



A Person-Centered, Longitudinal Approach to HCBS Outcome Measurement

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Rehabilitation Research and Training
Center on HCBS Outcome Measurement

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What is HCBS Outcome Measurement?

- **The goal of HSBS Outcome Measurement is to better understand...**
 - The **quality** of services and supports received by HCBS recipients
 - » Timeliness
 - » Based on best-practices
 - » Coordinated
 - » Meet the recipients' needs
 - **The *outcomes* recipients experience when services and supports are received**
 - » Are outcomes person-centered
 - » Meaningful, and
 - » Contribute to a high quality of life



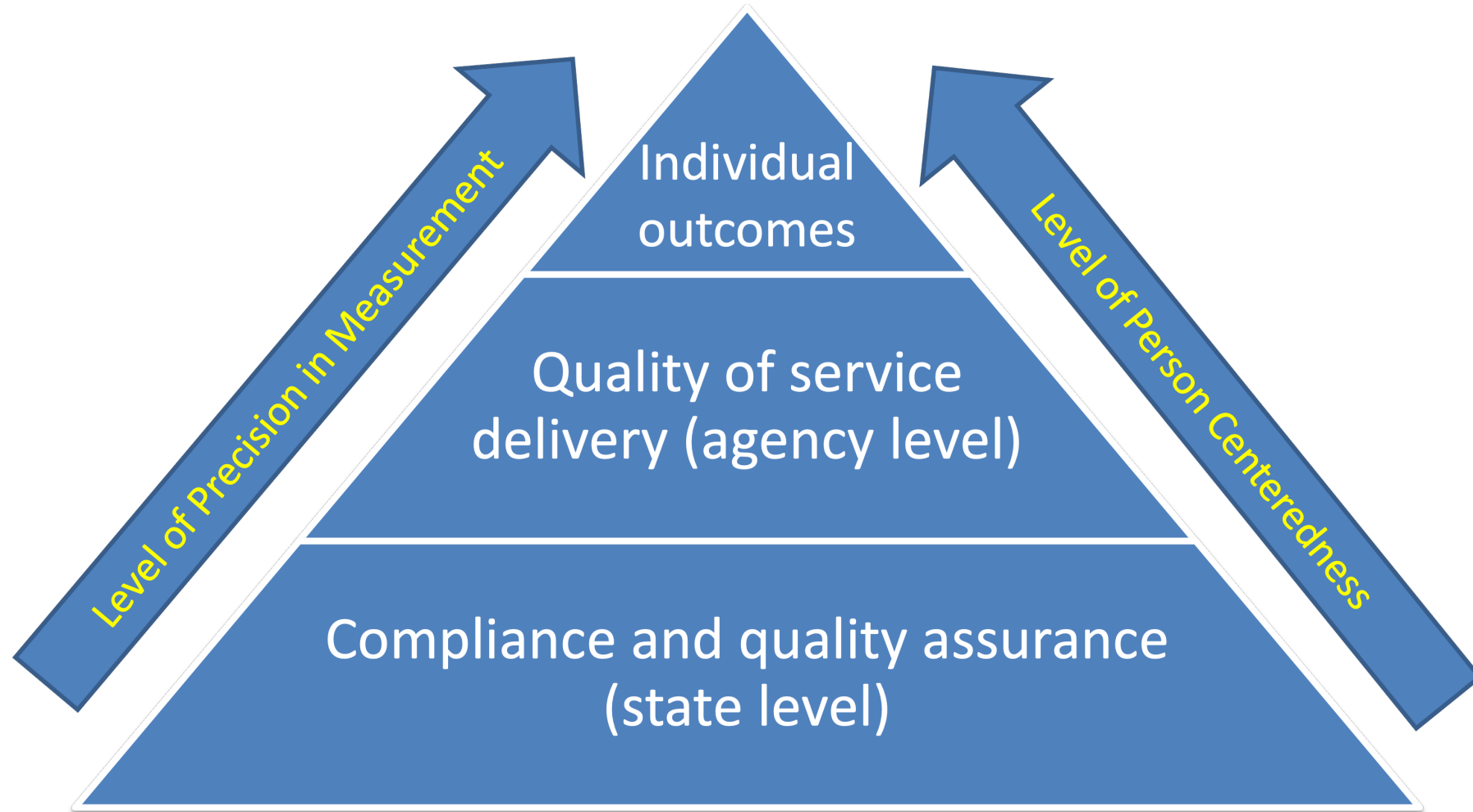
Source: GAO. | www.gao.gov

Levels of Measurement

- **HCBS measurement can take place at a variety of levels**

- **National**
 - **State**
 - **Provider**
 - **Individual**
- } Compliance with legislative & policy mandates
- } Recipient and family understanding of quality of supports provided & associated outcomes
