How State ID/DD Systems Can Use National Core Indicators to Assess Congruence with New CMS HCBS Settings Requirements

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What Will We Cover?

• History and Purpose of NCI
• Data collection and outcome indicators
• Selected findings from the consumer and family surveys
• How states have used NCI data
  ▪ A crosswalk between NCI and HCBS
  ▪ Quality assurance in the states
National Core Indicators

Background

- Launched in 1997 in 13 participating states
- Collaboration between NASDDDS, HSRI and 41 participating state DD agencies (including DC) and 22 sub-state regional entities.
- Current data base includes approximately 20,000 individuals receiving services and supports
- NCI tools assess performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
NCI State Participation 2014-15

41 states, the District of Columbia and 22 sub-state regions

- State contract awarded in 2014-15 through AIDD funding
- CA* - Includes 21 Regional Centers
- OH* - Also includes the Mid-East Ohio Regional Council
NCI Measures Offer a Unique View

- Person-centered
- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare
NCI System Performance Measures

**Individual Outcomes**
- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

**Family Outcomes**
- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections
- Crisis Response

**Health, Welfare, System**
- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability
National Core Indicators Design

**Valid**
- Measure what is intended to be measured

**Reliable**
- Provide consistent results over time and interviewers

**Risk Adjusted**
- Provides multiple state comparisons
What are the Data Sources?

- Adult Survey
- Family Surveys
- Systems Level Data
Use of Data to Identify Specific Policy Issues

Review of Selected Findings from the 2012-2013 Adult Consumer Survey
Diagnoses Other Than ID/DD

Mood Disorder, Anxiety Disorder, Behavior Challenges, Psychotic Disorder, and Other Mental Illness

42% has at least one mental illness/psychiatric diagnosis.
Diagnoses Other Than ID/DD

- Autism Spectrum Disorder: 12%
- Cerebral Palsy: 14%
- Brain Injury: 3%
- Seizure Disorder/Neuro. Problem: 24%
- Limited or No Vision: 6%
- Hearing Loss-Severe of Profound: 4%
- Alzheimer's Disease or Other Dementia: 2%
- Down Syndrome: 9%
- Other: 21%
Where People Live

Residence

- Specialized Institution (16+ residents): 4%
- Group Home (1-15 residents): 29%
- Agency-Operated Apartment Setting: 5%
- Own Home: 14%
- Parent's or Relative's Home: 38%
- Foster Care or Host Home: 7%
- Nursing Facility: 1%
Choice and Decision-Making

Everyday Choice:
- 82% daily schedule
- 91% free time
- 87% what to buy
### Basic Exams & Screenings

#### Health Exams and Screenings by residence

<table>
<thead>
<tr>
<th>Residence</th>
<th>Physical Exam in Past Year</th>
<th>Dental Exam Within Past Year</th>
<th>Eye Exam/Vision Screening in Past Year</th>
<th>Hearing Test Within Past 5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution</td>
<td>97%</td>
<td>94%</td>
<td>96%</td>
<td>94%</td>
</tr>
<tr>
<td>Community-Based Residence</td>
<td>90%</td>
<td>68%</td>
<td>71%</td>
<td>70%</td>
</tr>
<tr>
<td>Own Home</td>
<td>90%</td>
<td>69%</td>
<td>76%</td>
<td>47%</td>
</tr>
<tr>
<td>Parent’s or Relative’s Home</td>
<td>84%</td>
<td>54%</td>
<td>42%</td>
<td>41%</td>
</tr>
<tr>
<td>Foster Care or Host Home</td>
<td>92%</td>
<td>56%</td>
<td>41%</td>
<td>52%</td>
</tr>
<tr>
<td>Other</td>
<td>90%</td>
<td>82%</td>
<td>66%</td>
<td>70%</td>
</tr>
</tbody>
</table>

- Physical Exam in Past Year
- Dental Exam Within Past Year
- Eye Exam/Vision Screening in Past Year
- Hearing Test Within Past 5 Years
Medications and Mental Illness

