

National Core Indicators[®] - Intellectual and Developmental Disabilities (NCI[®]-IDD)



National Report 2022-23

Self-Direction

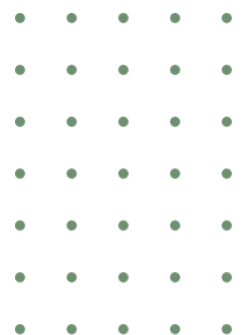


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Where do these data come from?

All information in this section comes directly from the person receiving services, or for some select questions, from a “proxy” respondent. A proxy respondent is someone who knows the person well (e.g., a family member), proxy respondents may not be a case manager/service coordinator. Items that allow for proxy respondents are noted in the table title. 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-IDD System Performance domain (or topic area) and comprise the “Self-direction” subdomain (a specific area of concern within the domain). The Self-direction sub-domain includes items that help determine whether “People who use a self-directed supports option have the information and support needed to actively participate in directing their own supports and services”. Read more about NCI-IDD domains and sub-domains in the Overview chapter of this report.

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*). 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.

Presentation of state and weighted NCI-IDD averages

Averages

In these tables, the states are listed in alphabetical order and are not tested for significance.

To protect people’s privacy, we do not show the data when 20 or fewer people from a state or residence type responded to a question (though their responses are included in the NCI-IDD average).

DATA CAUTION!

For questions that came from existing records, 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.

Important Note on Changes to the 2022-23 Survey Tool

NCI-IDD operates on a six-year revisions cycle to regularly ensure the current set of indicators meet the needs of state systems and reflect current needs in the field. Survey changes are guided by state managers, people with disabilities, and other experts in the field. The 2021-22 survey tool reflected changes based on this guidance and additional survey testing. Please note, any changes to the survey tool may affect comparison to previous years' data, therefore any cross-year comparison should be made with caution.

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

State (name abbreviated)	Institutional settings	Community-based Group Residential settings	Own Home or Apartment	Parent's or Relative's Home	Foster Care/Host Home	N
AL	0%	69%	10%	21%	0%	477
AR	0%	13%	43%	41%	4%	417
CA	7%	23%	13%	56%	1%	8808
CT	0%	48%	14%	35%	3%	600
DE	0%	54%	3%	40%	3%	414
DC	18%	38%	34%	6%	5%	133
FL	0%	36%	14%	50%	0%	524
GA	0%	37%	12%	39%	12%	406
HI	0%	4%	3%	52%	41%	344
IL	2%	47%	7%	43%	1%	398
IN	31%	19%	9%	41%	0%	1074
KS	0%	48%	20%	30%	3%	312
KY	0%	28%	9%	40%	23%	437
MD	1%	32%	10%	57%	0%	522
MI	0%	37%	18%	41%	3%	652
MN	0%	47%	9%	39%	4%	401
MO	2%	24%	33%	39%	3%	400
MT	0%	48%	31%	20%	0%	365
NE	5%	25%	15%	25%	30%	420
NV	0%	48%	14%	32%	6%	416
NH	1%	15%	9%	41%	33%	392
NJ	0%	38%	13%	47%	2%	459
NY	0%	41%	7%	51%	1%	1662
NC	6%	21%	6%	51%	15%	590
OK	0%	45%	19%	35%	2%	400
OR	0%	15%	10%	61%	14%	418
PA	8%	38%	11%	39%	4%	663
SC	1%	51%	14%	29%	5%	509
TX	5%	7%	8%	39%	40%	416
UT	7%	40%	10%	28%	16%	352
VA	0%	36%	9%	39%	17%	757
WI	4%	26%	31%	39%	0%	321
WY	0%	0%	45%	55%	0%	269
Weighted NCI-IDD Average	4%	31%	13%	46%	6%	24728

Table note: Institutional settings includes ICF/IID, Nursing Facilities, and other institutional settings

Charts and Tables

Is this person currently using a self-directed supports option?

