

National Core Indicators What Does it Mean for Providers?

Valerie Bradley
Human Services Research Institute

What is Prompting the Need for Change at the Federal and State Level?

- Exponential expansion of the HCBS waiver
- Increased complexity of ID/DD systems
- Pressure from stakeholders
- Improvement in technology
- Changes at CMS
- Interest in management accountability



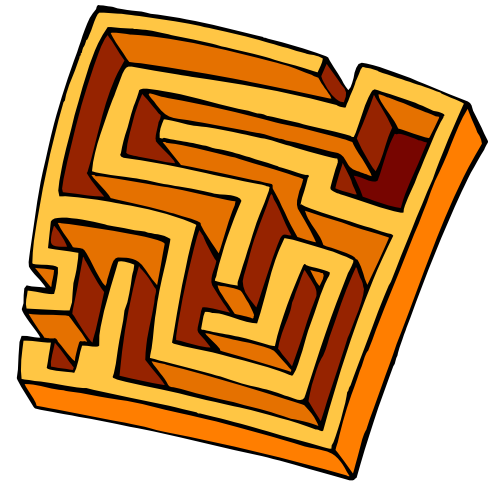
HCBS Waiver Rules in Developmental Disabilities

- Waiver programs for people with DD account for about 75% of all waiver spending
- There are about 100 DD waivers in operation
- In 2006, there were about 480,000 people with DD received waiver services v. 239,000 in 1998 (out of about 1.2 million total)
- The annual cost was about \$40,000
- Four times as many people receive waiver services than are served in ICFs/MR



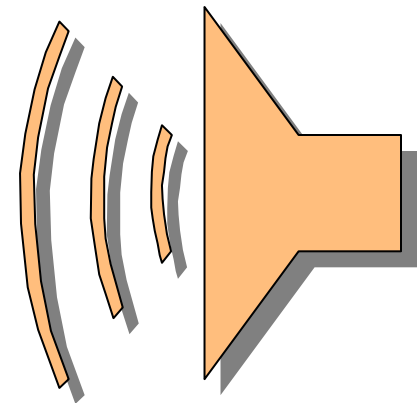
Increasing Complexity

- Settings smaller and more dispersed
- Relative ratio of public monitors to individuals served declining
- Self-determination and individual budgeting pose new challenges
- Risks and opportunities magnified



Pressure from Stakeholders

- Desire for more transparency is increasing
- As people have more choices, they need more information
- Conceptions of quality are changing
- People with disabilities have a more powerful and articulate voice



Self-Advocate Perspectives

- They want outcomes that reflect real lives
- They want to be at the table when we talk about quality
- They want us to be honest about institutions and the damage they have done to people with disabilities
- They don't think that information about quality should be a state secret

RIGHT-TO-KNOW CAMPAIGN

***A RIGHT TO QUALITY HUMAN SERVICES =
A RIGHT TO KNOW***

People with disabilities and their families have the right to make informed decisions on behalf of ourselves and our loved ones. We have the **right to know** if a public or private sector provider has a history of high turnover. We have the right to know a provider's record on abuse and neglect, staff turnover, medication errors, restraint usage, and staffing ratios. We have a right to know we will be safe in our own homes.

QUALITY CARE REPORT CARD	
<u>Category</u>	<u>Grade</u>
Staff retention	?
Abuse/neglect	?
Facilities	?
Finances	?
Medication errors	?
Staff ratios	?



“And lastly, for all eternity, French, blue cheese, or ranch?”

Improvements in Technology

- PDAs and laptops make data entry in the field much easier
- Increasing ability to merge data across platforms makes integrated analysis easier
- Providers are increasingly more sophisticated
- Web access makes data dissemination easier



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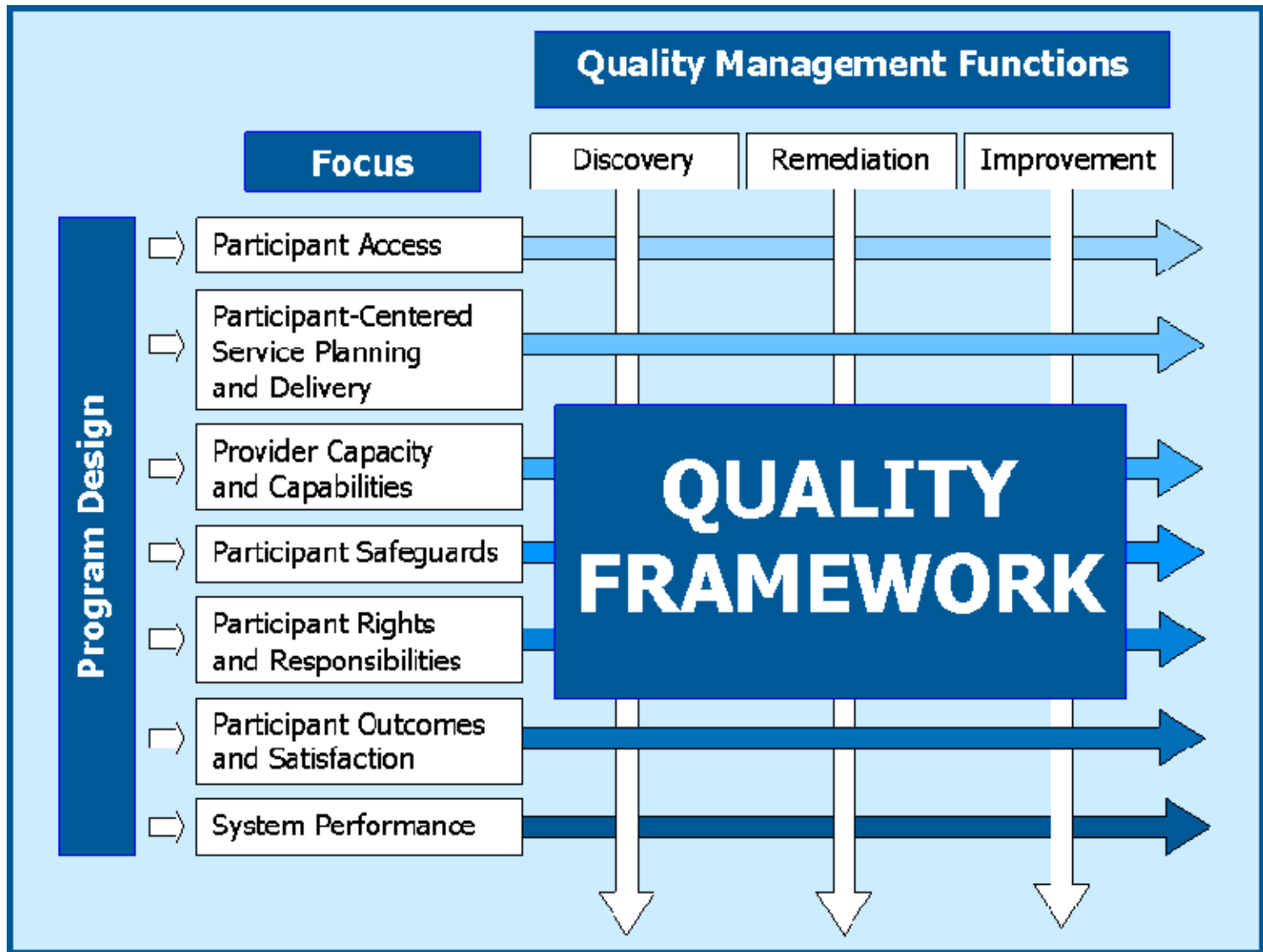
BY RINA PICCOLO



