

Self-Direction Experiences in Massachusetts

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PRESENTERS



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MDDDC Mission

Our mission is to empower individuals with intellectual and developmental disabilities (IDD) and their families to lead successful lives in their communities by promoting self-sufficiency, community inclusion, and opportunity.



What is MA21?

- The Massachusetts Alliance for 21st Century Disability Policy (MA21) was formed in 2007 to protect the rights of people with disabilities to self-direct, and through its efforts helped pass the Real Lives Law in 2014.
- MA21 is a partnership of self-advocates, family members, other stakeholders and disability advocacy organizations, including:
 - The Arc of Massachusetts
 - Massachusetts Advocates Standing Strong (MASS)
 - MassFamilies
 - Massachusetts Down Syndrome Congress (MDSC)
 - Advocates for Autism of Massachusetts (AFAM)
 - Massachusetts Sibling Support Network (MSSN)
 - Disability Law Center (DLC)
 - Massachusetts Developmental Disabilities Council (MDDC)



Survey Introduction

Self-Direction Experiences Survey



Aim:

- Explore self-direction experiences of MA residents
- Share findings with community members and DDS



Development:

- Informed by established self-direction measures
- MA21 input and feedback
- DDS input and feedback



Administration:

- Community collaboration for recruitment
- Thank YOU for your help!

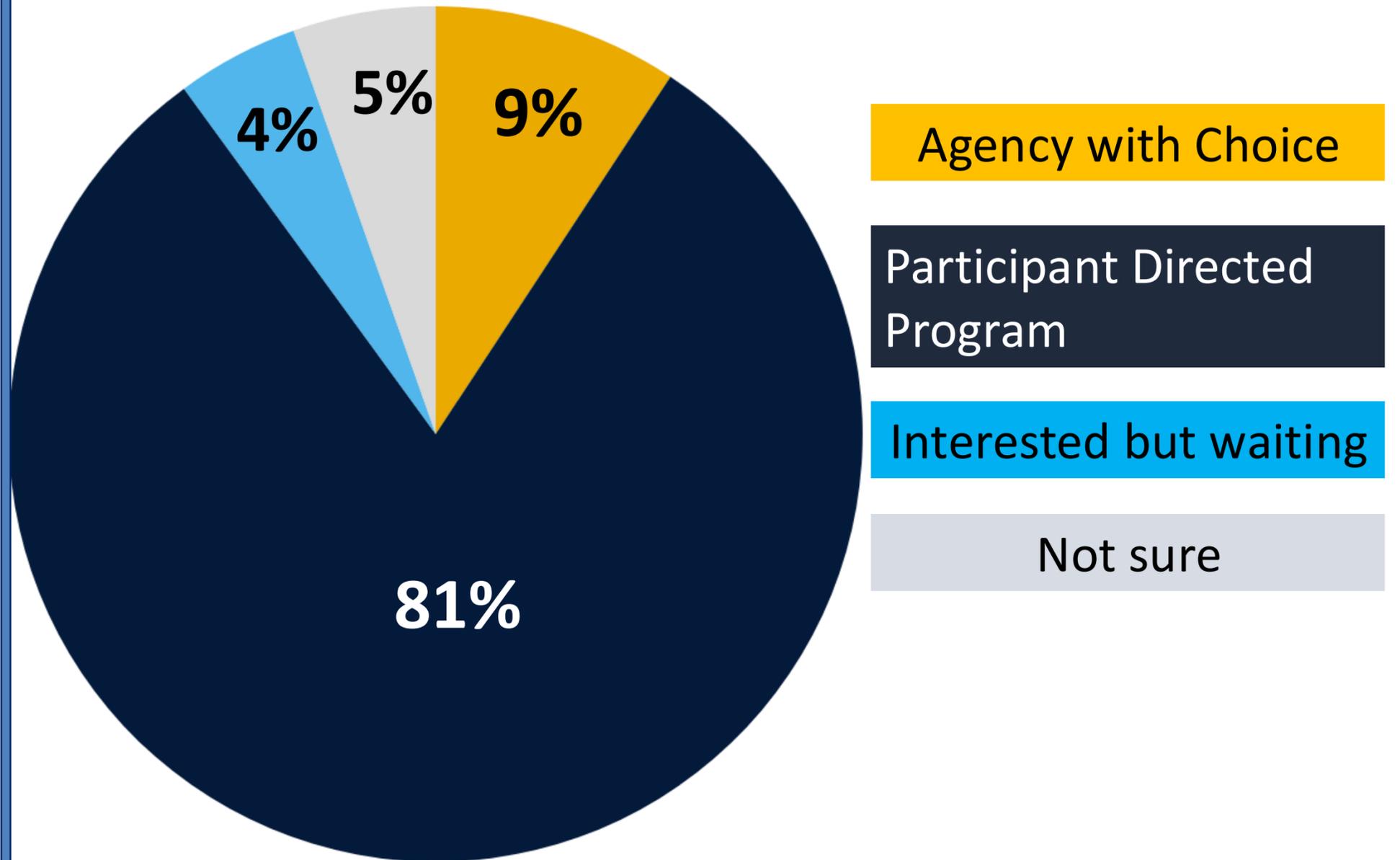
Who took our survey



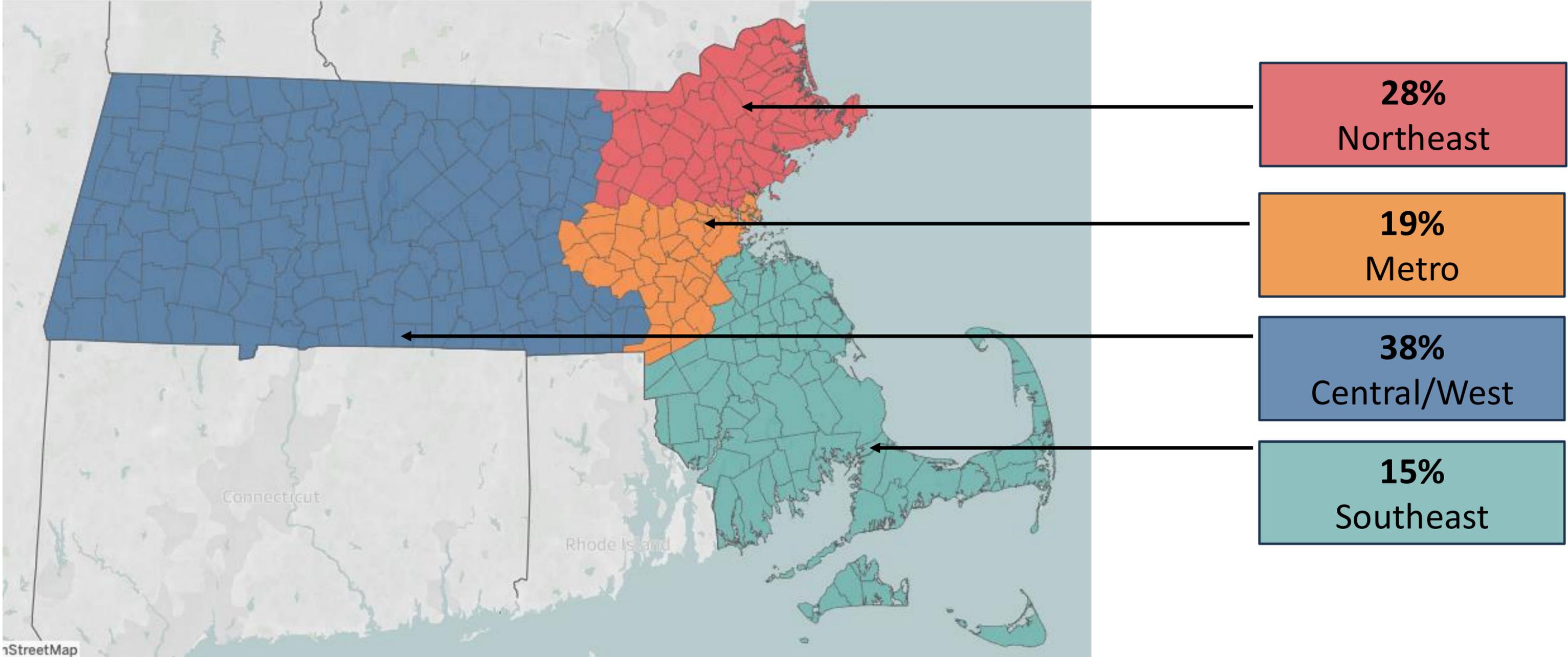
A total of **259** provided usable responses to our survey

