

Hidden Helpers: Supporting the Informal Caregivers Behind Our Members

*Laura Sankey
VP Product Strategy and Social
Determinants
Centene Corporation*

Why Caregiver Support?

PROBLEM:

- Informal caregivers taking care of members with functional or cognitive limitations lack support. This can lead to caregiver burnout, which may impact the members' ability to remain living at home within their community and may decrease the members' quality of life.

PURPOSE:

- To establish a formal caregiver support program that allows our members to remain in the home as long as possible by providing encouragement, information and tools to the informal caregivers who tend to their needs.

Various stages of need

- **Gradual Onset**
- **Sudden Onset**
- **Maintenance**



Gradual Onset

– **Ex. Alzheimer's/ Dementia**

- Need ongoing information through stages
 - Need to start documenting medical history and advance directives
 - Need to learn how to communicate when cognitive ability declines.
 - Need to take care of oneself as disease progression is often a long, lonely road
-

Sudden Onset

- **Ex. Traumatic brain injury or Stroke**
 - Need information to deal with what is happening NOW
 - Need to track various doctor appointments, medications, test results
 - Need to learn how to communicate in new ways and perform new tasks
 - Need to establish immediate support system and provide crisis information
-

Maintenance

- **Ex. Adult caring for a special needs child with established LTSS**
 - Need information as condition progresses or benefits change
 - Need to keep multiple providers informed and keep medical history up to date
 - Need to connect with support group to share experiences and feel less alone
-

Caregiver Support Program



Information



Organization



Support

Key activities: Gradual Onset

Engage the Member

- Inquire about caregiver during welcome call while scheduling HRA
- Assist member in documenting medical history including allergies, doctors seen, surgeries, test dates and results and any medications taken including OTC
- Discuss the importance of advance care directives and assist member in completing
- Explain person centered care plans, the role of the caregiver and the ICT and what it means to meet NFLOC and the benefit options available
- Assess ADL/IADLS during HRA or during change in condition assessment
- Discuss coping strategies and tips for communicating
- Continue to develop person centered care plans with member input as able
- Help schedule appointments and transportation and send reminders to member and caregiver

Engage the Caregiver

- During HRA introduce the “Caregiver Support Program” and complete the caregiver assessment in order to determine the caregiver’s level of stress, need for skills training, and any community resource needs.
- Confirm member and caregiver contact information and preferred method of communication.
- Provide contact list including 24/7 nurse line, crisis hotline and ICT members
- Provide dementia collateral
- Reiterate the importance of advance care directives and documenting the member’s medical history while the member’s cognitive ability is still intact
- Connect caregiver to online resources and community supports
- Reassess caregiver needs and develop strategies as appropriate
- Provide additional dementia collateral, including toolkit (dry erase board, labels, etc.)
- Educate on NEMT, respite, counseling and nutritionist benefits available
- Begin discussing “Compassionate Connections” palliative care program when appropriate
- Address social isolation by connecting to community events

Key Activities: Sudden Onset

- Shorter window for home vs. SNF. Need to help ASAP. Do this with good discharge planning and transition of care processes
 - Major focus on depression and anxiety for both member and caregiver due to changes in ability and roles
 - Connection to advocacy groups
 - It's a "journey to independence" versus end of life planning, although advance directives should be included
 - Phases include: Stabilization, Adjustment, Rehab and Independent living
 - Assist caregiver in navigating multiple medical professionals
 - Connect to local support resources (home modifications, financial support, meals)
-

Key Activities: Maintenance Mode

- Routines may already be in place
 - Already exposed to disease specific information
 - May need information on benefits, especially if new to managed care or have a significant change in condition
 - Still need to have organizational tools
 - May already have expanded supports due to length of condition, but still requires a respite break
-

Early Activities

- Started our Caregiving Collaborations™ journey in 2017 by creating caregiver workgroup with reps from various health plans
- Developed standardized caregiver assessment in collaboration with the National Alliance for Caregiving
- Still identifying baseline metrics/reporting needs
- Website upgrades- caregiver tool kit and resource links
- Caregiver journal

