

What the 2020-21 NCI[®]-IDD Family/Guardian Survey data tells us about

Family Access to Services and Supports across NCI-IDD States



This report tells us about:

- What NCI-IDD tells us about family access to services and supports
- Why this is important
- Where to find out more about access to services and supports 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 does not live 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 guardian who is not related to the person getting services will answer questions.

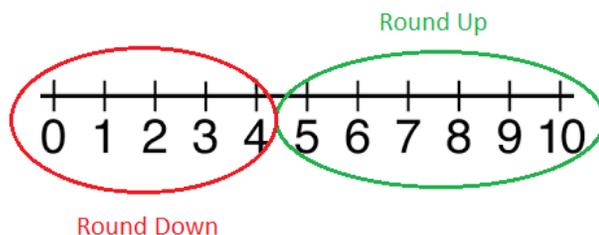
How are data shown in this report?

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 can see a dentist when needed, we “round up” to 90%.

If 12% of people say they are always able to get and use respite services when needed, 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?

When family members with IDD move out of their family homes, parents and other family members continue to be concerned about whether their well-being and whether their needs are being met. The Family Guardian Survey provides a way for these families to share what they know about whether their family member has access to those health and other supports needed to help them live a good life. Supports include equipment needed for mobility and communication as well as access to health providers. Families provide their perspective on whether these services and supports are adequate and timely. Feedback from families is important. This information can be shared with state officials (like a governor or mayor) and policy makers. If they

know when needs are not being met, they can try to find resources to help. This report gives families a way of letting state officials and policy makers know what is working for them and what is not working.

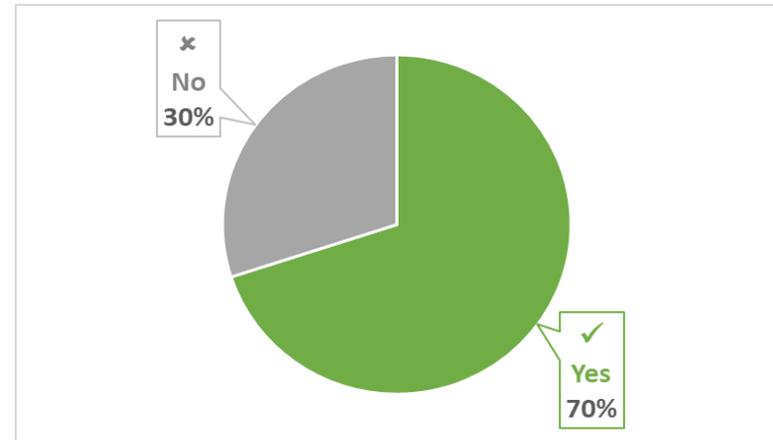
Access to Healthcare Services

It is important for people to be able to see healthcare professionals so they can stay healthy. Healthcare professionals are people like doctors, dentists, counselors and psychologists. NCI-IDD asks families if their family member who gets services from the state is able to see the healthcare professionals they need. NCI-IDD also asks if healthcare professionals understand their needs.

Reminder:

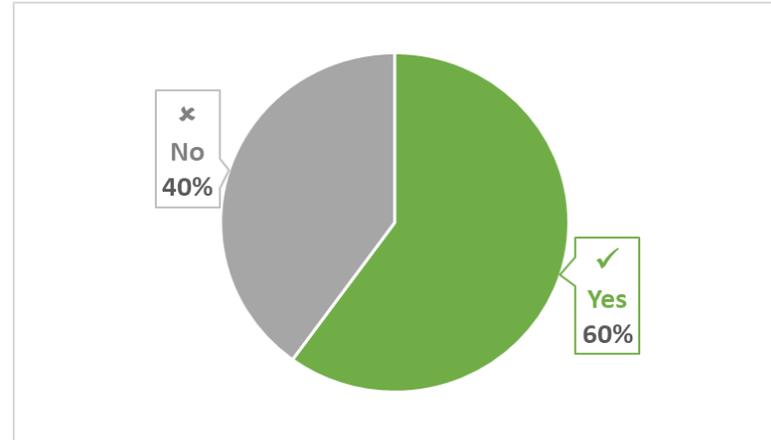
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean the **person who is getting services from the state**.

Can your family member always see health professionals (like a doctor or psychologist) when needed?



