Quality Indicators for Medicaid Services to People with Developmental Disabilities

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This work is being conducted under contract to the Centers for Medicare and Medicaid Services, contract number 500-96-0010/0005.
Purpose of the Project

- CMS interest in improving ways of measuring quality:
  - Ensuring quality of services that they purchase
  - Supporting providers in quality improvement efforts
  - Providing better information to consumers

- Develop a set of quality indicators for application to Medicaid services for people with developmental disabilities

- Indicators should be applicable both to institutional settings (ICFs/MR) and community-based settings (waiver homes)
Plan for Indicator Development

• Identify and review existing quality indicators
• Identify from existing indicators a set that could be subject to further testing, potentially including:
  – Indicators that are well developed and well tested; basically ready for use as is
  – Indicators that are well developed, but need to be validated
  – Indicators that need modification to definition and further testing
  – New indicators, developed to fill gaps, that need testing
• Conduct alpha test of selected indicator set
• Recommend set of indicators for further testing or use
Results of Indicator Review

- From our review, we determined:
  - Existing indicator sets, for the most part, have been developed to serve other purposes
  - Existing indicator sets often lack clear operational definitions, or do not meet standards for reliability and validity
  - May indicators are stated as goals, not indicators (i.e., neither rate-based nor sentinel events; not easily quantified/quantifiable)
- We identified a set of 33 indicators that addressed the key conceptual issues across domains for further definitional development
Focus of Existing Indicator Sets

- Individual program assessment
  - Program as a whole (Georgetown)
  - Person-level data, but for program only (CWC)
- System (state) assessment (COPAR, Core Indicators Project)
- External review of individual providers (Texas, Alaska)
- Certification (Massachusetts QUEST)
- Accreditation (The Council)
- Personal satisfaction (Ask Me!)
Guiding Principles of Indicator Development

- Indicators should address quality at the provider level
- Indicators should be useful for external quality monitoring
- Indicators should be helpful for internal quality improvement efforts
What Does Indicator Development Involve? Operational Definitions

- Each term is clearly defined in a way that can be understood and consistently applied
- The data elements needed to calculate the indicator are specified
- The methods for combining data elements to calculate the indicator are defined
What Does Indicator Development Involve?

Data Collection

- Data elements must be clearly defined
- There must be a consistent method for data collection
  - Data collection tool for quantitative data
  - Data collection protocol for qualitative data
- There must be instructions for how to collect data, so that people can collect data in ways that assure high inter-rater reliability
- Approaches to data collection must be feasible (costs, acceptability)
Approach to Indicator Development

- State as a quantifiable indicator, not a goal
- Address operational definitions, data collection instruments and protocols, and data collection instructions
- Multi-disciplinary team
- Iterative process
Possible Outcomes of Development Process

- Development of an indicator to point where it is ready for alpha testing
- Determination that an indicator cannot be feasibly developed
  - Terms cannot be defined in a way that can be reasonably and reliably measured
  - Data collection is too costly
- Determination that an indicator can be feasibly developed, but is not recommended for use
  - Applies to too limited a population
  - Is redundant with another, better indicator
  - Addresses an issue not reasonably within provider’s ability to change
Results of Initial Development Efforts

• Reviewed and discussed definitions for 33 indicators
• Identified questions for follow up
• Created basis to begin development of data collection instruments and protocols
• Developed operational definitions for some key concepts that are widely used, but not well defined
Initial Development Process: State as a Quantifiable Indicator

- Determine exactly what it is that the indicator is intended to measure
- Determine whether the indicator is more appropriately expressed as a rate or as a sentinel event
- Restate the concept as a quantifiable indicator
Quantifiable Language Example

**Original Language:**

Supporters assist people to communicate with and be understood by others

**Restate As:**

Proportion of people who receive needed communication assistance
Initial Development Process: Denominator

- Which clients/provider types does this apply to?
- Does this include clients and legal representatives or clients only?
- Any exclusions? (communication skills, developmental stage, etc.)
- **Goal:** Most indicators should apply to all clients
Denominator Examples

- **QI:** Proportion of clients who are free from abuse and neglect
  - Total number of clients

- **QI:** Proportion of people who receive needed communication assistance
  - Number of clients with communication disorders or difficulties (e.g., people with dysphasia from any cause, who are deaf, deaf/blind, or who are nonverbal for any reason)
  - *Do we need to exclude people below a certain age, who one would normally expect not to be communicative? What is the appropriate age cut-off?*
Initial Development Process: Numerator

- How do we define the event/process/outcome of interest?
- What does the concept include?
- How is it measured?
Numerator Example

- **QI: Proportion of clients being restrained**
  - Number of clients with any form of restraint, excluding mechanical devices used for body positioning or alignment, in the last 7 days.
  - Restraints include any manual, physical, or mechanical means of limiting people’s actions and their consequences. This includes time-out rooms.
Initial Development Process: Risk Adjustment

- Do we expect differential outcomes for different types of clients or providers, for reasons that are beyond reasonable efforts of the provider to intervene?
- How do we measure risk?
- How do we adjust for risk?
  - Categorical?
  - Statistical?
Risk Adjustment Example

- **QI**: Proportion of people who participate in inclusive work activities 10 hours or more every 2 weeks
  - High risk group: People who have severe, intractable seizures, who are quadriplegic, or who have severe or profound retardation
  - This is very controversial!
Indicator Development Process: Data

- How do we get the necessary information?
  - Client interview
  - Family/legal representative interview
  - Staff/provider interview
  - Provider records (care plans, incident reports, etc.)
  - Other sources?

