National Core Indicators: Listening to People with Disabilities for 20 Years
HCBS Conference, Baltimore MD Aug. 29, 2017

Valerie Bradley, President Emerita HSRI
Nancy Thaler, Director of Pennsylvania Office of Developmental Programs
Mary Lou Bourne, Director of NCI, NASDDDS
What is NCI?

• NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

• Collaboration began in 1997

• Currently 46 states and Washington D.C. represented plus 22 sub-state entities

• Coordinated by HSRI and NASDDDS
Where is NCI Today?

As of 2016-17: 46 states, the District of Columbia and 22 sub-state regions.
How Does NCI Collect Data?

- **Adult Survey**
  - In person interviews

- **Family Surveys (3)**
  - Mail out surveys—soon to be online entry

- **Staff Stability Survey**
  - Direct Entry by contracted provider agencies

**NCI Data Sources**

- National Core Indicators (NCI)
NCI Domains

Individual Outcomes
- Employment
- Community Inclusion
- Choice & Decision making
- Personal Relationships
- Self Determination

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
From the Perspective of People who use I/DD services: Why is NCI Important?
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Valerie Bradley
President Emerita, Human Services Research Institute
Antecedents to NCI

• Growing interest in outcomes as a means to understand the performance of IDD systems
• Pressure to block grant Medicaid (sound familiar?) and a fear that the particular concerns of the IDD system would be swamped
• Recognition of the increasing complexity of the IDD system as the community system began to significantly outpace institutional services
• Rising expectations about the ability of people with IDD to live real lives in the community
• Interest in transparency and the importance of making performance information public
Some of the Original “Fathers” of NCI

Bob Gettings, Former Director of the National Association of State Directors of Developmental Disabilities Services

Gary Smith, former policy director at NASDDDS

John Ashbaugh, Former Vice President of HSRI
Early Stirrings

• Formation of a Steering Committee made up of 13 state representatives – facilitated by NASDDDS and HSRI in 1997
• Development of overarching goals in the form of domains including employment, community inclusion, relationships, family support, choice, and health and safety
• Commitment to solicit the voices of people with disabilities and their families – not just process measures
• Identification of indicators – how would you know if it happened?
• Creation of data collection instruments
Six States Stepped Forward

- Six states volunteered to field test the tools in 1998
- Administration of the Adult Consumer Survey showed inter-rater reliability and test-retest reliability, and indicated the need to revise some of the questions
- The ICAP was administered in order to design risk adjustment criteria
- Based on the field test, NASDDDS members agreed that the Core Indicators Project (now NCI) would go forward.
- Numbers of member states continued to grow over the next two decades from the original 6 to 46 including the District of Columbia plus 22 sub-state entities
- In the last round of Adult Surveys, there were 17,682 respondents; the largest ongoing data base of outcomes of people with disabilities probably in the world.
What do Self-Advocates Tell Us About What’s Important to Them?
2015-2016 NCI Adult Survey

Has a Job (n=16,375)
- No: 81%
- Yes: 19%

Would like a Job (n=6,550)
- No: 53%
- Yes: 47%

Employment goal in Plan (n=2,808)
- No: 59%
- Yes: 4%

24% took classes, training, or did something to get a job or get a better job
Community Participation and Leisure

- **Able to go out and do things likes to do in the community** (state range: 65%-93%): 85%
- **Able to go out and do things likes to do in the community as often as wants** (state range: 54%-92%): 76%
- **Has enough things to do when at home** (state range: 62%-96%): 82%
Privacy and Rights

Privacy

- Has a key to the home: 46% Overall, 50% ICF/IID and other institutional settings, 28% Community-based residential setting, 13% Own home, 20% Parent or relative's home.
- Can lock the bedroom: 46% Overall, 46% ICF/IID and other institutional settings, 20% Community-based residential setting, 46% Own home, 43% Parent or relative's home.