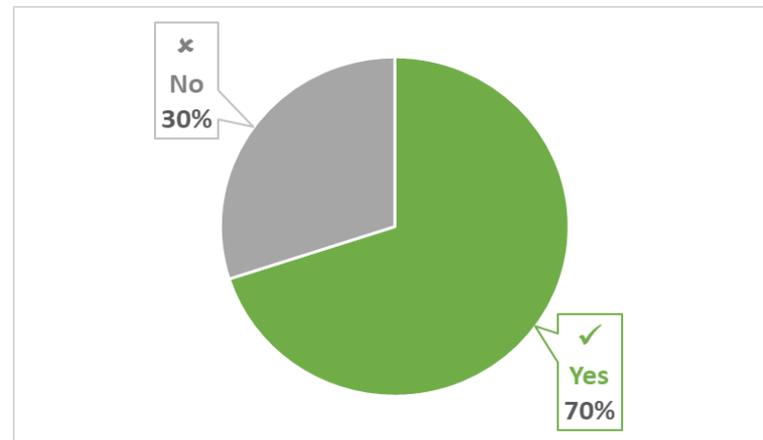
NCI-IDD tells us **7** out of every **10** people said **their family member can *always* see health professionals when needed**

Does your family member's primary care doctor always understand your family member's needs related to his/her disability?



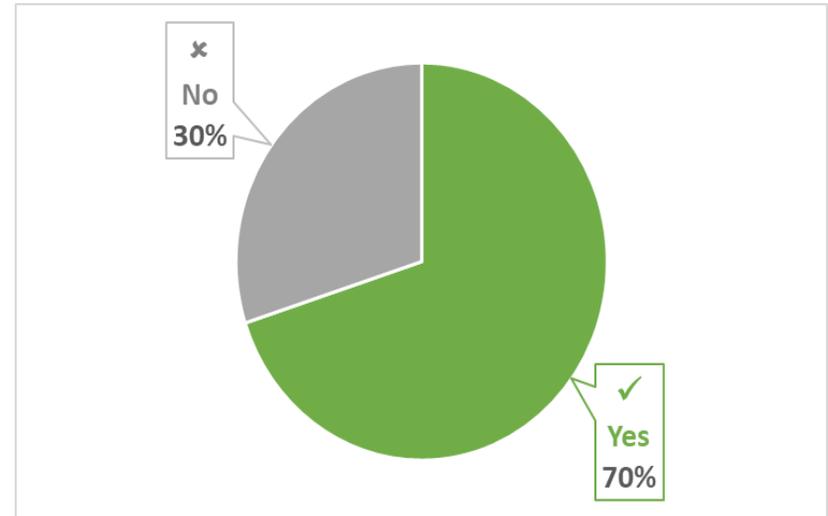
NCI-IDD tells us **6** out of every **10** people said **their family member's primary care doctor always understands their family member's needs related to his/her disability.**

Can your family member always go to the dentist when needed?



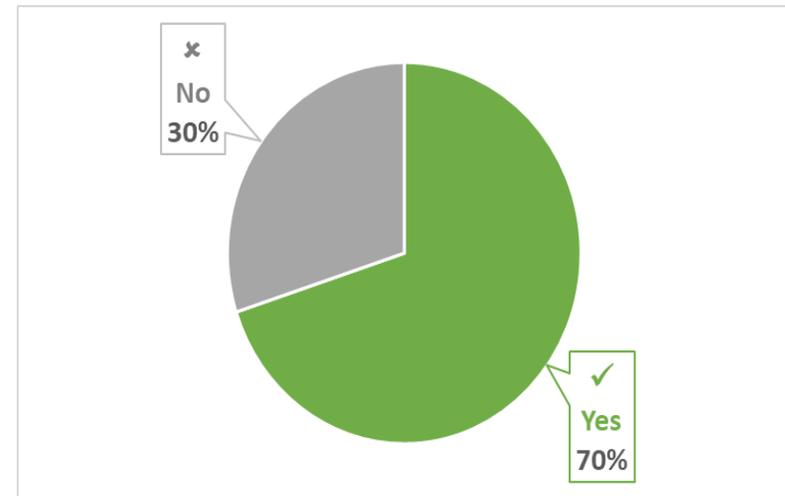
NCI-IDD tells us **7** out of every **10** people said **their family member can *always* go to the dentist when needed.**

Does your family member's dentist always understand your family member's needs related to his/her disability?



