





Services and Supports That Address Whole Person Health for Family Caregivers

Introduction

An estimated 53 million Americans provide care for an older adult or someone living with illness or disability. Family caregivers provide a wide range of services, such as transportation, food preparation, housekeeping and personal care, enabling care recipients to live at home or in the setting of their choice with dignity and independence. Without supportive services, nearly 62 percent of caregivers have suggested that the individual they care for would be living in a nursing home. Additionally, there are at least 2.4 million children being raised by grandparents or other relative caregivers, serving as a safety net and providing care when children's parents are unable.

This Action Guide is part of a series to help Aging Network organizations develop innovative caregiver services and supports that meet the needs of a growing population of caregivers.

A *family caregiver* is an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation. This includes any grandparent or relative adult who has primary responsibility for grandchildren or other children who cannot remain with their parents.⁴

Caregiving and Whole Person Health

The <u>Older Americans Act</u> (OAA) prioritizes serving older adults with the greatest social and economic needs, which aligns with the National Strategy to Support Family Caregivers focus on addressing the whole person health of family caregivers. Non-medical factors contribute to important health outcomes across the lifespan and include those "conditions where people are born, grow up/age, and live."⁵

Family caregiving can have a significant impact on one's ability to address basic needs like food, transportation and housing. Caregivers are more likely than non-caregivers to experience either food insecurity or hunger. Some caregivers even sacrifice their own housing stability. In one study of the older unhoused population, participants reported that caregiving was a factor in how they became unhoused. Additionally, while 80 percent of family caregivers provide transportation for their loved ones, only 25 percent of these caregivers receive help with transportation services.

A 2021 study found that 78 percent of caregivers had to cover costs out of their own pocket for caregiving expenses, spending an average of \$7,242 annually.⁹ Additional costs related to lost workplace productivity, such as taking a leave of absence or reducing work hours due to caregiving responsibilities, also affect the economic stability of family caregivers.

Many family caregivers provide care that is skilled and medically complex, which is associated with having a greater physical and emotional impact on the caregiver. Many family caregivers experience depression, ¹⁰ which

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contributes to decreased social engagement and feelings of disconnection. Family caregivers report high overall rates of loneliness (70 percent), and loneliness is significantly higher for caregivers with incomes less than \$20,000 (75.3 percent). High levels of financial and emotional stress may be alleviated for caregivers when they receive help with some of their responsibilities.

Action Steps

1. Explore innovative program examples and resources that address social and economic needs of caregivers.

The following program examples not only address the social and economic needs of care recipients but can also be part of the support system for family caregivers themselves.

Nutrition/Meal Programs:

Program Name: Food First Program

Organization: Detroit Area Agency on Aging

Program Description: The Detroit Area Agency on Aging implemented the "Food First" program, a technology-based platform that connects caregivers and care recipients to pre-paid, nutritious restaurant meals three times a week using a texting software platform. The software allows communication via text between the caregiver and restaurants located within 10 miles of the phone being used so the caregiver can order meals near their workplace or the care recipient's home.

Learn More: www.detroitseniorsolution.org

Housing Programs:

Program Name: Elder Cottage Housing Opportunity (ECHO)

Organization: Clearfield County Pennsylvania Area Agency on Aging

Program Description: ECHO project provides a creative housing solution by allowing manufactured homes on a relative's property for affordable rent. The 600-square-foot accessible units can be placed on the property of a family member and allow privacy for older adults while living near their family caregiver.

Learn More: www.mraaa.life/housing

Program Name: Intergenerational Housing Community

Organization: Bridge Meadows (Portland, OR)

Program Description: Bridge Meadows created housing communities in Oregon to address the interconnected social needs of three groups of people: children involved in foster care who have experienced trauma; foster parents and other caregivers, such as kin caregivers; and older adults who struggle with isolation and a lack of social connection. Bridge Meadows is designed to encourage connection between generations by living in the same housing community side-by-side, encouraging the use of multi-purpose community rooms and providing intergenerational events and activities. Additionally, Bridge Meadows offers a variety of therapeutic approaches, including support groups and counseling.

