

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



National Report 2023-24

Self-Direction

3/9/26: Edited note on Table 1.

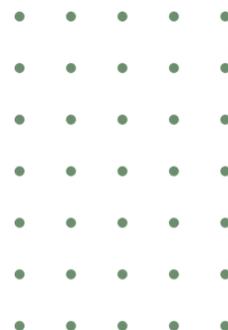


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Where do these data come from?

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 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. 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	Institutional Settings	Group Settings	Own Home or Apartment	Parent or Relatives Home	Host Home, Shared Living or Foster Care	N
AL	0%	65%	8%	27%	0%	600
AR	0%	13%	38%	46%	3%	389
CO	1%	21%	13%	45%	20%	1016
CT	0%	46%	11%	39%	4%	605
DE	0%	81%	0%	19%	0%	415
DC	9%	36%	33%	14%	9%	375
GA	0%	32%	12%	44%	12%	405
IL	1%	42%	7%	48%	3%	378
IN	11%	29%	9%	50%	1%	833
KS	2%	35%	16%	47%	0%	938
KY	0%	29%	9%	37%	26%	419
MD	1%	31%	10%	58%	0%	448
MA	0%	59%	11%	21%	9%	405
MI	0%	35%	17%	45%	2%	644
MN	0%	0%	15%	65%	20%	86
MO	0%	27%	37%	33%	3%	401
NE	6%	26%	19%	20%	28%	386
NV	0%	49%	13%	34%	4%	424
NJ	0%	68%	10%	20%	2%	488
NY	0%	51%	15%	33%	1%	1694
NC	10%	16%	7%	57%	10%	477
ND	14%	18%	41%	26%	0%	303
OH	0%	23%	39%	35%	3%	536
OK	0%	41%	17%	40%	3%	400
OR	0%	16%	11%	59%	14%	413
PA	5%	34%	12%	46%	2%	649
SC	1%	49%	10%	35%	4%	407
UT	7%	42%	9%	37%	6%	346
VA	0%	35%	8%	39%	18%	814
WI	1%	17%	21%	49%	11%	850
Weighted NCI-IDD Average	2%	37%	16%	40%	5%	16544

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

Charts and Tables

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

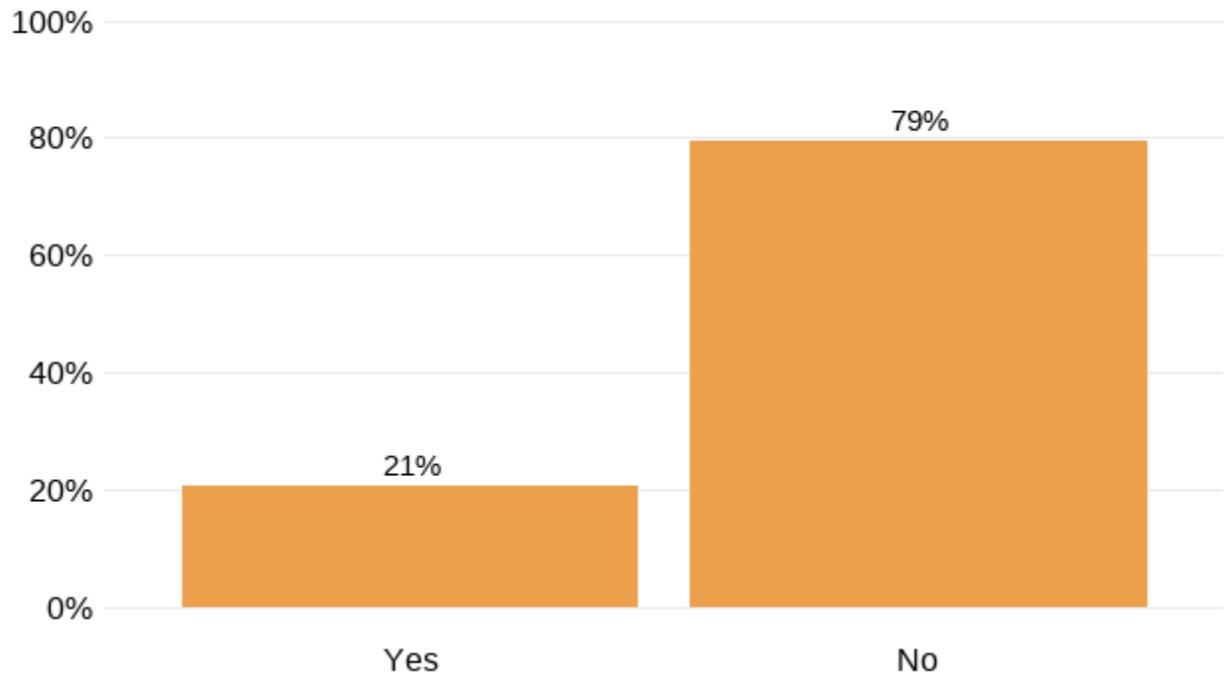


Table 1. Using a self-directed supports option*Information may have been obtained through state records*

