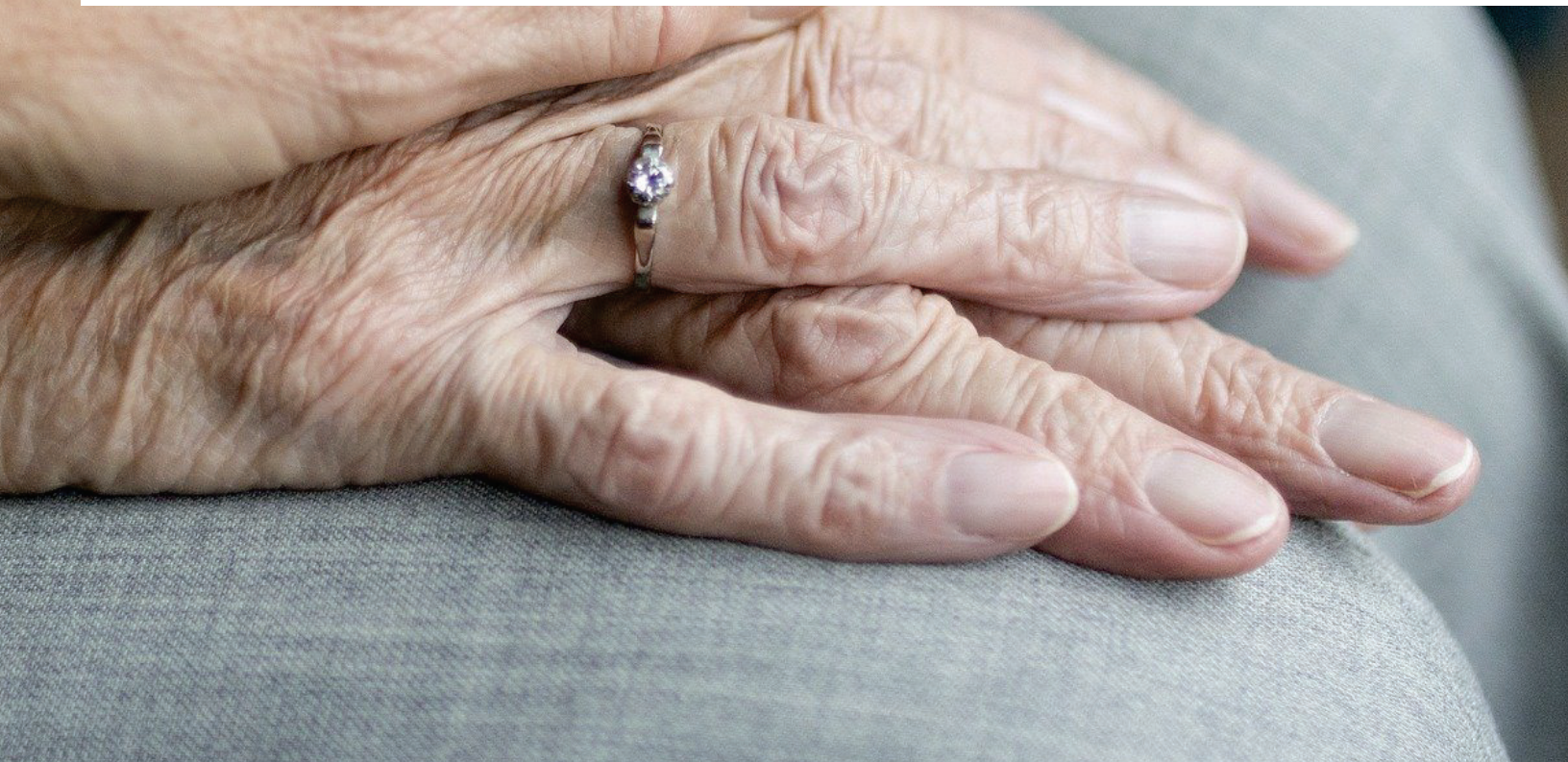




Needs Assessment and Environmental Scan Report

*Maintaining Physical and Mental Well-Being
of Older Adults and Their Caregivers During
Public Health Emergencies*



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Executive Summary

The coronavirus disease 2019 (COVID-19) caused by the novel coronavirus, SARS CoV-2, is a public health emergency that disproportionately impacts older adults.¹ Older adults over the age of 50 are at an increased risk for serious illness and death related to COVID-19, and this risk increases with age, with the highest risk among adults ages 85 and older.² Additionally, measures to prevent transmission of the virus, such as social distancing and stay-at-home orders, have contributed to adverse effects for older adult health and well-being, including social isolation and limited access to basic necessities.^{3,4} As a result of the COVID-19 pandemic, research also suggests older adults' needs and concerns differ from other age groups when managing chronic conditions during public health emergencies. They face increased barriers to regularly visiting health care providers, adhering to medications, and maintaining medical equipment, as well as heightened concern regarding rising virus transmission rates.⁵

Informal or unpaid caregivers of older adults have also assumed increased responsibilities due to COVID-19. Informal or unpaid caregivers, who are the focus of this report, are family or friends who provide assistance with an older adult's social or health needs; this may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation; giving emotional support; and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the care recipient's needs increase, which may result in additional strain on the caregiver.⁶

Caregivers' concerns for their own health and well-being during a public health emergency present multilayered challenges in caring for an older adult. For example, research suggests caregivers devote much of their time to assisting with activities of daily living and communicating and coordinating with health care providers and other organizations on behalf of their care recipients, while often neglecting their own health and well-being.^{7,8} Few public health resources and strategies exist to help caregivers support older adults and also care for their own health. It is imperative to examine the landscape of available resources for older adults and their caregivers during public health emergencies like COVID-19 to support their physical and mental well-being.

Purpose

The National Foundation for the Centers for Disease Control and Prevention (CDC Foundation), with technical assistance from the Centers for Disease Control and Prevention (CDC), contracted with NORC at the University of Chicago and its partners, TMN Corp, Burness, AARP, and The Scan Foundation, to conduct the study *Maintaining Physical and Mental Well-Being of Older Adults and Their Caregivers During Public Health Emergencies*. The purpose of this study was to examine the physical and mental well-being of community-dwelling older adults and their informal or unpaid caregivers during public health emergencies, such as COVID-19. This project also aimed to identify public health interventions and strategies available to support older adults and caregivers during public health emergencies.

While this study focused on the COVID-19 public health emergency, the intent was to use these findings to support people during future public health crises (e.g., disease outbreaks, natural disasters and severe weather, other emergencies). To accomplish these goals, NORC conducted two formative research activities: a needs assessment and an environmental scan.

The needs assessment aimed to identify the needs and concerns of community-dwelling older adults (people age 50+ who live either independently or with family or friends, and outside of institutional long-term care settings such as nursing homes), and informal or unpaid caregivers (family and friends age 18+) caring for older adults.

The environmental scan identified public health strategies and interventions to support the physical and mental well-being of community-dwelling older adults and caregivers during public health emergencies like COVID-19. The environmental scan explored five interrelated topics of concern for older adults and caregivers during public health emergencies: 1) deconditioning (the loss of muscle tone and endurance due to chronic disease, immobility, or loss of function⁹); 2) deferral of medical care; 3) management of chronic conditions; 4) social isolation; and 5) elder abuse and neglect.

Further, this study focused on understanding the needs of and interventions available to support racial and ethnic minorities,¹⁰ individuals with disabilities, rural populations, tribal populations, LGBT individuals, populations with limited English proficiency (LEP), and socioeconomically disadvantaged populations.

Research Questions

The primary research questions for the needs assessment and environmental scan were:

1. **What are the needs and concerns of older adults during public health emergencies such as COVID-19?** We explored the physical and mental health concerns of older adults during public health emergencies. Specifically, we identified the key needs and concerns of older adults and caregivers; particular types of assistance needed; and from whom and where older adults and caregivers seek information about COVID-19.
2. **What public health strategies and interventions are available in the United States to support the physical and mental well-being of older adults?** We explored the types of public health interventions and strategies available to support older adults and caregivers (e.g., community-based, faith-based, health care system). We characterized these interventions in different ways (e.g., population served, reach, geography, evidence base, outcomes).

Methods

We conducted six complementary formative research activities to identify the needs and concerns of older adults and caregivers: 1) a nationally representative survey of older adults age 50+ in the United

States (referred to as the “AmeriSpeak Omnibus survey”); 2) focus groups with community-dwelling older adults age 50+ and informal or unpaid caregivers age 18+ (family and friends) of older adults; 3) interviews with stakeholder organizations that serve older adults and caregivers; 4) a survey of stakeholder organizations that serve older adults and caregivers; 5) analysis of observational data from social media sites (referred to as “social data listening”); and 6) secondary data analysis of existing surveys of U.S. caregivers. For the environmental scan, we conducted searches of grey and published literature based on search terms, and categorized interventions related to the five topics of concern facing older adults and caregivers.

Key Findings: Needs Assessment

1. **Five key needs and concerns among older adults relative to the COVID-19 public health emergency were:**

- Social isolation
- Fear of transmitting and contracting the virus
- Access to and use of technology
- Obtaining household supplies and other necessities such as food
- Financial and economic impact of COVID-19

2. **Older adult subpopulations—specifically, rural populations, tribal populations, racial and ethnic minorities, people with low socioeconomic status, people with LEP, and individuals with disabilities—have been acutely impacted by the COVID-19 pandemic.** The needs and concerns among older adult subpopulations were consistent with those of older adults more broadly. However, several themes emerged among older adult subpopulations:

- Mental health and financial insecurity were concerns among racial and ethnic minority populations.
- Access to household supplies, food security, broadband infrastructure, and technology were needs and concerns among older adults living in rural communities and tribal communities.
- Access to health care, medications and medical supplies, food security, finances, transportation, and affordability of technology were needs and concerns of older adults with low socioeconomic status.
- Social isolation, challenges managing chronic conditions, and technology were concerns of older adults with LEP who speak Spanish.
- Food security, access to health care, transportation, getting in-home help, and access to medications and supplies were among the needs and concerns of older adults with disabilities.
- Adults ages 50-64 were more likely to experience financial and economic hardships due to the pandemic compared to older adults ages 65-74 or 75-84.

3. **Three key types of assistance needed by older adults were food delivery services, help with technology, and accurate information about COVID-19.** About half of older adults (50.5 percent) received assistance from family, friends, neighbors, or programs. Among older adults who received

assistance, the most common types were check-ins from family, friends, or neighbors; assistance with delivering groceries or basic supplies; and transportation. There were several important themes by subpopulation:

- Older adults ages 75-84 were more likely to receive help from family, friends, or neighbors than those ages 50-74, and older adults with disabilities were more likely to receive such help than those without disabilities.
- Among racial and ethnic minority populations, key needs were assistance with accurate information about COVID-19, help with food, broadband access, and transportation.
- Black and Hispanic older adults were more likely than White older adults to report having received assistance from family, friends, or neighbors. They were also more likely to report having received assistance from health care providers or other community programs since the start of the pandemic.
- Older adults with low socioeconomic status needed help getting household supplies; paying for basic expenses such as rent, food, or health care; prescription drugs; and home energy costs.
- Older adults with LEP who speak Spanish needed information about COVID-19 in Spanish and assistance with technology.
- Older adults with disabilities needed assistance with exercise options, in-home care, and cleaning.

4. **Older adults perceived news media and the internet as important resources for COVID-19 information.** Nearly nine out of ten (89 percent) of older adults participating in the AmeriSpeak Omnibus survey reported receiving information about COVID-19 from local and national news sources. Almost half (46 percent) have relied on guidance from government officials or on government websites, and four in ten (40 percent) reported using other webpages.
5. **Adults ages 50-64 were more likely to use social media for information about COVID-19 than adults ages 75-84.** According to the AmeriSpeak Omnibus survey, adults ages 50 to 64 were more likely than those ages 75-84 to rely on social media for information about COVID-19 (26 percent versus 16 percent). Stakeholder interviewees noted that social media platforms have recently become a more common source of information about COVID-19, with older adults using platforms including Facebook and WeChat.
6. **Older adults also relied on people they know, including health care providers, friends, and family members, for information about COVID-19.** Sixty-nine percent of AmeriSpeak Omnibus older adult respondents reported relying on their health care providers as sources of information about COVID-19. Those ages 50-64 and 65-74 were more likely than those ages 75-84 to rely on health care providers for information.
7. **Older adult subpopulations relied on a range of sources for COVID-19 information.**
 - Although eight out of ten Hispanic and White older adults lived in households with internet access according to the AmeriSpeak Omnibus survey, Hispanic older adults were less likely

than Whites to rely on the internet for information about COVID-19 (30 percent versus 42 percent).

- Older adults in rural communities were less likely to rely on health care providers for information about COVID-19 compared to older adults living in suburban areas. Tribal communities relied on social media, tribal websites, and radio programs to access information about COVID-19.
- Older adults with incomes below \$30,000 were more likely than older adults with incomes of \$60,000 to less than \$100,000 to rely on local and national news sources.
- Older adults with LEP who speak Spanish relied on family and friends and the internet for information about COVID-19.
- Older adults with one or more disabilities were less likely than those without disabilities to rely on comments or guidance from government officials or government websites (38 percent versus 50 percent) and to rely on health care providers for information about COVID-19 (64 percent versus 71 percent), according to the AmeriSpeak Omnibus survey. Compared to older adults without disabilities, those with one or more disabilities were more likely to seek information from social media (27 percent versus 21 percent).

8. Major concerns among caregivers were their own physical and mental health, the care recipient's physical and mental health, financial concerns, and the need for respite care.

Caregivers reported delaying their own medical appointments, routine visits, and preventive care, and were also concerned about the physical and mental well-being of the older adults in their care. Caregivers experienced financial insecurity during COVID-19 due to a loss of employment, or balancing employment and caregiving responsibilities. Caregivers voiced a strong need for respite services to grant them temporary relief from caregiving responsibilities, among other types of assistance such as food and medication delivery.

9. Organizations that served caregivers increased their virtual offerings to connect with caregivers. This included disseminating information about COVID-19 online and offering online support groups for caregivers. Also, many health care providers shifted to telehealth platforms, and caregivers are now using telehealth to help older adults access health care services.

10. Similar to older adults, caregivers relied on the internet as a primary source of information during COVID-19, including Google, WebMD, and hospital websites. Social data listening also identified Reddit as an important online community for caregivers. During the public health emergency, the site provided a forum for support, validation, and advice sharing, and was dominated by young and middle-aged adults.

11. Caregivers also relied on health care providers for information during COVID-19. Caregivers who participated in online focus groups reported relying on their care recipient's health care providers (including physicians and social workers) for information about COVID-19. However, social distancing precautions prevented caregivers from accompanying care recipients to medical appointments, which could create communication barriers.

12. **Caregivers' informational needs also reflected gaps in the knowledge and training necessary to perform their caregiving responsibilities, particularly among caregivers of older adults with memory loss or cognitive decline.** Most caregivers said they learned how to provide care on the job and the majority said they felt undertrained.

Key Findings: Environmental Scan

1. **A range of public health interventions and strategies implemented by national, state, and local organizations were available to serve older adults and caregivers.** The environmental scan identified a total of 298 public health interventions and strategies with respect to the five topics of concern for older adults: deconditioning (n=29); deferral of medical care (n=28); management of chronic conditions (n=48); social isolation (n=93); and elder abuse and neglect (n=25), as well as informal or unpaid caregivers (n=75). The most common interventions and strategies were programs and resources focused on educational interventions (i.e., informative materials/campaign/media); 2) direct services (i.e., support groups, counseling, direct/social services pertaining to legal/financial/housing assistance); 3) health care (i.e., telehealth/telemedicine); and 4) policy and system change (i.e., organizations pushing policy efforts and working with local, state, and national authorities to develop and strengthen one of the five topics of interest among older adults and caregivers).
2. **National, state, and local agencies, organizations, and advocates that were dedicated to promoting the health and well-being of older adults and caregivers developed most of the interventions.** While many stakeholder organizations addressed multiple areas of interest, including areas unrelated to those of this project, other organizations focused on one individual topic area, given their jurisdiction and specific area of expertise (such as elder abuse). These agencies and organizations included, but were not limited to: AARP, Administration for Community Living, Alzheimer's Association, ARCH National Respite Network and Resource Center, American Red Cross, Caregiver Action Network, CDC, Center for Advocacy for the Rights & Interests of the Elderly, Centers for Medicare & Medicaid Services (CMS), Consumer Finance and Protection Bureau, Department of Veteran Affairs, Family Care Alliance, Institute on Aging, National Association of Area Agencies on Aging, National Council on Aging, National Institute on Aging, The Commonwealth Fund, and the World Health Organization.
3. **Relatively few interventions were available to older adults for public health emergencies outside of COVID-19 (e.g., natural disasters).** However, there were several innovative interventions. For example, the U.S. Department of Health and Human Services emPOWER program provides data on the electricity-dependent Medicare beneficiaries by state, territory, county, and ZIP code to quickly identify older adults in need of immediate power reconnection after a natural disaster, to better support their medical needs and prevent catastrophic health impacts.¹¹ The Department of Veterans Affairs developed a Home-based Care During Hurricanes intervention to provide interdisciplinary care to older veterans with chronic conditions, focusing on preparedness planning, post-hurricane phone calls, and in-home visits.

4. **Most interventions developed in response to the pandemic have been online educational resources.** Government agencies and national and local organizations had dedicated COVID-19 webpages presenting resources to educate and empower the public to obtain help. These included blogs, toolkits, checklists, infographics, tip sheets, fact sheets, FAQs, PowerPoint slides, videos, webinars, research publications, contact information for social service agencies, and links to other relevant organizations. These online materials were widely accessible to anyone with broadband services.
5. **Across topic areas, the audience for interventions included older adults, caregivers, direct service providers, and other stakeholders (e.g., advocates, local chapters of national organizations, researchers).** Most interventions were targeted at older adults or caregivers and, to a lesser extent, advocates and direct service providers. While the majority of resources developed for older adults and caregivers focused on education, resources for direct service providers and advocates centered on sharing alternative solutions to service delivery (including interactions and communicating with older adults, workflow redesigns, and use of technology) and relevant research and literature reviews on evidence-based practices.
6. **Existing interventions have adapted services, largely by transitioning to remote delivery where possible.** In particular, the use of telehealth and other digital health technology has increased during the COVID-19 pandemic, and many interventions have adjusted components of their interventions to suit remote capabilities for older adults. These formats were particularly promising for reaching older adults and caregivers in rural areas.
7. **To a lesser extent, existing interventions have adapted components of service delivery by making wellness calls and fostering partnerships to expand outreach to—and check in on—older adults.** These modifications focused on ensuring regular contact through periodic telephone calls or fostering partnerships to expand or gain direct access to older adults. This included coordinating with local service providers, such as Area Agencies on Aging and Meals on Wheels, as well as developing public-private partnerships (e.g., Project Enhance).
8. **Few interventions for older adults addressed systems and policy level changes. Most focused on caregivers.** For caregivers, several federal and state policies and programs (such as waivers) were implemented to expand benefits or enhance support. For older adults, a small number of interventions focused on coordinating efforts or advancing policy, while the majority targeted individual education or service delivery.
9. **Evidence-based interventions addressing chronic disease management, deconditioning, social isolation, and caregivers have been adapted for the COVID-19 pandemic.** We identified a number of evidence-based interventions that addressed chronic disease management, deconditioning, and caregiver support during the pandemic, because they were delivered remotely or adapted for remote delivery. For interventions that had been adapted, modifications represented such a significant change to typical program activities that earlier study findings could not be applied to current operations. Notably, evaluations of a small number of adapted interventions addressing social isolation or loneliness were underway but not yet complete (e.g., PEARLS, Social Support Action Team).

