

What the 2020-21 NCI[®]-IDD Child Family 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 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.

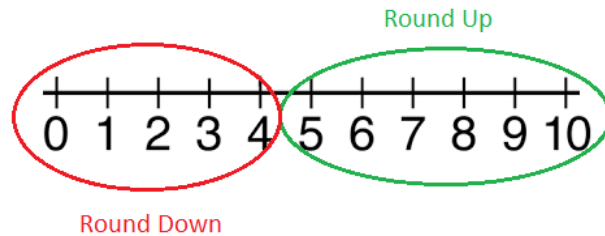
How are data shown in this report?

NCHDD 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 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?

Most of the children with IDD who get services and supports live with their families. It is important to know if families with children are getting their needs met. The Child Family Survey provides a way for these families to share what they know about whether their family member receives needed health and other supports to help them to grow and to develop the skills they will need to 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 available, adequate and timely. This feedback can be shared with state officials (like a governor or mayor) and policy makers. This report gives families a way of letting state officials and policy makers know what is working for them and what is not working.

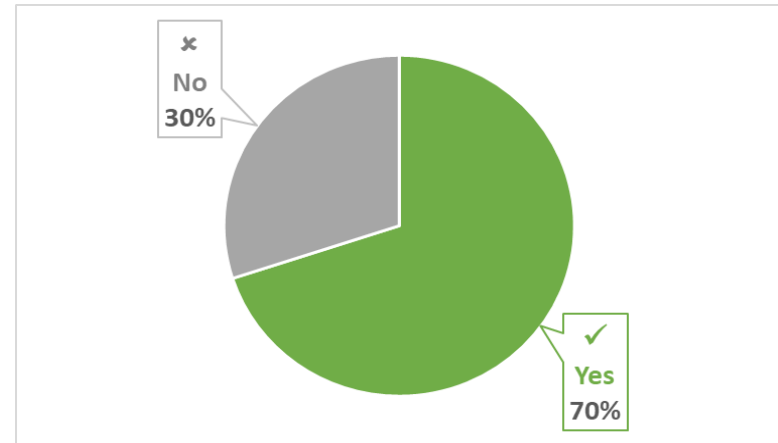
Access to Healthcare Services

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:

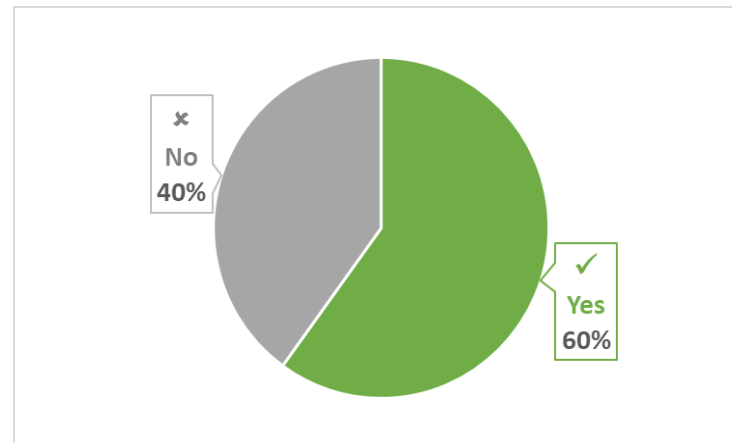
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**child**” we mean the **child who is getting services from the state.**

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



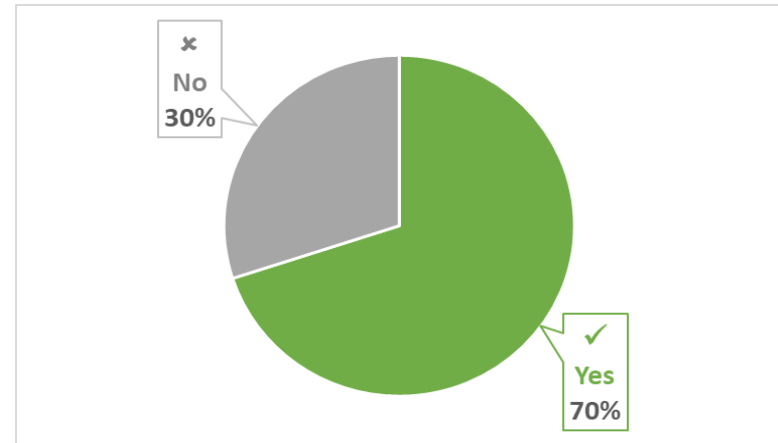
NCI-IDD tells us **7** out of every **10** people said **their child can *always* see health professionals when needed.**