- } Determine the extent to which HCBS recipients are living high quality lives

Levels of Measurement & Need for Precision



Importance to Providers

- **Documentation of high-quality services & outcomes**
 - Having data to market the quality of services and supports you provide to HCBS recipients
 - Meeting state and federal service provision guidelines
- **Quality improvement efforts**
 - It's difficult to fix something if you have no data that suggests that thing needs fixing
 - Data is needed to support that program innovations are having their intended outcomes



Principles Underlying Measure Development Process

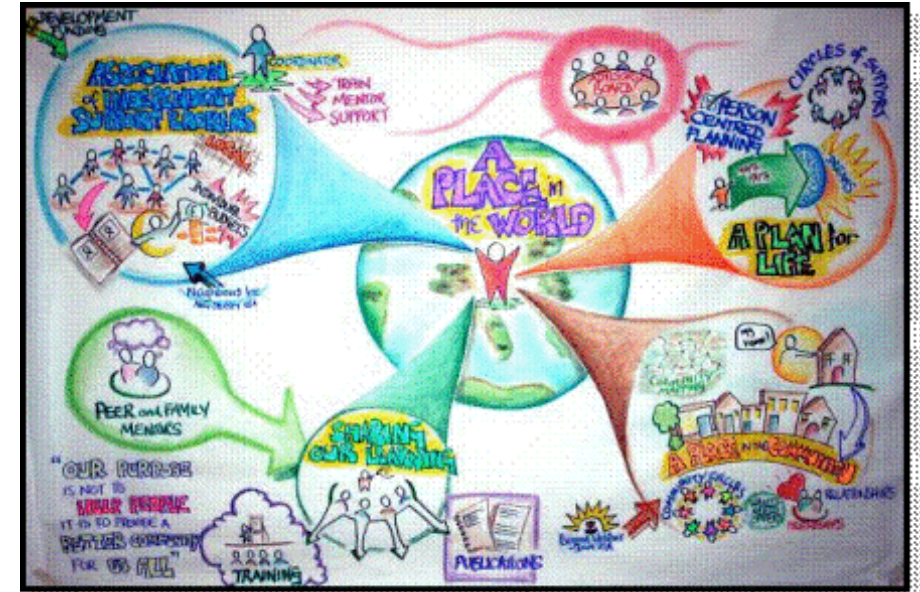
Outcome Measures need to be:

- Person-centered
- Sensitive to change over time (can be used longitudinally)
- Feasible to administer, minimizing respondent and provider burden
- Guided by National Quality Forum Framework for HCBS Outcome Measurement (revised); and
- Have utility at service provider and individual levels (actionable data) with the capacity to contribute to Quality Improvement efforts

