



Achieving Person-Centered Outcomes: The Importance of Developing New Outcome Measures

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Rehabilitation Research and Training Center on
Home and Community Based Services



Contributing Authors



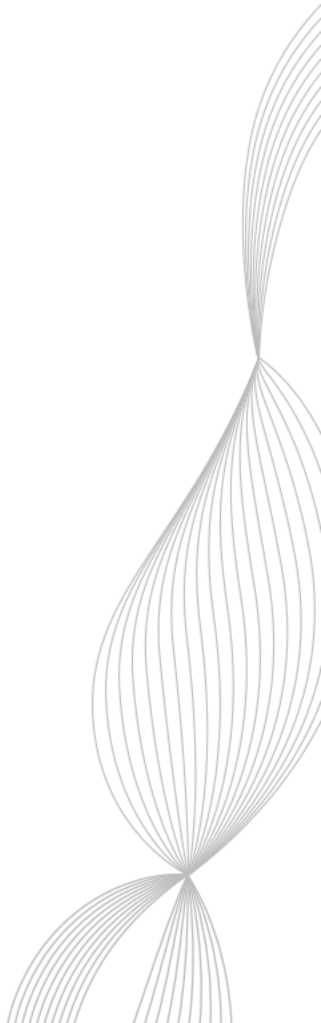
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Introduction

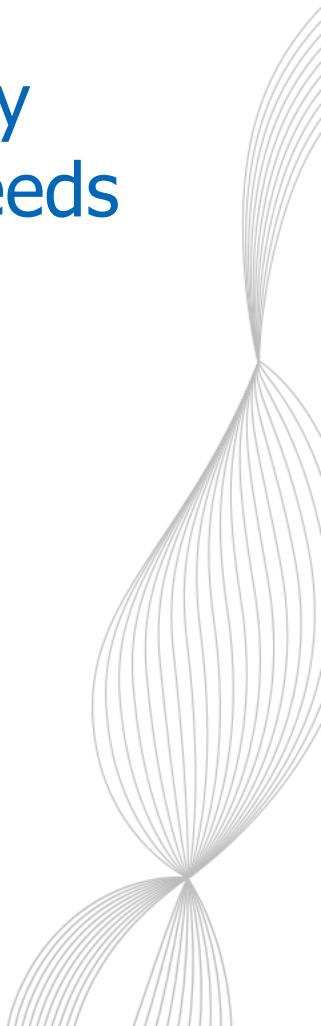


- Home and Community Based Services Person-Centered Outcomes and Measurements
- NIDILRR funded
- Today's presentation is about one task: development and testing of new HCBS quality measures
- Work is currently in progress
- Information being shared describes progress to date and next steps, but not results or recommendations

Home and Community-Based Services (HCBS)



- “an array of long-term supports that promote the independence, well-being, and choices of an individual of any age who has physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting” (National Quality Forum)



The Shift from Institutions to HCBS



- The federal government has promoted several efforts to serve more people in the community than in institutions.
- Recent years have brought a deeper understanding of and commitment to what community-based supports mean. This is largely a commitment to the principles of person-centered care.



Person-Centered Planning



“individual-directed, positive approach to the planning and coordination of a person’s services and supports based on individual aspirations, needs, preferences, and values”

“to create a plan that would optimize the person’s self-defined quality of life, choice, and control, and self-determination through meaningful exploration and discovery of unique preferences and needs and wants”

“The person must be empowered to make informed choices that lead to the development, implementation, and maintenance of a flexible service plan for paid and unpaid services and supports”

- National Quality Forum, 2020



Assuring Person-Centered Care



- Person-centered planning should result in person-centered care.
- What person-centered care means is continuing to evolve.
- Measures of HCBS quality also must evolve, to assess the achievement of person-centered outcomes and the effectiveness of services in supporting those.



Quality Measures



- “A quality measure is a tool for making ‘good decisions’ defined as decisions that make it more likely to experience a good result and less likely to experience an adverse result that was not foreseen or was not understood. Patient and families use quality measures to select high-performing clinicians. Healthcare providers use quality measures to assess their own performance. Selection and choice decisions based on sound quality measures increase the likelihood of desired health outcomes.” (Centers for Medicare and Medicaid Services)