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



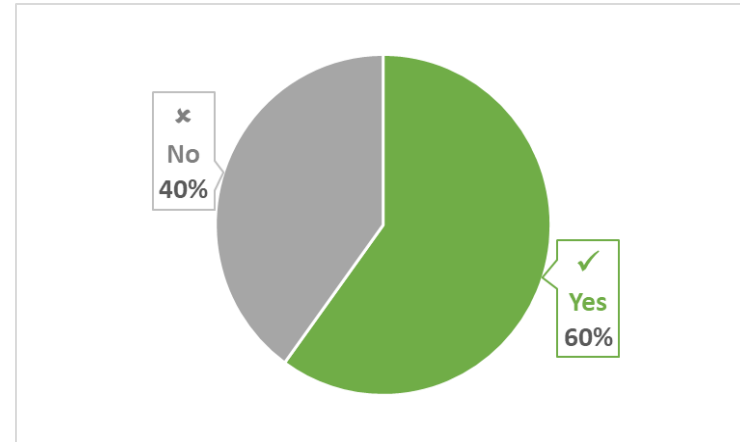
NCI-IDD tells us **6** out of every **10** people said **their child's primary care doctor always understands their child's needs related to his/her disability.**

Can your child always go to the dentist when needed?



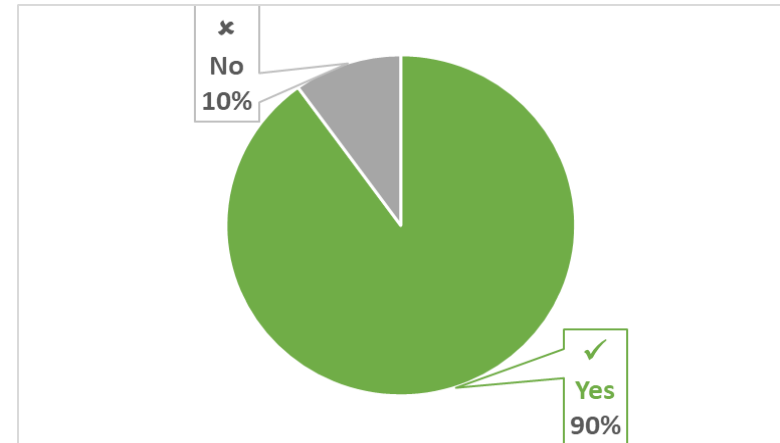
NCI-IDD tells us **7** out of every **10** people said **their child can *always* go to the dentist when needed.**

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



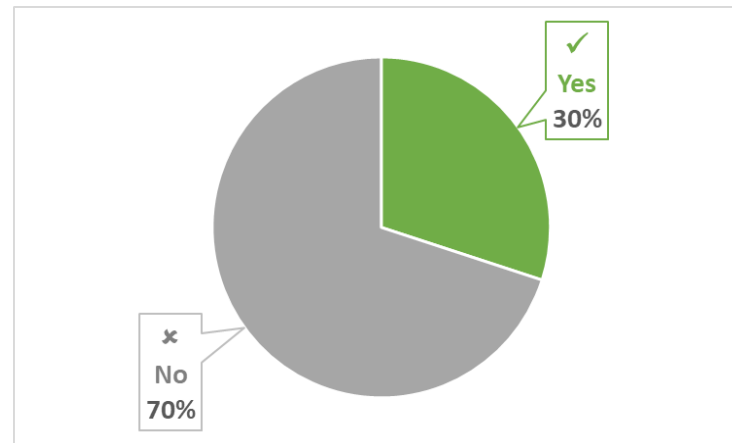
NCI-IDD tells us **6** out of every **10** people said **their child's dentist *always* understands their child's needs related to his/her disability.**