Changes at



- National Contractor
- Quality Framework
- New Waiver Application (3.5)



National Core Indicators



NCI in a Nutshell

NCI is an ongoing, multi-state collaboration of state ID/DD agencies interested in measuring how well public systems for people with developmental disabilities perform along several dimensions



Original Basis for NCI

- Problem: No widely recognized framework for assessing public system performance
- NCI: Vehicle for states to pool their expertise/resources to define and implement a practical framework

Project Beginnings



- **NASDDDS** and **HSRI** collaboration
- Launched in **1997**
- Seven field test states (plus steering committee)
- Currently 30 states and regional centers in California
- ~60 candidate performance indicators
- Development of data collection instruments

NCI Goals

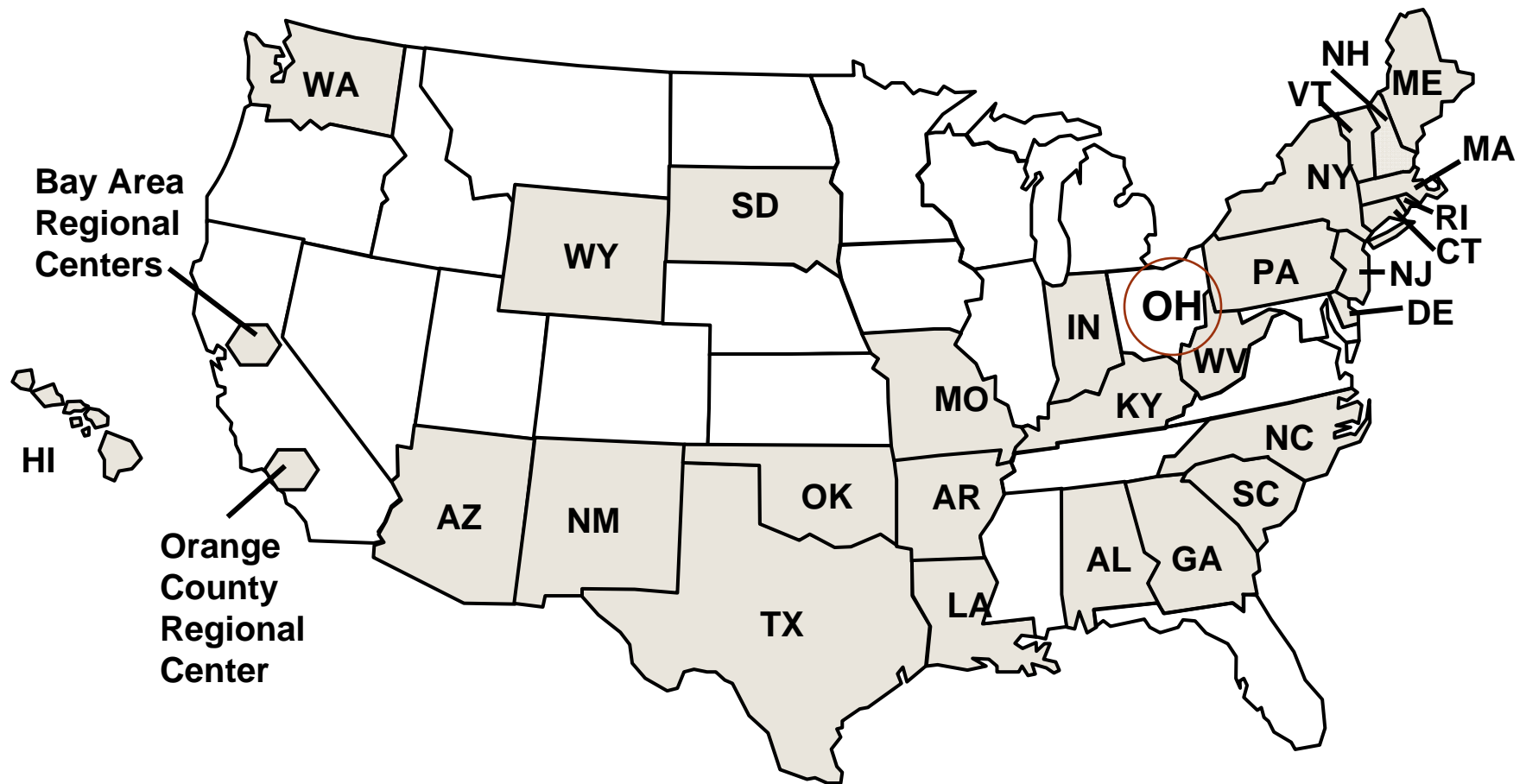
- Establish a **nationally recognized set of performance and outcome indicators** for DD service systems
- Develop reliable data collection methods & tools
- Report state comparisons and national benchmarks of **system-level** performance



NCI Framework

- Improving performance starts with measuring performance
- NCI aids states in measuring performance:
 - Over time (change from baseline)
 - Against multi-state benchmarks (our performance compared to performance elsewhere)

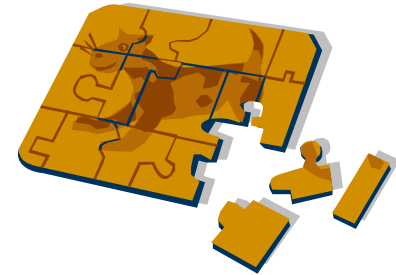
NCI Participating States 2007-2008



Roll Call

- Alabama
- Arkansas
- Arizona
- California
 - RC of Orange County
 - San Andreas RC
- Connecticut
- Delaware
- Georgia
- Hawaii
- Indiana
- Kentucky
- Louisiana
- Maine
- Massachusetts
- Missouri
- New Hampshire
- New Jersey
- New York
- New Mexico
- North Carolina
- Ohio
- Oklahoma
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Texas
- Vermont
- Washington State
- West Virginia
- Wyoming

Where does NCI fit in?



- One component of state Quality Management and Quality Improvement Systems
- Widely-used process for measuring consumer and family quality of life
- Included with other QA data in annual reports & strategic planning
- Produces system-level data
- Some states also use NCI to measure county- and provider-level performance

What are the Core Indicators?

- Consumer Outcomes:
 - Employment
 - Community Inclusion
 - Choice and Decision-making
 - Relationships
- System Performance
 - Service Coordination
 - Turnover
 - Incidents and mortality

What are the Core Indicators?

- Family Indicators
 - Information and Planning
 - Choice & Control
 - Access & Support Delivery
 - Community Connections
 - Family Involvement
 - Satisfaction
 - Family Outcomes

What are the data sources?

