What is National Core Indicators (NCI)?

Since 1997, state developmental disability service systems have used the National Core Indicators™ (NCI™) surveys to gather information about the satisfaction, quality of life, and critical life outcomes of those they support. States use this information to track their own performance over time and to compare results across states. NCI’s outcome data contributes key information to states seeking to improve services that support people with IDD to live and contribute as valued members of their communities.

What is the At-A-Glance Report?

This report uses graphics and icons to demonstrate selected NCI findings from all participating states for quick and easy reading.

Does something catch your eye?
Visit www.nationalcoreindicators.org for more info on NCI.

Cover Art:

Charlene Murphy was born in Massachusetts and spent most of her young adult life at Fernald State School.

While in her 20s, Murphy was placed at Gateway Arts as one of the original 8 Gateway artists over 40 years ago. Murphy loves to draw and paint, and primarily creates works in the fabric, paper, and folk art production studios. Murphy historically depicts men and women in the simplest form; however, her focus recently has turned to drawing and painting whimsical animals.

For more info, visit: https://www.gatewayarts.org/
Where are the statistics in this report from?

This report includes selected findings from the National Core Indicators 2018-19 Surveys. A brief description of each survey is on the following page.

Weighted NCI Averages

The data shown in this report are weighted NCI averages. This means that the calculations reflect the relative population sizes of participating states and their survey sample sizes. This way, a state that provides services to a larger number of people but uses a sample similar in size to other states has a greater influence on the overall NCI average. For more information, see the Methodology section of the NCI survey reports.

How are NCI reports used?

The NCI Team produces reports that inform state efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies, and compare state system performance with national norms. For more information on National Core Indicators, please visit www.nationalcoreindicators.org.

Want to learn more about data in this report?

For detailed information on samples, weighting, methodology and administration, please see the National NCI Reports from 2018-19, available at:

https://www.nationalcoreindicators.org/resources/reports/.
In-Person Survey

This survey is completed with adults with IDD age 18 and older receiving at least one paid service (in addition to case management) from the state DD agency. The survey instrument includes a Background Information Section, which gathers data about the person from agency records, and an in-person survey.

The in-person survey is composed of two sections: Section I includes subjective questions that can only be answered by the person receiving services from the state. Section II includes objective, fact-based questions that can be answered by the person or, if needed, a proxy respondent who knows the person well.

Family Surveys

The Adult Family Survey is completed by families who have an adult family member (age 18 or older) with IDD living in the family home. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed to families.

The Family Guardian Survey is completed by families or guardians who have an adult family member (age 18 or older) with IDD living outside the family home. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed to families or guardians.

The Child Family Survey is completed by families who have a child with IDD living in the family home. The child receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed to families.

Staff Stability Report

The Staff Stability Survey is an on-line survey of provider agencies supporting adults with ID/DD in residential, employment, day services and other in-home or community inclusion programs. The survey captures information about wages, benefits, and turnover of the direct care professional workforce, hired by agencies.

Agencies receive the survey through an email invitation (address provided by State) and agencies respond directly into ODESA.
**Respondents**

Adults with IDD age 18 and older receiving at least one service (in addition to case management) from the state DD service system.

- **Residence**
  - 38% parent or relative’s home
  - 32% community-based group residential settings
  - 18% own home or apartment
  - 7% foster care or host home
  - 4% ICF/ID or other institutional setting
  - 2% other or don’t know

- **89% Have ID diagnosis**
  - 39% mild
  - 29% moderate
  - 12% severe
  - 8% profound
  - 12% unspecified or unknown

- **Mental Health Diagnoses**
  - 32% mood disorder
  - 27% anxiety disorder
  - 11% psychotic disorder
  - 11% other mental health diagnosis

- **58% male**

- **Average age 43**

- **53% under guardianship**

*proxy respondents were allowed for some questions
96% reported having taken part in last service planning meeting

81% understood what was being talked about at last planning meeting

94% reported that they chose or had input in services gets as part of service plan

83% know who to ask to make changes to service plan

79% report having friends who are not staff or family

79% report that they can see friends when they want

81% report having other ways of talking or chatting with friends when cannot see them

48% want more help to make or keep in contact with friends

89% report being able to use phone or internet when wanted

56% report having a cell phone or smartphone

44% of those who do not have a cell phone or smartphone want a cell phone or smartphone
**Respondents**

Family members and/or guardians of adults who have I/DD and receive at least one service in addition to case management from the state DD service system. The respondent lives with the adult receiving services.

**Respondents....**

- 11% are over age 75
- 36% say they or a family member provide paid support
- 33% always have the respite services they need
- 28% reported an annual household income of $25K or less
- 73% reported services and supports reduced out-of-pocket expenses related to care for their family member

**Family member with IDD....**

- 60% are male
- 34 average age
- 88% take part in community activities
- 68% have friends other than family or paid staff
- 68% have a guardian
- 3% have a guardian, level unknown
- 11% limited guardianship
- 54% full guardianship

**NCI Averages:**

- Include all participating states
- Data are weighted

*2018-19 AFS participating states were: AZ, GA, LA MD, MN, MO, NC, OH, OK, PA, UT, VA*
79% have resources in the community the family can use

15% take part in family-to-family networks

96% feel services and supports have made a positive difference for their family member

39% say they *always* get enough information to help plan services

41% say services and supports *always* change when their family’s needs change

85% say they or another family member helped make the service plan

64% say their family member with IDD helped make the service plan

78% family member can *always* see health professionals when needed

68% family member can *always* go to the dentist when needed

53% crisis or emergency services were provided in the past year when needed

2018-19 Adult Family Survey
Respondents

Family members and/or guardians of adults who have I/DD and receive at least one service in addition to case management from the state DD service system. The respondent *does not live* with the adult receiving services.