State	Yes	No	N
AL	3%	97%	602
AR	n/a	n/a	n/a
CO	1%	99%	1045
CT	22%	78%	599
DE	10%	90%	415
DC	n/a	n/a	n/a
GA	2%	98%	405
IL	40%	60%	374
IN	n/a	n/a	n/a
KS	35%	65%	1170
KY	18%	82%	417
MD	8%	92%	452
MA	4%	96%	408
MI	19%	81%	638
MN	4%	96%	411
MO	15%	85%	403
NE	5%	95%	397
NV	n/a	n/a	n/a
NJ	8%	92%	495
NY	26%	74%	1699
NC	2%	98%	454
ND	5%	95%	407
OH	4%	96%	546
OK	5%	95%	400
OR	67%	33%	414
PA	16%	84%	651
SC	6%	94%	381
UT	28%	72%	337
VA	30%	70%	812
WI	51%	49%	941
NCI-IDD Average	21%	79%	15273

Table note: AR, IN, and NV do not offer self-direction. DC is not included, though a self-direction option is offered.

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

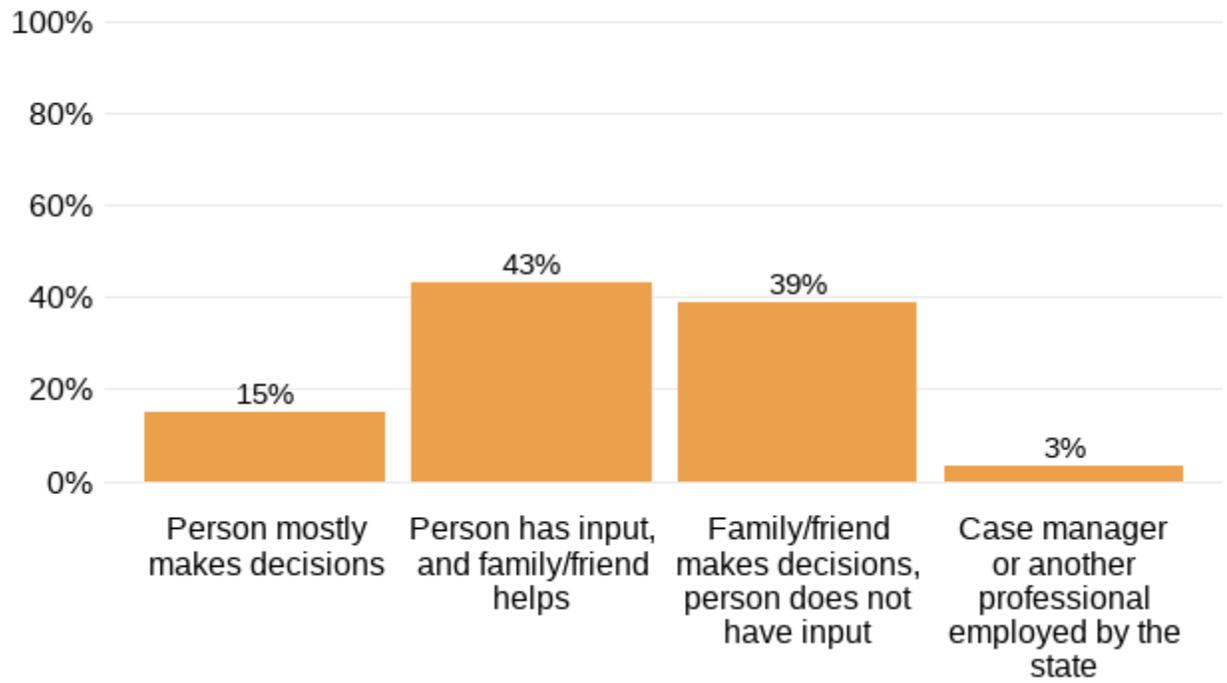


Table 2. People who make decisions or have input in making decisions about the services that are self directed

State	Person mostly makes decisions	Person has input, and family/friend helps	Family/friend makes decisions, person does not have input	Case manager or another professional employed by the state	N
AL	n/a	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a	n/a
CT	6%	32%	55%	7%	118
DE	5%	43%	45%	8%	40
DC	n/a	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a	n/a
IL	4%	56%	37%	2%	124
IN	n/a	n/a	n/a	n/a	n/a
KS *	6%	40%	53%	0%	228
KY	5%	75%	20%	0%	75
MD	12%	62%	26%	0%	34
MA	n/a	n/a	n/a	n/a	n/a
MI	7%	54%	37%	2%	100
MN	n/a	n/a	n/a	n/a	n/a
MO	12%	48%	38%	2%	60
NE	n/a	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a	n/a
NJ	0%	36%	64%	0%	42
NY	20%	44%	31%	5%	394
NC	n/a	n/a	n/a	n/a	n/a
ND *	n/a	n/a	n/a	n/a	n/a
OH *	n/a	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a	n/a
OR	25%	43%	28%	3%	253
PA *	17%	36%	40%	7%	58
SC	0%	9%	52%	39%	23
UT *	6%	28%	63%	3%	67
VA	7%	31%	62%	0%	213
WI	15%	32%	51%	2%	377
NCI-IDD Average	15%	43%	39%	3%	2344

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK. These responses are retained in NCI-IDD Average calculation. States with more than 25% missing or don't know responses are marked with an asterisk (*). AR, DC, IN, and NV do not offer self-direction.

