

Self-Direction in Disability Services

Summary

In our current system of services for Minnesotans with disabilities, there are not enough options for people to self-direct their supports. There are many inequities that create barriers to self-directed options that do exist.

It is important to provide more options for self-direction in all services for people with disabilities in Minnesota.

People must be able to control their own services, with any support they need to make their own decisions.

Beyond current options to self-direct one's own services, we must embed more self-direction into all of the support options available to Minnesotans with disabilities. Self-direction is not just a practice, but a philosophy that should guide all of the services and supports available to people with disabilities in Minnesota.

Issue

In our current system of services for Minnesotans with disabilities, there are not enough options for people to self-direct their supports. Most people do not have:

- control over their budgets
- choice in the services they access
- a role in hiring nor training their staff
- choice about the staff who support them

There are some options to self-direct one's own services that allow people to have more control over their budget, staff, and supports. However, there are many inequities that create barriers to self-directed options, such as:

- lower budgets
- less support with system navigation & service coordination
- added and hidden costs
- more paperwork and reporting requirements
- complex systems and processes that make decision making harder
- service or budget denials that limit choice and access

Barriers like those listed here show an ongoing bias toward more congregate, institutional services. Many of these services do not allow for:

- individual choice

- personal rights
- control in decision-making
- control over their personal cares, who provides those cares, and their bodies
- financial freedom

These types of services can lead to more isolation and segregation. There tend to be greater health risks, and more challenges in the direct support workforce. All of these factors do not allow people to fully experience their communities.

Position

Individuals with intellectual and developmental disabilities (IDD), their family members, and trusted supporters must be informed about all their options for self-direction, no matter how they access services.

Self-directed options can be more cost effective and more responsive to individual needs. Self-direction has been shown to improve individual satisfaction and quality of life.ⁱ Self-directed services allow individuals to use natural supports rather than more expensive formal services. This can reduce staff turnover and help avoid caregiver burnout.

Services for individuals with IDD must be reformed to incentivize self-direction and focus on principles of individual control and self-determination.

People must be able to control their own services, with any support they need to make their own decisions.

People should receive the same range of supports whether or not they are directing their own services. Everyone should have equitable access to services and supports.

They should have accessible information that helps them understand:

- the full range of service and support options available to them
- the risks and benefits of service options they may choose
- the cost of all services and supports they are eligible for
- how to change or dispute their services

In self-directing their services, everyone should:

- have accessible information that helps them understand how self-direction works
- Have total choice in providers for their services
- Direct the hiring, training, and termination of their staff

In self-directing their budgets, everyone should:

- Know what their budget is
- Have accessible information about how their budget was developed
- Be engaged in the process of developing their budget

- Everyone should have the help they need to self-direct their services

This list also applies to parents, family members, and other trusted supporters who are managing self-directed options on behalf of a child with IDD. They must also have accessible information, tools, resources, and support they need in this process.

When self-directed options are being used, budgets should not be lower just because they choose to self-direct their own services. We must reduce budget disparities, so people who are directing their own supports have adequate funds to meet their needs and help them thrive.

The Consumer Directed Community Supports (CDCS) option and other self-directed service options used in Minnesota have demonstrated the programs are cost-effective, accountable, and transparent.

Beyond current options to self-direct one's own services, we must embed more self-direction into all of the support options available to Minnesotans with disabilities. Self-direction is not just a practice, but a philosophy that should guide all of the services and supports available to people with disabilities in Minnesota.

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ⁱ DeCarlo, M.P., Bogenschutz, M.D., & Hewitt, A.S. (2018). Implementation of Self-Directed Supports for People with Intellectual and Developmental Disabilities in the United States. *Journal of Disability Policy Studies*, 30(1). <https://journals.sagepub.com/doi/full/10.1177/1044207318790061>