

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

Case Management and Staff Support

across NCI-IDD States



**NATIONAL CORE
INDICATORS[®]**
NASDDDS & HSRI

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 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.

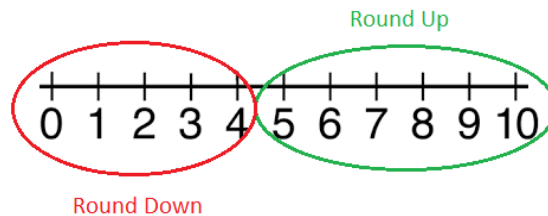
How are data shown in this report?

NCI-IDD 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 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?

Most of the children with IDD who get services and supports live with their families. The Child Family Survey provides a way for these families to comment on whether their family and their child with IDD are being supported to live a good life and to make choices about who supports them. It is important to know if family caregivers believe they are getting needed support from staff and their case managers and whether they can get in contact with staff and the case manager if they have problems. Families should also be able choose the staff who work with their child and they should be able to change their staff and case manager if they are not satisfied. Feedback from families on these issues can be shared with state officials (like a governor or mayor) in order to inform policy making and to increase staff and case manager responsiveness.

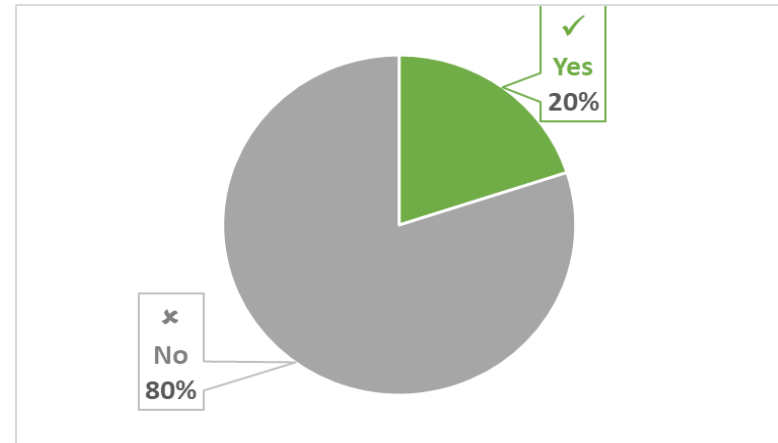
Choice

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 child with a disability.

Reminder:

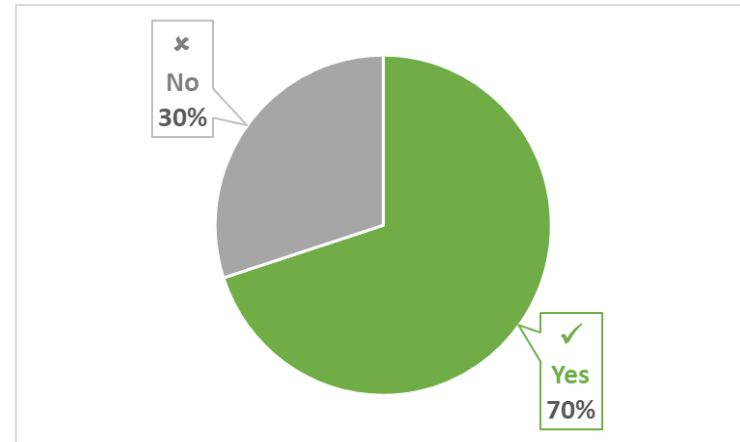
- When we say “**you**” we mean **the person who is answering the question** (most of the time, a parent).
- When we say “**child**” we mean the **child who is getting services from the state.**

Did your family choose your child's case manager/service coordinator?