- Consumer Quality of Life Survey
- Family Survey
 - Adult Family Survey (at home, 18+)
 - Family Guardian Survey (out-of-home)
 - Children Family Survey (at home, <18)
- Provider Survey
 - Staff Stability
 - Board Representation
- System Data
 - Incidents
 - Mortality

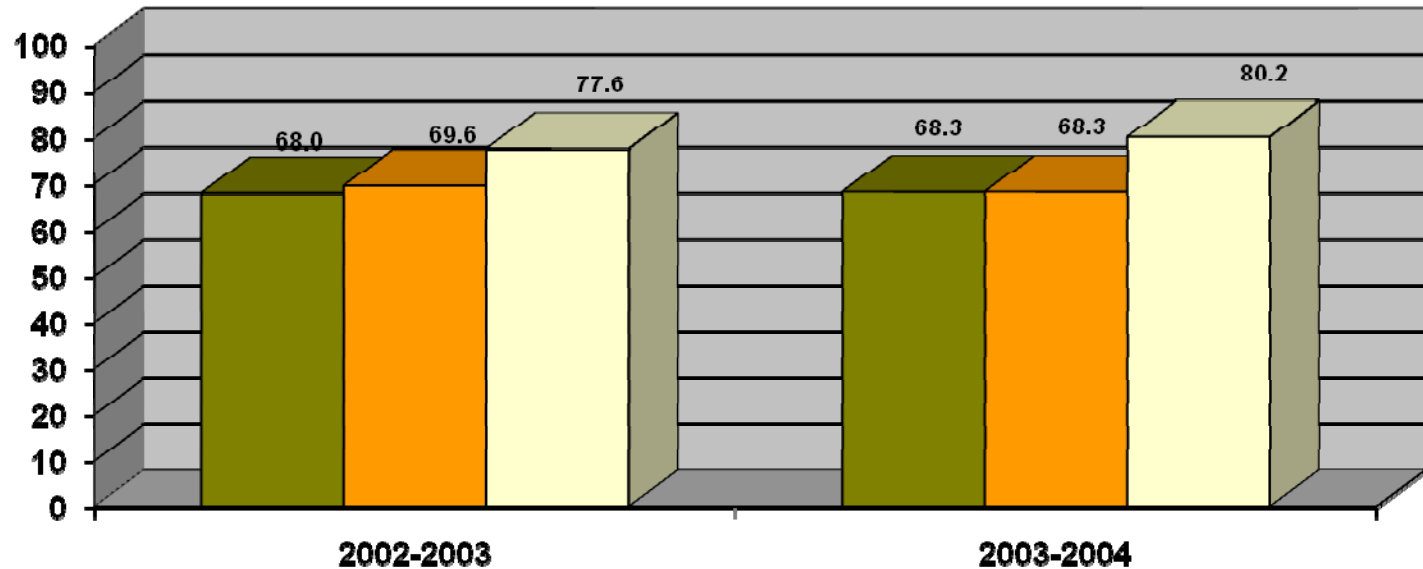
NCI Consumer Survey

- The best way to get information about the experience of people receiving services
- Keyed to important person-centered outcomes
- Measures system-level indicators related to employment, choice, relationships, case management, inclusion, etc.
- Has to be done carefully to ensure reliability

NCI Consumer Survey

- What is the NCI Consumer Survey?
 - Standardized, face-to-face interview
 - No pre-screening procedures
 - Adults Only (18 and over)
 - Should take approx. 35-40 minutes
 - Currently undergoing revision to include more items on health and self direction
 - Divided into 2 parts – only individual can answer part
 - Conducted on a minimum of 400 people

IF YOUR FAMILY (MEMBER) HAS A SERVICE PLAN, DOES THE PLAN INCLUDE THINGS THAT ARE IMPORTANT TO YOU?

