

# THIS WEEK IN CAREGIVING



August 25, 2021



## CAREGIVING IN THE NEWS

### **Time to Care: The Importance of Caregiver Voice in Healthcare, Drug Development, and Value Assessment**

The demands of caregiving, combined with limited formal training or external supports, can adversely impact the health and well-being of family caregivers. “Caregiver strain” is a concept that has been used to describe the spectrum of physical, psychological, social, and financial impacts experienced by family caregivers.<sup>3–5</sup> Dependence on family caregivers and high caregiver strain are most prominent in conditions that impose both physical and cognitive limitations, such as stroke, Alzheimer’s disease, and dementia, which predominantly afflict older individuals.

C. Grace Whiting, JD, the president and CEO of the National Alliance for Caregiving, stressed that, “Family caregivers are caring for multiple people ... [and] need care themselves to maintain their own health and wellness and to be the best care provider for a patient. When caregivers don’t have the support they need, it becomes more difficult for them to be a partner in care to the patient.”

*From: ISPOR | July/August Edition, 2021*

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### **Four Forecasts for Family Caregivers in a Post-Pandemic World**

When Harvard Business School published its 2019 Caring Companies report, finding that 3 out of 4 employees are also caregivers, the researchers couldn't have predicted that the workplace caregiving crisis was about to collide with the coronavirus crisis. Nor that the combination would accelerate a sea change in employers' attitudes and policies toward caregivers.

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"It is — and should be — impossible to have a meaningful conversation about recovering from this pandemic without addressing an aspect of Americans' lives that is too often invisible: caregiving," wrote Melinda Gates, co-chair of the Bill & Melinda Gates Foundation, in a recent Washington Post op-ed piece. "We overlook that it will require scaling up caregiving solutions...It's [also] hard to get back to work when you're responsible for children or older adults but have nowhere to turn for safe, affordable care."

*From: Next Avenue | June 26, 2021*

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caregivers.3–5 Dependence on family caregivers and high caregiver strain are most prominent in conditions that impose both physical and cognitive limitations, such as stroke, Alzheimer's disease, and dementia, which predominantly afflict older individuals.

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## EVENTS & OPPORTUNITIES

### Caring For Those Who Care: Meeting The Needs Of Hispanic Caregivers (webinar)

**August 26, 2021 | 2 PM EST | Online**

This webinar will help providers further their understanding of the experiences of Hispanic caregivers, and improve their multicultural capacities to meet these caregivers' needs. This webinar is part of the cultural competency training curriculum created by the staff of the Diverse Elders Coalition and its six member organizations, with the support of a grant from The John A. Hartford Foundation.

Much of the research and many of the statistics cited in the training were the result of a 15-month planning grant, during which the coalition completed a literature review, a survey of diverse family caregivers and a series of focus groups with family caregivers in diverse communities. The research was conducted nationwide, in eight languages, and was led by the older adults and caregivers represented by the coalition.

Participants in this webinar will be able to:

- Identify and address the unique needs and caregiving realities of Hispanic caregivers;
- Gain an understanding of how culture impacts Hispanic caregivers' perceptions of care and their health outcomes; and,
- Develop skills to deliver Hispanic-competent, person-directed care to improve health outcomes among Hispanic caregivers.

To register for this webinar, click [here](#). To learn more, click on the red button below.

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## **The Arc's 2021 National Convention will be held in New Orleans from September 27 - 29**

**Deadline to register at standard rate: August 27, 2021**

The Arc's National Convention is an unmatched opportunity to connect and learn with advocates, professionals, people with intellectual and developmental disabilities, and their families. If you are interested in employment, education, advocacy, housing, criminal justice, and more – our sessions are sure to challenge, inspire, and motivate!

To learn more about the convention click on the button below. Click [here](#) to register.

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## **The National Home-Based Primary Care Learning Network is accepting applications for its year-long participatory learning experience**

**Deadline to apply: August 30, 2021**

The goal of the Learning Network is to improve the care provided to homebound patients while promoting a culture of better care and continuous learning in home based medical care practices.

The Learning Network experience starts and ends with in-person meetings commencing and concluding the program. Between in-person meetings, the Learning Network will facilitate a series of video conference interactive learning sessions, technical assistance, and access to web-based quality improvement tools. Teams will complete an initial assessment of their current practice, identify opportunities for improvement, and will work between learning sessions to meet their aims.

To apply for this program, click [here](#). To learn more about it, click the button below.