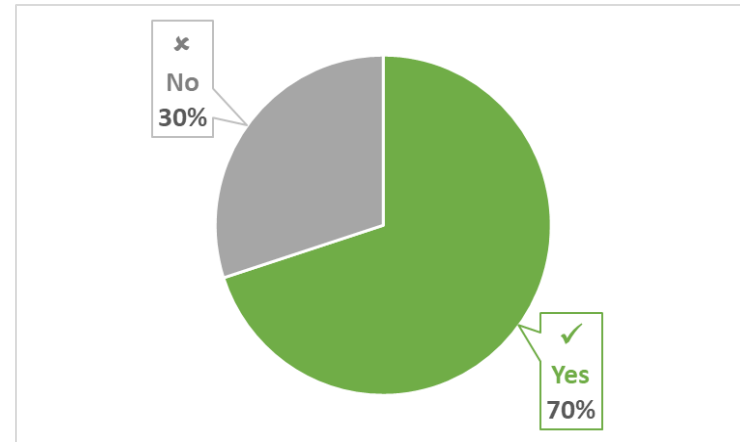
NCI-IDD tells us **2** out of every **10** people said **their family chose their child's case manager/service coordinator.**

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



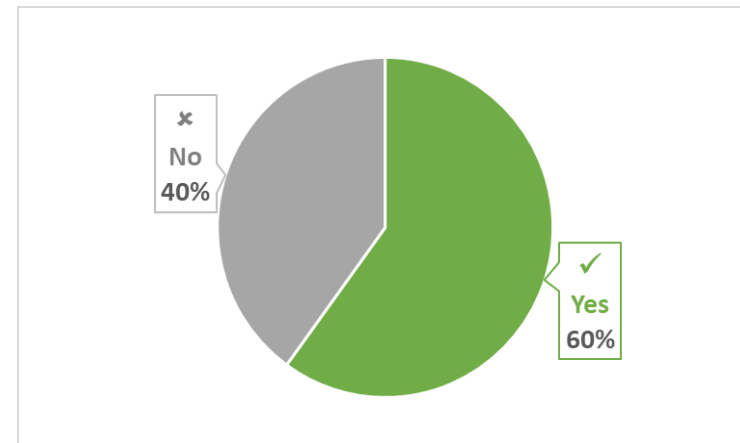
NCI-IDD tells us **7** out of every **10** people said **their family can *always* choose or change the agency that provides their child's services.**

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



NCI-IDD tells us **7** out of every **10** people said **their family can *always* choose or change their child'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 **6** out of every **10** people said **their family directly manages support staff.**

Case Managers/Service Coordinators and Support Workers

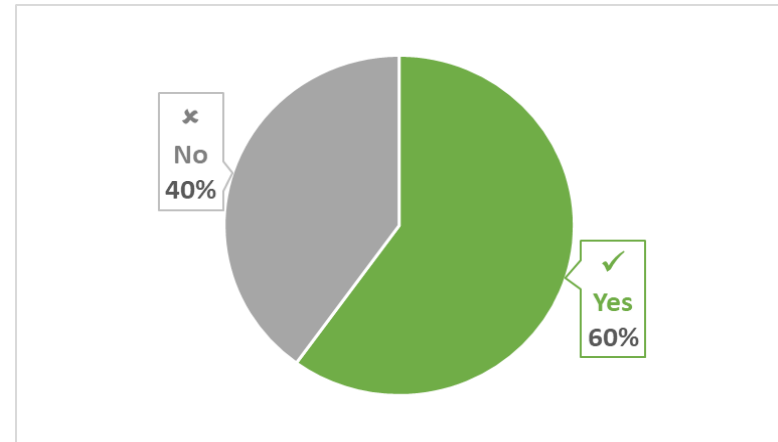
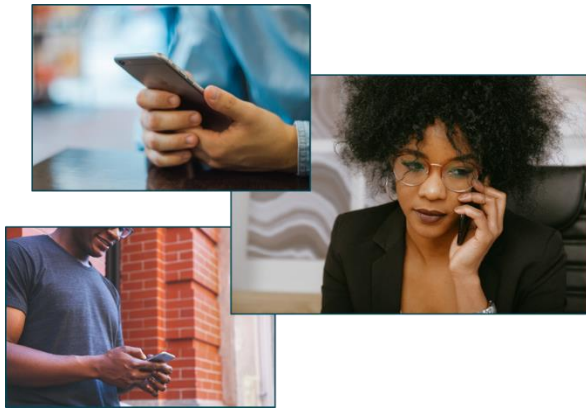
There may be many people who help families and children who get services from the state. Case Managers/Service Coordinators work closely with families to help families decide, organize and get the services they need. Support workers are paid to help at home, work and day program.