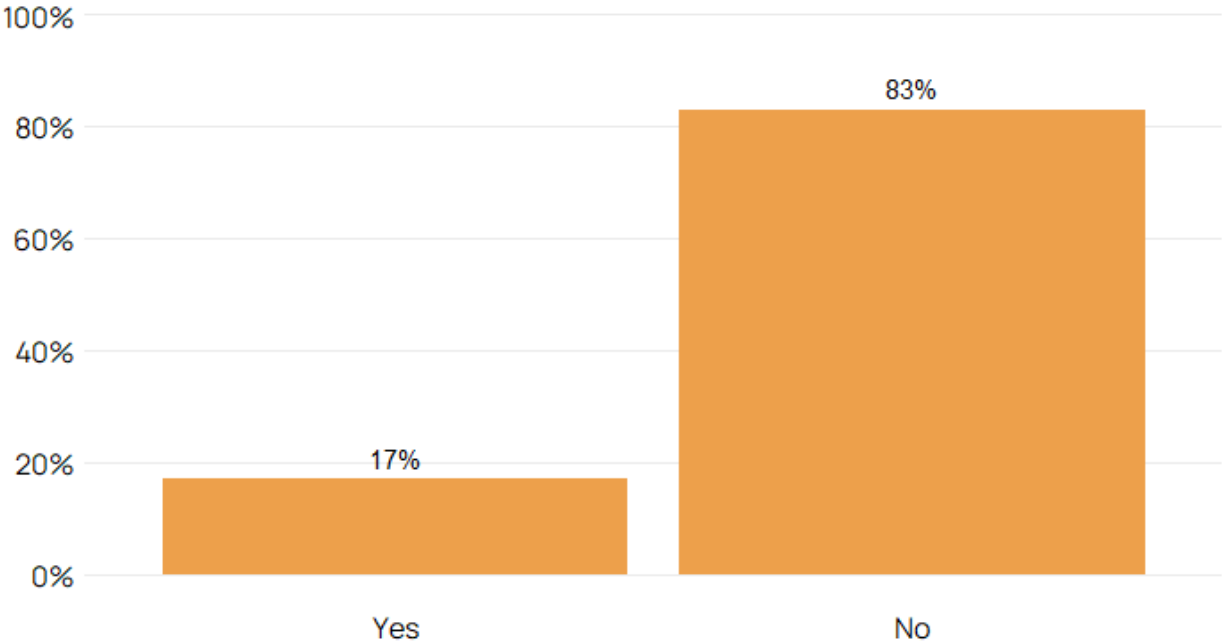


Table 1. Using a self-directed supports option*Information may have been obtained through state records*

State (names abbreviated)	Yes	No	N
AL	6%	94%	453
CT	18%	82%	595
DE	23%	77%	356
FL	10%	90%	524
GA	1%	99%	406
HI	22%	78%	348
IL	34%	66%	382
KS	23%	77%	307
KY	28%	72%	437
MD	10%	90%	527
MI	25%	75%	655
MN	17%	83%	403
MO	14%	86%	403
MT	12%	88%	359
NE	7%	93%	417
NH	33%	67%	393
NJ	34%	66%	458
NY	29%	71%	1,676
NC	3%	97%	574
OK	2%	98%	400
OR	67%	33%	417
PA	12%	88%	676
SC	11%	89%	491
TX *	8%	92%	301
UT	16%	84%	349
VA	29%	71%	752
WI	17%	83%	361
WY	20%	80%	424
NCI-IDD Average	17%	83%	22,660

*Table note: The following states do not offer self-direction and were not shown: AR, DC, IN, NV;**States with more than 25% missing or don't know are marked with **

Who makes decisions about the services that are self-directed?

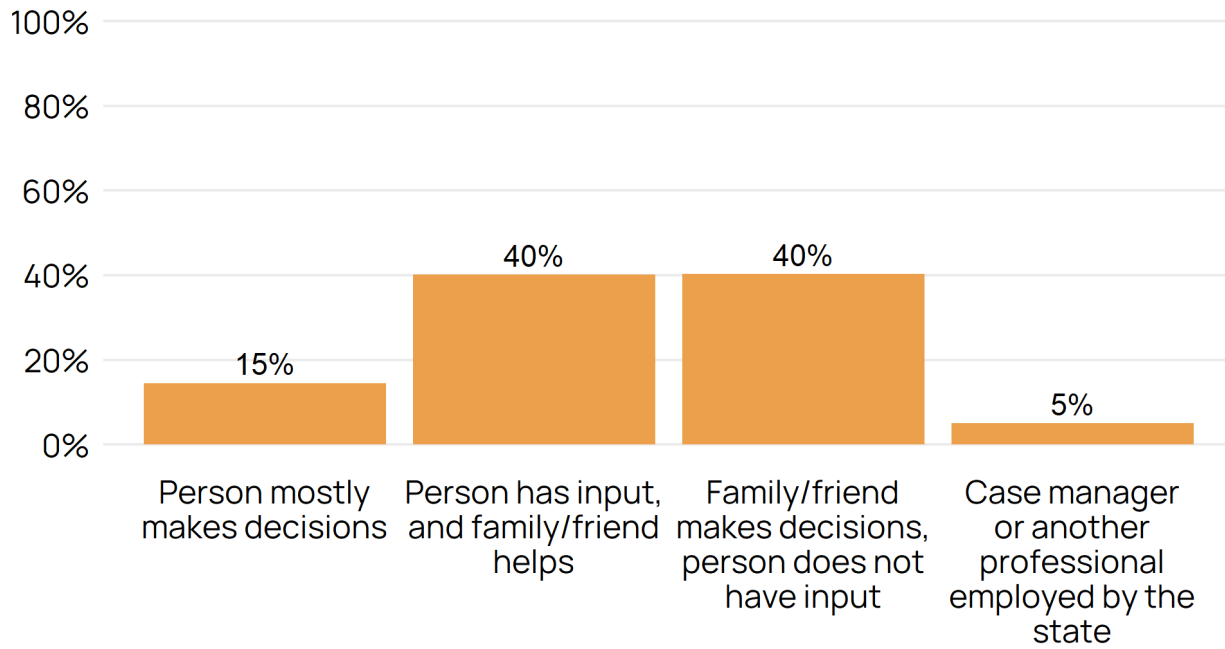


Table 2. People who make decisions or have input in making decisions about the services that are self directed

