

Self-Direction Experiences in Massachusetts

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PRESENTERS



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MDDC 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.





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!

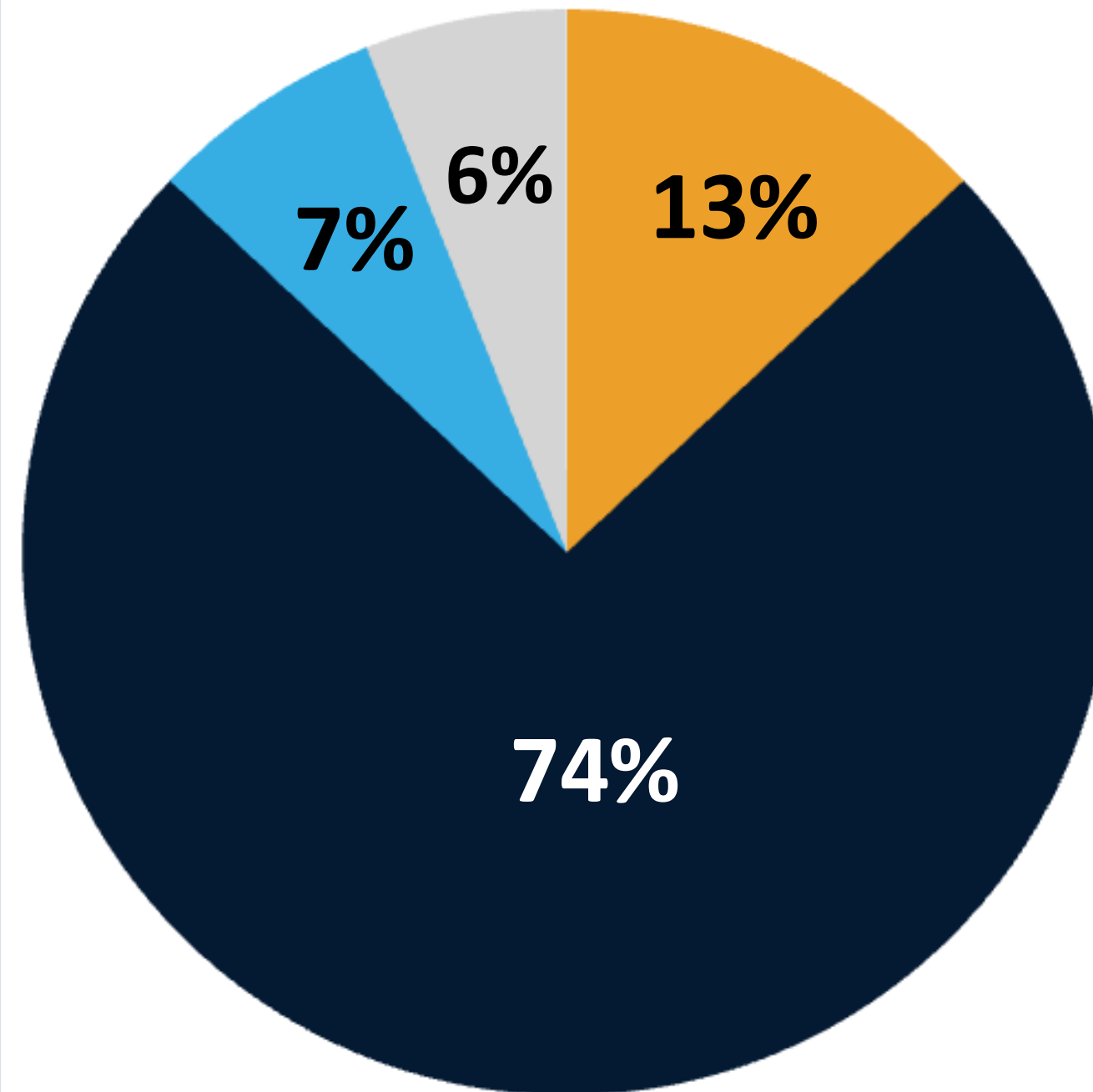
Who took our survey



A total of **118**
provided usable
responses to our
survey

- **85%** of participants were family members
- **10%** were people with intellectual and/or developmental disabilities (I/DD)
- **5%** had a different relationship with Self-Direction