Early Challenges

- Engagement and buy in of Care Managers
 - Additional administrative responsibility of managing the caregiver as well as the member
 - Additional assessment and system documentation
 - Talking points and empathy training
 - Standardized collateral for multiple markets
 - Review and restructuring of web site design
 - CMS/state approvals take time
 - Engagement of reporting team on establishing baseline metrics with multiple data sources
 - Competing with other clinical programs (ex. Fluvention[®], Compassionate Connections [®])
-

Measures of Success

- ED Diversion
- Reduced admissions/readmissions
- Improved QOL- via Caregiver survey
- Increase in advance directives
- Increase in respite utilization rates
- Length of time spent in the community

External Caregiver Resources

- National Alliance for Caregiving-
<http://www.caregiving.org>
 - AARP- <https://www.aarp.org/caregiving>
 - CAN- Caregiver Action Network-
<http://caregiveraction.org>
 - Family Caregiver Alliance- <https://www.caregiver.org>
 - Rosalyn Carter Institute for Caregiving-
<http://www.rosalynncarter.org>
-

Questions?

For more information please contact:

Laura Sankey

lsankey@centene.com

314-445-0539

Emerging Innovations in Managed Long-Term Services and Supports

Home and Community-Based Services Conference

August 30, 2018

Wendy Fox-Grage
Senior Strategic Policy Advisor
AARP Public Policy Institute

Barbara Edwards
Senior Fellow
Health Management Associates

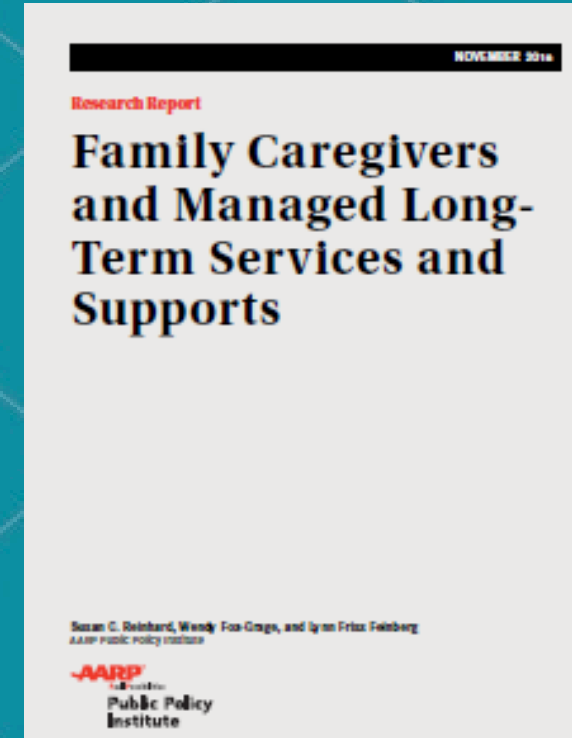
HEALTH MANAGEMENT ASSOCIATES



1st Major Research Report in this Emerging Field

Rationale:

- Family caregivers are major providers of care
- Some family caregivers are in need of support themselves
- Managed long-term services and supports is rapidly expanding
- Managed care plans can lead the way toward person- and family-centered care



Emerging Issue for Managed Care Plans

Family caregivers should include family, friends, neighbors, or anyone considered “family” by the member

Family caregiving supports is growing but not yet commonplace in managed long-term services and supports

Focus has been on support for the individual member, not the family unit

Stakeholders have focused on “preventing harm” and consumer protections

Several promising practices and lots of opportunities

How Can Health Plans Help Family Caregivers?

- The medical record and service plan can identify family caregivers.
- Family caregivers are assessed for their own needs and well-being.
- Family caregivers can participate in care planning.
- Family caregivers and care coordinators can have each others' contact information.
- Care coordinator can refer them to training to learn caregiving skills such as administering meds and wound care.
- Care coordinator can refer them to respite care and other needed services such as evidence-based caregiver support services, especially for dementia.
- Consumers and family caregivers are on advisory committees.

