



Self-Direction Experiences: Insights from the MDDC's Statewide Survey

Survey Background

- The Massachusetts Developmental Disabilities Council (MDDC) conducted a statewide survey to collect information on the experiences of people with intellectual and/or developmental disabilities (IDD) and their families using Self-Direction. Surveys were collected over a 4-month period between October 2025 and January 2026.
- This survey was developed with input from the [Massachusetts Alliance for 21st Century Disability Policy \(MA21\)](#), and the [Massachusetts Department of Developmental Services \(DDS\)](#).

Who took the survey?

- We heard from 259 people across all regions of Massachusetts.

84%

were family members
of a person self-directing

10%

were individuals
self-directing

6%

had a different relation
to a person self-directing

What is Self-Direction?

- People can receive Home and Community-Based Services (HCBS) in different ways.
- Most people use a **traditional model** for service delivery. This is when a provider agency is responsible for your budget, support staff, and programming.
- Some people use **Self-Directed** models of service delivery. This is when people receiving services and their families have or share responsibility for planning and managing services. This can include hiring and managing your own staff and budget.

Types of Self-Direction

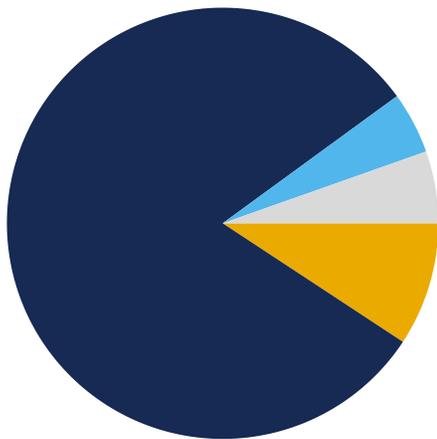
In Massachusetts there are two options for Self-Direction:

Agency with Choice (AWC)

A service agency helps with paperwork and paying staff. The person receiving services and their family still choose staff and help decide how supports are provided.

Participant-Directed Program (PDP)

The person and their family have the most control. They hire staff and manage the budget, with help from a Fiscal Intermediary to handle payroll and paperwork.



89% of our survey participants use PDP
9% of our survey participants use AWC

PDP **AWC** **Unsure**
Interested but waiting

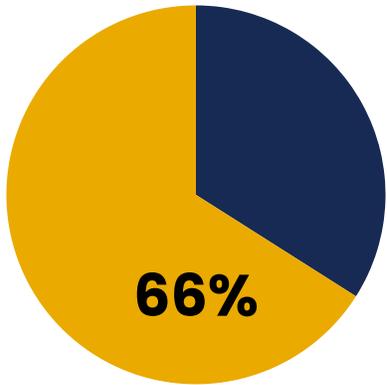
Why does Self-Direction matter?

- Over 38,000 people receive services from DDS in Massachusetts.
- About 2,700 people are using Self-Direction in Massachusetts.
- The **Real Lives Law** was passed in 2014. This law says people with IDD have the right to use Self-Direction to have control over their services and supports.

People can only exercise this right to Self-Direction if certain things are in place.

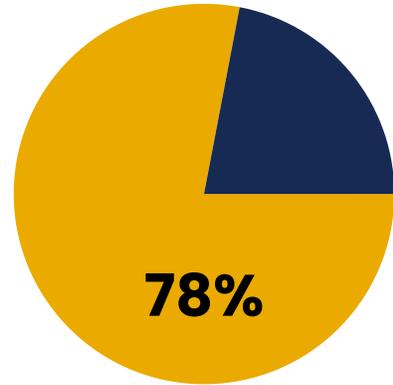
This includes having information about Self-Direction, supports for people to use this option, and access to adequate budgets.

Finding: Self-Direction helps people have more control over their lives.



66% of participants said that they have the amount of control they want in their services.

**"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**

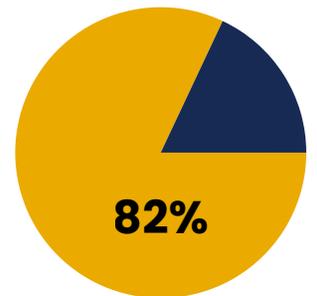


78% of participants said their services and supports are personalized to their needs.

**"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**

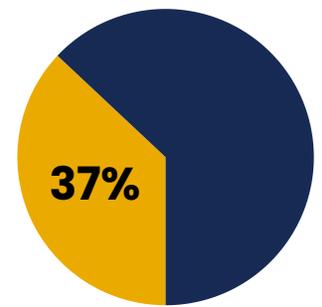
Finding: Hiring and maintaining staff can be a challenge. Self-Direction helped some people manage the challenges of the Direct Care Workforce crisis.

82% of participants said that they have employer authority, or control over who they hire and fire. Self-Direction was a pathway to hire trusted and quality staff.



**"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**

37% of survey participants hire family members to provide paid supports and services. This is restricted by laws in Massachusetts that do not allow family members with legal liability, like guardians, to provide paid supports.