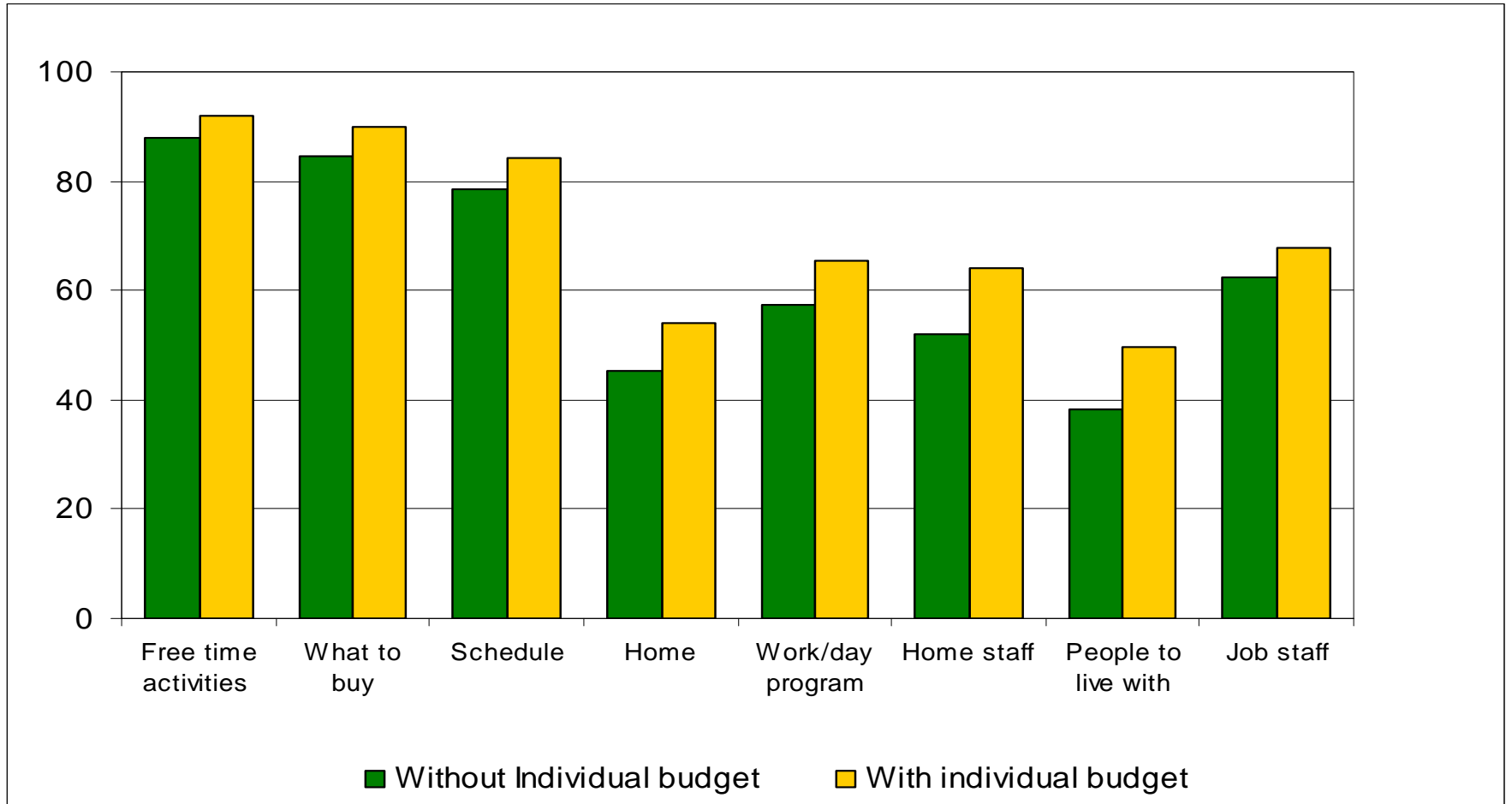


■ Child Family Survey

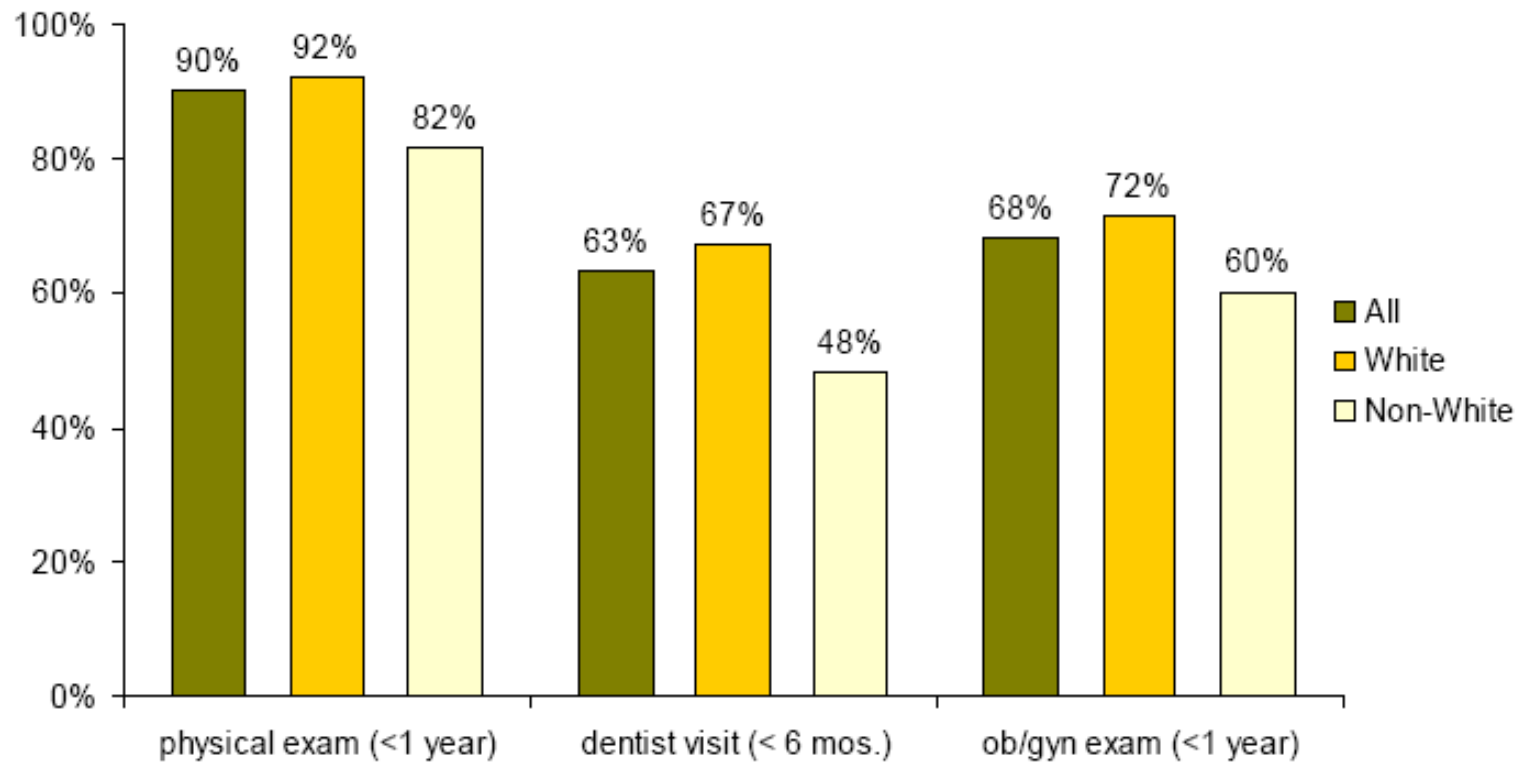
■ Adult Family Survey

□ Family Guardian Survey

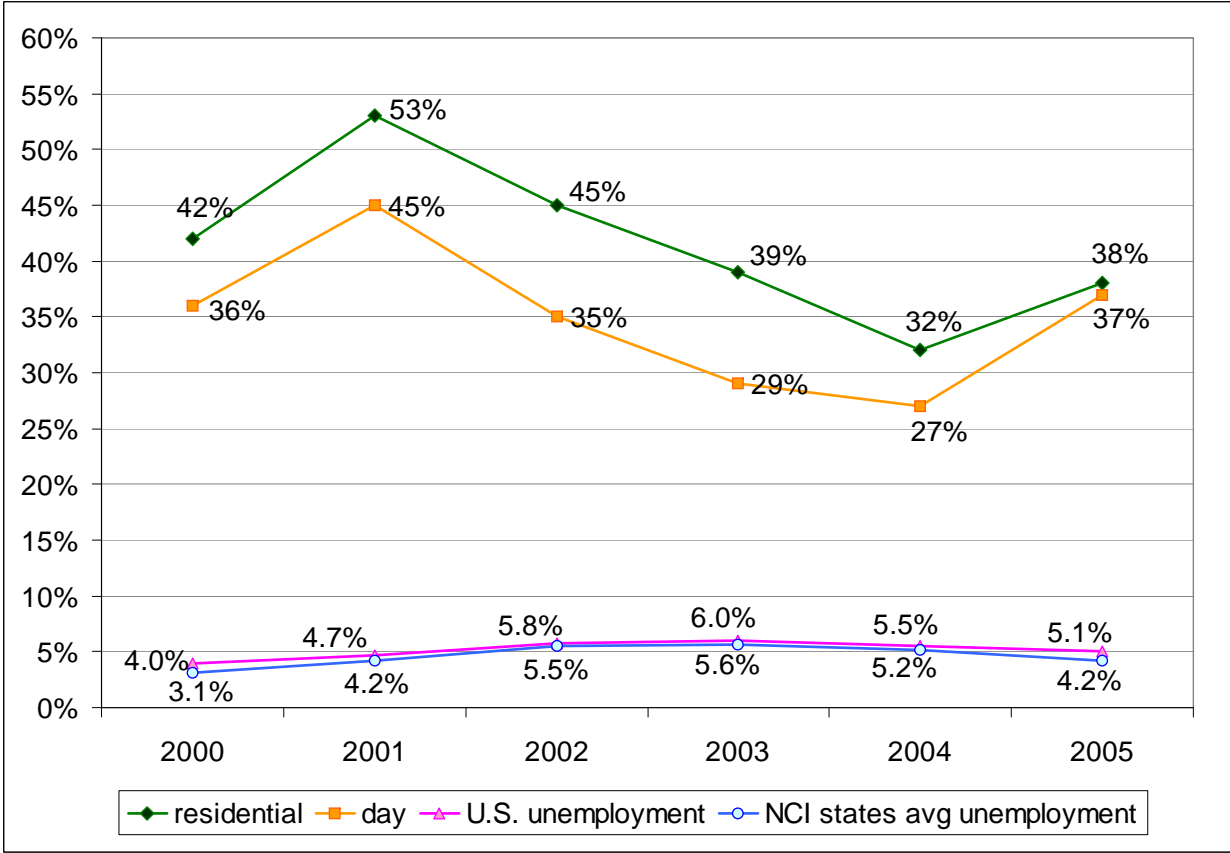
Individual Budgets v. Control Over Life Choices