- **84%** of participants were family members
- **10%** were people with intellectual and/or developmental disabilities (I/DD)
- **6%** had a different relationship with Self-Direction

Self-Direction Models Represented



Survey Participants: DDS Region



[DDS Regional Office Map](#)

*based on 174 of 259 responses

We collected information in different ways.

1. Sometimes participants were asked to **choose an answer** from different options.



- This helped us understand the proportion of, or how many, people had certain experiences.
- We created **charts** about these findings.

2. Participants were also invited to write **open-ended responses**.



- This helped us understand their unique stories and experiences.
- We share selected **quotes** to illustrate these findings.



Preliminary Findings

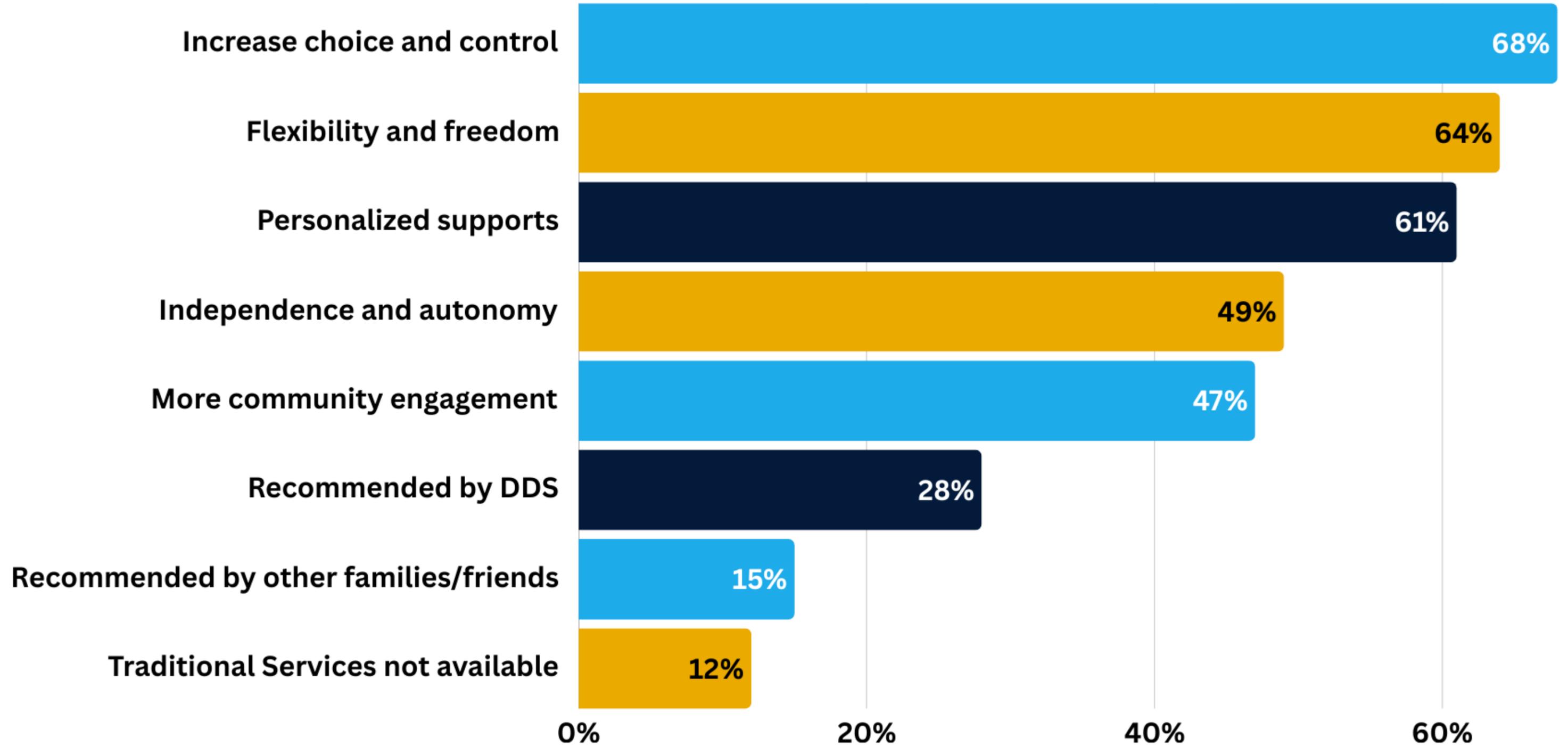


Self-Direction Experiences

Why Self-Direct?



Why Self-Direct?



Increase Choice and Control



“I chose self-direction because I want to have more control over my life, who supports me, how I spend my days, and the goals I am working toward. It lets me build a team I trust and create a life that really fits ME.”

- Individual Self-Directing

Flexibility and Freedom



“I love self-direction because it allows be to access activities and supports that I need and want. I love Unified who I do virtual workouts with, I love [Robin] I cook with her, I love my art therapist [Mary], I have a therapist, my brother [Rob] is a great role model for me and we do fun things. Being able to Uber to my job ... on Tuesdays and sometimes You're With Us at Gordon College. Makes me very independent and I love that.”

- Individual self-directing

“We love the flexibility of self-direction and the ability to explore new things or shift as things - like available mentors or programs – shift”

– Family member

Personalized Supports



“Not everyone has the same needs, and PDP lets us decide and try different things we think might work well or help, and if they don't we can change it and try something else”

- Family member

More Community Engagement



“When we have staff available, my daughter is in the community every day, working part time, volunteering doing something she loves, going to the gym, learning and practicing independent living skills. She enjoys the choice and freedom she has and feels bad for her friends who sit at home or in programs. She lives a meaningful life.”

