

THIS WEEK IN CAREGIVING



April 13, 2022



CAREGIVING IN THE NEWS

Will You Have To Support Your Aging Parents Financially One Day?

For most adult children with aging loved ones who were responsible investors, there is a sense of security. There is nothing to worry about. They have a seven-figure investment portfolio and they own their home outright. No one expects them to run out of money. But can they?

The answer depends on two things: how long they live and how much it costs to pay for needed care. Sometimes, even people considered wealthy (\$1M+ in net worth) are not as financially secure as they think or you may think. The costs of aging are truly shocking.

From: Forbes | Published: April 11, 2022

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How LinkedIn's 'Career Break' Feature Could Help Normalize Caregiving

After Yahaira Castro gave birth 15 years ago, she went back to her job in higher education while her husband stayed home with their new baby. After all, her job offered better health benefits, she said.

But while her return to work felt like a logical decision, it proved more emotionally difficult than she had expected. "I don't think I accounted for how hard it would be when I went back to work," said Castro, 47, who lives in Jersey City.

Millions Kept Out of Work Caring for Aging Parents, Sick Spouses

Courtney Russell loved her job managing a Charleston, S.C., candy store. But early in the pandemic when her husband's cancer returned, she felt she had only one choice: to quit.

Her husband, Doug Curtin, needed a bone-marrow transplant and months of chemotherapy. But hiring a home nurse, so she could keep working, seemed risky with rising coronavirus rates in early 2020.

From: The Philadelphia Tribune | Published: April 12, 2022

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NAC NEWS AND UPDATES



World Carers Conversation 2022: Register Now

May 19, 2022 | 8:00 AM - 6:00 PM EST | Online

As the uncertainty around the future of the global COVID-19 pandemic continues, support for carers remains critical. NAC is convening global leaders, experts, influencers, researchers, policymakers, innovators, and other stakeholders in caregiving to share their unique research, case studies, programs, interventions, and perspectives on the future of caregiving as part of this event.

This free event will be made available to the public via Zoom and Facebook Live. The 2020 World Carers Conversation enjoyed participation of caregiving experts and stakeholders from six continents (Africa, Asia, Europe, Oceania, North America, South America) and fifteen countries (Australia, Canada, China, France, Ghana, India, Ireland, Israel, Mexico, New Zealand, South Korea, Taiwan, United Kingdom, United States) with more than 4,000 attendees.

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

REGISTER





JUST RELEASED!

Reimagining Clinical Trial Recruitment Through A Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity

[DOWNLOAD NOW](#)

NAC Releases New Report: Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity

The National Alliance for Caregiving is proud to present *Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity*, a new report developed with sponsorship from Traverre Therapeutics. Building on the priority area of clinical trials recruitment and retention identified in NAC's 2019 report *Paving the Path for Family-Centered Design: A National Report on Family Caregiver Roles in Medical Product Development*, this report synthesizes outputs from a series of three roundtables. In collaboration with Health Leads, NAC mobilized its network of researchers, policymakers, innovators, patients, families and caregivers to discuss and develop strategies for improving how researchers engage caregivers from populations most impacted by structural inequities in order to better understand how to increase representation of diverse patients in clinical trials.

Included in this report:

- Summary of caregiver expert convening including their key insights on caregivers' role in clinical trials and barriers to patient and caregiver participation;
- Summary of clinical trial roundtable including current strategies that improve caregiver engagement and support caregiver roles related to trials;
- Direct quotations from caregiver experts about their experiences with clinical trial participation;
- Outputs of a co-design session with both caregiver experts and clinical trial experts;
- Individual-level, community-level and systems-level focus areas for acting on these co-developed recommendations.

NAC's report underlines that engaging caregivers more effectively in the clinical trials process to promote better trial enrollment diversity requires investment and collaboration from not only industry partners and sponsors, but also from federal regulatory agencies, policymakers, healthcare leaders, community care providers and patients and caregivers themselves. Recognizing the value – the contributions, the expertise, the health impact – of what caregivers do, as partners in innovation, is a key part of creating a more equitable, person and family-centered health care system.

