

# National Core Indicators: Intellectual and Developmental Disabilities

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI®-IDD) is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). In 2021-22, a total of 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD.

The NCI-IDD Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who lives with the respondent and receives at least one service in addition to case management from the state DD agency. The survey collects demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received.

Below are excerpts from surveys done in Missouri from 2017 to 2022.

## Missouri Demographics

Prepared by Spectrum Institute for  
[Missouri Medical Rights Workgroup](#)

### Observations:

1. Missouri is overusing guardianships compared to the rest of the nation.
2. A majority of families are not being advised of alternatives to guardianship.
3. Some 85% of adults with I/DD have a high school diploma, GED, or certification.
4. More than 35% of adults in the surveys do not have an intellectual disability.
5. About 25% of adults cannot always see a doctor when needed.
6. About 40% of adults cannot always see a dentist when needed.
7. About 45% of doctors and dentists do not always understand the patient's disability needs.
8. About 45% of mental health providers do not always understand the patient's disability needs.
9. When crisis services were needed, 45% did not receive them.

## 2021-2022: [Adult Family Survey](#)

**Disability Type:** Adult family members had various types of developmental disabilities. Intellectual (63%) / Autism (40%) / Cerebral Palsy (17%) / Vision (6%) / Hearing (5%) / Down syndrome (14%) Disability types were similar to the national averages.

**Location.** Urban or suburban (61%) / Rural (39%) More rural than national averages.

**Age.** Average age was 35. Similar to national averages.

**Gender.** Male (64%) / Female (36%) Slightly more male than national average.

**Race.** White (90%) / Black (6%) / Asian (1%) / Hispanic 4%. National averages were 54% white, 27% Hispanic, 10% Black, and 10% Asian.

**Language.** 98% spoke English.

**Education.** HS Diploma or GED (48%) / HS Certification (29%) / No HS (15%) Some college (3%) / College Degree (2%) Similar to national.

**Guardianship Status.** 78% had a guardian which is 13 points higher than national average. 98% of guardians were family members which is similar to national average.

**Alternatives to Guardianship.** 50% had not learned of alternatives. Similar to national. A 2021-2022 [survey](#) of families with children who had developmental disabilities revealed that 86% had not heard of alternatives to guardianship.

**See Doctor When Needed.** Always (78%) / Usually (18%) / Sometimes (3%) / Seldom or Never (2%) Similar to national.

**Does Doctor Understand Disability Needs.** Always (53%) / Usually (40%) / Sometimes (6%) / Never (1%) Similar to national average.

**See Dentist When Needed.** Always (62%) / Usually (17%) / Sometimes (10%) / Seldom or Never (10%) Similar to national average.

**Does Dentist Understand Disability Needs.** Always (51%) / Usually (34%) / Sometimes (11%) / Seldom or Never (5%) Similar to national average.

**See Mental Health Provider When Needed.** Always (51%) / Usually (19%) / Sometimes (8%) / Seldom or Never (23%) Similar to national average.

**Does Mental Health Provider Understand Disability Needs.** Always (51%) / Usually (39%) / Sometimes (5%) / Seldom or Never (5%). Similar to national average.

**Were Crisis Services Provided When Needed.** Yes (68%) / No (32%). Slightly better than national.

## **2020-2021: [Adult Family Survey](#)**

**Disability Type:** Adult family members had various types of developmental disabilities. Intellectual (65%) / Autism (41%) / Cerebral Palsy (20%) / Vision (12%) / Hearing (6%) / Down syndrome (17%) Disability types were similar to the national averages.

**Age.** Average age was 33.7. Similar to national averages.

**Gender.** Male (55%) / Female (45%) Slightly more male than national average.

**Race.** White (91%) / Black (7%) / Asian (2%) / Hispanic (2%). Native American (1%) (National averages were 72% white, 10% Hispanic, 16% Black, and 4% Asian.

**Language.** 98% spoke English.

**Education.** HS Diploma or GED (47%) / HS Certification (30%) / No HS (12%) Some college (4%) / College Degree (3%) Similar to national average.

**Guardianship Status.** 79% had a guardian which is 7 points higher than national average. 96% of guardians were family members which is similar to national average. A 2020-2021 [survey](#) of adults with I/DD showed that 74% were in guardianships, compared with only 45% nationally. Some 33% in Missouri had public guardians compared to 12% nationally. Some 66% in Missouri had a family member as guardian, similar to the national average.

**See Health Professionals When Needed.** Always (71%) / Usually (25%) / Sometimes (4%) / Seldom or Never (1%) Similar to national average.

