

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

Taking Part in the Community across NCI-IDD States



This report tells us about:

- What NCI-IDD tells us about community participation
- 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 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.

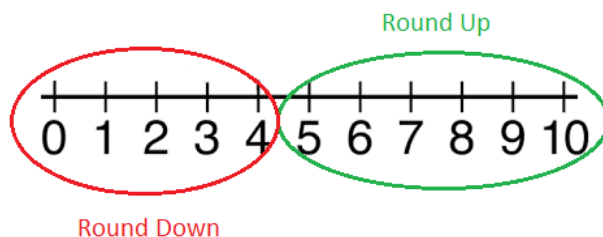
How are data shown in this report?

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 taking part in the community.

- 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 they have friends, we “round up” to 90%.

If 12% of people say they take part in any family-to-family networks, 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:

<http://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 comment on whether their family member has friends and is included in their communities. People with IDD need support to make the kinds of social connections that the rest of us enjoy. Having friends other than paid staff can help people to explore their communities. Joining groups, enjoying social events and being part of faith communities make people feel welcome and can minimize isolation and loneliness. Information from families can be shared with state officials (like a governor or mayor) in order to inform policy making and quality improvement to expand community engagement.

Going Out

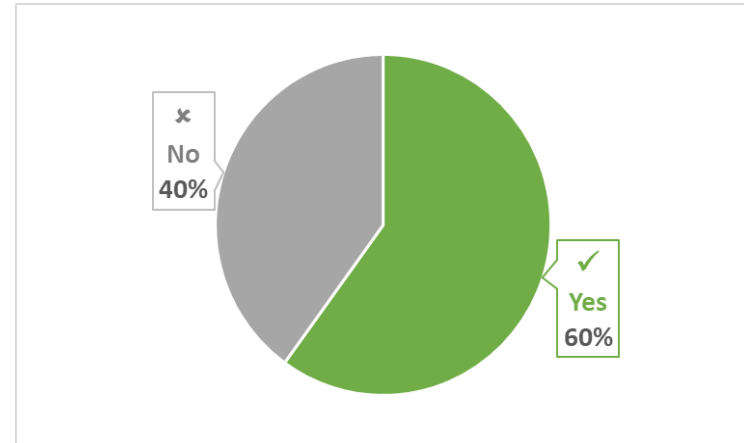
People go out in their community to do many things, like go to the movies, concerts, play sports and see friends. When we ask about community, we mean the places where people go out around their home. Places like parks, restaurants, or places of worship. NCI-IDD asks if people have friends they like to do things with and if they do things in their community.

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 have friends other than paid support workers or family?



NCI-IDD tells us **6** out of every **10** people said **their family member has friends other than paid support workers or family.**

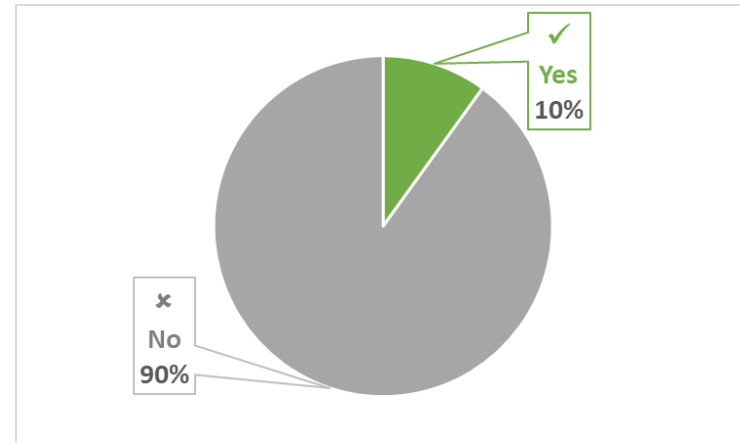
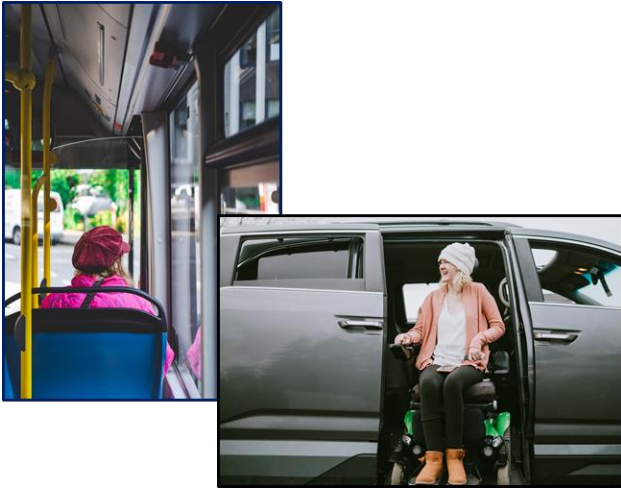
What makes it hard for people to do things in the community?

