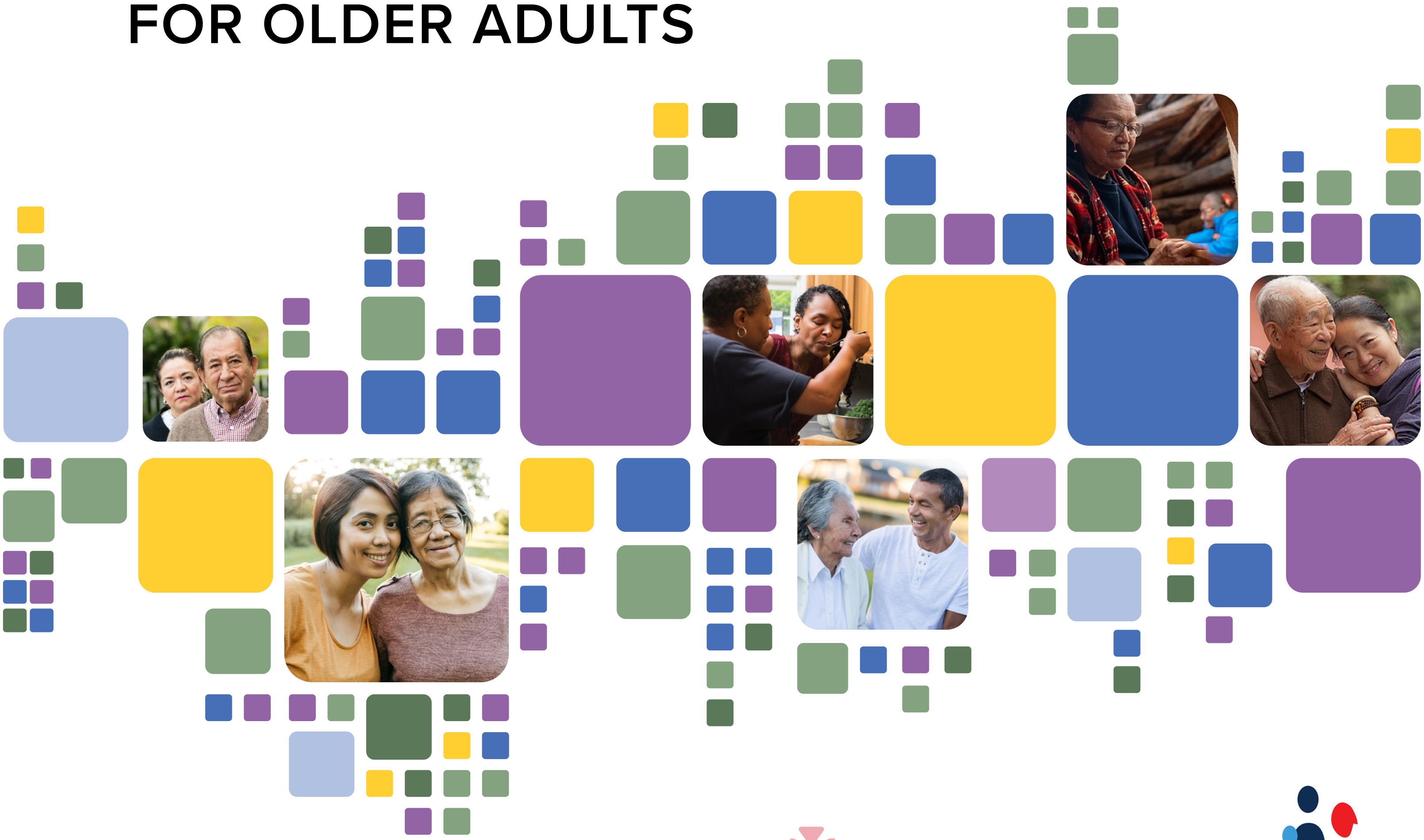
DECEMBER 2021

Family Caregiving in Diverse Communities

ADDRESSING THE NEEDS OF DIVERSE FAMILY CAREGIVERS FOR OLDER ADULTS



This report was created with support from
The John A. Hartford Foundation.

DIVERSE ELDERS COALITION

nac
National Alliance for Caregiving

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Introduction

WHO WE ARE

This report is the product of a series of activities conducted by the Diverse Elders Coalition and its member 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.

Founded in 2010, the **Diverse Elders Coalition (DEC)** advocates for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) people. In the decades to come, the communities represented by the DEC will collectively form the majority of older adults in the United States. The DEC is working to strengthen policies and programs to enhance the health and well-being of diverse elders; to educate and connect diverse older adults and their loved ones to key policy debates on aging; and to increase public support for issues that affect our communities.

Our member organizations—National Asian Pacific Center on Aging (NAPCA), National Caucus and Center on Black Aging (NCBA), National Hispanic Council on Aging (NHCOA), National Indian Council on Aging (NICOA), SAGE (Advocacy and Services for LGBT Elders), and Southeast Asia Resource Action Center (SEARAC)—are influential players in the federal advocacy arena and experts in the distinctive needs of the racial, ethnic, political, and cultural communities they represent. Through their actions in their respective communities, they are viewed as trusted members who provide services and resources for diverse caregivers and their aging loved ones. Together, we are uniquely positioned to effectively reach our communities in rural areas, cities and regions throughout the United States.