NCI-IDD tells us **7** out of every **10** people said **their family member's dentist *always* understands their family member's needs related to his/her disability.**

If your family member takes medications, do you always know what they're for?



NCI-IDD tells us **7** out of every **10** people whose family member takes medication said they *always* know what they're for.

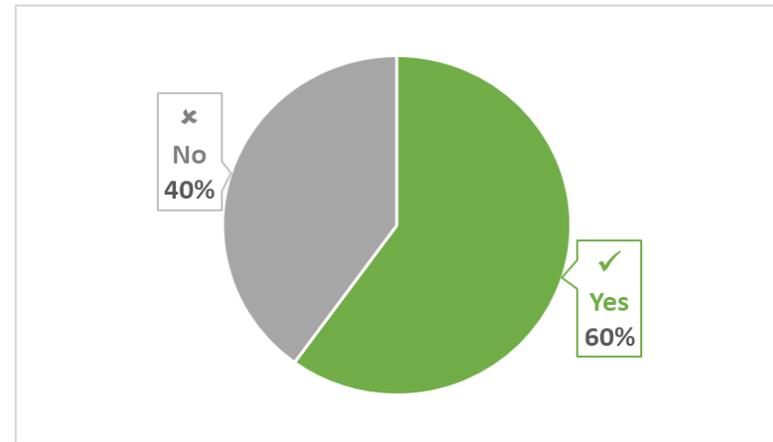
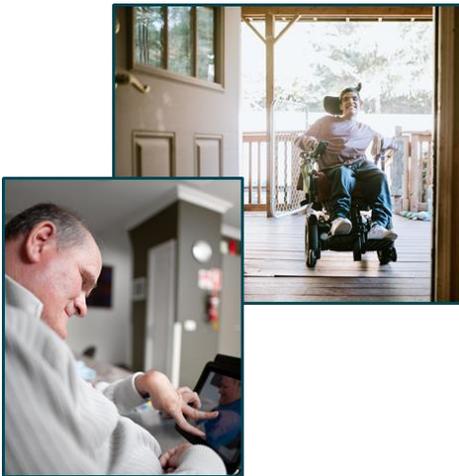
Access to Needed Services

People use many different kinds of services to help them. NCI-IDD asks if families get the services and supports they need.

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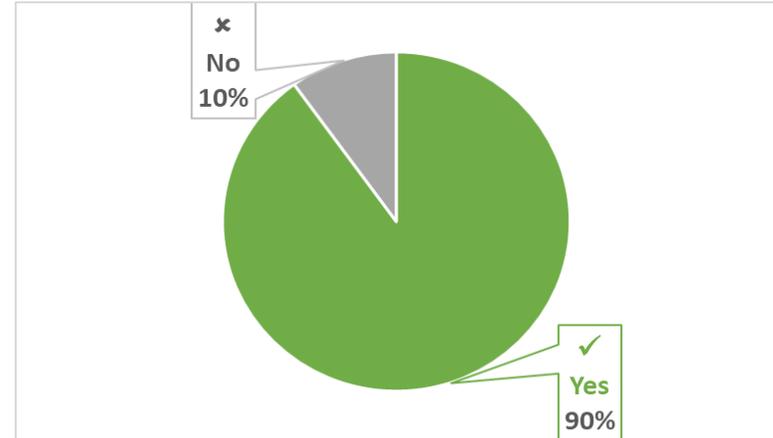
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean the **person who is getting services from the state**.

Does your family member have the special equipment or accommodations needed? Things like a wheelchair, ramp or communication board.



NCI-IDD tells us **6** out of every **10** people said **their family member *always* has the special equipment or accommodations needed.**

Does your family get the supports and services it needs?



