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LETTERS

2014 law should be a boon, but DDS leaves families struggling

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DARIIA/ADOBE

Challenges of Real Lives system have been laid on parents' shoulders

Re [“State needs to implement law that helps adults with developmental disabilities”](#) and [“Real families need the Real Lives law”](#) (Opinion, Feb. 20): Many thanks to The Boston Globe for highlighting the key issues raised, respectively, in the op-eds by Deborah Flaschen and Susan Nadworny. As parents of a 29-year-old son who has autism,

intellectual disabilities, and limited verbal abilities, we echo their concerns and join in their pleas to the state Department of Developmental Services to follow through with the mandates of the Real Lives law.

Like Flaschen's and Nadworny's families, we have been navigating the system for many years. We are one of the lucky families who have been able to assist our son Kevin in crafting a productive, fulfilling, and fully community-based life through self-direction. However, the numerous challenges in doing so rested squarely on our shoulders. We often struggled to see our way through due to the lack of clear and accurate guidance from DDS. At times, our efforts were nearly derailed as we were pressured to accept a more traditional program for our son in contradiction to the purpose of the Real Lives law.

We are grateful for the growth opportunities the self-direction movement has afforded supported individuals and their families. We would only hope — and expect — to see a stronger collaboration among DDS and all interested stakeholders so that the gains in creative and fiscally responsible programming for our children can be sustained long after we, as parents, are gone.

Cindy and John O'Connor

Andover

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Self-direction is not for everyone. Many rely on agency's stewardship.

In response to the two op-eds on the difficulty of raising a child with developmental disabilities, it is important to add a slightly different perspective. Some parents, ourselves included, are mindful of the challenges of substituting our efforts for those of agency officials and providers in creating sound programming for our loved ones.

Management of a self-directed program is not for everyone. For many of us, the hiring and supervision of staff, especially now, is a function best left to human resources departments and managers with human services experience. The many other elements of a successful program, requiring "piecing together" resources to meet a person's needs, could exhaust many working families.

It is clear that Department of Developmental Services programs are hurting. We can't fault parents whose frustration leads them to want to take the reins themselves. In any movement toward self-direction, however, it is important to keep up pressure on the Legislature, the governor, and the agency to stand up those programs for the many families who want and need them.

Jim and Lea Snow

Pembroke

Agency's draft regulations leave too many cracks in services

[The Real Lives law](#) states that the Department of Developmental Services shall “make efforts to ensure that participants are reasonably representative of the diversity of individuals eligible for services from the department.” However, [the draft regulations](#) issued by DDS in the fall make meaningful self-direction almost impossible for someone who lives in a group home and is nonverbal/nonliterate or has maladaptive behaviors.

The draft regulations have a circumscribed list of self-direction services for group home residents. For example, nothing on the list allows a group home resident unable to join a gym due to anxiety to work with a personal trainer at home. Many group home staff cannot ice skate; nothing on that list would allow someone to pay for a person to skate with them at an outdoor rink.

The draft regulations were issued eight years late, in 2022, while the governor and the health and human services secretary were lame ducks, with [public comment due the Monday of Thanksgiving week](#). The most charitable interpretation of this deadline is that the department has a poor sense of timing.

Catherine Boyle

Winchester

The writer is president of Autism Housing Pathways.

Rough introduction for families entering the program during the pandemic

The two op-eds from parent advocates for adults with developmental disabilities reflect the experiences and concerns of many families who care for disabled adults in Massachusetts.

My son takes part in the self-direction program with the Department of Developmental Services established by the Real Lives law. He has a wonderful life: He works with a

tutor, goes to the gym, plays trumpet in the [Berklee College of Music's accessible arts education program](#), attends a program at 3LPlace that facilitates continued growth, and works in a mailroom at a local college.

However, many of the experiences he has chosen for his schedule would not be accessible to him if DDS approves the restrictive proposed regulations discussed in Deborah Flaschen's op-ed because the rules would allow only for hiring individual staff, not for program fees and services in the community. It is also difficult to find and retain staff due to the post-COVID-19 workforce crisis, so my son's overall self-direction program is always at risk of falling apart when someone on his staff decides to move on.

Moreover, after a year of being the manager of my son's self-direction program, I have yet to be offered an orientation, and I can confirm that I don't really understand the ins and outs of the process. Parents like me who came into the DDS system for adult children during the pandemic are really flailing. We need much more support than the agency has provided.

Despite these challenges, our family has made self-direction work for our son. Meanwhile, many families are truly struggling. We need a change in direction from DDS to enthusiastically support the implementation of the Real Lives law. Supporting the individualized needs of adults with developmental disabilities is a matter of civil rights.

Karen E. Donovan

Ipswich

Lawmakers are making resources available, but effective follow-through is key

It was encouraging to see the Globe publish not one but two op-eds regarding the unfulfilled Real Lives law. These parents have attempted to make use of self-direction for their loved ones. They also have played leadership roles in advancing services, one (Susan Nadworny) through statewide advocacy and the other (Deborah Flaschen) by establishing an organization to offer alternatives to existing services.

[Self-direction as established in the 2014 law](#) can make a difference for constituents who are trying to build an inclusive life in the community or those who can't find a place in a day program or service. The Legislature anticipated a bridge to the future in [this year's state budget](#) for those served by the Department of Developmental Services. Resources are available. Transparency in funding allocations, clear policies that reinforce budget authority, and staff training in fully implementing the self-direction option will make a difference.

The post-COVID-19 crisis we face calls out for some short-term fixes that reflect the letter and spirit of the self-direction law.

Leo V. Sarkissian

Executive director

The Arc of Massachusetts

Waltham

Ultimately, it should be about community engagement

As a parent of a 34-year-old man who has an intellectual disability, I know firsthand the importance of community engagement and the role it plays in enhancing the lives of children like mine. The Department of Developmental Services needs to fully implement the Real Lives law in a transparent manner. The state needs all the partners it can

harness to fully support this population. It is evident to me that those who use the self-direction, or self-determination, option engage in more community support as a natural consequence.

The goal for DDS and our families should be to align in working together to create a life for our children in which they are able to learn how to make appropriate choices and thrive. For ultimately, the more independent living skills our children possess, the less they need to rely on others.

Michael Weiner

Medfield

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