Self-Direction Models Represented



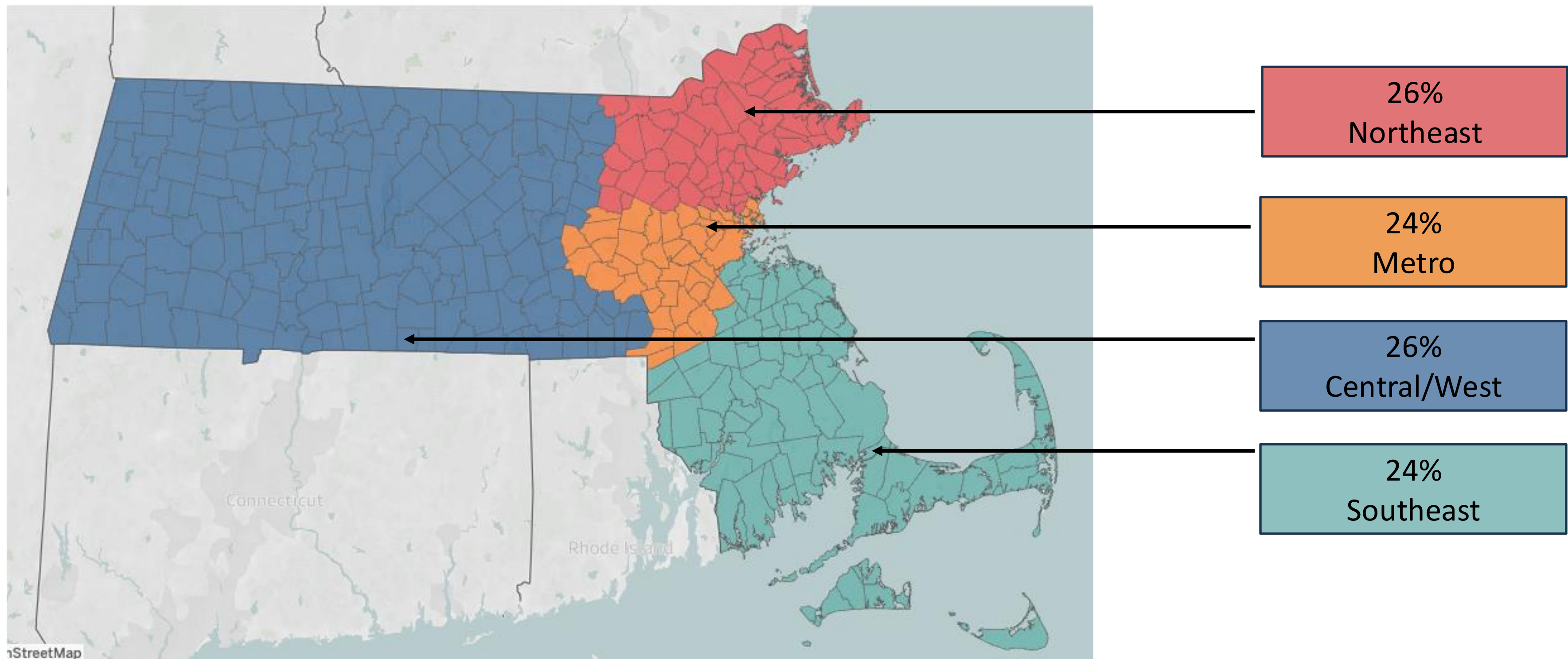
Agency with Choice

Participant Directed
Program

Interested but waiting

Not sure

Survey Participants: DDS Region





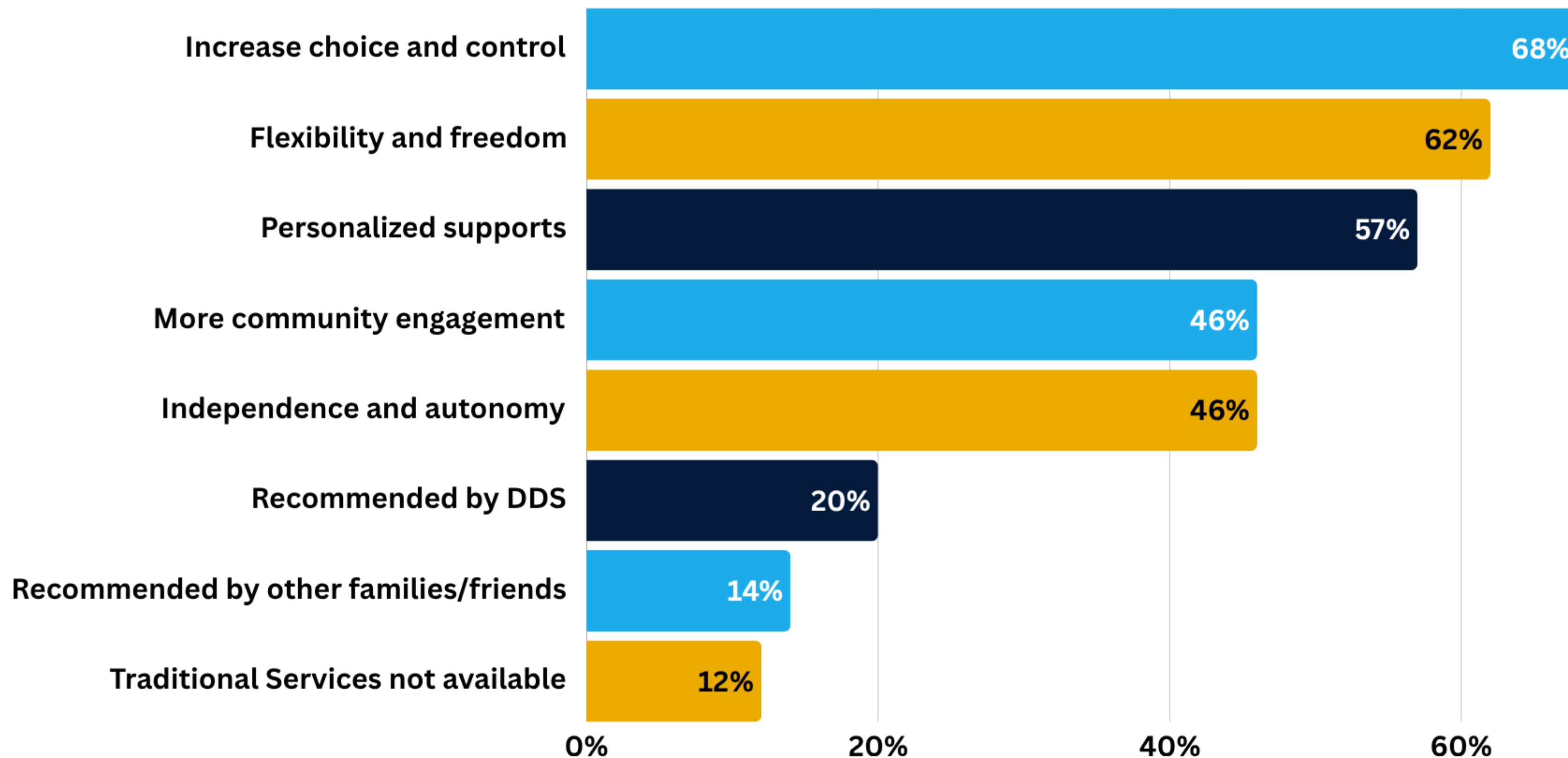
Preliminary Findings

Self-Direction Experiences

Why Self-Direct?



Why Self-Direction?



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.”

Flexibility and Freedom



“We have the flexibility of creating a schedule that fits my daughter’s capabilities, medical diagnosis, preferences, etc.”

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”

More Communit ity Engagem ent

“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.”