- Family member

Independence and Autonomy



“I get to choose my own staff and keep people I trust. I like being able to plan my own schedule so I can balance my support time with my work.”

- Individual self-directing

Traditional Services not Available or Suitable



“Traditional program options were wholly inadequate to meeting the goals of my son's life, to continue to develop skills to participate in life in the community.”
- Family member

Self-Direction Experiences

Wins and what's working well



Self-Direction: What's Working Well



**People with I/DD
are involved in
decisions about
Self-Direction**



**Personalized
Services and
Supports**



**Control over
services and
supports**

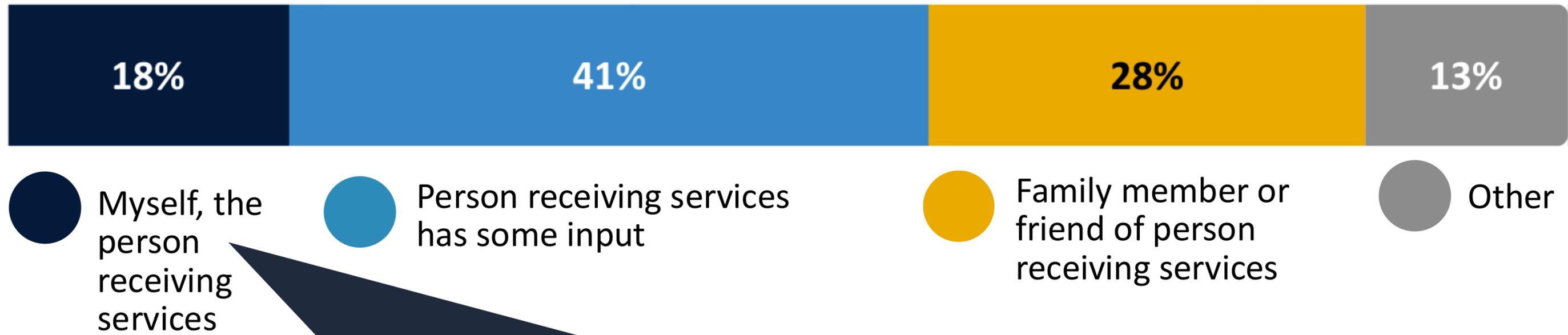


**Authority to hire
staff people want
to work with**



Decision-Making Power

Who makes the decisions about your self-directed services?



“There is so many things in the community I choose where I go to work, going school, volunteering, self- advocacy groups, singing lessons, going to the Gym, going to see plays.”
- Individual self-directing

Are the services and supports you receive personalized to your needs and goals?



 No  Sometimes  Yes

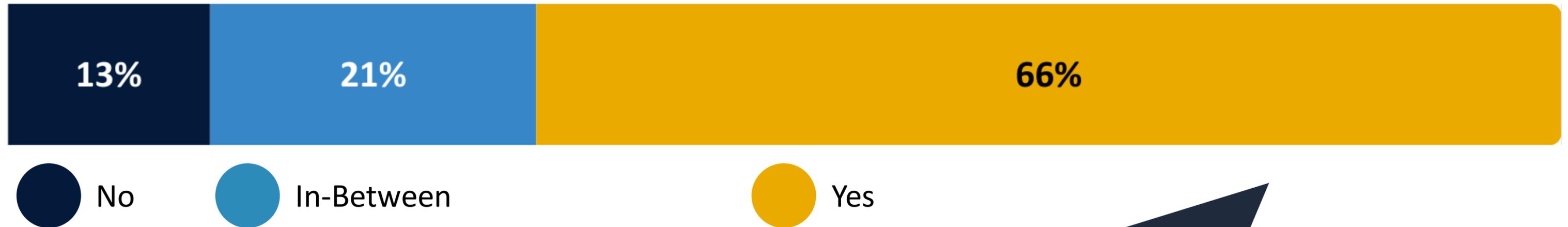
“My son is really able to mold his programming for what he needs. He has a combination of CBDS, employment support, in home support and flex funding that covers his recreational expenses.”

- Family member

“Self-directed choice allowed us to create a mold that is fitted just for our daughter. In so doing, we don’t have to force her into other molds that were created by others for other clients.”

- Family member

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



“Choice in staff that my son likes to be around and that are qualified to help him and enjoyable for him to spend time with. Ability to do what my son wants - play sled hockey, drum in a band, work at Fenway Park, go to the gym - my son needs help with doing all of this and self-directions provides that support to let him live his life in the community.”

- Family member

Hiring Staff

Do you feel like you have employer authority?



*“Freedom to hire personnel from similar cultural background and racial identity.”
-Family Member*

*“My brother requires a one/one and he’s had a lot of really bad ones! Self-direction allows us to pick our own person.”
- Family member*

Theme:

Self-Direction as *response* to the Direct Care Workforce Crisis

“The CBDS serving both my DDS-served sons goes through good waves, when staff take the guys into the community, and waves of low staffing where they sit around doing nothing in the building, the antithesis of the term Community-Based. By self-directing two days a week I get two days where I can assure my sons follow their interests and don't just sit around.”
- Family member

Theme:

Self-Direction as a pathway to hire quality, trusted staff

I worked with my caregiver before [group home] while I was still on the street, then with [group home] and when she retired she was asked to come back to work with me. I'm glad because I trust her and she treats me with respect. A lot of people don't treat people like me with respect, they think we are less."

-Individual self-directing

Theme:

Self-Direction *impacted by* the Direct Care Workforce Crisis

“There is a financial, physical and emotional toll on our family. Also in 14 years of doing this, there has been no change in our budget although I am just now starting to address with DDS. Up until now, the budget has worked because it is impossible to stay fully staffed at any time due to work force crisis. I need so many staff people because we cannot offer full time benefits due to our AWC partners unaffordable health plan costs that would be passed on to my sons’ budget.”

-Family Member

Paying Family Caregivers

Do you pay a family caregiver through Self-Direction?



“I would like to see the ability to pay family members be less restrictive. Especially the ability to pay guardians. When the guardian has to step in to work and complete the same activities the paid staff is, but is unable to due to illness or vacation, they should not have to do this without pay.”

