

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

Case Management and Staff Support across NCI-IDD States



This report tells us about:

- What NCI-IDD tells us about case management and staff support
- Why this is important
- Where to find out more about service planning across NCI-IDD States

What is NCI-ID?

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.

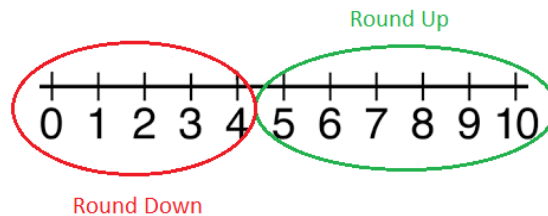
How are data shown in this report?

NCI-IDD 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 case management and support staff.

- 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 services and supports always change when needs change, we “round up” to 90%.

If 12% of people say they get the supports and services their family needs, 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 comment on whether their family member is being supported to live a good life and to make choices about who supports them. It is important to know if families believe their family member is getting needed support from staff and their case managers and whether they can get in contact with staff and the case manager when they need to. Families also respond to questions about whether their family member can change their staff and case manager/service coordinator if they are not satisfied. This information can be shared with state officials (like a governor or mayor) in order to inform policy making and quality improvement.

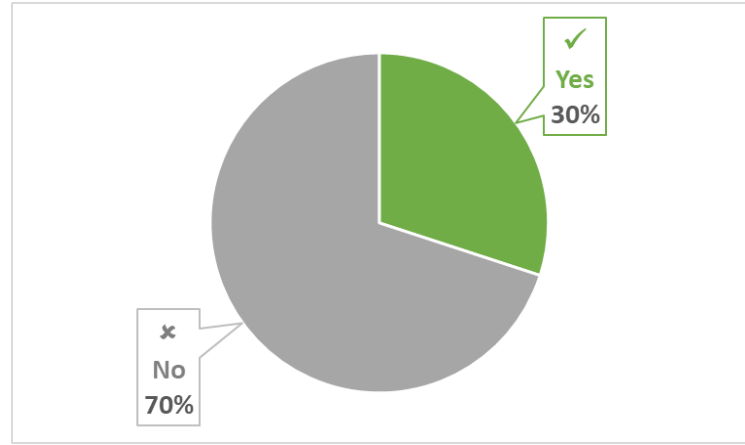
Choice

Sometimes families can make choices about the people who help them. NCI-IDD asks if families can make choices about the people who are paid to help their family member with a disability.

Reminder:

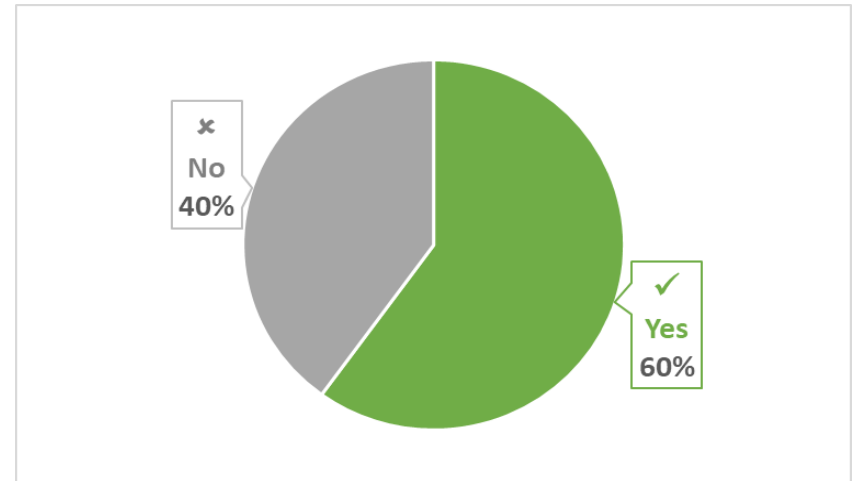
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**family member**” we mean the **person who is getting services from the state**.

Did your family choose, or can you change, your family member's case manager/service coordinator?



