What the 2020-21 NCI®-IDD Child Family Survey data tells us about

Family Involvement in Service Planning across NCI-IDD States





This report tells us about:

- What NCI-IDD tells us about family involvement in service planning
- Why this is important
- Where to find out more about service planning across NCI-IDD States

What is NCI-IDD?

Each year, NCI-IDD asks people with intellectual and developmental disabilities (IDD) and their families how they feel about their lives and the services they get. NCI-IDD uses surveys so that the same questions can be asked to people in all NCI-IDD states.

Who answered questions to this survey?

Questions for this survey are answered by a person who lives in the same house as a child who is getting services from the state. Most of the time, a parent answers these questions. Sometimes a sibling or someone who lives with the child and knows them well answers these questions.

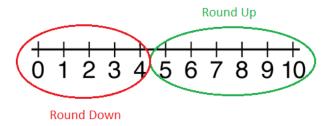
How are data shown in this report?

NCI-IDD asks questions about planning services and supports for children who get services from the state. In this report we see how family members of children getting services answered questions about planning services and supports.

- In this report, when we say "you" we mean the person who is answering the question (most of the time, a parent).
- In this report, when we say "child" we mean the child who is getting services from the state.

We use words and figures to show the number of **yes** and **no** answers we got. Some of our survey questions have more than a **yes** or **no** answer. They ask people to pick: "always," "usually," "sometimes," or "seldom/never." For this report, we count all "always" answers as **yes**. All others we count as **no**.

We round percentages to the nearest ten percent. To round, we look at the last digit in a number. If the digit is 5 or more, we "round up" to the next highest number with a zero. If the digit is 4 or less, we "round down" to the next lowest number with a zero.



For example:

If 87% of people say their family member gets all the services listed in their service plan, we "round up" to 90%.

If 12% of people say their family member helped make the service plan, we "round down" to 10%.

This report can help people talk about services and supports. If you want more information, you can look up the full report at: https://www.nationalcoreindicators.org



Making Connections – Why Is This Important?

Most of the children with IDD who get services and supports live with their families. The Child Family Survey provides a way for these families to comment on whether they get the information they need to be active participants in their child's planning process. Their child should also participate in the plan to the extent possible. Families need information about what services and supports are available to meet the specific needs of their child. With this information, family caregivers need to be given the choice about what staff and providers should provide those supports. It is important to know if families receive the services in their plan and whether plan includes all the services the family needs. Families should also be made aware of generic supports such as housing, food stamps and income support that may be available. Policy makers need to know whether these needs are being met.

Information about Services and Supports

It is important that people who help plan services have information to help them make choices. NCI-IDD asks questions about the information families get about services and supports.

Reminder:

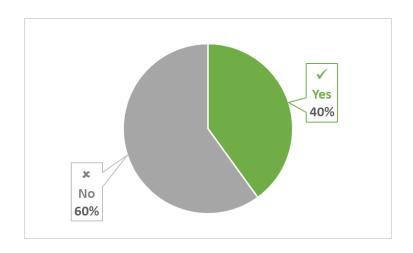
- When we say "you" we mean the person who is answering the question (most of the time, a parent).
- When we say "child" we mean the child who is getting services from the state.



Do you always get enough information to take part in planning services for your child?





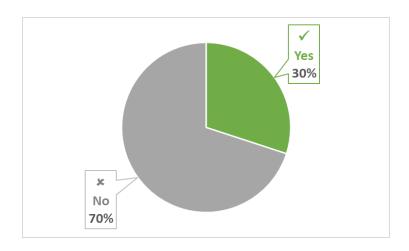


NCI-IDD tells us 4 out of every 10 people said they *always* get enough information to take part in planning services for their child.

Is the information you get about services and supports always easy to understand?





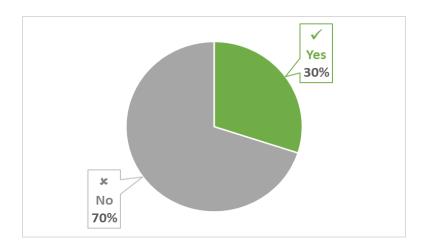


NCI-IDD tells us **3** out of every **10** people said the information they get about services and supports is always easy to understand.

Do you always have enough information about public services that your family can get (for example food stamps and SSI)?







NCI-IDD tells us **3** out of every **10** people said they *always* have enough information about public services their family can get.

Service Planning

People who get services from the state usually have a service plan (sometimes it is called an ISP or IPP). The service plan is a list of services the case manager/service coordinator will help get. NCI-IDD asks families about the service plan.

Reminder:

- When we say "you" we mean the person who is answering the question (most of the time, a parent).
- When we say "child" we mean the child who is getting services from the state.



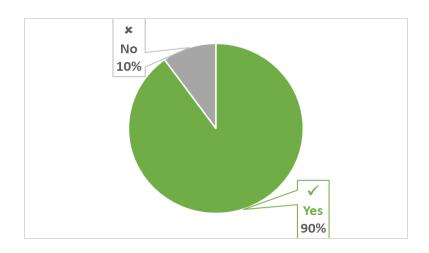
Does your child's service plan include all the services and supports your child needs?











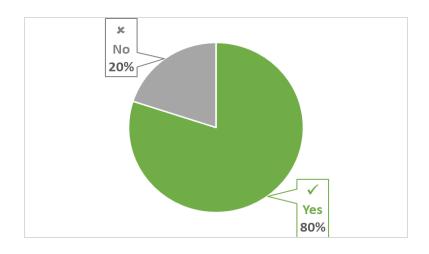
NCI-IDD tells us **9** out of every **10** people said the service plan includes all the services and supports their child needs.

Does your child get all the services listed in the service plan?









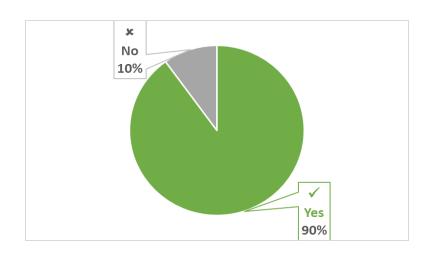
NCI-IDD tells us **8** out of every **10** people said **their child gets all the services listed in the plan.**

Did you or someone else in your family help make the service plan?







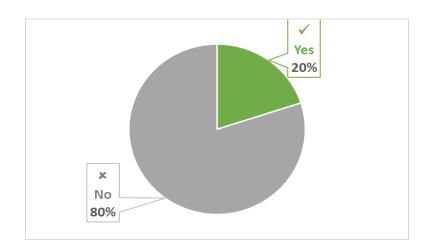


NCI-IDD tells us **9** out of every **10** people said they or someone else in their family helped make the plan.

Did your child help make the plan?







NCI-IDD tells us **2** out of every **10** people said **their child helped make the service plan.**



What Did Family of Children With Disabilities across NCI-IDD States Say?

40% Always get enough information to take part in planning services for their child

30% The information they get about services and supports is always easy to understand

30% Always have enough information about public services that their family can get (for example food stamps and SSI)

90% Their child's service plan includes all the services and supports their child needs

80% Child get all the services listed in the service plan

90% They or someone else in the family helped make the service plan

20% Child helped make the plan