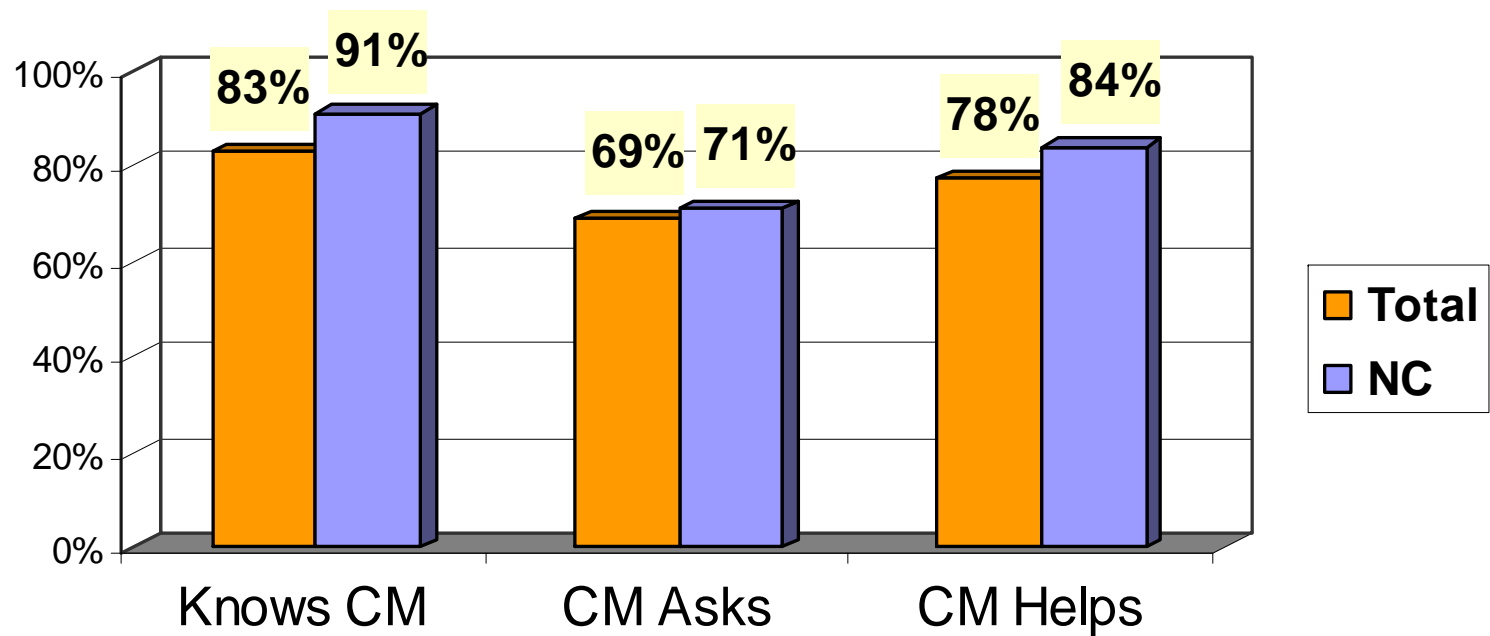
HEALTH CARE ACCESS BY RESIDENCE AND BY RACE



Staff Turnover v. Unemployment Rates



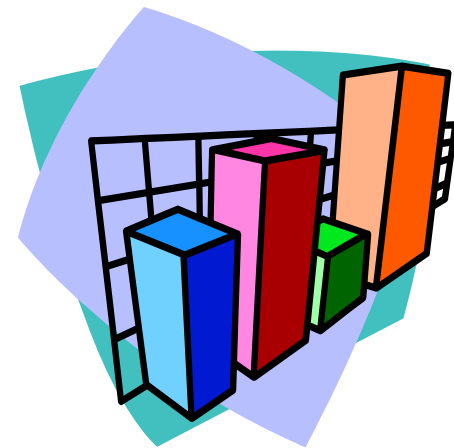
Service Coordination



- Do you know your CM (Knows CM)?
- Does your CM ask what you want (CM Asks)?
- If you ask for something, does your CM help you get what you need (CM Helps)?

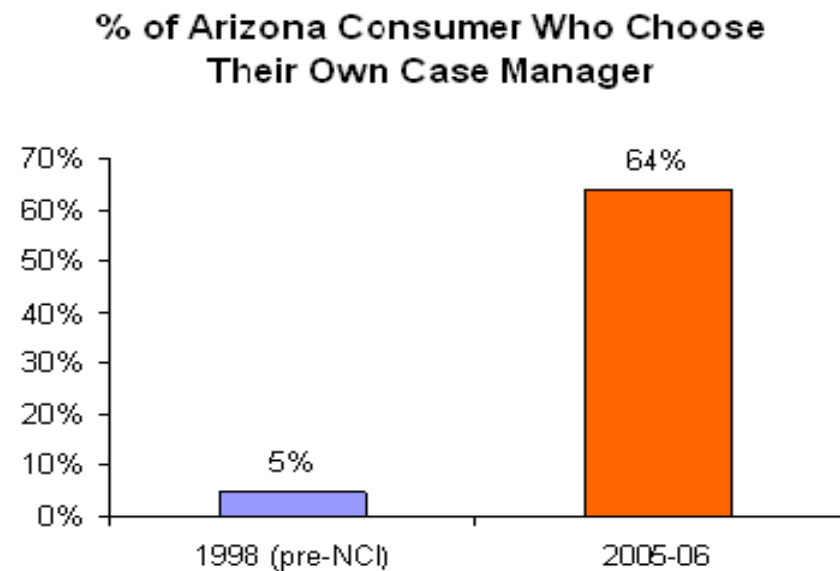
Ways States Use NCI Data

- CMS Waiver Requirements
- Quality Assurance/Improve Services
- State by State Comparisons
- Assist with Community Transition
- Quality and DD Councils
- Reports to State Legislatures

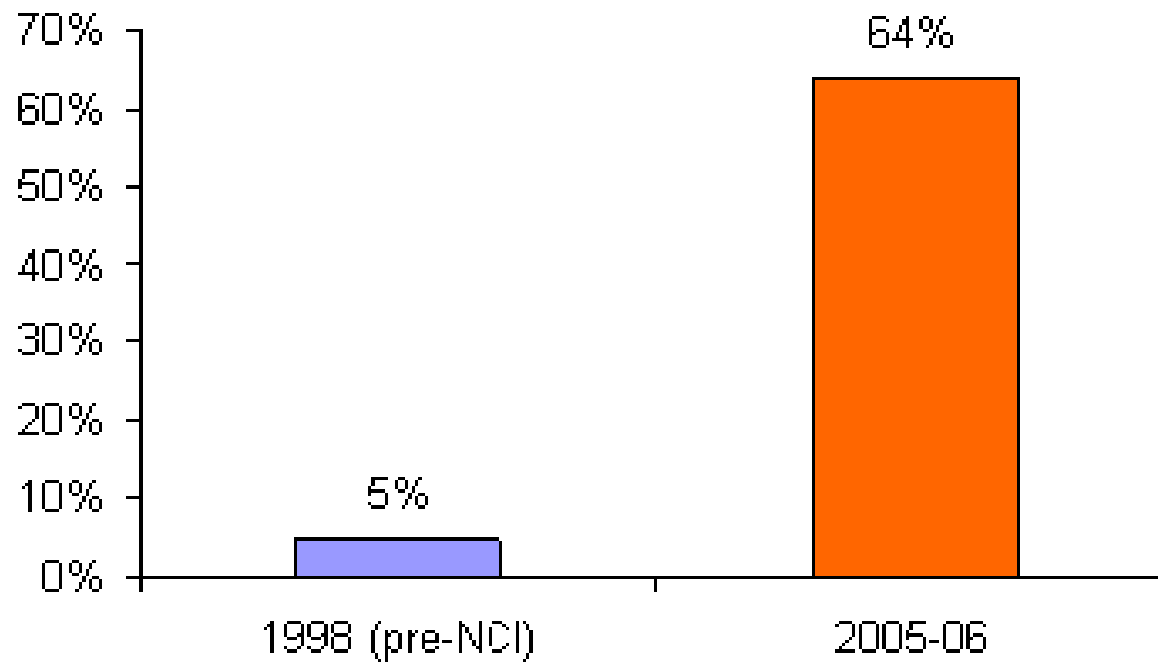


States Using NCI Data

- Arizona's Division of Developmental Disabilities
 - In 1998, only 5% of consumers chose their own Case Manager
 - One of their Annual PIP's (Performance Improvement Project) focused on their efforts to develop more flexible case management models
 - Using NCI data, the DDD tracked the improvement, and as of 2005-06, 64% of consumers chose their own Case Manager



% of Arizona Consumer Who Choose Their Own Case Manager



States Using NCI Data

- DD Council of Washington State
 - Have created an annual National Core Indicators Review Panel Report
 - Gives Recommendations and Ideas for Action to Washington's Division of Developmental Disabilities and the DD Council themselves
 - Example: Because about 1/3 of respondents state that they seldom or never get emergency services/supports, the Panel recommends the Division create a 24/7 response system for people with disabilities and their families.

