National Core Indicators: Celebrating 20 Years

Valerie Bradley, President Emerita
Human Services Research Institute
NASDDDS Annual Meeting
Alexandria, VA
November 8, 2017
Sweep of 20 Years of History

1997
NASDDDS and HSRI form Steering Committee to develop “core” indicators of program

1998
First consumer and family support data report

1999
Family Guardian survey in the field

2000
Child and Family Survey launched

2001
Autistic Self Advocacy Network Founded

2006
Money Follows the Person begins

2009
Convention on Rights of People with Disabilities

2010
Affordable Health Care Act

2011
HCBS Settings Rule

2013
14 states without institutions

2015
ABLE Act passes

2013
NCI for Aging-Disability is created

2014
Staff Stability Survey Piloted

2017
NCI membership reaches 46 states and 22 local entities

25th Anniversary of the ADA

Life expectancy of people with Down Syndrome increases to 60 years

2016
ACL grant to further develop NCI measures

Self Advocates Becoming Empowered is 7 years old

Olmstead Case Decided
Memory Lane -- 1997
Antecedents to NCI

Growing interest in outcomes as a way to understand performance

Interest in transparency and the importance of making performance information public

Rising expectations about the ability of people with IDD to live real lives in the community

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 systems as the community system began to significantly outpace institutional services
Who was There at the Beginning?

Bob Gettings, Former Director of NASDDDS

Gary Smith, former policy director at NASDDDS

Valerie Bradley
President Emerita of HSRI

John Ashbaugh,
Former Vice President of HSRI

Sarah Taub
Former NCI Project Director for HSRI
Early Stirrings

Formation of a Steering Committee made up of 13 state representative

Development of 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 it if it happened?

Creation of data collection instruments
Six States Stepped Forward

Six states volunteered to field test the tools in 1998

Field test showed that the Adult Consumer Survey was reliable

Some questions were revised

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.
Collaborations

Partnered with the University of Minnesota Institute on Community Integration for additional data analysis and publications

Partnered with University of Massachusetts Institute on Community Inclusion on employment data

Worked with individual states to develop special analyses

Worked with AUCD to ensure involvement of UCEDDs and graduate students

Received funding from the Administration on Developmental Disabilities

Partnered with National Association of States United for Aging and Disability to develop NCI-AD
Enhancements to NCI Over the Past Two Decades

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
Developed an online data entry platform
How Has NCI Stayed Dynamic and Reflective of Changes in the Field?

- Increased the richness of the employment data and wage data in collaboration with UMass ICI
- Expanded and enhanced the self-direction questions
- Expanded background questions on health conditions
- Re-examined questions on community inclusion to make them more person centered
- Added questions in line with the requirements of HCBS Settings rule
- Updated video training materials
How Have NCI Data Reflected Changes Over the Past 20 Years?
How have things changed?

Looked at the NCI average for indicators of interest in three years:

- 2002-03 (N=9552) and
- 2011-12 (N=12236) and
- 2015-16 (N=17682)
More People with an Autism Diagnosis

- 2002-03: 6.4%
- 2011-12: 11.7%
- 2015-16: 16.0%
Changes in Where People Live
(Response options have changed over time)

The percentage of people **living in a parent/relative’s home increased**

- **2002-03**: 29%
- **2011-12**: 33%

There was a **decrease** in the percentages of people **living in congregate settings** (group homes, ICF, specialized institutional settings, etc.)

- **2002-03**: 41%
- **2015-16**: 37%

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- **2002-03**: 41%
- **2015-16**: 37%
Employment

18.9% 8.9% 14.0% 19.0%
0.00% 10.00% 20.00% 30.00% 40.00% 50.00% 60.00% 70.00% 80.00% 90.00% 100.00%

2002-03: Supported employment (N=8514)
2002-03: Group employment (N=8444)
2011-12 Paid Community Job (N=11418)
2015-16 Paid Community Job (N=16375)
Legal Status

- 02-03 "Legally Competent Adult" (N=9047): 51%
- 11-12 "Independent of Guardianship" (N=11597): 46%
- 15-16 "Person Does Not Have a Guardian/Conservator" (N=16781): 46%
Has friends that are not staff or family

2002-03: 71.5%
2011-12: 70.2%
2015-16: 77.3%
Choice

Person had at least some input in the following choices:

- **Choosing schedule**: 82.3%, 81.4%, 84.0%
- **Choosing what to do in free time**: 90.9%, 90.4%, 92.3%
- **Choosing what to buy**: 86.6%, 87.9%, 88.0%

- **2002-03**
- **2011-12**
- **2015-16**
Issues that NCI Data Have Shed Light On
Those taking medication were significantly more likely to be overweight or obese.