10. **With the exception of selected resources for caregivers and older adults with chronic conditions, few interventions targeted specific subgroups (e.g., racial and ethnic groups, individuals with disabilities).** Most interventions that focused on specific subpopulations were developed for caregiving and managing chronic conditions, and to a lesser extent for addressing social isolation and deconditioning. These interventions were designed to assist individuals with disabilities; tribal elders; LGBT older adults; Hispanic or Latino immigrants with LEP; veterans; older adults with vision difficulties, functional impairments, or Parkinson's; and digitally excluded older adults. By contrast, we identified no interventions related to the deferral of medical care and elder abuse among specific groups. At most, resources were offered in languages other than English, including Spanish, Cantonese, Mandarin, Russian, Vietnamese, Korean, and Tagalog, among others.

Conclusion

The COVID-19 pandemic is an unprecedented public health emergency that has severely impacted older adults and informal or unpaid caregivers in the United States. This report offers important insights about the pandemic's effect on these populations. Specifically, it describes the major needs and concerns of older adults and caregivers during public health emergencies such as COVID-19, and the range of public health strategies and interventions available to support their physical and mental well-being.

Taken together, findings from the needs assessment and environmental scan offer salient lessons that could inform the CDC Foundation and CDC's efforts to further address the unmet needs of older adults and caregivers during public health emergencies. We have identified four key opportunities: 1) develop approaches that address the lack of broadband services for many older adults in the United States; 2) invest in programs that improve technology literacy among older adults; 3) focus on assisting specific subpopulations of older adults (e.g., racial and ethnic groups, individuals with disabilities, tribal communities); and 4) identify approaches to support caregivers in getting safe respite care. These approaches could help to mitigate the impact of future public health emergencies and promote physical and mental well-being of older adults and caregivers.

Introduction



Introduction

The coronavirus disease 2019 (COVID-19) caused by the novel coronavirus, SARS CoV-2, is a public health emergency (PHE) that disproportionately impacts older adults.¹² Older adults over the age of 50 are at an increased risk for serious illness and death related to COVID-19, and this risk increases with age, with the highest risk among adults ages 85 and older.¹³ Well-intentioned responses to mitigate the spread of COVID-19 among older adults (e.g., closures of community centers, gyms, adult day centers) have had unintended consequences for older adults' physical health.¹⁴ In addition, the pandemic has affected how older adults cope with social isolation and the mental health effects of loneliness and stress.¹⁵ A recent NORC survey, sponsored by The John A. Hartford Foundation and The SCAN Foundation, found one in three older adults reported feelings of loneliness.¹⁶ Many older adults and caregivers are also afraid of leaving their homes for routine and regular physician check-ups. The same NORC survey found that a majority of U.S. adults age 70 and older have canceled or delayed medical care, and many reported worries about getting the support they needed to manage medical conditions and activities of daily living amid COVID-19.¹⁶ The effects of social distancing guidelines and stay-at-home recommendations have compounded and worsened management of health care, especially among older adults with disabilities and dementia.¹⁷ Lastly, emerging evidence has suggested health disparities in the risk of contracting COVID-19, showing increased hospitalizations among racial and ethnic minority populations, including Black, American Indian and/or Alaskan Native, Asian, and Hispanic individuals, in 12 U.S. states.¹⁸ Further research bolsters the theory that biomedical factors and social determinants of health disproportionately affect minority populations.¹⁹

COVID-19 also has pervasive impacts on older adults' caregivers, who must juggle competing priorities and are at risk for stress and burnout, raising new concerns about elder abuse and neglect.^{20,21} Informal or unpaid caregivers are family or friends who provide assistance with an older adult's social or health needs; this may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation; giving emotional support; and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the care recipient's needs increase, which may result in additional strain on the caregiver.²² These informal and unpaid caregivers are the focus of this report. Given the policy recommendations to stop the spread of COVID-19, many caregivers face an increased burden in attending to the health care needs of their older adult care recipients. For example, recommendations to decrease the risk of exposure to the virus by staying at home have compelled caregivers who do not usually deal with technology to assist with older adults' needs for health care management (e.g., telemedicine visits for chronic disease management).²³ Further, recommendations for states to close adult day care facilities have increased duties for a growing number of family caregivers who are members of the "sandwich generation," balancing care for dependent children and aging parents at the same time, and adding to the stress of their responsibilities.²⁴ Better understanding the complexities of caregivers' own needs and concerns, as well as those of their care recipients during COVID-19, may help establish evidence-based interventions for future PHEs.

Project Background

The National Foundation for the Centers for Disease Control and Prevention (CDC Foundation), with technical assistance from the Centers for Disease Control and Prevention (CDC), contracted with NORC at the University of Chicago to examine the physical and mental well-being of community-dwelling older adults and their caregivers during PHEs such as COVID-19. This project also aimed to identify public health interventions and strategies that support older adults and caregivers during PHEs such as COVID-19. To accomplish these goals, NORC conducted two formative research activities: a needs assessment and environmental scan.

The purpose of the needs assessment was to identify the needs and concerns of community-dwelling older adults (people age 50+ who live either independently or with family or friends, outside of institutional long-term care settings such as nursing homes), and informal or unpaid caregivers (family and friends age 18+) caring for older adults.

The environmental scan aimed to determine the availability of public health strategies and interventions to support the physical and mental well-being of community-dwelling older adults and caregivers during PHEs like COVID-19. The environmental scan explored five interrelated topics of concern for older adults during PHEs: 1) deconditioning (decrease of physiological adaptation to normal conditions); 2) deferral of medical care; 3) management of chronic conditions; 4) social isolation; and 5) elder abuse and neglect. We conducted a second scan to identify public health strategies and interventions for caregivers during public health emergencies.

While this report focuses on older adults and caregivers during COVID-19, the key findings and lessons may broadly apply to future PHEs, such as disease outbreaks, natural disasters, and severe weather.

Research Questions

The primary research questions for the needs assessment and environmental scan were:

1. **What are the needs and concerns of older adults and caregivers during PHEs such as COVID-19?** We explored the physical and mental health concerns of older adults and caregivers during PHEs. Specifically, we identified the top needs and concerns of older adults and caregivers; particular types of assistance needed; and from whom and where older adults and caregivers seek information about COVID-19.
2. **What public health strategies and interventions are available in the United States to support the physical and mental well-being of older adults and caregivers?** We explored the types of public health interventions and strategies available to support older adults and caregivers (e.g., community-based, faith-based, health care system, employer-based, educational). We aimed to characterize these interventions in different ways (e.g., population served, reach, geography, evidence base, outcomes).

Structure of the Report

The remainder of this report provides an overview of methods for the needs assessment and environmental scan, followed by our key findings. Within the needs assessment, we organize our findings for each audience (older adults and caregivers, and by key subpopulations) along the following dimensions:

- 1) Needs and concerns during the COVID-19 PHE
- 2) Types of assistance needed
- 3) Information-seeking behaviors and resource preferences for these stakeholder groups

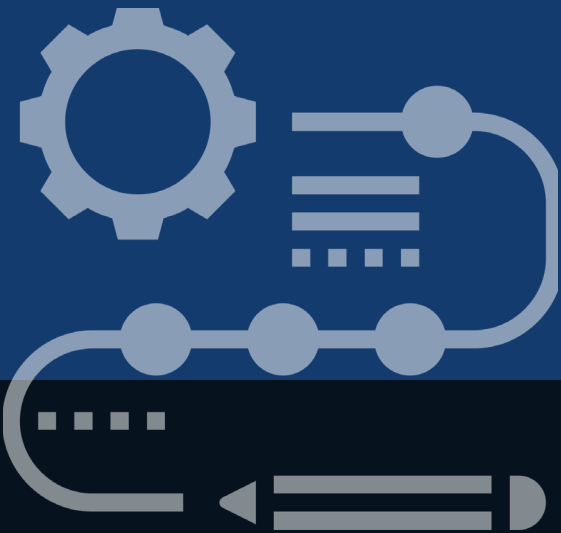
Next, we present five environmental scans of public health interventions and strategies to address these needs, organized around the following topics for older adults:

- 1) Deconditioning
- 2) Social isolation
- 3) Deferral of medical care
- 4) Management of chronic conditions
- 5) Elder abuse and neglect

We present an additional environmental scan focused on public health interventions and strategies to support caregivers of older adults.

Finally, the Conclusions section describes cross-cutting findings, as well as salient considerations for CDC Foundation and CDC for future programmatic activities in the field.

Methods



Needs Assessment Methods

We conducted six complementary activities to identify the needs and concerns of older adults and caregivers: 1) a nationally representative survey of older adults age 50+ in the United States (referred to as the “AmeriSpeak Omnibus survey”); 2) focus groups with community-dwelling older adults age 50+ and caregivers age 18+ (family and friends) of older adults; 3) interviews with stakeholder organizations that serve older adults and caregivers; 4) a survey of stakeholder organizations that serve older adults and caregivers; 5) social data listening; and 6) secondary data analysis of existing surveys of U.S. caregivers.

This study focused on understanding the needs of and interventions available to support specific subpopulations, including: racial and ethnic minorities,ⁱ individuals with disabilities, rural and tribal populations, LGBT individuals, populations with limited English proficiency (LEP),ⁱⁱ and socioeconomically disadvantaged populations.

NORC’s Institutional Review Board (Federal Wide Assurance #FWA00000142) reviewed the study protocols. The project received a public health emergency (PHE) Paperwork Reduction Act (PRA) waiver. Unless otherwise specified, we conducted all data collection activities between October 8 and 26, 2020. Below, we describe the methods for each activity.

AmeriSpeak Omnibus survey of older adults age 50+

The goal of this survey was to learn about the needs and concerns of older adults, including physical and mental well-being, and support systems for older adults age 50+ during COVID-19. We used NORC’s AmeriSpeak® Panel Omnibus survey. AmeriSpeak is a probability-based panel developed and funded by NORC that is designed to be representative of the U.S. household population. For the biweekly AmeriSpeak Omnibus survey, 1,000 nationally representative adults age 18 and older are drawn from the AmeriSpeak Panel and interviewed using computer-assisted web interviewing and computer-assisted telephone interviewing. We conducted two waves of the Omnibus (two surveys) in October 2020 to reach a sample of 1,000 older adults age 50+. The survey instrument contained 15 questions and was administered in English. Wave 1 of the survey was fielded October 8–12 and included 496 respondents. Wave 2 was fielded October 22–26 and included 534 respondents, for a total sample size of 1,030. The survey completion rate was 32.6 percent and the margin of error was 4.09 percentage points.

AmeriSpeak Omnibus data are weighted to national census benchmarks and are balanced by gender, age, education, race and ethnicity, and region. Basic descriptive statistics are conducted on the AmeriSpeak

ⁱ Race and ethnicity was classified using the Office of Management and Budget Standards. Ethnic Categories: Hispanic or Latino. Racial Categories: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; White.

ⁱⁱ Our online focus groups included older adults who speak Spanish and have LEP; other needs assessment research on populations with LEP was not limited to those who speak Spanish.

Omnibus survey results to analyze numbers of survey respondents; general respondent demographics including gender, age, education, race and ethnicity, household income, and urbanicityⁱⁱⁱ; and number and percentage of survey questions answered in the administered surveys. Disability status was determined by asking respondents to select “yes” or “no” to six questions adapted from the Medicare Current Beneficiary Survey (MCBS). These questions, which reflect the standard Department of Health and Human Services items that determine disability status, assessed whether the respondent has serious difficulty with hearing, vision, mobility, dressing or bathing, doing errands, or has cognitive difficulties.²⁵

Analyses include univariate and bivariate analyses on key variables to examine response distributions, identify outliers, and provide summary statistics. Findings from the bivariate analyses were included in this report if the difference was statistically significant at the 95 percent confidence level ($p=.05$).

Focus groups with older adults age 50+ and caregivers

We conducted four online focus groups with older adults (three in English, one in Spanish) and four with caregivers (three in English, one in Spanish) about their needs and concerns during COVID-19. The focus groups with older adults included: 1) older adults with disabilities,^{iv} 2) those with low socioeconomic status,^v 3) those who self-identified as racial and ethnic minority populations, and 4) those who speak Spanish and had LEP. Focus groups with caregivers consisted of: 1) caregivers of older adults with mild cognitive impairment (decline in cognitive abilities that included memory and thinking); 2) caregivers of older adults with disabilities; 3) caregivers of older adults with low socioeconomic status; and 4) caregivers who speak Spanish and had LEP.

We aimed to conduct focus groups with 24 older adults and 24 caregivers (six participants per group, eight groups in total). We contracted with a third-party focus group vendor to recruit a total of 37 participants (see Exhibit 1). We also recruited six participants by conducting outreach through two community-based organizations and WhatsApp, a text and voice messaging app. To determine participant eligibility, the focus group vendor and TMN Corp, a study partner, used recruitment screeners (one for older adults and one for caregivers, in both English and Spanish). All participants provided verbal informed consent and gave permission to record the discussion. For each focus group, we produced notes as well as a transcript, and conducted a content analysis of the notes and transcripts to identify themes, patterns, and findings.

ⁱⁱⁱ The urbanicity measure, which categorizes older adults living in rural, urban, or suburban areas, was computed based on primary rural-urban commuting area codes and whether the respondent’s census tract is located within a principal city.

^{iv} Older adults with disabilities were defined as those who were deaf or had serious difficulty hearing; were blind or had serious difficulty seeing even when wearing glasses; had serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; had serious difficulty walking or climbing stairs; had difficulty dressing or bathing; or had difficulty doing errands alone such as visiting a doctor’s office or shopping because of a physical, mental, or emotional condition.

^v Low socioeconomic status was defined as total annual household income under \$30,000. This included income from jobs, Social Security, Railroad Retirement, other retirement income, Supplemental Security Income, pensions, interest, and any other sources.

Exhibit 1. Characteristics of Focus Group Participants

Segment	Number of participants	Average age (range)	Gender
Older Adults			
Older adults with disabilities	6	60 (55–73)	4 female, 2 male
Older adults with low socioeconomic status	3	58 (54–63)	2 female, 1 male
Older adults - racial/ethnic minority populations ^{vi}	6	56 (49–68)	3 female, 3 male
Older adults who have LEP who speak Spanish	6	65 (55–76)	4 female, 2 male
Caregivers			
Caregivers of older adults with mild cognitive impairment	6	38 (21–51)	4 female, 2 male
Caregivers of older adults with disabilities	6	46 (44–51)	3 female, 3 male
Caregivers of older adults with low socioeconomic status	4	45 (40–55)	4 female, 0 male
Caregivers who have LEP and speak Spanish	6	44 (34–54)	2 female, 4 male

Stakeholder organization interviews

We conducted 27 virtual interviews with national, state, and local stakeholder organizations that served older adults and/or caregivers. We asked organizations about the needs of older adults and caregivers during PHEs such as COVID-19, the interventions available to serve them, and promising strategies to disseminate these interventions. With input from AARP, The SCAN Foundation, CDC Foundation, and other partners, the project team developed a stakeholder list that included 136 participants. We selected 27 organizations, with the goal of achieving diversity across characteristics such as organization type (e.g., community-based organizations, state and federal government agencies, faith-based organizations, national associations); organization size; location in the United States (geographic region, urban and rural area); and populations served (caregivers and older adults, older adult subpopulations of interest including racial and ethnic minorities, individuals with disabilities, individuals residing in rural areas, LGBT individuals, and socioeconomically disadvantaged populations). Appendix A provides a list of organizations that participated in this study through an interview and/or completion of the stakeholder organization survey (described below). We audio-recorded each interview with permission from participants and took detailed notes. We conducted a content analysis of the notes to identify themes, patterns, and findings.

Stakeholder organization survey

The purpose of this survey was to identify the needs and concerns of older adults and caregivers through the lens of stakeholder organizations that serve these populations. The survey also aimed to gather information about public health interventions and strategies available for these populations, including emerging programs that address needs during COVID-19, which may not be described on organizations’

^{vi} Racial and ethnic minorities were represented across all four older adult focus groups and included those who self-identified as Black/African American, Hispanic/Latino, American Indian/Alaska Native, and mixed race.

websites. The stakeholder survey was fielded online using the Qualtrics platform and sent to 101 organizations between October 8 and 26, 2020.^{vii} We solicited one response per organization and targeted leaders such as presidents, CEOs, and directors, to whom we emailed invitations to complete the online survey or to share the link with another person at their organization who could best complete the survey. Thirty-seven organizations participated in the survey (33 of which serve older adults and 27 of which serve caregivers of older adults). We also invited stakeholder organizations that completed the stakeholder interviews to take the survey; nine of these organizations completed the survey. The response rate was 37 percent. Of the respondents, a total of 25 (68 percent) were representatives of national organizations; 5 (13 percent) represented state; and 7 (19 percent) represented local organizations. Exhibit 2 presents key characteristics of organizations that responded.

Exhibit 2. Characteristics of Stakeholder Organization Survey Participants

Stakeholder Organization Characteristics (n=37)	
Organization Service Area	National: 68% State: 13% Local: 19%
Type of Organization*	Nonprofit: 36% Community program: 24% Health care provider: 5% Faith-based: 8% Employer program: 3% Health plan: 3% Government program: 11% Other: 21%**
Populations Served	Older adults only: 25% Unpaid caregivers only: 11% Both: 64%

*Respondents could select more than one type of organization.

**Other included a professional member society, advocacy organization, educational service center, technology support service, associations, and private foundations.

Social data listening

We used social data listening, which was based on observational data from social media sites, to understand how older adults and caregivers—and the stakeholder organizations that serve them—were talking about older adults’ and caregivers’ needs and concerns during the COVID-19 PHE. Social data listening involved two data collection approaches. First, we used primary and secondary search terms to collect data from publicly posted Twitter feeds, Reddit, public Facebook pages, Instagram, and YouTube (see Exhibit 3) to identify relevant posts about older adults and caregivers between February and September 2020.

^{vii} We sent the survey to 109 organizations. A total of eight surveys were undeliverable and/or we received a response from the organization that they did not serve older adults and/or caregivers.

Exhibit 3. Social Data Listening Search Terms

Primary search terms:

- Elderly/elder
- Older adult(s)
- Adult(s) aged 50+ (and other age group mentions including 55+, 60+, 65+, 70+, etc.)
- Senior(s)
- Aging
- Parent(s)/grandparent(s)
- Retiree/retired/retirement
- Gerontology
- Frailty
- Caregiver(s)/care-giver(s)

Secondary search terms:

- COVID
 - Coronavirus
 - Pandemic
 - Epidemic
 - Natural disaster
 - Hurricane
 - Wildfire
 - Public health emergency
-

We also leveraged existing data archives from these social media platforms to filter for relevant posts to include in the data analysis, de-identifying every individual and presenting the analysis in aggregate. Second, we reviewed public social media timelines of the stakeholder organizations to identify relevant social media content. To create the catalog of stakeholder organizations' social media accounts, we searched their official websites on Twitter, Facebook, and YouTube to obtain user profiles names, links to public pages, and number of followers. All data from these accounts were publicly searchable and accessible. We conducted thematic, sentiment, and content analysis of the social media data and analyzed the amount; content (e.g., themes, topic, sentiment); source; and reach and engagement.