• **48%** of people who need support for behavior issues take meds for behavior problems

• **7%** of people who do not need support for behavior issues take meds for behavior problems

• **86%** of people with MI or a psychiatric disorder take meds for mood, anxiety, or psychotic disorders

• BUT **52%** of people *not diagnosed* with MI or a psychiatric disorder *also* take meds for behavior, mood, anxiety, or psychotic disorders
Psychotropic medication use increases health complications

- Weight gain
- Abnormal glucose metabolism (diabetes)
- Cardiovascular disturbances
- Oral health issues
- Extra pyramidal symptoms, TD.

Lunsky & Elserafi (2011) Research in Developmental Disabilities
Use of Psychotropic Medications and Obesity

BMI and Medication

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>No Medication</th>
<th>Takes Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight</td>
<td>65%</td>
<td>35%</td>
</tr>
<tr>
<td>Normal Weight</td>
<td>51%</td>
<td>49%</td>
</tr>
<tr>
<td>Overweight</td>
<td>44%</td>
<td>56%</td>
</tr>
<tr>
<td>Obese</td>
<td>42%</td>
<td>58%</td>
</tr>
</tbody>
</table>
Takes At Least One Medication by Living Arrangement

Institution: 57%
Community-Based Residence: 70%
Independent Home/Apt: 54%
Parent/Relative's Home: 35%
Foster Care/Host Home: 61%
Other: 61%
Selected Findings 2012-13
Adult and Child Family Surveys

Families with Adults with ID/DD Living at Home
Age of Care Givers

66% of care givers for adults are over 55

- Under 35
- 35-54
- 55-74
- 75+

AFS  CFS
Family Income

AFS

- 44% Below $25,000
- 25% [CATEGORIZED NAME]
- 19% [CATEGORIZED NAME]
- 16% [CATEGORIZED NAME]
- 35% [CATEGORIZED NAME]

CFS

- 41% Below $25,000
- 22% [CATEGORIZED NAME]
- 15% [CATEGORIZED NAME]
- 22% [CATEGORIZED NAME]
- 17% [CATEGORIZED NAME]
- 24% Below $15,000

2012 HHS Poverty Guidelines for a Family of Four: $23,050
What Does NCI Tell Us About the Lives of People with ID/DD Compared to the General Population
Millennials

Millennials Living at Home

Pew Research data:
http://www.pewsocialtrends.org/2013/08/01/a-rising-share-of-young-adults-live-in-their-parents-home/
Medication Use

Medco Health Solutions 2010 data

• 1 in 5 took at least 1 psychiatric medication in 2010

• 1 in 4 women took at least 1 psychiatric medication in 2010


CA
Medication use for mood, behavior, anxiety, and/or psychotic disorder

- Medication for Four Conditions 5%
- Medication for Three Conditions 7%
- Medication for Two Conditions 14%
- Medication for One Condition 28%

Takes at Least One Medication 53%
Flu Vaccination

Preventive Screenings

- Pap Test (women, past 3 years): 73% (CDC), 68% (NCI)
- Mammogram (women 40 and older, past 2 years): 67% (CDC), 74% (NCI)
- Colorectal Cancer Screening (age 50-75, past year): 43% (CDC), 21% (NCI)

Flu Vaccination

- CDC: 42%
- NCI: 76%
Employment

**Bureau of Labor Statistics**
Employed, age 16 and older

- Yes: 58%
- No: 42%

**NCI**
Collected from the Background Information Section of the Adult Consumer Survey

- Yes: 15%
- No: 85%

Source: [http://www.bls.gov/news.release/empsit.t01.htm](http://www.bls.gov/news.release/empsit.t01.htm)
Employment

Employment by age group

Census data:
http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_1YR_S2301&prodType=table
Loneliness