Evolving HCBS Quality Measures



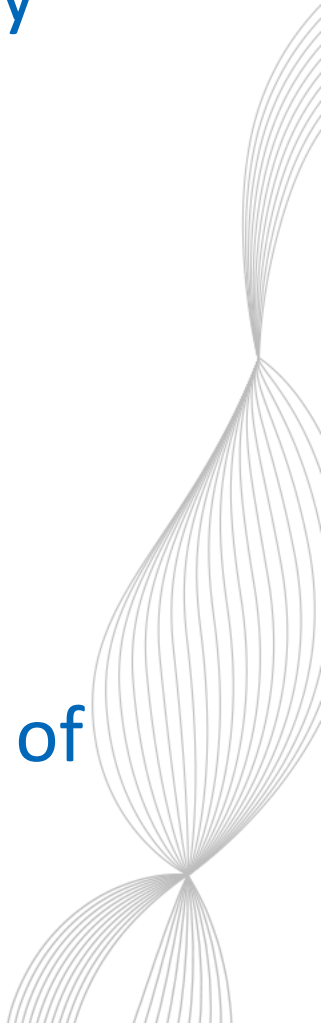
- Focus of many current measures
 - Outcomes that are defined by others
 - Service receipt process
- Person-centered measures require a different focus
 - Focus on the outcomes desired by the individual
 - Recognize that the outcomes desired may change over time
 - Recognize that outcomes may take varying amounts of time to achieve
 - Recognize that achievement of outcomes may require supports from multiple sources, which need to interact



Developing New HCBS Quality Measures: Identifying Key Concepts



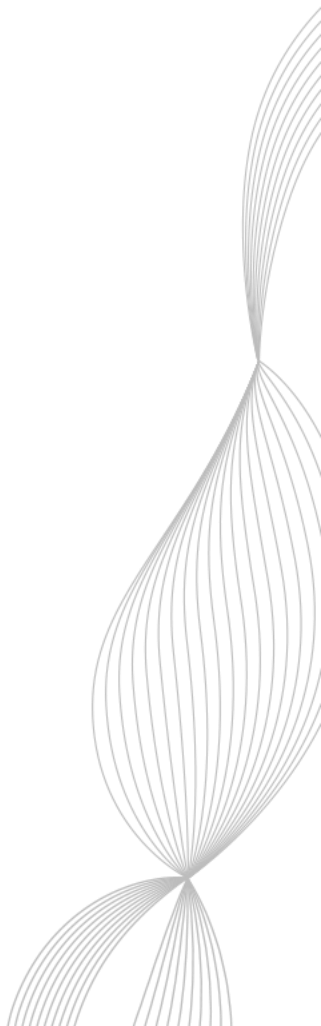
- National Quality Forum has defined domains of HCBS quality
- Only some of those domains address person-centered outcomes: choice and control, community inclusion, and holistic health and functioning.
- Focus group with Participant Advisory Council identified important concepts within those domains
- We identified those domains and concepts lacking strong, person-centered measures
- The Advisory Council provided input to identify the final set of 9 measure concepts for development



HCBS Measure Concepts Under Development



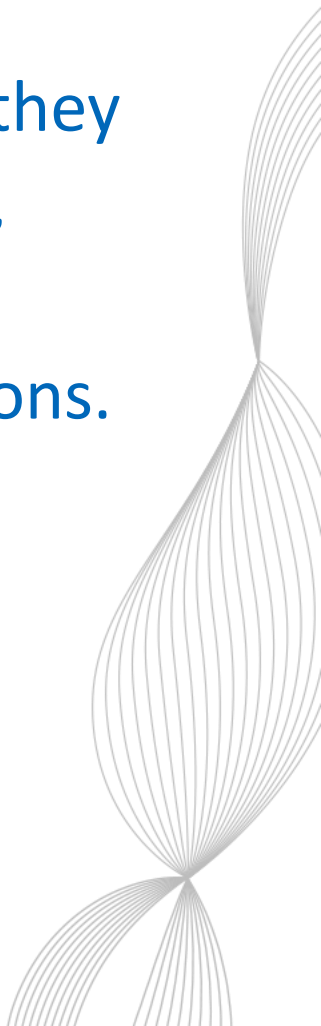
- Choice & Control over Personal Expression
- Choice & Control over Living Arrangement
- Choice & Control over Finances
- Choice & Control over Healthcare
- Choice & Control over Diet and Nutrition
- Choice & Control over Meaningful Relationships
- Choice & Control over How Time is Spent
- Community Engagement
- Dignity of Risk



Choice and Control Over Personal Expression



The level to which the person makes and acts on decisions about personal expression and style. That can include things such as how they dress, how they decorate their living space, the music they listen to, how they wear their hair. These choices may reflect one's culture of origin, religion, identity (sexual or gender), politics, or other affiliations.