Secondary analysis of caregiver surveys

To learn about the needs, concerns, and support systems of caregivers of older adults during COVID-19, we used six recent surveys of this population for the secondary analysis:

- The *AARP Research Report: Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+* was based on findings from a nationally representative online survey conducted by the National Alliance for Caregiving and the AARP Public Policy Institute. It included interviews with unpaid family caregivers who provided care to an adult age 50 and older.²⁶
- The *Long-Term Care Poll*, conducted by The Associated Press (AP)-NORC Center for Public Affairs Research with funding from The SCAN Foundation, included surveys of adults with experience providing long-term care to an aging family member or friend. We included the following AP-NORC Long-Term Care Poll surveys conducted from 2017-2020 in the secondary analysis: *Growing Older in America: Aging and Family Caregiving during COVID-19*; *Long-Term Care in America: Increasing Access to Care*; *Long-Term Caregiving: The True Cost of Caring for Aging Adults*; *Long-Term Caregiving: The Types of Care Older Americans Provide and the Impact on Work and the Family*; and *Long-Term Care in America: Views on Who Should Bear the Responsibilities and Costs of Care*.^{27, 28, 29, 30, 31}

We reviewed findings from the caregiver surveys and mapped them onto the research questions about the needs and concerns of caregivers during PHEs, then synthesized key findings. Appendix B includes more details about the caregiver surveys used in the secondary analysis.

Environmental Scan Methods

We conducted a targeted search of publicly available literature to identify interventions, policies, programs, and strategies to support the physical and mental well-being of community-dwelling older adults and caregivers during PHEs (see Exhibit 4). For older adults, we focused our search on five topics of concern that CDC and CDC Foundation identified: deconditioning (decrease of physiological adaptation to normal conditions); deferral of medical care; elder abuse and neglect; management of chronic conditions; and social isolation. We also conducted a targeted search of peer-reviewed and grey literature and the Web, using Google, PubMed, and Google Scholar (see Appendix C for search terms used). We expanded search terms based on a preliminary literature review and continued to review information sources. Given limited findings from the first search, we also reviewed sources cited in the initial sources and conducted additional targeted searches for more detail on interventions and strategies. We also conducted targeted searches of government agency and organizational websites (e.g., National Association of Area Agencies on Aging, Administration for Community Living, National Council on Aging, The John A. Hartford Foundation) as well as websites of local organizations serving older adults, including Area Agencies on Aging. While we limited our search from 2017 through the present, we included foundational sources published or implemented prior to 2017 that we found through snowball searches. Because COVID-19 is a substantial focus, many sources were from 2020. We catalogued all strategies and interventions in an Excel spreadsheet, which facilitated sorting. For each applicable source, we categorized and classified across the dimensions identified by NORC, CDC Foundation, and CDC, which are listed in Appendix D.

Exhibit 4. Needs Assessment and Environmental Scan Research Questions and Methods

Methods	Research Questions	
	What are the needs and concerns of older adults and caregivers during PHEs such as COVID-19?	What public health strategies and interventions are available in the United States to support the physical and mental well-being of older adults and caregivers?
Environmental Scan		✓
Social Data Listening	✓	✓
AmeriSpeak Omnibus Survey of Older Adults	✓	
Stakeholder Organization Survey	✓	✓
Stakeholder Interviews	✓	✓
Focus Groups with Older Adults and Caregivers	✓	
Secondary Analysis of Caregiving Surveys	✓	

Needs Assessment Findings





What are the needs and concerns of older adults and caregivers during public health emergencies such as COVID-19?

COVID-19 has damaged the physical, social, emotional, and mental health of older adults unlike any other public health emergency (PHE) in the United States. Understanding the landscape of the needs and concerns of older adults and caregivers during this pandemic can highlight the health care resources and social supports needed to overcome public health crises in the future. Within the needs assessment, we organize our findings in nine sections:

- 1) Needs and concerns among older adults
- 2) Needs and concerns among older adults, by subpopulation
- 3) Types of assistance needed among older adults
- 4) Types of assistance needed among older adults, by subpopulation
- 5) Information-seeking behaviors and resource preferences of older adults
- 6) Information-seeking behaviors and resource preferences of older adults, by subpopulation
- 7) Needs and concerns of caregivers
- 8) Types of assistance needed by caregivers
- 9) Information-seeking behaviors and resource preferences of caregivers

We conclude the needs assessment with a summary highlighting the key needs among older adults and caregivers during the COVID-19 PHE.

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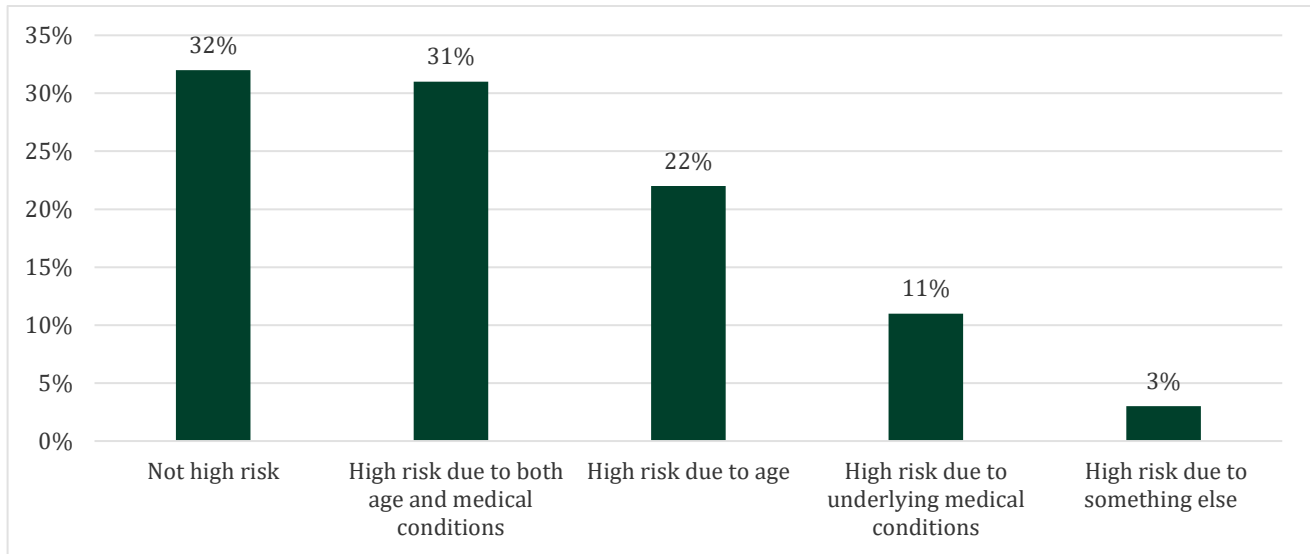
Needs and concerns of older adults during the COVID-19 public health emergency

This section reports on the needs and concerns identified by older adults based on the national AmeriSpeak Omnibus survey and focus groups with older adults, and the survey and interviews with stakeholder organizations that serve older adults. The five major needs and concerns identified in this assessment are 1) social isolation and loneliness, 2) fears of transmitting and contracting the virus, 3) access to and use of technology, 4) obtaining household supplies and other needed services, and 5) financial and economic impacts of the pandemic.

Social isolation emerged as a key concern among older adults during COVID-19. A consistent theme across all sources was that older adults reported feeling more socially isolated and lonely due to the restrictive orders in place to combat spread of the virus. A key public health recommendation is social distancing, which requires keeping a safe distance of at least six feet between yourself and other people who are not from your household, in both indoor and outdoor spaces.³² As a result of these measures, older adults see friends and family less than they did before COVID-19 began. Based on the AmeriSpeak Omnibus survey, nearly half (44 percent) of older adults reported feeling less socially connected since the pandemic began, and more than one quarter (26 percent) of older adults reported feeling more lonely or sad since the start of COVID-19. Seventy-nine percent of organizations (n=26) that serve older adults reported that social isolation was a major concern among older adults. Stakeholders and older adults who participated in focus groups also expressed that the closure of senior centers and senior programs as a result of the pandemic contributed to social isolation.

Transmitting and contracting the virus was also a major concern. According to the AmeriSpeak Omnibus survey, 67 percent of older adults believed they were at high risk for developing serious illness from COVID-19. Specifically, about one third (31 percent) reported a self-perceived high risk for COVID-19 due to both their age and medical conditions (see Exhibit 5).

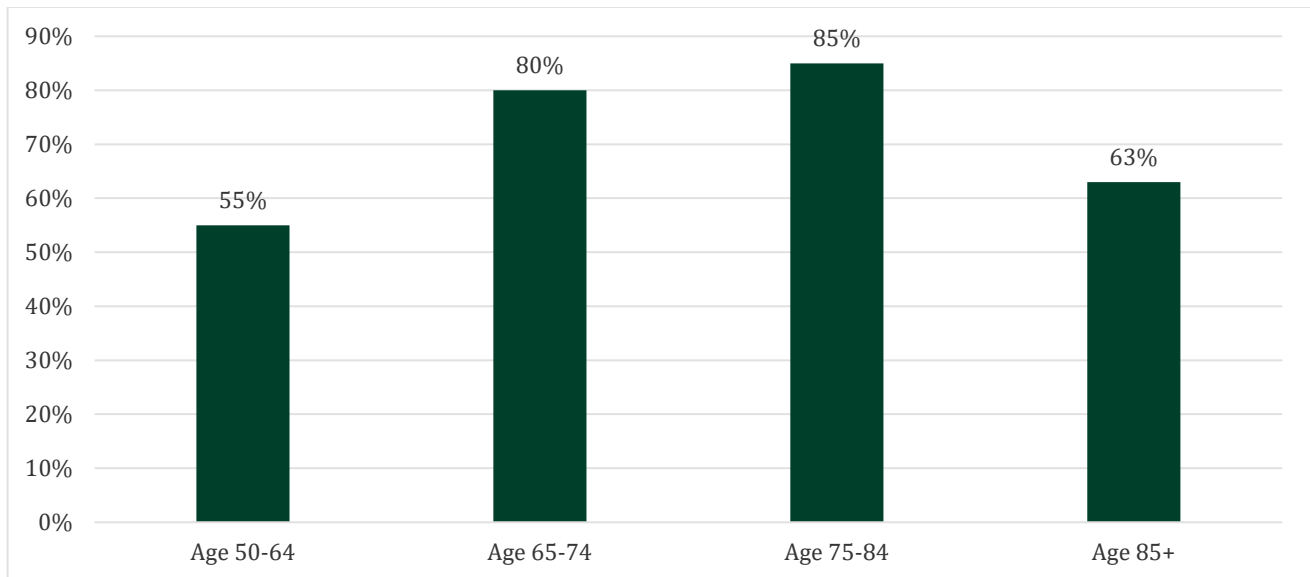
Exhibit 5. Self-Perceived Level of Risk of COVID-19 among Older Adults (ages 50+)



Source: AmeriSpeak Omnibus Survey, October 2020.

Further, the AmeriSpeak Omnibus survey highlighted that, compared to adults ages 50-64, those age 65 and over were more likely to consider themselves to be high risk for developing serious illness from COVID-19 (see Exhibit 6).

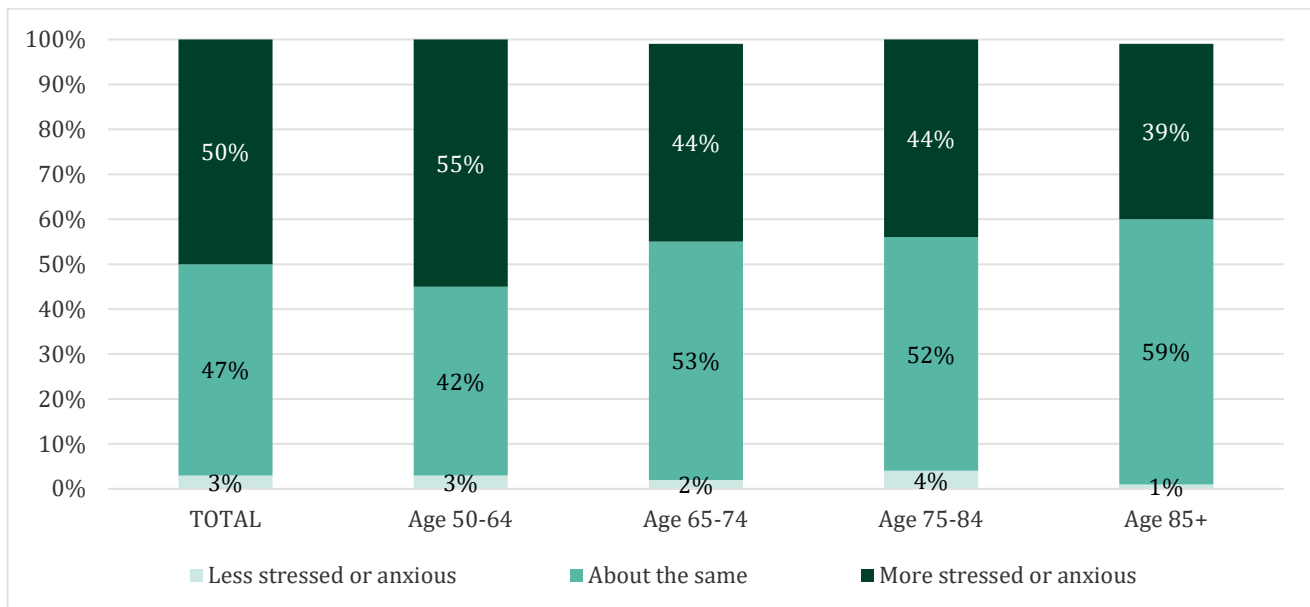
Exhibit 6. Self-Perceived High Risk of COVID-19 among Older Adults, by Age



Source: AmeriSpeak Omnibus Survey, October 2020.

In addition to having concerns of contracting COVID-19, 50 percent of older adults reported feeling more stressed or anxious since the pandemic began (see Exhibit 7). Those ages 50-64 reported feeling more stressed and anxious since the pandemic began than those over age 65.

Exhibit 7. Stress Levels among Older Adults since the Start of the Pandemic, by Age



Source: AmeriSpeak Omnibus Survey, October 2020.

Compared to older adults who do not consider themselves at high risk for COVID-19, those who believe they are high risk due to both their age and medical conditions are more likely to report feeling stressed or lonely. Among older adults reporting a self-perceived high risk due to both age and medical conditions, 60 percent reported feeling more stressed and 31 percent feeling more lonely or sad since the start of the pandemic.

Access to and use of technology were needs among older adults. Nearly half of stakeholder organizations participating in the survey (49 percent) identified help with technology as a need among older adults. In addition, stakeholder interviewees reported that older adults needed help accessing and using technology, given the push to transition in-person activities to virtual and remote opportunities to adhere to social distancing guidelines.

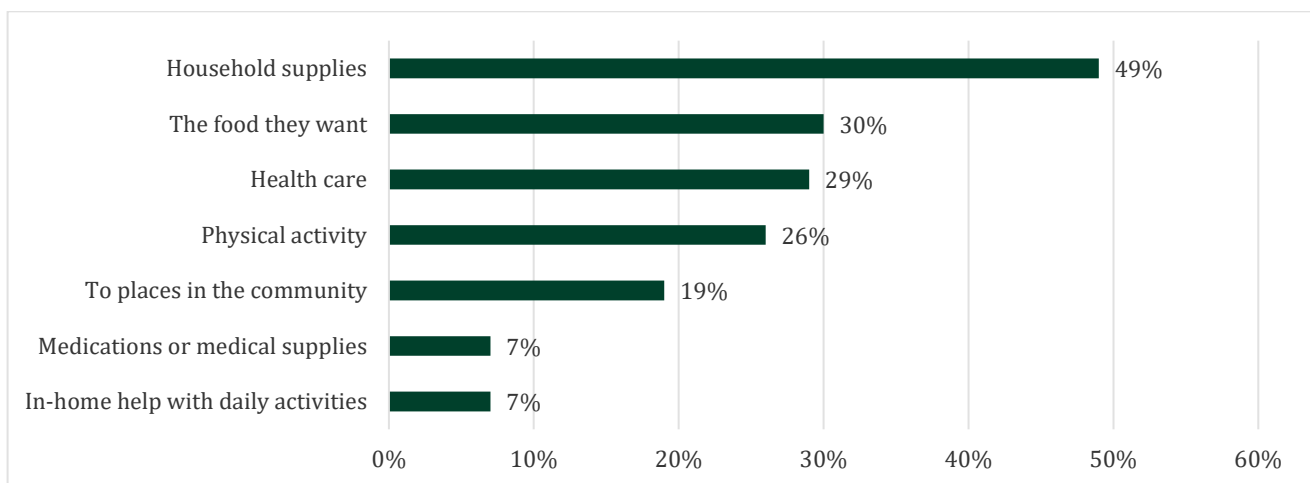
Older adults described obtaining household supplies and other necessities, such as health care services and food, as a major need during the pandemic. Nearly half of older adults (49 percent) reported in the AmeriSpeak Omnibus survey that, since the start of the pandemic, it was harder to get basic household supplies such as cleaning products (see Exhibit 8). The survey also revealed that almost a third of older adults were concerned about accessing health care services and getting the food they wanted. Stakeholder organizations echoed concerns about food security. Participants noted that access to nutritional meals, which was a need before the COVID-19 pandemic, has continued to grow as senior centers and adult day centers that previously served congregate meals have closed. According to social media data listening results, food access and food security emerged as high-priority needs among older adults.

Over one quarter of older adults in the AmeriSpeak Omnibus survey said it was more challenging to engage in physical activity. Focus group participants echoed this view, saying they were no longer able to participate in activities at senior centers and other activities due to closure of these programs.

Nineteen percent of older adults in the AmeriSpeak Omnibus survey reported challenges getting to places in the community. Other sources, such as participants in the stakeholder organization interviews and focus groups, reported that the COVID-19 PHE has compounded barriers for older adults needing transportation to get essential services such as groceries and medications. As the PHE and fear of contracting COVID-19 have limited modes of public transportation, including buses and metro or subway lines, older adults and their caregivers without vehicles have experienced transportation barriers. Finally, fewer than one in ten AmeriSpeak Omnibus participants noted that it was harder to get medications, medical supplies, and in-home help with daily activities.

Several types of access difficulties were more common among those ages 50-64 compared to those ages 65 and older, according to the AmeriSpeak Omnibus survey. Older adults ages 50-64 were more likely than those ages 65-74 to report difficulty accessing health care (33 percent versus 25 percent); accessing food (36 percent versus 26 percent); with transportation (23 percent versus 11 percent); and with getting in-home help with daily activities (9 percent versus 3 percent) since the start of the pandemic. Those ages 75-84 were also more likely to report difficulty with getting in-home help compared to those ages 65-74 (11 percent versus 3 percent). However, those ages 75-84 were less likely to report difficulty obtaining household supplies such as toilet paper compared to older adults ages 50-74 (36 percent among ages 75-84, 48 percent among ages 65-74, and 54 percent among ages 50-64).

Exhibit 8. Since the Start of the Pandemic, Older Adults (ages 50+) Report It Is Harder to Get...



Source: AmeriSpeak Omnibus Survey, October 2020.

Older adults reported a variety of negative financial and economic impacts due to COVID-19.