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

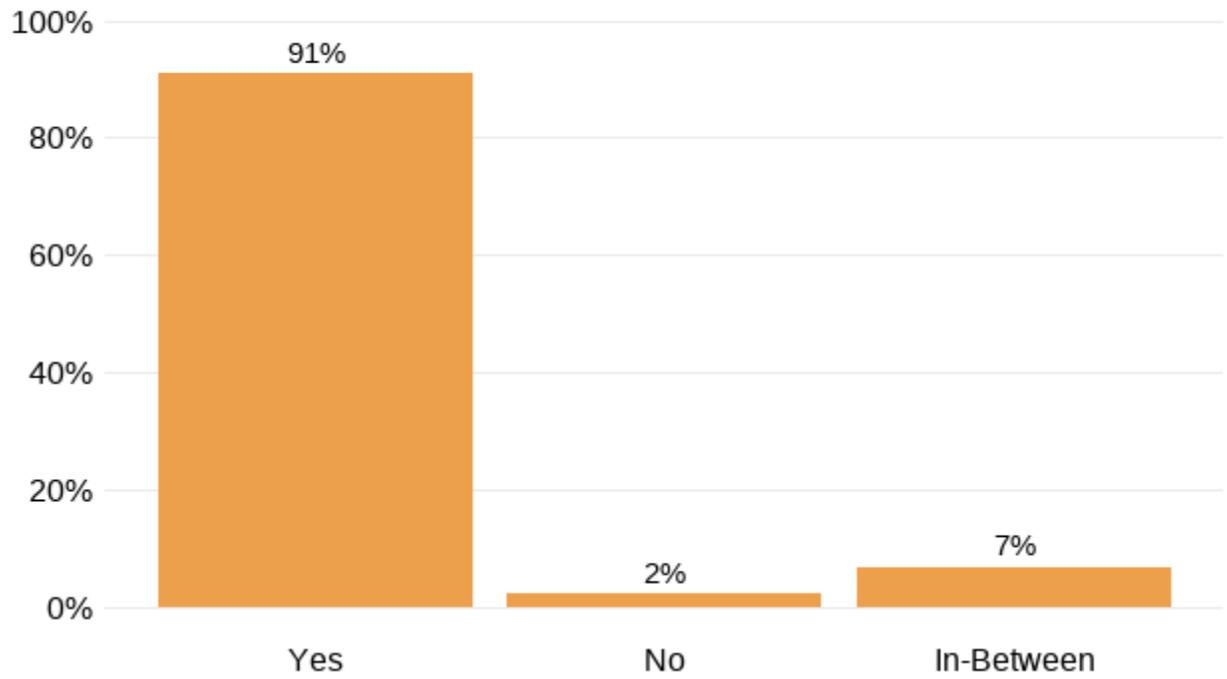


Table 3. Can make changes to individual budget/services if needed*Proxy respondents were allowed for this question*

State	Yes	No	In-Between	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	93%	3%	4%	94
DE	64%	18%	18%	33
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	95%	1%	4%	99
IN	n/a	n/a	n/a	n/a
KS	95%	1%	4%	210
KY	100%	0%	0%	66
MD	97%	0%	3%	32
MA	n/a	n/a	n/a	n/a
MI	86%	2%	12%	84
MN	n/a	n/a	n/a	n/a
MO	96%	0%	4%	48
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	94%	6%	0%	32
NY	93%	2%	5%	334
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	84%	4%	12%	230
PA	95%	0%	5%	44
SC	n/a	n/a	n/a	n/a
UT	98%	0%	2%	53
VA	85%	5%	10%	203
WI	93%	2%	6%	352
NCI-IDD Average	91%	2%	7%	2027