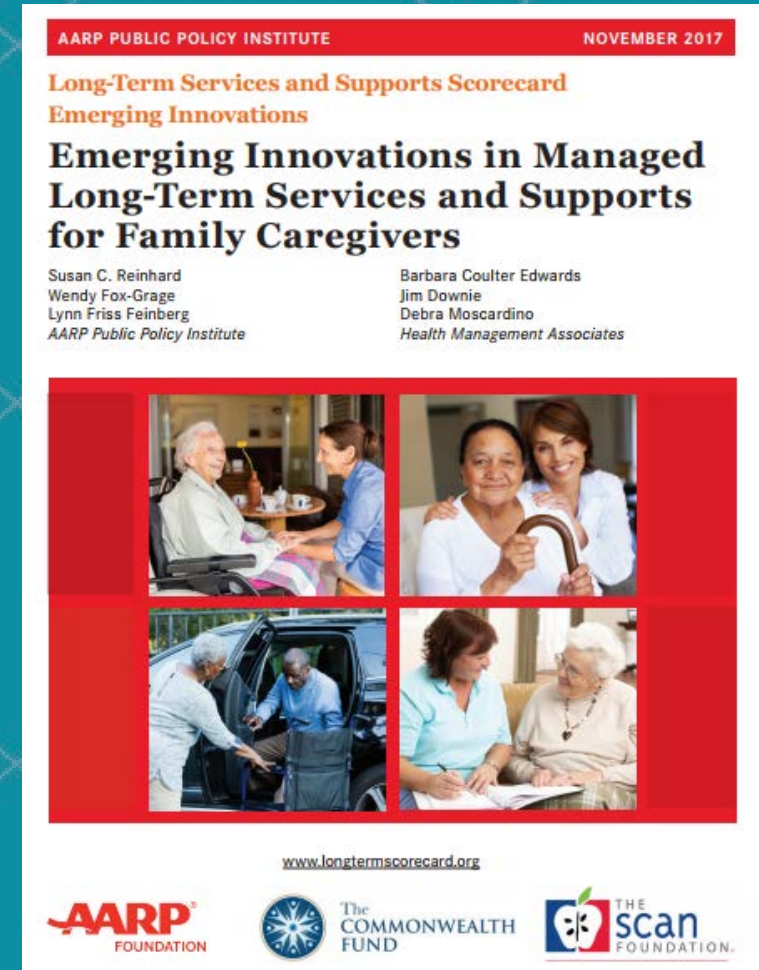
Truven Study for AARP: 19 Managed LTSS Contracts

Acknowledgement of Family Caregivers	Care Coordinator Contact Info Given to Family Caregivers	Training of Family Caregivers is a Covered Benefit
15 state contracts	9 state contracts	3 state contracts

Purpose of Our Report

To highlight how progressive managed care plans are supporting family caregivers who are caring for plan members with LTSS needs

To learn from each other and to adopt practices to better care for members and their family caregivers



Environmental Scan

- Contracted with Health Management Associates to conduct standardized telephone interviews with 42 administrators in 15 Medicaid-contracting managed care plans that cover long-term services and supports
- Administrators were corporate officers and staff with managed care organizations that contract in multiple states and state-level administrators of managed care plans in seven states (AZ, CA, MA, NJ, SC, TN, and WI)

Amerigroup NJ, Amerigroup TN, Anthem/Amerigroup, Centene, Commonwealth Care Alliance, Community Care, BCBS TN, Health Plan of San Mateo, Inland Empire Health Plan, LA Care Health Plan, Molina Healthcare, Select Health of SC, United Healthcare (MA), UnitedHealthcare (AZ)

- Structured Interviews Asked Medicaid MLTSS Plans:

- ✓ How they involved family caregivers in care planning and care coordination
- ✓ How they assessed the needs of family caregivers (for training, stress/burn-out, need for supports)
- ✓ What services or supports were available to support family caregivers, including any innovations underway

- Plans Told Us:

- The role of family is critical
 - in conducting an effective assessment of the individual's needs and the development of a care plan
 - in providing viable options for individuals with disabling conditions to remain in their own homes or in community-integrated settings
- Family members serve as:
 - Caregivers
 - Communication facilitators
 - Advocates

Caregiver Assessments

- All plans assess needs of family caregivers – but some plans are now developing and using stand-alone, formal tools focused on caregivers



Developed a national caregiver assessment tool that can be modified to accommodate state requirements. Use of this tool is encouraged, even in states that do not require a separate assessment of family caregivers.



