

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



National Report 2021-22

Self-Direction



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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. 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. Others are drawn from administrative sources. Items that allow for proxy respondents or may be collected from administrative records 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 2021-22 Survey Tool

NCI regularly updates survey tools to 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. Throughout this report, notes indicate new questions and questions that were modified. 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.

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

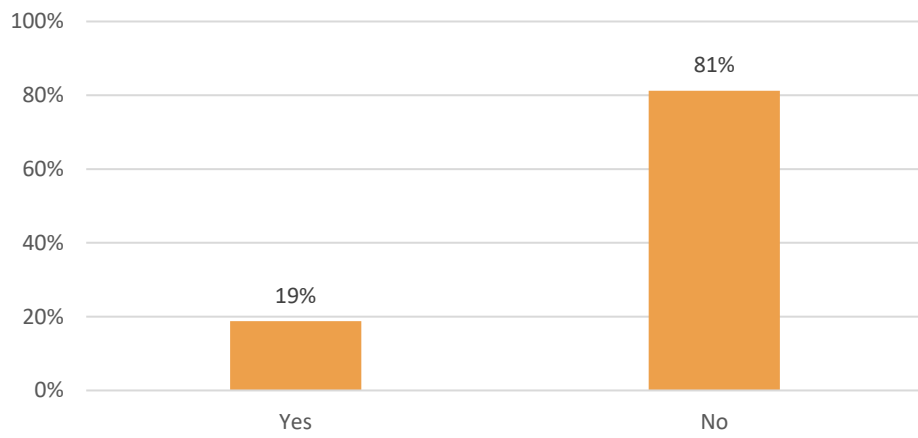


Table 1. Using a self-directed supports option

Information may have been obtained through state records; * indicates >25% missing data

State	No	Yes	N
CO	98%	2%	426
CT	76%	24%	435
DE*	94%	6%	173
FL	89%	11%	453
GA	98%	2%	407
IL	74%	26%	347
KS	80%	20%	382
KY	78%	22%	407
MA	99%	1%	392
MI	77%	23%	645
MN*	0%	100%	47
MO	89%	11%	401
NE	90%	10%	416
NJ	67%	33%	432
NY	79%	21%	1012
NC	98%	2%	458
OH	95%	5%	463
OK	97%	3%	300
OR	23%	77%	420
PA	91%	9%	622
SC	97%	3%	398
UT	85%	15%	490
VA	79%	21%	641
WI	44%	56%	512
Weighted NCI-IDD Average	81%	19%	10679

AR, IN, NV excluded

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

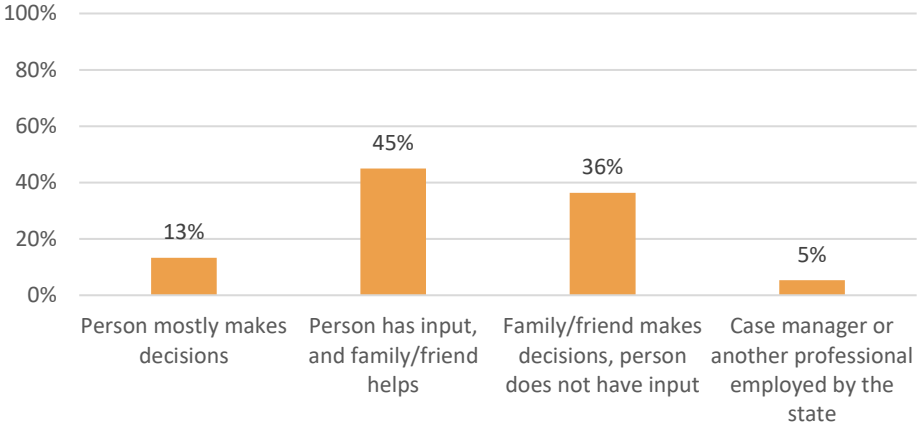


Table 2. People who make decisions or have input in making decisions about the services that are self directed