To read the report and access our findings, click on the red button below.

[LEARN MORE](#)





The Circle of Care Guidebook Series

The National Alliance for Caregiving's *Circle of Care* library is a series of guidebooks dedicated to providing resources, support and information to caregivers caring for someone in a specific disease space. Part of an ongoing effort of NAC, these first three guidebooks were developed with the assistance of both patient-advocacy and consumer-facing partners:

- **Circle of Care: A Guidebook for Mental Health Caregivers**
- **Circle of Care: A Guidebook for Caregivers of Children and Adolescents Managing Crohn's Disease**
- **The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Diseases**

NAC is proud to lend their expertise on caregiving through these guidebooks. To access the guidebooks for yourself and to share them with other caregivers in your life, please visit the link below.

[VIEW THE GUIDEBOOKS](#)





JUST RELEASED!

Caregiving in a Diverse America:
Beginning to Understand
the Systemic Challenges
Facing Family Caregivers

[DOWNLOAD NOW](#)





MADE POSSIBLE THROUGH SPONSORSHIP BY



NAC Releases New Report: Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Diverse Family Caregivers in the U.S.

The National Alliance for Caregiving is proud to present *Caregiving in a Diverse America: Understanding the Systemic Challenges Facing Family Caregivers in the U.S.*, a new report conducted with sponsorship by Amgen, Inc., with support from the Diverse Elders Coalition and in partnership with the National Minority Quality Forum. Based on a

secondary analysis of the survey results found in *Caregiving in the U.S. 2020*, the data presented includes multiple logistic regression analyses by Dartmouth College researchers. The report highlights significant disparities in support, caregiving intensity, health, and financial impacts among African American, Hispanic and Asian American and Pacific Islander caregivers, LGBTQ caregivers, as well as caregivers across different income brackets and geographical areas. While conducting the research for this report, it became clear that more inclusive methods of data collection are needed to inform research on the needs and possible supports and services that can be provided to diverse family caregivers.

The findings in this report highlight:

- African American, Hispanic, Asian American/Pacific Islander, LGBTQ, rural and socioeconomically diverse caregivers;
- Disparities in living situations, financial status, caregiving activities, self-reported health, and information and services used;
- Personal stories of diverse family caregivers that provide human context to the data;
- Next steps in ensuring data collection and research is inclusive of and equitable to all family caregivers;
- Future policies and improvements to supports, services and the health care system that can better the caregiver experience for diverse populations.

[LEARN MORE ABOUT THE NAC REPORT](#)



Addressing the Needs of Diverse Family Caregivers for Older Adults

This 20-page report is the product of a series of activities conducted by the Diverse Elders Coalition (DEC) and its members' organizations, and in partnership with the National Alliance for Caregiving, to better understand and highlight the lived experiences of diverse family caregivers for older adults. It highlights key findings from 300+ diverse caregivers for older adults from the DEC's constituent communities, including racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ+) people as they provide care through the pandemic. The goal of the full length report is to offer research and recommendations to help ensure services and supports for caregivers intentionally address health disparities and systemic barriers that diverse family caregivers for older adults face.

[READ THE REPORT](#)



EVENTS & OPPORTUNITIES

Call for Applications for the 2022-2023 Class of Health and Aging Policy Fellows

Are you committed to improving health and aging? Are you interested in learning about policymaking to increase your impact?

If so, we invite you to apply to join the next class of Health and Aging Policy Fellows!

As a Health and Aging Policy Fellow, you have the opportunity to join a dynamic community of 166 Fellows who are committed to improving health and quality of life for older Americans.

The one-year Fellowship runs from October 1 – September 30 and has full-time and part-time tracks. It is conducted as a hybrid program of mentoring, networking, learning and practicum experiences. Health and Aging Policy Fellows work across diverse fields of aging. They develop lifelong partnerships and networks. Individually and collectively they are improving the lives of older adults around the country.

