

People with disabilities and their families report that important information and resources that they need to self-direct are not being provided.

What is Self-Direction?

Self-Direction lets you choose your own services so you can live the life you want. When you self-direct your services, you have the flexibility to choose the right supports for you, the staff you want to work with and a schedule that works best for you. This means you would hire, purchase and manage services/supports with some help from the Massachusetts Department of Developmental Disabilities (DDS), family and others.

Why we have the right to Self-Direct.

In 2014 The Real Lives Law was passed to give people with disabilities and their families the right to choose the services and supports that they need through DDS. The law says that DDS needs to educate their staff and those they serve about self-direction to make sure this can happen.

Who is MA21?

The Massachusetts Alliance for 21st Century Disability Policy (MA21) was formed in 2007 to protect the right 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:

- Massachusetts Advocates Standing Strong (MASS)
- MassFamilies
- The Arc of Massachusetts (The Arc)
- 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)

What can you do to help make self-direction work?

Go to www.MA21Alliance.org to join the advocacy efforts of MA21 to make sure the Real Lives Law is put into effect. Use your voice, stay informed and get access to resources on self-direction. You can learn more by reading our recommendations to DDS on page 2.

Massachusetts needs to make the self-directed service model work for everyone who chooses it.

32,000⁺
adults supported by
DDS but fewer than
2,000
are self-directing
their services.



Self-directed
Research shows that people living a self-determined life are happier, better employed and educated and have a better overall quality of life.

For more information
www.ma21alliance.org
Call: 781-891-6270
email: MA21@ArcMass.org
or contact any of the
organizations listed.

Real Lives Law Requirements and What We Want DDS to Do.

The Right to Self-Direct:

The law states that DDS has to let everyone they serve know that they have the right to self-directed services, and provide information about how self-directed services work.

Current Status: People with disabilities and their families do not have the information and support they need to be able to self-direct.

Recommended Action:

DDS should use the tools from the Real Lives Law to offer self-direction as an option to all they serve. DDS must educate their staff and the individuals they serve about the right to decide how to live one's life, including the options that are available through self-direction. DDS's traditional services continue to be important and meet the needs of many; however, they are not always what people want or need.

Clear and Equal Budget Rights:

A person's budget should be created in a clear way based on their needs. This should happen through a process that is the same for everyone and should change when costs increase. The law requires self-directed budgets to be: the same amount to what the person would get in traditional services; change based on changes in the cost of traditional services and changes in the person's needs; and if you do not agree with your budget you have the right to ask for the budget to be changed.

Current Status: Right now budgets are created in an inconsistent way that can be confusing. Those served have to ask for more and have to prove that they need it because there is no process that is the same for everyone to create budgets. Self-directed budgets are not automatically increased like traditional services. There is no way for a person to ask for their budget to change other than asking a manager for more funding.

Recommended Action:

DDS is supposed to have a clear process to create budgets that are based on tests that show how much support a person needs for self-directed services. The budget should be the same amount as if the person used traditional services. There should be the same increase in self-directed budgets as there would be in traditional service budgets. A person's budget should be sent to them in written form with instructions telling the person they have the right to ask for a change in their budget, and how to ask for that change.

The Right to Control Your Budget:

You have the right to flexible supports, services and goods for self-direction. This includes the right to hire your own staff, contract with an organization or business for services, and use the vendors and suppliers you want.

Current Status: For the most part control over your budget is limited to hiring employees. Your freedom to hire an agency or vendor to provide supports, services and goods is severely limited. Further, there is little information on how much you can pay for the needed supports and services.

Recommended Action:

DDS should let people directly purchase supports and services from businesses and organizations. This includes letting services be done in a group and not just one-on-one.

DDS should let people who self-direct know what they are allowed to pay for services so they can make informed budget decisions.

Independent Advocacy Rights:

You have the right to hire someone to help you find services, supports, providers, and anything else you need help with to self-direct. This person is called an Independent Facilitator and they would have to meet the qualifications provided by DDS for this position.

Current Status: An Independent Facilitator is needed to make sure people can self-direct but nothing exists for the role, no qualifications or budget information.

Recommended Action:

DDS must allow Independent Facilitators and set qualifications.

Required Regulations:

The law says that DDS has to create regulations that support self-direction.

Current Status: There are no regulations that support self-direction.

Recommended Action:

DDS must create regulations to support self-direction. This must cover all information on self-directed services so that DDS staff and people served know that self-direction is a right and an option they have. They must cover how budgets are created, that individuals have control over how they spend their budgets, how they can challenge DDS decisions, that they can hire an Independent Facilitator, and full guidance on how to self-direct must be provided.