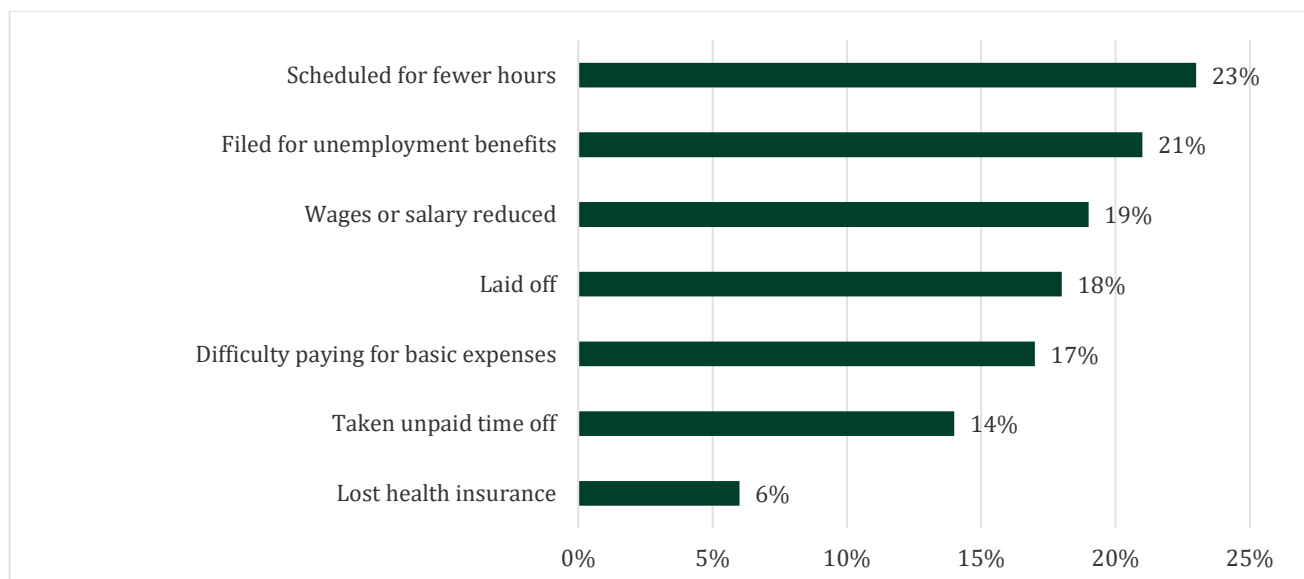
Beyond physical and mental health concerns, older adults and their household members reported experiencing a variety of negative impacts due to the pandemic, such as reduced hours at work; unemployment; reduced wages or salary; lay-offs; overall financial difficulties (i.e., difficulty in paying for basic necessities like rent, food, health care); and a loss of health insurance (see Exhibit 9). Several stakeholder organizations also reported that financial stress was a key concern for older adults. Specifically, one organization mentioned that many older adults who worked outside the home prior to COVID-19 had lost or left their jobs, resulting in increased stress about paying their bills or buying food.

“My biggest strength is my family. Especially when COVID started, because I was put out of a job. And even though I am disabled, I still own a company. My biggest challenge is people not wanting to do work. Clients, customers. I own a construction company. Everything stopped.”

— Focus Group Respondent, age 58

The AmeriSpeak Omnibus survey revealed that those ages 50-64 were more likely to experience financial and economic hardships due to the pandemic compared to those ages 65 and older. Over one quarter of older adults ages 50-64 reported that they or someone in their household experienced a reduction in their hours or schedule at work (31 percent), filing for unemployment benefits (27 percent), or a reduction in wages or salary (25 percent), while nearly one quarter reported being laid off (21 percent) or having difficulty paying for basic expenses (24 percent). In addition, 18 percent of those ages 50-64 reported taking unpaid time off from work and 7 percent lost health insurance coverage.

Exhibit 9. Pandemic Impacts among Older Adults (ages 50+) and Their Households



Source: AmeriSpeak Omnibus Survey, October 2020.

2

Needs and concerns of older adults during the COVID-19 public health emergency, by subpopulation

The COVID-19 pandemic has disproportionately affected specific subpopulations of older adults—such as racial and ethnic minority populations, individuals with disabilities, and people living in rural areas. This section reports key needs and concerns voiced by these populations of older adults and stakeholder organizations that support them.

Financial insecurity and mental health were concerns among racial and ethnic minority older adults. Older adult racial and ethnic minority populations who participated in focus groups reported significant mental health concerns, including stress, anxiety, and depression due to social isolation, lack of accurate information, and worries about their own health and health risks to their families. One focus group participant, who was an essential worker, described the toll that stress had taken on him because he was also a caregiver for his elderly mother and constantly worried that he may get his family sick. According to the AmeriSpeak Omnibus survey, Hispanic older adults reported facing higher levels of worry compared to White older adults. In addition, Black and Hispanic older adults reported greater financial difficulties than White older adults. Nearly one third (30 percent) of Black older adults and nearly one quarter (22 percent) of Hispanic older adults reported difficulty paying for basic expenses like rent, food, or health care, compared to 14 percent of White older adults. Hispanic older adults were also more likely than White older adults to report experiencing unemployment or lay-offs (27 percent versus 16 percent). Since the start of the pandemic, Hispanic and White older adults (59 percent and 52 percent) were more likely to report feeling more stressed compared to Black older adults (39 percent). However, 14 percent of Hispanic older adults reported feeling less lonely or sad, in comparison to 3 percent of White and 2 percent of Black older adults, and 18 percent of Black older adults reported feeling more socially connected, compared to 8 percent of White, non-Hispanic older adults. These findings suggest mental health resilience among racial and ethnic minority older adults.

Access to household supplies, food security, broadband infrastructure, and technology were top needs and concerns among older adults living in rural and tribal communities.

According to the AmeriSpeak Omnibus survey, older adults living in rural areas were more likely than those living in urban areas to report that getting household supplies had been harder since the start of the pandemic (53 percent versus 44 percent). Stakeholder organizations said food security was a prominent concern in tribal communities located in rural areas, with fewer options to purchase foods and other supplies such as personal protective equipment (e.g.,

“In terms of other challenges, a lot of our tribal communities are in rural, remote areas. How do we get to medical appointments? If it’s located in a town that is a couple of hours away, we can’t get there with the challenges COVID presents. There’s been a lot of talk about telemedicine or trying to figure out how to get telemedicine into our communities.”

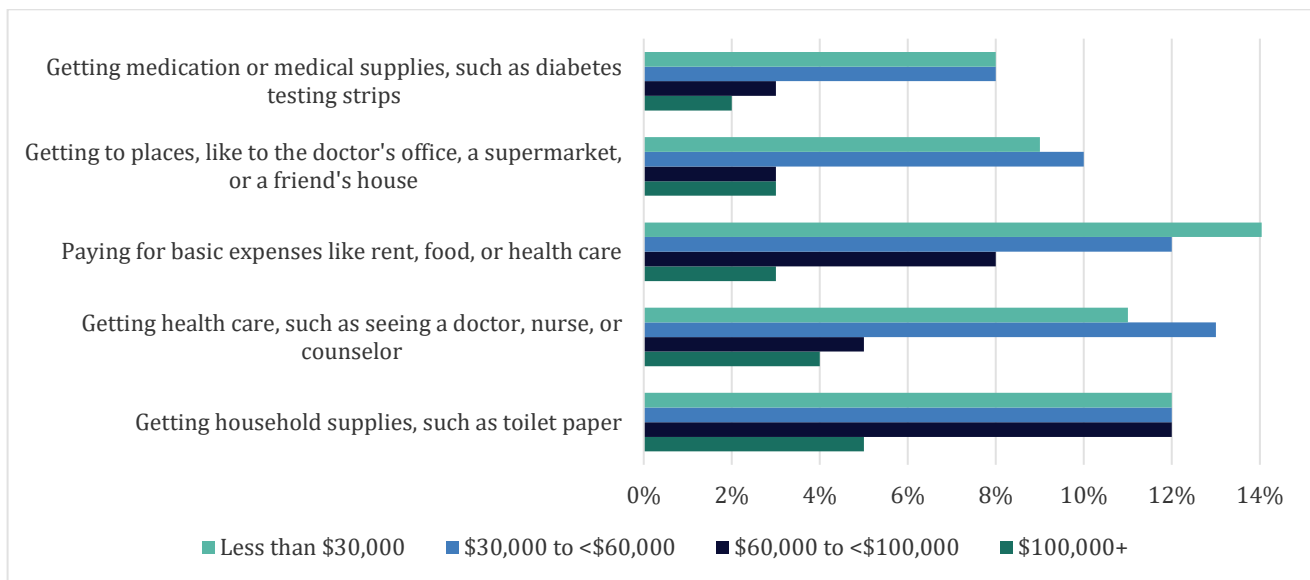
— Stakeholder Organization Representative

masks). During the pandemic, small stores near tribal lands were often out of stock or low on inventory. In rural areas more broadly, stakeholder reported that food delivery or transportation to grocery stores were challenges. Additionally, stakeholder organizations cited access to broadband infrastructure as a key concern in rural communities and tribal communities. A lack of broadband infrastructure creates barriers to receiving telehealth services, accessing online information about COVID-19, and participating in virtual social activities. Stakeholders also reported that older adults experienced challenges finding and using devices to access services or information on the internet.

Compared to older adults living in rural and suburban areas, urban older adults reported greater challenges engaging in physical activity or exercise since the start of the pandemic, according to the AmeriSpeak Omnibus survey. Among urban dwellers, over one third (36 percent) reported that exercising had been harder, compared to 22 percent of those living in rural areas and 23 percent of older adults living in suburban areas.

Access to health care, financial difficulties, transportation, and affordability of technology were the top needs and concerns of older adults with low socioeconomic status. According to the AmeriSpeak Omnibus survey, older adults with incomes below \$100,000 were more than twice as likely as those with incomes of \$100,000 or more to report facing difficulties paying for basic expenses because of the pandemic. Older adults with incomes below \$60,000 were more worried about getting health care services, transportation, and medications or medical supplies during the pandemic than older adults with incomes of \$60,000 or more (see Exhibit 10). Those with incomes below \$100,000 were also more likely to worry about getting household supplies, paying bills, and getting food.

Exhibit 10. Older Adults (ages 50+) and Worries Due to the Pandemic, by Income



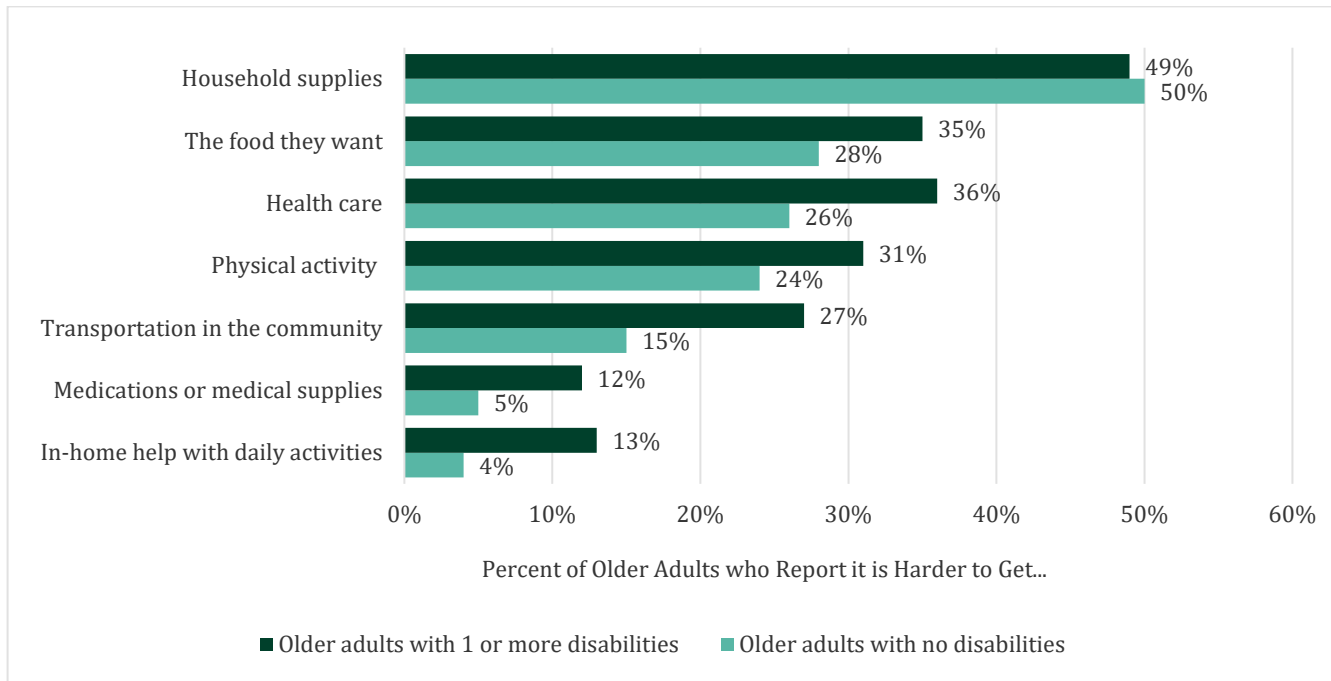
Source: AmeriSpeak Omnibus Survey, October 2020.

Older adults who participated in the focus groups noted that transportation, loss of employment income, and social isolation and mental health were their biggest concerns during the PHE. Focus group respondents shared that they wanted to use health care services, including services from counselors, but were worried about the financial costs and the virus. Respondents reported that they cancelled or postponed medical care during the pandemic. Many respondents mentioned concerns with accessing safe transportation options to attend health care appointments, go shopping, and visit family. Older adults with low socioeconomic status were also concerned about affording a device and internet service. Two stakeholders described devices on the market (e.g., GrandPads³³) that are designed for older adults with built-in applications and connectivity; however, these devices and plans can be costly.

Social isolation, managing chronic conditions, and technology were the key concerns among older adults with limited English proficiency (LEP). Participants in focus groups with older adults with LEP who speak Spanish described concerns related to social isolation. They reported anxiety about conducting everyday tasks, socializing, and attending faith-based services due to concerns about contracting the virus or transmitting it to loved ones. Another fear was managing chronic health conditions at home during the pandemic. All older adults with LEP who participated in focus groups were living with a health condition, including Parkinson’s disease, high cholesterol, diabetes, anxiety, and compromised immune systems (i.e., cancer survivor). These individuals described challenges related to using technology to access health care services (i.e., seeing their doctor using telemedicine, self-monitoring blood pressure). Notably, focus group participants wanted Spanish language technology resources, training, and coaching.

Access to food, health care, medications and supplies, in-home help, and transportation were among the top needs and concerns of older adults with disabilities. According to the AmeriSpeak Omnibus survey, one third of older adults identified as having a disability, with those ages 75 and older more likely to report having one or more disabilities than those under age 75. Older adults with one or more disabilities were more likely than those without disabilities to consider themselves at high risk for developing serious illness from COVID-19 (83 percent versus 59 percent). Compared to people without disabilities, older adults with one or more disabilities were more likely to report worrying about and experiencing challenges due to the pandemic with getting food; seeing healthcare providers, such as a doctor, nurse, or counselor; accessing medications or medical supplies (e.g., diabetes testing strips); getting help in their homes with daily activities; or getting to places outside of their home (see Exhibit 11). Older adults with disabilities were also more likely to report experiencing difficulties with paying bills than those without disabilities (22 percent versus 14 percent).

Exhibit 11. Older Adults (ages 50+) with Disabilities Were More Likely to Report Challenges Due to the Pandemic



Source: AmeriSpeak Omnibus Survey, October 2020.

Older adults with disabilities also reported a host of other concerns. A focus group of six older adults with disabilities revealed their fear of contracting COVID-19, having difficulties accessing health care, separating from their social network, and experiencing emotional distress and loss of income. Older adults with disabilities cancelled or postponed their medical appointments due to fear of contracting the virus, or due to a lack of transportation. One older adult with disabilities stated that his home health care service was temporarily disrupted. Focus group respondents also reported concerns about their mental health, describing their experiences with social isolation, grieving the loss of a family member to COVID-19, and navigating confusing and inaccurate information (i.e., misinformation) about the pandemic. One respondent explained, “My biggest challenge is trying to filter and understand what’s true and what’s not. We’ve got so much disinformation and it’s hard to take it all in and filter it.”

“I had an emergency in June, something that I should have been seen for right away. I had to wait until I had a COVID test to make sure I didn’t have COVID before they could do a pulmonary function test on me. Immediately after receiving the results, I was put in the ICU for a week. The process of getting there was sketchy. I needed to be seen right away, but couldn’t test me until they got COVID results.”

— Focus Group Respondent, age 57

3

Types of assistance needed by older adults during COVID-19

This section describes the types of assistance that older adults have needed and received during COVID-19, based on the AmeriSpeak Omnibus survey, focus groups, and a survey and discussions with stakeholder organizations serving older adults. Older adults needed three major types of assistance: food delivery services, help with technology, and accurate information on COVID-19. Family, friends, and neighbors have supported older adults by checking in with older adults; helping to deliver groceries and other basic supplies; and providing transportation. The AmeriSpeak Omnibus survey found that over a third of older adults (37 percent) reported receiving some help from family, friends, or neighbors, and over a quarter (28 percent) reported getting assistance from programs—through the government, health care providers, community organizations, faith-based groups, health plans, or employers—since the start of the pandemic. Among those ages 75 and older, a majority reported receiving some help from family, friends, or neighbors, and over one third reported getting help from programs.

“Some states have nurse case managers who were calling older adults [with chronic conditions] every day [or] every other day to try to be an ear to see if there’s something they need to get out to them. Sometimes that’s the only interaction that person is going to have for the day.”

-Representative of a National Membership Organization

Stakeholder organizations offered assistance on topics ranging from social isolation and loneliness to elder abuse. Following are our key findings.

Older adults have needed assistance with food delivery services, help with technology, and accurate information about COVID-19. Food delivery services were a common type of assistance needed among older adults. Stakeholder organization representatives explained that older adults were not comfortable going to the grocery store because they feared COVID-19 infection. Also, many of the food delivery services older adults relied on were temporarily disrupted due to COVID-19.

Another common need was for support with technology, namely internet and telephone. Forty-eight percent of stakeholder organizations serving older adults participating in the survey (n=16) said that older adults needed interventions and services to help them use technology for social support or telehealth.

