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 socioeconomicly 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.

The report makes clear that understanding the nuances of identity and culture are essential in understanding the challenges facing family caregivers and developing ways to support their needs. Even among diverse population groups, there are differences in needs, and a single solution cannot be applied to everyone.
How Build Back Better Is A Start To Support U.S. Caregivers

The Build Back Better Act (BBB) has brought family caregiving back into the spotlight. The BBB would expand the federal contribution to Medicaid's home and community-based care (HCBS) program by 6 percent annually or about $150 billion over 10 years. In addition, it aims to make a greater investment in family caregivers potentially.

According to 2009 data from CDC's state-based Behavioral Risk Factor Surveillance System, approximately 25% of U.S. adults 18 years of age and older reported providing care or assistance to a person with a long-term illness or disability. This is referred to as "informal or unpaid care" because it is provided by family or friends rather than paid caregivers. The one-year value of this unpaid caregiver activity was estimated at $450 million in 2009.

This is something cofounder and CEO Jessica Kim understands all too well. Kim cared for her mom during an almost 8-year cancer battle. At the time, she had to leave an executive-level position because of the demands of caring for her mom and her three little kids.

"My mom had pancreatic cancer," Kim shares. "After years of chemo and surgeries, the disease came back for the third time, and my parents moved in with me. I became her primary caregiver, which meant navigating all the medical responsibilities, performing nursing duties, and handling finances and logistics. I was also caring for my three young children and working full time. I was shocked by the lack of support and resources available and eventually had to make the difficult decision to leave my job to care for my mother and family. I later learned that my situation wasn’t unique."

From: Forbes | Published: November 30, 2021

UCLA Study Shows that California Caregivers Need Better Support

Understanding the scope of a challenge, starting with the demographics of the population of interest, is a critical first step in crafting solutions. In 2017, Archstone Foundation provided $510,000 to the UCLA Center for Health Policy Research in support of the California Health Interview Survey (CHIS). CHIS is largest state health survey in the nation, collecting information on health and health care across California. The Foundation supported a module of questions within CHIS to understand family caregivers, as questions on this important population have not been included in the survey for more than a decade.

Two leaders of the UCLA project team, Kathryn Kietzman, PhD, MSW, and Sean Tan, MPP, detailed their important findings from the caregiver study utilizing CHIS 2020 data during a webinar on Wednesday, December 1, 2021.

The researchers have created a rich, demographic profile of California caregivers, along with the characteristics of the people they are caring for. They have also compiled details about all the hidden costs of caregiving: The hours involved, the paucity of direct financial compensation, the missed opportunities for educational and career advancement, the shortchanging of caregivers' own physical, social, and emotional needs. And their work identifies how a disproportionate share of all the financial, physical, and mental stress is falling on women, people of color, and low-income households.

The powerful evidence of the varied pressures on family caregivers, a backbone of the long-term care system, points to why the Foundation's new strategic direction is focused on what we call the Three Ts: Teams, Training, and Technology.

From: Today | Published: November 30, 2021
Webinar: Understanding Aging and Dementia in Adults with IDD

Date: December 9, 2021 at 4:00 - 5:30 PM (EST)

At the end of this webinar, hosted by the National Task Group in Intellectual Disabilities and Dementia Practices, attendees will be able to:

• Understand the Impact of Aging on Adults with Intellectual Disabilities
• Provide an Overview of the Risk of Dementia in Aging Adults with Intellectual Disabilities
• Explain How the Challenges Unique to Intellectual Disabilities Impacts Service and Support Needs
• Understand What Dementia Is...And Isn't
• Increase Your Knowledge of Potentially Treatable Medical Conditions that Mimic Dementia
• Cite Established Guidelines for Diagnosing Dementia in Adults with Intellectual Disabilities

REGISTER HERE

AHHQI has an open RFP: 2022 Home Health Grant Request for Proposals

The Deadline is December 23, 2021

The Alliance for Home Health Quality and Innovation (AHHQI) seeks to sponsor a research project to help advance home health care and may seek to improve care delivery at home through quality and innovation. Funding will be awarded up to a total of $75,000 maximum (including indirect costs). Multiple projects may be funded if they do not exceed the total funding allocated for all projects of $75,000. Proposals are due by close of business on Thursday, December 23, 2021.

APPLY HERE

PATIENT AND CAREGIVER STUDIES
Black Male Dementia Caregiver Burden Study

GW School of Medicine and Health Sciences is actively recruiting Black men aged 30-85 who are either caregivers or non-caregivers of loved ones diagnosed with dementia. Participants will engage in a series of questionnaires, surveys, and a focus group, and can receive up to $125 in compensation. Click the link below for additional information.

COVID-19 Study

The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition. Are you a caregiver for an older adult with a chronic condition? Please consider taking part in this important research study to understand caregiving during #COVID-19. The University of Tennessee College of Nursing is seeking adults who are currently providing care (at least 8 hours a week) to an older adult with a chronic condition for a research study. The purpose of the study is to understand the experiences of caregivers during COVID-19. The study involves responding to an online survey questionnaire with questions related to caregiving and one interview to talk about their experiences using online caregiving resources. The one-time interview takes approximately 30–45 minutes to complete. Participants will receive a $25 Amazon gift card for completing the interview and a separate $10 Amazon gift card for completing the survey.