Reminder:

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

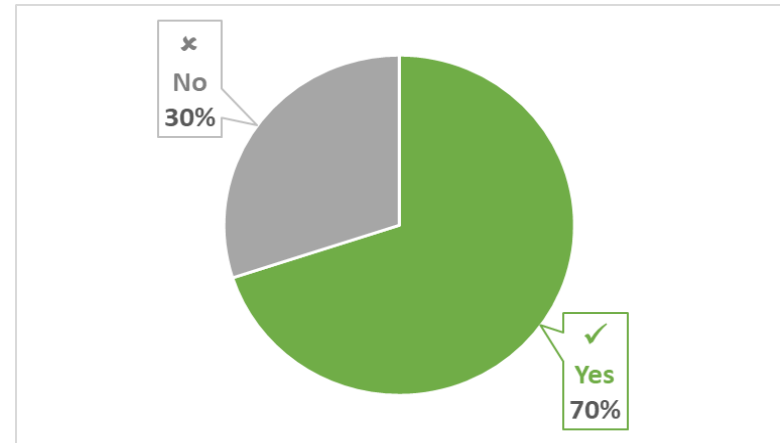
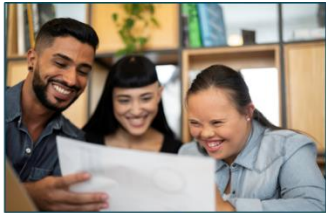


Are you or your child always able to contact the case manager/service coordinator when you want?



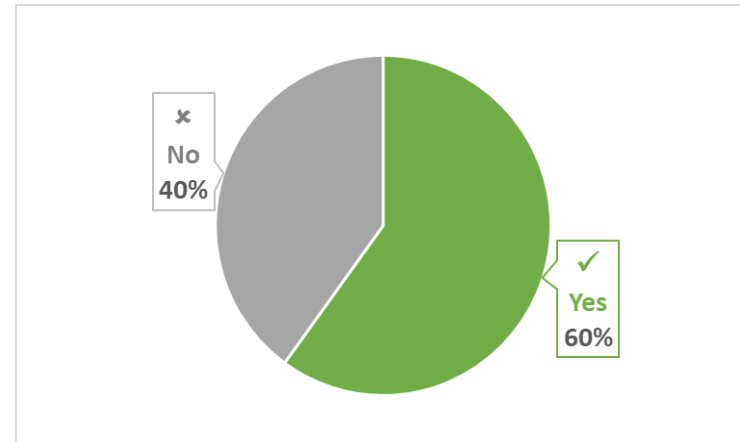
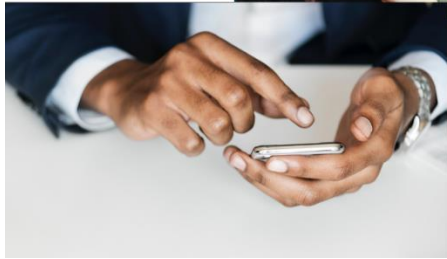
NCI-IDD tells us **6** out of every **10** people said **they or their child are *always* able to contact the case manager/service coordinator when they want.**