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

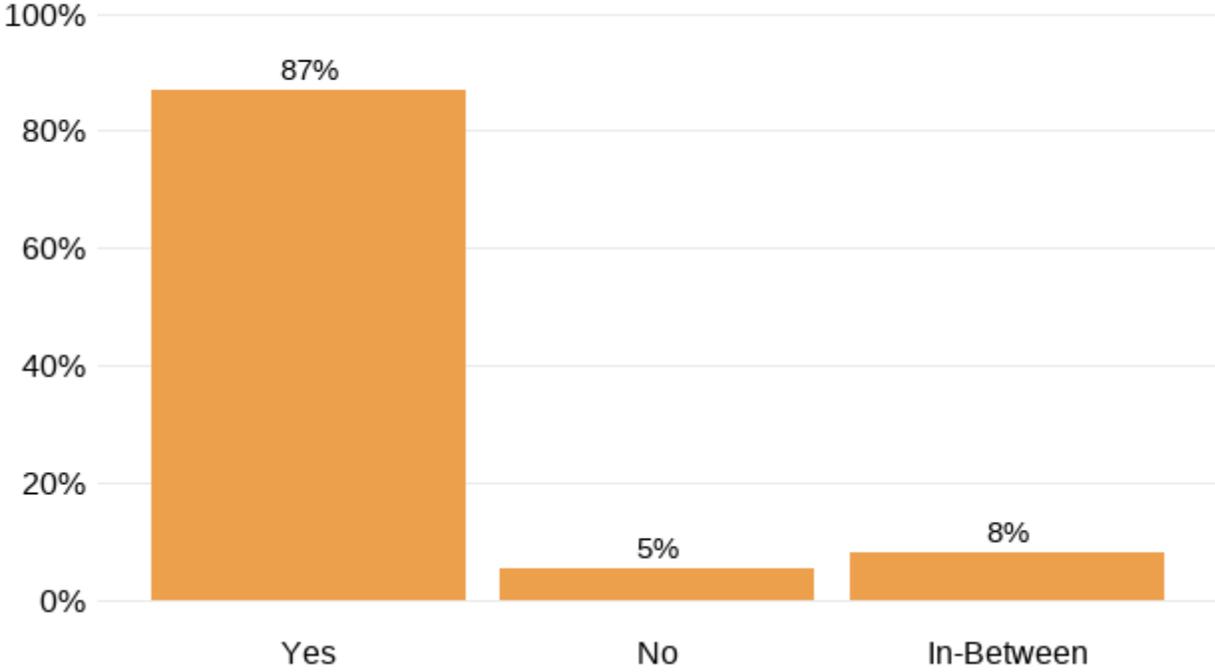


Table 4. Has enough help deciding how to direct services*Proxy respondents were allowed for this question*

State	Yes	No	In-Between	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	81%	15%	4%	96
DE	67%	6%	27%	33
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	97%	0%	3%	99
IN	n/a	n/a	n/a	n/a
KS	89%	5%	6%	211
KY	100%	0%	0%	65
MD	91%	0%	9%	33
MA	n/a	n/a	n/a	n/a
MI	75%	6%	19%	81
MN	n/a	n/a	n/a	n/a
MO	100%	0%	0%	49
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	85%	9%	6%	34
NY	88%	6%	6%	336
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	81%	8%	12%	234
PA	90%	0%	10%	42
SC	n/a	n/a	n/a	n/a
UT	93%	0%	7%	54
VA	84%	6%	9%	204
WI	88%	4%	8%	353
NCI-IDD Average	87%	5%	8%	2040

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

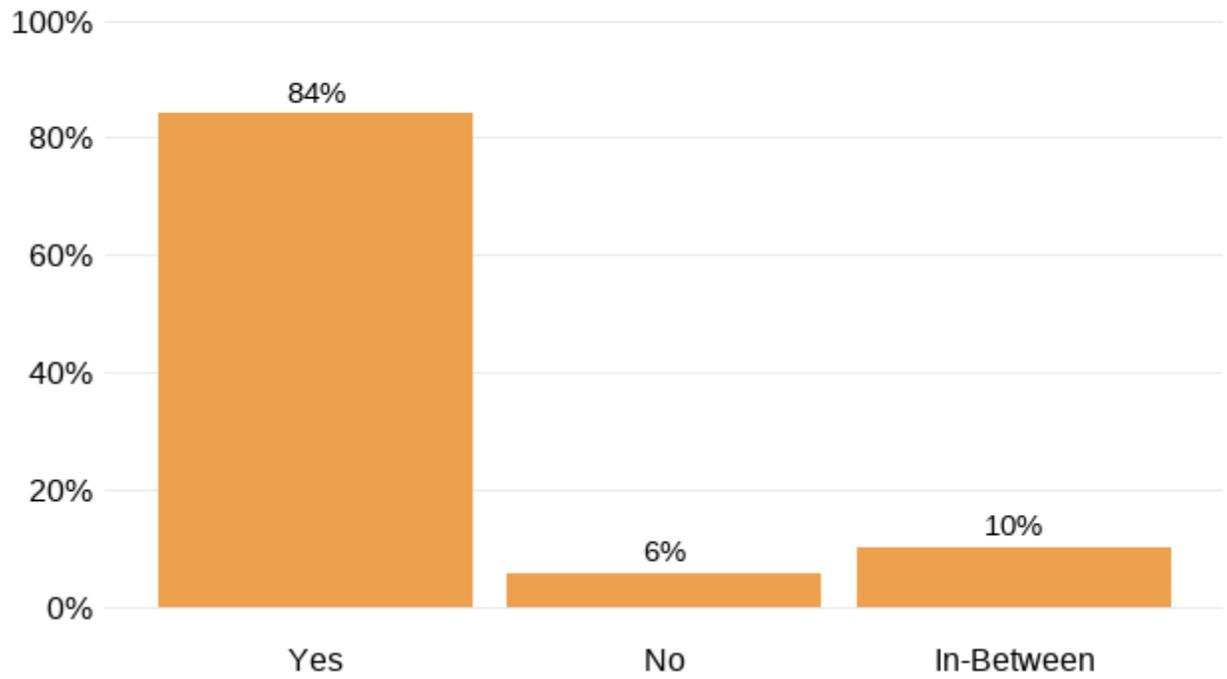


Table 5. Has the amount of control wanted with the services that are self-directed*Proxy respondents were allowed for this question*