Examples of State Applications

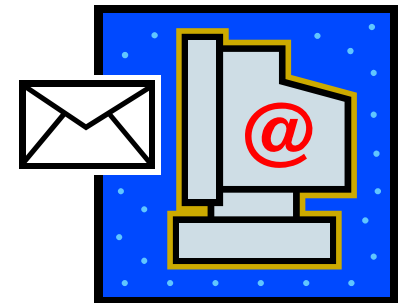
- Alabama
 - Choice and decision-making was identified as area for improvement; state responded with five year plan to increase # of PCP facilitators and offering SRV training to families
 - Also using consumer and family surveys to measure satisfaction pre- and post- community placement from closing of state facility

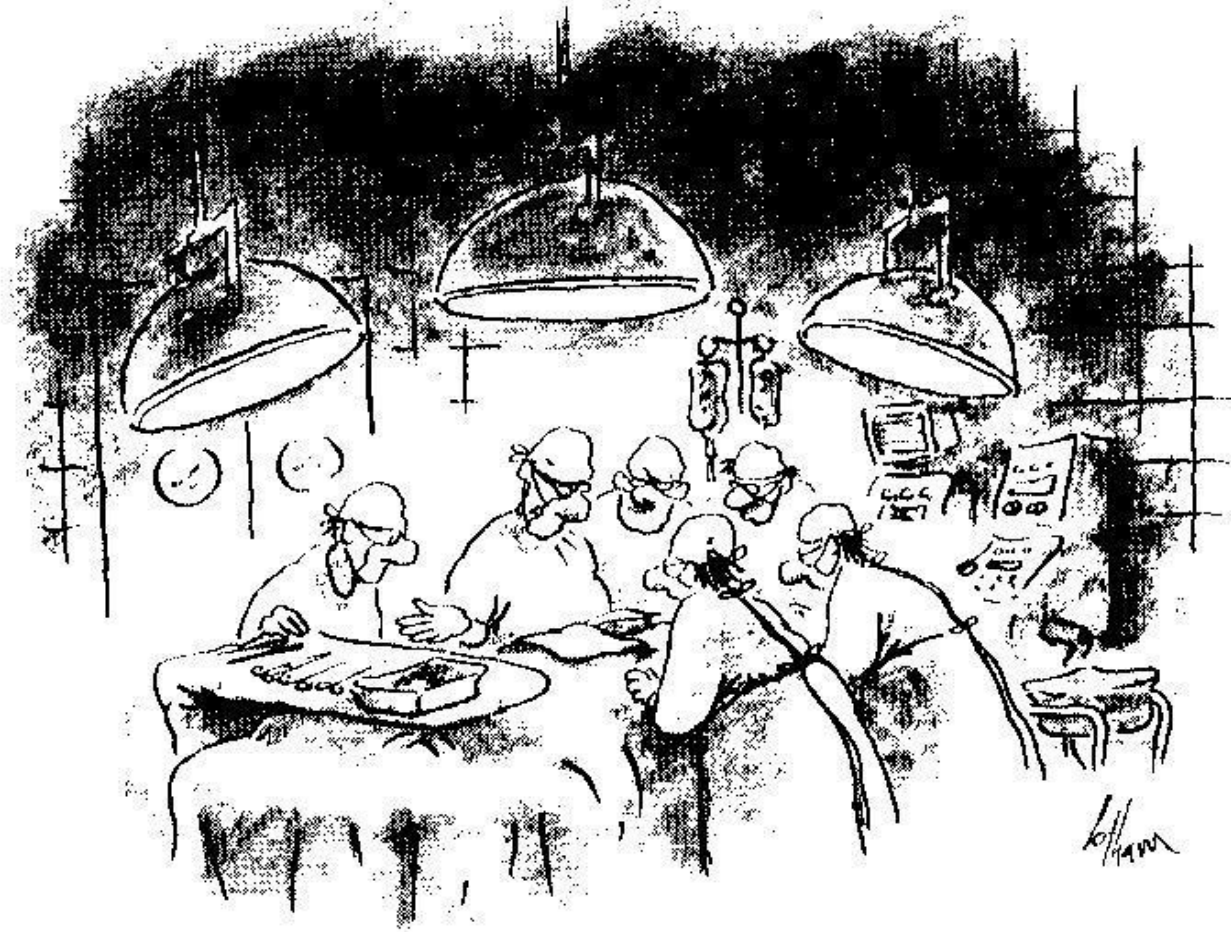
Examples of State Applications

- Arizona
 - Steps taken to improve women's health care outcomes resulted in rate of annual visits increasing from 30% to 70%
 - Asking the questions increases awareness about options (e.g., families can change support coordinators)

How are Results Disseminated?

- Reports of state results vs. national results posted on websites
- Presentations to staff, providers, community
- Summaries shared with families who filled out surveys (AZ)
- Accessible reports to participants





"Let's just start cutting and see what happens."

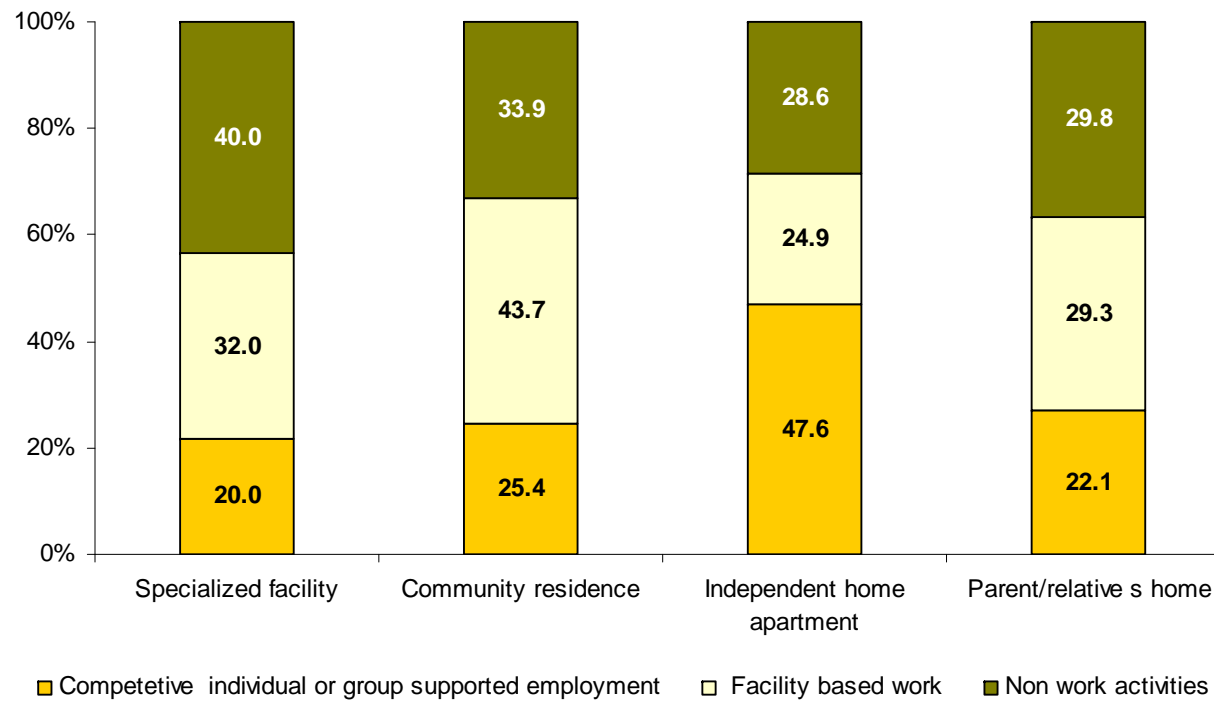
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Employment and Day Services