NCI-IDD tells us **9** out of every **10** people said **their family gets the supports and services it needs.**

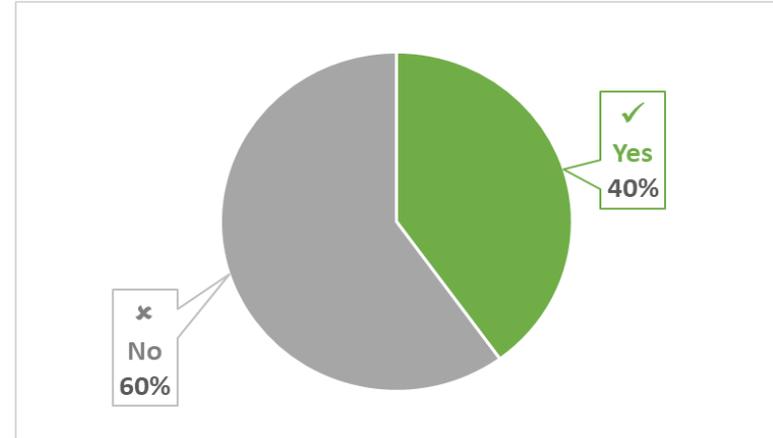
Satisfaction With Services and Supports

NCI-HDD asks families questions about how happy they are with the services they get.

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**.

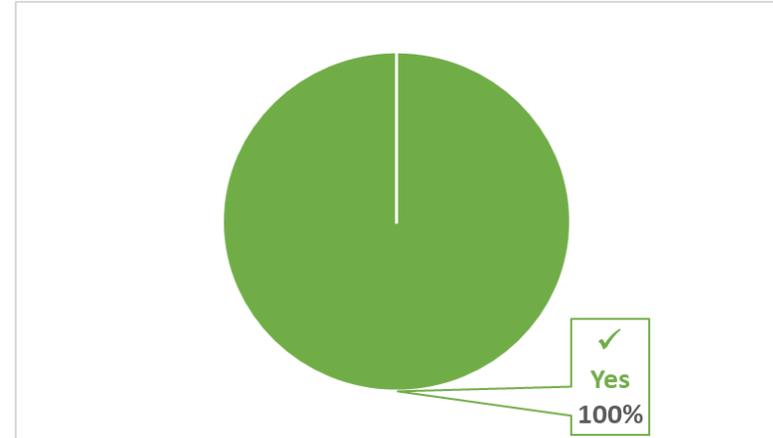
Overall, are you happy with your family member's services and supports?



NCI-IDD tells us **4** out of every **10** people said **that overall, they are always happy with their family member's services and supports.**

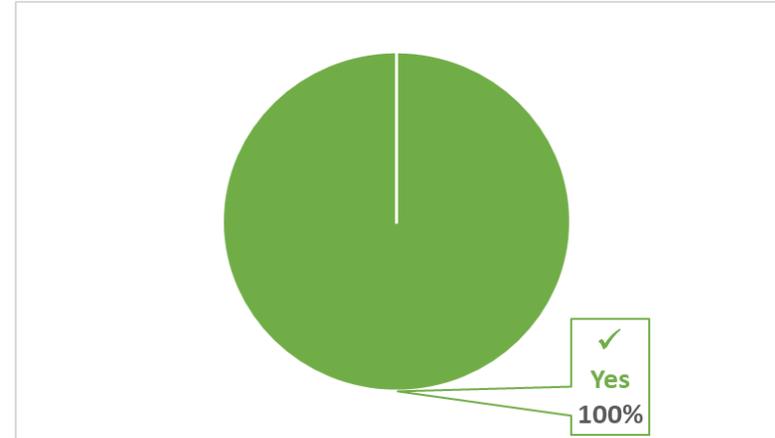


Do you feel that services and supports have made a positive difference in the life of your family member?



NCI-IDD tells us **10** out of every **10** people said **services and supports have made a positive difference in the life of their family member.**

Are services and supports helping your family member to live a good life?



NCI-IDD tells us **10** out of every **10** people said **services and supports are helping their family member live a good life.**



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

- 70%** Family member can always see health professionals (like a doctor or psychologist) when needed
- 60%** Family member's primary care doctor always understands his/her needs related to his/her disability
- 70%** Family member can always go to the dentist when needed
- 60%** Family member's dentist always understands his/her needs related to his/her disability
- 70%** Always know what family member's medications are for
- 60%** Family member has the special equipment or accommodations needed
- 90%** Family gets the supports and services it needs
- 40%** Overall, happy with your family member's services and supports
- 100%** Feel that services and supports have made a positive difference in the life of their family member
- 100%** Services and supports are helping family member to live a good life