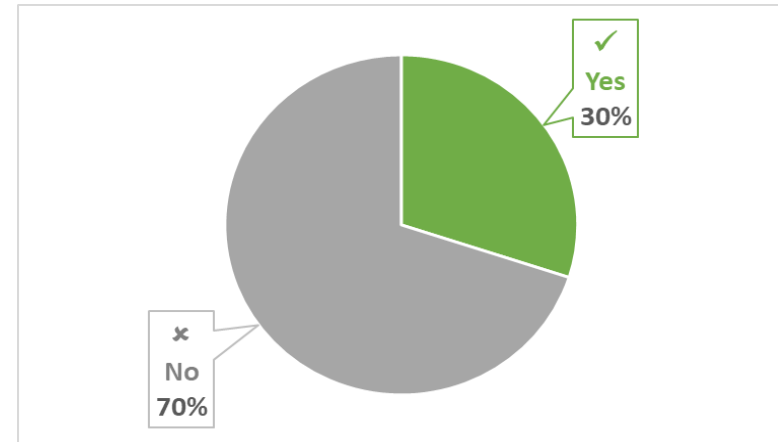
NCI-IDD tells us **3** out of every **10** people said **their family chose or can change their family member's case manager.**

Can your family always choose or change the agency that provides your family member's services?



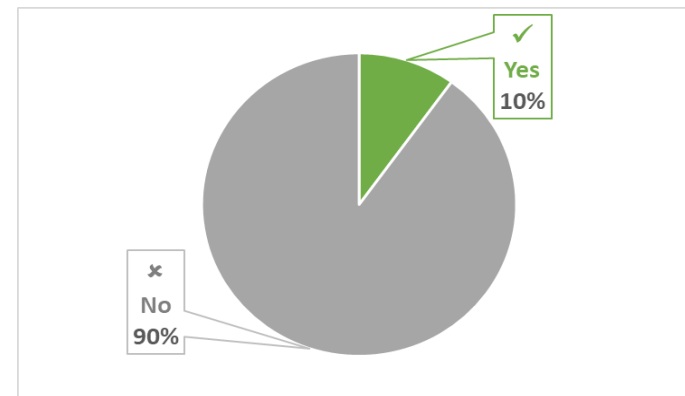
NCI-IDD tells us **6** out of every **10** people said **their family can *always* choose or change the agency that provides their family member's services.**

Can your family always choose or change your family member's support workers?



NCI-IDD tells us **3** out of every **10** people said **their family can *always* choose or change their family member's support workers.**

Does your family directly manage support staff? For example, does someone in your family hire support staff or schedule when they work with your family member.



NCI-IDD tells us **1** out of every **10** people said **their family *always* directly manages support staff.**

Case Managers/Service Coordinators and Support Workers

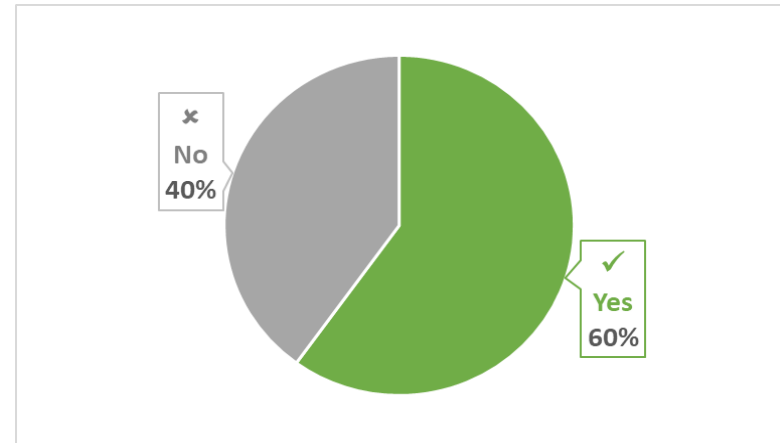
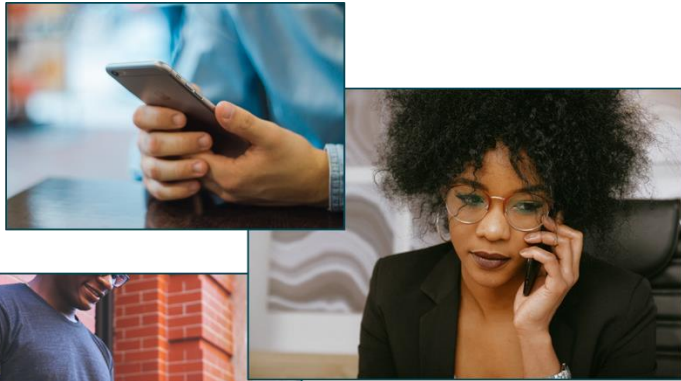
There may be many people who help families and family members who get services from the state. Case Managers/Service Coordinators work closely with families to help families decide, organize and get the services they need. Support workers are paid to help at home, work and day program.