State (names abbreviated)	Person mostly makes decisions	Person has input, and family/friend helps	Family/friend makes decisions, person does not have input	Case manager or another professional employed by the state	N
AL	10%	21%	7%	62%	29
CT	10%	41%	45%	3%	86
FL	6%	67%	27%	0%	52
HI	3%	22%	72%	3%	69
IL	7%	41%	50%	2%	111
KS	14%	22%	57%	6%	49
KY	4%	45%	45%	6%	122
MD	15%	58%	26%	0%	53
MI	6%	59%	29%	6%	137
MN	11%	27%	59%	3%	64
MO	16%	41%	41%	2%	56
MT	13%	50%	35%	3%	40
NE	11%	75%	14%	0%	28
NH	4%	35%	53%	8%	120
NJ	14%	30%	52%	4%	152
NY	20%	39%	36%	6%	449
OR	26%	38%	34%	3%	250
PA	5%	40%	33%	21%	57
SC	16%	4%	28%	52%	25
UT	9%	39%	52%	0%	54
VA	6%	43%	50%	1%	172
WY	10%	56%	31%	4%	72
NCI-IDD Average	15%	40%	40%	5%	2,375

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; The following states had a low count of responses (N<20) and were not shown: DE, GA, NC, OK, TX, WI; States with more than 25% missing or don't know are marked with *

Can you make changes to the services and supports you self-direct if you need to?

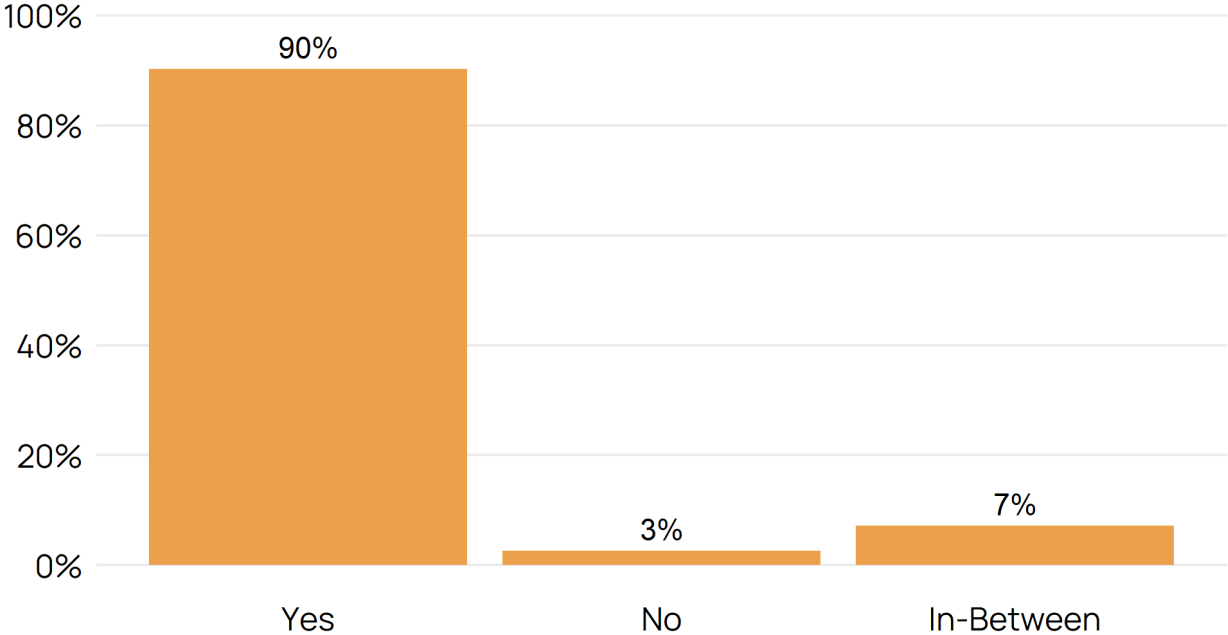


Table 3. Can make changes to individual budget/services if needed*Proxy respondents were allowed for this question*

State (names abbreviated)	Yes	No	In-Between	N
CT	93%	4%	3%	75
FL	93%	0%	7%	46
HI	90%	3%	6%	62
IL	93%	1%	6%	102
KS	100%	0%	0%	21
KY	92%	0%	8%	84
MD	94%	2%	4%	48
MI	81%	4%	15%	85
MN	88%	2%	10%	49
MO	91%	0%	9%	47
MT	85%	9%	6%	34
NE	78%	0%	22%	23
NH	78%	4%	18%	102
NJ	90%	0%	10%	120
NY	90%	4%	6%	371
OR	91%	1%	7%	222
PA	100%	0%	0%	32
UT	94%	0%	6%	47
VA	90%	6%	4%	165
WY	95%	3%	2%	64
NCI-IDD Average	90%	3%	7%	1,908

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI

Do you have enough help deciding how to direct your services?