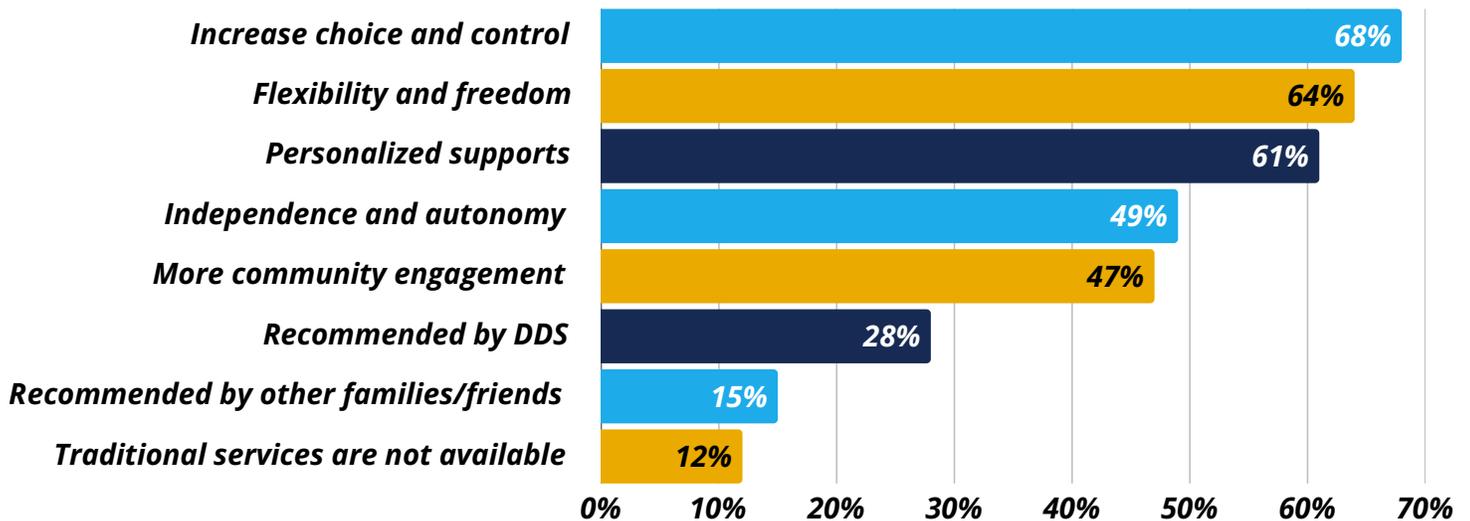
“I would like to see the ability to pay family members be less restrictive. Especially the ability to pay guardians. When the guardian has to step in to work and complete the same activities the paid staff is, but is unable to due to illness or vacation, they should not have to do this without pay.”

- Family Member

Finding: Self-Direction helps people participate in their community.

47% of participants said that they use Self-Direction to help improve community engagement. Many participants said traditional services were not able to meet their or their family member’s needs.

Why did you choose Self-Direction?



“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

Main finding: Self-Direction budgets are not keeping pace with the rising costs of services and the changing needs of service users. Self-Direction budgets are also not keeping pace with the budgets of services provided in the traditional delivery model.

Budget shortcomings are driven by two things:

1. Increase in support needs.
2. Increase in costs of services and supports.

Only 32% of survey respondents said that their budget was enough money for the services and supports they or their family member need.

68% of survey respondents said their budget was not enough, or only sometimes enough, to meet their service needs.

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

● No ● Sometimes ● Yes



No statistically significant differences by region.

“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

“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

50% of survey participants had increased needs in their services and supports, but very few experienced an increase in their budgets. For example, in 2025, **48%** of survey participants had an increase in needs, but **only 11%** of participants had a budget increase.

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

● Yes, I have more needs ● Yes, I have less needs ● No



“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

Main finding: Most people are struggling to use Acumen, the financial intermediary platform. This affects people’s ability to pay staff and get the services they need.

78% of survey participants said the information from Acumen is not easy to understand on their own. Acumen has created extra administrative burden for people using Self-Direction and their families.

Is the information you get from Acumen easy to understand on your own?

● No ● Some information, or I need help to understand ● Yes



“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

Additional Resources

You can learn more about MDDC's survey findings, including more quotes from survey respondents, via the slides and recording of a January 2026 webinar on our website: mass.gov/info-details/mddc-survey-experiences-with-Self-Direction.

More resources:

- [DDS - What is Self Direction?](#)
- [MA21 - Real Lives Law Fact Sheet \(Revised 12/2025\)](#)

Contact

For more information about this survey, contact **Kaitlin Stober, MDDC Policy Research Associate** at Kaitlin.Stober@mass.gov or (617) 770-7676 ext. 121.

About the MDDC

The Massachusetts Developmental Disabilities Council (MDDC) is an independent agency, funded by the federal government, dedicated to empowering people with developmental disabilities and their families to enjoy full productive lives by promoting self-sufficiency, community inclusion & opportunity.



The MDDC works to improve the system of supports for individuals with developmental disabilities and their families by bringing advocates together with policymakers to be sure people with developmental disabilities are included in policy decisions that impact their lives.

The MDDC also serves as an objective resource to inform public policy at the local, state and federal levels, to better meet the needs of individuals with developmental disabilities and their families.

Visit the MDDC online: mass.gov/mddc

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