Maryland Quality of Life Survey for People with Disabilities
Resource Coordinators Briefing
November 5, 2012
1:00 PM

Developmental Disabilities Administration
Maryland Department of Health and Mental Hygiene

National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute.
What is the Quality of Life Survey?

- a voluntary effort by state government agencies interested in measuring how well public developmental disabilities systems serve and support people.
- began in 1997
- 29 states represented plus 23 sub-state entities
- Managed Nationally by HSRI and NASDDDS
State Participation 2011-12
What is the Data Used For?

**Improve Service Quality and System Performance**

- policy development, planning and system change
- quality assurance, remediation and improvement
- state policy planning, development and implementation
- as evidence to guide or inform program operation and practice
- data is shared with the steering committee and stakeholders
What is the Data Used For?

Evidence to meet CMS quality assurances, program monitoring and system improvement

- *Assess system performance and track service quality* across a wide range of individual outcome; family outcome; health, welfare and rights; and system outcome measures.

- *Regularly included in reports and presentations by state policy-makers documenting performance* across a wide range of areas including health access, employment, home satisfaction, quality of life and choice and community participation.
Components of Survey

- **Consumer Face to Face Survey** – a survey asked directly of an adult consumer
- **Family Survey** – a survey sent to family members living with an adult consumer
- **Child/Family Survey** - a survey sent to families living with a child with developmental disabilities
- **Family Guardian Survey** - a survey of families/guardians whose adult family members are in residential placement.
How is this Different From Ask Me!?

- Ask Me! only surveyed consumers, QOL has separate surveys of family members and staff.
- QOL allows Maryland DDA to compare its services with other states.
- Ask Me! was only done at agencies, QOL includes New Directions participants and surveys people at their homes.
- Ask Me! asked surveyors to read questions and answers as written, QOL is a conversation.
Consumer Survey

- Uses conversations with adults receiving services to get information about their experiences
- Gets information on important person-centered outcomes
- Measures system-level outcomes related to: employment, choice, relationships, case management, inclusion, health
- Available in Spanish
Consumer Survey

- Pre-Survey Information: completed before the face to face survey
  Completed by Resource Coordinator using on-line form
- Background Information: completed before, during, or after the survey
  Completed by Resource Coordinator using on-line form
- Section 1- Survey completed by DDA consumers
- Section 2- DDA consumers answer, but can get help from staff or family if needed
Consumer Survey Teams

- Teams of 2 people work together
- 4 teams in Baltimore, the parts of Baltimore county near Baltimore, Ann Arundel County to Annapolis
- 1 team each:
  - Montgomery County West (355 and 97 Corridor)
  - Prince Georges, Montgomery County central, Howard(29 Corridor)
  - Prince Georges East
  - North Baltimore County, Carroll, Harford, Cecil
  - Western Maryland (Frederick and West)
  - Southern Maryland (Charles, Calvert St Mary’s)
  - Eastern Shore
Survey Team Responsibilities

- Appointments coordinated by IRI office staff
- Team member confirms appointment, records and submits completed surveys
- Two people do each survey: at least one is a person with a disability (who has the conversation), the other person records
- Travel the responsibility of survey team members
Refusals and No Contacts

- Individuals may refuse to take survey for any reason
- No contact -- close case after five attempts
What if…

- Someone else wants to participate
- The person…
  - Doesn’t understand the question
  - Talks about something else
  - Appears to be upset
  - Appears restless
  - Wants help to change something
  - Wants to be surveyed by phone
  - Says they are being abused
  - Doesn’t show up for appointment
Mail Surveys

- **Family Survey** – a survey sent to family members of adults with developmental disabilities who live with them
- **Child/Family Survey** - a survey sent to families who have a child with developmental disabilities who lives with them
- **Family Guardian Survey** - a survey of families/ guardians whose adult family members with a developmental disability are in residential placement.
Mail Surveys

- Prepared and mailed by MDAC directly to family/guardian address
  
  Respondents receive an advance letter followed by the survey

- Survey completed and mailed back to MDAC

- Follow up done by mail
  
  If necessary respondents receive a reminder postcard and second survey
  
  Respondents can call in if they need clarification or assistance completing questionnaire
Lessons Learned from the 1st Phase

- The team approach, consisting of at least one surveyor with a developmental disability was effective.
- Transportation is a major issue especially in rural areas such as the Eastern Shore.
- The process for collecting Pre-survey data should be revisited with a focus on determining whether the identified resource coordinator is the right person to provide the accurate data.
- North Baltimore should have more than one team due to its large geographical area.
- Simplify timesheets and add a way to track the work being done.
- Develop ways to improve the accuracy of the lists provided by DDA.
- Utilize a focus group of resource coordinators to data collection and evaluate process.
- *Other input for lessons learned from the first round of surveys?*
How Can Resource Coordinators Help

- Complete the on-line pre-survey and background information for identified consumers
- Support efforts to coordinate with service providers in scheduling face to face interviews
- Provide consumers with support and information on what will happen during the face to face survey
- Encourage families, guardians and service providers who are asked to take the survey
- Let us know if there are any issues or concerns
- Participate on advisory committee or focus group
For More Information or Questions
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Questions or Comments?