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HEALTH CARE AND HUMAN SERVICES POLICY, RESEARCH, AND CONSULTING - **WITH REAL-WORLD PERSPECTIVE**.

Tracking Services and Outcomes Nationally - Nursing Home Diversion Programs

NHD Grantee Call on Evaluation – March 11, 2009

The Goal of Our Discussion Today is to….

- Develop a shared understanding of the draft National Data Elements;
- Gather feedback from states regarding feasibility (including IT adaptations) and comprehensiveness of the proposed data elements

Importance of Data Collection for AoA

- AoA is exploring alternative funding streams for the delivery of LTC, moving towards consumer direction, and evaluating whether this project will keep people out of nursing homes and/or off of Medicaid in a cost-effective manner that promotes quality of life.

Importance of Data Collection for States

Use of Findings

- Improve or expand programs
- Identify training needs
- Support agency planning
- Guide budget allocations
- Justify resource allocations
- Promote the program to potential participants
- Promote the program to potential referral sources
- Gain credibility by demonstrating outcomes

Importance of Data Collection for Others: Funders, Legislators, Advocates, and Consumers

- Did this program make a difference? How? Why?
- How many nursing home placements did you prevent?
- Should funding be increased/decreased?
- Should the program be eliminated/sustained?

All are important questions that we must be able to answer for purposes of sustainability.

Content for Today's Discussion

- Discuss the feasibility of collecting the proposed set of core National Data Elements across all states;
  - Understand data elements that states are currently collecting and capacity of current systems to collect proposed elements
  - Learn from states that have data collection strategies in place (or have already collected information);
- Identify important data elements that are missing; and
- Share creative ideas for ongoing tracking and evaluation of this program

National Data Elements

Focus of today's call

Quality of Life

Administration and Financing*

Satisfaction with Services*

*Highly Recommended Items (composite of several domains)

Preservation of Financial Resources

Clinical/Functional Status*

Nursing Home Diversion*

Caregiver and Social Supports

Health Care Utilization

Demographics*

Why Only A Select Group of National Data Elements for AoA's Program Tracking?

- Want to keep the data collection/reporting task manageable for states;
- Choose elements that will demonstrate the depth and breath of the program;
- Choose variables that will be of interest to consumers, providers, state legislatures and Congress

National Data Elements – Highly Recommended Items

(Draft for Discussion and Consideration)

Collecting these HIGHLY recommended data elements will allow each grantee and AoA to readily and accurately provide descriptive information about the NHD and VD-HCBS projects. Further, it will assist in making the case for ongoing funding allocations.

***Content Areas:**

1) Demographic and Clinical/Functional Status
2) Administrative Data and Program Financing
3) Nursing Home and Medicaid Diversion
4) Client Satisfaction

*measures of consumer direction are spread across the four content areas

National Data Elements – Demographics and Clinical/Functional Status of *New* Enrollees

- **1) Total Number of Participants Newly Enrolled Between Last and Current Report (unduplicated count)**:
  - Veteran Care Recipients
    - Traditional
    - Self-directed
  - Non-Veteran Care Recipients
    - Traditional
    - Self-directed
  - Caregivers
    - Traditional
    - Self-directed
- **2) Number of New Enrollees by Referral Source**:
  - VAMC, Hospitals, ADRCs, CILs, other
- **3) Number of New Enrollees Served by Disability Type:**
  - Physical, Intellectual, Mental Illness, Deaf/Blind, Multiple Disabilities (for care recipients)
- **4) Number of New Enrollees Served by Demographics:**
  - Age (birthdate or categories)
  - Gender
  - Marital status
  - Living arrangement

National Data Elements – Demographics and Clinical/Functional Status of *New* Enrollees (continued)

