



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

What is Self-Determination/Self-Direction?

Self-determination/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 Services (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-determination 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. <https://ma21alliance.org/>

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)

1. Introduction: What can you do today to help make self-determination work:

- You can set June 18, 2024, in your calendar to attend the virtual public hearing on regulations for Self-Determination through self-direction (see below).
- You can review the proposed regulations and the Real Lives Law.
- You can start writing your testimony or written comments for the public hearing. (The written comments must be submitted by 5:00 p.m. on June 18, 2024.)

(Real Lives Law (RLL) is here <https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>)

On May 23, 2024, the Department of Developmental Services issued proposed regulations for Self-Determination and Self-Directed Services. (hereafter 5-23-2024 proposed regulations). A public hearing to consider the 5-23-2024 proposed regulations is scheduled for June 18, 2024, at 1:00 p.m.

The 5-23-2024 proposed regulations replaced the proposed regulations issued October 25, 2022, which were withdrawn after DDS received negative verbal and written comments at the November 21, 2022, public hearing.

MA-21 is asking you to attend the June 18, 2024, public hearing. MA-21. You can provide oral or written testimony. Whether you are a person with a disability – a family member or friend - or advocate or other staff sharing your experiences or an organizational representative, your story can advance self-direction!

Written testimony must be submitted by 5:00 pm on June 18, 2024. Learn more at the DDS site here: <https://www.mass.gov/info-details/dds-notice-of-public-hearing-and-opportunity-for-public-comment>

2. Your Story...Testimony is most effective when it includes some examples (note that oral testimony at the hearing is 3 minutes or so, but your written testimony can be longer, and used as a script for the hearing if you testify virtually.)

- What is your story? Reflect on your situation.
- Who is the individual with disabilities and his family and friends support network? What are the needs? Are the needs being met?
- Have you been provided the opportunity to participate in self-determination through self-direction?
- Have you been given sufficient information about self-determination through self-direction?
- If you participate in self-direction:
- Do you understand how the budget amount available to meet needs and pay for needed services is determined each year?
- Have you been informed of all the supports, services and goods available?
- Have you been told that you cannot choose and pay for certain services, supports and goods for which you have funds?.
- Have you been assisted on how your ISP can be modified so that these services, supports and goods can be purchased?

- Do you believe that you need help from an independent person (not employed by DDS and not service employee/provider)? If so, has DDS offered help to include such a person in your budget (e.g. personal agent).

3. Talking Points: And to help you with preparing your verbal and/or written testimony, here is a brief **analysis** of the 5-23-2024 proposed regulations against our MA21 Fact Sheet Priorities and/or The Real Lives Law (RLL), along with **some talking points**. These talking points are typically numbered after each of MA21 priority items.

A. Required Right To Participate in Self-Determination-Self-Direction:

MA21 Basic Fact Sheet:

Every individual eligible to receive services through DDS shall have the right to self-determine their supports, services and goods.

The proposed regulations¹ (referred to as RLR) now state in 115 CMR 14:04, that SDS (self-directed services) are available to all adults eligible for DDS. However, another provision singles out “safely served” to be a condition of using SDS. This condition appears unnecessary, since DDS would wish all persons safely served regardless of the options they choose as adults. Furthermore, SDS is based on the Individual Supports Plan (ISP) which requires all services allow for development and risk however, that the person's safety and well-being will not be unreasonably jeopardized (115 CMR 6:20 (2)).

We suggest removing 14.04 (1) b in enrollment, and 14.10 (2) b in termination, since the department already has those safeguards in existing regulations. Further that “safely served” can be “periodically determined” by the department, allows far too much leeway for area staff or others who may use this clause inaccurately or inappropriately.

B. Required Transparent Funding Allocation

MA21 Basic Fact Sheet:

Individual allocations/budgets should be determined in a transparent way based on needs assessed through a standard, objective process. Periodic adjustments should keep pace with inflation and the cost of traditional services. The law calls for self-directed budgets to be: equivalent to funding the individual would receive in traditional services; adjusted annually based on changes in the cost of traditional services and changes in assessed needs; and subject to specific rights of appeals.