State	Yes	No	In-Between	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	86%	6%	7%	96
DE	58%	15%	27%	33
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	95%	0%	5%	98
IN	n/a	n/a	n/a	n/a
KS	91%	3%	6%	207
KY	100%	0%	0%	66
MD	85%	6%	9%	33
MA	n/a	n/a	n/a	n/a
MI	71%	5%	24%	84
MN	n/a	n/a	n/a	n/a
MO	98%	0%	2%	49
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	82%	0%	18%	34
NY	82%	8%	9%	330
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	82%	6%	12%	231
PA	90%	2%	7%	42
SC	n/a	n/a	n/a	n/a
UT	85%	0%	15%	52
VA	81%	7%	12%	203
WI	86%	6%	8%	352
NCI-IDD Average	84%	6%	10%	2022

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

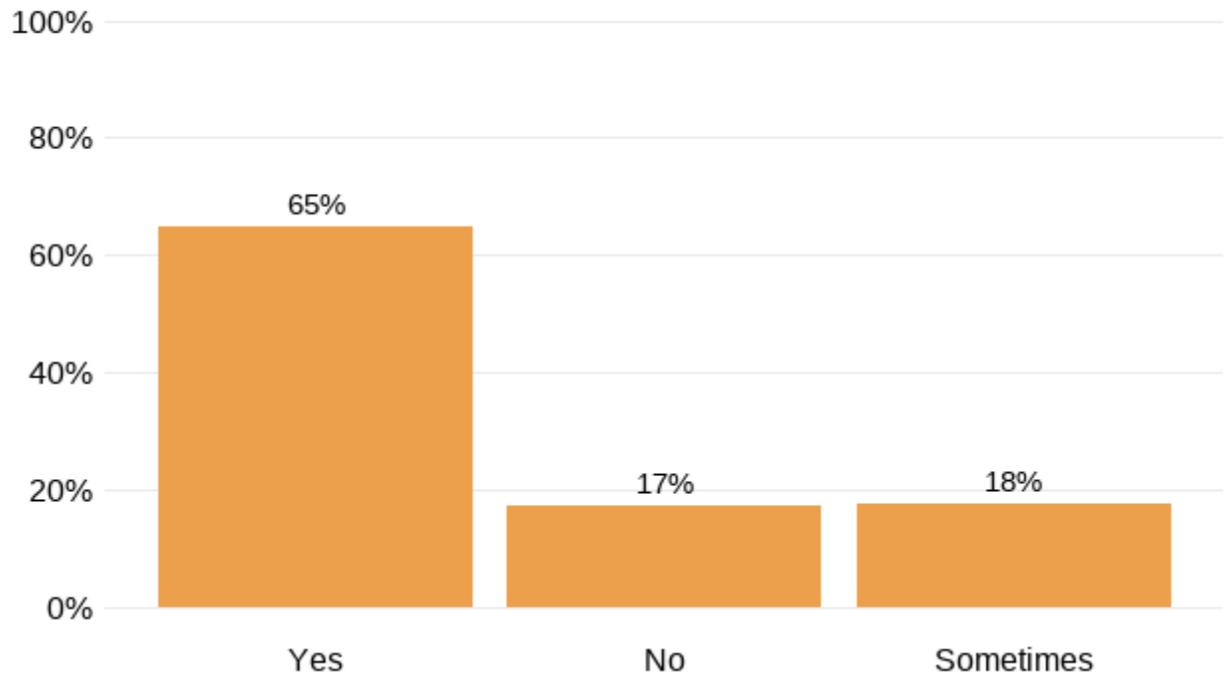


Table 6. The services and supports they want to self-direct are always available. This includes things like having the services that they want available when they want them and having enough staff to hire.

Proxy respondents were allowed for this question

State	Yes	No	Sometimes	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	62%	23%	15%	95
DE	39%	18%	42%	33
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	88%	1%	11%	99
IN	n/a	n/a	n/a	n/a
KS	67%	18%	14%	208
KY	92%	2%	6%	66
MD	63%	13%	25%	32
MA	n/a	n/a	n/a	n/a
MI	49%	23%	29%	84
MN	n/a	n/a	n/a	n/a
MO	64%	22%	14%	50
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	70%	18%	12%	33
NY	63%	19%	17%	332
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	63%	15%	22%	227
PA	68%	8%	25%	40
SC	n/a	n/a	n/a	n/a
UT	52%	4%	44%	52
VA	49%	31%	20%	203
WI	69%	19%	12%	350
NCI-IDD Average	65%	17%	18%	2016