- Family member

Self-Direction Experiences

Challenges and Areas to Change



Self-Direction: Challenges and Areas to Change



**Need for
more
information
about service
and support
options**



**Need more
support for finding
and hiring staff**

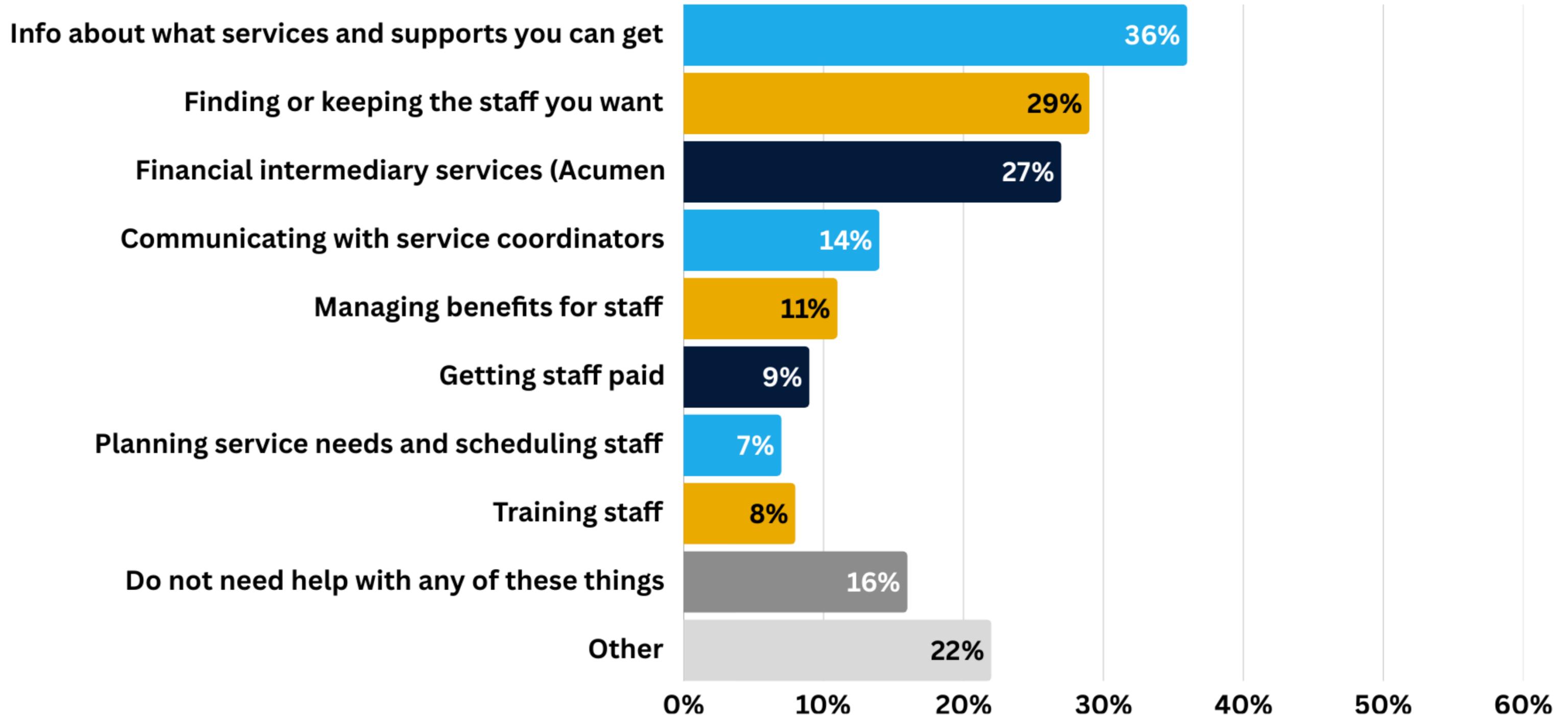


**Financial
Intermediary
(Acumen)
platform is not
accessible**



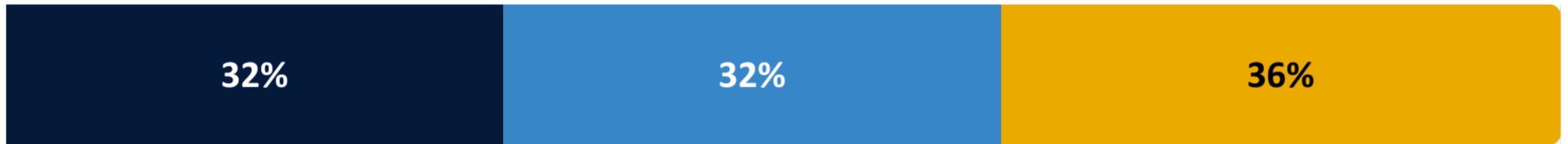
**Budgets are
not enough to
meet service
needs**