¹ 14.04: Enrollment in SDS

(1) SDS under 115 CMR 14.00 are available to:

- (a) individuals who are eligible for adult services through the Department; and
- (b) individuals who may be safely served as periodically determined by the Department and consistent with 115 CMR 6.20(2) (principles governing individual support planning) The Department shall consider the safety of the participant as well as the safety of others.

1. The proposed RLR (regulations) are now close to the law in requiring that the funding allocation of an individual's budget: 1) be based on current needs and 2) be equivalent to the cost of traditional services.² This is consistent with the law as a general framework.
2. However, the proposed RLR stops short of sharing how DDS staff will translate the assessed need into the cost of services.
 - a. The RLR should have a proposed methodology which participants can rely on at the present time. The process described is not transparent (as stated in the law), and most individuals who use SDS presently do not know how their allocations are determined to be "equivalent to traditional cost of services." See Real Lives Law (RLL) reference³.
 - b. Additionally, there are other regulations: 14.05 (1) d, 14.06 (4) & (5), and 14.09 (4), which state DDS may lower its funding based on other resources. Using 14.06 (5), it appears DDS penalizes SDS participants for their access to certain MassHealth or other resources:

"(5) In setting the individual budget, the Department shall consider all of a participant's resources, including income, recurrent payments, health insurance, scholarships, financial assistance programs, eligibility for government benefits, and other entitlements and resources. A participant's failure to apply for or accept services or benefits available to the participant from another public agency and for which a participant is otherwise entitled shall be considered as an available resource for the purpose of setting the individual budget."

These regulations can be applied to SDS but they are not applied for those accessing traditional services such as Community Based Day Supports (CBDS). Using the MassHealth PCA program as an example, what if a local decision-maker required someone to utilize his/her PCA allocation for an ISP objective, even though this would not be considered if he/she was using a CBDS program. Or, an adult day health or day habilitation program was offered as an alternative to the SDS funding even though they cannot be "tailored" to the individual's needs or goals. The whole point of someone NOT using a traditional service is to be able to "tailor" the resources for what they need and to meet their goals.

3. The proposed regulations (RLR) state that the funding allocation cannot exceed the equivalent cost of traditional services. The RLL does not contain this "cannot exceed" language. Although the Department does have a reasonable level of discretion in interpreting the RLL, is this a reasonable interpretation of the RLL's "equivalence" requirement or is this a violation of the RLL? An argument could be made about this regulation.

² See 14.06

³ "... set individual budgets in a fair, equitable and transparent manner in consultation with the participant and the participant's individual support plan . . . RLL19(e)(4)

C. Budget Authority

MA21 Basic Fact Sheet:

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.

1. The proposed regulations in 14.09 continue to unduly restrict the ability of participants to “tailor the support to meet the participant’s needs” as set forth in the RLL⁴, by limitations as outlined in 14.09. Although we do provide comments below, you may also want to see comments on budget authority for past proposed regulations. These arguments still apply to these new proposed regulations.⁵
2. Under 14.05 (2) a (2), the regulation states that DDS “disclose information to participants about providers and vendors who provide goods and services to participants;” However the restrictions for utilizing funds seem to be at odds with taking advantage of any such vendors or providers. List services you may need now or would like to use with your budget authority such as:
 - a. Paying a music center or company for lessons to increase/enhance your music skills (piano, voice, etc.)
 - b. Gym or athletic program or group activities that you want to use to address health and related needs, which is not allowed
 - c. An alternative educational program during the day which is not formally a CBDS or other rate-based service
 - d. A contractor has found you qualified staff but is not an “agency with choice” (AwC) provider, and your use of the company is limited.Sharing your story in relation to those OR other services would be appropriate for this regulation.
3. The regulation, (14.06 (4)), states: “The Department will review participants’ utilization of services and may adjust the individual budget accordingly.” More detail is required here in what circumstances would necessitate an adjustment, especially when the participant doesn’t agree with the change, nor does the ISP reflect such an adjustment.