<table>
<thead>
<tr>
<th>Medication Status</th>
<th>Overweight or Obese</th>
</tr>
</thead>
<tbody>
<tr>
<td>Takes at least one medication for mood, anxiety, psychotic and/or behavior</td>
<td>67%</td>
</tr>
<tr>
<td>Takes no medication for mood, anxiety, psychotic and/or behavior</td>
<td>58%</td>
</tr>
<tr>
<td>Takes at least one medication for behavior</td>
<td>67%</td>
</tr>
<tr>
<td>Takes no medication for behavior</td>
<td>61%</td>
</tr>
<tr>
<td>Takes at least one medication for mood, anxiety, psychotic</td>
<td>68%</td>
</tr>
<tr>
<td>Takes no medication for mood, anxiety, psychotic</td>
<td>58%</td>
</tr>
</tbody>
</table>
Percentage taking at least one medication for mood, anxiety, psychotic and/or behavior

<table>
<thead>
<tr>
<th>Residence Type</th>
<th>Percentage Taking Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICFs, nursing home and other institutional settings</td>
<td>61%</td>
</tr>
<tr>
<td>Group home settings</td>
<td>70%</td>
</tr>
<tr>
<td>Independent home or apartment</td>
<td>58%</td>
</tr>
<tr>
<td>Parent/relative home</td>
<td>36%</td>
</tr>
<tr>
<td>Foster care/host home</td>
<td>61%</td>
</tr>
</tbody>
</table>

Medication by residence type
Data Brief: Friendship and Life Outcomes

**Expanded Friendships**: Has friends who are not staff/family

**Limited Friendships**: No friends, or friends are only staff and/or family

**Employment**: Individuals who had expanded friendships were more likely to be employed in a paid community job.

**Rights and Privacy**: Those who had expanded friendships reported having more privacy; they also reported having their rights respected at greater rates.

**Community Inclusion**: Those with expanded friendships were more likely to have gone into the community to take part in specific activities; they also reported participating in these activities with greater frequency.
People with ASD were less likely to be independent of guardianship.

People with ASD were less likely than those without ASD to say they had friends who weren’t family or staff.

People with ASD were less likely to report having had at least some input in critical life choices such as choosing staff, daily schedule, free-time, etc.

People with ASD were significantly more likely to live in the family home, and significantly less likely to live in their own home and apartment.

How Has NCI Influenced State Policy Changes?
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
Use of NCI with Federal Regulations
NCI: 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
How Have States Used NCI Data?

- Benchmarking system performance
- Compare system performance with other states and to NCI average
- QA
- CMS assurances/HCBS transition plans
- Advocacy
What Are Some Recent Data Highlights?
2015-2016 NCI Adult Survey

Has a Job (n=16,375)

- Yes 19%
- No 81%

Would like a Job (n=6,550)

- Yes 53%
- No 47%

Employment goal in Plan (n=2,808)

- Yes 41%
- No 59%

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

<table>
<thead>
<tr>
<th>Has a key to the home</th>
<th>Can lock the bedroom</th>
</tr>
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<tr>
<td>Overall: 46%</td>
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</tr>
<tr>
<td>ICF/IID and other institutional settings: 13%</td>
<td>Community-based residential setting: 28%</td>
</tr>
<tr>
<td>Own home: 50%</td>
<td>Own home: 46%</td>
</tr>
<tr>
<td>Parent or relative's home: 81%</td>
<td>Parent or relative's home: 62%</td>
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Has Ever Voted in a Local, State, or Federal Election (or Chose Not to)

- State Range: 61% - 14%
- NCI Average: 39%
Where Do We Go From Here and What are the Challenges?
At the Forefront

Secure NQF certifications for some of the NCI Indicators

Continue to give states value for membership in NCI

Think through how NCI can work within a managed care context

Continue to ensure the validity and reliability of the data

Maximize the synergy with NCI-AD
And Now a Celebratory Video

NCI At 20!!!