National Core Indicators Project

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WHAT IS NATIONAL CORE INDICATORS (NCI)?

- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration
National Core Indicators

- National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- Human Services Research Institute (HSRI).
National Core Indicators

• The guiding principle of NCI has always been to enhance the transparency of information about system performance.
• Publications,
• Data reports,
• a customizable “chart-making” tool, and other important resources can be found at:
• www.nationalcoreindicators.org
National Core Indicators

• **gather** a standard set of performance and outcome measures that can be used to
• **track** their own performance over time, to
• **compare** results across states, and to
• **establish** national benchmarks.
NCI State Participation 2013-14

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

State contract awarded in 2013-14 through AIDD funding
CA*- Includes 21 Regional Centers
OH*- Also includes the Mid-East Ohio Regional Council
National Core Indicators

• 39 states using 4 main data sources:
  1. an Adult Consumer Survey ACS
     • e.g., rights and choice issues,
  2. family surveys
     • e.g., satisfaction with supports,
  3. a provider survey
     • e.g., staff turnover, and
  4. system data from state administrative records
     • e.g., mortality rates
<table>
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<tr>
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NCI in TN

National Data Measurement Project
May 2013
Adult Consumer Survey

• This face-to-face survey collects data on ~½ of the indicators
• individual demographic, service and health information about adults with IDD as
• valued outcomes directly from adults with IDD
• 400 randomly selected adults served by DIDD
• Interviewed by *People Talking to People* crews
Why NCI? Indicators selected are:

• Reflective of the mission, vision and values of the field;
• Measurable;
• Practical to implement;
• Reliable and valid;
• Sensitive to changes in the system;
• Representative of issues the states had some ability to influence; and
• Reflective of outcomes that were important to all individuals regardless of level of disability or residential setting.
Better Data for Cross-State Comparisons
Preferred data reporting system of AIDD/ACL
CQL: The Council on Quality and Leadership

- Questions are more open-ended, less specific
- Could lead to changes in CoS or ISP for individuals
- Being implemented by 1 state (TN)
- No statewide longitudinal data to compare to
- Person-Centered Practice

NCI: National Core Indicators

- Questions are succinct, measurable, and quantifiable
- May raise awareness, not designed to make change on individual level
- Being implemented by 38 states
- 10 years of longitudinal data in other states for comparison
- Focused on systemic change over time
How Have NCI States Used the NCI Dataset?

• As Evidence to Meet Home and Community-Based Waiver Assurances
• As Evidence of the Need for Improvement in State Planning and Implementation

NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances

• I. New HCBS Requirements and NCI Data
   *This section aligns the specific NCI data sources (from the multiple surveys) with new HCBS requirements.*
   - 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

• II. New HCBS Requirements and NCI Data: Quick View Tables
   *This section indicates exactly which questions apply to each requirement.*

• III. Revised HCBS Assurances and Sub-assurances and NCI Performance Indicators
   *This section focuses on the Revised HCBS Assurances and Sub-assurances and NCI data useful for evaluating statewide performance.*
   - Service Plan Sub-assurances and NCI Performance Indicators
   - Health and Welfare Sub-assurances and NCI Performance Indicators
   - Qualified Providers Sub-assurances and NCI Performance Indicators
   - Level of Care Assurance and Sub-assurances
   - Financial Accountability Assurance and Sub-assurances
   - Administrative Authority Assurance
2013-2014 NCI Sample

- Randomly drawn from individuals over 18 receiving at least one service from DIDD
- Collected Background Information on 436
- The Arc TN People Talking to People interviewed 408
- Number of people (n) changes with the question
- Percentages reflect the percentage of the number of people who answered the question
- When possible to characterize level of HCBS compliance, blue is used to reflect compliance, red is used to indicate non-compliance and purple is used to indicate a non-specific middle ground between the 2 categories.
Age distribution of the 2013-2014 NCI Sample

N  | 436
Mean | 46.26
Minimum | 20
Maximum | 84
Percentiles | Percent
25 | 34.00
50 | 47.00
75 | 58.00

Age groups in the NCI Sample

Age groups in increments of 10 years
Gender distribution of the 2013-2014 NCI Sample