The **National Alliance for Caregiving (NAC)** was founded in 1996 and our mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable non-profit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; and more than 50 advocates who work on national, state, and local platforms to support caregivers across the United States. In addition to our national work, NAC leads and participates in several global meetings on caregiving and long-term care, working closely with peer organizations in countries such as Australia, Canada, Denmark, Finland, France, Hong Kong, India, Nepal, Ireland, Israel, Japan, New Zealand, Sweden, Taiwan, and the United Kingdom.

DIVERSE ELDERS COALITION MEMBER ORGANIZATIONS

The **National Asian Pacific Center on Aging (NAPCA)** runs the National Resource Center on Asian American and Pacific Islander (AAPI) Aging, which provides technical assistance to professionals in the field of aging. They engage in research and dissemination to increase comprehension of the AAPI experience as caregivers and older adults. One of its primary goals is to help AAPI family caregivers gain access to the long-term services and supports they need to care for their loved ones.

The **National Caucus and Center on Black Aging, Inc. (NCBA)** is the only national aging organization that meets and addresses the social and economic challenges of low-income African American and Black older adults, their families, and caregivers, aged 60+. NCBA works to develop and implement strategies to improve the economic security and wellbeing of caregivers—both women and men—and enhance family caregiver supports at the local, state, and federal levels of government.

The **National Hispanic Council on Aging (NHCOA)** has been focusing on the unique needs of Hispanic family caregivers in recent years. NHCOA has also conducted a national survey of Hispanic family caregivers and a recent series of focus groups with Hispanic older adults in the U.S. and South and Central America to identify urgent needs and begin to craft solutions. They are also long-standing partners of the AllofUS research program that is aimed at creating the largest clinical database for diverse adults.

The **National Indian Council on Aging (NICOA)**'s Technical Assistance and Resource Center (TARC) provides outreach and education to American Indian and Alaska Native elders, the Aging Network, and Native focused and diverse aging groups, on the unique needs of Native elders and caregivers. NICOA co-created and launched the Tribal Long-Term Services and Supports National Resource Center, to empower tribal communities to develop and/or expand long-term services and support for American Indian and Alaska Native elders and persons with disabilities in their local communities.

SAGE is the world's largest nonprofit advocating for LGBTQ+ elders and their caregivers. For decades, SAGE has produced caregiving resources for and about older LGBTQ+ people and their families, including an LGBTQ+ person's guide to preparing for medical procedures, resources for those providing services and programming to LGBTQ+ caregivers, and a planning guide for caregivers in the LGBTQ+ community. SAGE runs the National Resource Center on LGBT Aging in partnership with the Administration for Community Living.

The **Southeast Asia Resource Action Center (SEARAC)** is a national civil rights organization that empowers Cambodian, Laotian, and Vietnamese American communities to create a socially just and equitable society. One of SEARAC's primary goals is to connect Southeast Asian American older adults and caregivers with resources that help overcome linguistic and cultural barriers to appropriate care.

REPORT SUMMARY

Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults focuses on understanding the lived experiences of family caregivers who support 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.

Based on research from the Diverse Elders Coalition, its members, and the National Alliance for Caregiving, this report highlights key findings from diverse caregivers for older adults prior to and throughout the pandemic. Key themes that have emerged include a lack of resources to adequately and culturally responsively address caregivers' mental health, social isolation, and financial strain. The report also highlights protective factors, or the ways in which our communities exercise resilience in spite of the pandemic and other inequities.

Finally, we bring together recommendations for how to integrate these findings into the landscape of national caregiving policy that is being developed, including implementation of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. The goal of this report is to offer research and recommendations to ensure systems of services and supports for caregivers intentionally address health disparities and systemic barriers that diverse family caregivers for older adults face.

CAREGIVING NATIONAL CONTEXT

Recent national conversations on issues related to care for older adults, social infrastructure investments, and the need to build a more resilient public health system—which was exemplified by the COVID-19 pandemic—have surfaced challenges that the over 53 million family caregivers in the United States face.[1] On a parallel track, our nation is continuing to reckon with racial injustices and systemic inequities that have been present for generations. These challenges are exacerbated by cultural and linguistic barriers and other social influencers of health that are not adequately addressed by health providers or larger health and social services systems. One of the biggest obstacles for diverse family caregivers is the lack of culturally responsive resources and services, which has led to many other issues that negatively affect the mental and physical health and well-being of both family caregivers and the older adults for whom they provide care. We must ensure that the systems of services and supports for caregivers intentionally address these health disparities and systemic barriers.

This conversation is timely, due to the current national debate over significant social infrastructure investments that, in part, aim to bolster the so-called "care economy" for older adults, people with disabilities, and their caregivers. Likewise, passage of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act in 2018 directed the Secretary of the Department for Health and Human Services to create a national strategy on family caregiving, building on the work of the RAISE Family Caregiving Advisory Council (FCAC). An initial Congressional report from the FCAC in 2021 included priorities and corresponding recommendations, established to outline the strategy's focus. The national strategy is expected to be drafted over the course of 2022.

Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults focuses on understanding the lived experiences of family caregivers who support older adults from diverse communities. This report includes recommendations from our research center on providing more robust and culturally responsive supports for caregivers of older adults, including racially and ethnically diverse family caregivers; American Indian and Alaska Native family caregivers; and LGBTQ+ family caregivers. We will cover findings from recent original research on diverse caregivers, takeaways from resource sharing sessions with Diverse Elders Coalition member organizations and caregivers, and

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[1] National Alliance for Caregiving and AARP. (2020, May). *Caregiving in the U.S. 2020*. Retrieved December 1, 2021 from www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf.

key policy recommendations that aim to better recognize and support diverse populations. This report will contribute to a greater understanding of the realities and the magnitude of different issues impacting diverse family caregivers in America, as well as actionable steps that can be taken to address them.

Many of the recommendations from this report align with, and would inform, how issues related to diverse populations can be interwoven into the forthcoming national caregiving strategy. They serve as a starting place to better integrate diverse family caregivers and older adults into healthcare and social service systems and would help to reach caregivers in a more person- and family-centered approach. By prioritizing the expansion of the national caregiver support infrastructure to reach diverse communities, there is potential to reach caregivers across a broader range of racial, ethnic, linguistic, and cultural backgrounds who have not previously been connected with such resources.

To ensure a more robust and inclusive system of services and supports that intentionally address health disparities and systemic barriers, we must overcome the challenges related to the cost or inconvenience of integrating diverse populations into program, policy, and research design. Rather than reinforcing institutions' assumptions that they know best, based on unrepresentative data and outdated cultural understandings of need, it's past time to move forward and become more inclusive to ensure interventions reach those they intend to serve.

This report highlights some general themes that can meaningfully improve the caregiving experience, reduce existing disparities, and advance the more equitable delivery of programs, resources, and services for caregivers and their care recipients.

Some of those themes include:

- Designing research that purposefully establishes objectives related to a better understanding of caregivers from diverse backgrounds and is inclusive, transparent, and representative of all communities.
- Acknowledging, incorporating, and continually improving cultural literacy into the development of programs, resources, and services designed for caregivers of diverse racial, ethnic, political, and cultural backgrounds, or with tribal affiliations.
- Ensuring that the eligibility criteria for programs and services designed for caregivers offer an inclusive definition of "family" to include siblings, aunts, uncles, cousins, nieces, nephews, grandparents, grandchildren, domestic partners, youth, members of the same tribe, friends, and/or community members that are not related by blood, but whose close association with the care recipient is the equivalent of a family relationship.[2]
- Recognizing and increasing access to caregiver programs, resources, services, and support networks that are designed to go beyond traditional notions of the family structure and are inclusive of and welcoming towards racially and ethnically diverse communities, American Indian and Alaska Natives, and the LGBTQ+ communities.
- Facilitating better access to programs, services, and resources to caregivers in rural areas and where access to technology is less readily available. Likewise, recognizing that a lack of technological literacy in rural, urban, and suburban areas alike may present a challenge for caregivers accessing formal supports.

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[2] *Family matters: Guide to defining family inclusively in workplace leave laws and policies*. A Better Balance (2020, February 20). Retrieved November 30, 2021 from www.abetterbalance.org/resources/family-matters-guide-to-defining-family-inclusively-in-workplace-leave-laws-and-policies.

Caregiving During the COVID-19 Pandemic

THE DEC'S CAREGIVING RESEARCH

In 2017, the DEC developed a long-range plan to address the special issues of formal and informal caregiving in the diverse communities that the Diverse Elders Coalition serves[3]—a consideration largely missing in national and local caregiving discussions and actions. The DEC, in partnership with researchers at the Benjamin Rose Institute on Aging (BRIA), and with support from The John A. Hartford Foundation, conducted a comprehensive review of both quantitative and qualitative research to understand the extent and types of knowledge that existed about caregiving among diverse communities and to identify what research was and is still needed. This process included interviews with 18 stakeholder organizations that provided valuable information on how best to develop culturally responsive trainings for the diverse populations they serve.

In 2019, with additional support from The John A. Hartford Foundation, BRIA researchers coordinated with the DEC and its member organizations to develop and implement a comprehensive survey of caregivers among their constituent groups in 8 languages, which has yielded nearly 1,100 complete survey responses to date. To supplement such caregiver survey data, DEC member organizations conducted 32 caregiver focus groups. These focus groups were held in 8 languages to capture the true essence of the unique diverse caregiver stories, and to compensate for the limitations of quantitative data. This research process has yielded the most comprehensive data to date on the experiences, issues, concerns, and outcomes of diverse family caregivers for older adults.