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

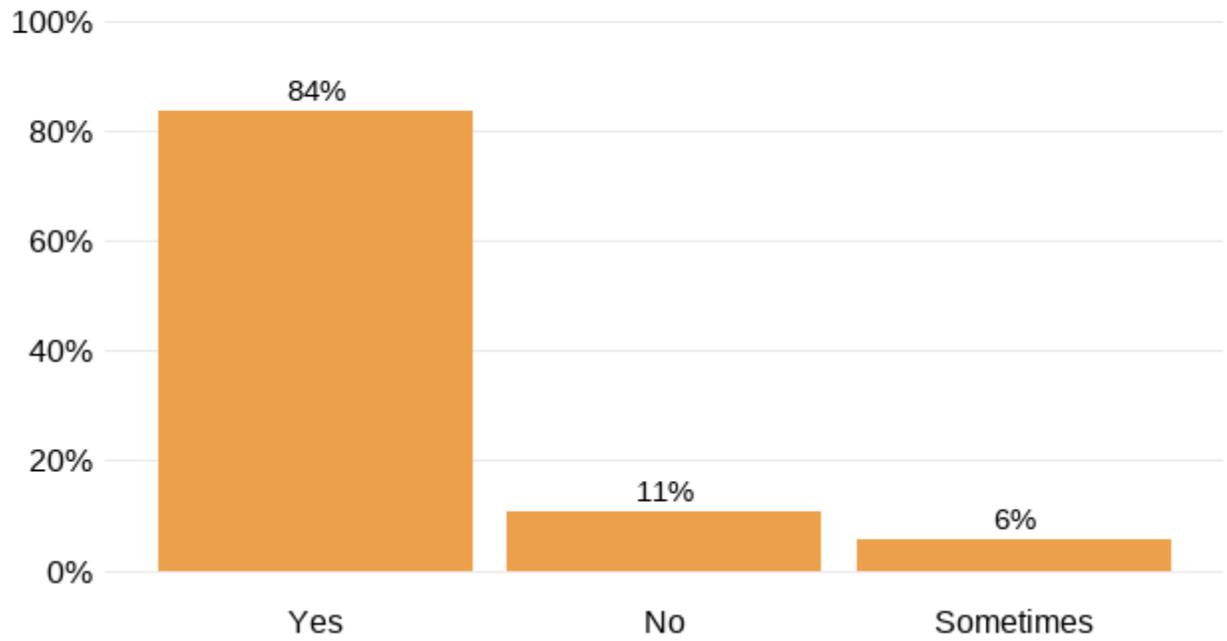


Table 7. Gets information about budget and services from financial management service (FMS)*Proxy respondents were allowed for this question*

State	Yes	No	Sometimes	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	87%	10%	3%	97
DE	38%	34%	28%	29
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	87%	5%	7%	94
IN	n/a	n/a	n/a	n/a
KS	55%	40%	5%	197
KY	100%	0%	0%	52
MD	85%	15%	0%	33
MA	n/a	n/a	n/a	n/a
MI	78%	12%	10%	82
MN	n/a	n/a	n/a	n/a
MO	88%	6%	6%	49
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	64%	30%	6%	33
NY	93%	6%	2%	328
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	87%	5%	8%	228
PA	81%	5%	14%	42
SC	n/a	n/a	n/a	n/a
UT	57%	7%	36%	44
VA	59%	35%	5%	202
WI	81%	15%	4%	347
NCI-IDD Average	84%	11%	6%	1965

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. States with more than 25% missing or don't know responses are marked with an asterisk (*). AR, DC, IN, and NV do not offer self-direction.