Independence and Autonomy



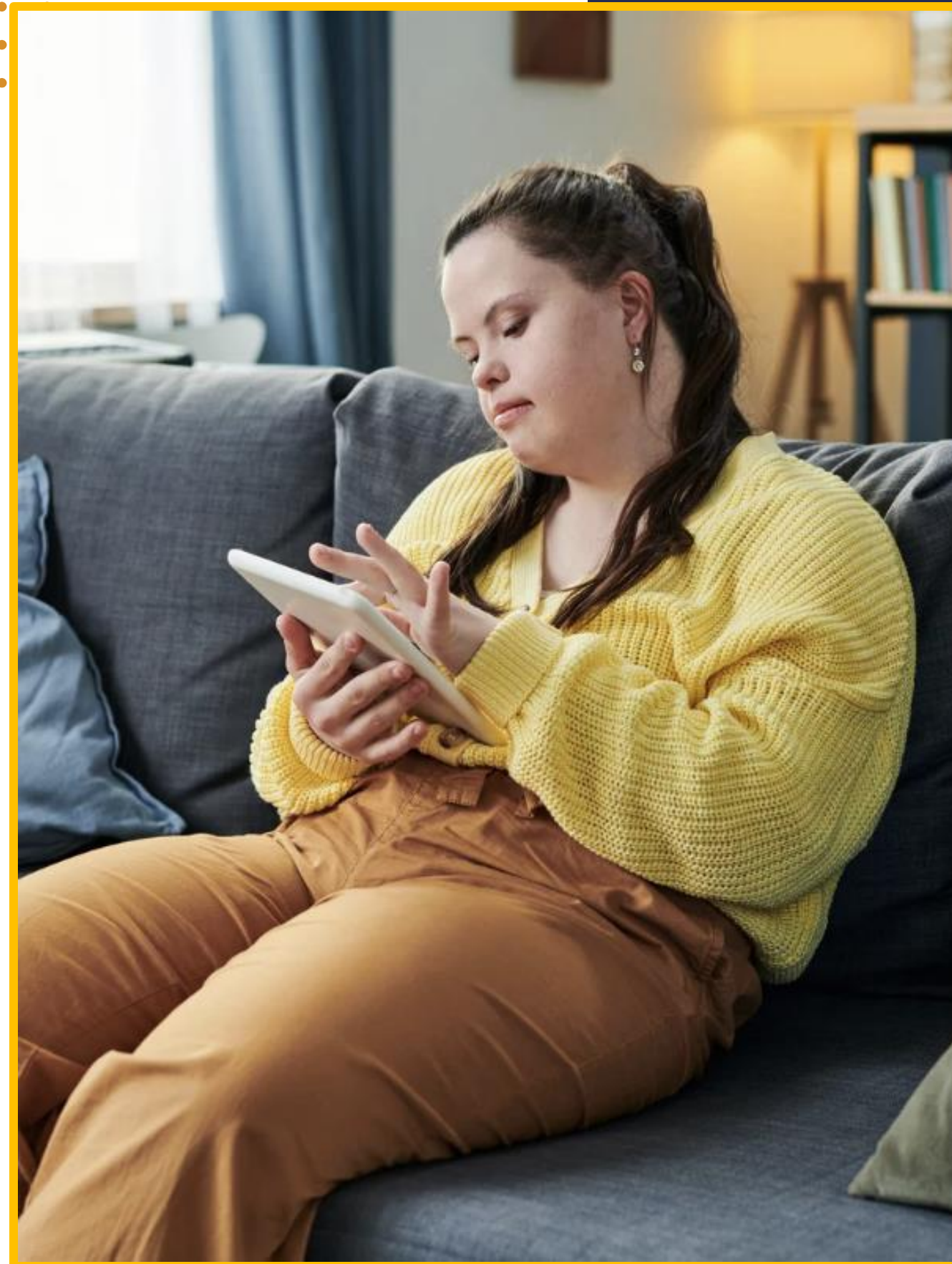
“I get to choose my own staff and keep people I trust. I like being able to plan my own schedule so I can balance my support time with my work.”

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.”

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**



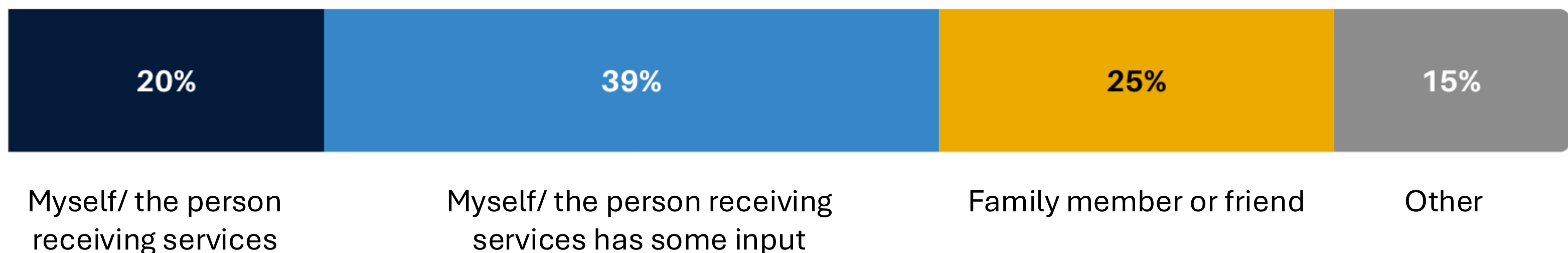
**Control over
services and
supports**



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

Decision-Making in Self-Direction

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.”