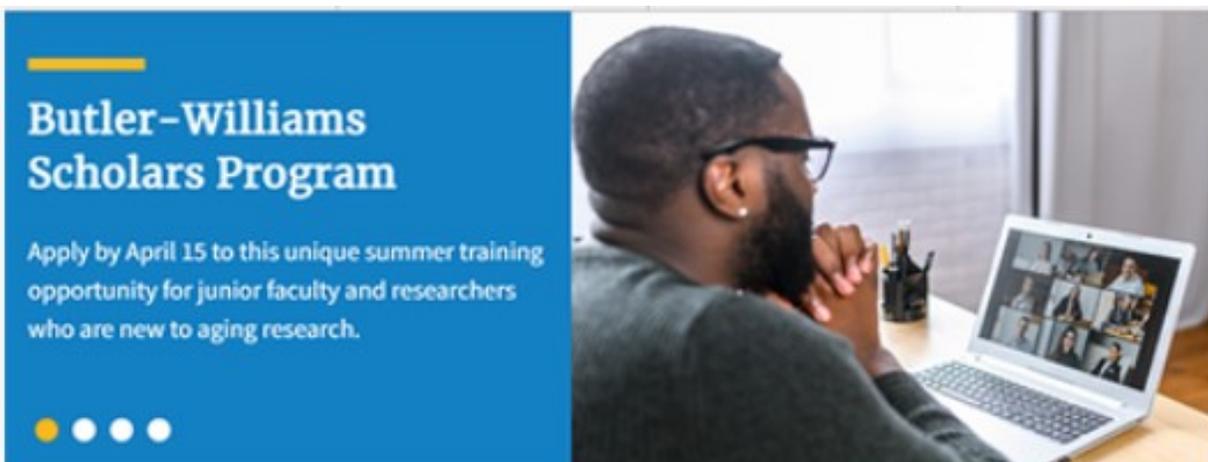
The Health and Aging Policy Fellows Program aims to create a cadre of leaders who will serve as change agents in health and aging policy to ultimately improve the health care of older adults. The year-long fellowship offers a rich and unique training and enrichment program that is focused on current policy issues, communication skills development, and professional networking opportunities to provide Fellows with the experience and skills necessary to help affect policy.

Submission deadline: April 15, 2022

Fellowship begins October 2022

To learn more about the fellowship, click [here](#). To apply, click the red button below.

CLICK HERE TO APPLY FOR THE FELLOWSHIP



**Butler-Williams
Scholars Program**

Apply by April 15 to this unique summer training opportunity for junior faculty and researchers who are new to aging research.

Call for Applications: The Butler-Williams Scholars Program 2022

The National Institute on Aging's (NIA) Butler-Williams Scholars Program has a call for applications for their 2022 cohort.

The program provides distinctive opportunities for researchers and faculty who are new to the field of aging to gain more knowledge about this field. It includes lectures, seminars, and small group discussions in research design relative to aging, including issues relevant to aging of ethnic and racial minorities. Lectures will cover topics in research on aging, including: the biology of aging; genetics and Alzheimer's disease; and health, behavior, and aging.

Researchers with an interest in health disparities research are encouraged to apply.

Applications are due April 15.

To learn more about the Butler-Williams Scholars Program, click [here](#).

To apply, click the red button below.

[CLICK HERE TO APPLY FOR THE PROGRAM](#)



VISION HEALTH

ADVOCACY COALITION

Thyroid Eye Disease Patient & Caregiver Event

April 16, 2022 | 8:30 AM - 10:30 AM EST | Rosemont, Illinois

Living with or caring for somebody with thyroid eye disease? Join us for a free discussion on living with and managing the disease.