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## **Webinar: Supporting Family Caregivers of Older Adults with Dementia and a History of Trauma: Unique Challenges and Trauma-Informed Approaches**

**August 31, 2021 | 2 PM EST | Online**

The Jewish Federations of North America (JFNA) Center on Aging and Trauma, a project of the Holocaust Survivor Initiative, invites you to participate in the webinar, **Supporting Family Caregivers of Older Adults with Dementia and a History of Trauma: Unique Challenges and Trauma-Informed Approaches** on Tuesday, August 31, 2021, from 2:00pm to 3:30pm ET.

Family caregivers of older adults with dementia and a history of trauma face a number of unique challenges, including trauma-related symptoms in their loved ones that can be

sudden, frightening, and difficult to explain; and fears of re-traumatizing their loved ones while managing their behavioral and cognitive symptoms during caregiving tasks. This webinar will provide an overview of the intersection between trauma and dementia and of the unique challenges of family caregivers of older adults with dementia and a history of trauma, and provide examples of how person-centered, trauma-informed approaches can help ameliorate these challenges and promote the health and well-being of this uniquely vulnerable caregiving population.

**Contact [Aging@JewishFederations.org](mailto:Aging@JewishFederations.org) with questions.  
To register for the webinar, click the button below.**

**REGISTER**  
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## The Legacy Interviews

**June 23 - September 8, 2021 | Online**

The American Society on Aging has released a 12-week webcast series that will feature interviews with diverse legendary pathfinders who have spent decades in the field of aging, health and social services. Each interview will be conducted by Ken Dychtwald, to capture the wisdom and character of gerontology's pioneers to inform, inspire and guide current and future professionals in the fields of aging and related services for years to come.

Click [here](#) to register for the webinar, Click on the red button below to learn more.

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## Registration for Informational Meeting for Prospective Applicants Extended

**Deadline to register: September 13, 2021**

The [ARCH National Respite Network and Resource Center](#) and the [Respite Care Association of Wisconsin](#), in collaboration with the [National Academy for State Health Policy \(NASHP\)](#) are seeking applicants to participate in a pilot project to field test a competency-based and enhanced entry-level respite provider training curriculum and recruitment campaign. The purpose of the initiative is to develop, test and scale a respite workforce recruitment, training and retention program to better meet the respite needs of families caring for individuals of any age or condition, particularly in light of the impact of the COVID-19 pandemic on the workforce.

Additional funding is anticipated to increase the number of pilot sites from six to twelve. To accommodate additional applicants, the deadline for application submission has been extended to September 13, 2021, midnight CST. Only one site per state will be selected and applicants demonstrating a statewide or multi-county reach will be given priority.

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## Community-based Dementia Programs: Learning from Challenges and Sustaining Successes

**September 14, 2021 | 1 PM EST | Online**

Please join the National Alzheimer's and Dementia Resource Center for the webinar, **Community-based Dementia Programs: Learning from Challenges and Sustaining Successes**, on September 14, 2021 from 1-2 p.m. ET.

Dozens of community-based dementia programs have been launched over the last few decades. In addition to supporting people living with dementia and family caregivers, most of these programs educate and provide training for professionals and members of the community. Addressing the wide range of training and support needs for these audiences has led to many lessons learned and provided the programs with a solid foundation for sustained success. This webinar provides an overview of the types of services and training provided by community-based dementia programs. In addition, participants will learn about lessons learned and methods for sustaining successful program activities from two community-based dementia programs.

To learn more, click [here](#). To register for the webinar, click the button below.

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## **Engaging Caregivers: A Program for Healthcare Workers**

**September 23, 2021 | 10 AM - 11 AM CST | Webinar**

Healthcare workers can better serve patients through partnership with caregivers, but there is limited formal training and support on how to engage caregivers in care planning. This series will explore the role of caregivers and their experiences in supporting the health of loved ones. We will examine issues including difficult behaviors, elder abuse and advocacy, diversity and cultural competence and we'll identify resources to support healthcare workers along the way. **Certificate of attendance provided upon request.**

Join us to discuss: **Defining Caregivers & Recognizing Their Experiences**

- What research tells us about caregiver experience, challenges, and well-being
- Are caregivers a resource, partner, or client?
- Self-care for caregivers and professional caregivers

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## **PATIENT AND CAREGIVER STUDIES**

### **Caregivers: How Much Do You Know About Managing Money?**

Help evaluate a free virtual program by the Alzheimer's Association about making financial decisions and planning for future care costs. Visit [alz.org/managingmoney](https://www.alz.org/managingmoney) to learn more.



### Caregivers:

Help evaluate a free virtual program by the Alzheimer's Association® about planning for future care costs.



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## AHEAD Study

Join a trial that aims to help prevent Alzheimer's disease, funded by the National Institutes of Health (NIH) and Eisai Inc., which is testing an investigational treatment aimed at delaying memory loss before noticeable signs of Alzheimer's disease begin.