Personalized Supports

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



“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.”

Control in Self-Direction

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.”

Hiring Staff

Do you feel like you have employer authority?



“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.”

Theme:

Self- Direction as response to the Direct Care Workforce

“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.”

Self-Direction Experiences

Challenges and Areas to Change



Self-Direction: Challenges and Areas to



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



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

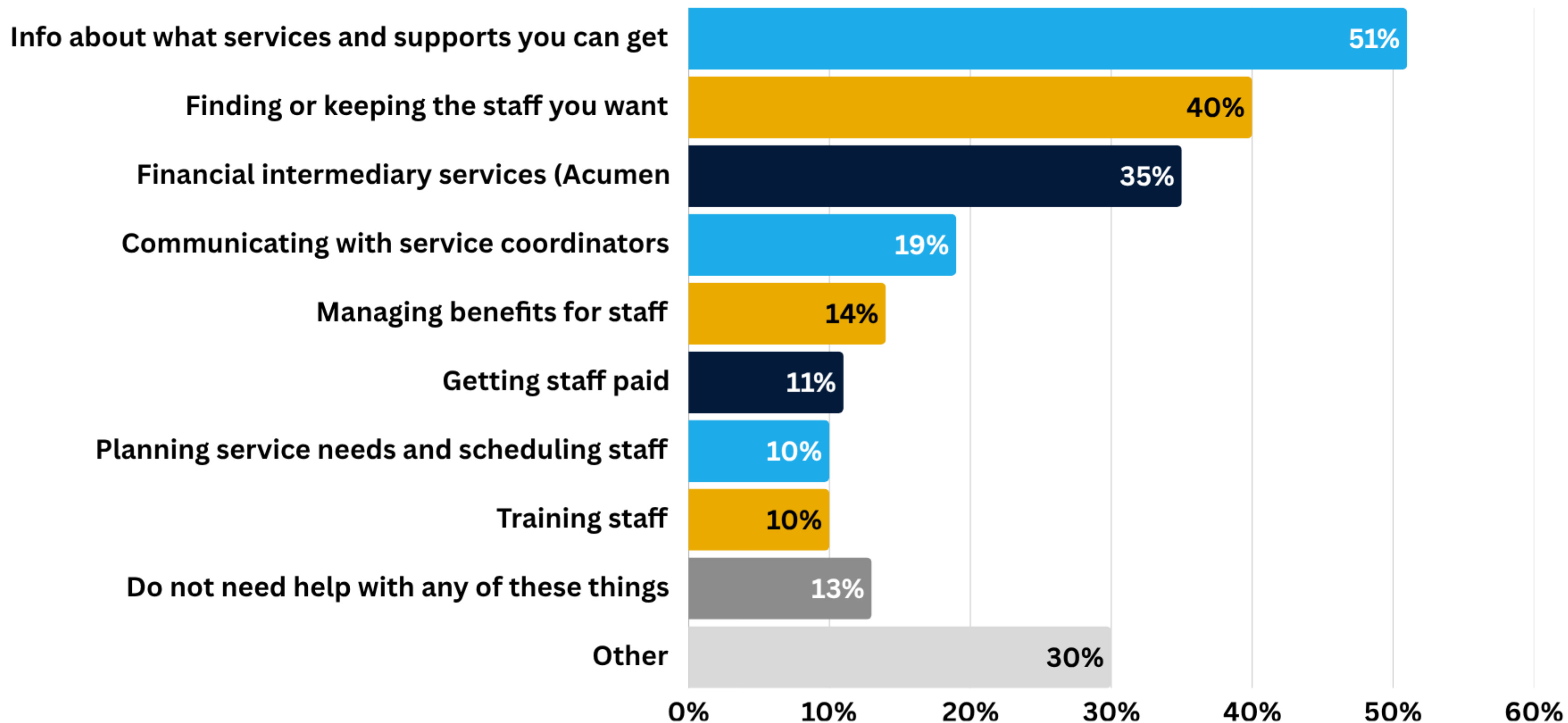