**Does Doctor Understand Disability Needs.** Always (52%) / Usually (39%) / Sometimes (8%) / Never (1%) Similar to national average.

**See Dentist When Needed.** Always (60%) / Usually (22%) / Sometimes (7%) / Seldom or Never (10%) Similar to national average.

**Does Dentist Understand Disability Needs.** Always (55%) / Usually (36%) / Sometimes (6%) / Seldom or Never (3%) Similar to national average.

**Does Mental Health Provider Understand Disability Needs.** Always (53%) / Usually (30%) / Sometimes (13%) / Seldom or Never (3%). Similar to national average.

**Were Crisis Services Provided When Needed.** Yes (45%) / No (55%). Slightly worse than national.

## **2019-2020: [Adult Family Survey](#)**

**Disability Type:** Adult family members had various types of developmental disabilities. Intellectual (62%) / Autism (39%) / Cerebral Palsy (21%) / Vision (11%) / Hearing (5%) / Down syndrome (16%) Disability types were similar to the national averages.

**Age.** Average age was 34.3. Similar to national averages.

**Gender.** Male (59%) / Female (41%) Slightly more male than national average.

**Race.** White (90%) / Black (8%) / Asian (2%) / Hispanic (2%). Native American (3%) (National averages were 59% white, 22% Hispanic, 13% Black, and 9% Asian.

**Language.** 98% spoke English.

**Education.** HS Diploma or GED (42%) / HS Certification (27%) / No HS (17%) Some college (4%) / College Degree (6%) Similar to national average.

**Guardianship Status.** 77% had a guardian which is 14 points higher than national average. 98% of guardians were family members which is similar to national average.

**See Health Professionals When Needed.** Always (74%) / Usually (19%) / Sometimes (5%) / Seldom or Never (1%) Similar to national average.

**Does Doctor Understand Disability Needs.** Always (54%) / Usually (39%) / Sometimes (5%) / Never (1%) Similar to national average.

**See Dentist When Needed.** Always (59%) / Usually (24%) / Sometimes (5%) / Seldom or Never (12%) Similar to national average.

**Does Dentist Understand Disability Needs.** Always (54%) / Usually (33%) / Sometimes (9%) / Seldom or Never (4%) Similar to national average.

**Does Mental Health Provider Understand Disability Needs.** Always (59%) / Usually (26%) / Sometimes (10%) / Seldom or Never (5%). Similar to national average.

**Were Crisis Services Provided When Needed.** Yes (56%) / No (44%). Similar to national.

### **2017-2018: [Adult Family Survey](#)**

**Disability Type:** Adult family members had various types of developmental disabilities. Intellectual (56%) / Autism (46%) / Cerebral Palsy (21%) / Vision (12%) / Hearing (8%) / Down syndrome (12%) Lower rate of intellectual disability than national rate.

**Age.** Average age was 32.7. Slightly younger than national average.

**Gender.** Male (60%) / Female (40%) Slightly more male than national average.

**Race.** White (89%) / Black (9%) / Asian (2%) / Hispanic (2%). Native American (2%) (National averages were 77% white, 1% Hispanic, 11% Black, and 4% Asian.

**Language.** 98% spoke English.

**Education.** HS Diploma or GED (40%) / HS Certification (25%) / No HS (17%) Some college

(7%) / College Degree (4%) Similar to national average.

**Guardianship Status.** 73% had a guardian which is 10 points higher than national average. 98% of guardians were family members which is similar to national average. A 2017-2018 [survey](#) of individuals found that 82% of adults who responded were in a guardianship, compared to 43% nationally. Of those, 35% in Missouri had a public guardian, compared with 10% nationally.

**See Health Professionals When Needed.** Always (70%) / Usually (25%) / Sometimes (3%) / Seldom or Never (1%) Similar to national average.

**Does Doctor Understand Disability Needs.** Always (54%) / Usually (37%) / Sometimes (7%) / Never (1%) Similar to national average.

**Access to Dental Services.** Always (57%) / Usually (17%) / Sometimes (9%) / Seldom or Never (15%) Similar to national average.

**Does Dentist Understand Disability Needs.** Always (63%) / Usually (25%) / Sometimes (8%) / Seldom or Never (5%) Similar to national average.

**Does Mental Health Provider Understand Disability Needs.** Always (60%) / Usually (32%) / Sometimes (5%) / Seldom or Never (3%). Similar to national average.

**Were Crisis Services Provided When Needed.** Yes (55%) / No (45%). Slightly worse than national.