

National Core Indicators[®]-- Intellectual and Developmental Disabilities 2020-21 In-Person Survey (IPS) Report

Self-Direction

People participate in directing their own supports and services.

What to know about the presentation of Self-Direction data:



Collapsed data

Here's what ["collapsed"](#) data are

This chapter **does not** include charts due to low response rates and multiple state who do not have people using a self-directed option in their sample



State and weighted NCI averages

The number of respondents (N) is not weighted

Here's what [weighting](#) data means for comparisons



DATA CAUTION!

Many states' have very low rates of individuals who were surveyed and were reported to use a self-directed supports option

Read about what this means [here](#)

Self-Determination

Table 1. Using a self-directed supports option ('yes' responses only; information may have been obtained through state records)	5
Table 2. People who make decisions or have input in making decisions for how budget for services is used (among those using a self-directed supports option; proxy respondents were allowed for this question).....	6
Table 3. Hires or manages staff (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question).....	7
Table 4. Can make changes to individual budget/services if needed (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question).....	8
Table 5. Has enough help deciding how to use their individual budget/services (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question).....	9
Table 6. Gets information about how much money is left in budget/services (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question).....	10
Table 7. Information about budget/services is easy to understand (among those using a self-directed supports option and who receive information about how much money is left in budget/services; 'yes' responses only; proxy respondents were allowed for this question).....	11
Table 8. Frequency with which the person gets information about budget/services (among those using a self-directed supports option; proxy respondents were allowed for this question).....	12

Where do these data come from?

Some of the information in this section comes directly from the person receiving services, or for some select questions, from a “proxy” respondent. Others are drawn from administrative sources; these instances are noted in the table titles.

Read more about why we allow proxy respondents for select questions in the IPS in the Overview chapter of this report.

Items in this chapter are a part of the NCI Individual Outcomes domain (or topic area) and comprise the “Self-Direction” sub-domain (a specific area of concern within the domain). The Self-Direction sub-domain includes items that help determine whether “people participate in directing their own supports and services”.

Read more about NCI domains and subdomains in the Overview chapter of this report.

What are “collapsed” data?

Many questions in the IPS allow respondents to answer a question with “middle” response like “maybe”, “sometimes” or “in-between”. The tables in this section present collapsed data. That means that two or more response options are grouped together if they are considered to reflect a positive outcome. The table titles explain which options were grouped.

To see the breakout of responses for each option, please see Appendix C.

What is weighting and why do we do it?

The NCI-IDD averages are “weighted” to reflect the states’ relative population and sample sizes. We created the weights using the state’s number of valid surveys and its total survey-eligible population. This way, a state that provides services to a larger number of people but uses a sample similar in size to other states has a greater influence on the overall NCI-IDD average (that is, its contribution is *proportional to its service population*).

In this survey year, CA intentionally oversampled by geographical regions to get more focused insights, so

their weights are calculated slightly differently (using the number of completed surveys and service population sizes in each subpopulation or region). You can read more about this in the Methodology section of the Overview chapter.

The number of respondents (N) for each question *is not* weighted.

DATA CAUTION!

Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

Presentation of state and weighted NCI averages

Averages

This chapter **does not** include charts due to low response rates and multiple state who do not have people using a self-directed option in their sample. State outcomes are shown in alphabetical order and are not tested for significance.

Tables that show significance also break out average results for each state by the type of residence: ICF/IID or other institutional settings, group residence, own home, parent/relative’s home, foster or host home. Figure A on the following page shows, by state, the percentage of people surveyed in each residence type. Please note though that:

- Significance testing was not performed on the breakouts by residence
- The number of people in each residential setting is often too small to allow for valid state-to-state comparisons
- And in many cases, statistically valid conclusions cannot be drawn about differences in results between residence types

Still, we provide this information for states’ internal purposes. It should not be used to compare one state with another.

Figure A. Percentage of people surveyed in each residence type by state

State	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home	N
AL	0%	76%	6%	18%	0%	391
AR	1%	14%	39%	45%	2%	397
CA ¹	10%	25%	13%	51%	2%	8,630
CO	0%	11%	9%	52%	27%	614
FL	0%	42%	16%	42%	0%	399
GA	0%	31%	15%	40%	14%	405
HI	0%	13%	6%	52%	29%	317
IL	0%	50%	10%	39%	1%	339
IN	0%	27%	28%	43%	2%	405
KS	1%	43%	25%	28%	3%	380
KY	1%	37%	7%	28%	27%	393
MI	0%	48%	15%	35%	3%	651
MN	1%	55%	7%	33%	4%	386
MO	1%	20%	45%	30%	4%	399
NE	8%	29%	21%	26%	16%	417
NV	0%	51%	22%	22%	5%	408
NH	2%	15%	10%	39%	33%	396
NJ	0%	48%	13%	34%	5%	406
NC	14%	14%	8%	50%	14%	383
OH	6%	12%	36%	44%	1%	329
OR	0%	21%	9%	50%	20%	419
PA	8%	40%	12%	39%	1%	605
SD	0%	53%	36%	10%	1%	398
TN	3%	39%	31%	24%	4%	317
VA	0%	44%	8%	30%	18%	718
WI	1%	22%	22%	54%	1%	739
Total	5%	30%	16%	43%	6%	19,641

¹ All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.