Self-Direction Support Needs



Availability of Services and Supports

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



No



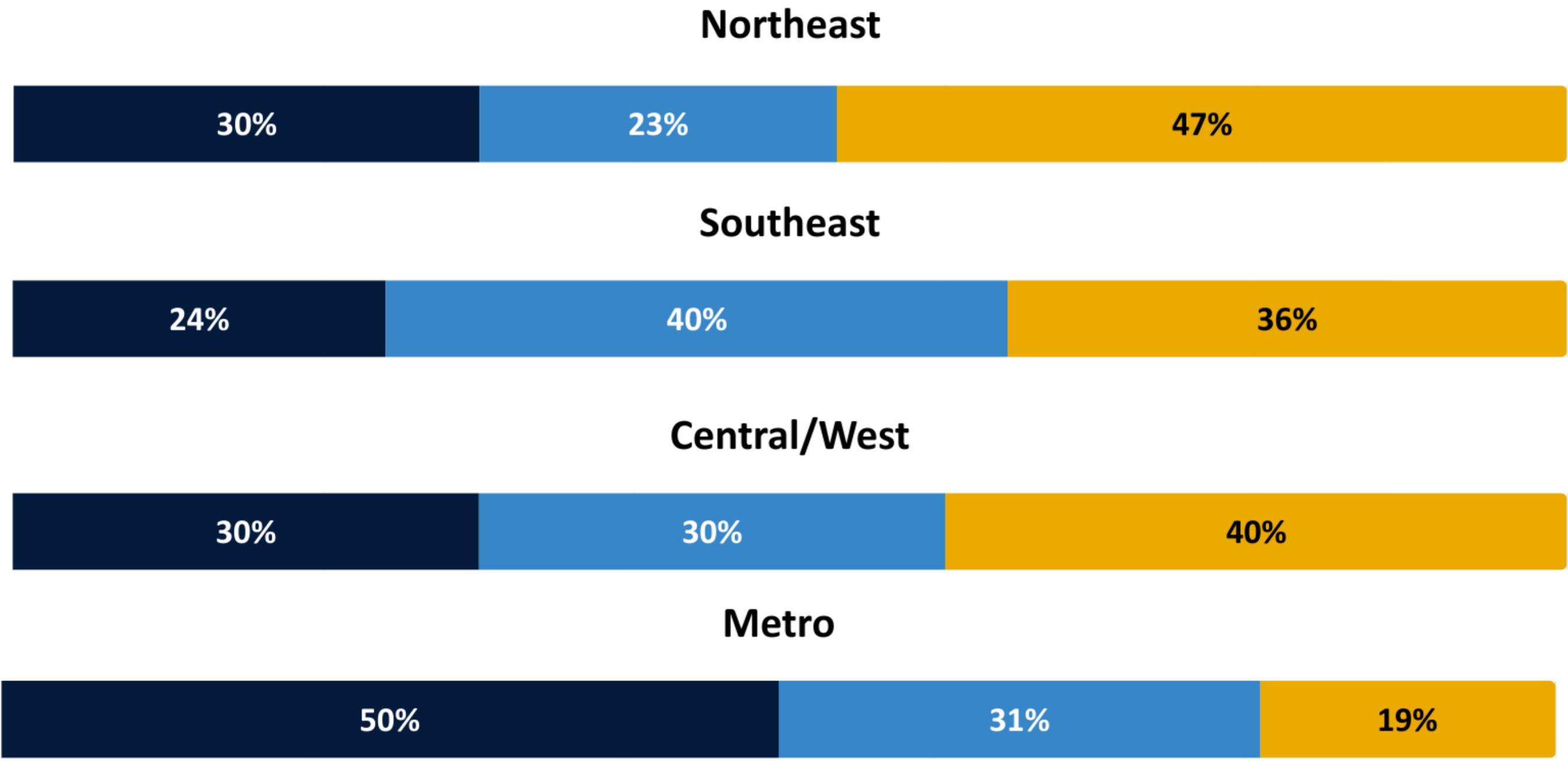
Sometimes



Yes

“We would like more flexibility in how we can use self-direction funds to support my son's person-centered plan. We are still in a space where I feel we hear about support that is available, only to then hear that it only is available under certain conditions (Agency with Choice instead of PDP, traditional services, etc.). Being able to have the services really meet the needs of the individual without restricting people to certain "programs" or codes would be really helpful.”

Availability of Services and Supports by Region

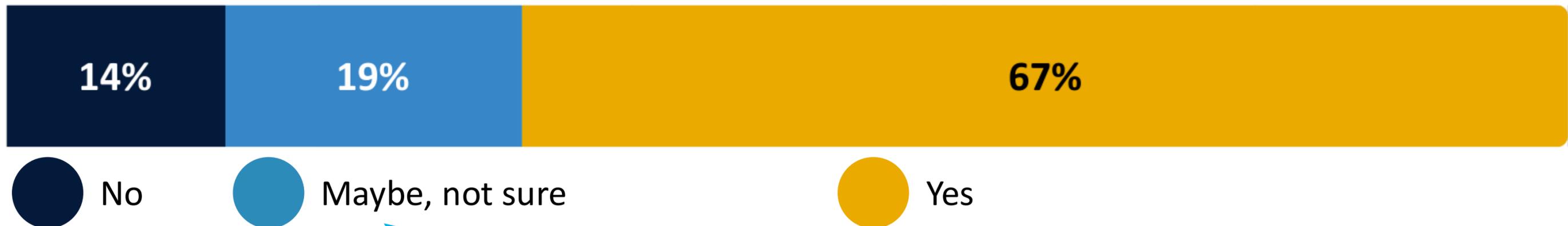


Differences are **not** statistically significant; only based on respondents who provided regional information

No
 Sometimes
 Yes

PDP: Access to Acumen Platform

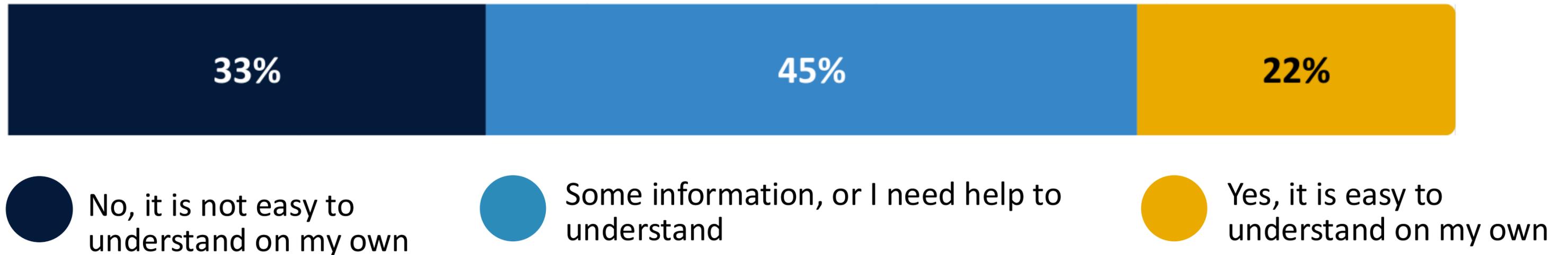
Are you able to access information about your budget and services from Acumen?



“Acumen is a big issue ...it is not user friendly ... not for the staff and to me managing the services.”

* Among PDP participants

Is the information you get from Acumen easy to understand?



“Fiscal Intermediary needs to be a simpler format with ability for simple access and viewing. Acumen is way too complex. I don't care to analyze information many different ways. I just want to see the basics. Who the providers are, have they been paid and when, what has been spent in each category and what is left.” – Family Member

Theme: Acumen Platform is difficult to understand

“My experience with PPL and Acumen has been frustrating and at some times totally unacceptable. DDS needs to pressure Acumen to update it's technology with regard to time entries, approval of hours, identifying budget numbers, and being able to access budget data in more comprehensive formats. Implementation of Acumen was a disaster which has leveled out, but the technology platform is marginal at best.”

Theme: Acumen and Administrative Burden

“Submitting forms for reimbursement to my DDS office is an onerous process that requires me to purchase a PDF converter program -at my own cost, then convert receipts. My current PDP program manger rejects screen shots and photos of receipts, when in the past this was acceptable. This creates more work and more time for a family.”

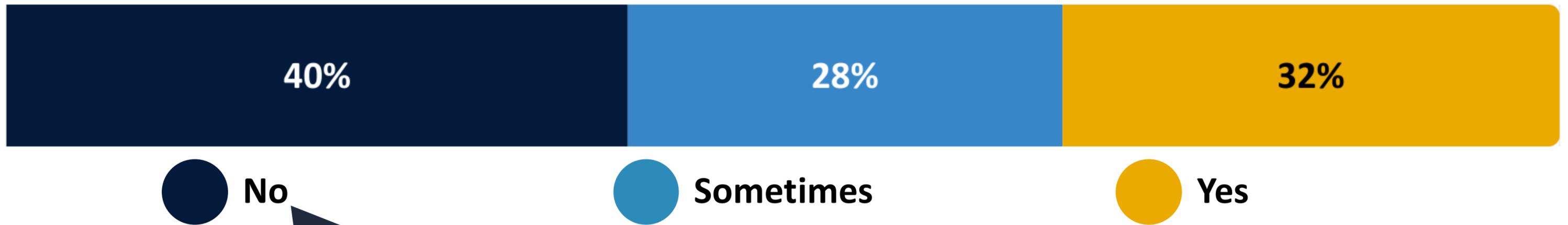
– Family Member

“The budget process is not user friendly. From the very beginning the process with DDS, PPL and now Acumen present a tremendous amount of paperwork which drains our time even more.”