State	Person mostly makes decisions	Person has input, and family/friend helps	Family/friend makes decisions, person does not have input	Decisions about what services are received are made by a case manager or another professional employed by the state	N
OR	25%	40%	28%	7%	277
PA	19%	33%	44%	3%	36
NY	17%	47%	31%	5%	192
MO	16%	33%	51%	0%	43
WI	15%	35%	41%	9%	256
CT	10%	55%	34%	1%	73
UT	10%	27%	63%	0%	73
KS	8%	26%	60%	6%	65
NJ	7%	60%	32%	1%	134
VA	7%	46%	46%	0%	71
KY	7%	51%	34%	8%	90
MI	6%	53%	34%	8%	119
FL	4%	62%	34%	0%	47
IL	3%	53%	43%	1%	89
NE	3%	78%	20%	0%	40
MN	0%	46%	51%	3%	39
Weighted NCI-IDD Average	13%	45%	36%	5%	1698

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

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

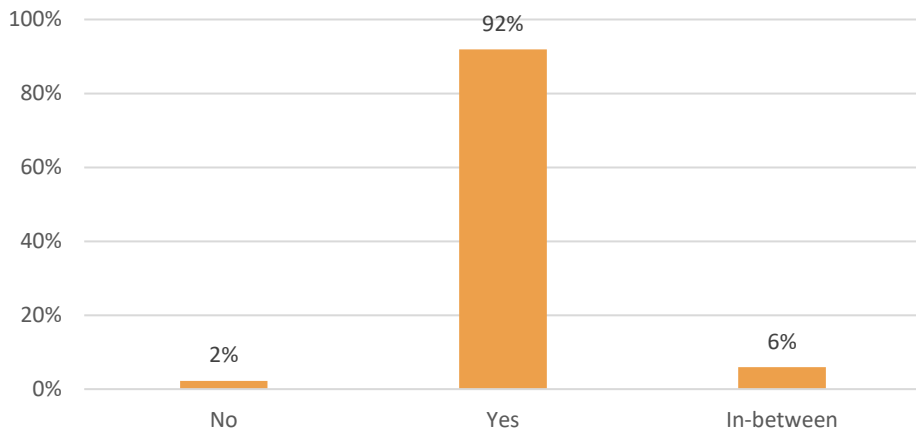


Table 3. Can make changes to individual budget/services if needed

Question changed from previous years; proxy respondents were allowed for this question

State	Yes	No	In-between	N
FL	100%	0%	0%	41
IL	100%	0%	0%	74
UT	98%	0%	2%	55
KS	97%	0%	3%	37
PA	97%	0%	3%	30
MO	95%	0%	5%	39
WI	94%	1%	5%	216
VA	94%	3%	3%	62
NY	91%	3%	5%	164
NE	91%	0%	9%	33
NJ	91%	0%	9%	130
OR	89%	5%	6%	231
KY	89%	0%	11%	61
MI	84%	3%	13%	76
CT	83%	2%	16%	58
MN	81%	13%	6%	32
Weighted NCI-IDD Average	92%	2%	6%	1381

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

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

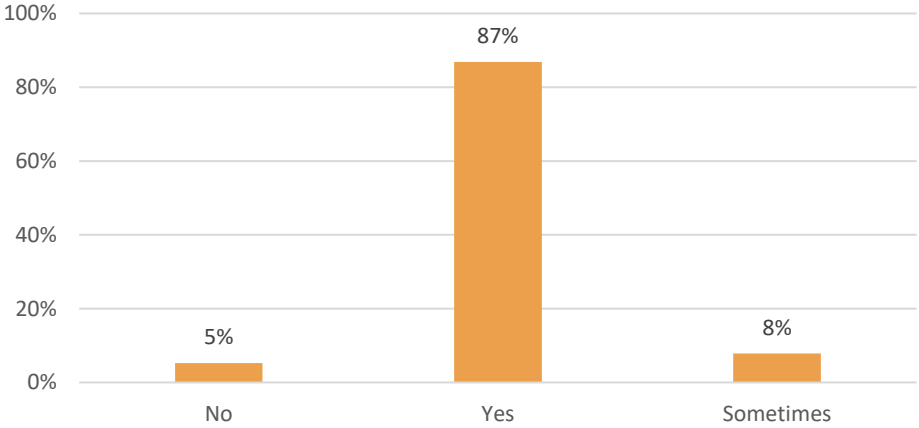


Table 4. Has enough help deciding how to direct services

Question changed in 2021-22; proxy respondents were allowed for this question

State	Yes	No	In-between	N
FL	100%	0%	0%	42
IL	100%	0%	0%	75
VA	95%	3%	2%	64
KS	95%	0%	5%	38
PA	93%	3%	3%	29
MO	92%	0%	8%	39
KY	92%	2%	6%	62
CT	92%	3%	5%	60
MN	90%	3%	6%	31
WI	88%	5%	7%	218
UT	85%	7%	7%	54
NY	85%	9%	7%	163
NE	82%	3%	15%	34
OR	82%	10%	8%	230
MI	79%	4%	17%	82
NJ	79%	2%	18%	130
Weighted NCI-IDD Average	87%	5%	8%	1393