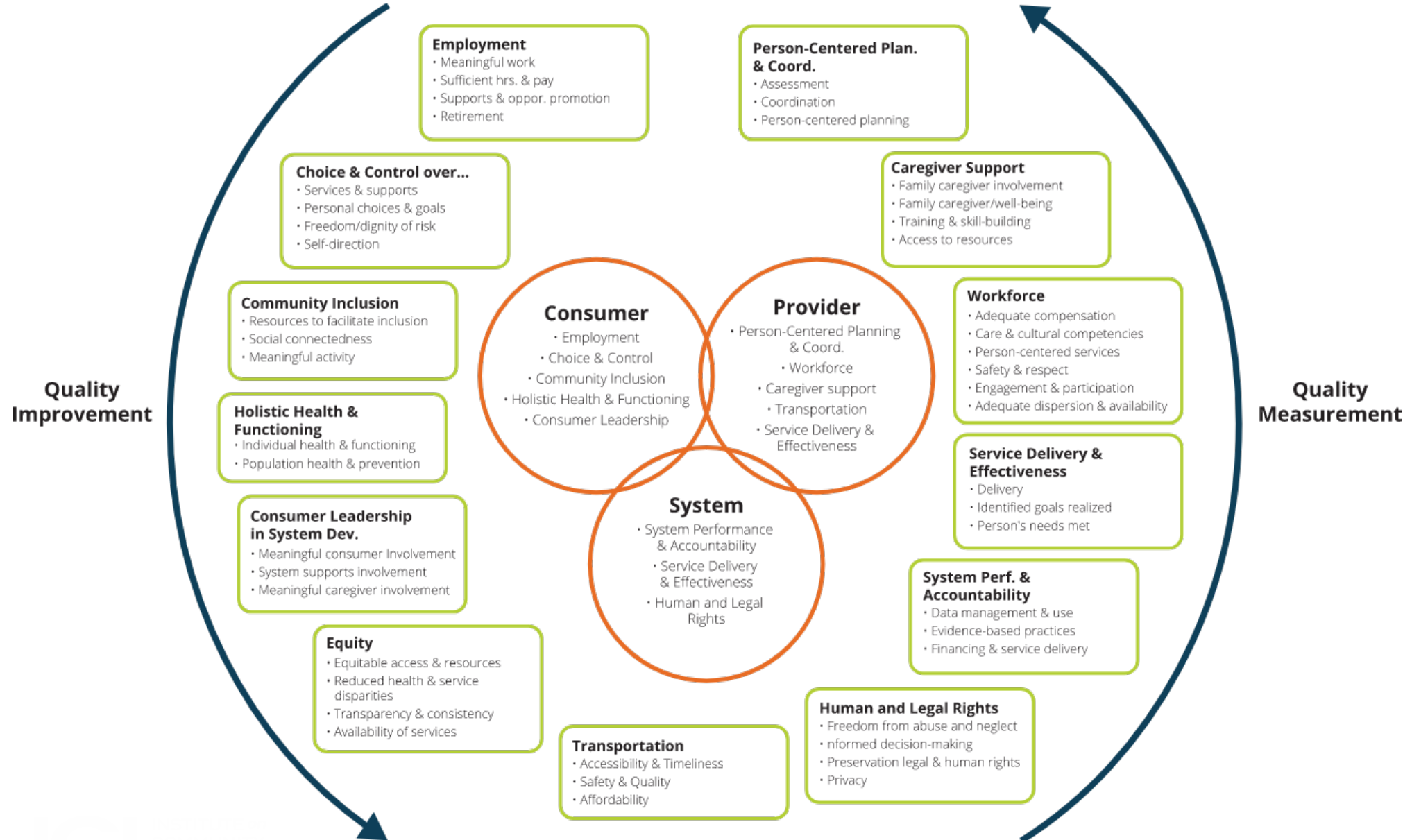


Person-Centered Measurement

- Measurement is person-centered when the individual's *experiences, needs, goals, and values*, as expressed by persons themselves, inform decisions about..
 - ❖ What we measure
 - ❖ How we assess outcomes, and
 - ❖ How we evaluate the performance of community-based supports
- Has many dimensions and is ***not the same*** as assessing person-centered supports and practices
 - ❖ Should underlie all measurement in this area
- Balances measurement of what is ***important for*** the person with what is ***important to*** the person.



Revised National Quality Forum Measurement Framework



Measure Development - Selecting Concepts

❖ Phase 1: Participatory Planning and Decision-Making w/ Stakeholder Groups

- People with disabilities, family members, providers, policy makers and researchers
- Provided input on NQF framework
- Importance weightings w/ respect to domains most important to measure

❖ Phase 2: Gap Analysis

- Development of RTC/OM database of existing measures, assessments
- Coded items on NQF Framework coverage from over 130 HCBS-related instruments
- Results with input from RTC/OM Leadership and National Advisory groups led to development of measures in 13 NQF Domains/ Subdomains.