– Family Member

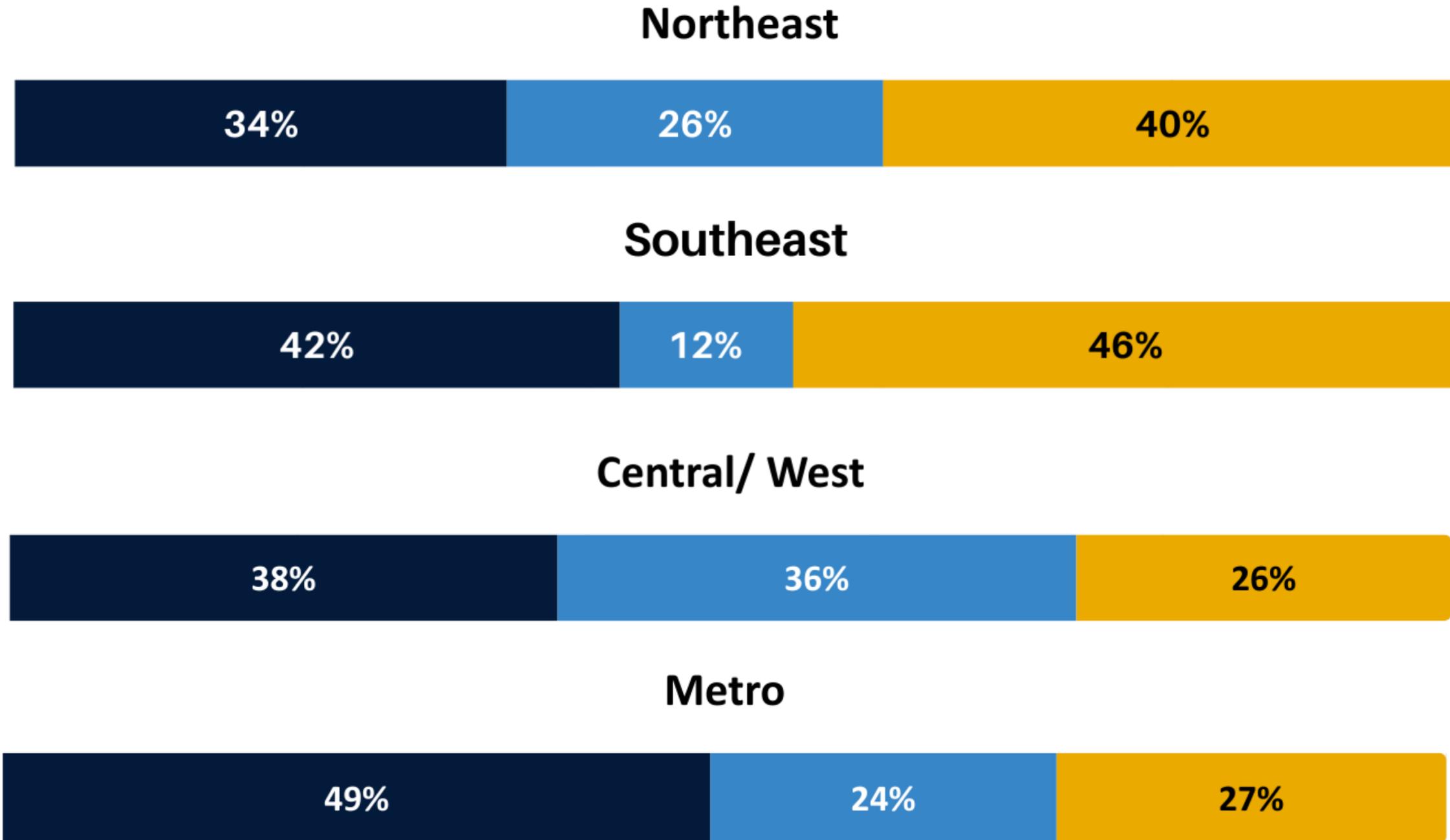
Self-Direction Challenges: Adequate Budget

Is your budget enough money for the services that you need?



“Our son's needs have significantly increased, and we will need to give raises to our staff to keep up with the increased needs (he has an intellectual disability and this year he suffered an accident and now has a spinal cord injury). We could also use more support on non-traditional days (weekends/evenings).” – Family Member

Self-Direction Challenges: Adequate Budget



Differences are **not** statistically significant; only based on respondents who provided regional information

No
 Sometimes
 Yes

Self-Direction Challenges: Changing Needs

Have your service and support needs changed during your time using Self-Direction?

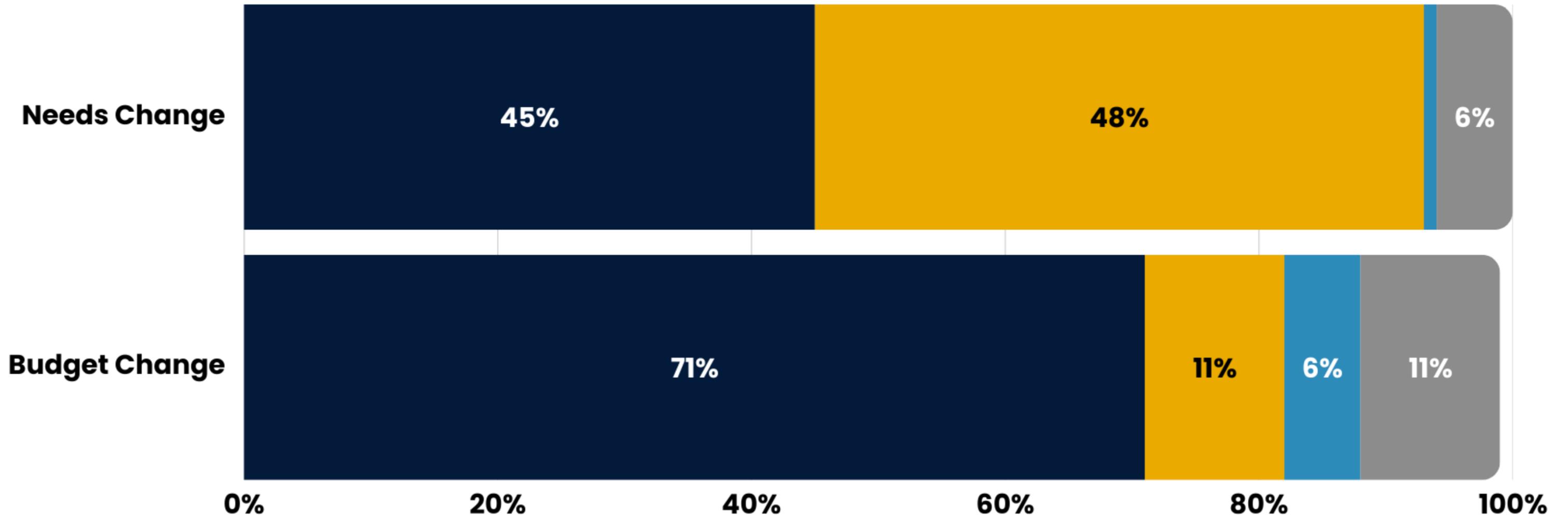


“Our son's needs have significantly increased, and we will need to give raises to our staff to keep up with the increased needs (he has an intellectual disability and this year he suffered an accident and now has a spinal cord injury). We could also use more support on non-traditional days (weekends/evenings).” – Family Member