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



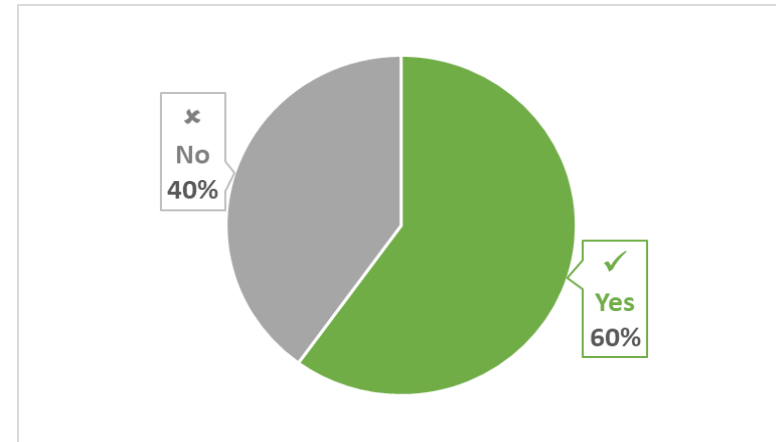
NCI-IDD tells us **7** out of every **10** people said **the case manager/service coordinator *always* respects their family's choices and opinions.**

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



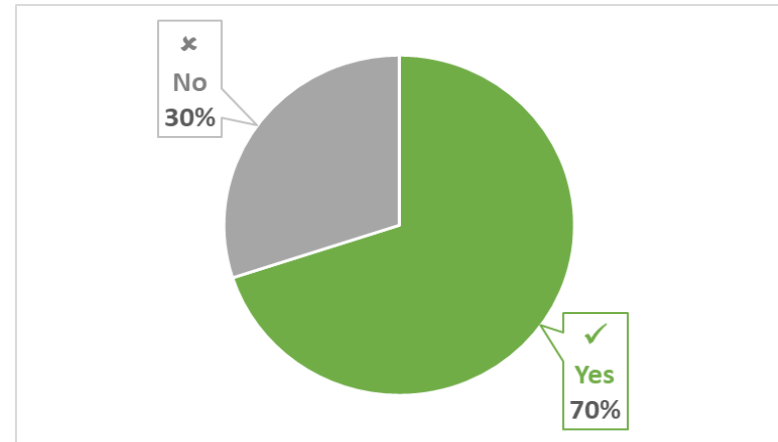
NCI-IDD tells us **6** out of every **10** people said **they are *always* able to contact support workers when they want.**

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



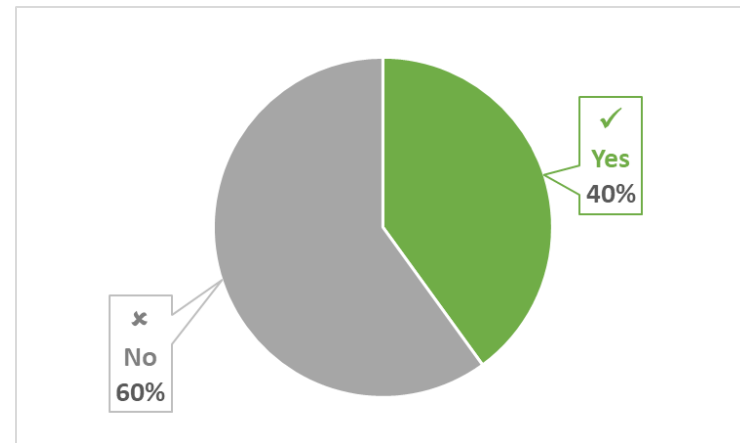
NCI-IDD tells us **6** out of every **10** people said **support workers always come and go when they are supposed to.**