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

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

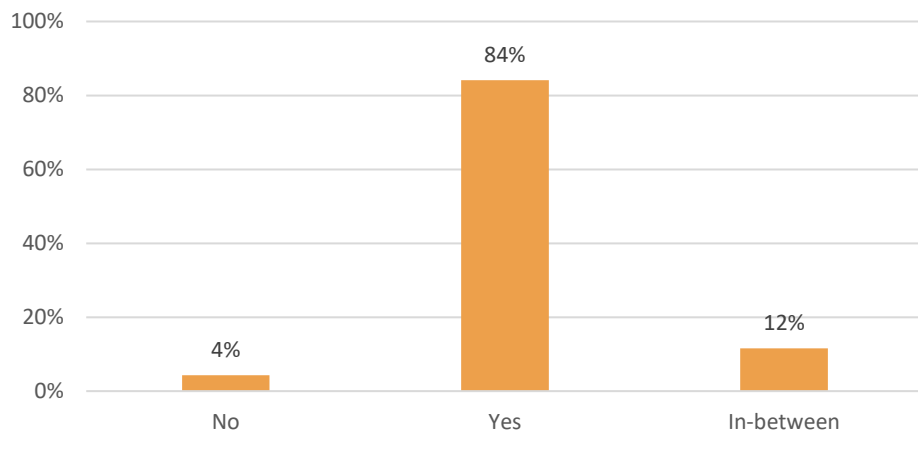


Table 5. Has the amount of control wanted with the services that are self-directed

New question in 2021-22; proxy respondents were allowed for this question

State	Yes	No	In-between	N
UT	100%	0%	0%	54
IL	99%	0%	1%	73
FL	98%	0%	2%	42
MO	97%	0%	3%	39
VA	91%	2%	8%	66
PA	89%	4%	7%	28
WI	87%	3%	10%	220
KY	85%	0%	15%	62
OR	84%	9%	7%	232
KS	84%	0%	16%	37
CT	81%	7%	12%	58
NY	80%	6%	14%	162
NE	76%	6%	18%	34
NJ	75%	4%	21%	127
MN	74%	3%	23%	31
MI	68%	8%	25%	80
Weighted NCI-IDD Average	84%	4%	12%	1387