General Population*:
• 20% feel lonely

Older Adults (60+)**:
• 43% feel lonely
• 18% who feel lonely live alone


Friendship

Number of Close Friends

- None: 4%
- One: 29%
- Two: 49%
- More than Two: 18%

On average people reported 2.03 close relationships

Source: http://www.nbcnews.com/health/health-news/you-gotta-have-friends-most-have-just-2-true-pals-f1C6436540
How States Use NCI Data

- Policy Planning
- Service Development
- Program Operation
- Quality Management
NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances

Practical Tools for States

Prepared by Elizabeth Pell, MSW, LCSW
Human Services Research Institute

May 29, 2014

National Core Indicators Publication www.nationalcoreindicators.org
NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances

- NCI Staff have prepared a publication, Practical Tools for States (Pell, 2014), to assist policy makers to monitor new CMS requirements including:

I. New HCBS Requirements and NCI Data
II. New HCBS Requirements and NCI Data: Quick View Tables
III. Revised HCBS Assurances and Sub-assurances and NCI Performance Indicators
I. New HCBS Requirements and NCI Data

• New HCBS Setting Requirements (Residential and Day Services)
• New HCBS Setting Requirements for Provider Owned/Operated Residential Settings
• New HCBS Person-centered Service Plan Process Requirements
• New HCBS Person-centered Service Plan Documentation Requirements
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

NCI Data:

• If person has a job in community (ACS, Employ/Day)

• If person does not have a job in the community, do they want one? (ACS, Employ/Day)

• Of people employed, if they like their job and if they want a different job. (ACS, Employ/Day)

• If person has integrated employment as a goal in their service plan. (ACS, Background Info)
Requirement: Home is chosen by the individual from among residential and day options that include generic settings.

NCI data are useful for demonstrating some aspects of alignment with this requirement (e.g., NCI does not cover whether generic settings were offered). NCI does collect data on residence type which includes generic settings such as family home, independent apartment.

NCI Data:
• Choice data are available by the type of home where the individual lives.
• If person chose their residence, work and/or day services (ACS, Choice).
• Did you/your family member choose the provider agencies who work with your family? (AFS & FGS, Choice & Control).
• Can you/your family member choose a different provider agency if s/he wants to? (AFS & FGS, Choice & Control).
Requirement: Privacy in their unit including entrances lockable by the individual (staff have keys as needed)

*NCI data are *useful in part* for demonstrating compliance. NCI does not cover lockable entrances or control of keys.*

**NCI Data:**
- If others announce themselves before entering home *(ACS, Home)*
- If others announce themselves before entering bedroom? *(ACS, Home)*
- If person has enough privacy *(ACS, Home)*
II. New HCBS Requirements and NCI Data: Quick View Tables

<table>
<thead>
<tr>
<th>HCBS Setting Requirements</th>
<th>NCI - System Level Data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is integrated in and supports access to the greater community</strong></td>
<td>X</td>
</tr>
<tr>
<td><strong>Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources</strong></td>
<td>X</td>
</tr>
<tr>
<td><strong>Ensures the individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS</strong></td>
<td>-</td>
</tr>
<tr>
<td><strong>Allows full access to the greater community</strong></td>
<td>X</td>
</tr>
<tr>
<td><strong>Is chosen by the individual from among residential and day options that include generic settings (Choice of provider in provider owned and operated settings guidance– CMS clarified that choice of provider is intrinsic to the setting.)</strong></td>
<td>X (in part)</td>
</tr>
</tbody>
</table>
## III. Revised HCBS Assurances and NCI Performance Indicators

