

Caregiving: A Lifespan Issue

What is a Family Caregiver?

Many caregivers just see themselves as being a good wife/mom/daughter or (husband/dad/son)

My lightbulb moment was during a Caregiver Community Action Network (CCAN) conference when I realized not all moms were still feeding baby food or changing diapers for their 4-5 year olds.

Caregivers can be parents of children with disabilities who may need lifelong care, “well-spouses”, or involved in eldercare.

The scope of the issue

"There are only four kinds of people in the world: those who have been **caregivers**, those who are currently **caregivers**, those who will be **caregivers**, and those who will need **caregivers**." Rosalynn Carter

There are 53 million family caregivers in the U.S.; 1 in 5.

More men are now caregivers than ever before.

Also, the American Association of Youth Caregivers estimates 3.4 million children are family caregivers.



Photo <https://aacy.org>

Caregiving-Additional Roles

Family caregivers can act as nurses, insurance advocates, case managers, home modifiers, medical equipment purchasers, etc.

Most caregivers are financially impacted. Work/caregiving is a balancing act. Caregivers need to know how to navigate public/private insurance and which programs are available (e.g. prescription assistance).

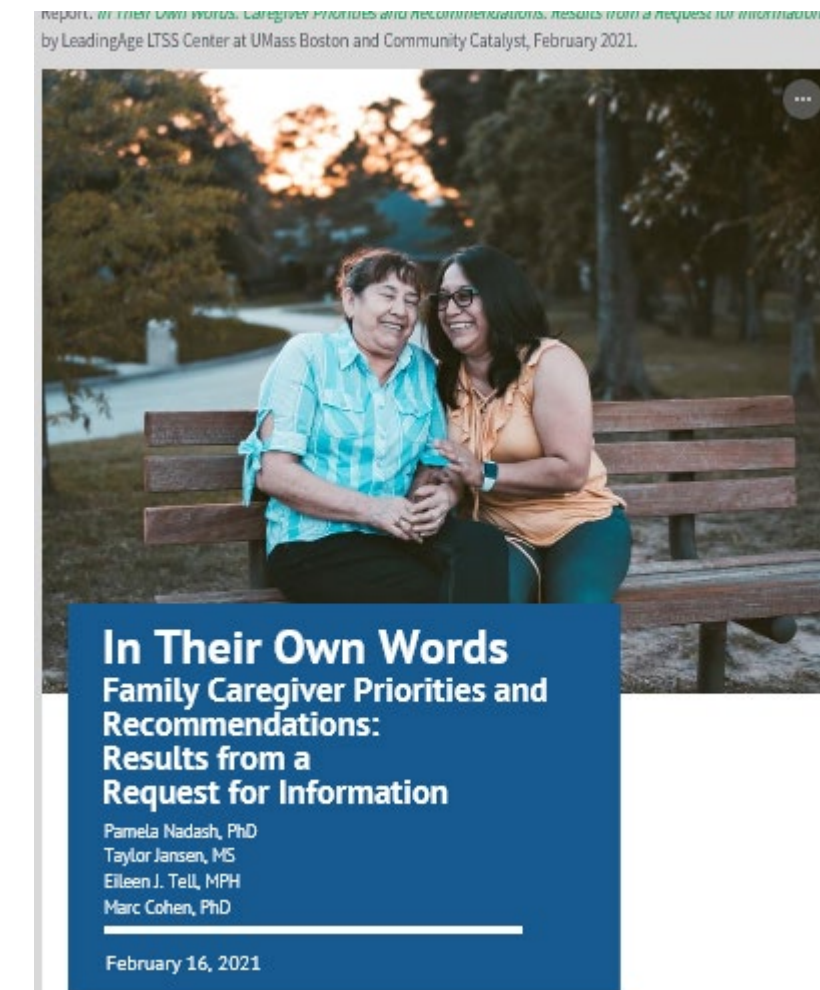
There is a lack of medical support, whether it's respite or getting private duty nursing. Independent living skills are a challenge and can be gained through CILs.

What do Caregivers Need?

#1 Respite! According to CCAN, more people enter institutional care due to caregiver burnout rather than deterioration of their condition.

A recent report highlighted other caregiver priorities:

- ❖ Financial help/employment resources
- ❖ Caregiver task resources i.e. training
- ❖ Increased rates/quality in paid providers



One state example- respite options

In NJ, families of children with either mental illness or developmental disabilities get respite. Once children age out of the Children's System of Care, families of those with DD still get respite paid through NJ Medicaid.

Some states have Cash & Counseling Programs, which allow family caregivers to be paid, and some use it as respite so their spouse can work (but it's not really respite.) NJ used to have "cash option respite" which allowed for flexibility for medical respite though at less hours, but this was discontinued.

During the pandemic, some states allowed families to provide HCBS (Home and Community Based Services) or other Medicaid flexibility and advocates are seeking to make changes permanent.

Next Steps

National paid family leave would help all caregivers!

The Family Medical Leave Act was a good first step, but many caregivers can't afford to take off without pay. Some states, like NJ, have paid leave but this is needed nationally. For more information and to get involved, see :

<https://www.nationalpartnership.org/our-work/economic-justice/paid-leave.html>



Resources

- ❖ Caregiver Community Action Network <https://www.caregiveraction.org>
- ❖ Cash & Counseling (Medicaid Programs with Consumer Direction) <https://www.payingforseniorcare.com/paid-caregiver/cash-and-counseling-program>
- ❖ Centers for Independent Living in each state www.ncil.org
- ❖ CDDs <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>
- ❖ FV/F2FHIC by state <https://familyvoices.org/>
- ❖ PTIs in each state <https://www.parentcenterhub.org/find-your-center>

Questions?

Thank you!

SPAN Parent Advocacy Network www.spanadvocacy.org

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