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HEALTHCARE

OBTAINING PARTICIPANT FEEDBACK ON HOME AND COMMUNITY BASED SERVICES QUALITY

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RESEARCH OBJECTIVE

- The Minnesota Department of Human Services sought to fulfill a legislative mandate to survey a representative sample of participants in four Medicaid programs it operated.
- Specifically, the Department was directed to seek feedback on Medicaid services provided to people with disabilities in their homes and communities through the Developmental Disabilities (DD), Traumatic Brain Injury (TBI), Community Alternative Care (CAC), and Community Alternatives for Disabled Individuals (CADI) waiver programs.
- To that end, Minnesota contracted with Thomson Reuters to develop a survey tool that:
  - Could be administered successfully to individuals with a range of intellectual, cognitive, and physical disabilities.
  - Covered working-aged adults and children;
  - Measured quality constructs that were actionable and valued by multiple stakeholders.
  - Assessed the effectiveness and quality of disability services.
  - Aligned with the federal government's statutory expectations for 1915c Home and Community Based Services waiver programs; and
  - Reflected CHOICE Life Domains recently adopted by the Disability Services Division as guiding principles for quality.

BACKGROUND

- The federal Centers for Medicare and Medicaid Services (CMS), through the Medicaid program, is the primary funder of long-term care services, in partnership with state governments.
- For services provided in home and community based settings (HCBS), CMS is increasingly emphasizing a continuous quality improvement approach, including direct participant feedback on program quality.
- HCBS programs serve individuals with a wide variety of disabilities and provide a diverse array of services.
- Unlike other Medicaid programs, services are generally not medical in nature, but rather support recipients in completing activities of daily living (bathing, dressing, eating, laundry, etc.), seeking and maintaining employment, and community integration.
- As a result, quality metrics may be appropriately defined through individual outcomes and experiences.
- The National Quality Forum and others have identified the consumer voice as missing in the quality conversation.
- The state of Minnesota has a long history of consumer and stakeholder involvement in the design and ongoing assessment of the long-term care services it funds. This project was viewed as an extension of that trend.

STUDY DESIGN AND METHODS

- The state requested that the new survey be modeled after the Participant Experience Surveys (PES), developed by Thomson Reuters under contract to CMS. For this project, Thomson Reuters partnered with the University of Minnesota's Institute on Community Integration. To develop the new survey, the research team:
  - Reviewed extant survey tools for one or more of the study populations to establish content validity, including modified, state-specific versions of the PES.
  - Developed survey domains in collaboration with a stakeholder advisory panel of self-advocates and family members, providers, advocates, and public sector staff to establish face validity.
  - Modified existing PES items where appropriate and drafted new items.
  - Conducted iterative cognitive testing of draft survey items using concurrent probes to establish construct validity.
    - 36 completed interviews
  - Mounted a small-scale field test to examine implementation logistics.
    - 40 interviews, 10 per program
  - Conducted a limited assessment of inter-rater reliability using paired interviewers to jointly code single interviews.
    - 90% or higher agreement
  - Developed training and other support materials.
  - Researched and provided recommendations on survey implementation logistics.
- Populations included in the project:
  - Adults and children with physical disabilities
  - Adults and children with intellectual and developmental disabilities
  - Individuals with traumatic brain injuries
  - Children with special healthcare needs/chronic conditions
  - Individuals dependent on medical technologies
- All testing protocols were reviewed and approved by the Institutional Review Boards of the University of Minnesota and the Minnesota Department of Human Services.

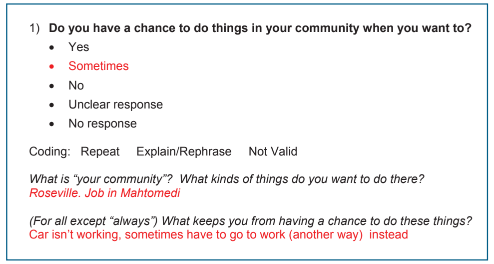

Figure 1. Sample Cognitive Testing Item with Probes and Responses

1) **Do you have a chance to do things in your community when you want to?**
   - Yes
   - Sometimes
   - No
   - Unclear response
   - No response

Coding: Repeat Explain/Rephrase Not Valid

What is "your community"? What kinds of things do you want to do there?
Roseville. Job in Mahtomedi

(For all except "always") What keeps you from having a chance to do these things?
Car isn't working, sometimes have to go to work (another way) instead

PRINCIPAL FINDINGS

- One central hypothesis was that the survey would need to include separate modules for different disability groups. Instead we found that the core quality constructs identified by the stakeholder group cut across populations and that distinct modules were required rather for specific services and service delivery models.
- In addition, we found that items for children needed to be structured differently for parent/guardian response and to recognize families' role in care provision and oversight, as well as age-appropriate expectations about self-care and community activities. This ultimately resulted in two separate surveys: one for adults and one for children.
- Other key findings:
  - Items must be specific and relevant to individual experience; screening items to establish relevance is essential.
  - Familiar and program-specific terms should be utilized; cognitive testing is valuable in identifying these.
  - Response patterns should be limited to a few alternatives; team developed response pattern specific to perceived individual control.
  - Complex concepts need to be broken down into multiple items to facilitate comprehension and response.
  - Cognitive testing is very important in establishing comprehension and interpretation.
  - The critiques and feedback of project stakeholders are invaluable in tool development.
  - Proxy respondents are necessary for many individuals with intellectual disabilities.
    - All interviews with minors and 6 of 28 (about 20%) of adult interviews were completed by proxies.
    - Five of the non-proxy adult interviewees received help in responding from another person.
    - All adults in the Developmental Disabilities waiver received at least some help answering questions.
  - Average length of administration time was under 35 minutes.
- Selected changes to the survey as a result of cognitive testing:
  - Created separate versions for adults and children.
  - Dropped several items from the children's versions including: choices about daily activities, foods, free time, etc.; all money questions; MN identity cards and voting questions; all questions for those who live at home; ability to go out in the community without supervision; unmet need in instrumental activities of daily living; community integration.
  - Created a module specific to participants who hire their own staff; added an item about denials for individual budget requests.
  - Created a skip pattern in the self-direction module for cases where all paid staff were family members.
  - Integrated service planning and case management sections.
  - Dropped all "how often" response patterns to simplify options.
  - Dropped transportation questions for children.
  - Dropped all choice questions about daily activities (e.g., when you get up, what you watch, when you eat) for adults who hire their own staff, who by definition do not live in adult foster care.
  - Created an "experience with congregate care" module.
  - Dropped items about MN identity card and sufficiency of social activities (too little, too much).
  - Changed "tease" to "intimidate" based on parental feedback.
  - Dropped item asking if people were aware of different options for daily activities.
  - Added "social worker" to the case management section, since this was a term used by some respondents.
  - Dropped "language you prefer" in communication items.
  - Added questions about appeal rights.

CONCLUSIONS

- It is possible to gather meaningful, valid, and reliable feedback on long-term care and HCBS experience and quality from individuals with diverse disabilities, including intellectual disabilities. This requires careful item design and testing, as well as judicious use of proxy respondents.
- The relevant constructs for children often differ appreciably from those for adults, primarily due to the role of parents as primary caregivers and age-appropriate expectations around self-care and social roles.

IMPLICATIONS FOR POLICY

- Increasingly, there are calls for including consumers' voices in quality measurement and improvement.
- This project shows the feasibility of collecting this type of feedback from individuals with diverse disabilities, as well as the special attention that must be paid to crafting and testing survey items.
- In addition, surveys for children with disabilities need to be adapted to reflect the role of families.