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

# Family Involvement in Service Planning across NCI-IDD States

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**NATIONAL CORE  
INDICATORS®**  
NASDDDS & HSRI

## **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 an adult 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 person and knows them well answers these questions.

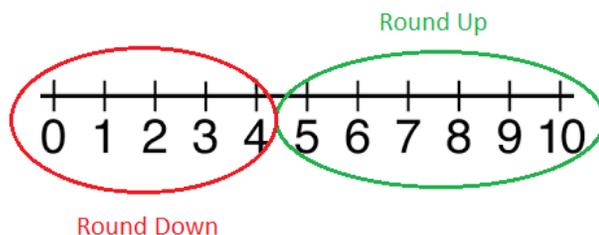
# How are data shown in this report?

NCHIDD asks questions about planning services and supports for people who get services from the state. In this report we see how family members of people 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 “**family member**” we mean **the person 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?

Many adults with IDD who get services and supports live with their families. NCI-IDD data tell us that across states 39% of people with IDD live their family. That's 2 out of every 5 people. In some states even more people live with their family. The services people get are part of the family member's service plan. It is important for people with IDD and their families to get information about services and supports. Information about services and supports helps people with IDD and families to take part in planning services and to make choices that are right for them. People with IDD and their family should take part in making the service plan. Sometimes, services listed in plan are not available, meaning the services cannot be used. It is important to know if people or families cannot get or use the services they need so people like the case manager or providers can help find other services. Families should also know about other supports that can help them. Things like housing supports, income supports, and food stamps.

# Information about Services and Supports

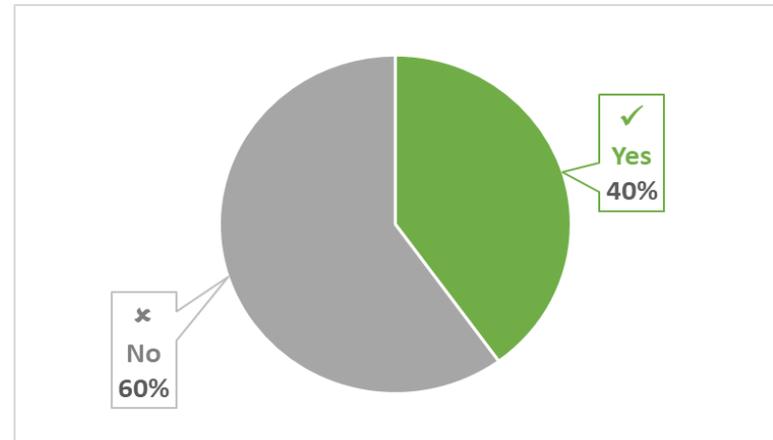
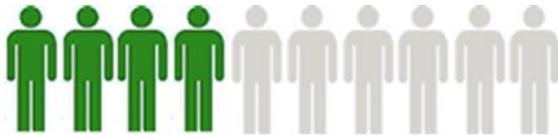
It is important that people who help plan services have information to help them make choices. NCI-IDD asks questions about the information families get about services and supports.

Reminder:

- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean **the person who is getting services from the state**.

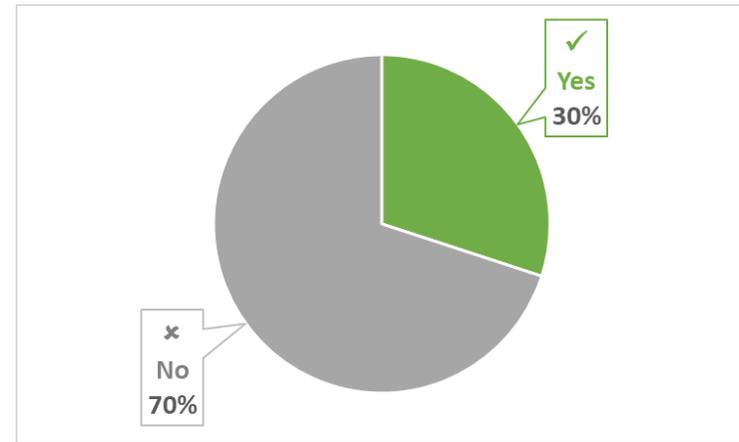


# Do you always get enough information to take part in planning services for your family member?



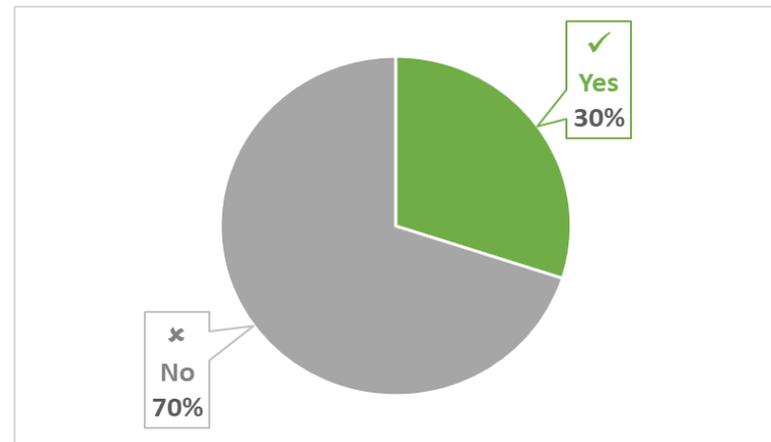
NCI-IDD tells us **4** out of every **10** people said **they *always* get enough information to take part in planning services for their family member.**

