What the NCI®-IDD data tells us about Rights and Privacy

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This report tells us about:

- What NCI-IDD tells us about rights, privacy and safety
- Why rights, privacy, and safety are important
- Where to find out more about rights, privacy and safety

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 is surveyed?

Each year people in many states take part in an NCI-IDD meeting. Every year a new group of people are asked to meet.

During the meeting, people are asked the NCI-IDD survey questions. Questions are asked to the person who gets services from the state. For some questions, a family member, friend, or staff member who knows the person well can answer.
How are data shown?

NCI-IDD asks questions about people’s rights, like if they have a key to their home or if they can lock their bedroom door. In this report we see how people answered questions about rights. There are also questions that ask about self-advocacy, voting, and feeling safe. Like “Are there any places you feel afraid or scared?”

Each page shows a different question and the answers. Each page also has a pie graph. It shows how many people said yes and how many said no to the question. There are also words and stick figures that show how many yes and no answers there were for each question. The answers are whole numbers (like 60% or 90%).
For this report 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 a key to their home, we “round up” to 90%.

If 12% of people say they did can lock their bedroom door, 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 Are Rights Important?

We all have rights. Like the right to vote, to speak out, and to be free from harm. People with disabilities also have rights under the Americans with Disabilities Act and the Developmental Disabilities Act. These rights include the right to be treated like everyone else and to be included in community life. For people receiving services, the federal government says people with disabilities have the right to privacy in their homes and the opportunity to work and to self-direct their services.
Rights and Privacy at Home

NCI-IDD asks questions about the rights people have in their home and if staff respect them.
Do you have a key to your home?

NCI-IDD tells us 5 out of every 10 people said they have a key to their home.
If you don’t have a key to your home, do you want a key to your home?

2 out of 10 people who do not have a key to their home said they want one.

NCI-IDD tells us 2 out of every 10 people who do not have a key to their home said they want one.
Do people who do not live with you ask before coming into your home?

NCI-IDD tells us 9 out of every 10 people said people who do not live with them ask before coming into their home.
Can you lock your bedroom door if you want to?

6 out of 10 people said they can lock their bedroom door if they want to.

NCI-IDD tells us 6 out of every 10 people said they can lock their bedroom door if they want to.
Do people let you know before coming into your bedroom?

NCI-IDD tells us 9 out of every 10 people said **people let them know before coming into their bedroom.**
Do you have a place to be alone in your home?

10 out of 10

NCI-IDD tells us 10 out of every 10 people said they have a place to be alone in their home.
Can you be alone with friends or visitors in your home?

9 out of 10

NCI-IDD tells us 9 out of every 10 people said they can be alone with friends or visitors in their home.
Are there rules about having friends or visitors in your home?

NCI-IDD tells us 4 out of every 10 people said there are rules about having friends or visitors in their home.
When people in your house go somewhere, do you have to go too, or can you stay at home if you want to?

NCI-IDD tells us 4 out of every 10 people said "when people in their house go somewhere they can stay at home if they want to."
Do people read your mail or email without asking first?

1 out of 10

NCI-IDD tells us 1 out of every 10 people said people read their mail or email without asking first.
Safety

NCI-IDD asks about feeling safe. Respondents are asked if there are places they feel afraid or scared and if they ever feel afraid, if there is someone they can talk to.
Are there any places where you feel afraid or scared?

NCI-IDD tells us 2 out of every 10 people said there are places where they feel afraid or scared.
If you ever feel afraid, is there someone you can talk to?

NCI-IDD tells us 10 out of every 10 people said they have someone to talk to if they ever feel afraid.
Advocacy

NCI-IDD asks about attending self-advocacy group meetings. A self-advocacy group is where people with disabilities meet together where they talk about things in their lives that are important to them and other people with disabilities. NCI-IDD also asks if a person has ever voted in an election.
Have you ever taken part in a self-advocacy group, meeting, conference, or event—or have you had the chance to participate and chose not to?

NCI-IDD tells us 3 out of every 10 people said they have taken in a self-advocacy group, meeting, conference, or event or had the chance and chose not to.
Have you ever voted in a local, state, or federal election or had the chance but chose not to?

NCI-IDD tells us 4 out of every 10 people said they have ever voted in a local, state, or federal election, or had the chance and chose not to.
What Did We Learn?

NCI-IDD tell us about people:

- 50% Have a key to their home
- 20% Who do not have a key to their home want one
- 90% Said people who do not live with them ask before coming into their home
- 60% Can lock their bedroom door if they want to
- 90% Said people let them know before entering their bedroom
- 100% Have a place to be alone in their home
- 90% Can be alone with friends or visitors in their home
- 40% Said there are rules about having friends or visitors in their home
- 40% Said when people in their house go somewhere they can stay at home if they want to
- 10% Said people read their mail or email without asking first
- 20% Said that there are places they feel afraid or scared
- 100% Have someone to talk to if they ever feel afraid
- 30% Have taken part in a self-advocacy group, meeting, conference, or event or had the chance and chose not to
- 40% Have ever voted in a local, state, or federal election, or had the chance and chose not to
Learn More About Rights, Privacy, and Safety

Have questions or comments, email us at: dhiersteiner@hsri.org