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



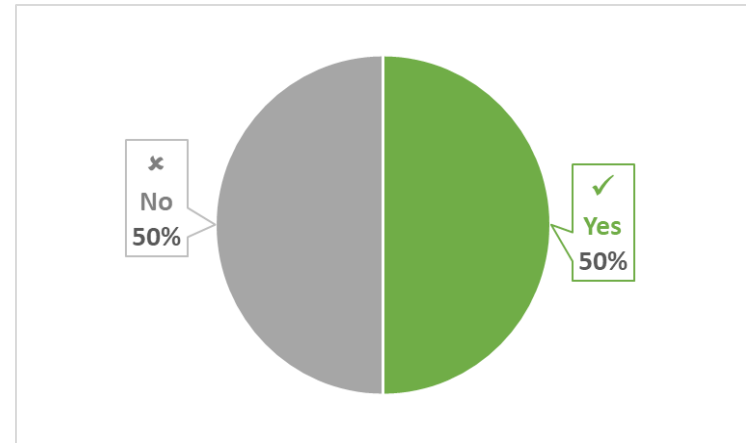
NCI-IDD tells us **7** out of every **10** people said **support workers *always* speak to them in a way they understand.**

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



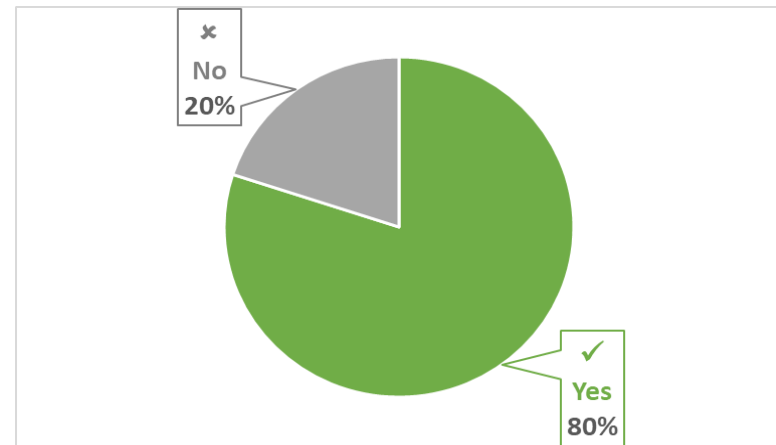
NCI-IDD tells us **4** out of every **10** people whose child does not communicate verbally said there are *always* support workers who can communicate with him/her.

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



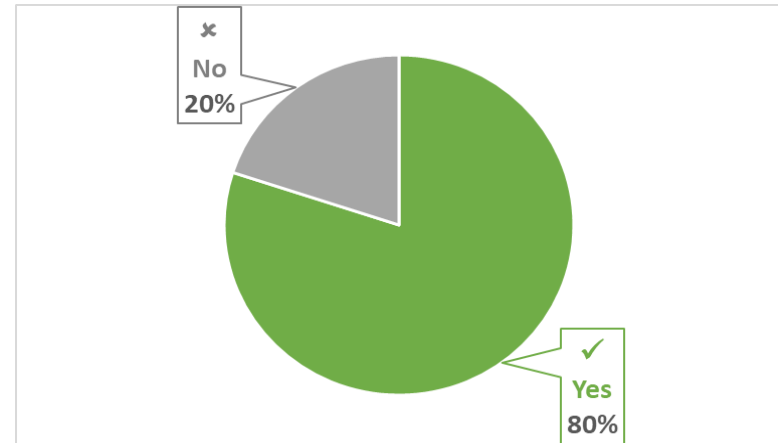
NCI-IDD tells us **5** out of every **10** people said **support workers *always* have the right information and skills to meet their family's needs.**

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



NCI-IDD tells us **8** 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 **8** 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 Children With Disabilities across NCI-IDD States Say?

20% They or their child choose their child's case manager/service coordinator

70% Their family always chooses or can change the agency that provides their child's services

70% Their family always chooses or can change their child's support workers

60% Their family directly manage support staff

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

70% The case manager/service coordinator always respect their family's choices and opinions

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

60% Support workers always show up to work on time and leave when they should

70% Support workers always speak in a way they understand

40% There always support workers who can communicate with their child if he/she does not communicate verbally

50% Support workers always have the right information and skills to meet their family's needs

80% Service providers work together to provide support

80% Services always delivered in a way that is respectful of their family's culture