Elected to use AMA Caregiver Self-Assessment Questionnaire in multiple states, and training care coordinators to assess issues



Uses a separate caregiver assessment tool, which goes beyond required state elements to include caregiver's own health and need for training. Collaborated with TN to allow telephonic assessment for more privacy and candid answers.

Respite Care Used Beyond Benefit Limits

- Respite care is commonly available, but policies vary by state; many plans interviewed described the use of respite beyond contract limits when needed



- AmeriHealth Caritas (Select Health in SC) has a caregiver quality improvement goal to increase the use of respite by 10% a year to relieve caregiver stress and burnout
- Multiple plans reported some family caregiver reluctance to use respite; some reported system barriers to sufficient use
- Plans also view adult day programs, in-home aides, home visits by doctors, and other services as potential support for family caregivers

Direct Engagement of Family Caregivers

- All states require plans to establish member advisory councils, but some plans described additional efforts to engage members and family caregivers



In AZ, developed 8 regional advisory councils to better promote local participation by members and caregivers. Purpose: education for caregivers, input to health plan.
In MA, has conducted a series of focus groups of caregivers and plans to launch a broader survey of caregivers to gain more information regarding instruction and other needs. Intent: develop programs in response.



Surveyed members and families to provide a better understanding of the needs of caregivers in the home. Revealed that caregivers are seeking peer connections for support and problem solving, access to holistic professional assessment of the members' needs, and increased education for physicians to understand the needs of complex populations.

Going Beyond “Linkage and Referrals”

- All health plans provide family caregivers with information on possible community resources, but some plans are doing more to make access to community resources a reality







Hires community outreach specialists and housing specialists in multiple states, modeled on the member advocate model required in the TN Medicaid market. Specialists work with members, family caregivers to meet needs in extraordinary circumstances. Promotes more effective self-advocacy by members and family caregivers (training, etc.) In NJ, hosts educational workshops for caregivers.








Offers unpaid family caregivers a coupon code, so they can access available online caregiver instruction (otherwise developed for paid caregivers). University of Wisconsin at Oshkosh and state department developed the training.

Partnering with Community-Based Organizations, Universities to Develop, Deliver Supports and Training

	<p>In AZ, created a member empowerment program, based on input from the advisory council; holds mini-conferences for members and caregivers that bring community organizations and local colleges together to engage members and caregivers through participatory workshops.</p>
	<p>Partners with Alzheimer's Association of Greater Los Angeles to offer instruction, hosted in plan's family resource centers and other community sites, and to train plan staff on the fundamentals of cognitive impairment, practical dementia care management skills, and caring for the caregiver.</p>
	<p>Sponsors and leads the Inland Empire Disabilities Collaborative, which builds relationships across a network of entities who support and serve individuals with disabilities to strengthen and expand system capacity. Joined county agencies, CBOs, and medical colleges in sponsoring caregiver instruction; plans to make online materials available to family caregivers.</p>
	<p>Linked with the local Area Agencies on Aging and Disability (AAADs) to provide family caregivers supports such as stress management. (National Family Caregiver Support Program under the Older Americans Act.)</p>

Focus on dementia and behavioral health

	<p>In NJ, includes behavioral health specialists as part of the multi-disciplinary team that supports the LTSS care coordinator. Also partners with local health educators and providers to offer training sessions in communities on Alzheimer's Disease.</p>
	<p>Provides alternative sources of respite opportunities (and alternative respite providers) to assist family caregivers for individuals with complex behavioral challenges. Developed online resources for care coordinators to assess caregiver burnout, especially related to dementia care. Develops in-house experts for dementia care and connects families to other organizations for supports regarding dementia such as local "memory cafes."</p>
	<p>In IL, encourages regular in-home family meetings. A behavioral health specialist can attend these meetings and offer support for members and caregivers as needed.</p>
	<p>Provides respite as a value-added service to provide relief for caregivers supporting members with Alzheimer's disease and other dementias.</p>
	<p>Offers in-home respite for caregivers who assist individuals with behavioral health challenges (not a formal Medicaid benefit). Redesigned Interdisciplinary Care Team structure to include LTSS and BH staff and increase participation by members.</p>

Under-developed: Community Partnerships to Advance Person- and Family-Centered Care