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

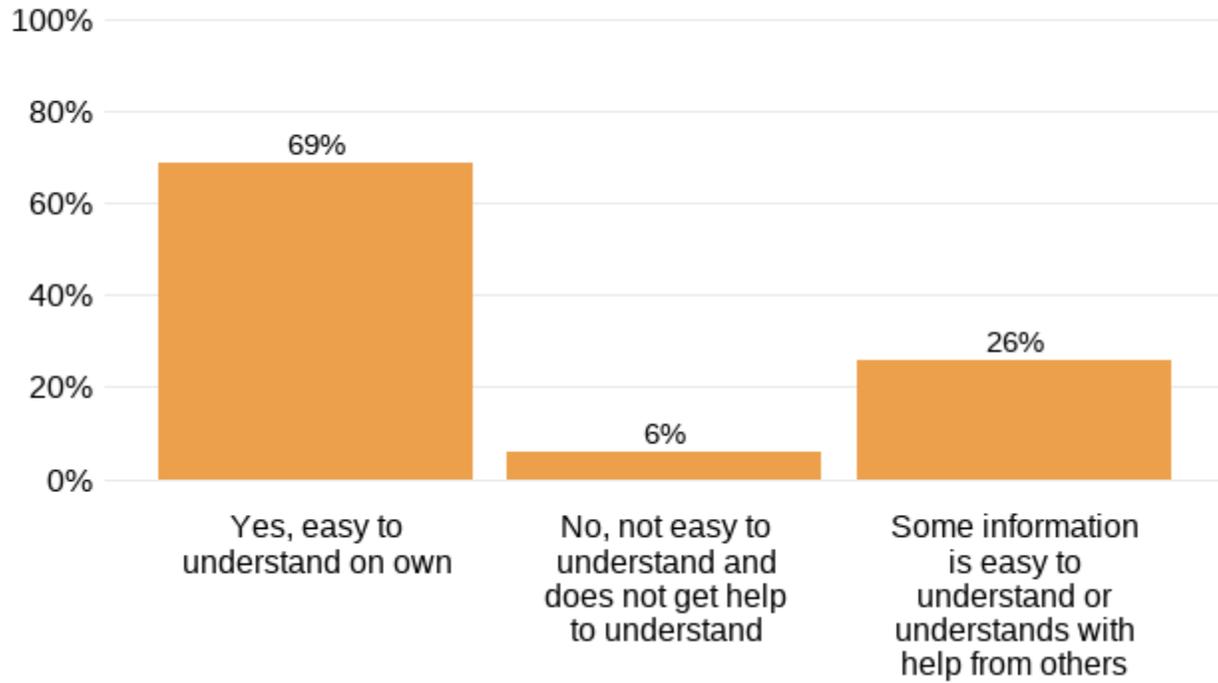


Table 8. Information from FMS is easy to understand*Proxy respondents were allowed for this question*

State	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
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	78%	7%	15%	81
DE	n/a	n/a	n/a	n/a
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	74%	3%	24%	80
IN	n/a	n/a	n/a	n/a
KS	81%	3%	17%	103
KY	80%	0%	20%	51
MD	52%	19%	30%	27
MA	n/a	n/a	n/a	n/a
MI	52%	11%	37%	62
MN	n/a	n/a	n/a	n/a
MO	45%	12%	43%	42
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	80%	0%	20%	20
NY	71%	4%	25%	302
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	74%	3%	22%	196
PA	77%	0%	23%	31
SC	n/a	n/a	n/a	n/a
UT	44%	4%	52%	25
VA	70%	2%	28%	118
WI	61%	11%	28%	278
NCI-IDD Average	69%	6%	26%	1500

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, DE, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

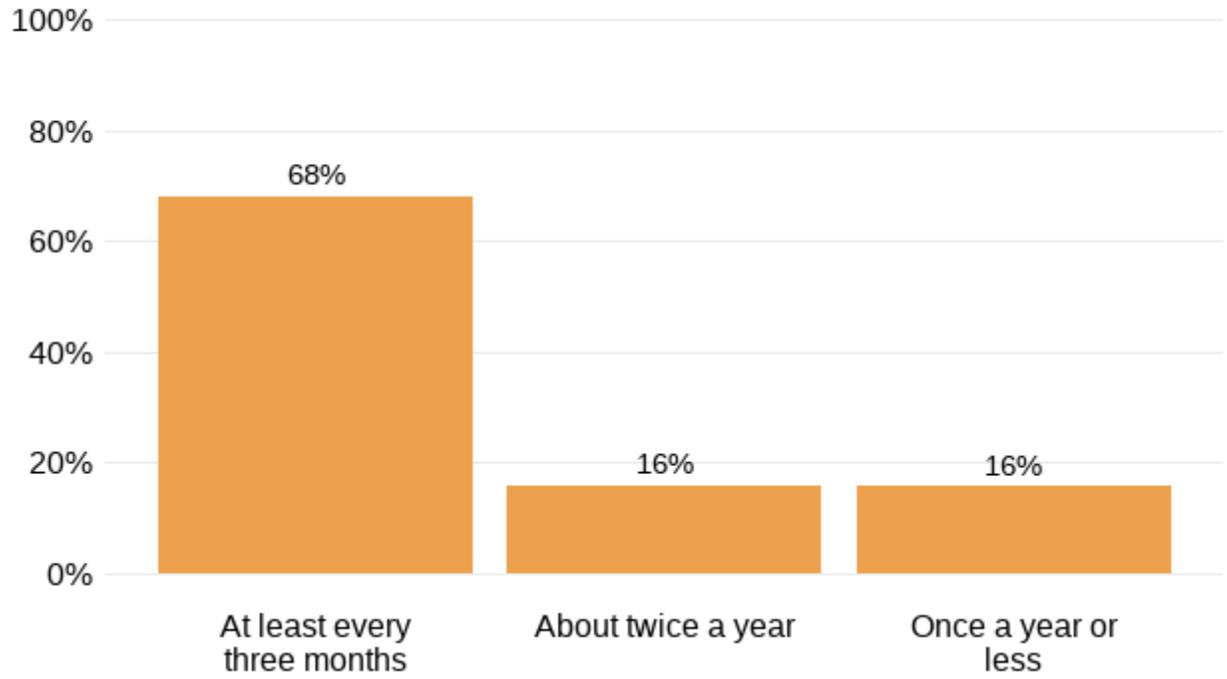


Table 9. Frequency with which the person gets information from FMS*Proxy respondents were allowed for this question*

State	At least every three months	About twice a year	Once a year or less	N
AL	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a
CT	86%	4%	9%	74
DE	n/a	n/a	n/a	n/a
DC	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a
IL	35%	32%	32%	71
IN	n/a	n/a	n/a	n/a
KS	67%	13%	20%	93
KY	83%	2%	15%	52
MD	73%	18%	9%	22
MA	n/a	n/a	n/a	n/a
MI	73%	9%	18%	56
MN	n/a	n/a	n/a	n/a
MO	98%	0%	3%	40
NE	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a
NJ	n/a	n/a	n/a	n/a
NY	80%	15%	5%	284
NC	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a
OR	36%	26%	38%	194
PA	54%	36%	11%	28
SC	n/a	n/a	n/a	n/a
UT	55%	36%	9%	22
VA	49%	13%	38%	113
WI	87%	6%	6%	267
NCI-IDD Average	68%	16%	16%	1411

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, DE, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.