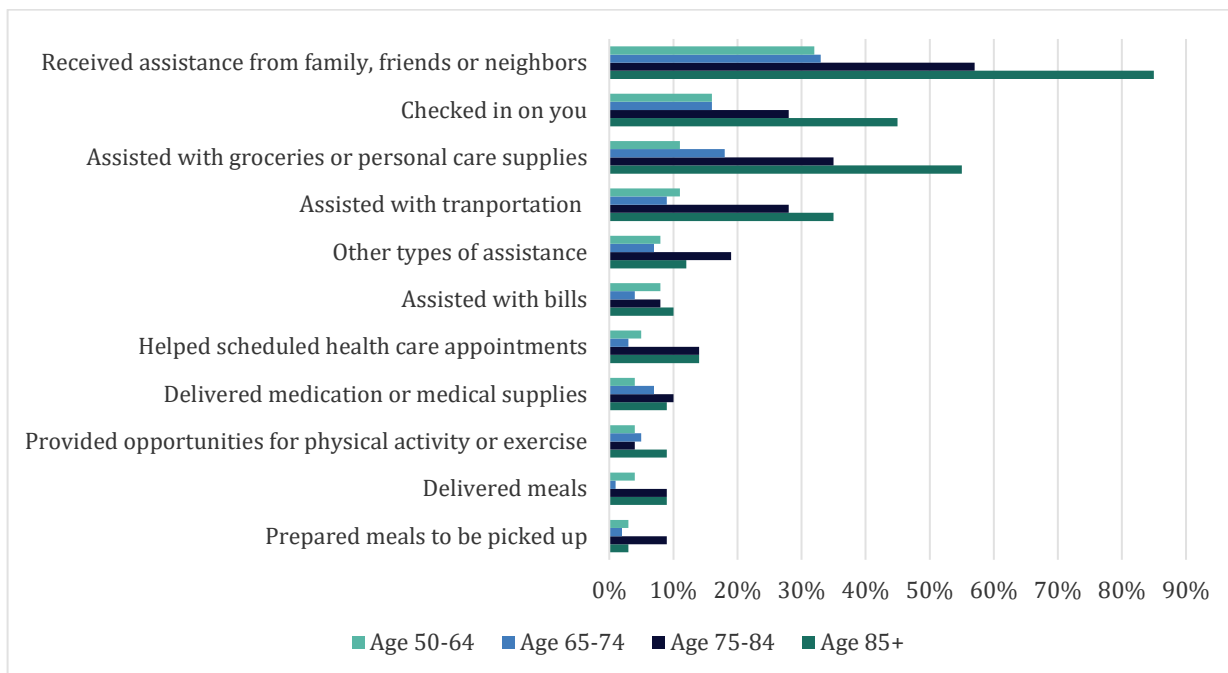
Stakeholders described the importance of social interaction in addressing social isolation, particularly because the nature of the COVID-19 PHE discouraged in-person gatherings. Telephone-based case management or wellness checks from health care providers or agencies served as an important source of regular contact for some older adults. Virtual meetings and gatherings using technology also became essential in preventing social isolation. Similarly, as telemedicine expanded during COVID-19, older adults needed help navigating telehealth services, in particular training and technical support in using digital

platforms such as Zoom and Skype. Older adults also reported needing help with acquiring and paying for broadband services, which was described earlier as a major need and concern.

The third most common need among older adults was for accurate information about the virus, how it can be transmitted, and how to stay safe, topics about which stakeholder organizations highlighted the demand for accurate information. Stakeholders noted their concern over the extensive amount of misinformation about COVID-19 that had been shared across the United States. Focus group respondents also described challenges related to sifting through misinformation online and identifying reliable information sources.

Older adults have received assistance from family, friends, or neighbors in the form of check-ins, help delivering groceries or basic supplies, and transportation. The AmeriSpeak Omnibus survey found that 18 percent of older adults age 50 and over reported that family, friends, or neighbors checked in on them. A total of 17 percent received help from their family, friends, or neighbors with delivering groceries or basic supplies. Thirteen percent of older adults also reported receiving transportation assistance from family, friends, or neighbors since the start of the pandemic. Those ages 75 and older were more likely than those ages 50-74 to report receiving help from their family, friends, or neighbors (57 percent versus 32 percent; see Exhibit 12).

Exhibit 12. Types of Assistance Older Adults (ages 50+) Received from Family, Friends, or Neighbors during the Pandemic, by Age

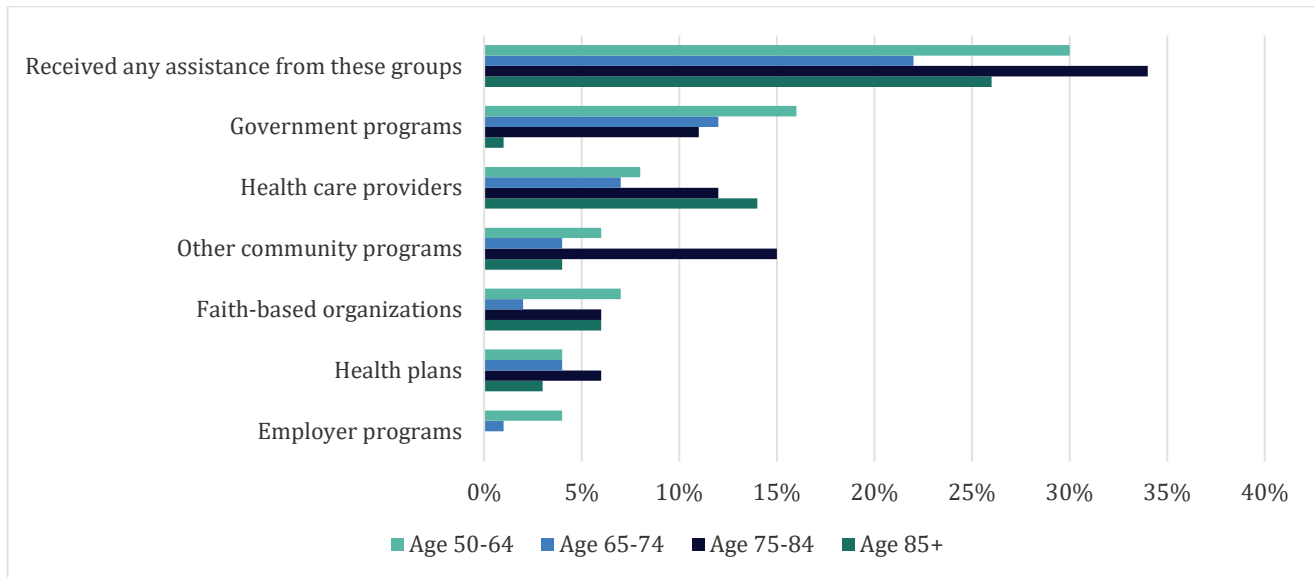


Source: AmeriSpeak Omnibus Survey, October 2020.

About half of older adults received some assistance from organizations or from family, friends, or neighbors during the COVID-19 pandemic. According to the AmeriSpeak Omnibus survey, 37 percent

of older adults reported receiving aid from family, friends, or neighbors since the start of the pandemic, and 28 percent reported receiving assistance from organizations such as government programs, health care providers, other community programs, faith-based organizations, health plans, or employer programs. Altogether, about half of older adults received help from either informal or formal sources. Older adults who reported receiving assistance from organizations were more likely to be ages 50-64 or ages 75-84 (see Exhibit 13).

Exhibit 13. Sources of Assistance Older Adults (ages 50+) Received during the Pandemic from Health Care Providers, Groups or Organizations, by Age



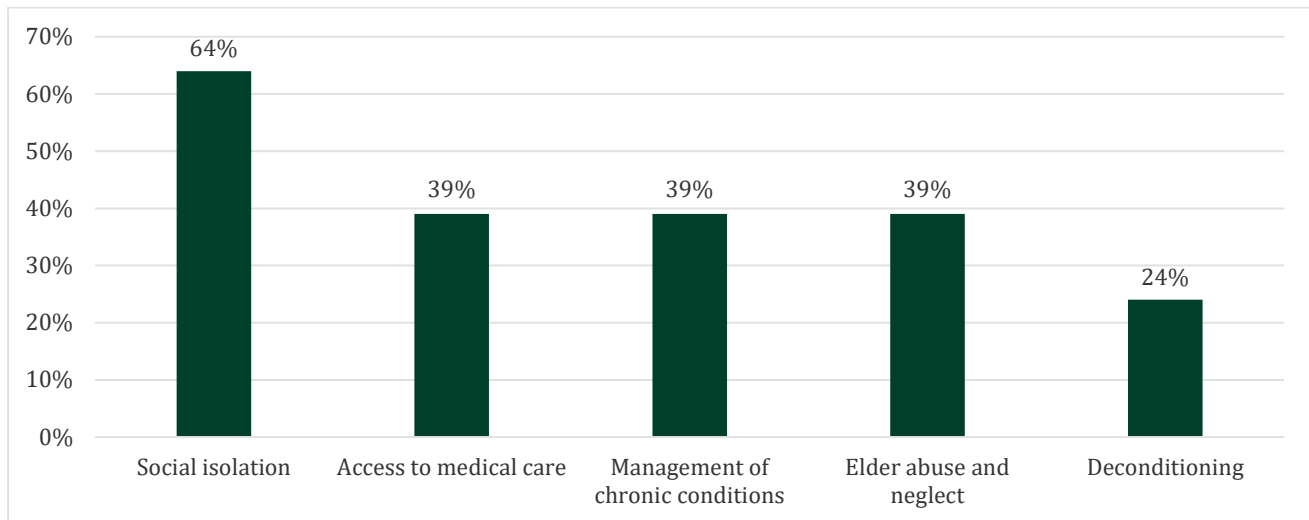
Source: AmeriSpeak Omnibus Survey, October 2020.

Older adults ages 75-84 were most likely to report receiving help from any source. Sixty-five percent of older adults ages 75-84 reported receiving any assistance from either formal or informal sources (organizations or family, friends, and neighbors) in comparison to 49 percent of older adults ages 50-64 and 45 percent of older adults ages 65-74 who reported the same. Older adults ages 75-84 were also more likely to report receiving help from both informal and formal sources, with 27 percent of older adults ages 75-84 reporting that they received help from both sources in comparison to 18 percent of older adults ages 50-64 and 14 percent of older adults ages 65-74 who reported the same.

Stakeholder organizations have offered assistance to older adults on a wide range of topics, including social isolation, access to medical care, chronic conditions, elder abuse, and deconditioning. Of the stakeholder organizations serving older adults who participated in the survey, over two-thirds (64 percent, n=21) offered assistance and interventions for social isolation and loneliness, followed by help accessing medical care (39 percent, n=13); addressing chronic conditions (39 percent, n=13); preventing elder abuse and neglect (39 percent, n=13); and addressing deconditioning (24 percent, n=8; see Exhibit 14). Social data listening revealed that organizations serving older adults offered online interventions and services focused on meal delivery, transportation services, and activities

aimed at engaging older adults. Additional interventions included webinars and downloadable reports on chronic conditions; advocacy tools for social justice and health equity; and resources about elder abuse and assistance with Medicare decisions during COVID-19. Many stakeholders also provided online resources and information for older adults about staying safe during COVID.

Exhibit 14. Focus Area of Interventions or Services Offered for Older Adults (ages 50+) by Stakeholder Organizations during the COVID-19 Pandemic



Source: CDC Foundation Stakeholder Organization Survey, October 2020.

4 Types of assistance needed by older adults during COVID-19, by subpopulation

Older adults within specific subpopulations were most likely to have received assistance from government programs, health care providers, health plans, faith-based organizations, and other community programs since the start of the pandemic. We present key findings about the types of assistance needed by older adults in specific subpopulations below.

Racial and ethnic minority populations of older adults have needed assistance with accurate information about COVID-19, food, broadband access, and transportation. Stakeholder organizations reported that racial and ethnic minority populations needed accurate information about COVID-19, citing the spread of misinformation. One stakeholder said, “In the beginning, they were hearing things like coronavirus was caused by 5G. And they were very concerned that the towers that were near the building, or that their cell phones were causing the, you know...So, we had to try to help dispel a lot of the myths. The information that they were getting. And the real challenge going forward is there is a real fear, specifically [among] African Americans on the vaccine.” Stakeholders said that the propagation of false information about the spread of the virus and how to stay safe was prevalent in racial and ethnic minority communities.

Stakeholder interviewees also reported that racial and ethnic minorities, especially Black and Native American populations, were more likely to need assistance related to food access; technology (notably, broadband access); and transportation. Stakeholders noted that racial and ethnic minorities living in urban areas tended to use public transportation to run errands or pick up groceries. As a result, they have faced substantial barriers to transportation during COVID-19 because routes have closed or have limited operations. Additionally, they had concerns about the safety of using public transportation during COVID-19.

The AmeriSpeak Omnibus survey found that Black and Hispanic older adults were more likely than White older adults to report receiving help from family, friends, or neighbors since the start of the pandemic (51 percent of Blacks, 44 percent of Hispanics, 34 percent of Whites). Black and Hispanic older adults were also more likely than White older adults to report having received assistance from any organizations and in particular from health care providers or other community programs. The survey also revealed that Black older adults were more likely than Whites or Hispanics to have received help from faith-based organizations, while Hispanic older adults were more likely than Whites to report having received help from health plans or employer programs.

Older adults with low socioeconomic status needed help with food, prescription drugs, and energy assistance. Older adults with lower household incomes (less than \$30,000 per year) were more likely to report receiving almost all types of assistance from family, friends, neighbors or organizations than those with higher incomes (\$30,000 a year or more). One stakeholder organization reported a large increase in the number of older adults applying for Supplemental Nutrition Assistance Program benefits. They also reported that older adults were seeking information on other benefits programs, such as the low-income subsidy for Medicare prescription drug coverage available under Medicare Part D, and the Low-Income Home Energy Assistance Program, a government program that helps households with energy costs.

During interviews, stakeholder organizations noted that some states used 1915(c) Home and Community-Based Services Waiver Appendix K for emergency preparedness and response to provide assistive technology to Medicaid beneficiaries.³⁴ For example, California's Medicaid program has been providing assistive technology, such as iPads, to adults with developmental disabilities to help them access services remotely.³⁵ During the early stages of providing iPads, one stakeholder noted several challenges, including requirements for the state Medicaid agency to track and recoup each dispensed iPad if the older adult is not using it. In addition, the stakeholder reported that older adults have had challenges in using the device.

Older adults with LEP needed information about COVID-19 in Spanish and assistance with technology. One organization that participated in the survey reported that individuals with LEP needed timely and accurate information about COVID-19 in Spanish. During interviews, stakeholder organizations described the challenges that individuals with LEP have faced during COVID-19. For example, one stakeholder group reported that individuals with LEP—in particular those in the Southwest who only speak Spanish—have struggled with finding timely and accurate information about COVID-19 in Spanish. Another stakeholder noted that they have two bilingual Spanish-speaking employees who have

made an effort to connect with older adults with LEP via telephone calls or other modes. Another common need among older adults with LEP was for technology support. During a focus group with older adults who speak Spanish and have LEP, participants reported misgivings about using telemedicine because they were not comfortable using a smartphone or digital platforms, and they relied on family members to handle technology.

Older adults with disabilities were more likely than those without disabilities to report receiving help from formal or informal sources; they needed assistance with exercise options, in-home care, and cleaning. Older adults with disabilities were twice as likely to report receiving help from family, friends, or neighbors as those without a disability, according to the AmeriSpeak Omnibus survey (57 percent versus 27 percent). The survey found they were also more likely to receive help from organizations (39 percent among those with disabilities versus 23 percent without). Older adult focus group respondents living with one or more disabilities stated that they most needed safe and accessible options for exercise, in-home health care, and cleaning assistance.

5 Information-seeking behaviors and resource preferences of older adults

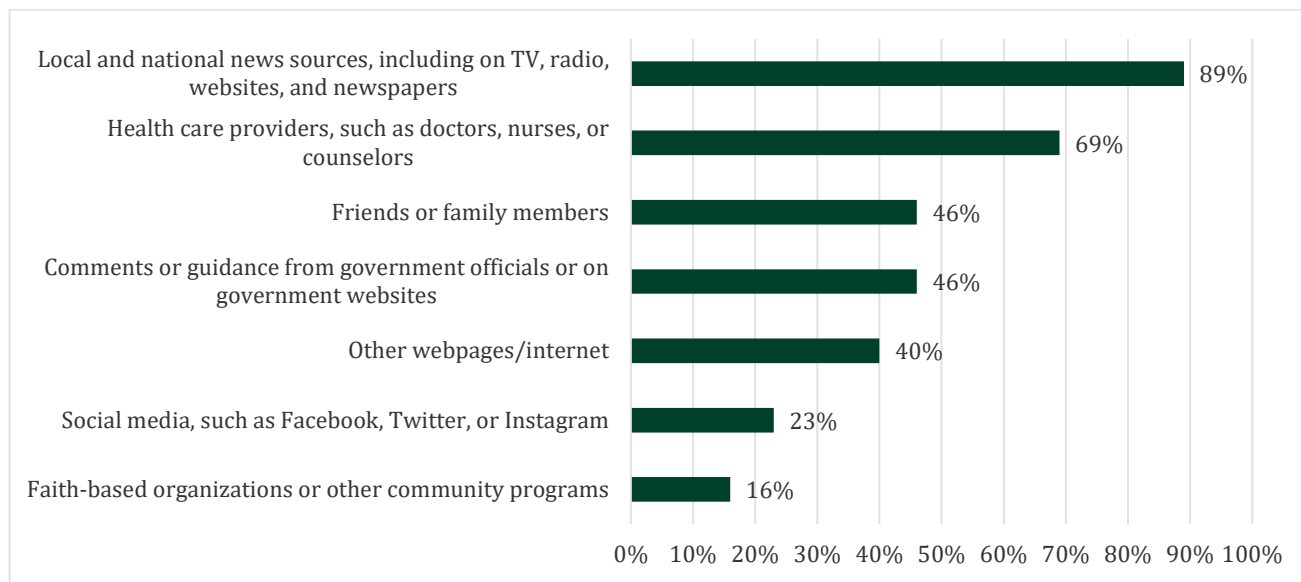
To stay up-to-date on information about COVID-19, older adults relied on local and national news outlets; health care providers; the government (officials and websites); friends and family members; social media platforms and other websites; and faith-based organizations and other community-based programs. This section describes information-seeking behaviors and resource preferences of older adults during COVID-19.

Older adults seeking COVID-19 information have perceived news media, the government, and the internet to be important resources. Nearly nine out of ten (89 percent) older adults participating in the AmeriSpeak Omnibus survey reported receiving information about COVID-19 from local and national news sources (including TV, radio, websites, and newspapers). Almost half (46 percent) have relied on comments or guidance from government officials or on government websites, and four in ten (40 percent) reported using other webpages (i.e., other than news or government websites; see Exhibit 15). Additionally, stakeholder organizations participating in interviews reported that websites have been a common information source for older adults. Stakeholder interview findings suggested that older adults viewed national, nonpartisan organizations such as AARP as trusted sources of information. One stakeholder explained, “There’s no group like AARP. If you want to reach 50 million people this is the place you do it, and right now we really need to get decent information out in a way that’s non-politicized.” In addition to posting information online, some AARP state chapters have been offering weekly or monthly virtual town halls as venues for sharing community-level information about the COVID-19 PHE, sometimes featuring local public health officials.

Findings from the survey of stakeholder organizations serving older adults indicated that organizations have begun offering more virtual services and interventions to engage with older adults, including virtual

support groups and distance learning. One respondent from a national organization reported, “Many of our 124 institutes began serving their older adult students for the first time with distance learning and videoconferencing.” Focus group respondents agreed they relied most on the internet as their information source, and many said they conducted Google searches or consulted different websites. One participant explained that print media is “not popular anymore.” The AARP print newsletter was cited as an exception.

Exhibit 15. Sources that Older Adults (ages 50+) Rely on for Information on COVID-19



Source: AmeriSpeak Omnibus Survey, October 2020.

Adults ages 50-64 and ages 65-74 were more likely than those ages 75-84 to rely on health care providers, government sources, or other internet pages for information about COVID-19. The AmeriSpeak Omnibus survey found that 69 percent of older adults ages 50-64 and 73 percent of those ages 65-74 reported relying on health care providers for information about COVID-19 compared to 58 percent of those ages 75-84. Similarly, nearly half of those ages 50-64 and 65-74 reported relying on government sources for guidance on COVID-19 compared to about a third of those ages 75-84. Those ages 75-84 were also less likely to rely on the internet for information about COVID-19.