- Managed care plan collaboration, formal relationships, even contracts with community based organizations could expand access to:
 - “Warm hand-offs” as a part of linking and referral to services
 - Support/peer groups for caregivers
 - Effective curriculum resources for family caregiver training
 - Culturally appropriate/diverse support options
 - New educational and training opportunities

Under-Used: National Family Caregiver Support Program

- Most administrators were uncertain whether their health plans had formal relationships or regularly referred family caregivers to the local National Family Caregiver Support Program
- Three plans reported that the local NFCSP program was an “important partner or resource” in providing caregiver supports
- Some reported that overtures to the local program had been unsuccessful – that the local program wanted to target its limited resources to non-Medicaid (or non-managed care plan) populations

Most Encouraging:

- Multiple plans identified that understanding and addressing the needs of family caregivers was a current priority for the plan; and
- All administrators expressed interest in learning more about promising practices and staying in dialogue on the topic



INTEGRATED HEALTH: HOW FAMILY CAREGIVERS ARE WORKING TO IMPROVE CARE AND REDUCE COSTS



C. Grace Whiting, J.D.

President and CEO

HCBS Conference 2018

ABOUT THE ALLIANCE

Established in 1996, the National Alliance for Caregiving is a 501(c)(3) non-profit organization dedicated to advancing family caregiving through research, innovation, and advocacy.

- Nearly 60 organizational members, including non-profits, corporations, and federal agencies
- Advocacy network of 80+ state/local caregiving coalitions and advocates
- Secretariat for the International Alliance of Carer Organizations (IACO)



Advocates sharing findings from *Rare Disease Caregiving in America* on Capitol Hill with Members of the Rare Disease and Assisting Caregivers Today's Congressional Caucus

“CAREGIVER” DEFINED

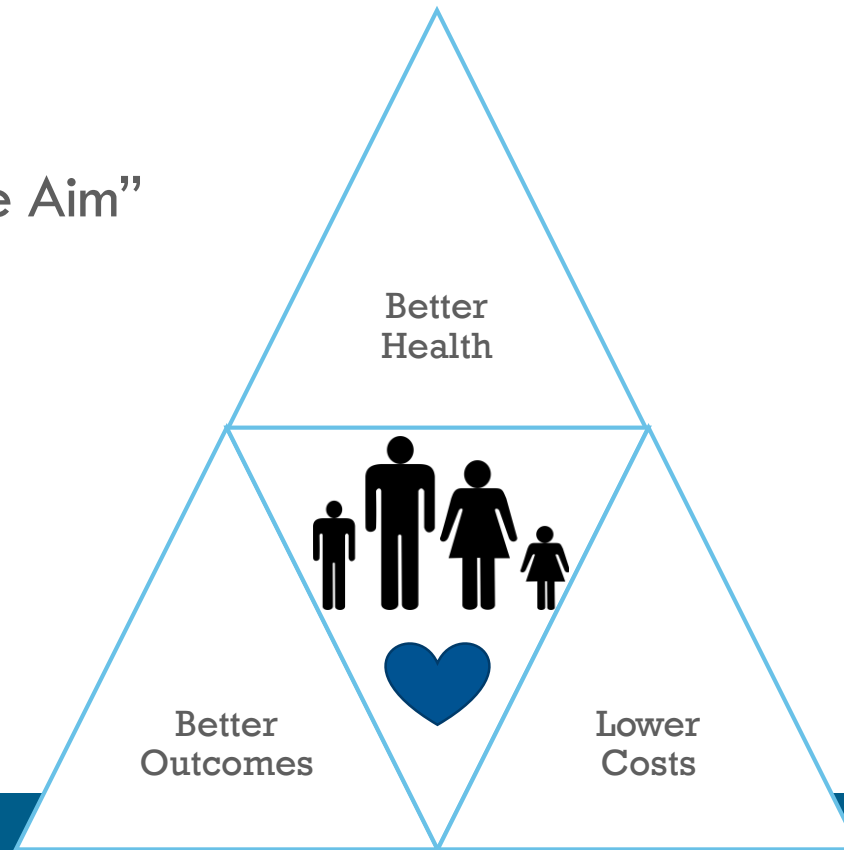
From the [RAISE Family Caregivers Act](#) of 2018 (P.L. No: 115-119):

“The term *'family caregiver'* means 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.”