Choice and Control Over Living Arrangement



The level to which an individual has choice and control over where they live, who they live with, and with whom they share a room (if relevant).

People may value different things when selecting a preferred living arrangement, and those values may be affected by different cultures and backgrounds.

Living arrangements include such things as living alone, living with others, and the type of communal setting. The living environment also is important, and is distinct from the living arrangement. The living environment addresses such things as the attitudes and beliefs of others in a shared living environment as they affect the individual (e.g., cultural biases/prejudices). Individuals may consider the living environment as part of their choice of the living arrangement.



Choice and Control Over Finances



The level to which individuals make choices and have control over how their money is spent. Financial control may include:

- having and exercising budget authority (i.e., control over how HCBS funds are allocated, including wages of staff, or decisions to purchase supplies);
- purchasing, owning, using, and selling goods or other assets;
- decisions over the appointment of a financial power of attorney, and direction of any such POA; and
- other decisions related to how one spends income.



Choice and Control Over Healthcare



The level to which HCBS consumers are enabled to make informed decisions about health care. People are enabled to make decisions when they have information that is provided in accessible, meaningful ways, and can access other necessary health care resources (e.g., physically accessible exam tables, testing equipment). People also need to be given the right to make choices about health care, or to designate others to assist in making decisions. Decisions should not be made for them without their consent and meaningful input.



Choice and Control Over Diet and Nutrition



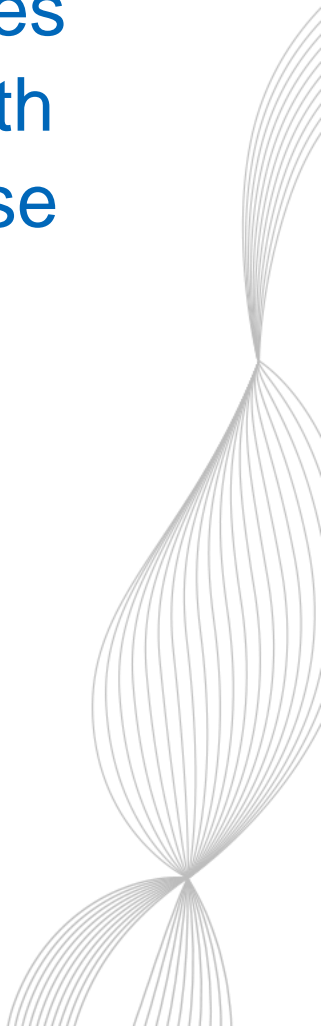
- The level to which the individual makes and exercises choices about what they eat. A person can make these choices for many different reasons. Reasons can include health, finances, culture, religion, politics, and personal preference.
- People should have choice and control even when others believe that foods may be unhealthy for them. People may be provided with information to assist them in making choices, and still have the control to make choices others believe are unwise. This is part of the dignity of risk.



Choice and Control Over Meaningful Relationships



The extent to which the individual makes and acts upon choices about forming and maintaining close, intimate relationships with individuals or communities of their choosing. Individuals choose who they want to have relationships with. Such relationships may be physical, sexual, and/or emotional. They may be with friends, family, or workers. People also may have meaningful relationships with animals, whether service animals or pets.



Choice and Control Over How Time is Spent



The extent to which the individual makes and acts upon choices about how to spend their time. This includes choices about the types of activities in which one takes part, decisions to spend time alone and in solitary activities. Control over how to spend time also requires flexibility, such that a person can choose to do different types of activities at different times, as they prefer.



Community Engagement



The level to which the individual is engaged with and integrated into communities of their choosing. Communities may be defined by culture, religion, sexuality, disability, or other shared interests or identities. The level and nature of engagement may vary by the individual's preferences. Such forms of engagement may include developing new communities, organizations, or activities; participating in the activities of a group; assuming a leadership role in a group; volunteering to contribute to a group's activities; developing and maintaining friendships; or any other way in which the person wishes to be engaged.