Help us get AHEAD of Alzheimer's

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## LEAF: Life Enhancing Activities for Family Caregivers



Life Enhancing  
Activities for  
Family Caregivers  
**LEAF**

Researchers at UCSF and Northwestern University are testing a program for family caregivers of people with Alzheimer's Disease designed to increase levels of positive emotion, which in turn can help lower stress and support ways of coping with the stresses of caregiving.

Click the red link below to learn more and click [HERE](#) to take the pre-screening survey.

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## Veteran User Experience Research Study

Are you a Veteran? Active duty or Reserves? A caregiver? A family member? The Department of Veterans Affairs wants to make it easier for you to explore, apply for, manage, and track your VA benefits. Teams at the VA want to hear your feedback about improvements they are making to VA websites, mobile applications, and other digital tools -- to ensure that these services are usable and relevant for you.

Click the red link below to learn more and click [HERE](#) to register.

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## IN CASE YOU MISSED IT...

### How do I organize my caregiving tasks?

During this [#carechat](#) with Aaron Blight, EdD, he provides tips for caregivers on ways to organize their loved ones' care, including questions to ask when organizing a care plan, navigating Medicaid, when to seek emergency help for your loved one, and much more.

Click below to view the video.



## RESEARCH & RESOURCES

### JUST RELEASED!

Are you or someone you know caring for a child with a rare and/or serious illness?

Download our new guidebook  
*The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses*

DOWNLOAD NOW

THE CIRCLE OF CARE GUIDEBOOK FOR CAREGIVERS OF CHILDREN WITH RARE AND/OR SERIOUS ILLNESSES

IN PARTNERSHIP WITH

**nac**  
National Alliance for Caregiving

**Global Genes**  
Allies in Rare Disease

MADE POSSIBLE WITH SUPPORT BY:

**Mallinckrodt Pharmaceuticals**

## NAC Presents The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

The National Alliance for Caregiving is proud to present *The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses*, a new resource designed in partnership with Global Genes and with support by Mallinckrodt Pharmaceuticals to provide caregivers with the support, services and specialized information they need to care for a child with a rare and/or serious illness. This guidebook offers an extensive list of resources to help a caregiver in any situation throughout the entirety of their journey as a rare disease caregiver, compiled by those in the rare disease space and caregivers themselves. This list is supplemented by the specialized information needed in order to care for a child with a rare and/or serious illness. If you or someone you know cares for a child living with a rare and/or serious illness, make sure to check out the guidebook at the link below.

You'll learn about:

- The process of getting an accurate diagnosis for a rare and/or serious illness;
- Genetic testing, clinical trials and support groups that can help;
- Information on treatment and care coordination with specialized teams;
- Understanding the cost of care and treatment;
- Advocating for your child, their care and in their disease space;
- Empowering your child to manage their rare and/or serious illness through all aspects of their life, including when they become an adult; and
- Caring for yourself and your family.

There is also an appendix with a comprehensive list of online resources, supports and services for caregivers, the child living with the rare and/or serious illness, and his or her family that are referenced throughout the guidebook.

**Click on the button below to access the Guidebook.**

[VIEW THE GUIDEBOOK](#)



### What's Public Health Got To Do With... Family Caregiving?

Trust for America's Health (TFAH) has published a blog, "What's Public Health Got To Do With... Family Caregiving?," to launch it's new monthly blog series on Age-Friendly Public Health Systems. This series is designed to stir up conversation, generate interest, and challenge healthy aging stakeholders to engage more deeply in age-friendly public health issues.

Author of this month's blog on "What's Public Health Got To Do With... Family Caregiving?," Megan Wolfe, TFAH's Senior Policy Development Manager, outlines five potential roles for public health departments to support caregivers, organized according to TFAH's AFPHS 5Cs Framework. The roles include collecting and disseminating data, coordinating existing supports and services, connecting and convening multiple sectors, communicating, and complementing existing supports.

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### Diverse Family Caregivers Toolkit

Download the Diverse Elders Coalition's **Resources for Providers: Meeting the Needs**

**of Diverse Family Caregivers Toolkit.** This toolkit offers topline information on what providers need to know, and key pieces from our comprehensive training curriculum, **Caring For Those Who Care: Meeting the Needs of Diverse Family Caregivers.** Whether you've already attended one or more of our trainings, or this is your first time looking into what's available to help you support diverse family caregivers, we think you'll find these resources to be invaluable in building a more welcoming, supportive practice.