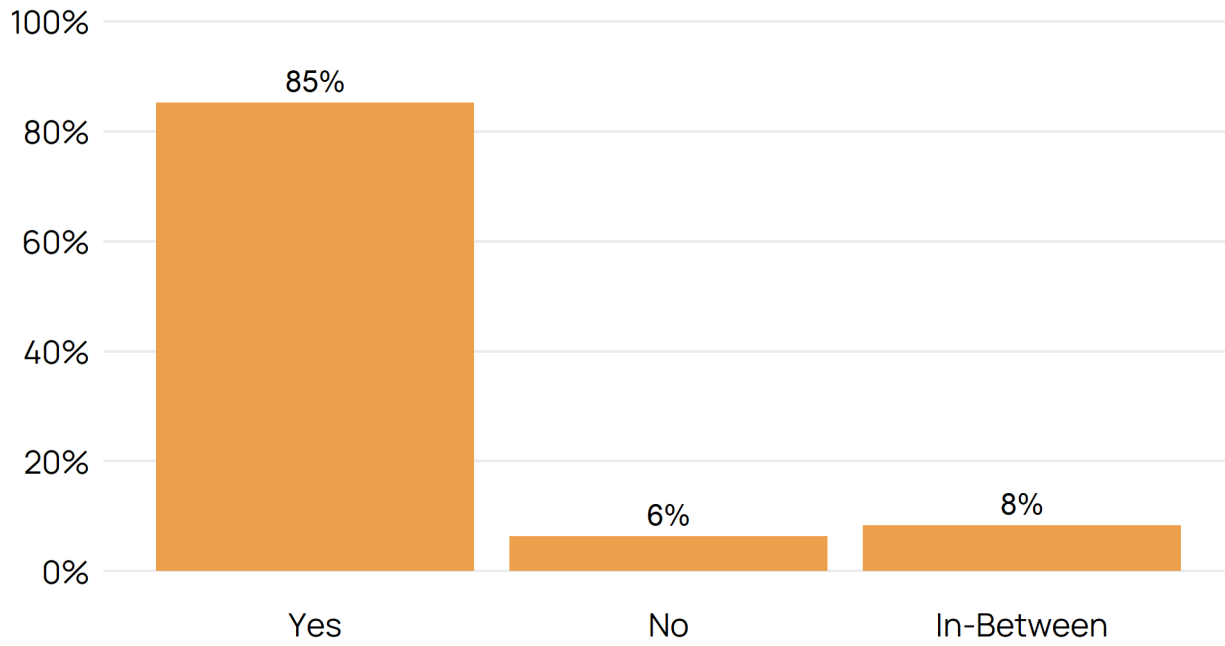


Table 4. Has enough help deciding how to direct services*Proxy respondents were allowed for this question*

State (names abbreviated)	Yes	No	In-Between	N
CT	85%	9%	6%	79
FL	91%	0%	9%	46
HI	90%	5%	5%	62
IL	95%	1%	4%	101
KS	100%	0%	0%	21
KY	89%	0%	11%	84
MD	87%	4%	10%	52
MI	75%	6%	20%	87
MN	83%	11%	6%	47
MO	89%	0%	11%	47
MT	65%	15%	21%	34
NE	78%	0%	22%	23
NH	76%	9%	16%	103
NJ	76%	10%	15%	115
NY	86%	7%	7%	370
OR	87%	7%	6%	225
PA	94%	3%	3%	31
UT	91%	0%	9%	46
VA	82%	9%	9%	165
WY	94%	3%	3%	65
NCI-IDD Average	85%	6%	8%	1,915

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI

Do you have the amount of control you want with the services you self-direct?

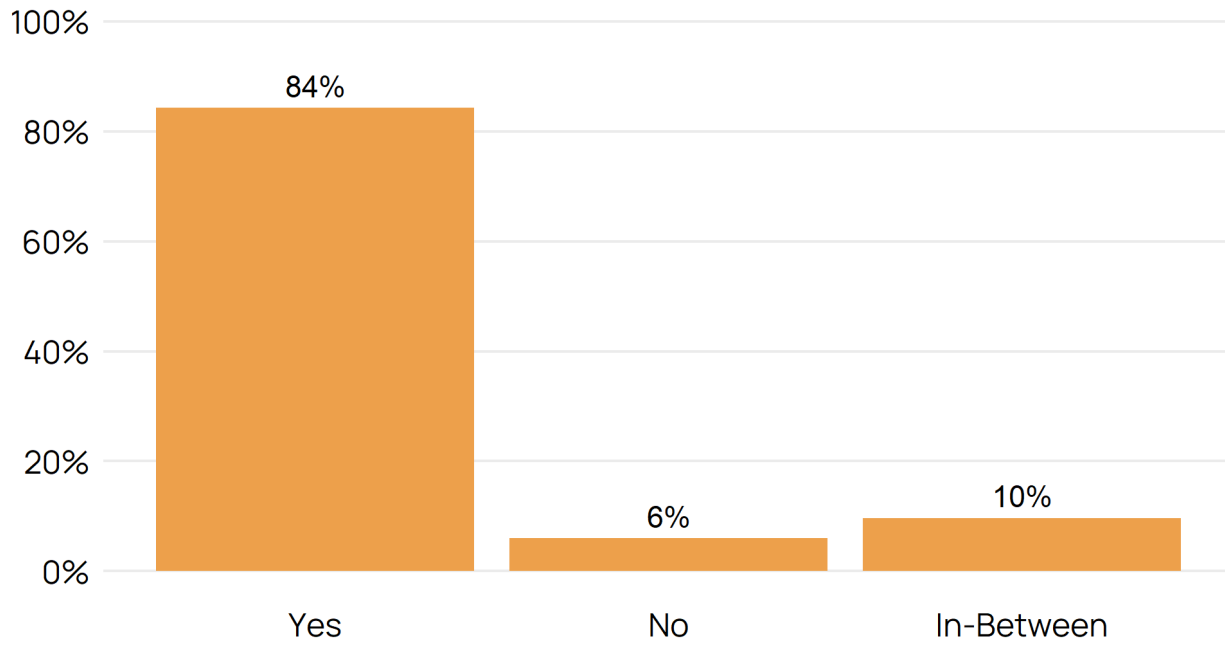


Table 5. Has the amount of control wanted with the services that are self-directed*Proxy respondents were allowed for this question*