Intuition Study

Biogen has officially opened enrollment for the virtual Intuition Study in the United States. Using everyday devices, this first-of-its-kind study aims to measure changes in thinking and memory in adults, as well as identify longer-term changes in brain health. For more information about who is eligible and how to enroll, click the link below.

IN CASE YOU MISSED IT...

MSNBC Caregiving Segment with NAC
President & CEO C. Grace Whiting

MSNBC speaks to National Alliance for Caregiving President and CEO C. Grace Whiting on the needs of family caregivers and in what ways the Build Back Better bill will support these needs if it is passed. Grace highlights respite infrastructure, Paid Family Medical Leave, and current ways in which caregivers can connect with other caregivers to find support, information, and those going through similar experiences in order to feel less isolated.

The purpose of the roadmap is to support states that are interested in developing and expanding supports for family caregivers of older adults by offering practical resources on identifying and implementing innovative and emerging policy strategies. The Financial and Workplace Security for Family Caregivers section is highlights how states are supporting employed family caregivers and promoting financial security among caregivers.

Congress enacted the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in 2018, which created an Advisory Council to develop the country’s first national Family Caregiver Strategy. NASHP created this roadmap with guidance from policymakers and leaders from across state government, using the RAISE Act goals and recommendations as a framework.
This new site aims to serve as a platform to support caregivers and adults with intellectual and developmental disabilities (IDD) who may be at risk of, or are living with Alzheimer’s disease or related dementia (ADRD). As an aging service provider who works closely with caregivers of all ages, demographics, and capacities, we are excited to provide a centralized tool that will provide direct access to webinars across the county, trainings, updated research, and resources.

The National Alliance for Caregiving Releases a New White Paper Analyzing Existing Incentives for Caregiver Services

Caregivers are not well integrated into U.S. healthcare systems. Across care settings, caregivers lack formal and consistent roles on the care receiver’s care team and can struggle to manage their care recipient’s needs with their own. Only 29 percent of caregivers report being asked by a healthcare professional about their caregiving needs; this rate drops to 13 percent when the question referred to what the caregiver needed to be able to care for themselves (2020 Report of Caregiving in the U.S.; AARP and National Alliance for Caregiving).
Is What Matters to You Today the Same as Two Years Ago?

Millions of people will travel to see friends and family in person over the upcoming holiday season, many for the first time in nearly two years. Our world and society have changed dramatically over the course of the COVID-19 pandemic and the upheaval has led many to reevaluate their own hopes and expectations for the future.

Now is a good time to talk about what matters to you with those who care about you, especially related to your health and care needs as you age. It’s also an opportunity to have conversations with people whose care you may be responsible for.

Whether you are a clinician or other professional working with older adults, or you are considering what matters in your own personal life, here are resources to help begin or facilitate these sometimes difficult conversations.

LEARN MORE

Livanta #MyRole Social Media Toolkit

To help improve public awareness of family caregivers and increase family caregivers’ self-identification, Livanta has created #MyRoleCounts, a social media toolkit for partners
Lessons from the Workplace: Caregiving During COVID-19

In the first article of its new Spotlight series, Social Innovations in Caregiving, the National Alliance for Caregiving details the hardships the COVID-19 crisis magnified for millions of working caregivers and explores the mismatch between what family caregivers need to meet the demands of working while caregiving and what benefits and supports employers offer. “The pandemic has exposed the reality that working Americans must too often choose between caring for loved ones and holding onto their jobs,” says Grace Whiting, President, and CEO of NAC.

Offering potential solutions on how employers can address this mismatch, NAC advances recommendations for workplace policies and practices that employers can provide to caregivers. These recommendations include flextime, compressed workweeks, and public policy strategies to help reinforce workplace solutions such as redefined paid leave criteria.
NAC's Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses

The National Alliance for Caregiving recently produced *The Circle of Care Guidebook for Caregivers of Children with Rare and/or Serious Illnesses*, 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.**

Dental Help for Adults With Disabilities

Special care dentistry (SCD) is a branch of dentistry that facilitates care for impaired patients with physical, intellectual, sensory, mental, emotional, medical, or social disabilities.
Special care dentistry is taught as a postgraduate course that equips dentists to offer dental services to patients with special care needs.

International organizations like the Special Care Dentistry Association (SCDA) are made up of oral dental professionals dedicated to promoting the oral health of persons with special needs.

Those qualified for special-care dentistry are people who need free comprehensive dental treatment. This includes:
- The elderly
- Disabled people
- Mentally and medically compromised persons

Best Practice Caregiving: Infographic Series on Dementia Caregiving Program

The Family Caregiver Alliance (FCA) is publishing a series of blogs and one-page infographics as part of a series about specific dementia caregiving programs that are found in Best Practice Caregiving.

Best Practice Caregiving (bpc.caregiver.org) is a free online database that helps health care and social service organizations identify, compare and adopt best-fit programs for their clientele and community.

Plain Language Resource for Crime Victims With Disabilities

A new fact sheet, created by The Arc's National Center on Criminal Justice and Disability, is designed for people with disabilities to understand their rights if they are victimized. The document outlines different types of abuse, what people with disabilities -- or the caregivers who help them -- can do if they become a crime victim, and where to go for help. Download it now and share it in your community!

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.
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.

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.

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
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.

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

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.

**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 the 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.