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OPINION

Adults with developmental disabilities deserve Real Lives

Although the Real Lives law, guaranteeing the right to self-direct and ordering the Department of Developmental Services to make it happen, was passed in 2014, DDS didn't even propose regulations governing self-direction until a few months ago.

By **Deborah Flaschen** Updated February 20, 2023, 3:00 a.m.



Shaving and hand washing instructions in the bathroom at 3LPlace Life College Residence, a community for young adults with autism and other developmental disabilities, in Somerville in 2014. THE BOSTON GLOBE/GLOBE FREELANCE

The adult services system for individuals with intellectual and developmental disabilities in Massachusetts is badly broken. Currently, [thousands of individuals are without services](#). They are stagnating at home, taxing the ability of their families to keep them safe, healthy, and engaged in anything meaningful. Time, resources, and the skills gained through years of special education are disappearing.

Everyone points to the nationwide workforce shortage to explain the ongoing crisis. But bad faith policy and administrative decisions made by the Massachusetts Department of Developmental Services are aggravating this untenable situation.

I am the mother of an autistic adult. When my son was transitioning to adult services, I explored the [traditional day program options offered by DDS](#). None of the programs offered the growth and community participation that he and his peers deserve. So, along with a few other parents, I started a more personalized program that focuses on learning, skill building, social opportunities, and inclusion. It's available through self-direction.

Self-direction is a 21st-century adult disability solution that began in the mid-1990s with [pilot grants from the Robert Wood Johnson Foundation](#). The idea is that individuals and their families should be able to choose the services and supports they need and use their allotted government funding to buy them.

In addition to offering choice, flexibility, and self-determination to adults with disabilities, self-direction is economically viable, as it leverages all the resources available for each individual, both public and private. People can, for example, use self-direction to pay for supports that will enable them to access learning, recreational, or vocational opportunities in the community. [Research shows](#) that people living self-determined lives are happier, better employed and educated, and have a higher overall quality of life.

The successful pilot programs led the federal government to offer matching funds for self-direction. In 2002, stimulated by this new federal guidance, many states began promoting self-direction opportunities. In [2014, Massachusetts enacted the Real](#)

[Lives law](#), guaranteeing the right to self-direct and ordering the Department of Developmental Services to make it happen.

The vision of the law's sponsors and promoters was far-reaching: Families, people with disabilities, providers, and DDS would work together as partners, sharing resources for solutions that would respect choice and maximize opportunities. Budgets would be transparent, families would have help from independent facilitators, and anyone eligible for services could participate.

But none of that happened. Although the law was passed in 2014, [DDS didn't even propose regulations governing self-direction until a few months ago](#).

ADVERTISING



As many as 135 people attended an [online public hearing hosted by DDS in November on the proposed regulations](#), and 58 people presented testimony.

Comments ranged from polite requests for wording changes to passionate outpourings from parents at their wits' end, confused by the system, frightened at their inability to care for their children, and certain the proposed regulations would make it worse.

A summation, of sorts, came from The Arc of Massachusetts, a venerable and judicious organization representing individuals, families, and agencies involved with developmental disabilities. [The ARC wrote](#): "The Department of Developmental

Services has proposed regulations which do not appear to properly implement or interpret the law which it has been directed to administer.”

The Real Lives law is at once both progressive and conservative. It is important human rights legislation. It recognizes the rights of individuals with disabilities to determine their own lives by making choices about how their budget can best be utilized to support their lives. It is conservative in that it promotes a market-based approach that supports the rights of individuals to make choices.

[States throughout the country](#) with diverse populations and politics are actively embracing self-direction, including Alabama, Pennsylvania, California, Wisconsin, New York, New Hampshire, Georgia, and New Jersey.

The workforce shortage crisis in Massachusetts that has marooned thousands of adults with disabilities has been intensified by DDS’s failure to implement the Real Lives law. It’s not that DDS didn’t realize it was missing the mark; [three separate reports](#) written by the respected Human Services Research Institute have critiqued the state’s progress since the law was passed.

The state agency responsible for implementing the law and its vision has fallen far short. I’m hopeful that Governor Maura Healey’s administration, with its strong commitment to equity, will quickly remedy that and bring Massachusetts’ adult disability services into the 21st century.

The future of my son, and thousands of other worthy individuals, depends on it.

Deborah Flaschen is a founder and volunteers as executive board chair of 3LPlace in Somerville, a learning center for adults with developmental disabilities.