2025 Budget vs. Needs

2025: Needs Change vs. Budget Change

● Stayed the Same
 ● Increase
 ● Decrease
 ● Not Sure

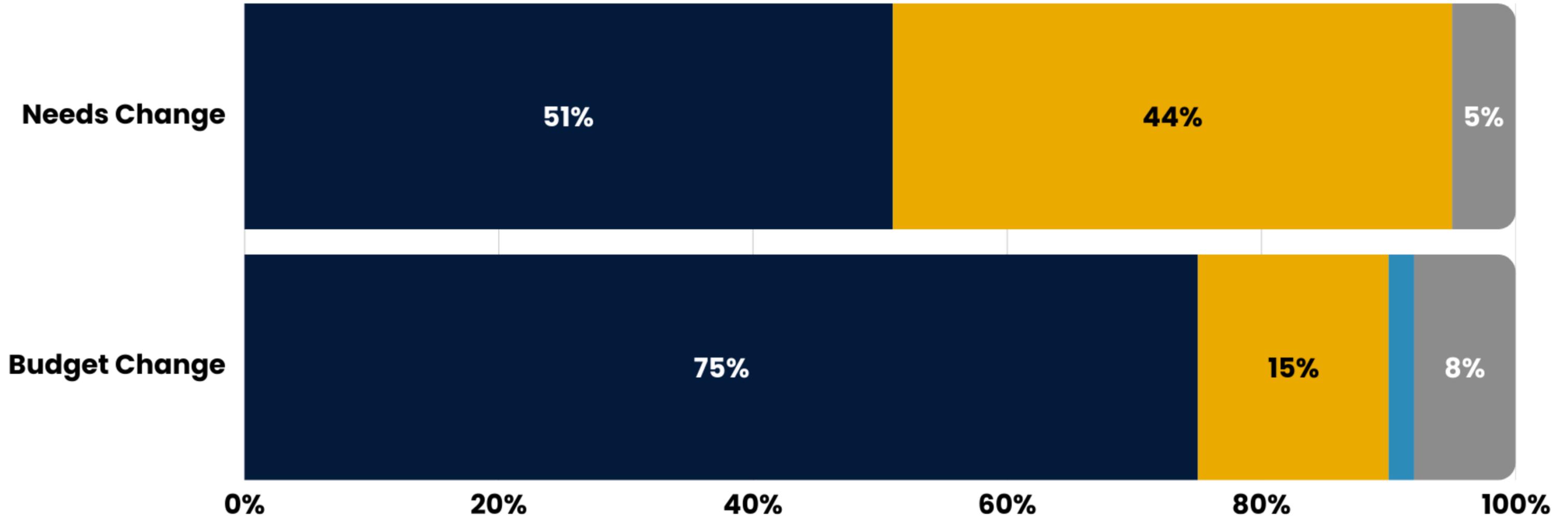


In 2025, only 16% of people's who's needs increased, had a budget increase (n=103)

2024 Budget vs. Needs

2024: Needs Change vs. Budget Change

● Stayed the Same ● Increase ● Decrease ● Not Sure

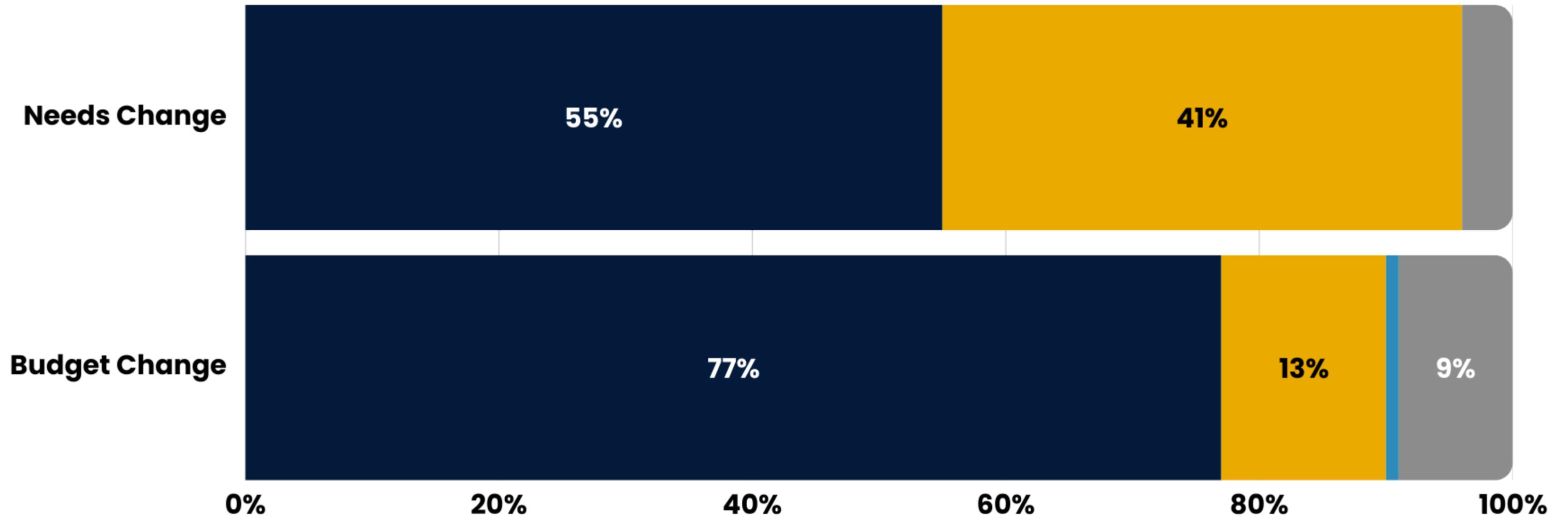


In 2024, only 28% of people's who saw their needs increase had a budget increase (n=87)

2023 Budget vs. Needs

2023: Needs Change vs. Budget Change

● Stayed the Same ● Increase ● Decrease ● Not Sure



In 2023, only 20% of people's who saw their needs increase had a budget increase (n=73)

Theme:

Budget not enough to meet service and support needs

“We are glad and grateful to be part of PDP. However, we are VERY concerned that this year DDS received a rate increase for day programs, but has not applied these funds to group day activities under PDP, even though the day rates for the program has increased. This poses a real budget challenge for our family.”

- Family member

Theme:

Budget not enough to meet service and support needs

“We have been involved in self-direction for 8 years. Our budget has not increased in 8 years, despite showing need and having to offer increased hourly rates to hire staff! This is not sustainable. Traditional programs have had increases....why not self-direction.”
- Family Member

Theme:
**Inadequate
budget
exacerbates
staffing
challenges.**

“My daughter’s budget is helpful, but it no longer reflects the true costs of providing quality support. Staffing rates have increased significantly, and it is becoming harder to retain skilled workers within the current budget limits. An adjustment that keeps pace with rising wages and service costs would help ensure she can maintain consistent, safe, and meaningful support through Self-Direction .”