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**.

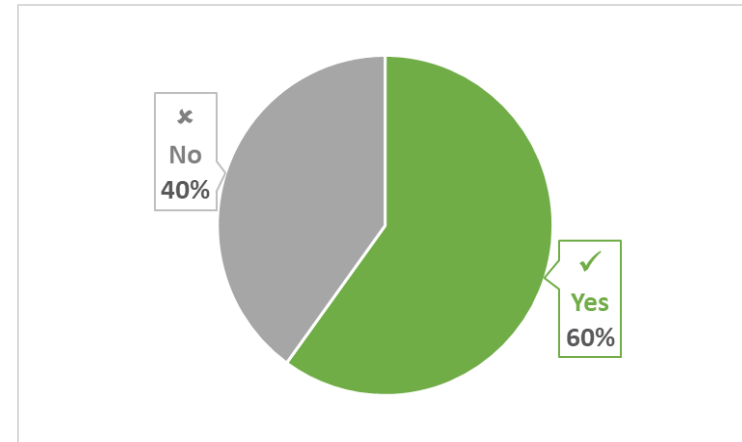


Are you or your family member always able to contact the case manager/service coordinator when you want?



NCI-IDD tells us **6** out of every **10** people said **they are *always* able to contact the case manager/service coordinator when they want.**

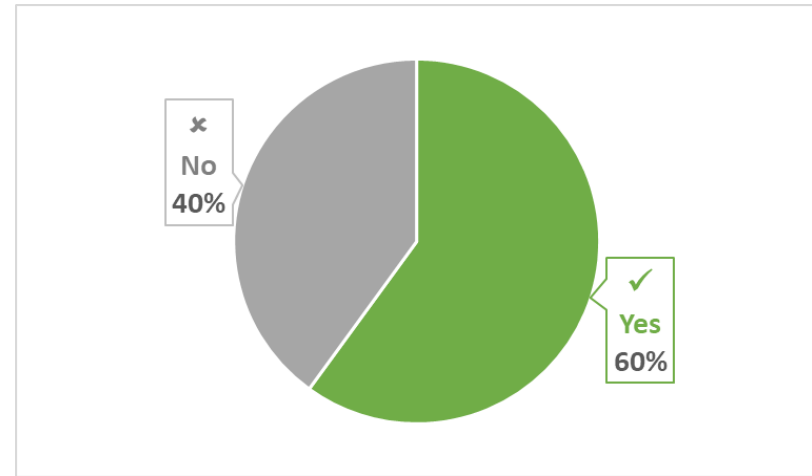
Does the case manager/service coordinator always respect your family's choices and opinions?



NCI-IDD tells us **6** out of every **10** people said **the case manager/service coordinator *always* respects their family's choices and opinions.**

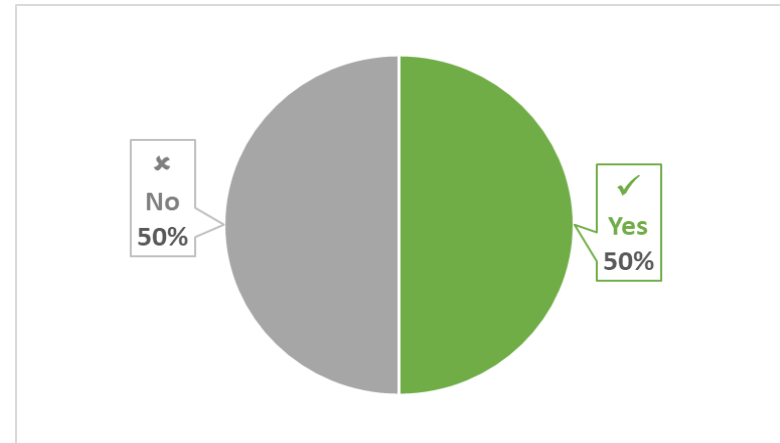


Are you or your family member always able to contact his/her support workers when you want?