About this event

Location:

Sheraton Suites Chicago O'Hare
6501 Mannheim Road
The Chicago Room
Rosemont, IL 60018

Schedule:

Saturday, April 16

- 8:30am - Complimentary Breakfast & Registration
- 9:00am - Program

Important COVID-19 Information:

To promote the health and safety of this indoor event and the community as a whole, all attendees will be asked to provide proof of either COVID vaccination or negative COVID test results (taken within 48 hours of event) at check in.

Parking is free and will be validated after the event.

Contact Information:

For any questions, please contact Lauren Carter-Early at lcarterearly@allianceforpatientaccess.org or (202) 951-7076.

To register, click the red button below.

[REGISTER FOR THE EVENT](#)





Virtual Event: C-TAC & Petrie Flom Center at Harvard Law School: Emerging Policy Opportunities for Community-Based Serious Illness Care

April 27, 2022 | 1:00 - 3:00 PM EST | Online

The pandemic has accelerated trends moving the delivery of care into the home or community. Yet, care at home largely remains the province of better-resourced individuals, due to limited funding by government programs. Medicaid, the federal/state program of health care for people of lower-income, has the potential to address these equity issues through waivers or plan amendments.

With little fanfare, States have been innovating new models of care within their Medicaid programs, such as community-based palliative care, to support people with serious illness and improve health equity. For example, California initiated the trend, and Hawaii has a multi-year effort to implement improved benefits for people with serious illnesses. Several states are actively working on a similar approach, and others have expressed interest.

C-TAC is partnering with the Petrie-Flom Center at Harvard Law School to explore the opportunities for states to bring a broad range of palliative care services to seriously ill persons, particularly through changes to their Medicaid programs. Join us at this virtual event to hear from experts engaged in this effort, including state and federal officials, about the progress to date, key learnings, and prognosis for success.

To register for the conference, click the red button below.

REGISTER



Bridging The Digital Divide To Increase Social Engagement

April 27, 2022 | 2:00 PM EST | Online

The April 27 webinar at 2:00 pm ET will focus on bridging the digital divide to increase social engagement of older adults. During the webinar, Older Adults Technology Services from AARP will highlight how its Aging Connected campaign can help the Aging Network connect more consumers to affordable broadband and access social engagement opportunities. The Federal Communications Commission will then provide details on the Affordable Connectivity Program and resources for the consumers you serve. Attendees will also hear from the Eastern Oklahoma Development District Area Agency on Aging on how it helped consumers connect to broadband and how organizations can create similar strategies.

To register for the conference, click the red button below.

REGISTER



Family Caregiving for People with Cancer and Other Serious Illnesses

A Workshop

May 16-17, 2022

The National Academies of SCIENCES
ENGINEERING
MEDICINE

Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

May 16th-17th, 2022

The National Academies of Sciences, Engineering, and Medicine (NAEM) is holding a public workshop on May 16 - 17, "Family Caregiving for People with Cancer and Other Serious Illnesses."

The workshop will feature invited presentations and panel discussions on topics that may include:

- Strategies to better capture, understand, and act on family caregiver input and experience to improve patient care and to support family caregivers.
- Research gaps and opportunities to improve the evidence base to guide caregiving for patients with serious illnesses.
- Potential policy and practice opportunities to support family caregivers and advance family-centered care for serious illness, including new models of care delivery and payment.
- Opportunities to better embed a health equity focus across family caregiving research, policy, and practice.
- Lessons learned from the COVID-19 pandemic (e.g., use of telehealth and other remote technologies) that could be applied in the context of caregiving for people with cancer and other serious illnesses.

This event can be attended virtually or in person at the Keck Center in Washington, DC. To learn more or to register for the conference, click the red button below.

REGISTER



SAVE THE DATE!

The Public Health Opportunities and Challenges of Dementia Caregiving

June 14th-15th, 2022

You are invited to the in-person BOLD Public Health Opportunities and Challenges of Dementia Caregiving Conference on June 14 & 15! Join the BOLD Public Health Center of Excellence in Dementia Caregiving in person @McNamara Alumni Center (MN), and hear from experts what states and communities are doing to elevate dementia caregiving as a public health issue.

