North Carolina Data
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 Intellectual and Developmental Disabilities (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 North Carolina 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/

This report was produced by the state of North Carolina.
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.

• In-Person Survey
• Adult Family Survey
• Family/Guardian Survey
• Child Family Survey
• Staff Stability Survey

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 online.
In-Person Survey (IPS)

651 adults with IDD participated across North Carolina

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
  - 52% parent or relative’s home
  - 19% Community-based group residential settings
  - 6% own home or apartment
  - 5% foster care or host home
  - 13% ICF/IID or other institutional setting
  - 3% other or don’t know

- Mental Health Diagnoses
  - 28% mood disorder
  - 26% anxiety disorder
  - 12% psychotic disorder
  - 11% other mental health diagnosis

- Percentages
  - 95% have ID diagnosis
  - 52% mild
  - 34% moderate
  - 20% severe
  - 14% profound
  - 5% unspecified or unknown

- Demographics
  - 61% male
  - 39 average age
  - 77% under guardianship

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

86% understood what was being talked about at last planning meeting

68% reported that they chose or had input in services they get 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

71% report that they can see friends when they want

72% report that they can be alone with friends or visitors at home

75% report having other ways of talking or chatting with friends when cannot see them

61% want more help to make or keep in contact with friends

60% report having rules about having friends or visitors at home

88% report being able to use phone or internet when wanted

50% report having a cell phone or smartphone

46% of those who do not have a cell phone or smartphone want a cell phone or smartphone
42% have a key to their home

97% have a place to be alone in their home

49% can lock their bedroom door if they want

28% can stay home if others they live with go somewhere

41% have voted or had the opportunity to vote and chose not to

9% report having other people read their mail or email without asking

57% report having input in where they live (if not at home)

7% report their name is on lease or other agreement

36% report having input in housemates or living alone

93% have enough choice in their daily schedule

58% do not have community job, but would like one

86% had input choosing where they work

36% have paid job, but want to work somewhere else

21% have community employment goal in plan
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...

- 8% are over age 75
- 49% say they or a family member provide paid support
- 38% always have the respite services they need
- 27% reported an annual household income of $25K or less
- 80% reported services and supports reduced out-of-pocket expenses related to care for their family member

Family member with IDD....

- 53% are male
- 32.3 average age
- 93% take part in community activities
- 71% have friends other than family or paid staff
- 93% have a guardian
  - 3% have a guardian, level unknown
  - 12% limited guardianship
  - 78% full guardianship

2018-19 Adult Family Survey (AFS)
224 families participated across North Carolina
81% have resources in the community the family can use

21% take part in family-to-family networks

98% feel services and supports have made a positive difference for family member

47% say they *always* get enough information to help plan services

42% say services and supports *always* change when their family’s needs change

90% say they or another family member helped make the service plan

55% say their family member with IDD helped make the service plan

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

71% family member can *always* go to the dentist when needed

62% crisis or emergency services were provided in the past year when needed
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....

15% are age 75 or older
55% say they visited their family member with IDD 12 or more times in the past year

Family member with IDD....

Where family member lives...

27% specialized facility for people with ID
50% group home or agency-operated apartment
5% own home or apartment
17% adult foster care or host home
0% other

80% full guardianship
15% limited guardianship
3% Have guardian, but level is unknown
98% have a guardian

44.3 average age
67% male
93% take part in community activities
65% have friends other than family or paid staff

209 families/ guardians participated across North Carolina
57% always kept informed by staff or residential agency about how family member is doing

80% 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

55% always get enough information to help plan services

48% services and supports always change when their family’s needs change

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

59% family member with IDD helped make the service plan

90% know how to report abuse or neglect related to their family member

77% know how to file a complaint about provider agencies or staff

71% 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.

Respondents....

- **8%** are under age 35
- **20%** say they or a family member provide paid support
- **32%** always have the respite services they need
- **40%** reported an annual household income of $25K or less
- **71%** reported services and supports reduced out-of-pocket expenses related to care for their child

Child with IDD....

- **62%** male
- **14.6** average age
- **88%** child takes part in community activities
- **82%** child spends time with children without DD
- **79%** have resources in the community the family can use
- **18%** take part in family-to-family networks

2018-19 Child Family Survey (CFS)

202 families participated across North Carolina
68% case manager/service coordinator always respects family’s choices and opinions

36% support workers always have the right information and skills to meet family’s needs

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

41% always get enough information to help plan services

34% services and supports always change when their family’s needs change

91% say they or another family member helped make the service plan

22% child with IDD helped make the service plan

72% family can always choose or change the agency that provides services

66% family can always choose or change their child’s support workers

85% child’s service providers work together to provide support
Staff Stability Survey

A total of 120 (22.4%) providers from North Carolina participated in the 2018 NCI Staff Stability Survey.