- Need to develop data collection instruments, sampling methods, and interview protocols
- Collected by staff or external evaluators
- Frequency of data collection
- Reporting period
Key Issue: Data Source

- Whose perspective is represented?
- How often can data be collected?
- What are costs and burdens of data collection?
- What is reliability of data from various sources?
- What is best source for specific items and uses of data?
Data Source Example

• **QI:** Proportion of people who are treated with respect
  - The primary source of data is on-site collection of information through client interviews.
  - Secondary sources are on-site observation to validate the interview information and to collect information about the treatment of people who are not interviewable.
  - Families/legal representatives are a tertiary source of information.
Responses from the Field (TEP/SG)

- People are interested in methods for advancing quality assurance and quality improvement
- There are many issues with much room for debate
  - Who defines quality
  - Quality of life vs. quality of care
  - Regulation vs. voluntary approaches and certification
  - Role of the consumer
- The weaknesses we’ve identified in current indicators are recognized by others
- The issues we are addressing are those considered important by others
- Concerns about comparing ICFs/MR and HCBW group homes
- Importance of maintaining broad participation
Unique Challenges

- need to be relevant to both institutional and community-based care settings
- lack of an existing, standardized data collection instrument
- multiple perspectives within the developmental disabilities field
Current Status

- Indicators have been developed, reviewed closely by TEP, SG, and CMS staff, and revised extensively
- Final report on definitions is being reviewed by CMS
- We have developed draft data collection tools
- Need to pre-test data collection approach
- Alpha tests this summer
Domains

- Dignity
- Health
- Integration and Inclusion
- Interpersonal Relationships
- Person-Centered Services and Supports
- Respect for Cultural and Linguistic Differences
- Rights
- Safety
- Self Determination
- Structure
Domain: Dignity

- Proportion of people who:
  - are treated with respect
  - have time, space, and opportunity for privacy
  - from whom staff routinely ask permission before entering their bedroom or private living space
  - make decisions about sharing personal information
Domain: Health

- Proportion of people who:
  - Have received routine, preventive health care in the past year
  - Have had a dental exam in the past year
  - Receive the support needed to define and achieve personal health and fitness goals
  - Receive drugs for behavior management
  - With knowledge of personal disease management
Domain: Integration and Inclusion

- Proportion of people who:
  - Participate in integrative, community activities
  - Have transportation and support to use it to travel to places of their choosing
  - Participate in inclusive work activities
Domain: Interpersonal Relationships

• Proportion of people who:
  – Receive needed communication assistance
  – Are happy with the people they live with
  – With active, natural support networks
  – Who are supported in having intimate relationships
Domain: Person Centered Services and Planning

- Proportion of people who:
  - Receive support to learn new things
  - Are being helped to pursue their goals
Domain: Respect for Cultural and Linguistic Differences

• Proportion of people who:
  – Have staff available who can communicate with them in their primary language
  – Whose cultures and value systems are respected and honored
Domain: Rights

- Proportion of people who:
  - Have access to telephone and mail
  - Are subject to physical restraint
  - Have opportunity to give, refuse, and withdraw consent
Domain: Safety

- Proportion of people who:
  - Are free from abuse and neglect
  - Report that they are free from abuse and neglect
  - Know how to report a situation in which they are being harmed
  - Have supports and strategies to enhance safety
  - Who feel safe
  - With an injury in the past 30 days
Domain: Self Determination

- Proportion of people who:
  - Make choices about their daily routines and activities
  - Make choices about food
  - Control their own finances (adults)
  - Control their own finances (children)
  - Have a statement of health care wishes on file
Domain: Structure

- Direct care staff turnover rates
- Direct care staff retention rates
Methodological Challenges

- Getting information from people with different kinds of communication styles
- Period of observation
- Reporting period
- Small sample sizes (denominators)
- Selecting appropriate peer groups
- Lack of benchmarks and gold standards
Are we on the same page?

- Do we know what the page is?
  - General agreement on important domains and key concepts of quality
- Do we know what we want to do?
  - Varying purposes
  - Shared goals of better information and improved quality
Using Data to Impact Policy Makers

- Highlight key concerns
- Identify “hot spots” (e.g., geographic, specific settings)
- Identify related factors
- Evaluate impact of new policies
- Aide in “value-based purchasing”
Can We Reach Consensus on a Core Set of Indicators?

- Do we want to reach consensus?
- Advantages and disadvantages of a core set of indicators
- Can a core set of indicators be a “living” thing?
- What might a core set of indicators look like?
- How might we reach agreement?