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



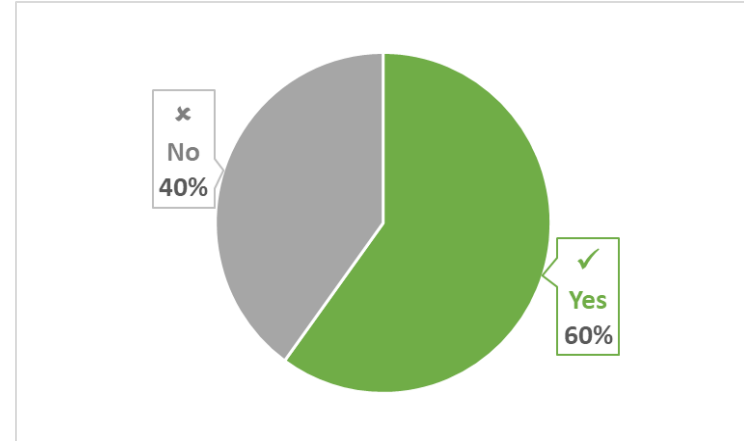
NCI-IDD tells us **9** out of every **10** people whose child takes medication said they *always* know what they're for.

If you need respite services, are you always able to use them?



NCI-IDD tells us **3** out of every **10** people who need respite services said they are *always* able to use them.

If you asked for crisis or emergency services during the past year, were services provided when needed?



NCI-IDD tells us **6** out of every **10** people who asked for crisis or emergency services in the past year, got the services when needed.

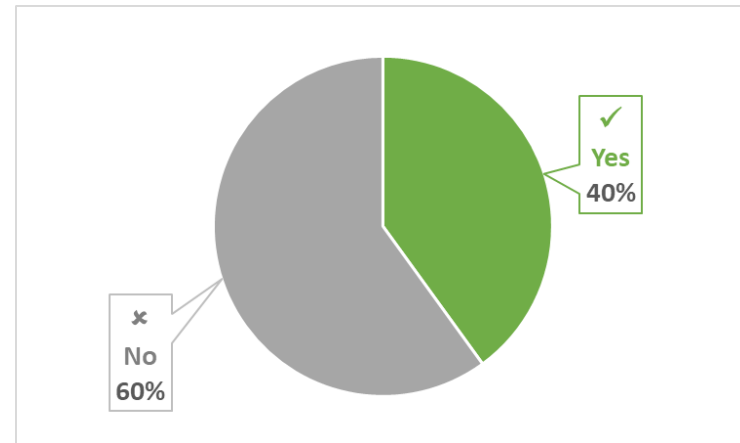
Access to Needed Services

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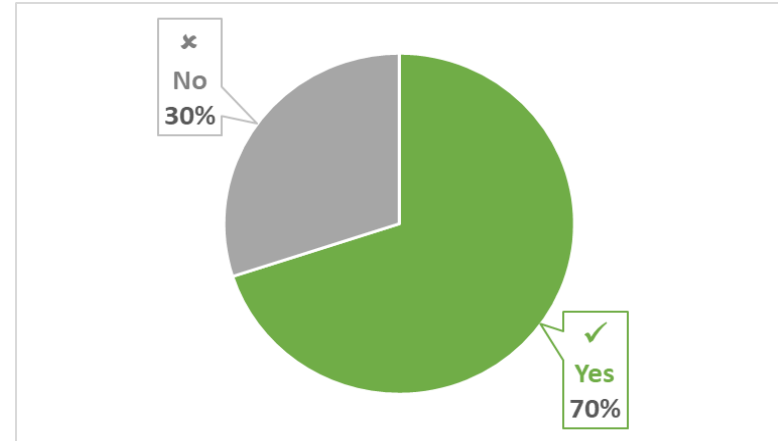
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**child**” we mean **the child who is getting services from the state.**

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



NCI-IDD tells us **4** out of every **10** people said **their child *always* has the special equipment or accommodations needed.**

Does your family get the supports and services it needs?