- Family Member

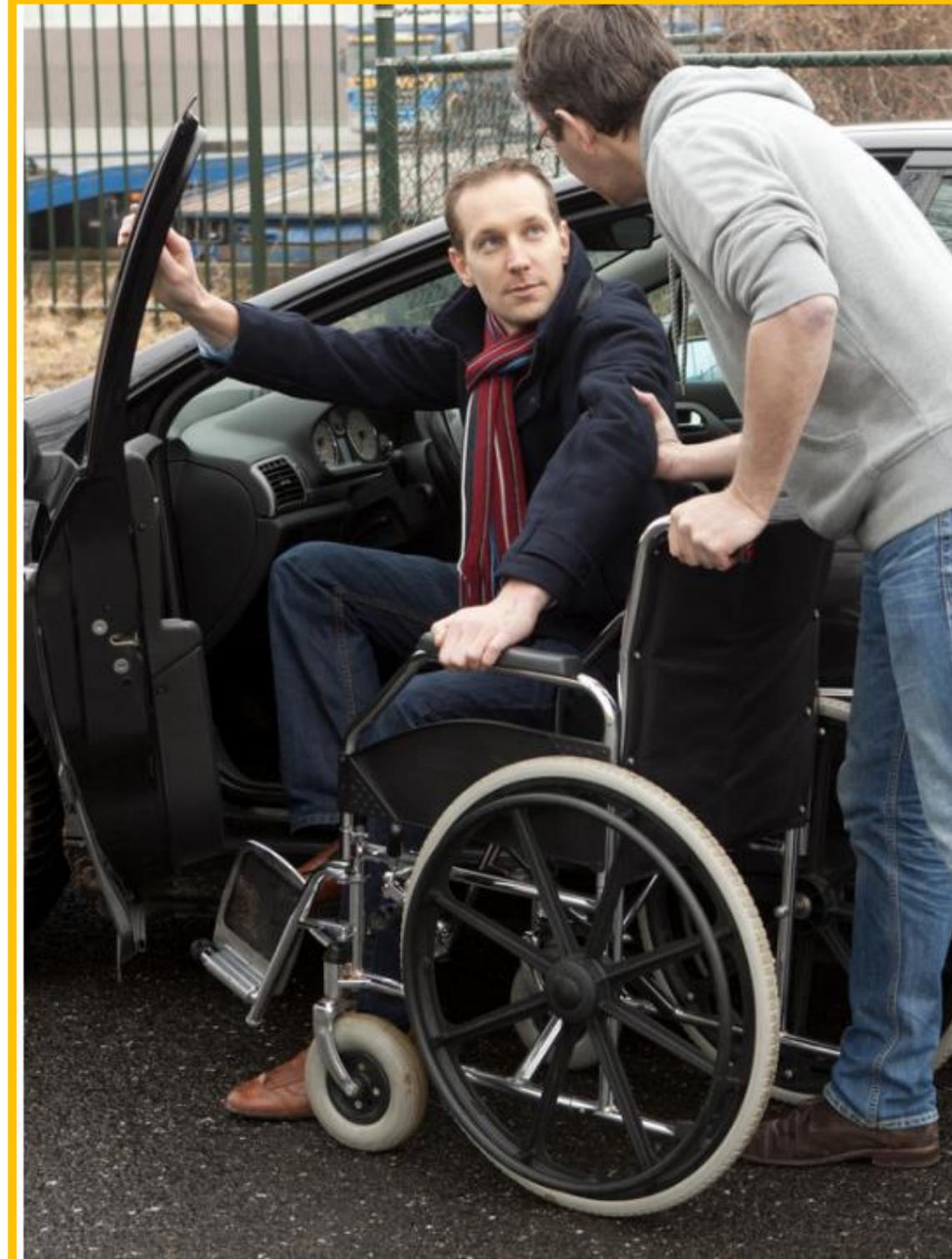
Theme:
**Inadequate
budget
exacerbates
staffing
challenges.**

“As previously noted, budgets should increase annually. Initially we paid \$25/hour for staff. We now pay \$35/hour. This cannot continue. Needs increase as you age, costs increase but the budget does not change. I was not aware that we can “appeal” our budget.”
- Family Member

“My sons aid works only 6.5 hours per day. With no health insurance. No retirement plan and no vacation time or sick time. Pay scale has to be increased to maintain good staff.” - Family Member

Discussion

- Thoughts or questions
- Next steps
- Application to advocacy





Advocacy

Opportunity:

H.1394/S.886

An Act relative to
family members

serving as
caregivers

- There are restrictions about who can be a paid family caregiver in Massachusetts.
- Currently, family members with “legal liability” (like parents who are legal guardians) are *not* allowed to be paid as caregivers in Self-Direction programs.
- H.1394 S.886 would change this restriction for all Home and Community-Based Service programs.
- You can track this bills progress on MDDC’s page for [priority and endorsed legislation](#).

Upcoming Opportunities

Looking for people of color who self-direct their services

 Community Living Equity Center
Centro para la Equidad en Vida Comunitaria

Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute
for Disability Policy



- Researchers at Brandeis University are doing a study about self-direction across the United States.
- They are interviewing people of color and their families who self-direct services.
- Participants receive a \$50 gift card for their time.
- You can learn more by contacting sdequity@brandeis.edu

Upcoming Opportunities



The graphic features a line drawing of the Massachusetts State House on the left. To its right are icons representing various types of disabilities: a person with a cane, a person in a wheelchair, a person with a white cane, a person with a hearing aid, a person with a white cane, a person in a wheelchair, and a person with a cane. Above the icons are the logos for the Massachusetts Developmental Disabilities Council and The Arc of Massachusetts.

Massachusetts Developmental Disabilities Council & The Arc of Massachusetts:
48th Annual Legislative Reception Advocacy Training

- MDDC and the Arc of MA are hosting a virtual advocacy training on **February 3rd, 12:30 – 1:30 PM.**
- This training will teach you strategies to share your story with your legislators.
- You can learn and register for the training at this [link](#).

Upcoming Opportunities



SAVE THE DATE

48th Annual Legislative Reception

Co-Hosted by:
The Massachusetts Developmental
Disabilities Council (MDDC) &
The Arc of Massachusetts

Tuesday, March 10, 2026
10 a.m. - 12 p.m.
Great Hall,
Massachusetts State House

Registration details to come soon.

- MDDC and the Arc of MA are hosting the 48th Annual Legislative Reception on **Tuesday, March 10th** from **10:00 – 12:00**.
- This takes place at the MA State House and is a great time to meet your legislators and other advocates.
- More details and registration will be available soon.



Feedback Request

We are always looking to improve the information we share to support our community. Please fill out this short survey about our presentation to share your thoughts.



Keep in Touch!



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