<table>
<thead>
<tr>
<th>Service Plan Sub-Assurances</th>
<th>NCI Performance Indicators</th>
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| i. Service plans address all members’ assessed needs (including health and safety risk factors) and personal goals, either by the provision of waiver services or through other means. | NCI data sources contribute in part to meeting this sub-assurance. Sub-assurance has two components: 1) whether plans include an individual’s personal goals and 2) if the individual’s assessed needs are addressed in the plan.  
**Adult Consumer Survey**  
- Proportion of individuals who report that they do not get the services that they need  
- Proportion of people reporting that service coordinators ask them what they want.  
- Proportion of people reporting that service coordinators help them get what they need.  
**Family Surveys**  
- Proportion of families who report their family member has a service plan that the family and/or family member helped create, the plan meets the needs of the family/individual, and includes things that are important to the family.  
- Proportion of families who report that services/supports are available when needed and meet the family’s needs, including in a crisis. |
How Are States Using NCI Data in Policy Planning?
Strengthening Service Delivery and Quality System-Wide

- Providing NCI survey findings to state and regional quality councils for review, analysis and feedback
- Identifying quality concerns and prioritizing service improvement activities
- Comparing the state’s performance against that of other states
- Targeting areas for remediation and improvement at the state and system levels in line with CMS requirements
QI Examples from Arizona
What AZ Does with Survey Data

• Charts data longitudinally from year to year to identify issues

• Presents survey findings to Statewide Management Team to identify areas of improvement

• Develops and implements district and/or statewide strategies for improvement (e.g., increasing provider rates to incentivize community and supported employment initiatives)

• Uses NCI data to evaluate progress with implemented strategies
What AZ Does with the Data

• Data from NCI surveys directly contributed to the creation and allocation of District Employment Specialist positions.

• Survey results are posted to the Division’s webpage.

• Survey data are presented to the DES Director’s Office, legislative staff, State Medicaid Agency, Division’s Quality Management Committee, Governor’s Council on Developmental Disabilities, Provider and Advocacy Agencies.

• Data shared with the Arizona Legislature and contributed to the creation of performance pay incentives for Department staff.
Other States Using NCI Data

• Alabama’s Division of Developmental Disabilities

  • Uses the overall satisfaction number and employment numbers in their SMART Plan which is a budgeting and planning process through the Governor’s office to gauge their success in meeting national benchmarks.
  • Currently conducting a pre/post survey analysis of people leaving Alabama’s last developmental center
  • A Summary is forwarded to providers and they are encouraged to use findings to include in their own agency Quality Plans.
Planning for Employment in MD

MD ranks higher than average in individuals who would like a job in the community.

<table>
<thead>
<tr>
<th></th>
<th>State</th>
<th>Overall In State</th>
<th>Community-Based</th>
<th>Individual Home</th>
<th>Parent’s Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD</td>
<td>64%</td>
<td>68%</td>
<td>n/a</td>
<td>59%</td>
<td></td>
</tr>
<tr>
<td>NCI Average</td>
<td>49%</td>
<td>51%</td>
<td>45%</td>
<td>48%</td>
<td></td>
</tr>
</tbody>
</table>

MD also ranks higher than average in individuals who have community employment as a goal in their service plan.

<table>
<thead>
<tr>
<th></th>
<th>State</th>
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<th>Community-Based</th>
<th>Individual Home</th>
<th>Parent’s Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD</td>
<td>40%</td>
<td>25%</td>
<td>61%</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>NCI Average</td>
<td>24%</td>
<td>21%</td>
<td>37%</td>
<td>23%</td>
<td></td>
</tr>
</tbody>
</table>
• Washington’s Division of Developmental Disabilities
  ▪ The Developmental Disabilities Council convened a review panel of self-advocates, family members, community providers and other professionals to review the results of the NCI survey data.
  ▪ As a result of their work, the review panel make recommendations to the Division
How States Use NCI Data

New York
• Publishes comparison data against other states
• Targeted campaigns to decrease obesity rates

Ohio Council of Governments
• Tracks person centered practices and changed the terminology of their planning process

Kentucky
• Issues formal report on service quality and community participation

Massachusetts
• Tracks and acts on health and wellness and safety data
Special Projects

NCI can be used beyond the sample size of 400 when...

• States want to track a particular population
• States want to compare systems within the state
• States want to ask additional questions
NCI Website

• State Reports
• Annual Reports
• Data Briefs
• Articles
• National data
• Chart function
• Technical reports