<table>
<thead>
<tr>
<th>GENDER</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>265</td>
<td>60.8%</td>
</tr>
<tr>
<td>Female</td>
<td>171</td>
<td>39.2%</td>
</tr>
</tbody>
</table>

![Pie chart showing gender distribution]
Level of Intellectual Disability within the 2013-2014 NCI Sample:

- **Mild to moderate:** 267 (63.3%)
- **Severe to profound:** 109 (25.8%)
- **Don't know or unspecified:** 46 (10.9%)
Racial Identification within the 2013-2014 NCI Sample

- 72% White
- 26% Black or African American
- 2% Other races

Total: 317
Requirement: Is integrated in and supports access to the greater community

Success # 1: Most Housing is HCBS Compliant
Requirement: Is integrated in and supports access to the greater community

Success # 2: Access to Family and Friends is HCBS Compliant
Requirement: Is integrated in and supports access to the greater community

Success #3: Almost ALL Adults are out in the Community!
Requirement: Is integrated in and supports access to the greater community

Opportunity #1 and Opportunity #2 for more integration.
Requirement: Is integrated in and supports access to the greater community

Opportunity #3 for more integration. Who are going with?
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.

Success #1: We are providing a lot of employment–related supports.
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and **control personal resources**

Success #2: Controlling personal resources.
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.

Success #3: There is high satisfaction with and interest in employment.
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

Success #4 / Opportunity #1: Time and Money
Requirement: Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.

Opportunity #2 and #3: Employment First is not yet universal.
Requirement: Ensures right to privacy, dignity and respect and freedom from coercion and restraint

Success #1: People feel good about their privacy.
Requirement: Ensures right to privacy, dignity and respect and freedom from coercion and restraint

Success #2: People feel safe.
Requirement: Optimizes autonomy and independence in making life choices

Success #3: People have choices about their free time.
Requirement: Allows full access to the greater community

Opportunity #1: Transportation is still largely group-based.
Requirement: Ensures right to privacy, dignity and respect and freedom from coercion and restraint

Opportunity #2: 22% can’t express whether they feel fear.
Requirement: Optimizes autonomy and independence in making life choices

Opportunity #3: People have few choices about some important issues.
C. New HCBS Person-Centered Service Plan Process Requirements

Requirement: *Service planning process is driven by the individual*

Success #1: People get the services they need.
Requirement: *Includes risk factors and plans to minimize them*

- takes medications for certain conditions including mental health
- is provided behavior supports

**Success #2:** Majority doing well with little need for behavioral or medical supports
Requirement: Conducted to reflect what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare

Success #3: Most get primary care medical supports and have good health habits
Requirement: Facilitates choice of services and who provides them

Opportunity #1: Service coordinators are not viewed as partners.
Requirement: Conducted to reflect what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare.

Opportunity #2: More women could be getting Pap screenings.
Requirement: Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible.

Opportunity #3: Self-directed supports are under-used and misunderstood.
# National Core Indicators

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Significant Factors affecting Paid Community Employment:

Region, Level of ID and Demonstrated Communication
Significant Factors affecting Work Composite:
Level of ID and Demonstrated Communication and Conservator Status
Significant Factors affecting All Outings:

Regional Differences
Significant Factors affecting Community Inclusion:
Regional Differences, Level of ID, and Demonstrated Communication
Significant Factors affecting Choice:
Regional Differences, Level of ID, and Demonstrated Communication and Conservator Status
# Health, Welfare and Rights

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Significant Factors affecting Relationship Score:

Regional Differences, Level of ID, and Demonstrated Communication and Conservator Status
Significant Factors affecting Health Access Score:

Level of ID

Average Health Access Scores reported by IWD in 2013-14 TN NCI
Sample by Demographic Variables

- Mild-moderate: 23.55
- Severe-profound: 24.19
- Unspecified*: 21.95
## Significant Factors affecting Health Access Score:

### Region, but only for Medication for Mood Disorders

**Average Medicine Usage of IWD in 2013-14 TN NCI Sample by Demographic Variables**

<table>
<thead>
<tr>
<th>Region</th>
<th>Mood Disorders?**</th>
<th>Anxiety?</th>
<th>Behavior Challenges?</th>
<th>Psychotic Disorders?</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>1.68</td>
<td>1.49</td>
<td>1.42</td>
<td>1.48</td>
</tr>
<tr>
<td>Middle</td>
<td>1.83</td>
<td>1.43</td>
<td>1.48</td>
<td>1.38</td>
</tr>
<tr>
<td>West</td>
<td>1.38</td>
<td>1.36</td>
<td>1.34</td>
<td>1.21</td>
</tr>
</tbody>
</table>

**Significance levels:**
- **: p < 0.05
- **: p < 0.01
Significant Factors affecting Wellness Score:

Level of ID

- Mild-moderate: 7.95
- Severe-profound: 7.28
- Unspecified**: 6.47
Significant Factors affecting Respect, Privacy, & Safety Score:

Regional Differences, Level of ID, and Demonstrated Communication and Conservator Status
**System Performance**

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Significant Factors affecting Satisfaction with ISCs and Service Planning Score: Regional Differences, Level of ID, and Demonstrated Communication and Conservator Status
Significant Factors affecting Satisfaction with Access Score:

- Level of ID, and Demonstrated Communication
<table>
<thead>
<tr>
<th>Areas of Concern Associated with Level of ID Findings</th>
<th>Poorer Outcomes</th>
<th>Better Outcomes</th>
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<td>Having severe to profound ID or unspecified level of ID</td>
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<td>Having severe to profound ID</td>
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<td>Having a unspecified level of ID</td>
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## Areas of Concern Associated with Region of Tennessee

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<td>Living in West and East TNs</td>
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<td>Areas of Concern Associated with Demonstrated Communication Level</td>
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<td><strong>Individual Outcomes</strong></td>
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<td>Work</td>
<td>Having a conservator</td>
<td>Not having a conservator</td>
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<td>Community Inclusion</td>
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<td></td>
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Recommendations for using NCI Data for Quality Improvement

- Generate State-Specific Charts on the Website
- Use the Data from this Report
- Create Groups to Review the Data
- Identify Areas for Improvement
- Develop Change Strategies
- Develop Benchmarks
- Share the Data in an Accessible Format
Next Steps

• Present finding of the report to interested audiences across the TN/US

• [http://vkc.mc.vanderbilt.edu/vkc/nci/](http://vkc.mc.vanderbilt.edu/vkc/nci/)

• [National Core Indicators.org](http://vkc.mc.vanderbilt.edu/vkc/nci/) National Reports
  – Audiences
    • Provider Community
    • Consumers: accessible version of the yearly report
    • Webinar for some of these audiences
    • TN Disability MegaConference
    • Publish findings of significance in research journals
      – Conservator Data
      – Communication
      – Home versus Group Care analyses
      – National Data: Above and Below Average Performance Rankings
Further Study
University Centers of Excellence in Developmental Disabilities (UCEDD)

• Research
  • Kentucky:
    • Charles Moseley, Harold Kleinert, Kathleen Sheppard-Jones, and Stephen Hall (2013)

• Training

• Dissemination
  • Pennsylvania:

• Model Projects
Compared to Other States: We’re #1!

**GRAPH 80. HAD A HEARING TEST (IN THE PAST FIVE YEARS)**

Had a Hearing Test in the Past Five Years

- **Tennessee N = 322**
- **NCI Average N = 9,019**
Compared to Other States: We’re #1!
Compared to Other States: We’re #1!
Graph 44: Receives Benefits at Paid Community Job

Seehs Paid Vacation and/or Sick Time at Paid Community Job

- Tennessee N = 41
- NCI Average N = 1,814

Below Average↓↓
Graph 51. Has Friends

- Has Friends

- Tennessee N = 289
- NCI Average N = 10,289

- Below Average

- Above Average
Thank you:

- Jessie Baird
- Elise McMillan
- Bob Hodapp
- Elisabeth Dykens
- Frank Meeuvis
- Valerie Jephson
- PTP Interview Teams
- Commissioner Debra Payne
- Hollie Campbell
- Laura Doutre
- Latrese Johnson
- Independent Support Coordinators
- Families and staff who cooperated
- Adults who agreed to participate