State (names abbreviated)	Yes	No	In-Between	N
CT	91%	3%	6%	79
FL	91%	2%	7%	46
HI	82%	6%	11%	62
IL	96%	1%	3%	101
KS	86%	0%	14%	21
KY	98%	0%	2%	84
MD	86%	4%	10%	49
MI	70%	9%	21%	86
MN	73%	6%	20%	49
MO	94%	2%	4%	48
MT	76%	15%	9%	34
NE	61%	4%	35%	23
NH	64%	14%	22%	103
NJ	77%	10%	13%	121
NY	84%	9%	7%	369
OR	85%	3%	12%	223
PA	94%	3%	3%	31
UT	96%	0%	4%	46
VA	82%	6%	12%	164
WY	91%	8%	2%	65
NCI-IDD Average	84%	6%	10%	1,913

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI

Are the services and supports you want to self-direct always available?

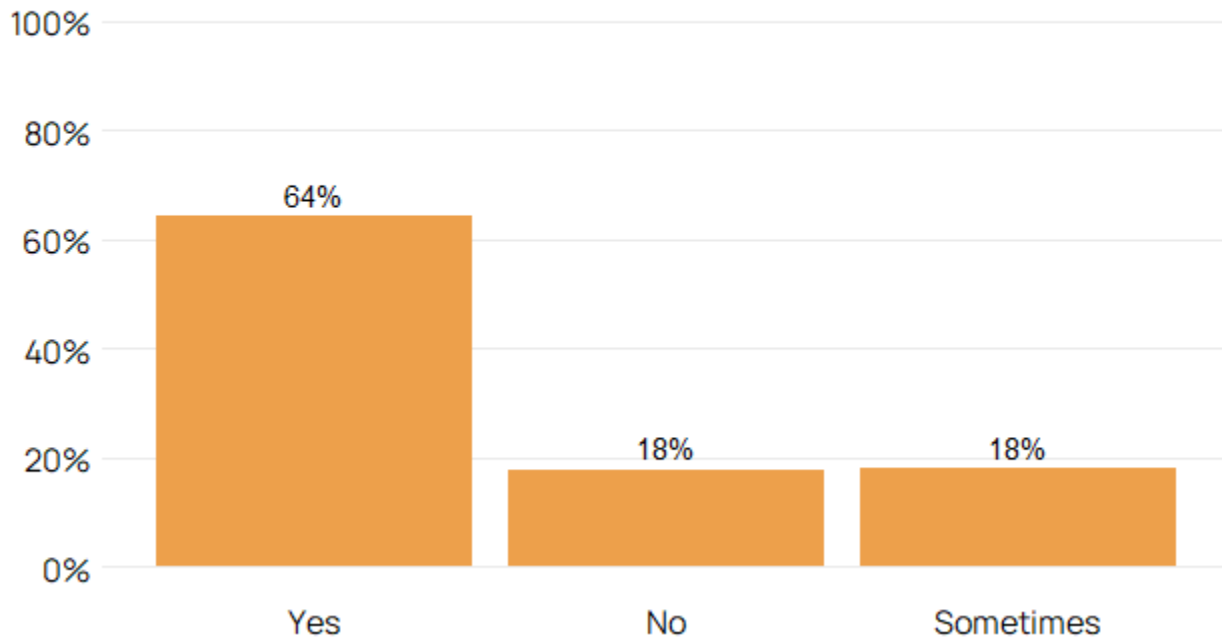


Table 6. The services and supports they want to self-direct are always available. This includes things like having the services that they want available when they want them and having enough staff to hire.

Proxy respondents were allowed for this question

State (names abbreviated)	Yes	No	Sometimes	N
CT	68%	22%	10%	79
FL	66%	11%	23%	44
HI	66%	16%	18%	61
IL	90%	0%	10%	101
KS	76%	5%	19%	21
KY	89%	0%	11%	84
MD	55%	28%	17%	47
MI	52%	30%	18%	87
MN	59%	18%	22%	49
MO	63%	17%	21%	48
MT	56%	29%	15%	34
NE	65%	13%	22%	23
NH	55%	24%	22%	102
NJ	54%	22%	24%	119
NY	66%	17%	17%	366
OR	56%	25%	19%	222
PA	74%	10%	16%	31
UT	61%	13%	26%	46
VA	58%	24%	18%	165
WY	64%	25%	11%	64
NCI-IDD Average	64%	18%	18%	1,902

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI

Do you get information about your budget and services from your financial management service (FMS)?

