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Self-Direction of Home and Community-Based Services in the Time of COVID-19

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ABSTRACT

During the COVID-19 pandemic, nursing homes and assisted living facilities have accounted for over 20% of all infections, adult day care and other congregate sites have closed, and traditional home care agencies are facing staff shortages. In this environment, self-direction of home and community-based services, where the participant can hire their own staff and manage a budget that can be used for a broad range of goods and services including home modifications and assistive devices, is seen as a promising intervention. Using self-direction participants can minimize the number of people who enter their homes and pay close family and friends who were already providing many hours of informal care, and now may be unemployed. The Center for Medicare and Medicaid Services is encouraging this approach. This commentary presents information on how states have responded using the new CMS Toolkit by expanding who can be a paid caregiver, increasing budgets and broadening the kinds of items that can be purchased with budgets to include items like personal protective equipment and supports for telehealth. This Commentary concludes with policy and research questions regarding how the delivery of long-term services and supports (LTSS) may change as the world returns to"normal".

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Over a fifth of the deaths from COVID-19 in the United States are tied to nursing homes or other long-term care facilities. Families are now reluctant to let their older members go to nursing facilities (Dolan & Hamilton, 2020).

As the pandemic continues, adult day centers are closing and home health agencies, already plagued by staff shortages, are finding that many workers are staying home to care for their own families or to protect themselves.

Concurrently, millions of Americans are laid off from their jobs and authorities have directed communities to "shelter in place".

In this environment, numerous states, with encouragement from the Centers for Medicare and Medicaid Services (CMS), are turning to self-direction of home and community-based services (HCBS). Under self-direction, available under Medicaid and via Veteran-Directed Care, participants can recruit and

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manage workers of their own choosing. Some programs allow participants to manage and control a budget which they can use, not only to employ care workers, but to pay for other supports. In self-direction, participants have support from a counselor to find creative ways to meet their needs, develop back-up plans, and locate necessary resources. Participants also have the help of financial management services agencies to pay bills, and act as payroll agents ensuring compliance with tax and labor requirements and preventing fraud.

Results from a randomized control experiment with thousands of participants have shown that self-direction reduces unmet needs, increases satisfaction with distinct aspects of care, improves health outcomes, and increases life satisfaction while leading to less financial, physical and emotional stress for families (Carlson et al., 2007). Availability of self-direction has grown steadily. By 2015 every state had at least one Medicaid-funded self-directed option. Nationally, about one third of eligible Medicaid HCBS recipients self-direct their services. The 2016 National Inventory reports 1,058,889 individuals self-directing in 253 programs (The National Resource Center for Participant-Directed Services, 2017).

But, why is the self-direction model especially helpful during this COVID-19 emergency? In addition to the shortage of other options, there are three major reasons:

(1) People with preexisting conditions want to limit the number of people in and out of their homes to reduce their exposure to COVID-19. Agency workers often see several clients and turnover frequently.
(2) Close family and friends, many of whom live with or near individuals with disabilities and already provide unpaid care, may be newly unemployed. By paying family caregivers, recipients are able to compensate those close to them instead of worrying that the care is an added burden. Research has shown that receiving assistance from people that the individual with disabilities already knows is beneficial (Newcomer et al., 2012). Conversely, family members experience less stress because they do not have to worry about the adequacy of care (Foster et al., 2007).
(3) Self-direction provides significant flexibility. The individual with disabilities can switch between agency-delivered and self-directed services at any time. When the program participant has control of the budget, (s) he can purchase needed goods and services including personal protective equipment (PPE), a cellphone, or internet connection to facilitate telehealth.

Recognizing that alternatives were needed, CMS released a toolkit to respond to the COVID-19 pandemic and increase access to alternatives to care in congregate settings. The Appendix K template, which helps states expedite changes to their 1915(c) home and community-based services waivers, explicitly

permits states to request expansion of self-direction. Many of the same changes can be made to state plan-funded services using Section 1135.

Below are some highlights of what states have done in the first month after the CMS Toolkit was released to expand self-direction options under Appendix K.