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

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

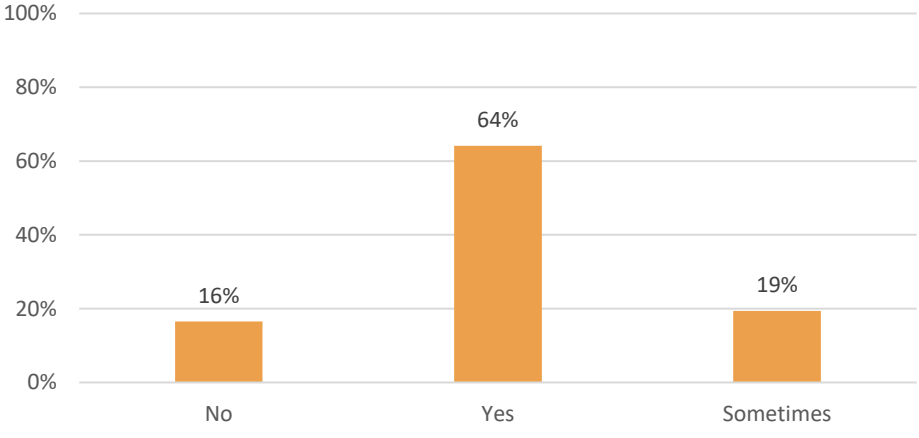


Table 6. The services and supports they want to self-direct are always available

New question in 2021-22; proxy respondents were allowed for this question

State	Yes	No	In-between	N
FL	93%	2%	5%	42
IL	92%	3%	6%	72
KY	77%	0%	23%	62
WI	73%	14%	13%	215
PA	67%	20%	13%	30
VA	65%	18%	17%	65
UT	64%	24%	13%	55
KS	62%	14%	24%	37
NY	62%	20%	18%	158
MO	62%	21%	18%	39
CT	57%	18%	25%	61
OR	55%	26%	19%	233
NE	50%	15%	35%	34
MI	49%	22%	28%	81
NJ	48%	16%	37%	128
MN	41%	22%	38%	32
Weighted NCI-IDD Average	64%	16%	19%	1385

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

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

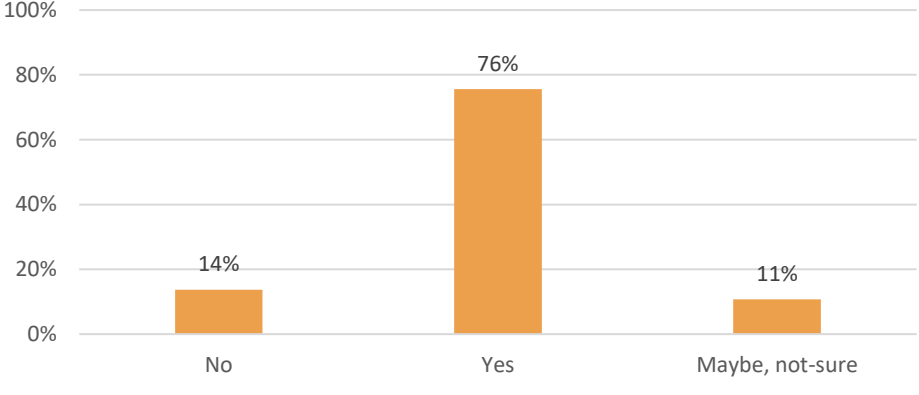


Table 7. Gets information about budget and services from financial management service (FMS)¹

Proxy respondents were allowed for this question

State	Yes	No	In-between	N
MN	97%	3%	0%	31
FL	95%	2%	2%	42
PA	93%	7%	0%	30
IL	89%	5%	5%	73
UT	89%	8%	4%	53
KY	87%	8%	5%	60
MO	86%	3%	11%	36
MI	86%	6%	8%	77
WI	79%	13%	8%	217
CT	77%	9%	14%	57
NY	74%	16%	10%	163
KS	74%	18%	8%	38
OR	66%	23%	12%	221
NE	59%	21%	21%	34
NJ	55%	12%	33%	119
VA	51%	35%	14%	57
Weighted NCI-IDD Average	76%	14%	11%	1350

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

¹ Please note: OR replaced “FMS” with “CME”