- **5) Number of New Enrollees Served by Functional Status**:
  - ADL Impairments (for care recipient)
- **6) Number of New Enrollees Served by Financial Status**:
  - Number with incomes between: 100-199% of poverty; 200-249% of poverty; 250-299% of poverty; 300+ of poverty
  - Number with assets between: $0-$5,000; $5,001-$10,000; $10,001-$20,000, $20,001-$30,000; over $30,000
- **7) Number of New Enrollees Using Different Types of Services:**
  - Personal care, home delivered meals, homemaker, nursing, home modification, PERS, respite care
- **8) Of Those Hiring Paid Caregivers:**
  - Number hiring friends and family members
  - Number hiring non-friends or non-family
- **9) Number of Referrals Determined to be Inappropriate or Ineligible:**
  - Veteran Care Recipients
  - Non-Veteran Care Recipients
  - Caregivers
- **10) Average Days Elapsed Between Initial Referral to NHD and First Day of Service**

National Data Elements – Administrative Data and Program Financing for *All* Current Participants

- **1) Number of Active Participants Between Last and Current Report:**
- **2) Total Hours of AAA Staff Time Spent Between Last Report and Current Report:**
  - Include counselor time, care management and other functions
- **3) Total Program Expenditures Between Last Report and Current Report:**
  - Include FMS, CM, individual monthly budgets, other administrative costs
- **4) Total Dollar Amount Allocated to Individual Budgets for all Current Clients Between Last Report and Current Report**
- **5) Total Dollar Amount of Individual Budgets Expended by Clients Between Last Report and Current Report**
- **6) Total Number of Individuals Exceeding Monthly Budget at Least One Time Between Last Report and Current Report**
- **7) Percentage of Individual Consumers Who Claimed Expenses and Had Bills Paid by FMS Within Two Weeks of Receipt Between Last Report and Current Report**

National Data Elements – Nursing Home Diversion and Medicaid Diversion

- **1) Number of Participants Entering Nursing Home/Institution Between Last and Current Report:**

- **2) Number of Participants Enrolling in Medicaid Between Last and Current Report:**

National Data Elements – Client Satisfaction (2-3 national measures)

Examples for Discussion Only!

- **1) Do the services that you receive improve the quality of your life?**
  - A lot
  - Somewhat
  - A little
  - Not at all
- **2) How satisfied are you with the services that you receive?**
  - Very satisfied
  - Somewhat satisfied
  - A little satisfied
  - Not at all satisfied
- **3) How likely is it that you would have gone into a nursing home without these services?**
  - Not at all likely
  - Somewhat likely
  - Very likely
  - Almost certain
- **4) To what extent do the services that you receive help you? Would you say….**
  - They help a lot
  - They help a little
  - They do not help
  - They make things works
- **5) How much choice did you have in deciding who would help you?**
  - A lot
  - Somewhat
  - A little
  - Not at all

National Data Elements – Optional Supplemental Indicators

- The list of optional supplemental indicators fall into seven broad categories:
  - **Clinical/Functional Status**
  - **Health Care Utilization**
  - **Satisfaction with Services**
  - **Quality of Life**
  - **Caregiver and Social Supports**
  - **Nursing Home Diversion**
  - **Preservation of Financial Resources**

- With limited budgets and practical program constraints, we understand it is not feasible (nor advisable) to measure everything listed on the following slides. This is simply a limited inventory of options. We encourage each NHD program to develop an evaluation strategy customized to its programs goals, budget, and operating environment.

Supplemental Evaluation Measures – Clinical/Functional Status

While there are many and varied purposes for capturing an individual's clinical and functional status, a systematic approach provides the opportunity to learn more about the client, plan interventions, record individual progress, and evaluate/improve programs.

Content Areas:

- Self-rated Health
- Functional/Cognitive Status
- Behavioral/Mental Health Status
- Health/Chronic Conditions Checklist
- Depression
- Health Service Utilization
- Alcohol Screen
- Fall Risk

Clinical/Functional Status

Sample Items:

- Katz Activities of Daily Living (ADL) inventory
- Center for Epidemiologic Studies Depression Scale (CES-D)
- Checklist of health conditions (e.g., diabetes, cancer, hypertension)
- Number of prescription medications
- Falls in the last 12 months

Supplemental Evaluation Measures – Health Care Utilization

Collecting and interpreting health care utilization data can be complicated. However, this information serves as a proxy for severity of illness and level of support needs associated with ongoing health maintenance.