Family caregivers that are racially, culturally, and/or linguistically diverse often have to perform tasks such as interpreting in a medical appointment or translating important health-related documents. Some family caregivers are navigating the immigration and naturalization processes. We refer to these as "cultural tasks." One key finding of our research was that caregivers who report difficulties performing cultural tasks for care recipients have significantly higher levels of work strain, isolation, relationship strain, both physical and emotional strain, and depression. This subgroup also reports lower ratings of the healthcare given to their care recipients and lower satisfaction with support from others in helping them provide care. Another important finding is that caregivers for diverse

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[3] The Diverse Elders Coalition's research and polling data includes some, but not exhaustive, representation of caregivers for older adults from the Black and African American community, the Hispanic community, the LGBTQ+ community, the American Indian and Alaska Native Community, the Southeast Asian American Community, and the Asian American Community. We did not have meaningful data gathering from Middle Eastern or North African (including Arab, Chaldean, and Assiyrian) communities, or from the following communities typically categorized as Asian American, Native Hawaiian and Pacific Islander: Native Hawaiian communities, Pacific Islander communities, South Asian, or Central Asian communities.

older adults are themselves diverse. This survey data indicated that there are considerable differences *among* the DEC's constituent groups in terms of caregiving-related challenges, such as financial strains, language barriers, inadequate support networks, and other factors – all of which exemplify the need for a truly comprehensive and culturally responsive understanding of, and training for, caregivers for older adults.

The COVID-19 pandemic's implications for social isolation, depression, complex risks and health issues for older adults highlight the importance of continuing our research on diverse family caregivers. We also observed the need to provide tailored resources and emotional support for diverse family caregivers through a series of webinars and one in-person listening session that highlighted caregiver resources and also offered opportunities for caregivers to share feedback on their lived experiences of caregiving through the pandemic.

With support from The John A. Hartford Foundation, the DEC and its members developed and delivered 9 webinars specifically for diverse caregivers and their loved ones. Poll questions were administered during Zoom webinars to learn more about diverse family caregivers' concerns, strains, and desired resources amid the pandemic. These webinars were facilitated throughout 2020 and concluded in 2021. There were more than 300 participants across nine different unique webinars. While the DEC itself hosted one webinar open to all diverse family caregivers for older adults, all other webinars and the one in-person listening session were aimed at reaching a particular demographic of caregiver served by the host organization. For example, the two webinars co-hosted by the National Asian Pacific Center on Aging and the Southeast Asia Resource Action Center were focused on providing resources to and creating a safe, supportive space for Asian American and Pacific Islander family caregivers. While 9 of these resource-sharing events took place in English, one webinar focused on Hispanic/Latinx LGBTQ+ caregivers was conducted in Spanish.

CAREGIVING EXPERIENCE: KAREN

Karen is an only child in a small family, and after her father passed, she was the one there to care for her mother, Mimi. By 2016, Karen was facilitating a home health aid service for Mimi, and she stayed with her at the hospital when she had a bad fall and caught pneumonia. After the hospital, Karen tried to help Mimi stay at home as long as possible according to her wishes, but after a second fall it became necessary to put her into a long-term care facility.

The pandemic made caring for her mother at the facility much harder. Karen had a hard time contacting Mimi, and did not receive communication from the staff about how Mimi was doing. Karen was concerned that Mimi was not receiving proper care and attention, and that her mother was too isolated, since services at the facility had stopped; she knew her mom was sitting in her room all day.

Karen is part of a caregiver support group run by SAGE, an elder LGBTQ organization. She feels a lot of respect and awe for stories she hears from caregivers who are caring for a parent who did not accept them or their sexuality. In spite of this, those caregivers are giving their care recipient the best life possible.

From a policy standpoint, Karen believes there needs to be more communication with the public from care facilities and medical staff, especially after what she experienced with Mimi's nursing home. It is exhausting for her to have to continuously reach out to people to find out how her mother is being cared for. There needs to be more planning and support around long-term care and the finances that are required for long-term care.

THE NAC'S CAREGIVING RESEARCH

To underscore further work recently conducted on this subject, the National Alliance for Caregiving partnered with the DEC and the National Minority Quality Forum in 2020 and 2021 to produce a report called *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. The report contains many examples of the challenges experienced by diverse family caregivers using data from the *Caregiving in the U.S. 2020* dataset, a report that was conducted prior to the pandemic, in partnership with the AARP Public Policy Institute. The report includes nationally representative quantitative data on African American and Black caregivers, Hispanic and Latinx caregivers, and Asian American and Pacific Islander caregivers, as well as caregivers from the LGBTQ+ community and caregivers stratified by income level and geographical location.[4]

To account for possible confounding variables that may unknowingly impact the association between groups and outcomes, NAC commissioned researchers at Dartmouth College to conduct multiple logistic regression analyses to determine if associations exist independent of confounding variables. The overarching research question of the logistic regression analysis was:

> **Do caregivers identifying with diverse backgrounds, including race/ethnicity, income, and LGBTQ status, experience different outcomes regarding strain, Intensity of Care Index, ADLs/IADLs, and information/services used?**

Additionally, the report includes a series of snapshots of caregivers from diverse backgrounds: narrative stories personalizing caregiving journeys and offering insight into caregivers' daily lives. While statistics are critical to understand the state of caregiving in the United States, these stories are aimed to further portray the many faces of caregiving in our country.