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

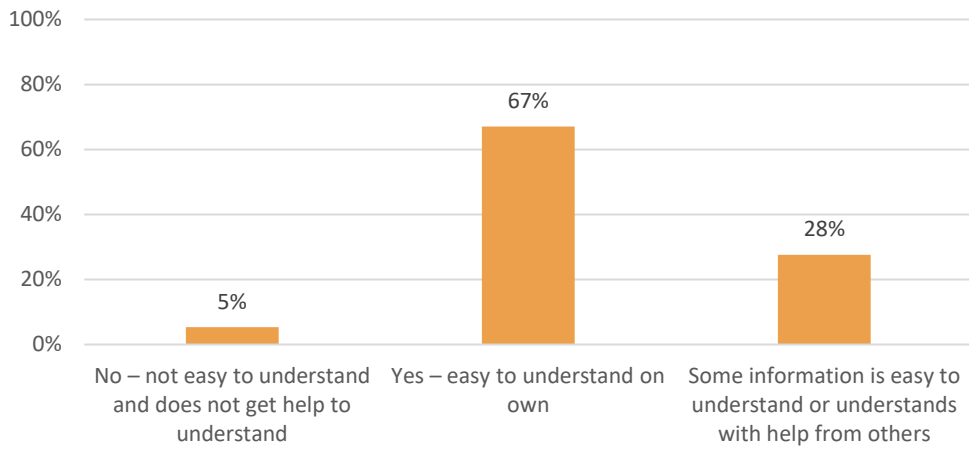


Table 8. Information from FMS² is easy to understand

Proxy respondents were allowed for this question

State	Yes	No	In-between	N
VA	86%	0%	14%	28
MN	80%	0%	20%	30
OR	75%	6%	18%	141
WI	74%	6%	21%	170
KS	73%	0%	27%	26
KY	73%	0%	27%	52
FL	68%	0%	32%	38
IL	68%	0%	32%	63
NJ	68%	0%	32%	65
PA	61%	18%	21%	28
NY	59%	3%	38%	120
CT	52%	12%	36%	42
MI	49%	17%	34%	65
UT	48%	26%	26%	46
NE	45%	5%	50%	20
MO	42%	10%	48%	31
Weighted NCI-IDD Average	67%	5%	28%	997

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

² Please note: OR replaced “FMS” with “CME”

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

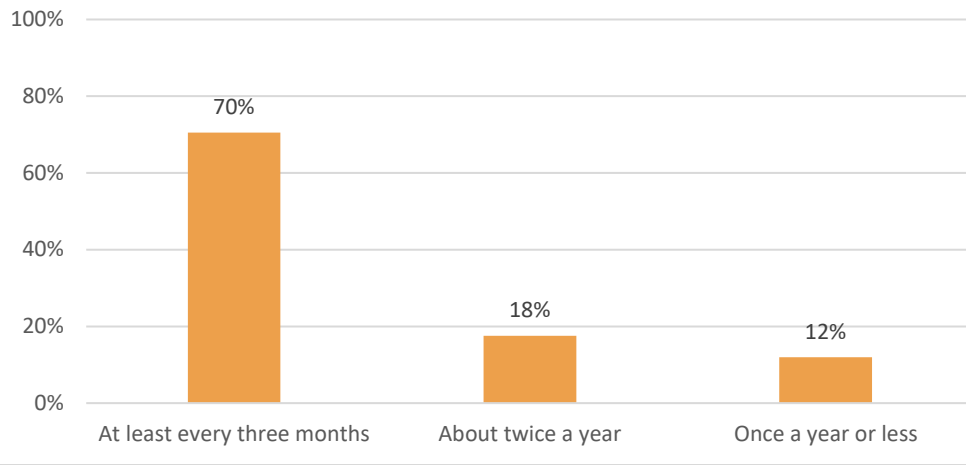


Table 9. Frequency with which the person gets information from FMS³

Proxy respondents were allowed for this question

State	At least every three months	About twice a year	Once a year or less	N
UT	91%	4%	4%	46
FL	87%	10%	3%	39
CT	86%	12%	2%	42
MO	84%	8%	8%	25
KY	84%	16%	0%	50
WI	82%	13%	4%	164
NY	78%	17%	5%	110
MN	77%	10%	13%	30
MI	76%	13%	11%	63
KS	71%	21%	7%	28
VA	68%	20%	12%	25
PA	59%	32%	9%	22
IL	58%	35%	7%	55
NJ	50%	32%	18%	50
OR	36%	18%	46%	130
Weighted NCI-IDD Average	70%	18%	12%	927

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC, NE not shown due to low counts.

³ Please note: OR replaced “FMS” with “CME”