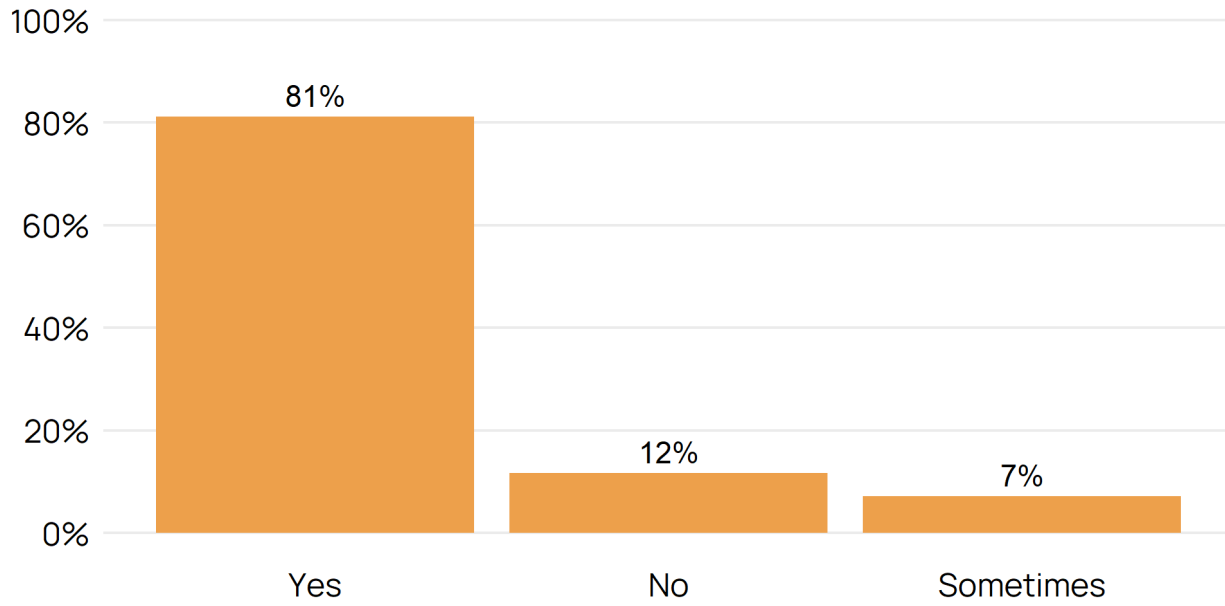


Table 7. Gets information about budget and services from financial management service (FMS)

Proxy respondents were allowed for this question

State (names abbreviated)	Yes	No	Sometimes	N
CT	91%	9%	0%	77
FL	86%	9%	5%	43
HI	89%	8%	3%	61
IL	93%	1%	6%	103
KS	76%	10%	14%	21
KY	95%	1%	4%	83
MD	82%	10%	8%	50
MI	74%	17%	8%	86
MN	88%	6%	6%	48
MO	79%	15%	6%	48
MT	69%	9%	22%	32
NE	73%	5%	23%	22
NH	88%	7%	5%	100
NJ	59%	34%	7%	120
NY	92%	5%	3%	365
OR	66%	14%	20%	208
PA	70%	22%	7%	27
UT	89%	4%	7%	46
VA	64%	28%	8%	152
WY	79%	19%	2%	62
NCI-IDD Average	81%	12%	7%	1,860

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; OR used the term “CME” (Case Management Entity) instead of “FMS”; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI

Is the information you get from the FMS easy to understand?