Learn More: bridgemeadows.org

Transportation Programs:

Program Name: Trusted Ride Certified Chaperone Program **Organization:** South Central Connecticut Area Agency on Aging

Program Description: Provides alternative transportation options for caregivers who are unable to accompany loved ones to medical appointments. It uses screened, trained and certified volunteers, allowing for added safety and security in trips to and from medical procedures and doctor's office visits. Chaperones provide reminder phone calls, go to the home, ride with the care recipient to the appointment, stay in the waiting room and then return home with the client.

Learn More: www.aoascc.org or (203) 785-8533

Program Name: Multi-Agency Rural Transit Partnership

Organization: Central Plains Area Agency on Aging and Reno County Area Transit in Kansas

Program Description: A Multi-Agency Rural Transit Partnership between Central Plains Area Agency on Aging and Reno County Area Transit in Kansas developed a transit option for riders in rural areas to access medical, retail, financial and other vital services in the Sedgwick County/Wichita area. Riders or caregivers make one call, and the transit agencies plan and coordinate the ride. Caregivers can ride with the older adult or older adults can travel on their own. Employed caregivers of older adults report this program has helped them achieve better work attendance and decreased stress.

Learn More: www.cpaaa.org

Assistive Technology/Social Support Programs:

Program Name: Senior Safety Program **Organization:** North Dakota Assistive

Program Description: For over 20 years, the North Dakota Assistive's Senior Safety Program has provided free assistive safety devices to help older North Dakotans remain safe in their homes. Devices provided through the program include grab bars, tub rails, smart home devices for home monitoring, medication dispensers and reminders, emergency response systems, adaptive silverware, alerting systems for hearing loss, voice amplifiers and more.

Learn More: ndassistive.org

Program Name: Caring Together, Living Better Program

Organization: Age Options (Oak Park, IL)

Program Description: The Caring Together, Living Better Program was developed to reach African American and Hispanic/Latino family caregivers in the western suburbs of Cook County, IL. The program offers regular in-person and virtual social engagement programming, including chair yoga events, Caregiver Paint Nights, Caregiver Cafes, virtual activity nights and friendly phone visiting.

Learn More: <u>ageoptions.org/resources/caring-together-living-better-ctlb</u>

Program Name: Family and Community Caregiving

Organization: Alzheimer's and Dementia Services of Northern Indiana (ALZNI)

Program Description: ALZNI provides a wide array of services for caregivers. They regularly host free activities for caregivers, including a gardening group, Memory Café, pet therapy, exercise classes and movie nights. In addition to these activities, they provide meals and host educational and peer support group events for caregivers to connect with one another.

Learn More: alzni.org/caregivers/caregiving

2. Stay informed about local community needs.

- Review your local <u>community health needs assessment</u> results to assist in determining how to focus efforts. What are the greatest social and economic needs reported by the community you are serving?
- Review Information and Referral community needs data. There are several states that participate in 211 Counts. Click on any of the listed states to view a dashboard with data on unmet needs.
- Create and implement an action plan based on recommendations from the community needs assessment report. Start with three to five priority areas to implement. Broadly advertise the action plan and related services to caregivers in your community.
- Also remember that there are opportunities to be creative. The Illinois Family Caregiver Coalition released
 <u>a collection of caregiver stories</u> highlighting caregiver needs and preferences through their unique
 experiences.

3. Identify new funding sources and leverage existing financing resources to implement social and economic needs programs for caregivers.

• Explore national and community foundations that focus on funding caregiving initiatives, such as those listed in the Grantmakers in Aging Care is Fundamental Guide.