Has Ever Voted in a Local, State, or Federal Election (or Chose Not to)

State Range = 61% - 14%
NCI Average = 39%

National Core Indicators (NCI)
92%

Services and supports help person live a good life
What Changes Have Taken Place Over the Past 20 Years?
Enhancements to NCI

- Refinements of the Adult Survey to include more information on employment, wages, health, and self-direction
- Addition of Child/Family Survey
- Advent of Data Briefs on key topics
- Launch of the Sarah Taub Webinar Series
- Development of the Staff Stability Survey
- Circulation of the Fortnightly newsletter
- Training materials and videos
- Annual Meeting of State NCI Coordinators
Recent Data Briefs

• What Do NCI Data Show About Respondents Who Need Support for Self-Injurious Behavior? (Bradley, Hiersteiner and Rotholz – May 2017)

• What Do NCI Data Show About Friendship and Life Outcomes for Adults With Intellectual and Developmental Disabilities? (Giordano, Hiersteiner, and Pell, September 2016)

• Working in the Community: The Status and Outcomes of People with Intellectual and Developmental Disabilities in Integrated Employment (Hiersteiner, Butterworth, Bershadsky, and Bonardi, May 2016)
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Nancy Thaler
Director, Pennsylvania Office of Developmental Programs
Why Pa Helped to Found NCI in 1997

• The HCBS waiver program was growing nationally.

• There was controversy about the quality of community services.

• State legislatures were starting to ask questions about “these waivers.”

• There was absence of any measures or data to defend the program.

• If “we”, the states, don’t create a set of quality measures, someone else will.
Why Pa. Continues to be an NCI State

- It provides data to measure quality from the experience of the people we serve
- It is standardized and tested for validity and we could never create the same caliber instrument
- Because 46 states and DC use NCI, we can compare our performance to other states
- It is a way to engage consumers and families in measure quality
- Stakeholders do not squabble with the findings because of the integrity of the instrument – they embrace the results and we focus on making things better.
How We Use it

• 48 Independent Monitoring for Quality (IM4Q) teams conduct about 5,500 interviews each year.

• The teams are consumers, families, advocates and citizens in the community.

• The results are used with our Advisory Committee to measure progress and plan improvements for the 12 recommendations in our Everyday Lives Plan.
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Mary Lou Bourne
Director, National Core Indicators and Quality Assurance
NASDDDS
How do we let others know the results?

• Reports –
  ▪ National
  ▪ State
  ▪ At-A-Glance
  ▪ User Friendly

• Webinars

• Data briefs

• State Specific Reports/Special Studies
State Reports

ACS

Has a Way to Get Places When S/He Wants to Go Outside Of Home (Like to See Friends, For Entertainment, Or Do Something Fun)

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<th>NCI Average</th>
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<tr>
<td>N=291</td>
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<td>83%</td>
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AFS

Respondent or Family Member Is Able to Contact Case Manager or Service Coordinator When S/He Wants

<table>
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<th>Mississippi</th>
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<tr>
<td>Always</td>
<td>66%</td>
<td>64%</td>
</tr>
<tr>
<td>Usually</td>
<td>28%</td>
<td>27%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Seldom or Never</td>
<td>2%</td>
<td>2%</td>
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National Core Indicators (NCI)
User-Friendly Report

Have you gone to a self-advocacy meeting?

Yes, I have gone to a self-advocacy meeting - 30%

No, I have not gone to a self-advocacy meeting - 70%

NCI tells us 3 out of every 10 people said they have gone to a self-advocacy meeting.
At-A-Glance Report

Employment
- 19% of respondents were reported to have a paid community job (Individual and or group)
- 24% reported taking classes or training to get a job or do better at the job they have
- 47% who do not have a paid community job want one
- 30% had paid community employment as a goal in their service plan

Choice, Decision-making and control
- Adjusted variables
  - Chose or had some input in choosing where he/she lives
    - 57%
  - Chose or had some input in choosing housemates
    - 47%
  - Chose or had some input in choosing daily schedule
    - 84%
  - Chose or had some input in choosing what to buy with spending money
    - 88%

Access
- 83% report having adequate transportation when they want to do something for fun
- 93% report having adequate transportation when they need to get somewhere

Community Inclusion, Participation and Leisure:
Percentage of respondents that report having done the following activities in the community at least once in the past month

- Shopping: 91%
- Out on errands: 88%
- Out for entertainment: 77%
- Out to eat: 88%
- Out to religious service or spiritual practice: 48%

2015-16 Adult Consumer Survey
Data Briefs

• Data Briefs: highlights of data findings across states, usually focused on a particular indicator or group of indicators.
• Designed to spark your interest and raise awareness of things we find in the data.
• Released every 3 months.
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
https://www.nationalcoreindicators.org/