Table 1. Using a self-directed supports option ('yes' responses only; information may have been obtained through state records)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
AL	1%	387	n/a	0%	4%	3%	n/a
CO	2%	655	n/a	0%	3%	4%	0%
FL	8%	400	n/a	0%	3%	18%	n/a
GA	2%	404	n/a	0%	3%	3%	0%
HI	23%	312	n/a	0%	n/a	38%	6%
IL	35%	330	n/a	4%	57%	70%	n/a
KS	21%	381	n/a	1%	9%	65%	n/a
KY	13%	395	n/a	1%	16%	43%	0%
MI	18%	640	n/a	3%	25%	36%	n/a
MN	12%	406	n/a	1%	7%	34%	n/a
MO	9%	402	n/a	0%	5%	24%	n/a
NC	5%	377	0%	0%	11%	8%	0%
NE	13%	398	0%	4%	21%	24%	3%
NH	29%	394	n/a	2%	54%	58%	4%
NJ	24%	406	n/a	3%	29%	56%	0%
OH	3%	333	n/a	0%	2%	5%	n/a
OR	55%	420	n/a	2%	46%	100%	0%
PA	10%	612	0%	0%	8%	25%	n/a
SD	3%	400	n/a	0%	1%	26%	n/a
TN	12%	317	n/a	6%	8%	24%	n/a
VA	20%	699	n/a	6%	25%	49%	7%
WI	51%	800	n/a	5%	48%	71%	n/a
Weighted NCI-IDD Average	18%	9,868	1%	2%	15%	37%	3%

Multiple states are not included in tables due to low or no N's

See all un-collapsed state data showing responses for all possible response options in Appendix C

Table 2. People who make decisions or have input in making decisions for how budget for services is used (among those using a self-directed supports option; proxy respondents were allowed for this question)

State	Individual	Individual Has Input and Family or Friends Also Help With Decisions	Family Member or Friends Makes Decisions, Person <u>Does Not</u> Have Input	Case Manager or Other State Employee	N
AL	n/a	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a	n/a
FL	6%	28%	66%	0%	32
GA	n/a	n/a	n/a	n/a	n/a
HI	4%	16%	71%	9%	56
IL	5%	18%	73%	3%	93
KS	2%	33%	57%	8%	61
KY	0%	11%	78%	11%	46
MI	8%	44%	39%	8%	71
MN	5%	20%	68%	7%	44
MO	8%	25%	61%	6%	36
NE	10%	41%	49%	0%	49
NH	4%	43%	47%	5%	95
NJ	7%	29%	63%	2%	91
NC	n/a	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a	n/a
OR	16%	25%	46%	13%	193
PA	0%	32%	62%	5%	37
SD	n/a	n/a	n/a	n/a	n/a
TN	6%	19%	47%	28%	36
VA	n/a	n/a	n/a	n/a	n/a
WI	9%	25%	57%	10%	378
Weighted NCI-IDD Average	8%	27%	58%	8%	1,367

Multiple states are not included in tables due to low or no N's

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Table 3. Hires or manages staff (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
FL	79%	24	n/a	n/a	n/a	77%	n/a
HI	74%	31	n/a	n/a	n/a	73%	n/a
IL	53%	34	n/a	n/a	n/a	57%	n/a
KS	73%	26	n/a	n/a	n/a	71%	n/a
KY	96%	23	n/a	n/a	n/a	95%	n/a
MI	81%	48	n/a	n/a	n/a	84%	n/a
NE	96%	45	n/a	n/a	n/a	96%	n/a
NH	72%	75	n/a	n/a	n/a	73%	n/a
NJ	79%	58	n/a	n/a	n/a	78%	n/a
OR	82%	131	n/a	n/a	n/a	82%	n/a
PA	78%	23	n/a	n/a	n/a	n/a	n/a
WI	64%	267	n/a	n/a	58%	66%	n/a
Weighted NCI-IDD Average	72%	865	n/a	39%	68%	75%	n/a

Multiple states are not included in tables due to low or no N's

See all un-collapsed state data showing responses for all possible response options in Appendix C