In addition to the Older Americans Act, explore funding opportunities to support social and economic needs of family caregivers, such as exploring establishing partnerships with health care entities. Check out resources from the Aging and Disability Business Institute for more information.

4. Offer specific training and/or technical assistance on how to include caregivers as a target population when screening for social and economic needs.

- Start by including a question on the intake form for the older adult requesting or being referred for services to determine whether a caregiver is involved in their care or support.
 - a. Review commonly used caregiver assessment measures, such as Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners.
 - b. Monitor the National Caregiver Support Collaborative website for additional information on caregiver assessment best practices.
- If a caregiver is identified, screen him/her for potential eligibility for food, housing and transportation programs and offer available services to address their related needs.

5. Leverage state multisector plans on aging to strengthen cross-sector approaches to caregivers' needs.

- Engage in the development of multisector state plans on aging to ensure that a focus on addressing social and economic needs of caregivers is included.
- Advocate in the multisector plan development process for inclusion of caregivers' social care needs.
- Resource examples:
 - a. Involving Family Caregivers to Shape Multisector Plans for Aging-Center for Health Care Strategies
 - b. Aging | Including Kinship/Grandfamilies in State and Area Plans on Aging-Grandfamilies & Kinship Support Network

Conclusion

Addressing the greatest social and economic needs of family caregivers can significantly impact the caregiver's ability to continue to provide care, allowing care recipients to live in their homes and communities for as long as possible.

Additional Resources

- ACL-National Family Caregiver Support Program
- ACL-National Strategy to Support Family Caregivers
- ACL-Nutrition and Aging Resource Center
- Aging and Disability Business Institute
- AmeriCorps Seniors
- Family Caregiver Alliance–Caregiver Resources
- Commit to Connect
- Consumer Financial Protection Bureau
- Caregiver Action Network–Family Caregiver Toolbox
- engAGED
- Generations United and USAging-Kinship/Grandfamilies: The Role of Area Agencies on Aging and Title VI **Native American Programs**
- Miami University Scripps Gerontology Center-Enhancing Caring Communities Toolkit

- National Aging and Disability Transportation Center
- National Academy for State Health Policy-Supporting Family Caregivers: A Roadmap for States
- USAging—<u>Building Community Capacity to Serve Older Adults: The Role of Area Agencies on Aging in</u>
 Home Modifications and Repairs
- USAging-Home Modification and Repair Services and Needs in Indian Country
- State Assistive Technology Programs
 State-by-state list
- WISER Financial Caregiving Hub

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References

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¹ AARP and NAC (2020). Caregiving in the U.S. 2020–AARP Research Report.

² Administration for Community Living (2014). National Family Caregiver Support Program.

³ The Annie E. Casey Foundation (2021–2023). Accessed September 2024. <u>Kids Count Data Center: Children in Kinship Care in the United States.</u>

⁴ Administration for Community Living (2022). National Strategy to Support Family Caregivers.

⁵ National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Committee on Integrating Social Needs Care into the Delivery of Health Care to Improve the Nation's Health. (2019). Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health.

⁶ Horner-Johnson W, Dobbertin K, Kulkarni-Rajasekhara S, Beilstein-Wedel E, Andresen EM. (2015).

Food Insecurity, Hunger, and Obesity Among Informal Caregivers. Preventing Chronic Disease.

⁷ UCSF (2023). <u>California Statewide Study of People Experiencing Homelessness</u> | Benioff Homelessness and Housing Initiative.

⁸ AARP and NAC (2020). Caregiving in the United States 2020.

⁹ AARP (2021). <u>Family Caregivers Spend More Than \$7,200 a Year on Out-of-Pocket Costs</u>.

¹⁰ Family Caregiver Alliance (2016). <u>Caregiver Statistics: Health, Technology, and Caregiving Resources</u>.

¹¹ Pendergrast C., Menne H. (2021). <u>How Lonely are Older Americans Act National Family Caregiver Support Program Participants?</u> Innovation in Aging.