**Financial
Intermediary
(Acumen)
platform is not
accessible**



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

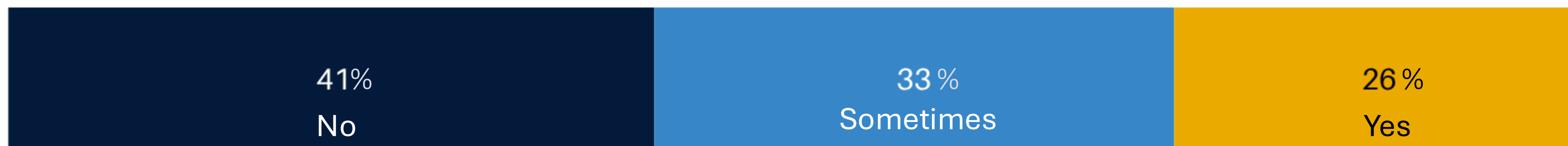
Self-Direction Support Needs





Availability of Services and Supports

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



"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 PCP, 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."

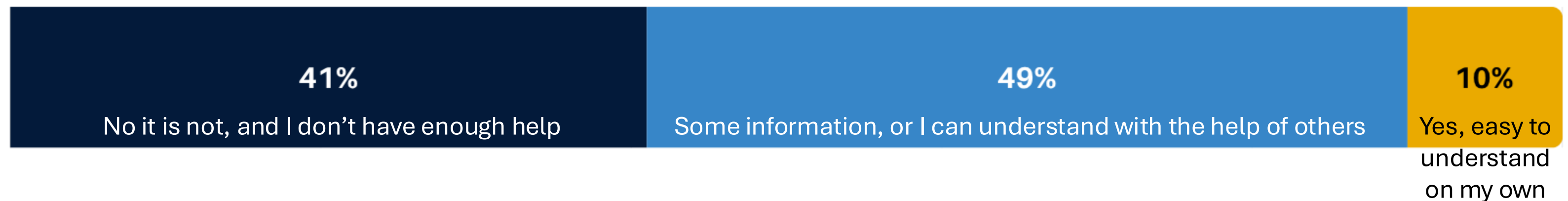


PDP: Access to Acumen Platform

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



Is the information you get from Acumen easy to understand?



* Among PDP participants

Acumen Platform is difficult to understan d

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.