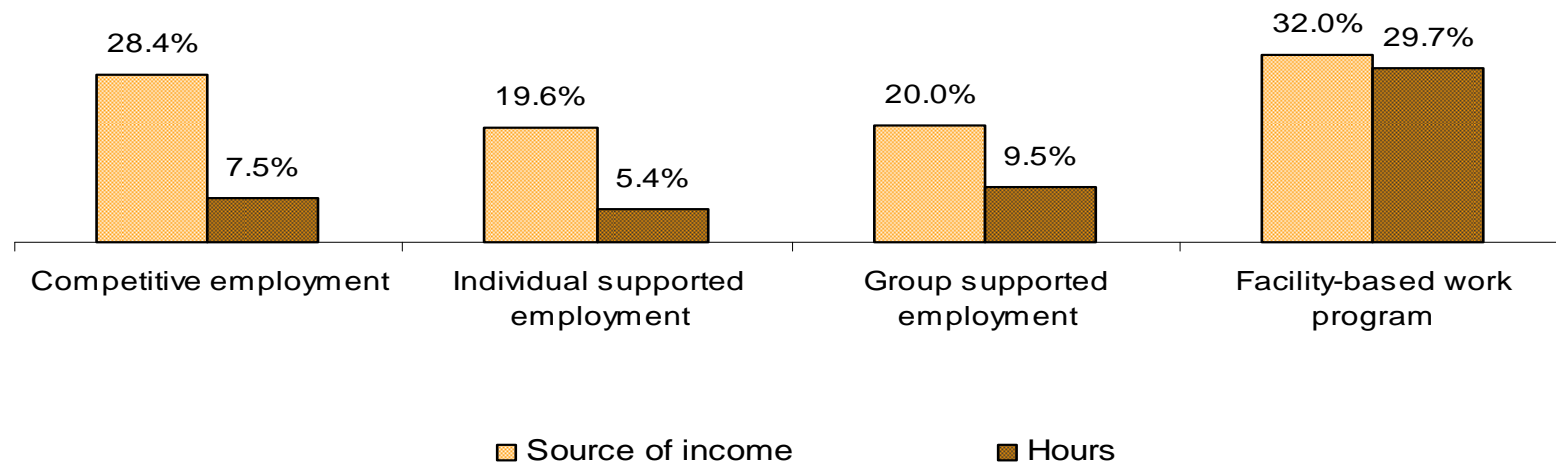
Table 1. Employment Type by Level of Intellectual Disability

	% Community-based activities	% Facility- based work activities	% Non-work activities
No Label or Mild	35.8	32.8	26.7
Moderate	20.0	35.2	39.5
Severe or Profound	7.9	22.7	62.9
Total	24.1	30.9	39.7
N	820	1052	1353

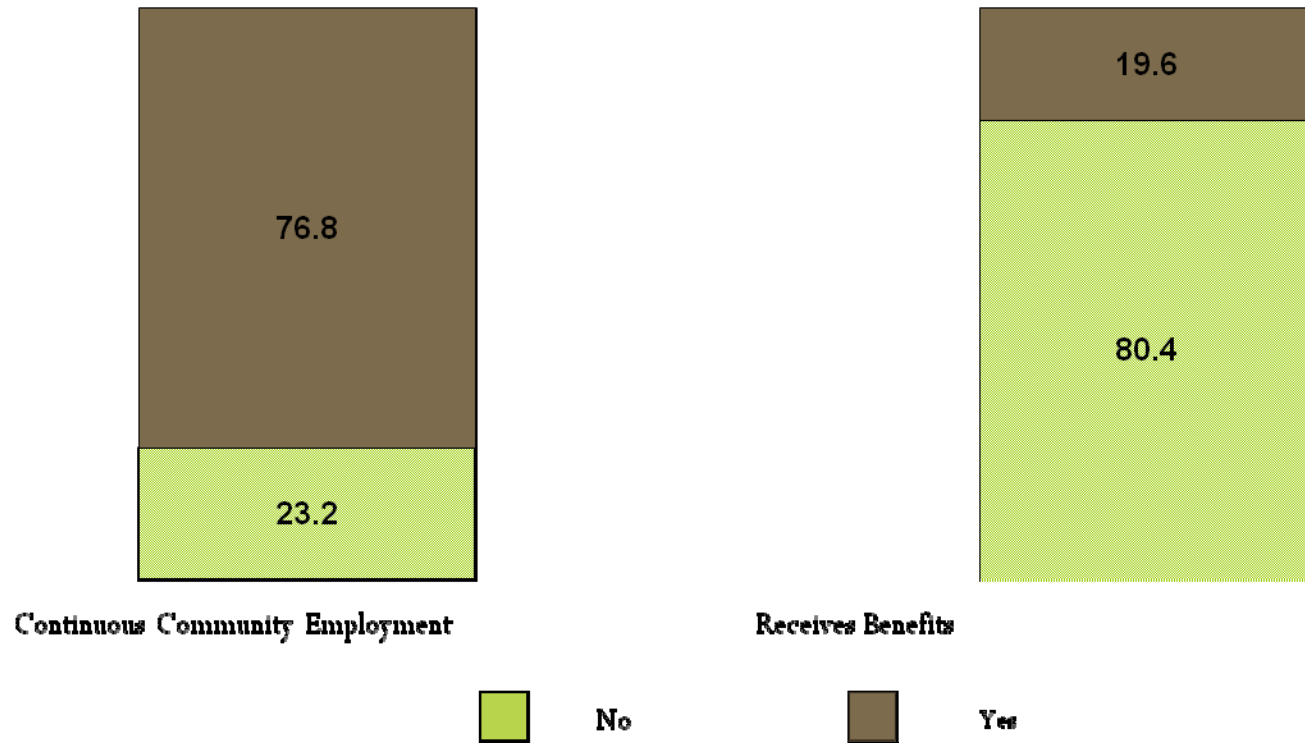
Employment Type by Residential Setting for People with Mild/Moderate or No Intellectual Disability (N=1007)