Adults ages 50-64 were more likely to use social media for information about COVID-19 than adults ages 75-84. Social media is a platform that provides information during COVID-19. According to the AmeriSpeak Omnibus survey, older adults ages 50-64 were more likely than those ages 75-84 to rely on social media for information about COVID-19 (26 percent versus 16 percent). Stakeholder interviewees noted that social media platforms have recently become a more common source of information about COVID-19, with older adults using platforms including Facebook and WeChat. Stakeholder organization survey respondents also cited social media as a common information source for older adults. Social media platform preferences may vary by racial and ethnic group, which we describe in greater detail in the next section.

Older adults also relied on people they knew, including health care providers, friends, and family members, for information about COVID-19. Many older adults, including 69 percent of AmeriSpeak Omnibus respondents, relied on their health care providers as sources of information about COVID-19. Yet, some populations reported less reliance on or greater distrust of health care providers, as described in the next section. Older adult focus group participants described communication with friends and family as another source of information, as did nearly half (46 percent) of AmeriSpeak Omnibus respondents. One focus group participant explained, “I’m in the field all day so my mom is my contact and everything. So she was the first one who told me about certain masks you can’t wear, a certain type of percentage of alcohol for sanitizer, she was the first who told me what was closing or opening.”

Challenges related to using the internet as an information source included access barriers and misinformation or politically polarized discourse. Lack of internet access has been caused by geographic limitations (e.g., in tribal areas), lack of access to necessary technology, and affordability. In addition, political polarization and misinformation were identified as barriers to accessing accurate information about COVID-19. One focus group respondent noted that social media platforms such as Twitter or Facebook were “not a source for accurate news.” Further, the volume of Twitter audiences’ posts that were relevant to older adults focused mainly on political news or disagreement. This, combined with audience descriptions of their unmet needs despite the existence of stakeholder tweets about interventions or services that address those needs, suggests that tweets related to politics may obscure helpful content about local services or resources. Finally, focus group respondents identified the lack of a coordinated national response to the PHE, the lack of a centralized information source about available resources, and a lack of funding and implementation of local and state programs as barriers to connecting the public with needed services.

Information-seeking behaviors and resource preferences, by subpopulation

Older adults within specific subpopulations had different information-seeking behaviors and preferences. We present key findings for racial and ethnic minority populations, rural and tribal communities, individuals with low socioeconomic status, people with LEP, and populations with disabilities below.

Racial and ethnic minority populations relied on a range of information sources. In general, racial and ethnic minority older adult focus group participants reported seeking information from a variety of information sources, including government agencies such as the CDC, Department of Veterans Affairs, and National Institutes of Health; websites including WebMD; news outlets; friends and family members; and health care providers. One respondent also described the alerts he received from his health plan several

times per week and reported that this format suited his busy lifestyle. According to the AmeriSpeak Omnibus survey, Black and Hispanic older adults were twice as likely as White older adults to rely on faith-based organizations or other community programs for information about COVID-19 (27 percent of Blacks, 26 percent of Hispanics, and 12 percent of Whites). Stakeholder organizations also reported that faith-based organizations were often trusted sources of information among racial and ethnic minority populations, especially Black communities. Stakeholders reported that communities of color, including Black populations, were less trusting of health care providers, especially when related to taking a COVID-19 vaccine in the future.

“We don’t have [a] uniform [resource] to help people. That needs to be fixed right away, where everyone has access to lists of services throughout the country. That is currently missing...a national response.”

*- Focus Group Respondent,
age 68*

Racial and ethnic minority populations discussed the importance of technology in getting information about COVID-19.

Older adult focus group participants discussed the importance of technology in accessing timely and accurate information, noting barriers such as costs; lifestyle (“I’m not at a computer all day”); and lack of knowledge about how to set up and use technology. They said that financial support to help them pay for internet, smartphones, and data plans; delivery of devices; and training, coaching, and technical assistance for using devices would lessen this challenge. One focus group participant also noted that a centralized, national source of information about available services would help people access the services they needed, but this kind of national resource did not exist.

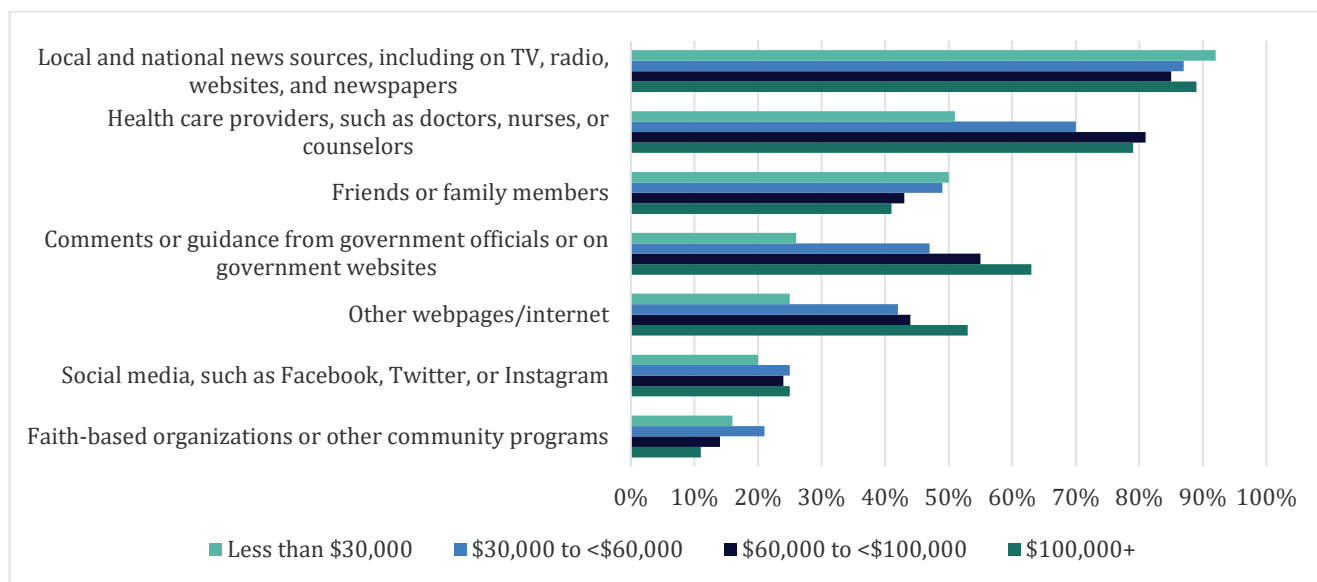
Older adults in rural and urban communities were less likely to rely on health care providers for information about COVID-19. Tribal communities relied on social media, tribal websites, and radio programs to get information about COVID-19.

According to the AmeriSpeak Omnibus survey, older adults living in suburban areas were more likely than their rural or urban counterparts to rely on health care providers for information about COVID-19. Stakeholder organizations reported that Native American communities used Facebook, tribal websites, and radio programs (due in part to a lack of internet access in tribal areas) to access information about COVID-19. Stakeholders reported that Native American populations were less trusting of health care providers, especially related to taking a COVID-19 vaccine.

Older adults with low socioeconomic status relied less on health care providers, government sources, and the internet for information about COVID-19.

According to the AmeriSpeak Omnibus survey, older adults with incomes below \$30,000 were less likely than older adults with incomes of \$30,000 or more to rely on health care providers, comments from government officials or government websites, or the internet as sources of information about COVID-19 (see Exhibit 16). However, older adult focus group participants with low socioeconomic status reported similar information sources to other groups of older adults, including health care providers, government agencies such as CDC, websites such as WebMD and AARP, and news outlets. Respondents disagreed on whether social media channels including Facebook and Twitter were reliable news sources.

Exhibit 16. Sources that Older Adults (ages 50+) Rely on for Information about COVID-19, by Income



Older adults with LEP relied on family and friends, and the internet for information about COVID-19. Older adult focus group participants who speak Spanish and have LEP reported relying on family and friends to stay up-to-date on the news. Older adults with LEP also used the internet, but relied on stories shared by friends and family rather than conducting their own research. Stakeholders noted variation in social media preferences among different racial and ethnic groups. One stakeholder organization respondent explained that Facebook was an effective channel for reaching Spanish-speaking populations, while WeChat, a smartphone application that enables messaging and social media, had better reach among Asian communities. Older adult focus group participants with LEP cited YouTube and WhatsApp, which enables users to make calls and share information, as information sources. Some respondents with LEP also expressed unfamiliarity with technology, specifically smartphones. Focus group respondents described using social media to share stories about the COVID-19 pandemic in other countries and communicate with people abroad.

Over one quarter of older adults with disabilities sought information about COVID-19 from social media. According to the AmeriSpeak Omnibus survey, older adults with one or more disabilities were more likely than those without disabilities to rely on social media for information about COVID-19 (27 percent versus 21 percent), but less likely to rely on health care providers (64 percent versus 71 percent) or on comments or guidance from government officials or government websites (38 percent versus 50 percent). Older adult focus group participants with disabilities reported seeking information from health care providers, social media, and websites such as WebMD and news outlets to access information. One focus group respondent said she does not view the “medical system” as a trustworthy source of information.

Older adult women were more likely to rely on social media and family and friends for information about COVID-19. According to the AmeriSpeak Omnibus survey, women were more likely

to rely on social media for information about COVID-19 than men (28 percent versus 17 percent), but less likely to rely on other internet sources (36 percent versus 44 percent). Women were also more likely to rely on friends or family members for information regarding COVID-19 in comparison to men (50 percent versus 41 percent).

7

Needs and concerns of informal or unpaid caregivers during the COVID-19 public health emergency

Informal or unpaid caregivers are family or friends who provide assistance with an older adult's social or health needs; this may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation; giving emotional support; and helping to manage a chronic disease or disability. Caregiving responsibilities can increase and change as the care recipient's needs increase, which may result in additional strain on the caregiver.³⁶

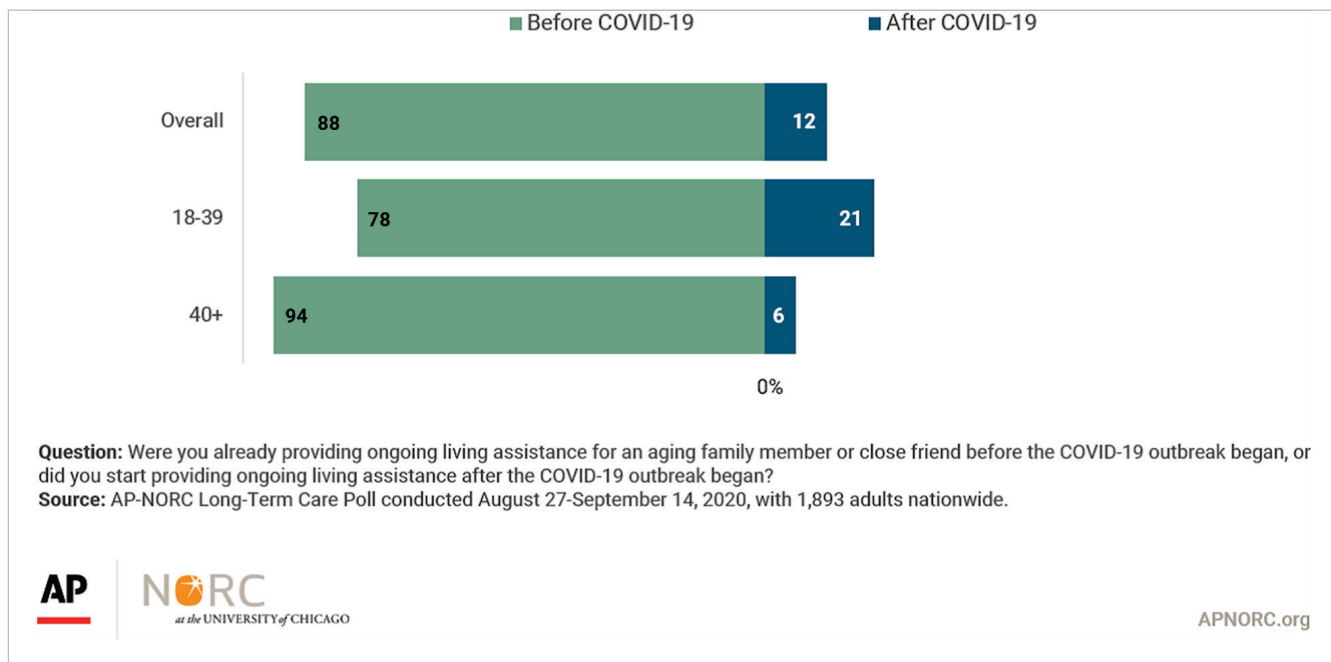
Nearly one fifth (17 percent) of Americans ages 18 and older were caregivers for an older adult family member or friend during the COVID-19 pandemic (as of October 2020).³⁷ Among the 12 percent of American adults who began providing care for the first time since the start of the pandemic, over half (52 percent) cited various reasons specific to COVID-19.³⁸ These included pandemic-related restrictions that made the care recipient less able to care for themselves; concern with the safety of previous care situations; the usual caregiver becoming infected with COVID-19; or the care recipient being infected with COVID-19. The percentage of younger caregivers of older adults increased, with 21 percent of caregivers ages 18-39 beginning to provide care after the start of the pandemic, compared to just 6 percent of caregivers ages 40 and older (see Exhibit 17).³⁹ In this section, we describe the top needs and concerns of caregivers, the types of assistance they needed, and their information-seeking behaviors.

"I find being a caregiver, and being a parent and a teacher, a lot of times people want to focus on the person 'in need' and a lot of attention goes to the person 'in need,' but there's an insane amount of stress placed on the person who's the support. It's like you're invisible. You don't exist. You're a bookcase holding everything up...You're the tree. If someone's chopping at the roots, you need to take care of yourself first."

— Focus Group Participant, age 43

The needs assessments findings highlighted the impact of the pandemic on caregivers of older adults. All sources from the needs assessments identified managing physical, emotional, and mental stress and health as a top need among caregivers. Further, top interventions offered to caregivers were information and referrals rather than direct services. Organizations serving caregivers focused on new interventions to provide virtual platforms for information exchange during the pandemic.

Exhibit 17. Share of Caregivers Who Began Providing Care before COVID-19 versus after COVID-19



A top concern among caregivers was their own physical and mental health. Focus group respondents expressed concern about their own health and well-being during the pandemic. With regard to their physical health, caregivers reported delaying their own medical appointments, routine visits, and preventive care. With regard to social and emotional health, caregivers reported a decline in their social activity and interaction with others. Mental health concerns and needs were strongest among familial caregivers of older adults, who reported extreme exhaustion and emotional, physical, and financial stress. Some explained how they weighed the desire to participate in socially distant activities with the fear of contracting and transmitting COVID-19. Many caregivers spoke of the negative impact of COVID-19 on their mental health, including increased fear, anxiety, frustration, and depression. Stakeholder organizations corroborated this theme, noting that managing emotional and physical stress among caregivers was a top need and concern (see Exhibit 18).

Exhibit 18. Top Needs of Caregivers, as Reported by Stakeholder Organizations (n=27) that Serve Caregivers*

Needs of Caregivers	% of organizations reporting this in the top three needs
Managing their own emotional and physical stress	56%
Having respite services available (i.e., temporary relief from caregiving)	56%
Keeping the home of an older adult safe	26%
Having a doctor, nurse, or social worker ask what they need to provide care for an older adult	22%
Figuring out forms, paperwork, or eligibility services or support for an older adult	22%
Having a doctor, nurse, or social worker ask what they need to take care of themselves	15%
Using technology to care for an older adult	15%
Managing their own health and safety	11%
Choosing a home care agency, assisted living facility, or nursing home	11%
Managing or handling caregiver’s own employment	7%
Getting transportation for an older adult	7%
Managing or handling caregiver’s own personal finances	7%
Managing an older adult’s challenging behaviors, such as wandering	7%
Finding non-English language educational materials	4%
Making end-of-life decisions for an older adult	0%
Identifying activities to do with an older adult	0%

* Organizations could select up to three responses for the question “What are the top three needs of unpaid caregivers of older adults during the COVID-19 (i.e., March 2020) public health emergency?”

Source: CDC Foundation Stakeholder Organization Survey, October 2020.

Our social media analysis found that caregivers were concerned about their own mental and emotional health during COVID-19. Many relied on information posted on Reddit, a collection of online social forums where individuals can share information and ask for recommendations. The social data listening findings showed that most content found on Reddit was related to caregivers; for example, caregivers were posting content and interacting with other caregivers about caregiving. Reddit was not a forum for older adults themselves. On Reddit, caregivers discussed difficulties and offered mutual advice and encouragement. Reddit gave them a forum for support and validation, in the form of personalized and detailed advice, as well as sympathy.

“It has been tough. I travel a lot for work so that has been really scary. I come home and self-quarantine. It has been really scary—even going on the subway or going to the office. The biggest concern is what is...the best thing to do and puts people at the least amount of risk without losing my job.”

– Focus Group Participant, age 21

Findings showed that many caregiver needs continued trends in place before COVID-19, particularly in terms of the financial burden and stress associated with balancing work and caregiving.

According to the 2017 AP-NORC Long-Term Care Poll, prior to the COVID-19 pandemic the majority (64 percent) of caregivers of older adults worked at the same time while providing care, with nearly half (47 percent) of working adults struggling to balance work and caregiver duties. The 2018 AP-NORC Long-Term Care Poll found that caregivers experienced financial challenges providing care for older adults, with nearly 80 percent paying for caregiving expenses out-of-pocket. Additionally, one quarter (25 percent) reported that they reduced how much they saved for retirement to pay for caregiving expenses, suggesting long-term financial implications for caregiving. The AP-NORC Long-Term Care Poll also highlighted that caregivers of older adults who experienced a COVID-19-related financial hardship were more likely to report that their caregiving duties had increased since the start of COVID-19. Similar to these findings, stakeholder organizations reported that caregivers experienced financial insecurity during COVID-19 due to a loss of employment when the economy shut down. Caregivers who participated in focus groups shared the benefits and drawbacks of balancing employment and caregiving. For some, working from home made it easier to be a caregiver; however, others whose work hours were not flexible had to call off work to take their older adult to an appointment, which jeopardized their employment.

“My biggest thing is trying to get her to keep in touch with everybody...Being stuck in the house and watching TV all day is not healthy. I want to make sure that she has mental stimulation other than myself.”

*– Focus Group Respondent,
age 55*

Caregivers were also concerned about the physical and mental health and well-being of the care recipient. According to the 2020 AP-NORC Long-Term Care Poll, 44 percent of caregivers of older adults were extremely or very concerned with the older adult they cared for getting infected with COVID-19, in comparison to only 28 percent who were extremely or very concerned with the risk of infection for themselves. Additionally, during focus groups, caregivers worried about providing enough mental stimulation and social connection for older adults in their care. Further, caregivers were anxious about providing care to older adults who were living independently during the pandemic. Specifically, according to the 2020 AP-NORC Long-Term Care Poll, 34 percent of caregivers reported that they were not able to provide care as often if the older adult was living independently.

The adult protective services work we do is to protect older consumers from their own family sometimes. We haven't been able to send workers into homes so caseloads went way down. Now they are able to go back in and the numbers are very high, if you're burning out and there is no place to put mom, things are going to happen.”