Some people are not always able to do things they want in the community, things like going to the movies, going to concerts or spending time with friends. NCI-IDD asks people what makes it hard to do things in the community when they want to.

Reminder:

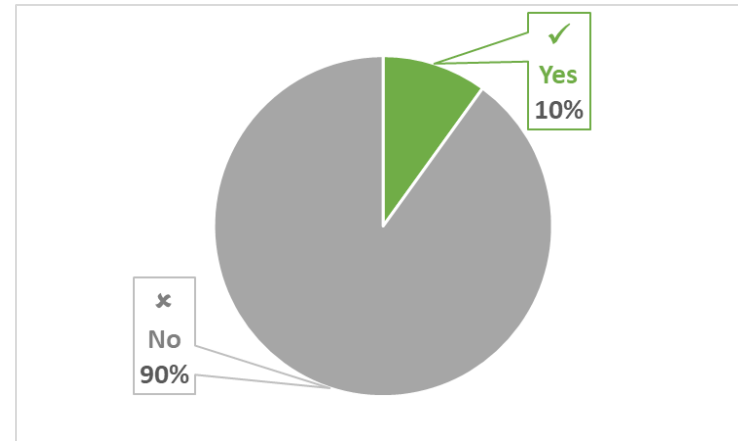
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean **the person who is getting services from the state**.

If it's hard for your family member to do things in the community, is it because of transportation?



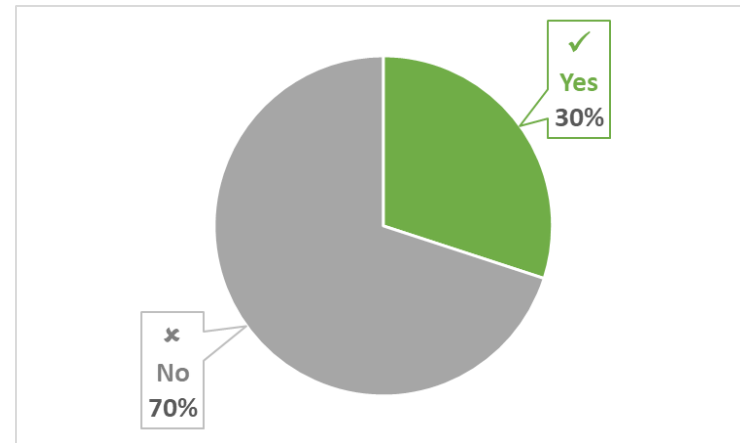
NCI-IDD tells us **1** out of every **10** people said **not having enough transportation makes it hard for their family member to do things in the community.**

If it's hard for your family member to do things in the community, is it because of the cost?



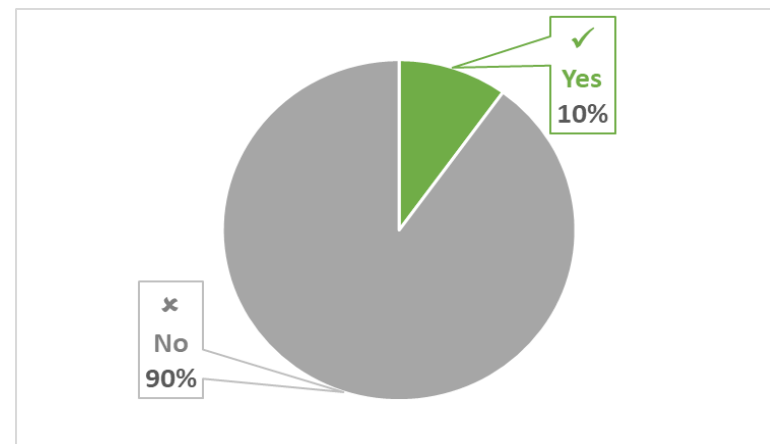
NCI-IDD tells us **1** out of every **10** people said **cost makes it hard for their family member to do things in the community.**

If it's hard for your family member to do things in the community, is it because there are not enough support staff?