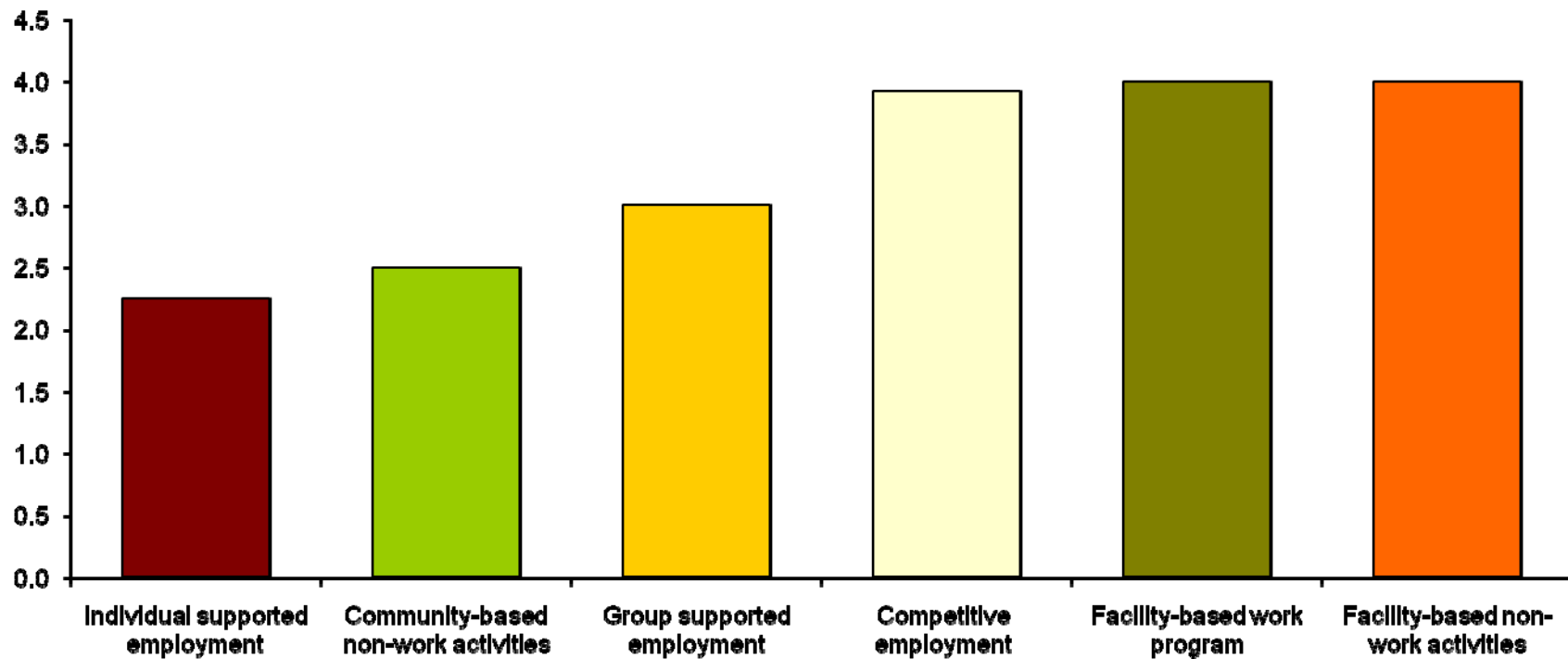
Distribution of Mean Hours Worked and Mean Income by Type of Employment



Length of Time in Community Employment (10 or More Months in the Past Year) and Availability of Benefits



Median Length (in Years) of Activity by Type of Activity



Median Length of Activity (in Years) by Type of Activity and Level of Intellectual Disability

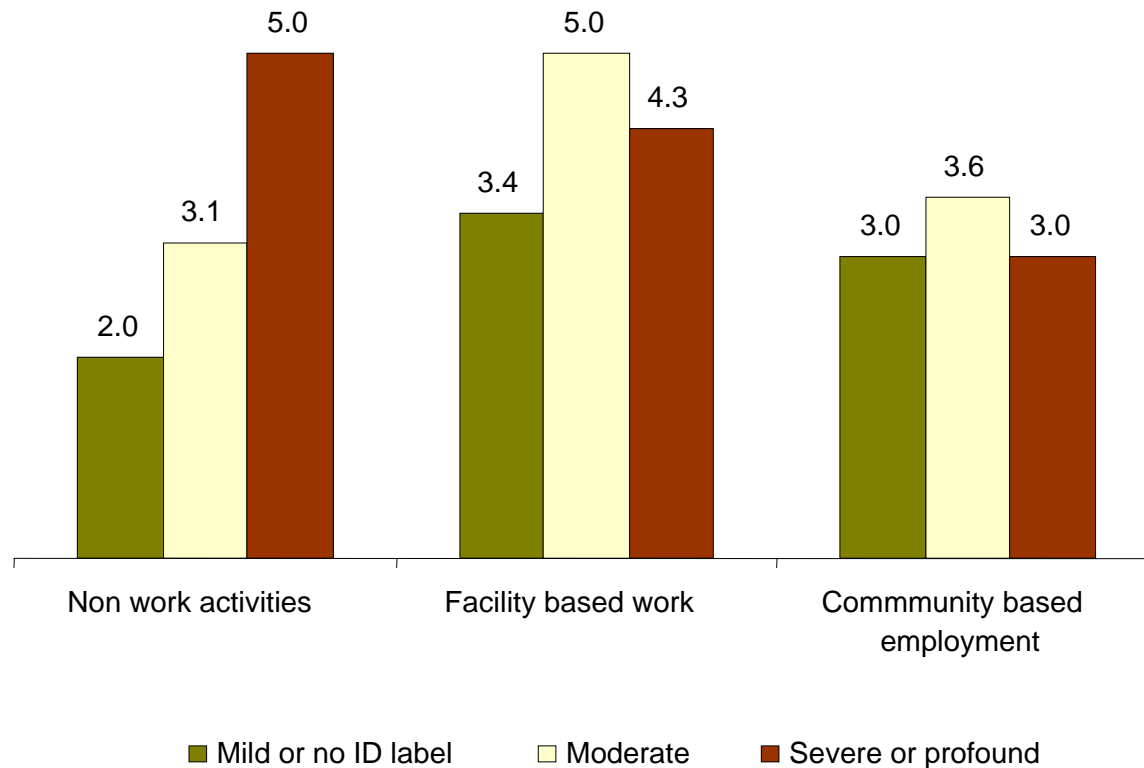


Table 2. Type of Employment/Day Activity and Level of Satisfaction and Socialization

	Like work or day program	Has friends	Can see friends	Ever feel lonely	Sees family
Community-Based Work Activities	92.1	78.1	85.8	7.7	78.6
Facility-Based Work Activities	91.6	78.1	84.4	7.2	81.7
Non-Work Activities	93.0	75.7	84.0	10.5	80.4
N (Unduplicated)	1439	2601	2391	2551	2213

Type of Employment/Day Activity and Degree of Choice

	Choose what to do in free time	Chose job or day activity	Chose job staff	Visited more than 1 job
Community Based Work Activities	98.0	85.5	71.5	82.2
Facility Based Work Activities	96.3	73.9	69.5	71.2
Non-Work Activities	92.7	62.3	69.8	73.8
N	3683	3137	2917	2775

Immediate Impact

- Family members will be surveyed
- Some of your clients may be interviewed as part of the consumer survey
- Opportunities will become available to assess progress toward collective goals
- Outcomes that people value should be validated
- Other performance information can become available (e.g., staff turnover)

Longer Term Impact

- Integration of NCI with other data collection efforts
- Increased interest in performance measurement
- Opportunity to bring people with disabilities and family members into the conversation
- Possibility of using data to assess regional performance
- Stimulus to engage your clients, staff, and other stakeholders in a conversation about quality

Other Quality Concerns

- Explore the enhancement of internal quality management and quality improvement strategies
- Engage direct support staff in the conversation about quality
- Develop internal quality indicators across your organization
- Set up an internal and external group to review performance
- Join with your colleagues to share resources

What to do Next?

- Find resources (CMS website – Go to section on 1915c waivers and then to Quality Toolkits)
- Ensure that the information that is collected is disseminated
- Participate in the interpretation of the results
- Crosswalk the indicators with existing indicators
- Sponsor a conference on performance measurement
- Standardize quality management tools