To learn more or register for the conference, click the red button below.

REGISTER



PATIENT AND CAREGIVER STUDIES

Welcome to the WeCareAdvisor Research Study!

Are you a family caregiver for a person living with dementia? The WeCareAdvisor Study may be right for you!

The WeCareAdvisor is an innovative tool developed by researchers at Drexel University and University of California, Davis to help family caregivers manage common behavioral and psychological symptoms of dementia like anger, irritability, asking repeated questions, pacing, or refusing needed help. The WeCareAdvisor walks caregivers through a step-by-step approach to understand why behaviors may be occurring, and to provide strategies that are customized to the situation that caregivers can use to manage the behaviors. Enrolled caregivers are randomly assigned to one of two groups, both of which have access to WeCareAdvisor. Caregivers also complete four phone interviews over six months, and receive a \$15 Amazon e-gift card for each completed interview.

The study is good fit for family caregivers who are 21 or older; able to read, speak, and understand English; the primary caregiver of a person diagnosed with dementia for at least the past 6 months; currently managing challenging dementia-related behaviors; have an internet-capable device, such as a computer, tablet, or smartphone; and have Internet access.

For more information, email WeCare@drexel.edu, call us at 267-359-1111, or visit <http://wecareadvisorstudy.com>.



Cancer Experience Registry

The Cancer Experience Registry (CER) is an IRB-approved research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify critical unmet needs among cancer patients, survivors, and caregivers. Our research is one of a kind because it captures the lived experiences of people impacted by cancer through longitudinal data collection, as well as patient and caregiver data that can be linked to understand how their experiences impact each other.

Who can take the survey? The CER is open to any adult who has been diagnosed with cancer at any point in their life or has been a family or informal caregiver to someone with cancer. Participants must live in the United States, a U.S. territory, or Canada and be able to read and understand English.

To learn more about the registry, click the red button below.

[LEARN MORE](#)

SHUT*i*CARE

Sleep Healthy Using the Internet - Caregiver Acceptability Research

SHUTi CARE Research Study

Many caregivers have sleep problems. Our team of researchers from the University of Virginia and the University of Pittsburgh developed and tested SHUTi, an interactive, web-based training program to improve the sleep of adults with insomnia. SHUTi provides a tailored educational program to individuals who are experiencing sleep difficulties, including those having difficulty falling asleep, waking in the middle of the night, or waking too early in the morning.

SHUTi has been tested and found successful in helping adults in the general population. The purpose of this study is to understand how caregivers who have sleep problems use and benefit from SHUTi.

To learn more about the study, click [here](#). To participate, click the red button below.

[PARTICIPATE IN THE STUDY](#)



Are You a Nurse and Family Caregiver?

What is this research study about?

We want to understand the issues that impact emotional and financial well-being for nurses who are also family caregivers.

What will I do?

If you qualify for this study you may:

- *Take a 30 minute survey
- *Participate in a 60 minute interview
- *Participate in a 90 minute focus group

You may qualify for this research study if:

- *You are 18 years of age or older
- *You care for someone with a chronic illness for 10 or more hours per week
- *You have worked as a nurse in the past two years

Participants will receive compensation for each phase of the study.

To learn more about this study, click the red button below.

LEARN MORE ABOUT THE STUDY



Study of Caregivers Caring for Parents Who Mistreated Them

The University of Wisconsin is seeking to interview adult children who are caring for a parent who caused them harm in childhood. The leads of this study hope to understand these caregivers' experiences, motivations and interactions with the healthcare system. The goal of the study is to inform the creation of more robust support and resources for these caregivers and assist healthcare professionals to recognize, assess, and intervene more effectively when working with individuals and families with this history.

To learn more about the study, click the red button below. To view the Facebook group for this study, click [here](#). To participate, click the red button below.

