



The Real Lives Law Legal Status

Right to Self-Direction

Under the Real Lives Law, every adult eligible for services through the Massachusetts Department of Developmental Services (DDS) has the right to self-determine their supports, goods, and services.

Current Status: Many individuals with disabilities and their families continue to report ongoing challenges getting information and guidance they need to fully understand and use self-directed services.

Next Steps

DDS can strengthen self-direction by using the tools provided by the Real Lives Law, such as person-centered planning, annual individualized budgets, and access to Independent Facilitators.

DDS may consider expanding training and education for both DDS/Provider staff and the individuals they serve about options available through self-direction.

Required Funding Allocations/Budgets

Individual allocations/budgets should be determined in a transparent way based on assessed needs and a standard, objective process that supports the individual's person-centered plan.

The Real Lives Law calls for self-directed budgets to be equivalent to what DDS would fund under traditional services, adjusted annually based on changes in assessed needs and/or the cost of traditional services, and accompanied by clear rights of appeals. Without a clear, transparent funding process, there is no way to determine if this is happening.

Current Status: Individuals and families continue to report that allocations/budgets are set without information or consistency. Self-directed allocations are not automatically increased to keep pace with increases in the funding level of traditional services. There is no way to ensure that DDS-approved hourly rates for self-direction stay in line with increases in traditional service rates.

Next Steps

The Real Lives Law requires DDS to use a transparent process to set self-direction budgets based on a fair, objective needs assessment and equivalent to what DDS would spend on traditional services.

Adjustments to individual funding allocations/budgets must be based on changes to assessed needs and keep pace with increases to the cost of traditional services.

Funding allocation decisions must be formally communicated in writing by DDS to the individual, including notice of applicable rights of appeal.

Required Budget Authority

The Real Lives Law gives participants the right to flexibility in designing the supports, services, and goods that best meet their needs. This includes the right to hire staff directly or contract with an organization, business, or other provider. The law refers to providers, organizations, and businesses, as well as vendors and suppliers to describe the people participants can work with.

Current Status: Under current DDS practices, individuals are most often required to hire their support providers as employees. Although the Real Lives Law allows participants to hire contractors, DDS requirements make it challenging to do so. Participants' control over their budgets is significantly restricted, limiting the ability to obtain supports, services, and goods through various agencies and vendors. Rates for some self-directed services are restricted, and the rate information is not published or shared. This makes access to needed services more difficult. Participants often learn about rate limits only when they become obstacles to hiring staff or obtaining services.

Next Steps

Individuals who self-direct their services should be allowed to use both Employer Authority and Budget Authority as defined and permissible by the Centers for Medicare & Medicaid Services (CMS).

Individuals must get clear and consistent information from DDS about any rate limits related to budget authority and employer authority. Participants cannot make informed decisions without knowing the rate restrictions, if any, which apply to self-directed services.

Independent Facilitators Requirements

Independent Facilitators selected by participants will help them develop their person-centered plan and make informed choices about self-direction. This includes assisting with both short- and long-term planning goals and helping the participant transition into self-direction.

Current Status: On October 25, 2024, DDS regulations established the minimum qualifications for Independent Facilitators. The Real Lives Law specifies that participants must have access to a list of Independent Facilitators; however, this list has not yet been made available. As a result, individuals still do not have access to this resource, even though the law was enacted eleven (11) years ago.

Next Steps

It is recommended that DDS prioritize its obligation under the Real Lives Law to ensure participants have the opportunity to retain an Independent Facilitator and access a list of Independent Facilitators on the DDS website.