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

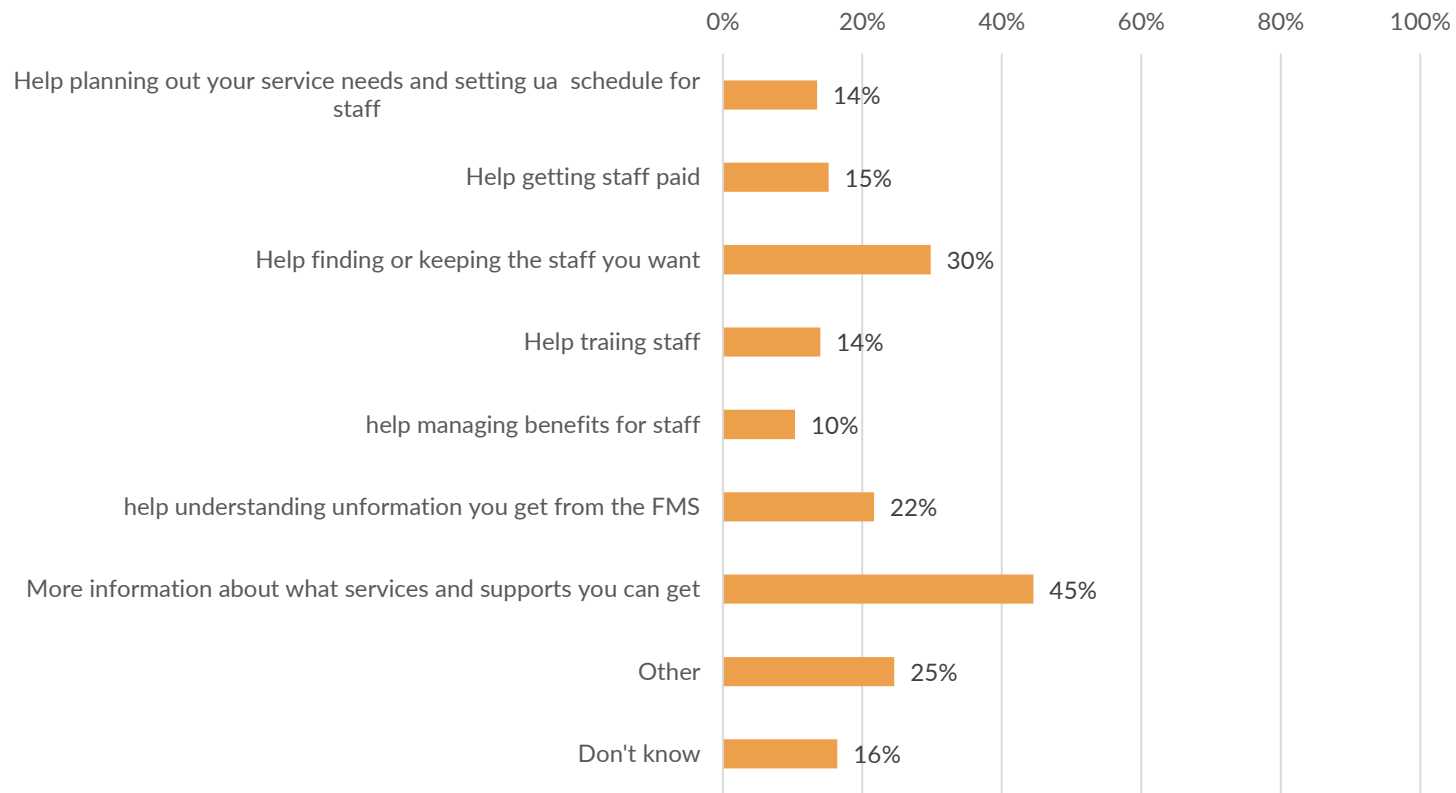


Table 10. Needs help with these elements of self direction

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 the FMS ⁴	More information about what services and supports can get	Other	Don't know, no response, unclear response	N
CT	19%	20%	39%	17%	7%	17%	41%	15%	20%	54
FL	10%	14%	10%	5%	10%	14%	43%	19%	24%	21
IL	2%	4%	4%	2%	0%	2%	20%	24%	54%	50
KS	3%	10%	23%	6%	3%	3%	3%	0%	71%	31
KY	0%	8%	10%	4%	0%	10%	27%	65%	4%	48
MI	13%	32%	42%	23%	21%	32%	54%	28%	15%	71
MN	0%	19%	37%	15%	11%	11%	52%	11%	22%	27
MO	9%	9%	34%	9%	3%	13%	6%	31%	25%	32
NE	23%	67%	70%	70%	0%	27%	30%	10%	3%	30
NJ	5%	8%	29%	9%	5%	31%	57%	27%	4%	100
NY	24%	14%	33%	18%	18%	22%	43%	30%	15%	164
OR	17%	16%	31%	17%	9%	28%	64%	18%	7%	130
UT	2%	14%	35%	4%	4%	22%	47%	20%	6%	49
VA	8%	20%	30%	14%	10%	22%	36%	30%	10%	50
Weighted NCI-IDD Average	14%	15%	30%	14%	10%	22%	45%	25%	16%	907

Table notes: AR, IN, NV excluded.

CO, GA, MA, NC, OH, OK, SC not shown due to low counts.

⁴ Please note: OR replaced “FMS” with “CME”



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