❖ Phase 3: Technical Expert Panels

- Weightings of Importance, utility, & feasibility of measures



Phase 4: Measure Development - Prioritized Domains/Subdomains

- **Choice & Control**
 - **Community Inclusion**
 - **Employment**
 - **Human/Legal Rights**
 - **Transportation**
 - **Consumer Leadership in System Development**
 - **Person-Centered Planning & Coordination**
- **Personal Choices & Goals**
 - **Choice of Services & Supports**
 - **Self-Direction**
 - **Meaningful Community Activities**
 - **Social Connectedness**
 - **Currently Employed**
 - **Seeking Employment**
 - **Freedom from Abuse/Neglect**
 - **Access to, affordability & quality of transportation**
 - **Meaningful Involvement**
 - **System Support & Resources**
 - **Person-Centered Assessment**
 - **Person-Centered Planning**
 - **Person-Centered Service Delivery & Coordination**

Phases of Measure Iterative Development Process

- **Initial Measure Development**

- ❖ National Quality Forum HCBS Outcome Measurement Framework
- ❖ Intensive review of current research literature related to each measurement construct
- ❖ Development of guiding questions/claim statements

- **Designed for 5 Disability Groups**

- ❖ Intellectual and Developmental Disabilities
- ❖ Physical Disabilities,
- ❖ Psychiatric Disabilities,
- ❖ Traumatic/Acquired Brain Injury, &
- ❖ Age-Related Disabilities



Characteristics of the Measurement System

- **Modular in Format**
 - ❖ Each measure can be used independently or in conjunction with other measures
- **Ability to be Used Longitudinally**
 - ❖ Measures need to be able to be sufficiently sensitive to detect changes in outcomes in response to policy and programmatic changes
- **Two - Tiered Measure Structure**
 - ❖ **Tier 1:** 3-5 general items intended to provide overview of outcomes within subdomain
 - ❖ **Tier 2:** 10-15 specific items intended to provide more specific, actionable data
- **Respondents**
 - ❖ Persons with disabilities (whenever possible)
 - ❖ Proxy nominated by person and knows them well



Measure Development Trajectory *(CMS Measure Development Blueprint)*



Measure Development and Testing

- **Technical Expert Panels Item Reviews**
 - ❖ Each measure reviewed and revised following feedback from 10-20 national content and measurement experts
- **Cognitive Testing**
 - ❖ 27 PWD from across disability groups
 - ❖ Comprehension, Judgement, Retrieval, and Response Options
- **Pilot Testing**
 - ❖ Tested for feasibility with 107 participants from across disability groups in 2 states
 - ❖ Initial psychometric estimates



Pilot Study - Sample

Sample: N=107 from across five disability groups

- MN and PA
- Age: 22 - 101 years
- Race: Representative of U.S. pop.
- Geographic representation:
 - » Rural - N=31
 - » Urban/suburban - N=76



Pilot Study - Data Collection

- **Structured Interview**
 - ❖ Qualtrics survey platform (offline app)
- **Interview Type**
 - ❖ In-Person (n=85) & Video Conference Interview (n=22)
 - ❖ Verbal-Only Response Scale or Verbal with Visual Representations
- **Inter-Rater Observations**
- **Test-Retest at 10-14 Days**



Pilot Summary Table

Measure	Internal Consistency (α)	Test-Retest	Inter-Rater
Abuse and Neglect	.62	.81	.98
Employment: <i>Job Experiences</i>	.81	.99	.89
Employment: <i>Barriers</i>	.70	.95	.89
Choice and Control (<i>overall</i>)	.85	.76	.94
<i>C&C: Services and Supports</i>	.77	.74	.93
<i>C&C: Personal/Daily Choices</i>	.75	.72	.98
<i>C&C: Self-Directed Supports</i>	Insufficient sample size	Insufficient sample size	Insufficient sample size
Transportation	.86	.76	.92
Social Connectedness	.88	.91	.94
Meaningful Activity	.94	.79	.92