The Caregiving in the U.S. 2020 dataset is one of few caregiving datasets with a vast demographic representation of family caregivers in the United States. Despite the robustness of this dataset, the study has some scope limitations in understanding diverse caregivers. Among those limitations, *Caregiving in the U.S. 2020* is a cross-sectional study, therefore, it is not possible to determine causality between predictors and outcomes. Additionally, the survey was fielded in English and Spanish only.

Two of the key recommendations we highlight specifically address challenges that were apparent in the crucial effort to better understand diverse communities in the United States using nationally representative data. For future data collection and reporting efforts that will ensure we are reaching a broader range of people who are underrepresented in the current data set, we must:

- Address the lack of American Indian/Alaska Native representation in research
- Address the lack of intersectionality and segmentation in research

From the DEC and the NAC's combined research, we are highlighting findings[5] from key theme areas important to diverse caregivers for older adults throughout the pandemic: mental health and social isolation; financial strain; and protective factors.

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[4] National Alliance for Caregiving. (2021, November). *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. Retrieved December 1, 2021 from www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf.

[5] In survey results to follow, note that caregivers were able to select multiple options in their responses.

MENTAL HEALTH AND SOCIAL ISOLATION

Anxiety (58%) and increased isolation (56%) were the top two selections by caregivers across all DEC-hosted webinars when asked about challenges they faced during the COVID-19 pandemic. Across all webinars, 56% of polled caregivers selected "taking care of myself" as their top concern. Additionally, 43% of diverse caregivers who were surveyed desired more emotional support, further emphasizing the mental health strain and social isolation brought on during the pandemic.

By comparing the DEC's data from surveys, focus groups, and key informant interviews, we observe that the COVID-19 pandemic has only exacerbated pre-pandemic mental health strain on diverse caregivers. In the DEC's aforementioned research, more than 25% of caregivers reported being more isolated due to caregiving (n=691), with Hispanic and LGBTQ+ caregivers reporting the highest rates of social isolation at 30.3% (n=99) and 37.7% (n=146), respectively.[6]

Similarly, pre-pandemic, 23.4% (n=692) of caregivers reported more physical and mental health strain due to caregiving, with higher rates among African American and Black, Hispanic and Latinx, and Southeast Asian American caregivers. One can infer that the COVID-19 pandemic has only worsened rates of both physical and mental health strain.

CAREGIVING EXPERIENCE: MELANIE

Melanie is a member of the Millie Lacs Band of Ojibwe in the Minnesota region. Previously, she cared for her mother, who had dementia and related health conditions, and her sister, who was diagnosed with terminal cancer. Currently, she cares for her brother, who has an undiagnosed immunosuppressant disease.

Melanie has experienced similarities and differences in her caregiving roles. For her mother and sister, she has cared for them with the rest of her family at home, helping them out of bed, getting them food, and providing other basic needs. She found the experiences both stressful and heartbreaking to see someone she loves so ill and unable to help them. She often found herself confronted with guilt that she wasn't doing enough or when she had to travel away from home for work. She also feels guilt when caregiving takes away from her time with her grandkids.

Melanie's brother lives in their tribe's assisted living unit, but Melanie and her family do not utilize the staff, instead doing all tasks themselves, because of concern over the Covid-19 pandemic. Melanie and her sister even do specialized medical tasks for their brother like administering meds through a stomach tube, a process Melanie was taught by her sister, and not by any official training, especially due to the fact that the staff at the unit is not trained for this task. While Melanie felt that caring for her mother was her responsibility and not a caregiving role, she definitely feels like a caregiver for her brother.

As an Anishinabe, Melanie feels there is an unspoken law to care for others in your community, especially family members. She has started petitioning her reservation to provide more support for long-term care that families can't manage on their own. For Melanie, all governments, from local to federal, need to pass legislation that pays caregivers, provides Paid Family Leave, and gets them support. Those making legislation also need to realize every community's cultural needs are different, and they cannot all be relegated to one box. These laws should be flexible so communities can care for their own people the way they see fit.

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[6] Schaffer, R., Bass, D., Powers, S., McDavid, J., & Le, O. (2019). Culture-related task difficulties and negative consequences for caregivers from diverse communities. *Innovation in Aging*, 3 (Supplement_1). https://doi.org/10.1093/geroni/igz038.3461.

To add to the understanding of issues related to mental health and isolation among caregivers, findings from the NAC analysis suggest[7]:

- Despite increased caregiver burden and lower self-reported health, some African American and Black caregivers may be less likely to experience emotional strain and more likely to find meaning in their caregiver experience compared to some other populations.
- Hispanic and Latinx caregivers are often the sole caregivers for their care recipient, with few options for support. They reported significantly lower levels of psychological and physical well-being, most notably when caring for care recipients with dementia.
- The self-reported health of Asian American and Pacific Islander (AAPI) caregivers has declined over the last five years (2015-2020), and this may be related due to the burden of tasks that AAPI caregivers experience. A majority of Asian American and Pacific Islander caregivers (61%) feel they had no choice in taking on their caregiving responsibility.
- LGBTQ+ caregivers are more often the primary caregiver for their care recipient and report feeling alone. LGBTQ+ adults are half as likely to have a partner, twice as likely to live alone, and four times as likely not to have children compared to non-LGBTQ+ individuals, likely due to continued bias and discrimination against same-sex marriage and family planning in the LGBTQ+ community.[8] This could lead to less formal familial structures which might result in less overall support for LGBTQ+ caregivers.