LEARN MORE ABOUT THE STUDY



INVITATION TO TAKE PART IN THE



Stress and Well-Being in the Lives of Caregivers Study

The University of Michigan's SWELCare study focuses on the daily experiences, well-being, and cardiovascular health of individuals living with a family member or friend who is experiencing cognitive decline. The study team is looking for caregivers and persons with cognitive decline over the age of 18 to participate. No formal diagnosis of dementia is required.

WHO CAN TAKE PART IN THE STUDY?

Individuals who are Black or White, living with and helping a family member or friend who has Alzheimer's or related dementia and are residents of the state of Michigan.

WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

YES! The family member/friend and the person living with dementia will receive a combined amount of up to \$400 for taking part in the study.

To learn more about the study, click [here](#). To participate, click the red button below.





IN CASE YOU MISSED IT...

Timing it Right: Providing Support and Resources Along the Caregiving Trajectory



If you see patients living with complex, chronic disease or frailty due to aging, you will likely see their family or friend caregivers too. In those moments – in as little as 10 seconds – you have the opportunity to enhance your impact by connecting with those family caregivers.

Evidence shows that caregivers who are supported earlier in their caregiving journey are better able to maintain their caregiving role. Our health system relies on family caregivers to provide about 80% of the care patients need. When we extend support for caregivers we support better outcomes for patients. It's that simple.



RESEARCH & RESOURCES

Making Decisions for Someone at the End of Life

Making health care decisions for someone at the end of life can be overwhelming. It can be even more difficult if you don't have written or verbal guidance from them. If you're making care decisions without specific guidance, you may want to consider the following questions:

- Have they ever expressed an opinion about someone else's end-of-life treatment?
- What were their values and what gave meaning to their life?
- Have you spoken to the person's medical team about a treatment plan?
- What treatments are available and what are their possible outcomes?

To learn more, click the red button below.

Learn More





Report Offers Action Steps for Supporting Family Caregivers

Family caregivers are a critical link in the network of providing long term services and supports (LTSS). Yet their needs are often overlooked. By collecting concerns, suggestions, and priorities from a diverse range of stakeholders working with family caregivers, a new report from the Leading Age LTSS Center @UMass Boston and Community Catalyst's Center for Consumer Engagement in Health Innovation presents a strategic roadmap for better support.

To read the report, click the red button below.

[READ THE REPORT](#)

Frequently Asked Questions About Palliative Care

Planning for care during a serious illness can be challenging. Palliative care is an option that can help patients and their families. To learn more, explore answers to frequently asked questions about palliative care below.

What is Palliative Care?

Palliative care is specialized medical care for people living with a serious illness. Palliative care can be received at the same time as your treatment for your disease or condition. It focuses on providing relief from the symptoms and stress of serious illness. The palliative care team works to prevent or ease suffering, improve quality of life for both the patient and their family, and help patients and their families make difficult health care decisions. When a patient decides to forgo treatment for their serious illness or is near the end of life, they may decide to enter **hospice care**.

To learn more, click the red button below.

[Learn More >](#)

What Do We Know About Diet and Prevention of Alzheimer's Disease?

Can eating a specific food or following a particular diet help prevent or delay dementia caused by Alzheimer's disease? Many studies suggest that what we eat affects the aging brain's ability to think and remember. These findings have led to research on general eating patterns and whether they might make a difference.

The Mediterranean diet, the related MIND diet (which includes elements designed to lower blood pressure), and other healthy eating patterns have been associated with cognitive

benefits in studies, though the evidence is not as strong as it is for other interventions like [physical activity, blood pressure and cognitive training](#). Currently, researchers are more rigorously testing these diets to see if they can prevent or delay Alzheimer's disease or age-related cognitive decline.

To learn more, click the red button below.

Learn More



What It's Really Like Growing Up as a Military Caregiver (Podcast)

What is it really like to grow up as a caregiver for a wounded warrior? A mother and son share their heart-wrenching perspectives and what types of support have helped them through hard times.