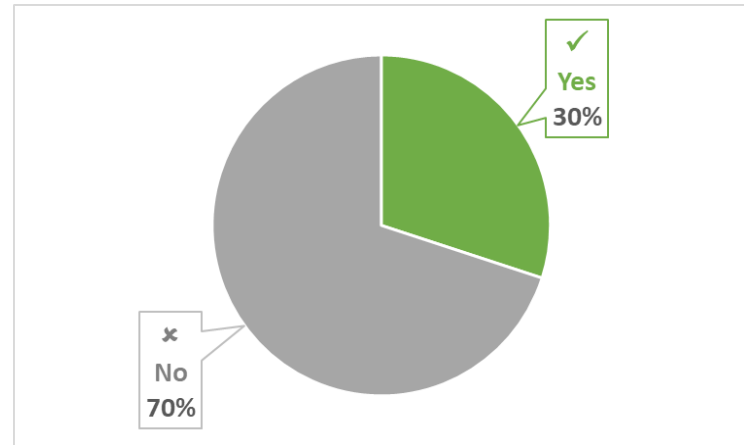
NCI-IDD tells us **3** out of every **10** people said **not having enough support staff makes it hard for their family member to do things in the community.**

If it's hard for your family member to do things in the community, is it because of stigma (other people acting badly or negatively toward your family member)?



NCI-IDD tells us **1** out of every **10** people said **stigma makes it hard for their family member to do things in the community.**

Are there other things that make it hard for your family member do things in the community?



NCI-IDD tells us **3** out of every **10** people said **there are other things that make it hard for their family member to do things in the community.**

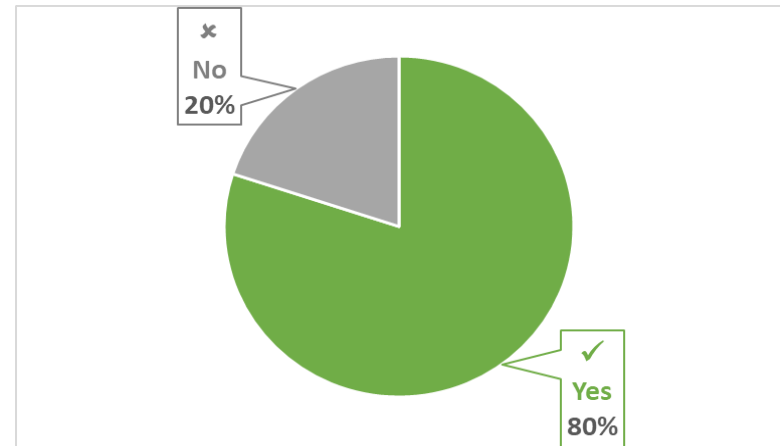
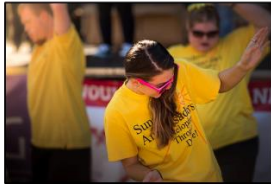
Community Resources

Many people get help from staff in their home, at their day program and at work. Some families can also get help from people in their community. NCI-IDD asks if families get help from people in their community

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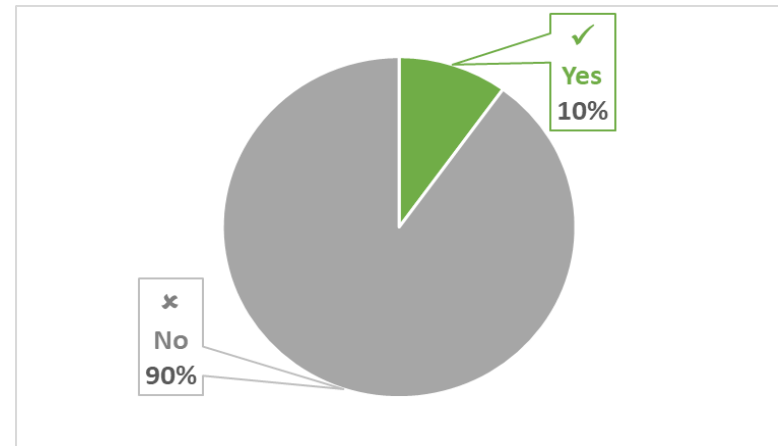
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean **the person who is getting services from the state.**

Are there supports in your community that your family can use that your family does not get from the I/DD agency? Supports are things like public transportation, recreational programs or community groups.



NCI-IDD tells us **8** out of every **10** people said **that there are there supports in their community that their family can use that their family does not get from the I/DD agency.**

Does your family take part in any family-to-family networks? Family-to-family networks are groups like Parent to Parent and sibling groups, where people who have a family member with a disability share information.



NCI-IDD tells us **1** out of every **10** people said **that their family takes part in family-to-family networks.**



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

60% Their family member has friends other than paid support workers or family

10% If it's hard for their family member to do things in the community, is it because of transportation

10% If it's hard for their family members to do things in the community, is it because of the cost

30% If it's hard for their family members to do things in the community, is it because of there are not enough support staff

10% If it's hard for their family members to do things in the community, is it because of stigma (other people acting badly or negatively toward your family member)

30% There are other things that make it hard for their family member do things in the community

80% There are supports in the community that their family can use that they do not get from the I/DD agency

10% Family takes part in any family-to-family networks