CAREGIVING EXPERIENCE: PEDRO

Pedro is originally from Brazil, and moved to the United States when he was 21. While he lived in Brazil, he was a caregiver from the age of 12 for his grandmother, who had pulmonary fibrosis. Pedro was one of several family members who cared for his grandmother, but he was mostly responsible for her on the weekends, monitoring her oxygen levels and looking out for her needs. As Pedro grew older and his grandma's care needs evolved, he began caring for her during the weekdays as well, along with his aunt and cousins.

Pedro's grandma preferred to have her family be the ones caring for her, and Pedro explains that this is a very natural desire in his culture. He didn't feel like he was pressured into caring for his grandma because it was something he wanted to do for her in order to give her the best care. Pedro experienced a lot of personal growth while caring for his grandma, because she would teach him about life and what to look forward to. He did not recognize himself as a caregiver until he came to the U.S. because helping your family to care for your elders in Brazil was an everyday part of life. Pedro's family would have never dreamed of putting their grandma in a nursing home.

Pedro acknowledges how stressful it can be to be a caregiver and to see your loved one deteriorating. He thinks mental health is extremely important for caregivers, and spoke of his own experiences of seeing a psychologist. He thinks mental health services should be provided to caregivers by the government, along with some sort of pay in order to support their care duties, especially when working a day job on top of caregiving responsibilities becomes impossible.

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[7] National Alliance for Caregiving. (2021, November). *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. Retrieved December 1, 2021 from www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf.

[8] SAGE. *The Facts of LGBT Aging*. Retrieved December 1, 2021 from www.sageusa.org/wp-content/uploads/2018/05/sageusa-the-facts-on-lgbt-aging.pdf.

FINANCIAL STRAIN

Along with mental health, participants also selected financial strain (35% average) as a top challenge during the pandemic. Financial strain was more highly reported among participants in the webinar hosted by the National Indian Council on Aging (NICOA) for American Indian and Alaska Native caregivers (39%) and in a joint webinar co-hosted by the Southeast Asia Resource Action Center (SEARAC) and the National Asian Pacific Center on Aging (NAPCA) (43%) for Southeast Asian and Asian American and Pacific Islander caregivers.

It is imperative that diverse family caregivers have access to financial education, in addition to financial assistance. On average, 54% of webinar participants selected "Preparing for the future financially" as a top concern during the pandemic. Sadly, many diverse caregivers are not receiving needed financial assistance. On average, 34% of caregivers who participated in our webinars selected financial help as a desired service that they are not receiving at this time. These findings were consistent with the DEC's original research done pre-pandemic revealing that only 17.9% (n=179) were utilizing financial assistance from governmental or financial assistance programs (such as food stamps, cash assistance, etc.).[9]

Unfortunately, financial challenges that have arisen during the pandemic will only worsen family caregivers' pre-existing financial burdens. In our research, on average, 4 out of 10 (n=246) diverse family caregivers paid expenses for their loved ones' care, with the highest rates among LGBTQ+ and American Indian and Alaska Native caregivers.

To add to the understanding of issues related to financial strain among caregivers, findings from the NAC analysis highlight the following points related to the influence of socioeconomic status on caregiving[10]:

- Collectively, family caregivers spend over $500 billion a year in costs associated with providing care to their care recipients. These costs may create an additional burden for caregivers from low-income families compared to higher-income families.
- For caregiving tasks, caregivers in the lowest income bracket (<$15K per year) showed significantly higher odds of assisting with several caregiving tasks compared to caregivers at a higher income level (>$150K per year). These tasks most often include assisting their care recipient in and out of the bath/shower, grocery shopping, meal preparation, and housework.
- With respect to information and services used:
  - Caregivers in lower income brackets had nearly double the odds of using respite services compared to caregivers at a higher income level.
  - Caregivers in lower income brackets also had nearly double the odds of having home modifications made due to caregiving.
  - Caregivers in the lowest income bracket showed double the odds of requesting information regarding caregiving through the internet compared to caregivers at a higher income level.

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[9] Stratton, L., Bass, D., Schaffer, R., Powers, S., Le, O., & McDavid, J. (2019). Comparison of caregivers from diverse communities who immigrated to or were born in the US. *Innovation in Aging*, 3 (Supplement_1). https://doi.org/10.1093/geroni/igz038.3465

[10] National Alliance for Caregiving. (2021, November). *Caregiving in a Diverse America: Beginning to Understand the Challenges Facing Family Caregivers*. Retrieved December 1, 2021 from www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf.

PROTECTIVE FACTORS

Even before the pandemic, diverse caregivers did not readily utilize formal services from paid helpers or professionals. In the 2019 research done by the Diverse Elders Coalition, diverse caregivers rarely utilized services from providers. On average, diverse caregivers utilized only 2.4 supportive services from providers (n=770).