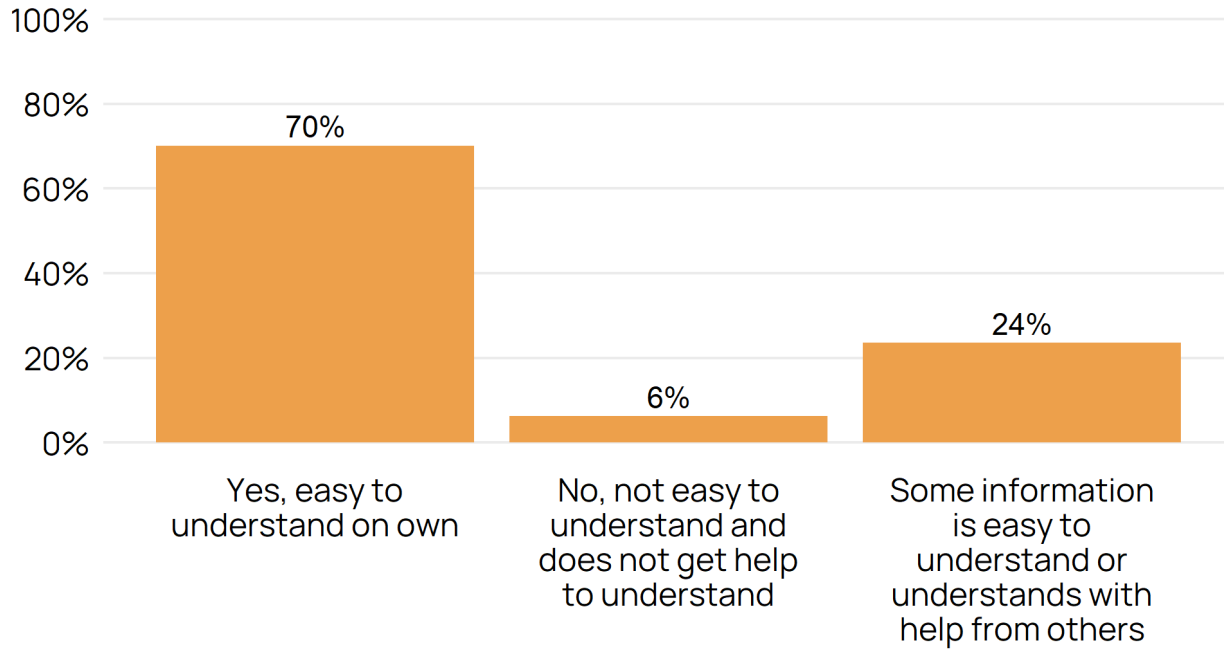


Table 8. Information from FMS is easy to understand

Proxy respondents were allowed for this question

State (names abbreviated)	Yes, easy to understand on own	No, not easy to understand and does not get help to understand	Some information is easy to understand or understands with help from others	N
CT	74%	12%	14%	69
FL	51%	6%	43%	35
HI	87%	4%	9%	53
IL	87%	0%	13%	95
KY	82%	0%	18%	79
MD	53%	21%	26%	38
MI	58%	11%	31%	64
MN	61%	2%	37%	41
MO	68%	8%	24%	38
MT	43%	24%	33%	21
NH	68%	10%	22%	87
NJ	70%	7%	23%	71
NY	67%	8%	26%	333
OR	76%	1%	23%	134
UT	68%	11%	21%	38
VA	81%	6%	13%	94
WY	52%	6%	42%	48
NCI-IDD Average	70%	6%	24%	1,473

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; OR used the term “CME” (Case Management Entity) instead of “FMS”; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, KS, NE, NC, OK, PA, SC, TX, WI

How often do you get the information about your budget and services from your FMS?

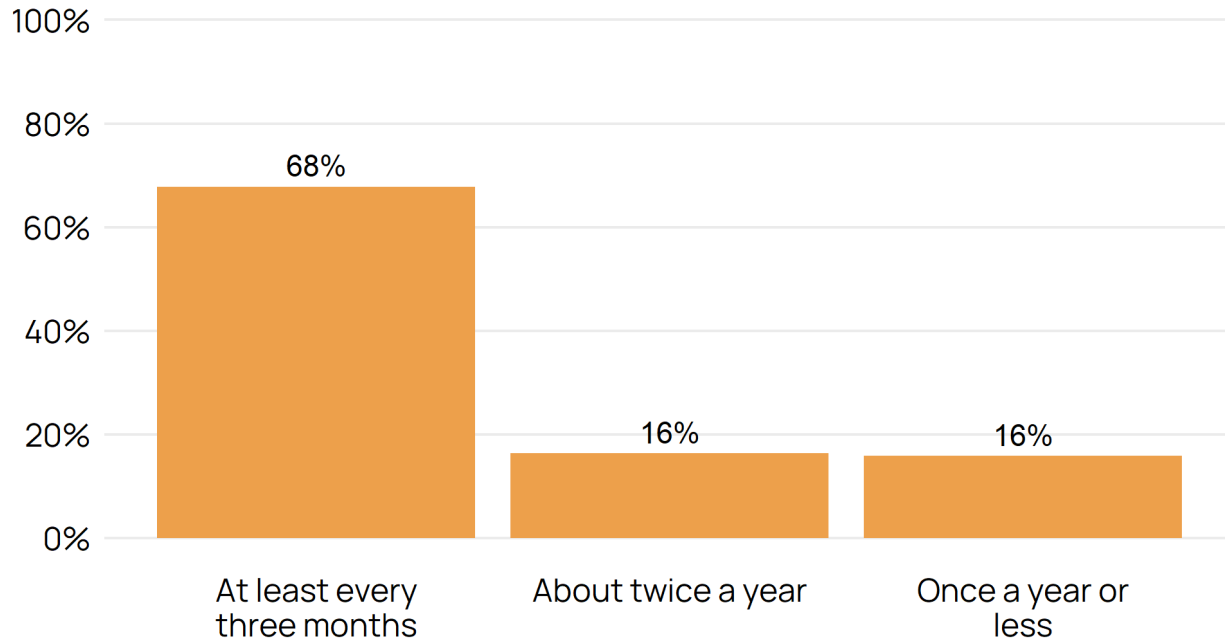


Table 9. Frequency with which the person gets information from FMS*Proxy respondents were allowed for this question*

State (names abbreviated)	At least every three months	About twice a year	Once a year or less	N
CT	97%	0%	3%	67
FL	86%	11%	3%	35
HI	70%	16%	14%	50
IL	63%	28%	9%	89
KY	92%	6%	1%	77
MD	86%	3%	11%	35
MI	68%	11%	21%	62
MN	71%	21%	7%	42
MO	68%	12%	21%	34
MT	62%	10%	29%	21
NH	95%	2%	2%	85
NJ	48%	29%	23%	65
NY	80%	15%	6%	314
OR	23%	20%	57%	131
UT	91%	9%	0%	35
VA	47%	10%	43%	89
WY	79%	12%	10%	42
NCI-IDD Average	68%	16%	16%	1,404

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; OR used the term “CME” (Case Management Entity) instead of “FMS”; The following states had a low count of responses (N<20) and were not shown: AL, GA, KS, NE, NC, OK, PA, SC, TX, WI

Do you need help with any of these parts of self-direction?

