What We Learned from the National Core Indicators (NCI) Family/Guardian Survey

NCI Results from Families Across Alta California Regional Center
User-Friendly Version, 2016-17
A Collaborative Effort of:

NASDDDS
National Association of State Directors of Developmental Disabilities Services

Cover art by Donald Roberts (1962 - 2009)

Donald was a former member of the statewide Consumer Advisory Committee in California, Valley Mountain Regional Center Board of Directors, Olmstead Advisory Committee, California Memorial Project, and Self-Advocacy Council 6. Donald was dedicated to the empowerment of people with disabilities and expressed his experiences and dreams through his artwork.
Who helped with this report?

We’d like to thank the 2010 members of the California Developmental Disabilities Consumer Advisory Committee. Their ideas helped make this report easy to understand! We’d also like to thank everyone who let us take and use their pictures. They helped make this report interesting.

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What is the National Core Indicators (NCI) Family/Guardian Survey?

Each year, we try to find out how people with intellectual and developmental disabilities and their families feel about the services they get. We use surveys to ask people all around the country, and each year we ask different people. States can use the answers to find out if people like their services. They can also compare across years to see if this is changing over time.

The NCI Family/Guardian Surveys are mailed to families in many states. States use the surveys to find out if families are happy with the services their family member receive. California mails surveys to families across regional centers. Each regional center can use surveys to see how they are doing.

Who answers the questions on a Family/Guardian Survey?

The questions on the Family/Guardian survey are answered by a family member or guardian of an adult who gets services from the state (like a parent or other family member). The person who answered the survey does not live with the person getting services from the state. The person who answered the questions is not the person who gets the services.

How do we show their answers?

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. In fact, some ask people to pick: “always,” “usually,” “sometimes,”
“seldom,” or “never.” For this report, we count all “always” or “usually” answers as yes. All others we count as no. (If you want to see the full range of answers separately, you can find those here: http://www.dds.ca.gov/QA/rcReports.cfm.)

We also use graphs to show the answers in percentages. Percentages go from 0% to 100%. Higher percentages mean that more people answered a certain way. For example, 90% means 9 out of 10 people answered the same way. Lower percentages mean that fewer people answered in a certain way. For example, 20% means 2 out of every 10 people answered the same way.

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 feel safe at home, we “round up” 90%.

If 12% of people say they have a paid job, we “round down” to 10%.
Before you start reading...

Remember, these questions were answered by someone who does not live with the person receiving services but knows the person well. Usually the person’s parent or guardian answers the question.

In this report, “family member,” means the person with a disability receiving services from the state. “You” is the person who answered the question. The person who answers questions is not the person with a disability.

There are also a few words in this report that can mean different things:

- Service Coordinator can mean Case Manager or Support Coordinator
- IPP means Individual Service Plan
- Conservator can mean Guardian, this is someone who makes some choices for the person
- Support Workers can mean staff
NCI asked families and guardians about the information they get to help plan services.
Do you get enough information to help plan services for your family member?

NCI tells us 8 out of every 10 people said they always or usually get enough information to help plan services for their family member.
Is the information you get about services and supports easy to understand?

NCI tells us 9 out of every 10 people said the information they get about services and supports is always or usually easy to understand.
Do staff who help your family member at home tell you about how your family member is doing?

<table>
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<th>30%</th>
<th>People who help family member at home do not tell family or conservator how family member is doing</th>
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<tr>
<td>70%</td>
<td>Staff who help family member at home do tell family or conservator about how family member is doing</td>
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NCI tells us 7 out of every 10 staff said people who help family member at home tell them about how their family member is doing.
Does the service coordinator respect your family’s choices and opinions?

NCI tells us 8 out of every 10 people said the service coordinator always or usually respects the family's choices and opinions.
People receiving services have an Individual Program Plan (IPP). The IPP should include things the person wants and needs. NCI asked families and guardians about their family member’s IPP.
Does the IPP have all of the things your family member needs?

NCI tells us 9 out of every 10 people said the IPP has all the things their family member needs.
Did your family member help make the IPP?

NCI tells us 7 out of every 10 people said their family member helped make the IPP.
Did you or someone in the family, other than the person receiving services, help make the IPP?

NCI tells us 8 out of every 10 people said someone in the family, other than the person receiving services, helped make the IPP.
Sometimes people want to talk with their service coordinators. NCI asked if families and guardians could contact service coordinators when they wanted to.
Can you or your family member contact support workers when you want to?

NCI tells us 9 out of every 10 people said they or their family member can always or usually contact support workers when they want to.
Can you or your family member contact your family member’s service coordinator when you want to?

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NCI asked if families and guardians can choose the support workers and service coordinators who work with their family member.
Can your family choose or change your family member’s provider agencies?

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<td>NCI tells us 8 out of every 10 people said they can always or usually choose or change their family member's provider agencies.</td>
<td>20% Family or conservator cannot choose or change their family member's provider agencies</td>
<td>80% Family or conservator can choose or change their family member's provider agencies</td>
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Can your family choose or change your family member’s support workers?

NCI tells us 6 out of every 10 people said they can always or usually choose or change their family member's support workers.
Does the agency providing home services include your family member in important decisions?

NCI tells us 8 out of every 10 people said the agency providing home services includes their family member in important decisions.
NCI asked whether family members took part in community activities (like go out to eat or do something for fun).
Does your family member take part in community activities?

NCI tells us 9 out of every 10 people said their family member takes part in community activities.
Does your family member have friends other than staff or family?

NCI tells us 7 out of every 10 people said their family member has friends other than staff or family.
Does your family member have enough support to work or volunteer in the community?

NCI tells us 7 out of every 10 people said their family member has enough support to work or volunteer in the community.
NCI asked how families and guardians feel about the services and supports their family member gets.
Are you happy with the services and supports your family member gets?

NCI tells us 8 out of every 10 people said they are always or usually happy with the services and supports their family member gets.
Have services and supports made a positive difference for your family member?

NCI tells us 9 out of every 10 people said services and supports have made a positive difference for their family member.
What We Have Learned from the National Core Indicators Family/Guardian Survey

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http://www.nationalcoreindicators.org/

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