In contrast, diverse family caregivers also reported experiencing some positive outcomes from the COVID-19 pandemic. Due to the lockdown and related restrictions, many webinar participants noted spending more time with family (55%) and decreased commute times (48%) as positive outcomes. With more time spent online, an average of 44% also selected “learned or used new technology” as a positive outcome during the pandemic. Self-reported positive outcomes in spite of the pandemic highlight the resilience among diverse communities and emphasize the importance of interventions on the local, state, and federal level to better reach diverse caregivers where they are—be that physically, linguistically, or culturally.

This data demonstrates that although financial strains and lack of mental and physical health resources had negative impacts on most diverse caregivers we spoke to, diverse communities have remained resilient and have relied on one another (rather than formal services) to persevere through these difficult times. It is time institutions collaborate with diverse communities to provide meaningful interventions to alleviate many of these strains and to ultimately resolve these disparities that have long-existed before the pandemic.

To add to the understanding of positive outcomes related to the protective factors among caregivers, findings from the NAC analysis suggest[11]:

- In the past five years (2015 to 2020), African American and Black caregivers have experienced notable changes in the role they take in shared decision-making with their care recipients, including advocating for their care recipients, monitoring the severity of their care recipients’ health conditions, and communicating with healthcare professionals about their care recipient’s health:
    - In 2020, roughly two thirds of African American and Black caregivers (62 percent) advocated for their care

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[11] National Alliance for Caregiving. (2021, November). *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. Retrieved December 1, 2021 from www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf.

CAREGIVING EXPERIENCE: SANARY

Sanary is a Cambodian American who moved with her family to the United States at a young age as a refugee. As the daughter in a refugee family, she feels she has filled the role of caregiver all her life, starting by acting as the English translator and interpreter for her parents. She helped care for her brother, who had cancer, when she was young, and now, she acts as the care coordinator and financial head for her parents, who are aging. She anticipates that soon she will be much more hands on in their day-to-day care.

A challenge Sanary experiences in her caregiving role is the joint decision-making process. Sometimes she and her parents don't always see eye-to-eye on what is best for their health, causing frustration. This can also be hard because Sanary acts as the language go-between for her parents, translating their conversations with their doctors. She has found she's had to set boundaries, because culturally it's expected that she do whatever her parents ask of her. However, Sanary wants to continue to care for her parents because of everything they've done in their lives and for her—from surviving the war to moving to America. She cannot imagine putting them in a facility and having them live out their days not surrounded by family.

Sanary wants others to understand that just because she wants to and is willing to be a caregiver for her parents, she shouldn't be expected to shoulder everything. Employers need to realize that time off is needed for taking care of loved ones, including elders. Caregivers need financial support in order to continue caring and living their own lives. She believes strongly that policymakers need to start listening to caregivers' personal stories in order to understand the nuances of their needs and to connect with them on a human level. Sanary believes these stories, and the nitty-gritty details they tell, will provide those who can help with a better understanding of the caregiving role.

  recipients with healthcare providers, community services, and government agencies, compared to less than half of African American and Black caregivers in 2015 (47 percent).

  - Approximately 74 percent of 2020 African American and Black caregivers monitored the severity of their care recipient's conditions so that they could adjust care accordingly, compared to 62 percent in 2015.
  - Roughly 71 percent of 2020 African American and Black caregivers communicated with healthcare professionals like doctors, nurses, or social workers about their care recipients, compared to 56 percent in 2015.
  - Additionally, African American and Black caregivers (59 percent) report that being a caregiver gives them a sense of purpose or meaning in life.

- Despite the increased burden that Hispanic and Latinx caregivers face with respect to caregiving tasks, self-reported health and finances, they are less likely to attribute these burdens to the caregiving experience.
- Asian American and Pacific Islander caregivers are typically married or living with a partner. When asked about their living situation, a majority of Asian American and Pacific Islander caregivers live in the same homes as their care recipients.
- While prior literature indicated LGBTQ+ caregivers display more financial strain, this effect disappeared when controlling for caregiver income.

An Inclusive National Strategy on Family Caregiving

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, which became law on January 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers, and will include:

- Promoting greater adoption of person- and family-centered care in all healthcare and long-term service and support settings, with the person and the family caregiver at the center of care teams.
- Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers.
- Information, education, training supports, referral, and care coordination.
- Respite options.
- Financial security and workplace issues.

To support the development and execution of the strategy, the RAISE Act also directed the establishment of the Family Caregiving Advisory Council. The council is charged with providing recommendations to the Secretary of Health and Human Services on effective models of both family caregiving and supports to family caregivers, as well as improving coordination across federal government programs.