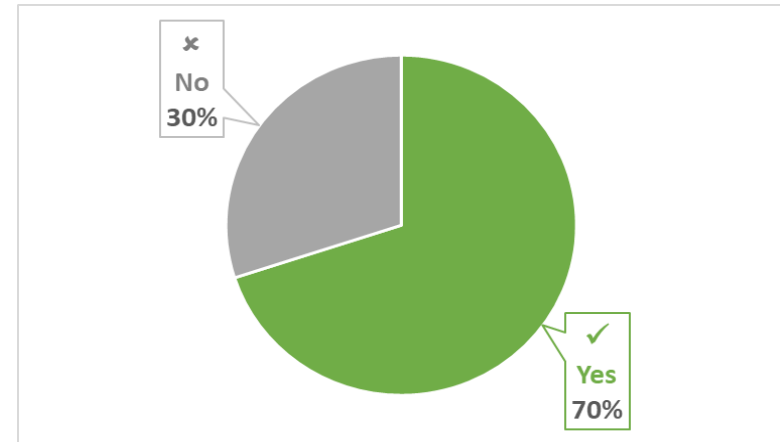
NCI-IDD tells us **6** out of every **10** people said **they are *always* able to contact support workers when they want.**

Do support workers always come and go when they are supposed to?



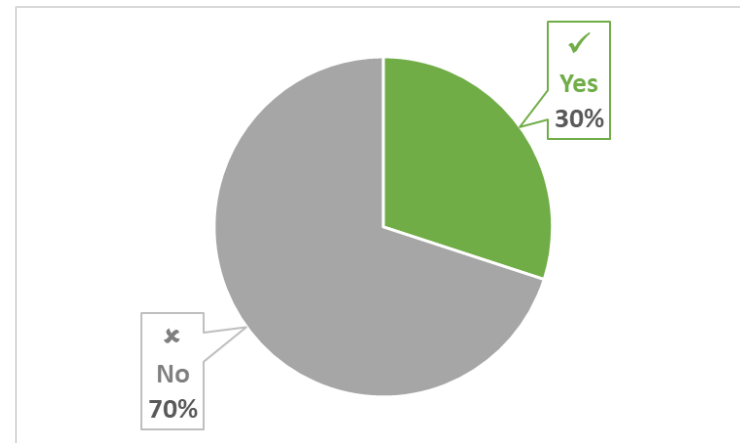
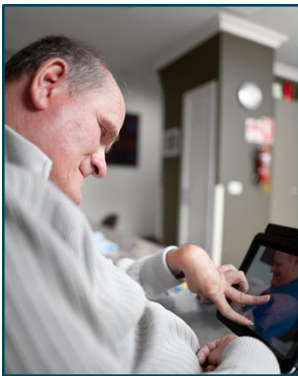
NCI-IDD tells us **5** out of every **10** people said **support workers *always* come and go when they are supposed to.**

Do support workers always speak to you in a way you understand?



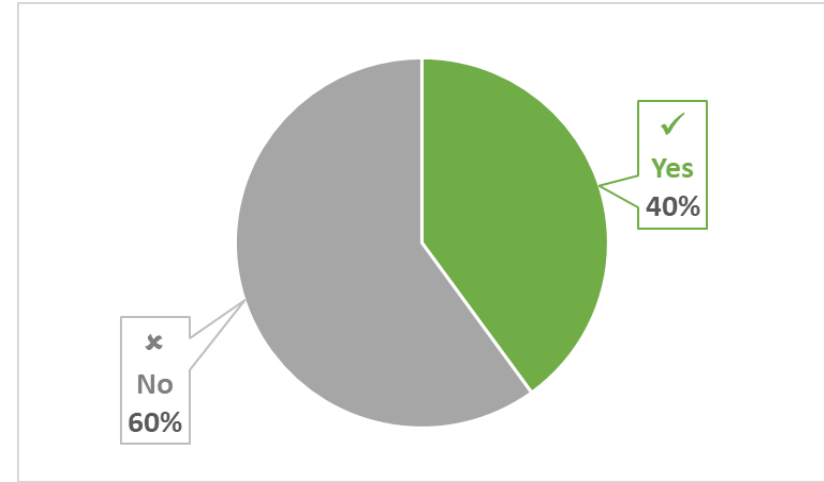
NCI-IDD tells us **7** out of every **10** people said **support workers *always* speak to them in a way they understand.**

If your family member does not communicate verbally, are there always support workers who can communicate with him/her?



