National Alliance for Caregiving Announces Jason Resendez as New President and CEO

For 26 years, NAC has been a relentless force for improving the lives of family caregivers through agenda-setting research and public policy and I couldn’t be more excited to assume this role at a crucial time in our nation’s care crisis. Caregiving connects us all and it is past time that we honor that bond through bolder federal and private sector action. - Jason Resendez

The Board of Directors of the National Alliance for Caregiving (NAC) is pleased to announce that it has selected Jason Resendez as its next President and Chief Executive Officer. He will assume leadership of the nation’s preeminent caregiving research, advocacy and innovation organization on July 5, 2022 after taking paternity leave.

“We are fortunate to find someone of Jason’s caliber and experience to lead the National Alliance for Caregiving through its next phase of impact and growth,” said Janet McUlsky, board chair of NAC. “After conducting a nationwide search and assessing a strong pool of candidates, the Board was impressed by Jason’s ability to translate research into advocacy and innovative program initiatives to advance economic and racial justice for caregivers and their families.”
“The volume of interest in the position and impressive slate of candidates highlights the strong community of advocates, policymakers, and providers who are committed to supporting family caregivers. As we moved through our hiring process, it became clear that Jason is an inspirational leader who can maximize the impact of this expanding community to advance the wellbeing of family caregivers.”

From: The National Alliance for Caregiving | Published: April 20, 2022

---

Caregiving for Someone with Dementia is Hard. Answers to These Questions Can Lighten the Load

Donna Gonlag has spent most of the last two decades caring for two people with dementia, first her husband’s aunt and then, for the last eight years, the man she married almost 43 years ago.

Both experiences have been challenging, but different.

“It’s been easier with David than his aunt,” she said. “We didn’t connect with the Alzheimer’s Association with her. We didn’t even know there was one available.”

From: The Buffalo News | Published: April 8, 2022

---

Caring for Others? Remember to Care for Yourself Too

Caregiving is a selfless act, but finding the right balance between caregiving and your personal well-being is essential. It may seem counterintuitive to think of yourself first when others are your focus, but it takes the “best you” to offer the best help to your loved ones.

That starts with getting your house in order, physically, emotionally and financially. While there is no single formula for combatting caregiving fatigue, there are several steps that can help you care for yourself—and your wallet.

From: Morgan Stanley | Published: April 12, 2022
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 >**

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

**JUST RELEASED!**

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

**DOWNLOAD NOW**
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 Travere 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

NAC Releases New Report: Caregiving in a Diverse America: Understanding the Systemic Challenges Facing 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, 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

NADRC Webinar: Supporting Persons with Dementia Where They Live - Dementia Education for Building Management, a Chicago Model

April 21, 2022 | 1:00 - 2:00 PM EST | Online

Building managers are the first line of contact for early identification of problems with older adult residents. Through a collaborative community-academic partnership between the City of Chicago Age-Friendly Commission/DFSS and University of Illinois Chicago, we created a Dementia Training Program for building management staff to address the problem of the changing health status of older adults living independently in high-rise buildings throughout Chicago. The data demonstrate the participants consider the dementia training webinar to be beneficial, with 94.5% of participants (n = 85) rating the program Excellent-Good, 98% of participants found it useful and 92% were confident in their ability to refer residents to needed city services. Thus, educating building managers through a dementia training program creates a workforce that will recognize and address the changing healthcare needs of older adult residents, particularly those experiencing
Changes in cognition.

Participants in this webinar will be able to:

- Recognize key elements and strengths of a dementia training program for building management staff developed by a collaborative academic-community partnership.
- Analyze key challenges encountered in designing and delivering a dementia training program, particularly in challenging learning environments such as those created by the COVID-19 pandemic.
- Discuss the impact of a dementia training program on building management staff's knowledge of dementia, preparedness to communicate effectively with dementia residents, confidence and ability to link residents to appropriate services.
- Understand the development of the Chicago model for providing dementia training to building managers.
- Discuss the multilayered outreach techniques used to support apartment managers.

To learn more about the webinar, click here. To register, click the red button below.

REGISTER >
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.

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
Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop
May 16th-17th, 2022

The National Academies of Sciences, Engineering, and Medicine (NASEM) 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.
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>

Apply to Be a Macy Faculty Scholar

Deadline: August 1, 2022

The Macy Faculty Scholars Program, now in its second decade, aims to identify and nurture promising early career educators in medicine and nursing. The Program will help develop the next generation of national leaders in medical and nursing education by identifying outstanding educators, physicians, nurses, and role models—individuals who represent the breadth of diversity seen in learners, patient populations, and health care settings around the country. By providing the Scholars with resources—especially protected time, mentorship, and a professional network of colleagues—the Program aims to accelerate Scholars’ careers, to turn their teaching practice into scholarship, and to help them become impactful leaders locally, nationally, and beyond.

To learn more about the Macy Faculty Scholars Program, click here. To apply, click the red button below.

APPLY>

PATIENT AND CAREGIVER STUDIES
Volunteers Needed for Studies to Advance Dementia Research

Interested in volunteering for research on Alzheimer’s disease, related dementias, and cognitive health? Learn about new and featured studies near you with the Alzheimers.gov Clinical Trials Finder by clicking on the red button below.

To learn more about other resources available at Alzheimers.gov, click here.

FIND AN ALZHEIMER'S STUDY

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 >

SHUTi CARE Research Study

Many caregivers have sleep problems. Our team of researchers from 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.

---

**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.

---

**INVITATION TO TAKE PART IN THE**

**SWEL Care 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...

**A ‘Shark Tank’ Winner on Dementia Caregiving**

Tracey Wheeler Noonan speaks of her experience caring for her mother Judith Ann Wheeler and late father Edward James Wheeler, who were both diagnosed with Alzheimer’s in their mid-70s. Hoping to offer people a sense of companionship through What The Family!, Noonan discusses her inspiration for co-writing the TV script about her family’s journey with dementia.

Meanwhile, Noonan, a winner on the TV show Shark Tank, shares her gratitude for those around her as she navigated the challenges of being both a caregiver and the co-founder of the company Wicked Good Cupcakes. Reflecting on her learnings from over the years, Noonan offers advice on balancing work life with caregiving,
Planning for the Future After a Dementia Diagnosis

If you or a loved one has been diagnosed with Alzheimer’s disease or a related dementia, it may be difficult to think beyond the day to day. However, taking steps now can help prepare for a smoother tomorrow.

Over time, the symptoms of Alzheimer’s and related dementias will make it difficult to think clearly. Planning as early as possible enables you to make decisions and communicate those decisions to the right people.

Below are important legal documents to consider, and resources and tips that can help with planning ahead for health care, financial, long-term care, and end-of-life decisions.

To learn more, click the red button below.

White Paper on Why Older Adult Mental Health Matters

In anticipation of National Mental Health Awareness Month (MHAM) in May, the National Coalition on Mental Health and Aging (NCMHA) has developed a set of materials emphasizing the growing need to address older adult mental health issues, including a white paper on the importance of mental health in older adults.

To read the white paper, click the red button below. For additional NCMHA materials on this topic, click here.

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.
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.

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.

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.

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.
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 >

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
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

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

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.

READ THE REPORT

READ THE RECOMMENDATIONS

READ THE REPORT >

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.
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.