

New Report Spotlights Families' Voices on State Developmental Disability (DD) Service Systems Nationwide

Nearly 38,000 Families Share What's Working, and What's Still Missing, in State-Funded DD Supports

CAMBRIDGE, MA, UNITED STATES, August 4, 2025 /EINPresswire.com/ -- National Core Indicators – Intellectual and Developmental Disabilities® (NCI-IDD®), a collaboration between [Human Services Research Institute](#) (HSRI) and the National Association of State Directors of Developmental Disabilities Services ([NASDDDS](#)), announces the release of the 2023-24 Family Survey

National Reports. Data were gathered from 37,888 family members of children and adults receiving state-funded DD services across 18 states. NCI data can be used to examine the impact of Medicaid-funded disability services on the lives of those receiving services and their families.



Listening to these voices [of families navigating disability services] is essential for building systems that truly work for people with IDD and their families."

*Dorothy Hiersteiner, NCI-IDD
Co-Director*

The NCI-IDD Family Surveys capture the perspectives of those who know the service systems best: families of people with intellectual and developmental disabilities (IDD). The national reports include results from three distinct surveys:

- Family Guardian Survey (FGS): For families of adults with IDD who live outside the family home
- Adult Family Survey (AFS): For families of adults with IDD who live at home
- Child Family Survey (CFS): For families of children with IDD who live at home

Together, these surveys provide a detailed, family-centered perspective on access, satisfaction, and the quality of state-funded developmental disability services.



National Core Indicators - IDD logo



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FAMILIES SEE THE VALUE IN SERVICES, BUT ACCESS REMAINS UNEVEN

Across all three surveys, families overwhelmingly feel that services help their loved ones with IDD live a good life.

- More than 90% of respondents agreed with this sentiment, regardless of survey type.

However, not all families are getting the support they need:

- 88% of Family Guardian Survey respondents say their family gets needed services
- 73% of Adult Family Survey respondents say the same
- 64% of Child Family Survey respondents report having adequate support

ROOM FOR IMPROVEMENT IN SATISFACTION

Although services are seen as helpful, fewer than half of respondents said they are always satisfied with the supports they receive.

The reports also provide detailed insights on other essential areas, including:

- Access to planning and service information
- Choice and control in support decisions
- Workforce challenges and community integration
- Health, safety, and overall wellbeing

DATA THAT DRIVES CHANGE

“These reports represent the real, lived experiences of families navigating disability services,” said Dorothy Hiersteiner, NCI-IDD Co-Director. “Listening to these voices is essential for building systems that truly work for people with IDD and their families.”

HSRI and NASDDDS will continue to work alongside state agencies to ensure this data leads to real improvements in service access, quality, and outcomes.

ACCESS THE REPORTS

[View the full 2023–2024 NCI-IDD Family Survey National Reports.](#)

About National Core Indicators - Intellectual and Developmental Disabilities - Family Survey National Reports 2023-2024

The NCI-IDD program is a collaborative initiative involving state DD systems, Human Services Research Institute (HSRI), the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and people with disabilities and their families. As a research and quality monitoring enterprise, the NCI-IDD Family Surveys gather data directly from individuals



National Association of State Directors of Developmental Disabilities Services logo

using state DD system supports and their families.

Questions or comments?

We are always interested in collaborating closely with people with lived experience with intellectual and developmental disabilities. If you'd like to help us improve our research, please contact us at nci@nationalcoreindicators.org or visit our website:

<https://idd.nationalcoreindicators.org/>.

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