⁴ Quoting the RLL: “...the participant may tailor the support to meet the participant’s needs,”

⁵ The [MA21 Library](#) contains these written comments (see pages 11-14 of the MA21 Library)

https://docs.google.com/document/d/1m6e80q-gGHyxPdW_KCY57_lbCsytbyJSOuoRjfVw/edit#heading=h.a0whwr6jqeq9

- Anne Fracht, page 1 and Conclusion
- AFAM page 3, (7)
- Rep. Carmie Gentile page 3 paragraph stating with “A second area of concern...”
- Robert Beckett (Anderson Krieger law firm) pages 3 (Flexibility) page 7 (Federal Funding).
- Ed Underwood pages 6-8 (4. Full Budget Authority)
- The Arc- Massachusetts page 5 (14.07)
- Deborah Flaschen pages 1-3, pages 6, 7 (4.)
- MDSC pages 2, 3 (5)

D. Independent Facilitator

MA21 Basic Fact Sheet:

Independent Facilitators

Independent Facilitators selected by participants will help them with short- and long-range planning and decision making. DDS will establish minimum qualifications for this position. (Sect 19, (a))

1. The proposed regulations define Independent Facilitator and now establish minimal qualifications⁶.
The minimal qualifications are bare bones: over 18 years of age, fingerprinting, and having “at least two (2) years’ experience working with individuals with intellectual or developmental disabilities.” From a positive perspective, the “bare bones” qualifications minimize barriers to a participant choosing an independent facilitator.
But perhaps the requirement: “at least two years (2) years’ experience working with individuals with intellectual or developmental disabilities” is more restrictive than one might initially assume. What if a participant wants a friend/neighbor who is a licensed social worker or licensed counselor who has many years’ experience but whose practice has not included “at least two (2) years’ experience working with individuals with intellectual or developmental disabilities.” Many states attempt to ensure performance, but not unduly restrict access, by requiring completion of a training course. Continuing education/training could also be required. Such training would not be an undue barrier.
2. The regulations appear to provide that the cost of the Independent Facilitator will be taken from the funding allocation – but will not be an additional amount added to the funding allocation. The RLL allows DDS, in the regulations, to decide to add the cost of the Independent Facilitator to the funding allocations, which is a position we support.
3. Regulation recommendation:
 - a. Remove the clause, “at least two (2) years’ experience working with individuals with intellectual or developmental disabilities,” and replace with “at least two (2) years’ experience working with or connection to individuals with intellectual or developmental disabilities.”
 - b. A training program which ensures minimum competency benchmarks.

E. Appeal Rights:

RLL Section 19, (e) (6) ensure that the value of a participant’s individual budget is equivalent to the amount the department would have spent providing services, supports or goods to the participant if the participant had chosen to receive services, supports and goods through a traditional service model supported by the department; provided, that the department shall establish an appeals process for decisions regarding the individual budget;

⁶ 14.08 (1) Independent Facilitator

1. The proposed regulations (14.11) now provide 30-days to appeal consistent with provide that an individual can appeal the Department’s denial of right to self-direct in addition to appealing funding allocations, choosing services and Department termination actions.
2. We support a regulation which states that the DDS provide content explaining the decision relative to self-determination including the requirement that such notices contain appeal rights.

F. Definition of Participant:

1. The RLL defines “Participant” and includes in the definition: “where appropriate, ...parents”. The 5-23-2024 proposed regulations omit “parents” from the definition of “participant.” Parents and individuals with disabilities are often interdependent. Over 60% of individuals live or are supported by family often “underserved” by public resources. However, the regulation removes parent from the definition which is in the RLL. Given this reality, the language omission is especially troubling.
2. Recommendation: Either add “parent” with the clarification as in the law or recite verbatim the definition of “participant” as set forth in the RLL which is – “an individual with disabilities receiving department services and, when appropriate, an individual’s parents, legal guardian, conservator or other authorized representative, who has voluntarily agreed to take part in, and has been deemed eligible for, the self-determination option.”