

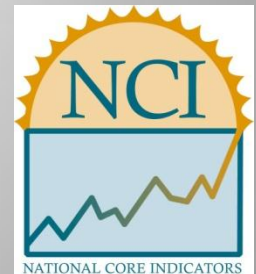


# Maryland Quality of Life Survey for People with Disabilities Resource Coordinators Briefing

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.*



Inclusion Research Institute



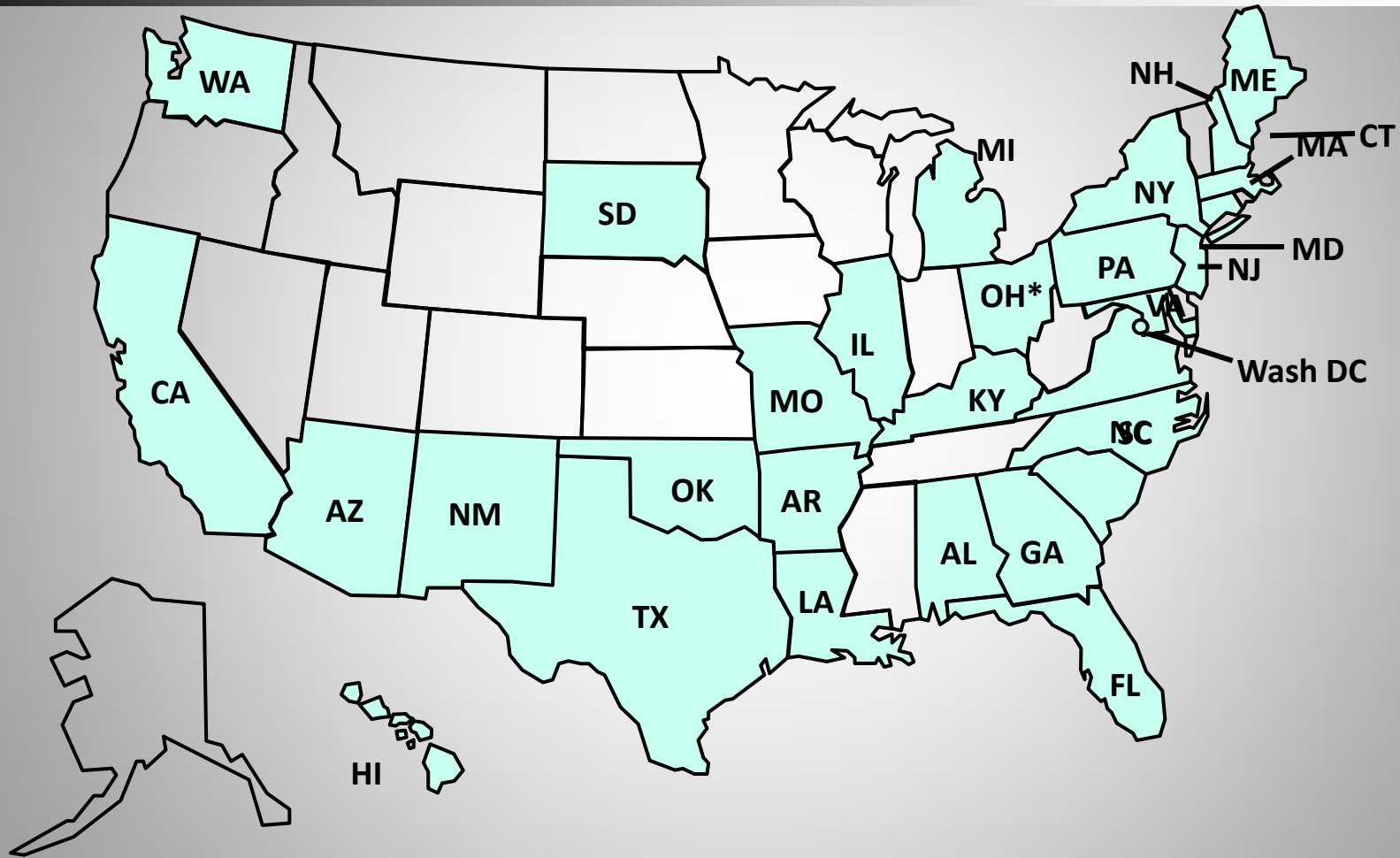


# What is the Quality of Life Survey?

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- 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?

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## **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 stake holders

# What is the Data Used For?

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## **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

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- **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!?

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- 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

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- 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

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- 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

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- 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

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- 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

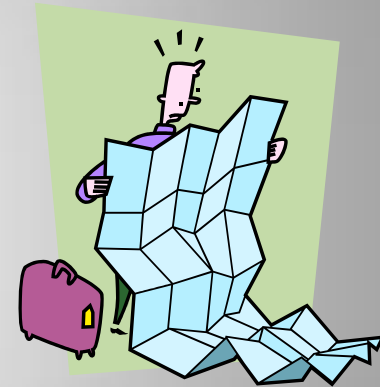
# Refusals and No Contacts

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- 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

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- **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

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- 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

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- 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

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- 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 Contact:

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Questions or  
Comments?