– Stakeholder Organization Representative

Stakeholder organizations, focus group participants, and social media users identified the need for respite care. With the closure of senior centers and other activities, stakeholder organization representatives, focus group respondents, and Instagram users reported that caregivers' responsibilities increased exponentially due to COVID-19. Caregivers who participated in the focus groups noted that it was more challenging to get appointments and referrals for older adults. Caregivers expressed concerns about whether they were advocating in the best way for older adults in their care—such as getting them the right care, giving correct guidance, and providing appropriate medications. Lastly, social data listening indicated that some caregivers reported challenges communicating with their care recipient's health care providers.

Last, this study found that elder abuse was a growing concern during COVID-19. Social data listening revealed that caregivers (adult children) described their concerns over the deteriorating health of their parents. They also discussed having to balance the competing demands of an aging parent with the needs of their own spouses and children. Social data listening identified that caregivers were reporting growing resentment. In addition, stakeholder organizations noted that caregiver burnout, due to greater responsibilities in caring for older adults, increased the number of cases of elder abuse by caregivers. According to one stakeholder organization, adult protective services were curtailed for several months during COVID-19, and when home visits resumed, the organization was seeing growing numbers of caregiver abuse.



Types of assistance needed by caregivers during COVID-19

Caregivers and organizations that serve older adults and caregivers described different types of assistance during COVID-19. Following are our key findings.

Caregivers voiced a strong need for respite services, among other types of assistance, to give them temporary relief from caregiving responsibilities. Focus group participants expressed the need for more services focused on mental health to support caregivers. Focus group participants also recommended other resources, including an online training program for “how to act in certain situations,” services that run errands for older adults, virtual yoga classes for caregivers, and personal protective equipment (PPE) and COVID-19 testing for caregivers. Social data listening results found that stakeholder organizations provided links to online interventions on social media platforms to address the needs and issues of caregivers, for example, their mental and emotional health (e.g., depression, social isolation).

Caregivers valued food and medication delivery services. Focus group participants noted that prescription delivery helped caregivers during COVID-19. Also, caregivers reported signing up for food assistance for their older adult care recipient. Caregivers said they used Meals on Wheels, food services available in their community, or local food banks. One participant raised the importance of identifying “culturally appropriate” meal services. The 2020 AP-NORC Long Term Care Poll showed that half of

caregivers of older adults reported using food or pharmacy delivery and telehealth services. Caregivers ages 18-39 most frequently reported using meal delivery services (58 percent), while caregivers ages 40 and older most frequently reported using telehealth services (50 percent) and video chats (47 percent).

Since the COVID-19 pandemic began, many health care providers have shifted to telehealth platforms, and caregivers have been using telehealth for older adults.

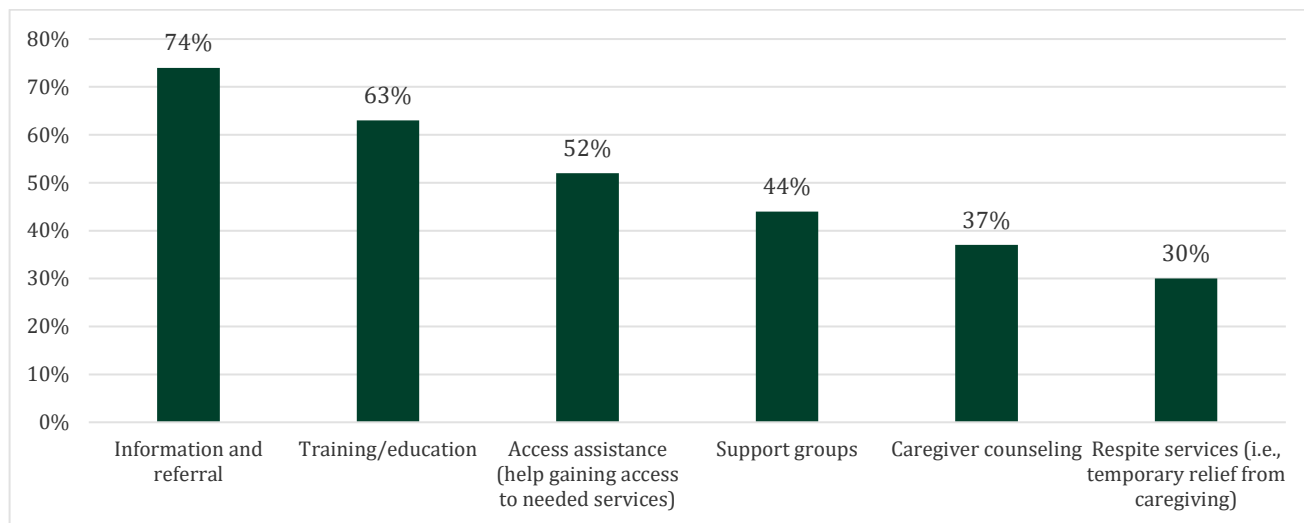
According to the 2020 AP-NORC Long Term Care Poll, three quarters (75 percent) of caregivers reported that their care recipient has used telehealth services of any kind during the COVID-19 pandemic, including telephone, video service, email, or text message.

“I take care of my mom. She used to go to...daycare three to four times per week. It was nice to get relief, and I got an emotional outlet. Now with COVID, she’s inside all the time.”

– Focus Group Respondent, age 42

Caregivers asked for information and referral services, among other types of assistance. According to the stakeholder organization survey, the most common type of assistance that organizations serving caregivers provided during the COVID-19 pandemic was information and referral services (74 percent), followed by education and training assistance (63 percent), and help with gaining access to needed services (52 percent; see Exhibit 19). During a focus group with caregivers with low socioeconomic status, one respondent emphasized the need for help with identifying benefits for which the older adult care recipient was eligible, noting, “The paperwork and the phone calls...are a full-time job.”

Exhibit 19. Types of Interventions or Services Stakeholder Organizations (n=27) Offered to Caregivers of Older Adults (ages 50+) during COVID-19

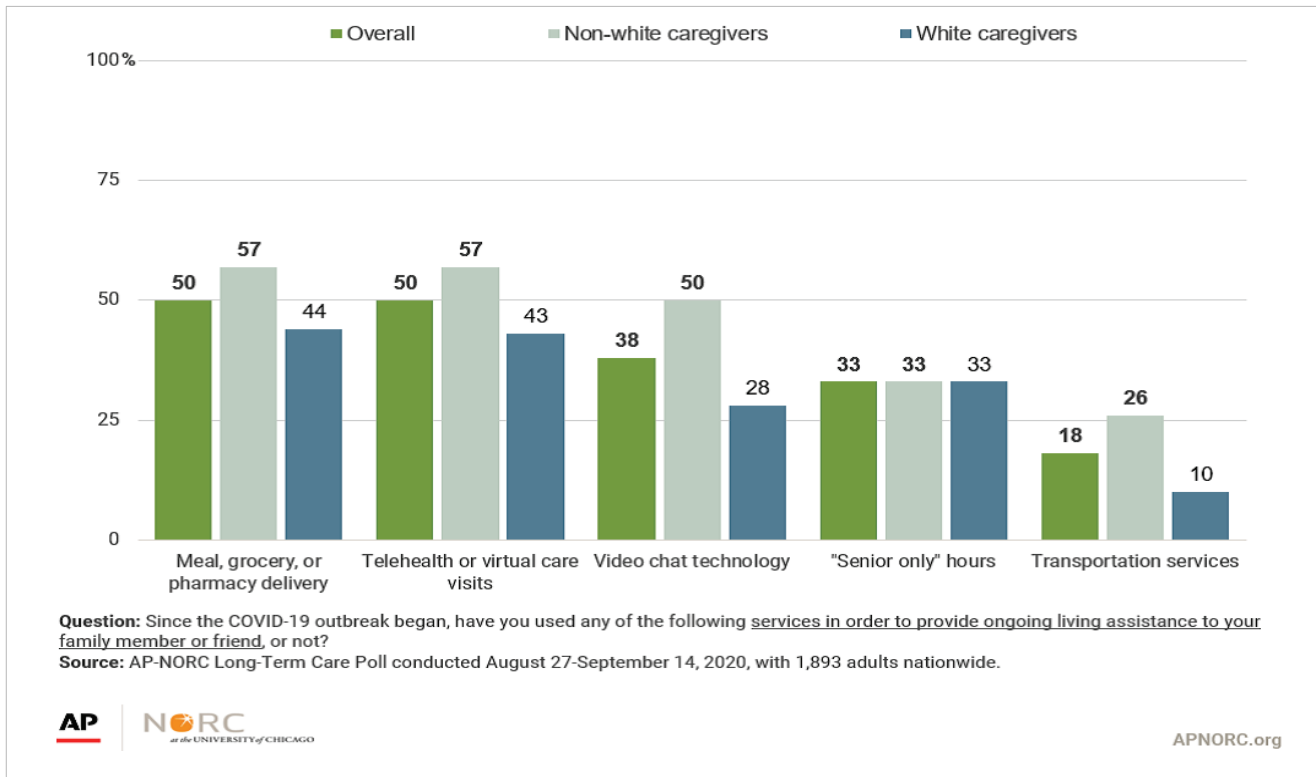


Source: CDC Foundation Stakeholder Organization Survey, October 2020.

Non-White caregivers were more likely than White caregivers to report using nearly every type of service to provide ongoing care for older adults. The 2020 AP-NORC Long-Term Care Poll found that

non-White caregivers were more likely than White caregivers to report using meal, grocery, or pharmacy delivery; telehealth or virtual care visits; video chat technology; “senior only” hours (when grocery stores across the United States set aside earlier hours for older adults to shop); and transportation services. This difference was especially large for video chat technology, with 50 percent of non-White caregivers using this service, compared to 28 percent of White caregivers (see Exhibit 20).

Exhibit 20. Caregivers’ Use of Services to Provide Ongoing Living Assistance to a Family Member or Friend during COVID-19



9 Information-seeking behaviors and resource preferences of caregivers

Informal or unpaid caregivers have relied on different sources for information during the PHE, including the internet and health care providers. This section describes information-seeking behaviors and resource preferences of caregivers during COVID-19.

Similar to older adults, caregivers have used the internet as a primary source of information during the PHE. Caregivers who participated in online focus groups reported using the internet, including Google, WebMD, and hospital websites, to get information about the COVID-19 PHE. They also reported talking to friends or relatives who were health care providers for advice, as well as trusted

organizations such as AARP. One respondent explained, “I get some AARP bulletins that give you general coping guidelines and tips. It says I’m not alone, and this is a very common situation for people to be in.” Caregivers cited use of social media platforms, including Facebook and Nextdoor, to share resources and connect with other people who have had similar experiences. One focus group respondent described the value of Nextdoor in identifying local resources: “We don’t know a lot of things until we hear it on Nextdoor, like food donations or services that will drive your loved one.”

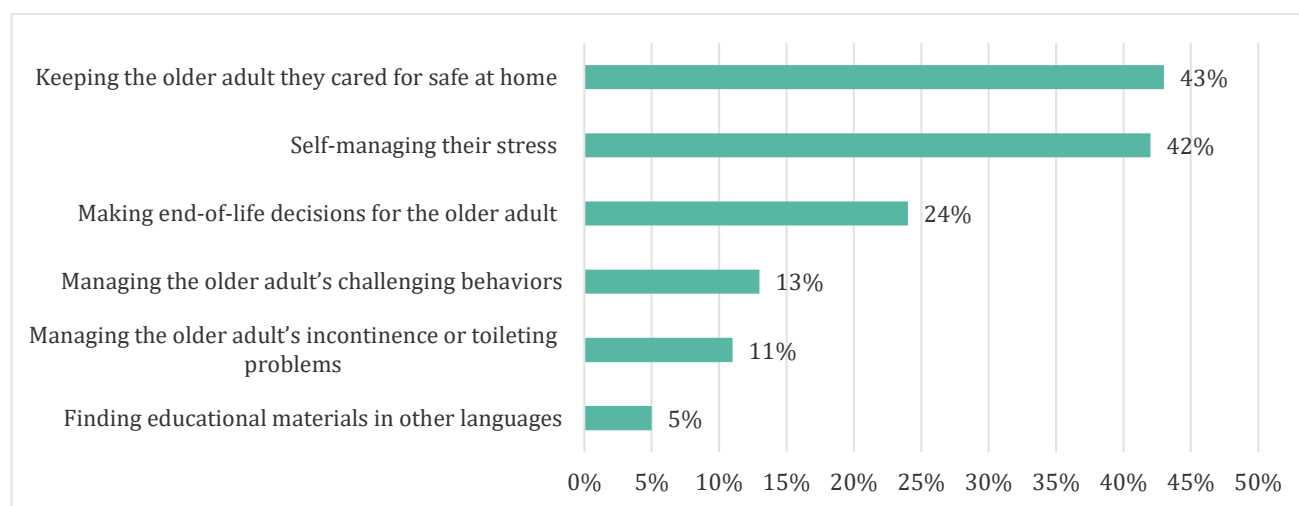
Social data listening identified Reddit as an important online community for caregivers; the site has provided a forum for support, validation, and advice sharing. This platform was dominated by young and middle-aged adults, rather than older adults, and much of the content reflected caregivers’ experiences. In different forums dedicated to topics of interest for older adults and caregivers, Reddit users discussed their experiences caring for aging parents, balancing responsibilities for their aging parents with their own needs and independence, and the competing demands of caring for their aging parents as well as their spouses and children, which often creates resentment. Familial caregivers often reported exhaustion and stress (emotional, physical, and financial) and Reddit users shared advice on emotional coping, existing government and nonprofit resources, and potential legal or administrative action that a caregiver could take to address a given challenge.

Caregivers also relied on health care providers for information during COVID-19. Caregivers who participated in online focus groups said they relied on their care recipient’s health care providers (including physicians and social workers) for information about COVID-19. However, social distancing precautions have imposed barriers to accompanying care recipients to medical appointments, which can create communication barriers for caregivers, especially for those caring for older adults with mild cognitive impairment. According to a 2014 survey by AARP, caregivers seldom reported using health care providers as a source of information. One-third of caregivers stated that health care providers asked about the needs of the older adults they cared for, yet only 16 percent reported that health care providers asked about their own needs as caregivers.⁴⁰ Similarly, the 2018 AP-NORC Long-Term Care Poll found that less than one quarter of caregivers (24 percent) talked to their personal doctors about their caregiving responsibilities. Among those who had, most received information about self-care and other resources for caregivers: three-quarters (75 percent) discussed self-care, and more than half learned about respite services (59 percent), received information about other services for caregivers (56 percent), or were informed about social support networks for caregivers (53 percent).⁴¹

One caregiver who participated in an online focus group indicated that her mother’s insurance company had provided helpful COVID-related updates and sent a nurse for an annual home visit; the nurse built a relationship with her mother and gave her useful information. Caregivers also reported relying on friends and family members who were frontline health care workers for advice on what to do and how to stay safe.

Caregivers of older adults had unique informational needs, primarily related to managing their caregiving responsibilities. According to the AARP report *Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50+*, over 80 percent of caregivers of older adults reported needing more information or help specific to caregiver topics.⁴² Most commonly, caregivers wanted information on keeping the older adult they cared for safe at home (43 percent) and self-managing their stress (42 percent). Caregivers also wanted more information on making end-of-life decisions for the older adult (24 percent); managing the older adult’s challenging behaviors (13 percent); managing the older adult’s incontinence or toileting problems (11 percent); and finding educational materials in other languages (5 percent). Caregivers of adults age 85 and older were more likely to ask for information on incontinence and end-of-life decisions.⁴³

Exhibit 21. Information Needs of Caregivers of Older Adults (ages 50+)



Question: Which of the following topics do you feel you [need/needed] more help or information?

Source: AARP’s *Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50+*, 2015.

Caregivers’ informational needs reflected gaps in the knowledge and training necessary to perform their responsibilities, particularly among caregivers of older adults with memory loss or cognitive decline.

Most caregivers said they learned how to provide care on the job and the majority said they felt undertrained. A 2017 AP-NORC Long-Term Care Poll found that just 31 percent of caregivers had received some formal training in how to be a caregiver. When asked how they learned to provide care, most caregivers said that they taught themselves how to do it (87 percent), while 61 percent had talked to a health professional, 34 percent talked to friends or family members with caregiving experience, and 26 percent searched online for information about caregiving. Those caring for someone with memory loss or cognitive

“I think that my mother-in-law’s doctor is a great source of truth. I don’t really, I don’t know, other sources of information. We take her to an acupuncturist, so other medical professionals. Also, I’m really big on technology and social media so we do have support groups where we try and disseminate information.”

*-Focus Group Respondent,
age 21*

decline were more likely than other caregivers to seek information from health professionals and friends or family members with caregiving experience, and to conduct online searches.

Organizations that served caregivers indicated in the stakeholder organization survey and stakeholder interviews that they have increased their virtual offerings to caregivers. Their increase, which is similar to that of stakeholder organizations serving older adults, includes disseminating information about COVID-19 online and offering online support groups for caregivers. This finding is consistent with caregiver focus group discussions about participating in online support groups or subscribing to relevant listservs.

Needs Assessment: Key Findings

The most common needs and concerns of both older adults and caregivers were social isolation and loneliness, fear of transmitting and contracting the virus, mental health, financial and economic impacts, access to health care services, access to and use of technology, and food security. Older adults had other concerns, including obtaining household supplies, access to transportation, obtaining medications and supplies, and getting physical activity. Caregivers' major needs and concerns were getting information and referral services and respite care, and preventing elder abuse and neglect.

Exhibit 22. Needs and Concerns of Older Adults and Caregivers during COVID-19

Needs and concerns of older adults and caregivers during COVID-19	Population	
	Older Adults	Caregivers
Social isolation and loneliness	✓	✓
Fear of transmitting and contracting the virus	✓	✓
Mental health and well-being	✓	✓
Financial and economic impacts	✓	✓
Access to health care services	✓	✓
Access to and use of technology	✓	✓
Food security and food delivery services	✓	✓
Obtaining household supplies	✓	
Access to transportation	✓	
Obtaining medications and supplies	✓	
Manage chronic conditions	✓	
Getting physical activity	✓	
Information and referral services		✓
Respite care		✓
Elder abuse and neglect		✓

Environmental Scan Findings



What public health strategies and interventions are available in the United States to support the physical and mental well-being of older adults?

In this environmental scan, we identified public health strategies and interventions available in the United States that support the physical and mental well-being of community-dwelling older adults and caregivers during public health emergencies (PHEs) such as COVID-19. We explored strategies and interventions to support caregivers as well as five interrelated topics of concern for older adults during PHEs: deconditioning, deferral of medical care, management of chronic conditions, social isolation, and elder abuse and neglect. In the sections that follow we present high-level findings for each of these topics, organized as follows:

- Overview of the topic
- Summary of findings
- Findings by intervention type: education, direct services, health care, and policy and system change
- Size and scope of interventions identified (e.g., national, local)
- Interventions identified for specific subpopulations (e.g., individuals with disabilities, racial and ethnic minorities, people with limited English proficiency [LEP])
- Evidence base for identified interventions

The Environmental Scan Interventions Tables attachment presents descriptions of all the interventions identified across the scans.