In North Carolina the average turnover rate for DSPs in 2018 was 32%. States ranged from 30.7% to 62.7%.

Full-Time Vacancy Rate: 4.8%
Part-Time Vacancy Rate: 9.5%

Across all service types, agencies paid a median hourly wage of $11.10.

Among DSPs who were employed as of 12/31/18...
• 14% were employed less than 6 mos.
• 13.5% were employed 6-12 mos.
• 72.6% were employed 12 mos. or longer

Among DSPs who separated from employment in 2018...
• 23.5% had been employed less than 6 mos.
• 19.4% had been employed 6-12 mos.
• 42.2% had been 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/
National Trend Comparison: Where NC Shows Above Average

In-Person Survey (IPS); Family/Guardian Survey (FGS); Adult/Guardian Survey (AGS); Child/Family Survey (CFS)

- **Rights and Respect**
  - Voted or had the opportunity to vote (IPS)

- **Satisfaction with Services and Supports**
  - Know how to report abuse or neglect related to their family member (FGS)
  - Know how to file a complaint about provider agencies or staff (FGS)
  - Services and supports reduced out of pocket expenses related to care for their family members (AFS)

- **Community Involvement**
  - Take part in family-to-family networks (AFS)
  - Take part in community activities (AFS)

- **Information and Planning**
  - Families always get enough information to help plan services (AFS, FGS, CFS)
  - Family member/guardian helped make the service plan (AFS, CFS)
  - Crisis or emergency services were provided in the past year when needed (AFS)
  - Always kept informed by staff or residential agency about how family member is doing (FGS)

- **Choice, Decision Making, and Control**
  - Family can always choose or change the agency that provides services (CFS)
  - Family can always choose or change their child’s support workers (CFS)
  - Child’s service providers work together to provide support (CFS)

- **Access and Delivery of Services and Supports**
  - Services are always delivered in a way that is respectful of family’s culture (FGS)

- **Staff Stability**
  - Vacancy rates are lower than national average. Staff are employed longer in NC as compared to other states.
GUARDIANSHIP
• Guardianship in NC continues to rank high in comparison to the national NCI average. There is a higher percentage discrepancy under full guardianship. Continued education to the I/DD community regarding alternatives to guardianship is needed.

CLIENT RIGHTS
• Additional training and education in client rights and respect may support individuals to have more freedom to make friends and spend time with them in a format of their choosing. The NCI national average for having rules about friends and visitors is 35%, while NC rates at 60%. NC also has a lower percentage of people reporting that they can see friends when they want, that they can be alone with friends or visitors at home, and that they have other ways of talking or chatting with friends when cannot see them than the national average. 61% of members in NC want more help to make or keep in contact with friends as compared to the national average of 48%.

EMPLOYMENT
• Education about and updates to employment service practices may support more individuals. 58% of people supported do not have a community job but would like one; the national average is 44%. 21% of individuals in NC have community employment goals in their plan compared to the national average of 29%. Nationally, 25% of individuals that have a paid job, but want to work somewhere else, and 36% of individuals supported in NC with a paid job want to work elsewhere.
PERSON-CENTERED PLANNING

• More education of Person-Centered Planning practices to current best and promising practices could be beneficial. Lower percentages of people supported in NC reported that they chose or had input in services gets as part of service plan, say their family member with IDD helped make the service plan, and understood what was being talked about at last planning meeting as compared to the national average. Also, 36% of parents of children receiving services say their support workers always have the right information and skills to meet family’s needs while the national average is 43%.

INDEPENDENT LIVING

• Additional training and education on independent living and HCBS. In NC 6% of individuals live in their own home or apartment, in comparison to 18% nationally. 7% report their name is on a lease or other agreement in NC and the national average is 23%. The national average for people being able to stay at home while others they live with go somewhere is 43%, but in NC the rate is 28%. The NC rates of people reporting having input in housemates or living alone as well as having a key to home are also significantly below the national average.

STAFF STABILITY

• Systemic review of staff stability. Staff Stability Participation Rate was 120 out of 535 providers participated. NC needs to find ways to encourage provider participation. The median hourly wage of $11.10 in NC as compared to $12.00 nationally.
For more information about NCI, visit: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)
Comments or questions, email: Dhiersteiner@hsri.org