

Post-Briefing FACT SHEET

Milbank Memorial Fund

STATE LEADERSHIP NETWORK

Virtual Briefing: Supporting Family Caregivers

September 28, 2021

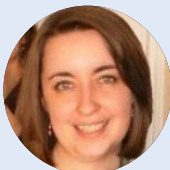
PANELISTS:



Richard (Dick) N. Gottfried,
Representative,
New York's 75th
Assembly District



Linda Miller, Director,
Iowa Department on
Aging



Beth Ultis, Interim
Program Manager,
Idaho Home Choice



**Invited Moderator
Marie Ganim, PhD**

Background

About 40 million Americans provide vital informal care to an older adult. These family caregivers often help with daily activities such as bathing and dressing, as well as supports such as medication management. Surveys of preferences confirm that older adults overwhelmingly prefer to age in their homes rather than move into a nursing home. In addition, remaining in the community is typically less costly for both families and the state Medicaid programs that cover long-term services and support for eligible people.

Without support, however, family caregivers for older adults can face emotional and financial stressors as care obligations increase to the point that they must cut back on work hours or neglect their own physical and emotional health. A growing number of states have enacted policies to support family caregivers, but as noted by both the presenters and participants of the briefing, much more needs to be done.

New York's Experience:

- A recently amended [paid family leave law](#) enables working people to take up to 12 weeks of paid leave. Among other permissible reasons for taking leave, this can be used to assist loved ones with needed care.
- New York's Medicaid-funded [Consumer Directed Personal Assistance Program \(CDPAP\)](#) enables a household member (other than a spouse or parent) to be paid as a caregiver if the consumer or a family

member has the capacity to direct the aide. High demand for this program and rapid growth has dramatically increased spending, which is a source of tension in the annual state budget process.

"Enabling a household member to be hired at Medicaid expense as the consumer-directed personal care assistant has been an enormously popular program. Older adults can direct that aide to do things that ordinarily a home health aide can only prompt, such as providing medication." — *Dick Gottfried*

Iowa's Experience:

- Iowa reviewed and standardized its many distinct family caregiver assessments, as well as its service caregiving-related definitions, both of which are used by [Iowa's Area Agencies on Aging](#). These changes resulted in a 67% increase in family caregivers who received supports from the state between 2019 and 2021.
 - These family caregivers were between 20 and 95 years old and provided daily care; many of them had been caregivers for longer than three years.
 - 33% of them worked outside their homes and 47% cared for people with Alzheimer's disease.

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- In 2018, the Iowa legislature appropriated funding for a pilot program, “[Iowa Return To Community](#)” (IRTC), which provides long-term care support to assist non-Medicaid-eligible seniors who want to return to their community after a nursing facility or hospital stay.

“In the data that we received from the Iowa Return to Community program we found that home modifications, transportation, and respite for family caregivers were the three highest priorities of people who want to stay in their homes and age safely there. So that changed the entire approach and the strategies from the department on aging. In the end it actually changed our culture. Rather than looking solely at the Administration for Community Living funding streams for services, we now look at the patient or the person more as a whole, and then we put together multiple funding streams that can work to make him or her stay at home safely.” – *Linda Miller*

Idaho’s Experience:

Idaho’s [Family Caregiver Navigator Project](#) focuses on meeting the needs of the caregivers to help them avoid burnout. The project assesses caregivers and then refers them to a navigator who partners with them on an ongoing basis.

“In the past, I think most of our approach has been about ensuring the individual being given care is getting the resources they need....But to sustain caregiving activity, family caregivers need resources in order to stay mentally and physically healthy. The navigator tries to identify areas where the caregiver could use additional health supports, or additional social support or respite services, and sets them up with a plan.” – *Beth Ultis*

This virtual MSLN briefing was a part of series of expert briefings on topics that are highly relevant to today’s state policymakers.