# 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

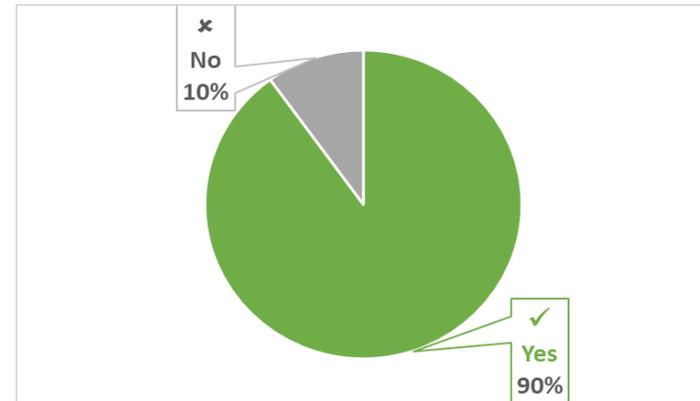
People who get services from the state usually have a service plan (sometimes it is called an ISP or IPP). The service plan is a list of services the case manager/service coordinator will help get. NCI-IDD asks families about the service plan.

Reminder:

- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean **the person who is getting services from the state**.

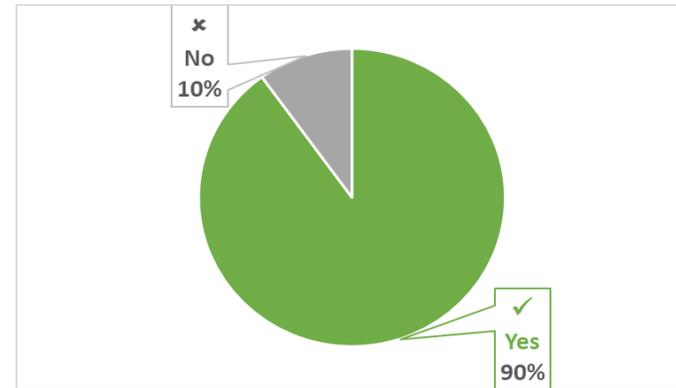


# Does your family member's service plan include all the services and supports your family member needs?



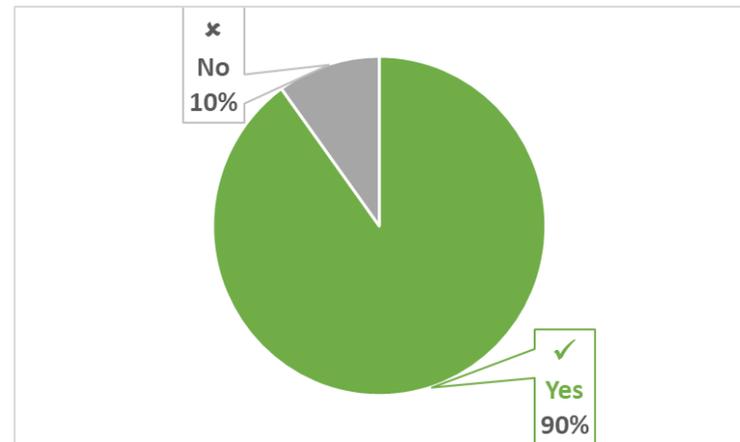
NCI-IDD tells us **9** out of every **10** people said **the service plan includes all the services and supports their family member needs.**

# Does your family member get all the services listed in the service plan?



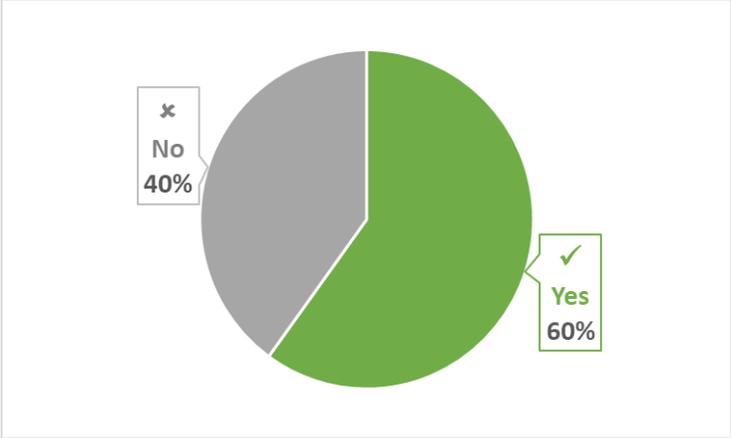
NCI-IDD tells us **9** out of every **10** people said **their family member gets all the services listed in the plan.**

Did you or someone else in your family (besides your family member with a disability) help make the service plan?



NCI-IDD tells us **9** out of every **10** people said **they or someone else in their family (besides your family member with a disability) helped make the plan.**

# Did your family member help make the plan?



NCI-IDD tells us **6** out of every **10** people said **their family member helped make the service plan.**



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

**40%** They always get enough information to take part in planning services for their family member

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

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

**90%** Their family member's service plan includes all the services and supports their family member needs

**90%** Their family member gets all the services listed in the service plan

**90%** They or someone else in your family (besides their family member with a disability) helped make the service plan

**60%** Their family member help make the plan