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## Paid Leave Video from National Partnership for Women & Families

The ability to take time off when we're sick and need to rest. To accompany a loved one to a dialysis appointment. To spend time with a newborn or adopted child. Some of us have this option, but far too many people in the United States do not.

The National Partnership for Women & Families brought together cross-sector business leaders who have been advocating for paid leave — Airbnb, Levi's, Patagonia, Seven Seven Six, Sun Life, Thinx, ThirdLove, Brew HaHa! (a main street business in Delaware), and Melinda French Gates.

The message is loud and clear from business leaders: no one should have to choose between our families and our jobs — and paid leave is what every business needs to thrive.

Watch our **new video** as these leaders each share why they think ensuring all workers can take time off work to care for themselves or a loved one is why the time is now for paid leave. And **join them** in the call for paid leave for all.

Click [here](#) to learn more or click on the red button below to view the video.

VIEW VIDEO



## Dementia Care Providers Database

Best Practice Caregiving is a free online database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

In the Best Practice database you will find detailed information about:

- focus of each program
- (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation
- research findings
- direct utilization experiences of delivery sites
- program developer information.

Click [here](#) to learn more about the database or click the button below to access it.

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## Home Is Where the Care Is

What if you were one of the 2 million adults who are homebound in the United States? Wouldn't you want care to come to you? With the nation's older adult population increasing, home-based primary care is quickly becoming the future of health care for patients who are medically complex. New resources share needed information about delivering primary care in the home:

- The **Better Care Playbook's Home-Based Primary Care Collection** provides research, resources and tools for delivering care at home. The collection includes blogs from Rush@Home detailing its care model elements and implementation insights, and the Department of Veterans Affairs highlighting its successful program.
- A **Home Centered Care Institute (HCCI) House Calls 101 course** offers a simulated educational experience to help you get started with home-based primary care.

Click [here](#) to the online course. Click the button below to browse the collection.

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## Report: The United States Should Recognize and Support Caregiving Youth

In the United States, more than 5.4 million children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance.

In this policy study published in the Society for Research in Child Development's *Social Policy Report*, the authors describe youth's care for the family and highlight the increasing prevalence, global challenges, and uneven successes of measurement and categorization. They briefly summarize research on how caregiving affects youth's academic, social, and emotional well-being. Next, they present novel, emerging evidence from the public school-based 2019 Youth Risk Behavior Survey for the State of Florida, which suggests that as many as 24 percent of middle school students and 16 percent of high school students provide at least some care to the family on a regular basis. Drawing on this evidence, the authors' discuss targeted social programs which have been shown to promote the well-being of caregiving youth outside of the United States, as well as a 13-year-old school-based intervention in The School District of Palm Beach County, Florida.

The report concludes with specific recommendations for a path toward recognizing and supporting caregiving youth via policy and practice in the United States. Its aim is to increase the awareness and feasibility of identifying and supporting caregiving youth and their families via government-organized data collection and targeted social policies.

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## 2021 Global State of Caring Report

The International Alliance of Carer Organization's 2021 Global State of Care report provides an in-depth profile of the issues, approaches, policies, and innovations that are needed to support carers. It profiles the carer policies and practices in 18 countries. This

interacting tool features carer initiatives addressing six universal carer priorities:

- Recognition: Legislation and awareness campaigns
- Financial support: Income support, pensions, and benefits
- Work and education: Carer-friendly workplaces and educational initiatives
- Health and well-being: Health and social supports
- Information and knowledge: Resources and education
- Evidence-informed practices: Innovative policies and practices

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## The John A. Hartford Foundation's Dissemination Center

Funded and disseminated by **The John A. Hartford Foundation**, The American Association of Retired Persons (AARP) has released a new series of how-to videos and accompanying resource guides that walk family caregivers through what to expect before, during, and after a planned or emergency hospital stay.

The videos and resource guides, many of which are available in both English and Spanish, are free of charge and were developed by **Home Alone Alliance** members—the

The “How-To” videos and resource guides for family caregivers are on specific medical/nursing tasks – including preparing special diets, managing incontinence, wound care, mobility, and managing medications.

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## Navigating the Pandemic: A Survey of U.S. Employers

Employers play a vital societal role by providing employment, work experience, employee benefits, and the ability for workers to save and invest for a secure retirement. This report examines the pandemic's impact on employers across company, their response, and timely opportunities. A strong employee benefits package, including retirement benefits, health insurance, workplace wellness programs, and caregiver support, can create a win-win situation for employers and their employees. Especially now, as our nation is emerging from the pandemic, employers need support from policymakers to continue paving the way for their recovery and to make it as easy as possible to enhance their business practices and expand their benefits offerings.

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