Hiring legally responsible relatives

During the COVID-19 crisis, hiring legally responsible relatives (for example, a spouse or parent of a child with a disability) has become one of the most popular modifications requested. As of April 23, fourteen states have modified their waiver programs to permit the temporary hiring of legally responsible relatives, thus expanding the labor market significantly.

Increasing rates and budgets

Twenty-one states are increasing self-directed budgets, benefit limits, and/or rates.

Implementing other strategies

North Carolina is increasing budget limits by over 800 USD to allow more supplies and equipment to be purchased. Many states have added PPE to the list of permissible purchases. Colorado and New Jersey have increased individual budget limits to permit additional overtime. West Virginia is working with hospital discharge planners to bypass nursing home placements and enroll individuals directly into HCBS. Florida added personal supports and transportation to those services that may be self-directed.

Nearly half of all states use managed care plans to administer Medicaid HCBS. States typically require managed care plans to offer self-direction to their enrollees. New Jersey's State Plan 1115 waiver where 18,000 people are enrolled is a good example. Participants can spend up to 10% of their budgets for goods and services and a small amount of the budget can even be paid in cash.

Other changes allowed under the CMS toolkit are making the option more accessible; streamlining operations allowing (re)assessments and monitoring by phone, electronic signatures, timesheets submitted by phone, and temporarily waiving background checks and fingerprinting (which may be less necessary when hiring close family and friends).

The COVID-19 pandemic serves as a natural experiment. CMS and states have temporarily suspended various requirements which are meant to ensure safety and quality, but also slow, and in some cases seriously impede, timely access to HCBS. The pandemic offers an opportunity to reassess some of these requirements and ask whether they are really useful or might be modified once the immediate crisis is over. Benefits such as sick leave and health insurance

coverage may become more widely available for personal care workers. If so, these jobs would become more attractive, easing the long-term worker shortage.

The data presented here are only for the first month when emergency provisions were in place. It will be interesting to measure changes in the delivery system over time. Perhaps change will occur due to societal values and preferences, and not just because of regulatory changes. How long will it be before people are comfortable placing a relative in a nursing facility? How long will close family, who are now able to provide additional care, be without other jobs? Will some family stay on as paid providers? Previous research suggests the answer is "Yes" (Benjamin et al., 2008).

Anthony Fauci, M.D. and other scientific experts have warned that the U.S. may never entirely return to "normal". At first this may seem ominous, but need not be so. If we reflect back in time, it was the polio epidemic that led to the self-direction movement as the people affected by that disease fought for greater control over their lives (Shapiro, 1994). Just as crises in the past have spurred new ways of thinking, COVID-19 may be opening our eyes anew to the value of self-direction. Who knows what the new "normal" will be?

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References

Benjamin, A. E., Matthias, R. E., Kathryn, K., & Furman, W. (2008). Retention of paid related caregivers: Who stays and who leaves home care careers? *The Gerontologist*, *48*(1, 1), 104–113. https://doi.org/10.1093/geront/48.Supplement_1.104

Carlson, B. L., Foster, L., Dale, S., & Brown, R. (2007). Effects of cash and counseling on personal care and well-being. *Health Services Research*, *42*(1 Pt 2), 467–487. https://doi.org/10.1111/j.1475-6773.2006.00673.x

Dolan, J., & Hamilton, M. (2020, April 7). *Consider pulling residents from nursing homes over coronavirus, says county health director*. Los Angeles Times Communications, LLC (Nant Capital): Los Angeles Times. https://www.latimes.com/california/story/2020-04-07/coronavirus-nursing-homes-residents-remove-la-county

Foster, L., Dale, S. B., & Brown, R. (2007). How caregivers and workers fared in cash and counseling. *Health Services Research*, *42*(1 Pt 2), 510–532. https://doi.org/10.1111/j.1475-6773.2006.00672

The National Resource Center for Participant-Directed Services. (2017). *Publicly funded self-directed long-term services and supports programs in the United States*. AARP.

Newcomer, R. J., Kang, T., & Doty, P. (2012). Allowing spouses to be paid personal care providers: Spouse availability and effects on Medicaid-funded service use and expenditures. *The Gerontologist*, *52*(4), 517–530. https://doi.org/10.1093/geront/gnr102

Shapiro, J. P. (1994). *No pity: People with disabilities forging a new civil rights movement*. Broadway Books.