



National Center on Advancing Person-Centered Practices and Systems

Transcript from a short video “Why We Need Self-Direction” a video from our Pandemic Wisdom series

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Hi, this is Kevin Mahoney, I'm Professor Emeritus at Boston College School of Social Work and I wanted to talk with you about self-direction during the pandemic.

Clearly, during this COVID-19 pandemic options for meeting long-term service and supports needs are few and far between. People are afraid to go into nursing homes or assisted living facilities -- and perhaps rightly so as more than twenty percent of all the infections have been in such facilities -- and, you know, now there are even restrictions on visitors. Adult day-care and other kinds of congregate supports are closed. And home-care agencies, who already were having some trouble with a shortage of staff, are finding that many of their staff are needing to stay home to take care of their own loved-ones or their own health. So self-direction becomes especially important.

What does self-direction mean? At the basic level, people have the right to hire whomever they want -- hire and manage their own staff, even close family members. But, beyond that, in many states people get control of the budget. And they can use it anyway that helps that remain safe, independent, and in the community -- and that includes buying assistive devices, meal delivery, and even personal protective equipment. People aren't left alone. They have a coach --some states call it a Support Broker or Counselor -- who can help them think creatively if they need to develop a backup plan, help find the resources. People also get the support of a financial management service, to pay the bills, keep track of the records, taxes, et cetera. Self-direction has had great research results, study after study has shown it helps people better meet their needs, people are more satisfied with different aspects of their services, there are fewer unmet needs, even better health outcomes, family feeling less financially, physically, and emotionally stressed.

So why is self-direction so important during the pandemic? It isn't just that the other alternatives are less desirable or available, it's three other reasons.

One: people don't want a lot of strangers in and out of their house, they are afraid of being infected, and they know that home care agencies have different staff on different days and their home-health aides are visiting other people.

Second: during this period, so many of your close-friends and relatives are unemployed, they lost their jobs or been furloughed, they're already providing a lot of care for you, now you can

pay them -- even a spouse, even the parent of children with disabilities. You have a way to receive care from people, and provide them something in return.

Thirdly: if you control the budget, you can use it to meet things you especially need during this pandemic. It might be a cellphone, or internet service, ways of improving tele-health, delivering meals. So those are the three big reasons. Knowing this, recognizing it, the Center for Medicare and Medicaid Services has, during this pandemic, expanded some emergency provisions that allow states to provide better access to home-care. Fourteen states have already used this to expand who can be your care-giver, as I say, even parents of children with disabilities or spouses. And twenty-one states have used this authority to increase budgets, expand budget limits or pay rates.

So, in conclusion, self-direction may be the best, or a very valuable option during this pandemic. And you have to remember that the whole self-direction movement came out of even the polio epidemic. People's creative responses to how they can keep control and flexibility over their lives. In this period, and this pandemic, self-direction may be the answer we're looking for.