NCI-IDD tells us **7** out of every **10** people said **their family gets the supports and services it needs.**

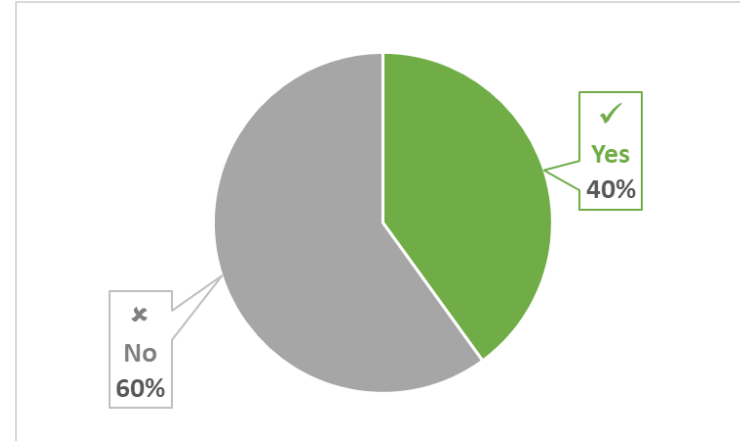
Satisfaction With Services and Supports

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

Reminder:

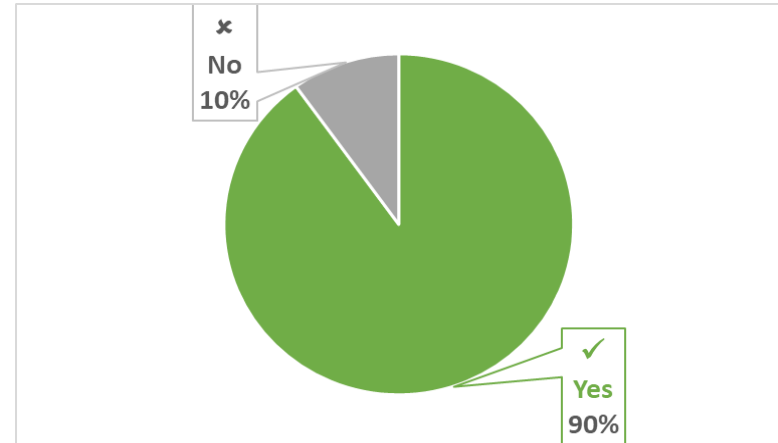
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**child**” we mean the **child who is getting services from the state**.

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



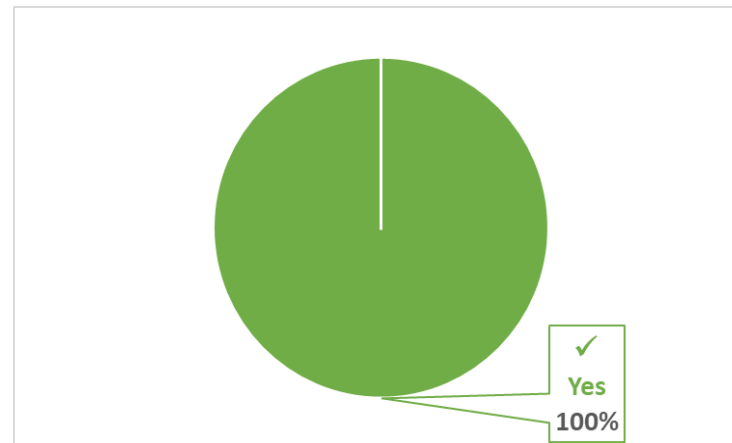
NCI-IDD tells us **4** out of every **10** people said **that overall, they are always happy with their child's services and supports.**

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



NCI-IDD tells us **9** out of every **10** people said **services and supports have made a positive difference in the life of their child.**

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



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



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

- 70%** Child can always see health professionals (like a doctor or psychologist) when needed
- 60%** Child's primary care doctor always understands his/her needs related to his/her disability
- 70%** Child can always go to the dentist when needed
- 60%** Child's dentist always understands his/her needs related to his/her disability
- 90%** Always know what child's medications are for
- 30%** Always able to use respite services if needed last year
- 60%** Crisis or emergency services were services provided when needed, if they were needed last year
- 40%** Child has the special equipment or accommodations needed
- 70%** Family gets the supports and services it needs
- 40%** Overall, happy with child's services and supports
- 90%** Feel that services and supports have made a positive difference in the life of their child
- 100%** Services and supports are helping child to live a good life