Content Areas:

- Hospital Visits
- Emergency Room Visits
- Clinic/MD Visits

Health Care Utilization

Sample Items:

- Hospitalizations in the past 12 months
- Emergency room visits in the past 12 months
- Clinic/MD visits in the past 12 months

Supplemental Evaluation Measures - Satisfaction with Services

Increasingly, the home is becoming an alternative for individuals who would normally end up in long-term care facilities. Remaining in the community often includes the provision of myriad services and supports, many of which consumers choose to self-direct. Determining whether consumers are satisfied with the services and supports is now recognized as an important outcome and a basic responsibility of those who authorize and provide care.

Content Areas:

- Satisfaction with Services
- Extent of Unmet Need
- Agency Satisfaction

Satisfaction with Services

Sample Items:

- Participant Experience Survey (PES)
- Participant Status and Outcome Measure (POSM)
- Boston College Instruments
- Various check-lists that are program specific

Supplemental Evaluation Measures - Quality of Life Measures

Quality of life (QoL) is a broad, multi-dimensional measure to assess the experiences of participants in a holistic manner. In many ways, quality of life is the "bottom line" for any health and human service program. Some of the quality of life measures below focus on community integration and isolation – key considerations for in-home long term care.

Content Areas:

- QoL/Satisfaction
- Community Integration
- Socialization/Social Supports
- Choice and Control
- Respect and Dignity
- Transportation
- Accessibility

Quality of Life Measures

Sample Items:

- Short Form (SF-8, 12, 36)
- How many days per week, on average, do you leave home for any reason?
- What kinds of difficulty do you have getting the transportation that you need?
- Is your home physically accessible?

Supplemental Evaluation Measures - Caregiver and Social Supports

Providing care can be associated with significant strain or burden. Both caregiver stress and burden has been linked to increased mortality, depression, and higher risk of cardiac events. A critical factor that contributes to successful in-home long term care is the provision of support and care from friends and family.

Content Areas:

- Care Provider QoL
- Satisfaction with Relationship with Client
- Caregiver Self-rated Health
- Caregiver Competency/Confidence
- Caregiver Burden
- Social Supports for Caregiver

Caregiver and Social Supports

Sample Items:

- Short Form (SF-8, 12, 36)
- Zarit Burden Inventory
- Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

Supplemental Evaluation Measures - Nursing Home Diversion

Everyone wants to know, how do I know that my state's program is keeping people out of nursing homes? We recommend approaching it from multiple perspectives to assemble a strong body of evidence.

For many, this is the fiscal case for sustaining and expanding NHD programs – demonstrating that they actually keep people out of more expensive institutional settings.

Content Areas:

- Self-Perceived NH Avoidance
- Length of Time in Community
- Housing and Living Arrangement
- Clinical Comparison to NH/Waiver Population
- NH Admission/Utilization

Nursing Home Diversion

Sample Items:

- Items from the Minimum Data Set (MDS-home care version)
- How likely is it that you would have gone into a nursing home without these services?
- How long have you lived in your present community setting?

Supplemental Evaluation Measures - Preservation of Financial Resources

Another key area of interest in this demonstration is, will the program allow people to preserve their financial resources, help them spend their existing resources more judiciously, and avoid spending down their assets to the point of enrollment in Medicaid?

Content Areas:

- Individual/family financial Resources
- Length of Enrollment in NHD
- Reason for termination of NHD Services
- Medicaid Enrollments of Clients
- New Medicaid Enrollment is Service Area
- Average Medicaid Utilization in Service Area

Preservation of Financial Resources

Sample Items:

- Income between specified poverty thresholds
- Number of individuals who left the NHD program by reason
- Number of NHD clients enrolling in Medicaid at 3, 6, and 12 months after admission into NHD

Questions, Comments, Feedback

Technical Assistance

We are here to provide assistance, guidance, examples, and supports specific to the needs of your program.

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