About the guests:

Elizabeth Rotenberry works as a fellows program manager at the Elizabeth Dole Foundation, and her son, Kris Rotenberry, is a senior in high school. They are caregivers for their husband and father, a Marine veteran who sustained a traumatic brain injury in an IED in 2011 and also lives with severe post-traumatic stress. Their family lives in Baltimore, Maryland.

To learn more about the podcast, click the red button below.

LEARN MORE



Black and Aging in America

Black and Aging in America®, a new report by the National Caucus and Center on Black Aging (NCBA), presents summaries, statistics, and perspective on the status of Older African Americans. By examining social, economic, health and other indicators, in comparison to other racial and ethnic groups, this report illustrates progress as well as the many challenges that remain.

Some organizations, academic studies, and government agencies consulted for this report define seniors as over age 55. However, unless otherwise noted, this report reflects information on the 65-and-older cohort. Black and Aging in America® condenses this broad spectrum of information into one simplified presentation—a readily accessible portrait of the status of Older African Americans.

To read the report, click on the red button below.

READ THE REPORT



USAging
Answers on Aging



Answers On Aging Podcast

Answers on Aging is a monthly podcast inviting listeners to take a deep dive into the work of USAging and our members on hot topics, current events, their work in the field and more. Stream the **first episode** now to hear from USAging CEO Sandy Markwood who shares with us her thoughts about the road ahead for USAging members and the entire Aging Network.

To learn more about the podcast, click the red button below.

LEARN MORE



The Hospital-at-home Presents Novel Liabilities for Physicians, Hospitals, Caregivers, and Patients

Healthcare is increasingly provided in a patient's home, with potential cost savings and clinical improvements. But the hospital-at-home also raises unique liability issues not only for physicians and hospitals but also for caregivers and patients.

A new article in the journal *Nature* discusses these issues as they pertain to medical professionals as well as unpaid caregivers. To read the article, click the red button below.

READ THE ARTICLE





Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile

Family caregivers are experiencing higher levels of isolation and stress due to COVID-19, which has complicated access to respite care and in-home paid caregiving.

Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile describes an ongoing project to enhance counseling, training, and other services offered by California's 11 nonprofit Caregiver Resource Centers (CRCs).

Published by the Family Caregiving Institute at UC Davis in Sacramento, CA, the report highlights the CRCs' deployment of an interactive online system to assess and meet caregivers' needs during the pandemic. The report also proposes using data collected in that system to support evaluation of the CRC service model.

Notably, compared with other caregiver populations, CRC clients are more likely to:

- Provide complex medical/nursing care at home
- Live with a care recipient
- Care for people who have dementia and cannot be left alone

[READ THE REPORT](#)



Supporting Family Caregivers of Older Adults with a History of Trauma: Implementation Recommendations for the National Family Caregiving Strategy

The Administration on Community Living has played a crucial role in ongoing efforts to develop a national family caregiving strategy.

In support of those efforts, agencies representing diverse populations and experts from various disciplines have drafted recommendations on person-centered, trauma-informed care for family caregivers of elders with a history of trauma.

The recommendations are aimed at:

- Increasing the use of family caregiver support services
- Promoting better outcomes for both caregivers and care recipients

[READ THE RECOMMENDATIONS](#)



Improving Primary Care for People With Disabilities

The National Association of Councils on Developmental Disabilities (NACDD), with support of UnitedHealthcare Community & State (UHCCS), partnered with the UHCCS National Federally Qualified Health Center (FQHC) Advisory Board and the National Advisory Board (Boards) to more fully understand the challenges individuals with disabilities face when accessing primary care and to identify ways the health care system can be strengthened to deliver comprehensive, person-centered care that best meets their needs. NACDD coordinated community surveys of individuals with disabilities, caregivers, state Developmental Disability (DD) Council leaders, and health care professionals from across the nation in August 2021 to collect feedback and anecdotal evidence on primary care access. These surveys were promoted through the Boards, within the NACDD network of consumers and advocates, and to health care provider partners. The brief provides an overview of those findings with insights from members of the Boards.

[READ THE BRIEF](#)



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