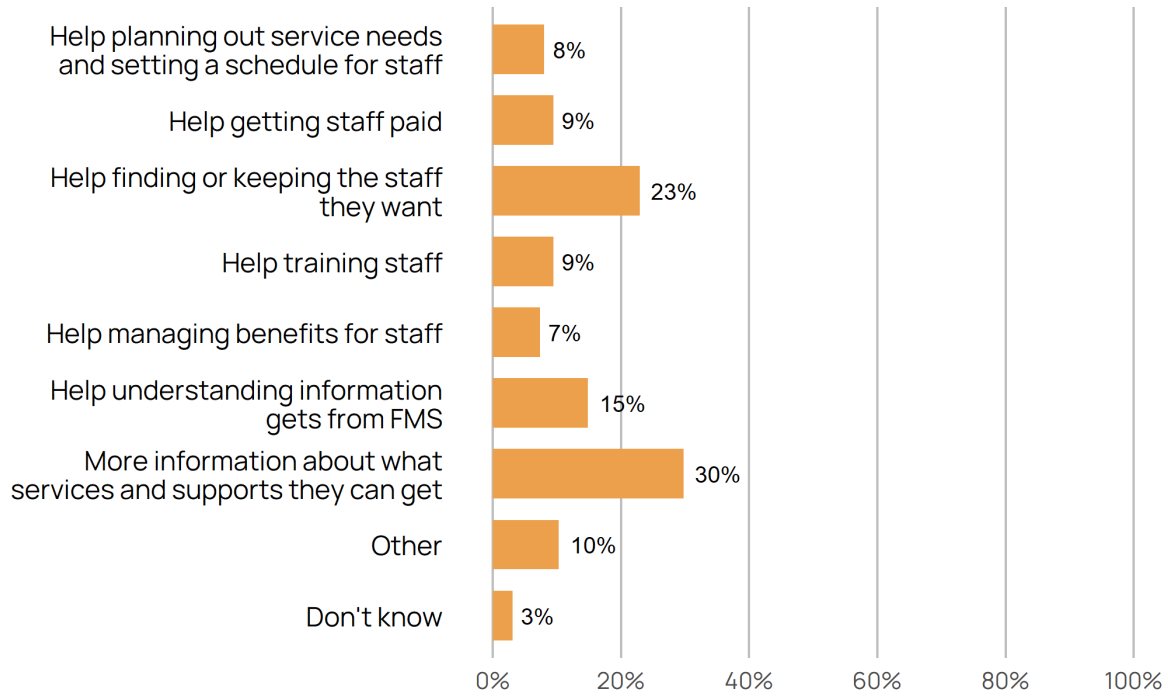


Table 10. Needs help with these elements of self direction

Proxy respondents were allowed for this question

State	Help planning out service needs and setting a schedule for staff	Help getting staff paid	Help finding or keeping the staff they want	Help training staff	Help managing benefits for staff	Help understanding information gets from FMS	More information about what services and supports they can get	Other	Don't know	N
CT	9%	9%	28%	10%	13%	15%	46%	6%	3%	78
FL	2%	2%	17%	7%	4%	4%	22%	2%	2%	46
HI	8%	6%	30%	16%	10%	19%	40%	19%	0%	63
IL	5%	6%	6%	2%	4%	4%	13%	1%	6%	102
KS	0%	0%	14%	5%	0%	5%	0%	0%	14%	21
KY	1%	1%	6%	0%	1%	4%	12%	4%	0%	84
MD	10%	31%	25%	12%	23%	44%	40%	13%	2%	52
MI	9%	25%	33%	20%	15%	21%	38%	33%	2%	85
MN	10%	8%	27%	6%	6%	10%	20%	6%	0%	49
MO	6%	10%	23%	2%	6%	19%	6%	6%	0%	48
MT	9%	13%	31%	16%	9%	38%	34%	19%	0%	32
NE	33%	33%	42%	50%	8%	13%	17%	0%	13%	24
NH	12%	18%	38%	12%	12%	19%	24%	24%	2%	103
NJ	5%	5%	14%	6%	5%	13%	35%	12%	1%	105
NY	10%	10%	29%	13%	9%	20%	35%	13%	2%	376
OR	6%	7%	18%	7%	3%	9%	36%	4%	6%	230
PA	6%	10%	6%	0%	0%	10%	19%	6%	10%	31
UT	4%	9%	20%	7%	9%	20%	17%	11%	0%	46
VA	9%	13%	43%	15%	11%	9%	33%	12%	5%	150
WY	18%	17%	29%	14%	12%	23%	32%	15%	2%	65
NCI-IDD Average	8%	9%	23%	9%	7%	15%	30%	10%	3%	1,905

Table note: AR, DC, IN, and NV do not offer self-direction and were not shown; OR used the term “CME” (Case Management Entity) instead of “FMS”; The following states had a low count of responses (N<20) and were not shown: AL, DE, GA, NC, OK, SC, TX, WI



Human Services Research Institute

Human Services Research Institute (HSRI)

2336 Massachusetts Avenue

Cambridge, MA 02140



NASDDDS

National Association of State Directors
of
Developmental Disabilities Services

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

301 N Fairfax Street, Suite 101

Alexandria, VA 22314

May 2024

Questions/Comments: nci@nationalcoreindicators.org