

After COVID-19, a better way to support the elderly and people with disabilities

There is a successful alternative to institutional care that allows people of all ages with disabilities to live at home with support: self-directed care.

By Kevin Mahoney Updated May 26, 2020, 3:00 a.m.

COVID-19 has thrown America's elderly into extreme peril and their families into a state of panic, while making it more difficult for all people with disabilities to get the care they need. In Massachusetts, about 60 percent of all COVID-19 deaths have been tied to nursing homes or other long-term care facilities. Meanwhile, families, unable to visit their loved ones, agonize over their health and safety and the care they are receiving.

Many long-term care facility residents would be far safer in their own homes, but they need assistance with everyday living. Even people already receiving services at home from home care workers are finding that, during the coronavirus pandemic, those workers are less available and that following stay-at-home orders can be complicated.

There is a successful alternative to institutional care that allows people of all ages with disabilities to live at home with support: self-direction of home and community-based services, available under Medicaid and the Veterans Administration's [Veterans Directed Care program](#). The self-direction model has enabled tens of thousands of Americans with disabilities — [including nearly 42,000 Massachusetts residents](#) currently — to enjoy a higher quality of life in their homes rather than in an institution. Given the serious risks of congregate living during a viral pandemic, Congress should step up support for self-direction.

In self-direction programs, consumers can recruit and supervise caregivers of their own choosing, including family members or friends. These informal caregivers help with daily activities such as dressing, bathing, food shopping, meal preparation, and housekeeping. Some programs allow consumers to manage a budget that they can use not only to employ caregivers but also to pay for services like meal delivery, laundry, or transportation. They also have access to counselors to help them figure out how best to meet their needs and pay their bills. The original idea behind self-direction was to restore choice and control to people who wanted to live as independently as possible at home. During the coronavirus pandemic, this approach also offers greater safety and peace of mind.

To reduce their exposure, people with disabilities, especially those with underlying health conditions like heart disease or diabetes, need to limit who goes in and out of their homes. Under self-direction, the consumer decides who those people are and what hours they will

work. In addition, family members or friends providing unpaid care may be newly unemployed. Being able to pay their caregivers means that consumers can compensate those close to them during the crisis and help alleviate their financial stress. And family members don't have to worry about their relatives' safety or the quality of care they are receiving.

Self-direction provides consumers with considerable flexibility and control. It's up to the consumers to decide what works best for them. Consumers managing a budget can use it to buy such items as personal protective equipment, a cellphone, or a computer and Internet connection to support telehealth if needed.

[Research shows](#) that self-direction reduces consumers' unmet needs, increases their satisfaction with care, improves their health, and increases their satisfaction with life overall, while decreasing financial, physical, and emotional stress for families. It is truly a win-win. The federal [Centers for Medicare and Medicaid Services has recognized the benefits of self-direction](#) as a response to COVID-19 by giving states greater flexibility. States are taking advantage of the new options, too. As of last month, 14 states had modified their self-direction programs to permit the temporary hiring of legally responsible relatives, such as spouses or parents of children with disabilities. Twenty-one states are increasing self-directed budgets, benefit limits, or pay rates.

Massachusetts has also made some tweaks to its self-direction program. For example, self-direction workers who have continued to work during the pandemic are earning 10 percent more in "hazard pay" over pre-coronavirus levels. Consumers who are having difficulty finding workers can now hire their spouses.

Meanwhile, the House Energy and Commerce Committee is considering new COVID-19 legislation that would strengthen self-direction programs. The legislation has bipartisan support, and Congress should approve it.

During a pandemic, people with disabilities and their families need an alternative to congregate care. Self-direction is a proven model for supporting safe and independent living. It could be the answer that many families are searching for right now.

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