Dignity of Risk



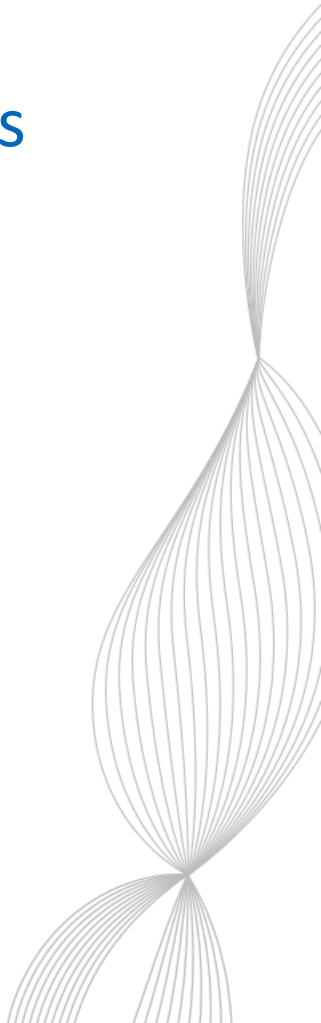
- The level to which people make and act upon decisions, regardless of the risk that others believe such decisions pose. This includes receiving the necessary information and supports to assess risk, and to act on the decisions one has made, even when others believe those are unwise decisions.
- Risk is not only about things that present a possible danger to one's self or to others. Risk also includes taking a chance on pursuing things that could be very promising, such as applying for a job or promotion. Risks also may include such things as signing contracts; decisions related to health; pursuing an emotional relationship; getting married; managing money; having a child; pursuing physical risky activities (e.g., skydiving); and other activities.
- Dignity of risk is about who has control of decision making.



Focus of Measures Being Developed



- Achievement of person-centered outcomes
- Effectiveness of HCBS in supporting the person-centered outcomes



Achievement of Person-Centered Outcomes



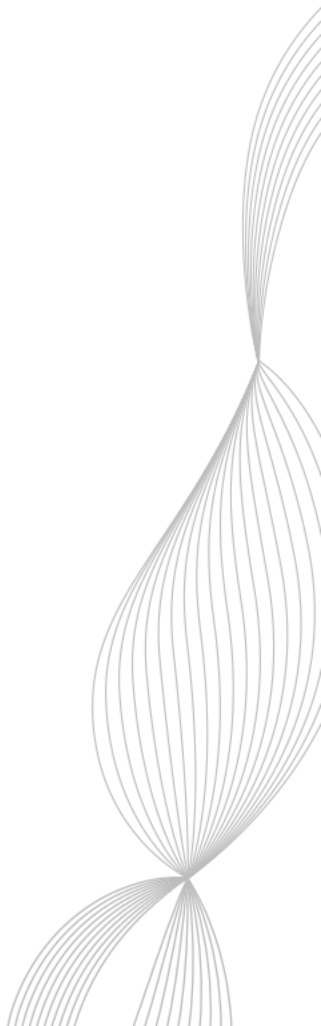
- Outcomes can take varying amounts of time to achieve, for various reasons
- Progress toward outcomes can more or less positive, depending on the situation
- Achievement of an outcome may or may not be an end point



Effectiveness of Supports



- Supports may come from a variety of sources
 - Family and friends
 - Community organizations
 - HCBS provider
 - Transportation services
 - Service recipient
 - Other
- Quality measures are focused on the effectiveness of the HCBS providers



Current Stage of Development



- Data collection tools are being revised with input from two Advisory Councils
- Data collection tools will undergo cognitive testing and revision
- Data will be collected from HCBS participants, to test the reliability and validity of the data and resultant measures



Would You Like to Be Involved?

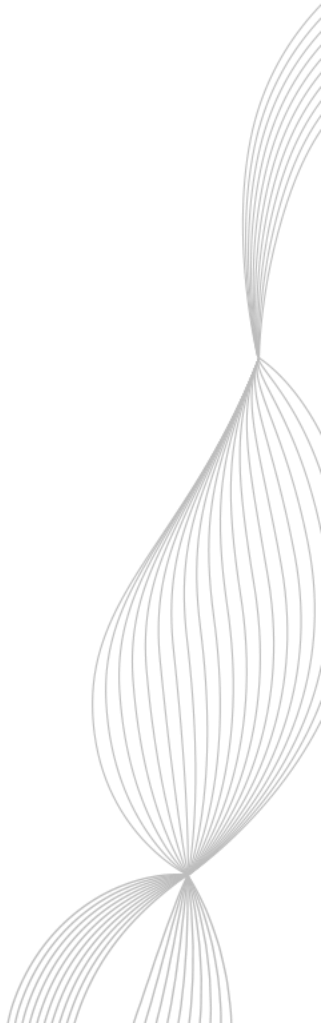


- We will be reaching out to states and HCBS providers to serve as partners in testing.
- If you are interested in knowing about this opportunity, please contact:

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or

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Questions?