The legislation defines "family caregiver'' as "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation."[12]

The council is tasked with creating and submitting an initial report and biennial updates thereafter. The preliminary report will include an inventory of federally funded efforts to support caregivers and recommendations to improve these efforts and effectively deliver services based on the performance, mission, and purpose of a program. The goal of this inventory is to highlight areas of overlap as well as gaps in federal programs that support caregivers. The initial report will also review the financial, social, and emotional challenges of caregiving and the impact of caregiving on Medicare and Medicaid. This will inform the National Family Caregiving Strategy that will be developed by the Secretary of Health and Human Services, the council, and heads of other federal agencies. The strategy will identify recommended actions that federal, state, and local governments; communities; and health and long-term services and supports providers can take to support family caregivers with diverse needs.

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[12] RAISE Family Caregivers Act, S. 1028, 115th Cong. (2019). www.congress.gov/bill/115th-congress/senate-bill/1028.

The Administration for Community Living solicited public input via a Request for Information (RFI) process to help inform the national strategy. The information contained in the responses were used to: (1) assist the council in formulating goals, objectives, and recommendations in support of the initial report to Congress and the development of the national caregiving strategy, and (2) inform public listening sessions. The following recommendations come from analysis of DEC and NAC data, as well as comments submitted by DEC member organizations NAPCA, NCBA, NICOA and SAGE under the RAISE council's five priority areas:

PRIORITY AREA 1: Increased awareness of family caregiving.

Recommendation: Use more inclusive language in literature, programs, resources, etc. that recognizes and invites participation from caregivers from diverse, racial/ethnic, and other groups.

> *Examples:* LGBTQ+ caregivers, tribal caregivers, diverse caregivers (defining who is eligible for services as family caregivers)

PRIORITY AREA 2: Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded.

Recommendation: Add more inclusive language in literature, programs, resources, etc. on who qualifies as a "family caregiver."

> *Examples:* family of choice, immigrant caregivers, Limited English Proficient (LEP) caregivers, tribal caregivers for non-family tribe members, long distance caregivers

PRIORITY AREA 3: Increased access to services and supports to assist family caregivers.

Recommendation: Include and invest into more resources to overcome language and cultural barriers and prioritize providing translated resources, services, and information.

> *Examples Using Supporting Evidence:*

- Self-reported increases in experiencing isolation and anxiety among diverse caregivers
- The pandemic has necessitated mental self care for diverse caregivers
- Diverse caregivers have reported the need for more accessible emotional support services

PRIORITY AREA 4: Increased financial and workplace protections for caregivers.

Recommendation: Financial support resources for diverse caregivers should focus on preparing care for the future, future finances, and financial education as indicated in polling results.

> *Examples:* Training in becoming a power of attorney, the risks and benefits of sharing finances with care recipients, creating wills and trusts, etc.

PRIORITY AREA 5: Better and more consistent research and data collection.

Recommendation: Public-private partnerships should focus on community-based organizations (CBOs) working with diverse caregivers to increase diverse caregiver participation in research.

> *Example:* Partnerships with CBOs who have established community trust by serving Limited English Proficient older adults and caregivers can work through long-term funded relationships to facilitate increased participation in research studies, like the DEC's caregiving survey or focus groups.

Conclusion

DEC, DEC member organizations, and the National Alliance for Caregiving continue our unwavering dedication to better understanding and highlighting the lived experiences of family caregivers from diverse communities.

We recognize that, like all aspects of health and social services delivery, systemic improvements will need to be responsive to the nuances of the changing landscape due to factors such as evolving healthcare policy implementation efforts, including forthcoming and ongoing implications related to the COVID-19 pandemic.

These recommendations are general suggested best practices that align with principles of inclusion, diversity, and equity. We encourage and support continuous direct engagement with diverse family caregivers to ensure services and supports are meeting all communities in a way that is in line with personal and family preferences.

It is without doubt that this much needed dialogue with diverse communities must address a lack of culturally responsive resources to support caregivers' mental health, social isolation, and financial strain, without losing sight of the strengths inherent in the ways in which our communities exercise resilience. We must have the research, data collection, and reporting on all populations to avoid further marginalization, to enhance meaningfully multicultural patient and family engagement, and to be culturally responsive in a way that proactively supports caregivers of older adults, including racially and ethnically diverse family caregivers; American Indian and Alaska Native family caregivers; and LGBTQ+ family caregivers.

Acknowledgments

Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults, as well as the original research and polling data that were used in creating this report were made possible by the six members of the Diverse Elders Coalition—NAPCA, NCBA, NHCOA, NICOA, SAGE and SEARAC—the National Alliance for Caregiving, the Benjamin Rose Institute on Aging, Bernadette Wright, Meaningful Evidence, LLC, and the more than 300 caregivers who generously shared their time and experiences with us. Additionally, we would also like to acknowledge the 18 stakeholders interviewed who guided us in the creation of our curriculum to improve the capacities of providers serving diverse caregivers and older adults.

This report was written with generous funding from The John A. Hartford Foundation. Based in New York City, The John A. Hartford Foundation is a private, nonpartisan philanthropy dedicated to improving the care of older adults. Established in 1929, the Foundation has three priority areas: creating age friendly health systems, supporting family caregiving, and improving serious illness and end-of-life care.

Our sincerest thanks to Karen, Melanie, Pedro, and Sanary for sharing your stories of caregiving for your loved ones. You inspire us.

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