**An estimated [1.4 million children](#) in the U.S. are unpaid caregivers. While their contribution is invaluable, this initial project will focus on caregivers age 18+.*



The “Triple Aim”



Family caregiving is a solution to rising health care costs

THE VALUE OF UNPAID FAMILY CAREGIVING TO HEALTH SYSTEMS

1

Family caregivers provide high-quality care (better outcomes) as informal members of a person's health and long-term care teams.

2

When supported, family caregivers can reduce health care costs and improve the delivery of health care and long-term services and supports.



There are 43.5 million family caregivers in the U.S., providing an estimated economic value of \$470 billion in care.

Data from Caregiving in the U.S., AARP & National Alliance for Caregiving (2015) and Valuing the Invaluable, AARP (2015 Update). Learn more at www.caregiving.org/research.

DEMOGRAPHICS:

- ❖ 60% Women
- ❖ 40% Men

- ❖ 13% African American/Black
- ❖ 6% Asian American Pacific Islander
- ❖ 17% Hispanic/Latino
- ❖ 62% White

- ❖ 24% Millennials (18 -34)
- ❖ 23% Gen Y (35 – 49)
- ❖ 46% Over 50
- ❖ 7% Over 75

- ❖ 9% LGBT
- ❖ 28% Rural
- ❖ 10% Military Vets
- ❖ 32% Living without a partner/spouse
- ❖ 47% Household income under \$50,000

**CAREGIVING IS
BECOMING
INCREASINGLY
DIVERSE AS
AMERICA AGES**

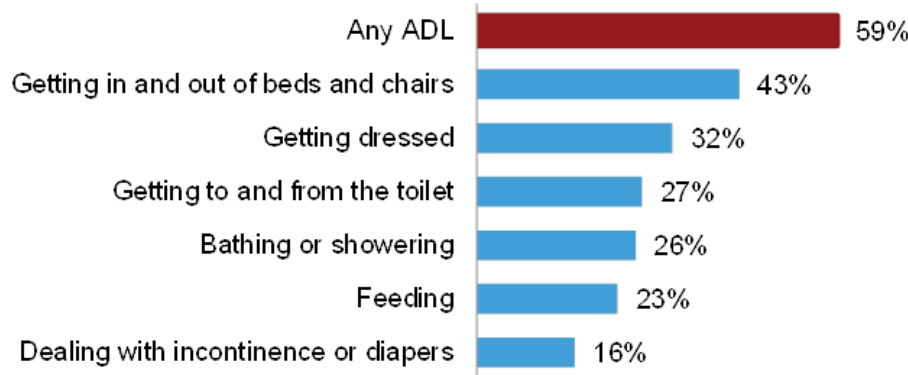
*National Alliance for Caregiving & AARP,
Caregiving in the U.S. (2015),
www.caregiving.org/caregiving2015*



CAREGIVING TASKS INCLUDE HELPING WITH ACTIVITIES OF DAILY LIVING

Q22. Which of these do/did you help your [relation] with?

Base: Caregivers of Recipient
Age 18+ (n=1,248)