Table 4. Can make changes to individual budget/services if needed (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
FL	96%	24	n/a	n/a	n/a	95%	n/a
HI	81%	31	n/a	n/a	n/a	85%	n/a
IL	83%	35	n/a	n/a	n/a	75%	n/a
KS	78%	23	n/a	n/a	n/a	n/a	n/a
KY	100%	24	n/a	n/a	n/a	100%	n/a
MI	71%	48	n/a	n/a	n/a	63%	n/a
NE	80%	44	n/a	n/a	n/a	83%	n/a
NH	80%	75	n/a	n/a	n/a	78%	n/a
NJ	89%	64	n/a	n/a	n/a	90%	n/a
OR	82%	135	n/a	n/a	n/a	83%	n/a
PA	82%	22	n/a	n/a	n/a	n/a	n/a
WI	86%	265	n/a	n/a	81%	86%	n/a
Weighted NCI-IDD Average	84%	870	n/a	97%	85%	83%	n/a

Multiple states are not included in tables due to low or no N's

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Table 5. Has enough help deciding how to use their individual budget/services (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
FL	96%	24	n/a	n/a	n/a	95%	n/a
HI	77%	31	n/a	n/a	n/a	77%	n/a
IL	88%	34	n/a	n/a	n/a	83%	n/a
KS	92%	25	n/a	n/a	n/a	n/a	n/a
KY	100%	24	n/a	n/a	n/a	100%	n/a
MI	75%	48	n/a	n/a	n/a	66%	n/a
NE	66%	44	n/a	n/a	n/a	68%	n/a
NH	89%	75	n/a	n/a	n/a	86%	n/a
NJ	89%	63	n/a	n/a	n/a	90%	n/a
OR	81%	136	n/a	n/a	n/a	82%	n/a
PA	87%	23	n/a	n/a	n/a	n/a	n/a
WI	93%	269	n/a	n/a	100%	90%	n/a
Weighted NCI-IDD Average	88%	878	n/a	91%	92%	87%	n/a

Multiple states are not included in tables due to low or no N's

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Table 6. Gets information about how much money is left in budget/services (among those using a self-directed supports option; 'yes' responses only; proxy respondents were allowed for this question)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
FL	92%	25	n/a	n/a	n/a	91%	n/a
HI	80%	30	n/a	n/a	n/a	81%	n/a
IL	76%	33	n/a	n/a	n/a	73%	n/a
KS	83%	24	n/a	n/a	n/a	n/a	n/a
KY	100%	25	n/a	n/a	n/a	100%	n/a
MI	74%	46	n/a	n/a	n/a	72%	n/a
NE	63%	43	n/a	n/a	n/a	64%	n/a
NH	87%	75	n/a	n/a	n/a	86%	n/a
NJ	75%	63	n/a	n/a	n/a	73%	n/a
OR	45%	121	n/a	n/a	n/a	47%	n/a
PA	59%	22	n/a	n/a	n/a	n/a	n/a
WI	86%	271	n/a	n/a	88%	86%	n/a
Weighted NCI-IDD Average	76%	857	n/a	89%	79%	75%	n/a

Multiple states are not included in tables due to low or no N's

See all un-collapsed state data showing responses for all possible response options in Appendix C

Table 7. Information about budget/services is easy to understand (among those using a self-directed supports option and who receive information about how much money is left in budget/services; 'yes' responses only; proxy respondents were allowed for this question)

State	Average Within State	N	ICF/IID, Nursing Facility and Other Institutional Settings	Community-based Group Residential Settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care or Host Home
FL	70%	23	n/a	n/a	n/a	67%	n/a
HI	85%	27	n/a	n/a	n/a	83%	n/a
IL	63%	27	n/a	n/a	n/a	n/a	n/a
KS	83%	23	n/a	n/a	n/a	n/a	n/a
KY	100%	23	n/a	n/a	n/a	100%	n/a
MI	64%	39	n/a	n/a	n/a	64%	n/a
NE	17%	29	n/a	n/a	n/a	n/a	n/a
NH	62%	71	n/a	n/a	n/a	64%	n/a
NJ	92%	49	n/a	n/a	n/a	92%	n/a
OR	91%	58	n/a	n/a	n/a	91%	n/a
WI	76%	240	n/a	n/a	79%	74%	n/a
Weighted NCI-IDD Average	77%	700	n/a	n/a	78%	77%	n/a

Multiple states are not included in tables due to low or no N's

See all un-collapsed state data showing responses for all possible response options in Appendix C

Table 8. Frequency with which the person gets information about budget/services (among those using a self-directed supports option; proxy respondents were allowed for this question)

State	At Least Every Three Months	About Twice a Year	Once a Year or Less	N
FL	92%	0%	8%	24
HI	74%	17%	9%	23
IL	57%	38%	5%	21
KY	92%	8%	0%	24
MI	83%	9%	9%	35
NE	0%	67%	33%	27
NH	92%	5%	3%	66
NJ	57%	22%	22%	46
OR	39%	17%	43%	46
WI	94%	3%	3%	232
Weighted NCI-IDD Average	79%	10%	10%	639

Multiple states are not included in tables due to low or no N's

See all un-collapsed state data showing responses for all possible response options in Appendix C