General Takeaways & Highlights

- Overall, measures demonstrated good psychometric properties
 - internal consistency
 - test-retest
 - interrater reliability)
- *Abuse and Neglect and Employment (Barriers)* measures had insufficient internal consistency



What We Learned, Challenges, & Changes - Part 1

- Disability groups did not significantly differ with respect to their responses to measures
 - ❖ Initial evidence that we can use similar measures *across different disability groups*
 - ❖ Indirect evidence for usefulness of NQF Conceptual Framework for HCBS Outcome Measurement
- Similar measure completion times for tests and retests across disability groups
- Evidence that individuals with significant cognitive disabilities could respond to items in a manner that appear valid and reliable
- Several response scales changed to ensure sufficient variance (some scales initially appeared to have a ceiling effect)



What We Learned, Challenges, & Changes - Part 2

Tier 1 and Tier 2 questions across measures

- Tier 1: 2-4 questions intended to broadly capture construct
- Tier 2: Additional items that dig deeper into more specific aspects of the construct
- Strong relationships between global and specific items
 - ❖ Relationship will be further explored in field study
- This study will provide data to analyze these items
 - ❖ Factor analysis to investigate Global-Specific subdomains
 - ❖ Examine the relationship between measures



Field Study

- Nationally diverse sample of 1,000 across disability groups - target
 - ❖ Organizations supporting recruitment & data collection include UCEDDS, ACL, and data collection organizations
- 8 original measures + 5 additional measures
- Online (Zoom) - majority with in-person data collection option
- Three data collection points – to ensure sensitivity to change
- Group of up to 400 individuals without disabilities who will complete an abbreviated online version



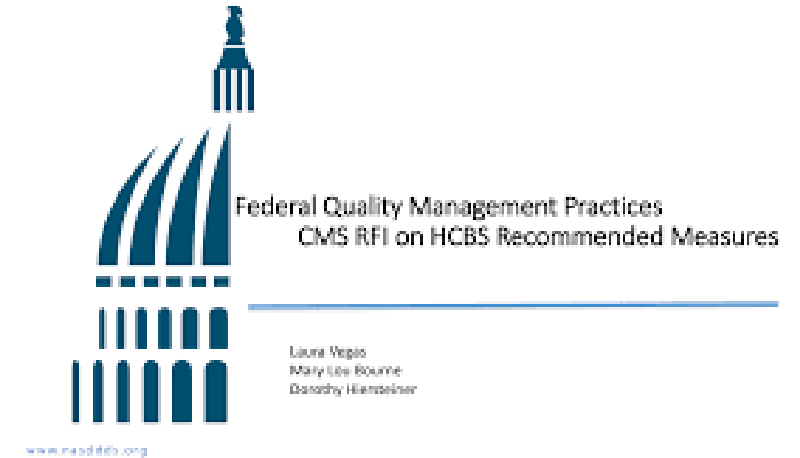
Recruiting for the Field Study!

- We continue to seek MCOs & HCBS provider organizations in the U.S. interested in partnering with us on recruitment of the people they serve to test these measures
 - ❖ Respondents receive gift cards each time they are interviewed
 - ❖ Minimal effort on part of providers
 - ❖ Contribute to development of measures you can use to determine whether the people you serve are experiencing the outcomes they desire
- Contact Matt Roberts (Center Coordinator) at: robe0290@umn.edu if you are interested in helping us recruit participants from your organization.



Looking Toward the Future

- Current measurement programs:
 - ❖ Goal is “sell” the program either to states or providers
 - ❖ Organization supports data collection, analysis, & interpretation
- RTC/OM goal is **not** to develop a measurement *program* but rather...
 - ❖ Generate and validate high quality, person-centered measures that provide *actionable data* for use...
 - *At the state and provider level*
 - *In quality improvement efforts*
 - ❖ Educate others (States, MCOs, Provider Organization, Advocacy & Self-Advocacy groups on how to most effectively utilize measures developed to enhance...
 - *Quality of services received by HCBS recipients and*
 - *The outcomes they experience*
- Give this information away in a manner that ensures it will be used effectively and ethically to improve the lives of HCBS beneficiaries.



Thank you!

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