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

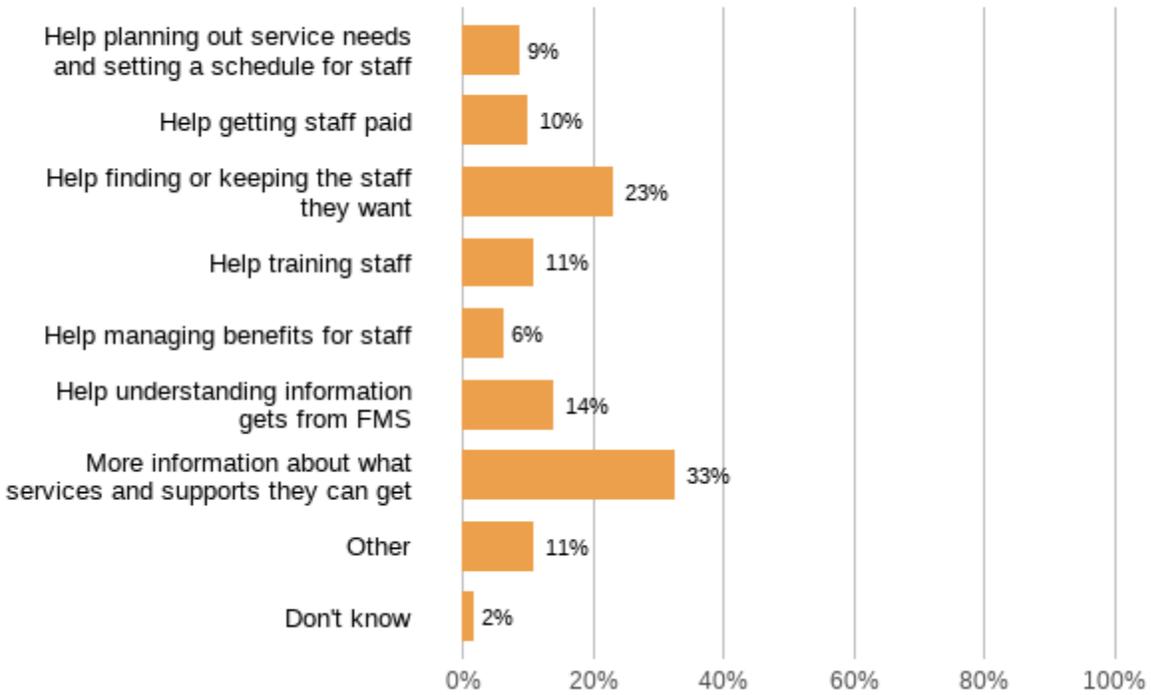


Table 10. Needs help with these elements of self direction

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
AL	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
AR	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
CO	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
CT	7%	19%	29%	15%	10%	17%	43%	22%	1%	96
DE	6%	3%	9%	6%	0%	15%	27%	12%	3%	33
DC	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
GA	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
IL	0%	3%	2%	0%	1%	0%	3%	1%	3%	100
IN	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
KS	6%	9%	24%	9%	7%	16%	27%	20%	1%	210
KY	0%	0%	8%	0%	0%	4%	6%	2%	0%	52
MD	12%	24%	36%	21%	12%	39%	45%	21%	0%	33
MA	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
MI	6%	21%	34%	15%	7%	26%	48%	31%	1%	85
MN	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
MO	0%	4%	24%	2%	2%	20%	2%	10%	2%	50
NE	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NV	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NJ	6%	25%	19%	9%	9%	6%	19%	9%	3%	32
NY	14%	12%	31%	15%	11%	19%	41%	12%	2%	342
NC	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
ND	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
OK	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
OR	9%	3%	12%	9%	2%	9%	29%	7%	1%	237
PA	2%	2%	5%	2%	2%	5%	18%	2%	5%	44
SC	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
UT	4%	11%	8%	2%	4%	2%	28%	2%	2%	53
VA	6%	10%	39%	15%	2%	5%	39%	28%	0%	205
WI	8%	9%	23%	9%	6%	15%	40%	6%	0%	350
NCI-IDD Average	9%	10%	23%	11%	6%	14%	33%	11%	2%	2037

Table note: Data display is suppressed (i.e. shown as n/a) for the following states with low counts of responses (n<20): AL, CO, GA, MA, MN, NE, NC, ND, OH, OK, SC. These responses are retained in NCI-IDD Average calculation. AR, DC, IN, and NV do not offer self-direction.



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April 2025

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