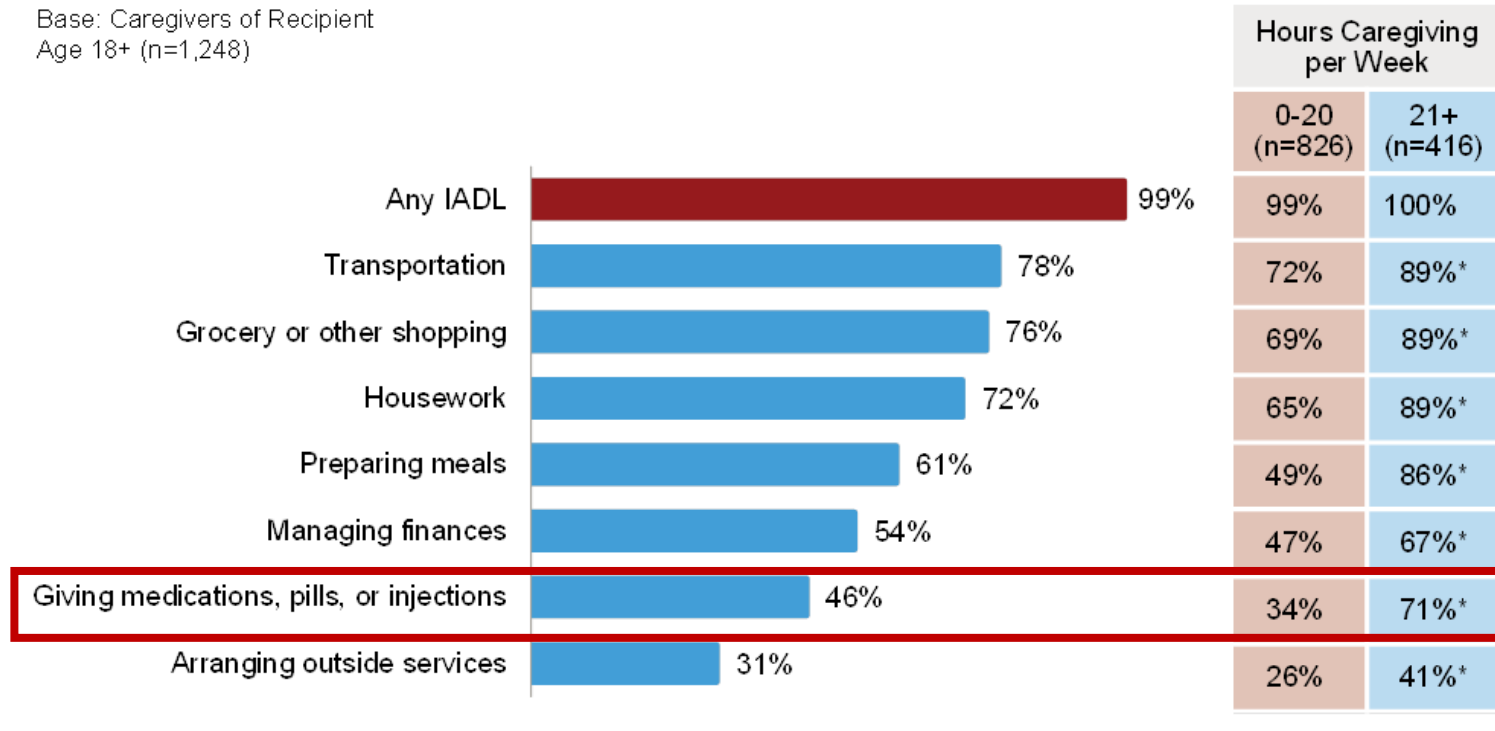
Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
51%	75%*
36%	59%*
22%	51%*
21%	40%*
17%	45%*
18%	36%*
9%	31%*

Data from Caregiving in the U.S., AARP & National Alliance for Caregiving (2015). Learn more at www.caregiving.org/research.

HELPING WITH INSTRUMENTAL ACTIVITIES OF DAILY LIVING

Q23. Do/Did you provide help to your [relation] with...?

Base: Caregivers of Recipient
Age 18+ (n=1,248)



Data from Caregiving in the U.S., AARP & National Alliance for Caregiving (2015). Learn more at www.caregiving.org/research.

HELPING WITH MEDICAL/NURSING TASKS

- More than 8 in 10 higher-hour **caregivers are performing medical/nursing tasks** without any prior preparation.
- The more complex the care, the more likely the caregiver performs medical/nursing tasks **without any preparation.**
 - ❖ 62% of high-burden caregivers are in this situation

Data from Caregiving in the U.S., AARP & National Alliance for Caregiving (2015). Learn more at www.caregiving.org/research.

CAREGIVERS AS “VOICE OF CARE”

Caregiving Activity	All Caregivers (n=1,248)	Cancer Caregivers (n=111)	Dementia Caregivers (n=372)
Communicating with healthcare professionals (doctors, nurses, social workers) about his/her care	66%	82%*	80%*
Monitoring severity of recipient’s condition to adjust care accordingly	63%	76%*	79%*
Advocating for him/her with health care providers, community services, government agencies	50%	62%*	65%*