**Respondents....**

19% are age 75 or older

57% say they visited their family member with IDD 12 or more times in the past year

**Family member with IDD....**

Where family member lives...

- 14% specialized facility for people with ID
- 65% group home or agency-operated agency
- 11% own home or apartment
- 7% adult foster care or host home
- 3% other

2,709 families participated across 9 states*

NCI Averages:

- Include all participating states
- Data are weighted

*2018-19 AFS participating states were: AZ, GA, KY, LA, MD, NC, OH, PA, VA
46% always kept informed by staff or residential agency about how family member is doing

74% services are always delivered in a way that is respectful of family’s culture

96% feel services and supports have made a positive difference for their family member

43% always get enough information to help plan services

44% services and supports always change when their family’s needs change

81% say they or another family member helped make the service plan

62% family member with IDD helped make the service plan

81% know how to report abuse or neglect related to their family member

71% know how to file a complaint about provider agencies or staff

76% who filed a complaint in the past year were satisfied with the way it was handled and resolved
Respondents

Family members and/or guardians of children who have I/DD and receive at least one public service in addition to case management from the state DD agency. The respondent lives with the child receiving services.

**Child Family Survey (CFS)**

14,816 families participated across 12 states*

NCI Averages:

*Include all participating states

• Data are weighted

*2018-19 CFS participating states were: AZ, CA, CO, LA, MN, MO, NC, OH, OR, SD, WA, WI

---

**Respondents**

- 14% are under age 35
- 33% say they or a family member provide paid support
- 39% always have the respite services they need

---

**39%** reported an annual household income of $25K or less

**73%** reported services and supports reduced out-of-pocket expenses related to care for their child

---

**Child with IDD**

- 69% male
- 11 average age
- 81% child takes part in community activities
- 88% child spends time with children without DD
- 81% have resources in the community the family can use
- 21% take part in family-to-family networks
69% of case managers/service coordinators always respect family’s choices and opinions.

43% of support workers always have the right information and skills to meet family’s needs.

92% feel services and supports have made a positive difference for their child.

30% always get enough information to help plan services.

31% services and supports always change when their family’s needs change.

83% say they or another family member helped make the service plan.

18% child with IDD helped make the service plan.

73% child’s service providers work together to provide support.

50% family can always choose or change their child’s support workers.

50% family can always choose or change the agency that provides services.
Staff Stability Survey

A total of 4,400 providers from 26 states and the District of Columbia participated in the 2018 NCI Staff Stability Survey.

Across states, the weighted average turnover rate for DSPs in 2018 was 51.3%. States ranged from 30.7% to 62.7%.

Full-Time Vacancy Rate: 11.9%
Part-Time Vacancy Rate: 18.1%

Across all service types, agencies paid a median hourly wage of $12.00.

Among DSPs who were employed as of 12/31/18...
- 19.6% were employed less than 6 mos.
- 14.7% were employed 6-12 mos.
- 65.7% were employed 12 mos. or longer

Among DSPs separated from employment in 2018...
- 34.7% were employed less than 6 mos.
- 20.3% were employed 6-12 mos.
- 33.7% were employed 12 mos. or longer

For more info on the survey and methodology, see the 2018 Staff Stability Report available here: https://www.nationalcoreindicators.org/staff-stability-survey/
<table>
<thead>
<tr>
<th>NCI National Team Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alexandra Bonardi</td>
</tr>
<tr>
<td>HSRI Director of NCI</td>
</tr>
<tr>
<td><a href="mailto:abonardi@hsri.org">abonardi@hsri.org</a></td>
</tr>
<tr>
<td>Laura Vegas</td>
</tr>
<tr>
<td>NASDDDS Director of NCI</td>
</tr>
<tr>
<td><a href="mailto:Lvegas@nasddds.org">Lvegas@nasddds.org</a></td>
</tr>
<tr>
<td>Valerie Bradley</td>
</tr>
<tr>
<td><a href="mailto:vbradley@hsri.org">vbradley@hsri.org</a></td>
</tr>
<tr>
<td>Dorothy Hiersteiner</td>
</tr>
<tr>
<td><a href="mailto:dhiersteiner@hsri.org">dhiersteiner@hsri.org</a></td>
</tr>
<tr>
<td>Stephanie Giordano</td>
</tr>
<tr>
<td><a href="mailto:sgiordano@hsri.org">sgiordano@hsri.org</a></td>
</tr>
<tr>
<td>Henan Li</td>
</tr>
<tr>
<td><a href="mailto:hli@hsri.org">hli@hsri.org</a></td>
</tr>
<tr>
<td>Rachel Fink</td>
</tr>
<tr>
<td><a href="mailto:rfink@hsri.org">rfink@hsri.org</a></td>
</tr>
<tr>
<td>Karen Gruber</td>
</tr>
<tr>
<td><a href="mailto:kgruber@hsri.org">kgruber@hsri.org</a></td>
</tr>
<tr>
<td>Eric Lam</td>
</tr>
<tr>
<td><a href="mailto:elam@hsri.org">elam@hsri.org</a></td>
</tr>
<tr>
<td>Julie Bershadsky</td>
</tr>
<tr>
<td><a href="mailto:jbershadsky@hsri.org">jbershadsky@hsri.org</a></td>
</tr>
</tbody>
</table>

For more information about NCI, visit: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)
Comments or questions, email: [Dhiersteiner@hsri.org](mailto:Dhiersteiner@hsri.org)