Self-Direction Challenges: Adequate

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



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



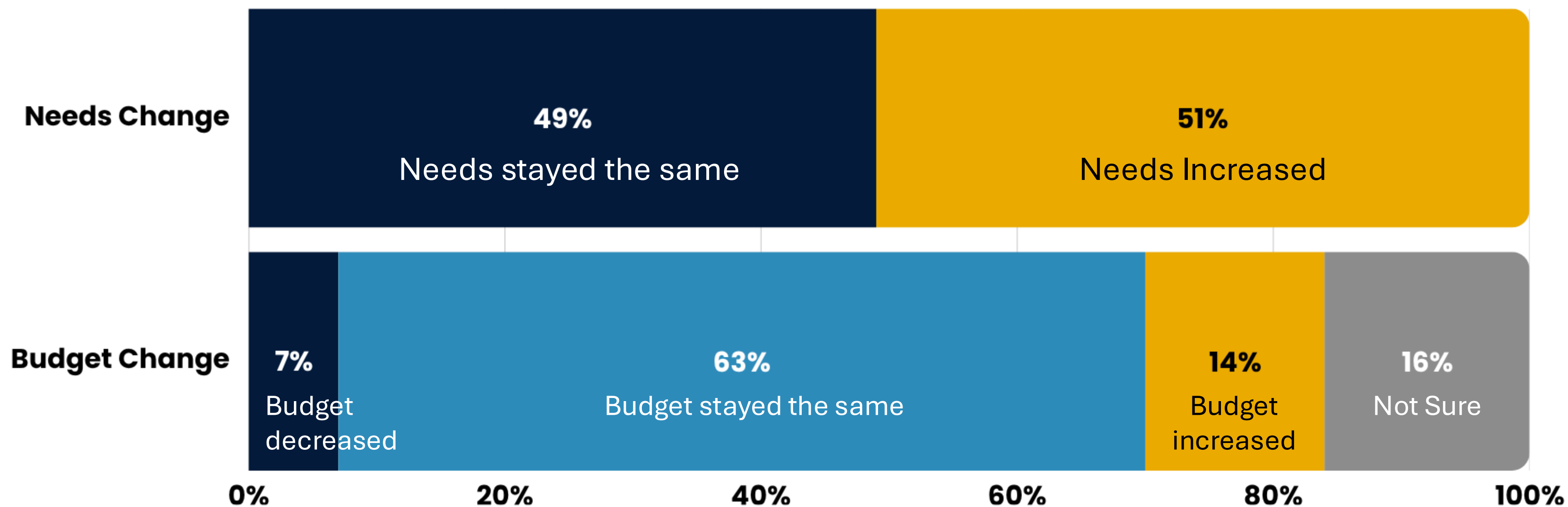


**Budget
not
enough
to meet
service
and
support
needs**

“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.”

2025 Budget vs. Needs

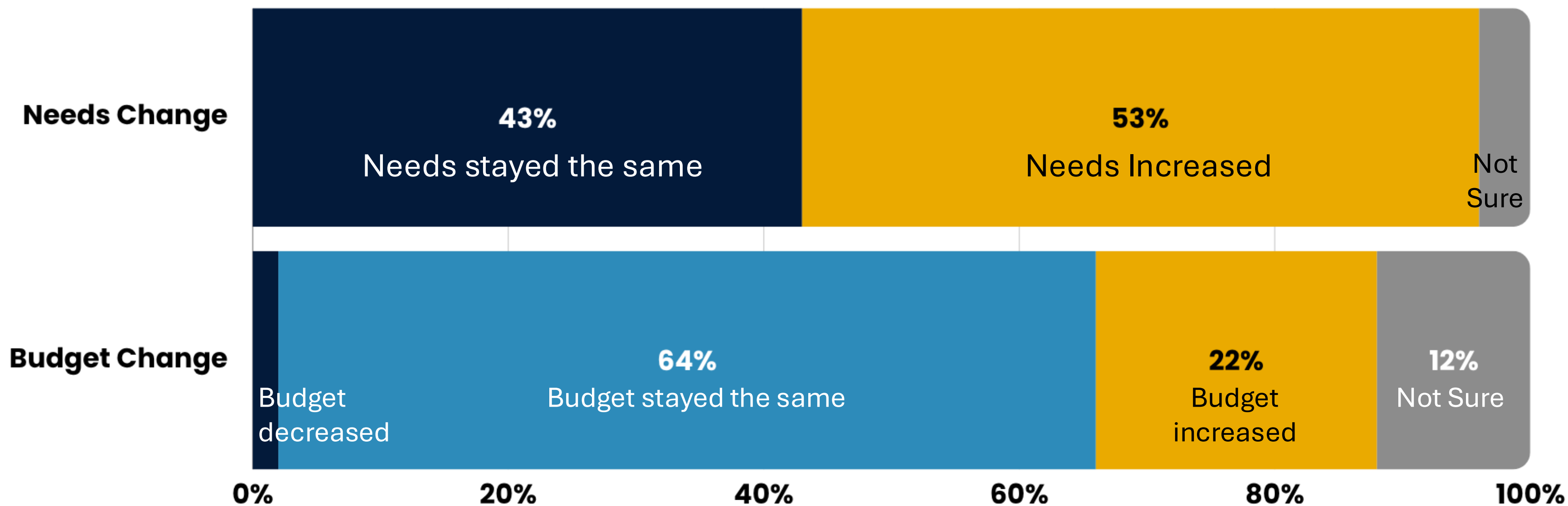
2025: Needs Change vs. Budget Change



In 2025, only 17% of people's who's needs increased, had a budget increase

2024 Budget vs. Needs

2024: Needs Change vs. Budget Change



In 2024, 52% people with need increases had a budget that stayed the same

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. .”

Discussion

- Thoughts or questions
- Next steps
- Application to advocacy





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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