker Skill, Knowledge and Training

- Do you feel that other people accept you?
- Do you feel that other people respect you?

Positive Expectations

- Do you feel that your dreams, hopes and wishes will happen?

Recovery Oriented Systems Indicators Measure (ROSI)

The ROSI is developed from and grounded in the lived experiences of adults with serious and prolonged psychiatric disorders. Thus, the ROSI consumer self-report survey and administrative profile are designed to assess the recovery orientation of community mental health systems for adults with serious and prolonged psychiatric disorders.

Website/Citation:

<https://www.power2u.org/wp-content/uploads/2017/01/ROSI-Recovery-Oriented-Systems-Indicators.pdf>

Primary population: MH

Method of data collection: Self-assessment

Level of measurement: System

Questions or Indicators:

Focus on the Person

- Staff do not understand my experience as a person with mental health problems.
- Staff respect me as a whole person.
- Staff see me as an equal partner in my treatment program.
- I am treated as a psychiatric label rather than as a person.
- Mental health staff help me build on my strengths.
- My treatment plan goals are stated in my own words.

Choice and Self-determination

- I do not have enough good service options to choose from.
- I have a say in what happens to me when I am in crisis.

Availability of Services and Supports

- I do not have the support I need to function in the roles I want in my community.
- I cannot get the services I need when I need them.

Accessible Information

- My family gets the education or supports they need to be helpful to me.
- I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.
- Staff give me complete information in words I understand before I consent to treatment or medication.

Support Worker Skills, Knowledge and Training

- Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc.).
- Staff listen carefully to what I say.

Positive Expectations

- There is at least one person who believes in me.
- Staff encourage me to do things that are meaningful to me.
- Staff stood up for me to get the services and resources I needed.
- Staff believe that I can grow, change and recover.

Mental Health Statistics Improvement Plan (MHSIP)

The MHSIP Consumer Survey consists of 36 items, each answered using a 5-point Likert scale ranging from one (strongly agree) to five (strongly disagree). These questions create seven domains, which are used to measure different aspects of customer satisfaction with public behavioral health services.

Website/Citation:

<https://www.dhcs.ca.gov/formsandpubs/MHCCY/InfoNotice12-02Enclosure1.pdf>

<https://www.hsri.org/publication/the-mhsip-quality-report-toolkit>

Primary population: MH

Method of data collection: Mail-out, online

Level of measurement: System

Questions or Indicators:

Focus on the Person

- I do things that are more meaningful to me.
- I am better able to take care of my needs.
- I am better able to handle things when they go wrong.
- I am better able to do things I want to do.

Choice and Self-determination

- I, not staff, decided my treatment goals.

Community Participation

- I feel I belong in my community.

Availability of Services and Supports

- The location of services was convenient.

- Staff were willing to see me as often as I felt it was necessary.
- I was able to get the services I thought I needed.
- In a crisis, I would have the support I need from family or friends.

Accessible Information

- Staff helped me obtain information so that I could take charge of managing my illness.

Support Worker Skills, Knowledge and Training

- Staff returned my calls within 24 hours.
- Staff respected my wishes about who is, and is not, to be given information about my treatment.
- Staff were sensitive to my cultural/ethnic background.

Positive Expectations

- Staff here believe I can grow, change and recover.

Mental Health Statistics Improvement Plan – Youth (MHSIP – Youth)

The MHSIP Youth Services Survey For Youth (YSS) consists of 26 items, each answered using a 5-point Likert scale ranging from one (strongly agree) to five (strongly disagree) and nine demographic questions.

Website/Citation:

<https://www.dhs.wisconsin.gov/forms/f0/f01389a.pdf>

Primary population: MH and/or IDD

Method of data collection: Mail-out

Level of measurement: System

Questions or Indicators:

Focus on the Person

- The services I received were right for me.
- I got the help that I wanted.

Choice and Self-determination

- I helped to choose my services.
- I helped to choose my treatment goals.
- I participated in my own treatment.

Availability of Services and Supports

- I got as much help as I needed.

Support Worker Skills, Knowledge and Training

- Staff treated me with respect.
- Staff respected my family's religious or spiritual beliefs.
- Staff spoke with me in a way that I understood.
- Staff were sensitive to my cultural or ethnic background.

Yale Program for Recovery and Community Health – The Recovery Self-Assessment (RSA)

The Recovery Self-Assessment (RSA) is a 36-item measure designed to gauge the degree to which programs implement recovery-oriented practices. It is a self-reflective tool designed to identify strengths and target areas of improvement as agencies and systems strive to offer recovery-oriented care.

The RSA contains concrete, operational items to help program staff, persons in recovery, and significant others to identify practices in their mental health and addiction agency that facilitate or impede recovery.

There are four versions of the RSA targeted to different groups:

- Person in recovery
- Family member/advocate
- Provider
- CEOs and Directors

Since development, PRCH has received many requests for the RSA from agency directors; indicating that with the RSA they have found a concrete tool to integrate recovery-oriented practices into their agencies.

Website/Citation:

https://medicine.yale.edu/psychiatry/prch/tools/rec_selfassessment/

Primary population: MH

Method of data collection: Self-assessment

Level of measurement: Individual

Questions or Indicators:

Focus on the Person

- Staff welcome me and help me feel comfortable in this program.
- This program offers specific services that fit my unique culture and life experiences.

- I am given opportunities to discuss my spiritual needs and interests when I wish.
- I am given opportunities to discuss my sexual needs and interests when I wish.
- Staff help me to include people who are important to me in my recovery/treatment planning (such as family, friends, clergy, or an employer).
- Staff talk with me about what it would take to complete or exit this program.
- Staff help me keep track of the progress I am making towards my personal goals.
- Staff work hard to help me fulfill my personal goals.
- Staff help me to develop and plan for life goals beyond managing symptoms or staying stable (e.g., employment, education, physical fitness, connecting with family and friends, hobbies).

Choice and Self-determination

- I can change my clinician or case manager if I want to.
- Staff listen to me and respect my decisions about my treatment and care.
- I am encouraged to be involved in the evaluation of this program's services and service providers.
- I am encouraged to attend agency advisory boards and/or management meetings if I want.

Community Participation

- Staff help me to get involved in non-mental health/addiction related activities, such as church groups, adult education, sports, or hobbies.

Support Worker Skills, Knowledge and Training

- Staff regularly ask me about my interests and the things I would like to do in the community.
- Staff encourage me to take risks and try new things.
- Staff introduce me to people in recovery who can serve as role models or mentors.
- Staff offer to help me connect with self-help, peer support, or consumer advocacy groups and programs.
- I am/can be involved with staff trainings and education programs at this agency.
- Staff listen, and respond, to my cultural experiences, interests, and concerns.
- Staff are knowledgeable about special interest groups and activities in the community.

- Agency staff are diverse in terms of culture, ethnicity, lifestyle, and interests.

Positive Expectations

- Staff encourage me to have hope and high expectations for myself and my recovery.
- Staff believe that I can recover.
- Staff believe that I have the ability to manage my own symptoms.
- Staff believe that I can make my own life choices regarding things such as where to live, when to work, whom to be friends with, etc.

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, first-hand experience of using long-term services and supports).

NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance.

You can find us at <https://ncapps.acl.gov>

This document is publicly available for use in the administration and improvement of supports for older adults and people with long-term service and support needs. All uses should acknowledge NCAPPS, and the developers of this content.

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