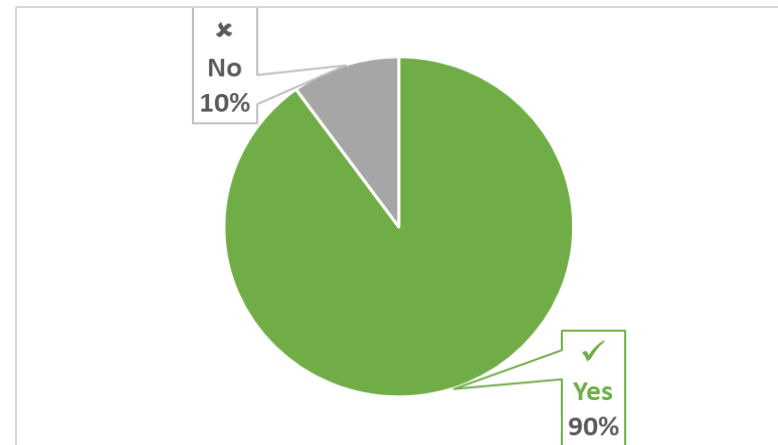
NCI-IDD tells us **3** out of every **10** people whose family member does not communicate verbally said there are *always* support workers who can communicate with him/her.

Do support workers always have the right information and skills to meet your family's needs?



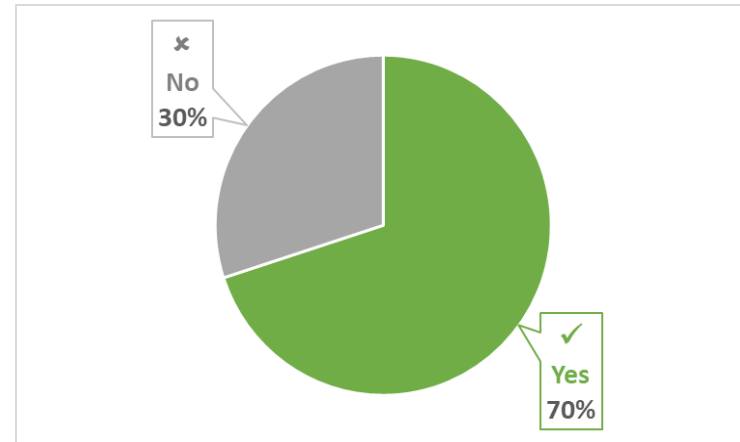
NCI-IDD tells us **4** out of every **10** people said **support workers *always* have the right information and skills to meet their family's needs.**

Do service providers for your family member work together to provide support? For example, does the agency providing transportation work together with the day program?



NCI-IDD tells us **9** out of every **10** people said **providers work together to provide support.**

Are services always delivered in a way that is respectful of your family's culture?



NCI-IDD tells us **7** out of every **10** people said **services are *always* delivered in a way that is respectful of their family's culture.**





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

30% They or their family member choose their family member's case manager/service coordinator

60% Family always choose or change the agency that provides their family member's services

30% Family always choose or change their family member's support workers

10% Families directly manage support staff

60% They or their family member are always able to contact the case manager/service coordinator when they want

60% The case manager/service coordinator always respect their family's choices and opinions

60% They or their family member are always able to contact support workers when they want

50% Support workers always show up to work on time and leave when they should

70% Support workers always speak in a way they understand

30% There are always support workers who can communicate with their family member if he/she does not communicate verbally

40% Support workers always have the right information and skills to meet their family's needs

90% Service providers work together to provide support

70% Services always delivered in a way that is respectful of their family's culture