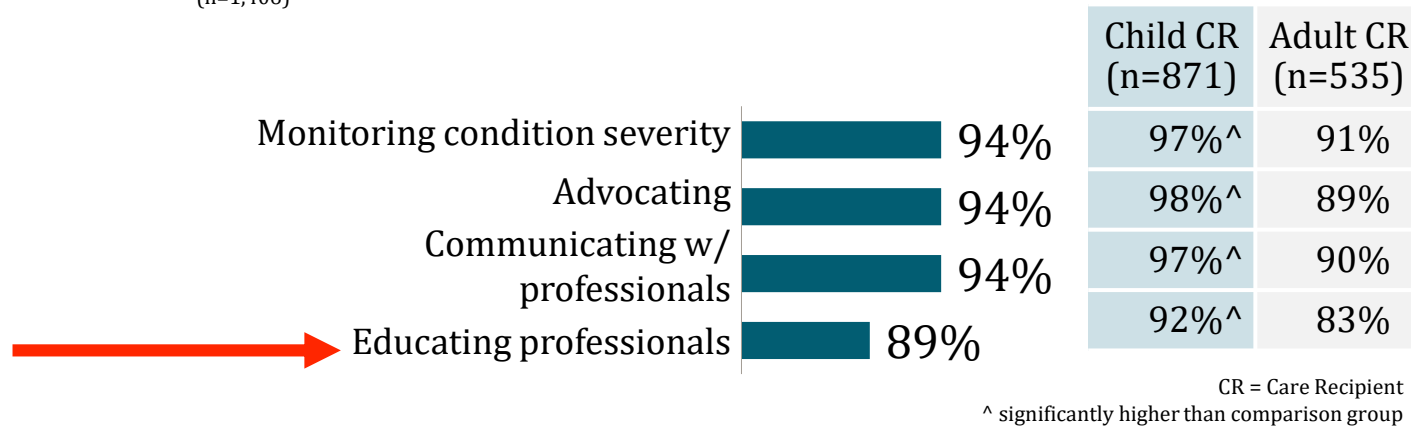
**Indicates statistically significant difference when compared to all caregivers.*

National Alliance for Caregiving & AARP, Caregiving in the U.S. (2015), caregiving.org/caregiving2015 and see also, Cancer Caregiving in the U.S. (2016) and Dementia Caregiving in the U.S. (2017), caregiving.org/research/condition-specific.

PATIENT ADVOCACY IS ESPECIALLY IMPORTANT FOR COMPLEX DISEASES, SUCH AS RARE DISEASE

Figure 27: Caregiving Support Activities in Rare Disease Caregiving

(n=1,406)



National Alliance for Caregiving & Global Genes, Rare Disease Caregiving in America (February 2016), www.caregiving.org/rare

RARE DISEASE CAREGIVING: CLINICAL TRIAL SUPPORT

Figure 29: Clinical Trial Support

Among those whose recipient has participated in a clinical trial (n=365)



CR = Care Recipient

^ significantly higher than comparison group

National Alliance for Caregiving & Global Genes, Rare Disease Caregiving in America (February 2016), www.caregiving.org/rare

Many caregivers face strain on their own health, wealth, and wellness—which can impact care delivery to the patient



For example, dementia caregivers

49%

say caregiving is emotionally stressful

1/5

report fair or poor personal health

8/10

of caregivers with high emotional stress say caregiving has made their health worse

28%

have difficulty accessing affordable support services

WHEN SUPPORTED, CAREGIVERS CAN IMPROVE INDIVIDUAL AND POPULATION HEALTH

- Caregivers can reduce avoidable hospital readmissions in discharges to the home.
 - ❖ By 25% at 90 days and by 24% at 180 days
- Sometimes, caregivers can help an older adult or person with a disability to live in the community longer, delaying costly institutionalization.

Rodakowski, et al. "Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis," *Journal of the American Geriatric Society* (April 2017), <http://onlinelibrary.wiley.com/doi/10.1111/jgs.14873/full>
Mittleman, et al. "An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers," *Gerontologist* (1993), <https://www.ncbi.nlm.nih.gov/pubmed/8314099>

TO LEARN MORE:

C. GRACE WHITING, J.D.
PRESIDENT AND CEO
NATIONAL ALLIANCE FOR CAREGIVING
4720 MONTGOMERY LANE, SUITE 205
BETHESDA, MARYLAND 20814

(301) 718-8444 OFFICE
(202) 525-8985 MOBILE
GRACE@CAREGIVING.ORG

WWW.CAREGIVING.ORG