Deconditioning: Public Health Interventions and Strategies

The U.S. population is increasing in age and living longer, two factors that contribute to an increase in the proportion of older adults with disabilities.⁴⁴ The loss of muscle mass and strength, both of which are debilitating and have serious consequences for overall health, tends to speed up with age. In addition, older hospitalized adults are 61 times more likely to develop a disability, including problems walking and taking care of themselves, than those who are not hospitalized.⁴⁵ Both aging and hospitalization are associated with deconditioning, or the loss of muscle tone and endurance due to chronic disease, immobility, or loss of function.⁴⁶ Deconditioning may include multiple, potentially reversible changes in body systems brought about by physical inactivity and disuse, and can have functional and clinical consequences. Deconditioning commonly occurs in response to 1) a sedentary lifestyle (even in the absence of significant disease or disability and may result in slow, chronic decline in physical fitness); and 2) bed or chair rest during an acute illness. Myriad physical and occupational therapy interventions address deconditioning among older adults at home.

The COVID-19 pandemic has compounded these challenges and significantly altered the physical and social lives of people throughout the United States. First, older adults are disproportionately more likely than individuals in other age groups to require hospitalization due to the presence of severe symptoms related to the coronavirus.⁴⁷ Second, the resulting public health policy and social distancing guidelines have led to months of isolation at home for millions of older U.S. adults. The dramatic decrease in physical activity, such as group exercise classes, running errands, or regular physical therapy sessions, threatens existing efforts to help older adults remain mobile and capable of performing everyday tasks.

NORC's research focused on strategies and interventions at local, state, and national levels to support older adults' physical activity and mobility in a manner consistent with COVID-19 social distancing guidelines. Following CDC's definition of deconditioning, NORC centered its research on resources that aim to assist those with physical disabilities or difficulties with activities of daily living (ADLs) or instrumental activities of daily living (IADLs). These refer to activities or fundamental skills required to independently care for oneself, by increasing or maintaining their mobility and physical activity/exercise and improving their ADLs/IADLs.

Summary of Findings. We identified a total of 29 interventions, found mainly in searches through grey literature and websites. We discovered that many national organizations, health care providers, and private businesses (e.g., physical therapy offices) were providing similar information to older adults and their caregivers, including health providers and therapists, on how to remain active during the pandemic. A number of additional interventions offered commentary or suggested evidence-based interventions. Although the majority of the interventions drew on evidence-based research, none of the interventions implemented during the pandemic were systematically evaluated.

Type and format of interventions. The majority of interventions available to older adults during the pandemic were educational or direct services, focusing on exercises or activities that older adults (with or without their caregivers) can perform at or near the home to minimize deconditioning.

Education. All educational interventions for older adults (e.g., handouts, booklets, toolkits, videos) focused on home-bound or close-to-home exercises and activities for older adults. For example, the National Institute on Aging has provided a compilation of articles for exercise and physical activity during COVID-19 and practical exercise guides in their Go4Life program.⁴⁸ Another example is the Arthritis Foundation's program, Walk with Ease, which offered an online tool as part of a low-cost, six-week walking program for older adults.⁴⁹

Direct Services. For the most part, foundations and private-public partnerships have provided resources to help older adults remain physically active at home during the pandemic, most of which are evidence-based exercise programs adapted to a remote format. These included Project Enhance, an evidence-based intervention developed by Sound Generations in partnership with the University of Washington and GroupHealth, which provided exercises (Enhance@Fitness) and a behavior change program (Enhance@Wellness).⁵⁰ Moving for Better Balance, an evidence-based 12-week group exercise program founded on the principles of Tai Chi, usually offered at YMCAs, is available remotely via videoconference.⁵¹

Health Care. An additional 11 interventions provided similar resources for caregivers or therapists related to safely and effectively delivering services at home or remotely during the pandemic. These included compilations of tips or resources for physiotherapists, clinicians, organizations, clinical educators, program providers, and other health care providers for how to either adapt programs to COVID-19 guidelines or encourage older adults to remain active during the pandemic. Of these interventions, six included telehealth or virtual components.

Physio/physical therapists and older adult-focused organizations developed the majority of interventions targeting health care and community service providers. The former provided resources that helped professional therapists adapt their services during the pandemic. The latter provided tailored guidance based on the type of caregiver and the nature of their organization. For example, the World Health Organization developed guidance for clinicians on how to provide rehabilitation and general care services to older adults throughout all stages of the COVID-19 disease continuum (i.e., screening to discharge) and in understanding how patients' needs and goals may influence exercise management.⁵² The National Council on Aging (NCOA) provided communication tips and resources for organizations about the importance of staying active and how to do so during the pandemic.⁵³ Three additional interventions, including those created by the American Physical Therapy Association, targeted both older adults and their caregivers with similar compilations of resources on how to keep older adults active and independent at home during the pandemic.⁵⁴

We identified a number of commentaries, rapid literature reviews, and suggestions drawn from existing evidence-based research developed by medical professionals and researchers. For example, Oxford

COVID-19 Evidence Service team, Centre for Evidence-Based Medicine provided a rapid review on how to minimize development of frailty in people who were previously mobile but are now housebound due to COVID-19 isolation.⁵⁵ Other resources summarized tips from experts and experiences learned from prior public health crises on how to address deconditioning among older adults. Most developed specific recommendations on how to adapt or create interventions to meet the identified unique, emerging needs through technology, best practices, and targeted exercises.

Size and scope. The majority of interventions are online resources targeting older adults and their caregivers for use at home. Given the online nature of these interventions, even if they are produced by a local organization, they are available only to those with internet access. Similarly, interventions in the form of commentary or reviews are available to caregivers and older adults in any location with internet access.

We also identified interventions that were offered in multiple locales around the United States. These provide one-on-one therapy for older adults and tend to be offered locally. One such intervention, CAPABLE, was developed by the Johns Hopkins School of Nursing.⁵⁶ The program was initially offered only in the Baltimore area, but has since grown to 25 locations in the United States and Canada. Another example is Enhance® Fitness, which started in Seattle but has expanded across the United States.⁵⁷ One pilot of a separate study on telehealth exercise programs for older adults with functional impairments was limited to one participant and was conducted at the University of South Carolina.⁵⁸

Focus on subpopulations. We did not identify many interventions designed for specific subpopulations. However, a few did target older adults with specific conditions or disabilities. These included: frailty (Disaster Feeding Support Team⁵⁹); functional impairments (pilot study described in Middleton et al. 2020); dementia (Health Innovation Network, Alzheimer’s Society, NIHR⁶⁰); and digitally excluded adults (i.e., with limited access to internet or other technologies; the Healthy Aging Research Group). The majority of interventions targeted older adults and/or their caregivers.

Evidence base and outcomes. The majority of interventions identified in the scan were emerging and had not yet been evaluated. Nine interventions were evidence-based. These included longstanding behavior change, exercise, and fall prevention programs such as [Enhance®Wellness](#) (Sound Generations, University of Washington, Kaiser)⁶¹; [Moving for Better Balance](#) (Oregon Research Institute)⁶²; [GeriFit®](#) (GeriFit)⁶³; [On the Move: Group Exercise for Improved Mobility in Older Adults®](#) (University of Pittsburgh)⁶⁴; [Bingocize®](#) (Western Kentucky University)⁶⁵; and the [Otago Exercise Program](#) (University of North Carolina at Chapel Hill).⁶⁶ However, adaptations made for the pandemic (e.g., offering a virtual program that was previously in person) have not been evaluated.



Social Isolation: Public Health Interventions and Strategies

Social isolation, defined as an objective lack of social connections, has been extensively linked with adverse health outcomes in rigorous, peer-reviewed studies. Loneliness is defined as an unpleasant state that accompanies a perceived discrepancy between one's desired and one's actual social contact. The two constructs are related yet distinct. Individuals can feel lonely despite having a large social network or frequent contact with loved ones. Conversely, those with few social ties

or connections may not feel lonely. Social isolation and loneliness have each received substantial scientific attention, with a large body of literature in each area spanning several decades.

Older adults are generally more vulnerable to social isolation, due to the fact that they are more likely than younger adults to have lost a spouse, family, or friends; to live alone; to have a chronic illness that restricts social activity due to pain; and to experience decreased mobility. The National Academies of Sciences, Engineering, and Medicine reported that nearly one-fourth of adults ages 65 years and older are socially isolated.⁶⁷ COVID-19 is exacerbating these challenges, uniquely affecting older adults given their increased risks of infection and severe illness from COVID-19. Case fatality rates are much higher for adults ages 65 and older than for those under age 45.⁶⁸ Quarantine and social distancing measures have amplified already high rates of social isolation among older adults through a decrease in social activities.

The purpose of this scan is to identify public health strategies and interventions available in the United States related to social isolation for community-dwelling older adults and their caregivers. Social isolation interventions have increased exponentially during the last decade, and this review is limited to those programs that have been modified, or developed and implemented, during PHEs like COVID-19. This review focuses on local, state, and national public health interventions and strategies to support older adults who are socially isolated.

Summary of Findings. We identified a total of 92 interventions and strategies, found mainly through web searches rather than searches of peer-reviewed literature. Many news sites, national organizations, and local senior center sites were posting similar information on how older adults could prevent or reduce social isolation. These were predominantly educational resources (e.g., tip sheets to reduce social isolation); direct services (e.g., friendly phone calls to older adults); or connections to direct services (e.g., websites that pointed older adults to organizations in their area that provide social support and other services). The majority of these 74 interventions did not include an evaluative component or did not explicitly state that they were collecting data during the pandemic with the goal of evaluation in the future. However, some interventions were based on evaluations or data pre-dating COVID-19, and a few were emerging interventions that lacked evaluations. The COVID-19 pandemic was the only PHE referenced among the interventions.

New or modified social isolation interventions have been rapidly emerging during the COVID-19 PHE, and we acknowledge that coverage of this area will require frequent updating. For instance, on October 15, 2020, the Administration for Community Living and the Office of the Assistant Secretary for Health announced finalists and Phase 1 winners in their “Competition to Combat Social Isolation.” The competition elicited 38 entries, eight of which were selected as finalists.⁶⁹ Some of these interventions are entirely new, while others are extensions of existing services that include new geographic areas or new populations. Still others are directed toward service providers to help them identify resources for older adults. One existing service currently being adapted to a remote format during the pandemic is TechPals—a nonprofit startup that pairs older adults with tech-savvy millennials who teach them how to use various technologies (e.g., Zoom, iPhones, MacBooks).⁷⁰ It will be important to monitor this continually evolving field to identify promising new approaches and evidence of effectiveness.

Some interventions that have not directly focused on social isolation may nevertheless offer benefits to older adults experiencing social isolation, loneliness, or both. Wenger & Burholt (2004) remarked, “Lonely people have been found to benefit more from groups designed to meet some other need, such as housing, rather than loneliness.”⁷¹ This may help explain the reduction in social isolation and loneliness observed among older adults who participate in programs that offer meaning and purpose to their lives (e.g., the AARP Foundation’s Experience Corps, which engages adults age 50+ as literacy tutors for children).⁷² During COVID-19, efforts to provide opportunities for older adults to volunteer, especially in intergenerational contact, may help reduce social isolation while simultaneously rendering the benefits of older adults’ service.^{72,73} The MIT AgeLab helps to organize a program called Opportunities for Multigenerational Exchange, Growth, and Action (OMEGA) that, although not targeting social isolation, offers safe ways of fostering connections between older adults and high school students (e.g., sharing talents through virtual performances, video chat, virtual or telephone tutoring, grocery shopping).⁷⁴ A similar example is The Concordium, a nonprofit technology-based start-up that specifically avoids the notion of an “intervention,” but instead fosters natural conversations between young and older adults that benefit both generations, using a videoconferencing platform.⁷⁵

Type and format of interventions. Many programs and resources were available to prevent and mitigate social isolation among older adults during PHEs, such as the COVID-19 pandemic. Some of these interventions were available before COVID-19, but have grown in size and scope to address the increase in social isolation during a pandemic that mandates physical isolation. Physical distancing mandates, in turn, have limited the types of social isolation interventions that can be safely offered during a pandemic. Because face-to-face interventions have been largely eliminated, the interventions 1) offered educational information, 2) focused on the safe provision of direct services such as social support, or 3) provided resources for local community-based organizations to help older adults receive social support and companionship. The interventions were mainly developed by national organizations. However, many interventions originated from state or local organizations, such as local chapters of national organizations, academic institutions, or local governments.

Education. The majority of educational interventions were websites and fact sheets. The interventions most often directly targeted older adults (90 interventions; 23 also targeted caregivers); few

interventions solely targeted caregivers (three interventions). In other cases, interventions targeted organizations and agencies intending to help them provide services directly to older adults in their local communities. These included community organizations and Area Agencies on Aging (AAA; 25 interventions); health care providers (21 interventions); and government agencies (15 interventions).⁷⁶ These resources suggested ways that older adults can stay connected with others, such as communicating with friends and family via phone, video, or written notes/cards; calling toll-free numbers for social support; attending virtual events such as concerts or tours of art exhibits or museums; going for a walk and saying hello to others while keeping a six-foot distance; participating in virtual exercise classes; or volunteering from home through technology to share skills and mentor others (e.g., through a local AAA). Other resources directly educated older adults on how to use technology to connect with their loved ones (e.g., Nancy's Tech Help).⁷⁷

Direct Services. Some organizations provided direct service interventions, such as social support or companionship, to older adults. Older adults have had access to several forms of physically distanced or remote social connectivity with others. For example, they could sign up to receive social support by phone, video, or written communication either from students (Seniors Overcoming Social Isolation,⁷⁸ Age-friendly Student Senior Connection,⁷⁹ Social Bridging Project,⁸⁰ Students to Seniors⁸¹) or general community volunteers (Community Connections,⁸² Letters to Seniors to Address Social Isolation,⁸³ Daily Call Sheet,⁸⁴ Baltimore Neighbors Network,⁸⁵ We Care/We're Careful,⁸⁶ SoFIACare,⁸⁷ SAGEConnect,⁸⁸ Pen Pals for Seniors,⁸⁹ Meals on Wheels,⁹⁰ Friendship Network,⁹¹ and Maintaining Engagement through Spiritual Support⁹²). In addition, national hotlines (e.g., Institute on Aging's Friendship Line,⁹³ AARP's Friendly Voices,⁹⁴ the Helpline of the National Alliance on Mental Illness⁹⁵) were readily available for older adults to call for social support and companionship at any time. AAAs also offered non-human social support (e.g., pets) to isolated older adults.

Other organizations offered social support indirectly by connecting older adults with resources or agencies that provide direct services in their local area. Examples included: Far From Alone (a collaborative effort by Humana, Uber Health, Papa, the Coalition to End Social Isolation and Loneliness, and the NASA-funded Translational Research Institute for Space Health)⁹⁶; Illinois Call4Calm Text Line⁹⁷; and the AARP Foundation's Connect2Affect website.⁹⁸

Size and scope. Of the 62 national interventions, the implementing organizations included those focusing specifically on older adults (e.g., AARP, the National Association of the Area Agencies on Aging, the National Council on Aging, the Institute on Aging, Meals on Wheels), as well as organizations without a particular focus on older adults (e.g., the American Psychological Association, Mental Health America). Some national health care providers have also developed programming (e.g., Aetna, United Healthcare).

Of the 92 identified interventions, 20 operated at the local level and 15 at the state level. These smaller-scale resources were developed by local chapters of national organizations (e.g., AAA of Tarrant County in Fort Worth, Texas); academic institutions (e.g., Northwestern University); or local governments (e.g., California Volunteers [Office of the Governor], Florida Department of Elder Affairs, Texas Health and Human Services, Illinois Department of Health). We identified interventions at the state or local level

across all regions of the United States, with the greatest number in the West and Midwest, followed by the Southeast, Northeast, and Southwest. An additional 10 interventions were linked with multiple sites across states and in different regions of the country, or were geographically unspecified.

None of the interventions explicitly addressed social isolation in rural communities. Given that information and resources were often freely available online or by phone, these resources are plausibly available to older adults in rural locations.

Focus on subpopulations. We identified few interventions designed for specific subpopulations, such as older adults of a particular age group, racial and ethnic minority populations, and those with disabilities or certain chronic conditions. However, there were exceptions. For example, one intervention focused on serving isolated older adults who are LGBT. Other resources focused on older adults with dementia (Art at Your Own PACE,⁹⁹ It's Never Too Late,¹⁰⁰ and Project VITAL¹⁰¹) and vision difficulties (15 Smartphone Apps for Older Adults to Use while in Social Isolation during the COVID-19 Pandemic).¹⁰² In addition, one intervention targeted Hispanic or Latino older adults who were immigrants or who had LEP to provide social engagement activities via Zoom (Weaving Hearts Intergenerational Program).¹⁰³

Evidence base and outcomes. Of the interventions identified, almost one-fifth (18) were supported by some level of research evidence. Although these studies were largely carried out prior to the pandemic, a small number of evaluations were underway to assess the effectiveness of interventions' adaptations to service delivery.

Only one intervention—Program to Encourage Active, Rewarding Lives (PEARLS)—was evidence-based, with multiple studies showing PEARLS to be effective in decreasing depressive symptoms in older adults.^{104, 105} An evaluation of PEARLS's adaptations in response to the pandemic (shifting delivery to phone, video, and mailed materials) is currently underway to assess its ability to improve social connectedness among low-income older adults.¹⁰⁶ Two interventions achieved an evidence level of “effective,” including Meals on Wheels (MoW) and iN2L. A large body of research has documented the value of home-delivered meals on older adults' health and well-being, and at least one rigorous study (using a quasi-experimental design) has demonstrated that the individuals who receive Meals on Wheels have higher rates of health care utilization, compared to those who do not use these services.¹⁰⁷ To meet the increased demand for services during the pandemic, Meals on Wheels has established a Meals on Wheels COVID-19 Response Fund to subsidize additional transportation and personnel costs and enable tech-based efforts to check in on isolated seniors. With respect to iN2L (a touch screen technology system to support social interaction in senior living communities), several studies have found positive outcomes, including one quasi-experimental pre/post study design showing a greater reduction in psychotropic drug use for iN2L participants, compared to two other study groups.¹⁰⁸ Founded in 1999, the technology has since been adapted for the pandemic, including how to use and clean/disinfect devices.

We identified 12 interventions as either “promising” or “emerging” in their level of evidence. These interventions showed initial positive results that were supported by less rigorous designs (pre/post studies, post-only studies, participant satisfaction surveys, case studies, etc.) or were in the process of

being evaluated. Included in this latter category is the Commonwealth Care Alliance’s Somerville-Cambridge Elder Services, which connects volunteers with older adult buddies for weekly phone calls.¹⁰⁹ These services will be evaluated to examine their potential impacts on reducing loneliness.

The remaining 80 percent of interventions identified either had no evaluation data or were not relevant for assessing levels of evidence. A little over 36 percent of interventions (34) had no history of research studying their effectiveness. Many of these were developed or adapted in response to the pandemic and had yet to be evaluated. Lastly, 44 percent of the interventions (41) were educational resources (compiling and posting materials on websites) for which evidence levels did not apply. A small number of interventions were emerging and had evaluations underway but were not yet complete, such as the Commonwealth Care Alliance’s Somerville-Cambridge Elder Services programming.¹¹⁰ These services will be evaluated to examine potential impacts on loneliness. Researchers are evaluating the Social Support Action Team¹¹¹—an intervention developed by Aging and Disability Services and several other collaborating institutions to provide social support to older adults through one-on-one check-in calls and small group peer-support opportunities.



Deferral of Medical Care: Public Health Interventions and Strategies

The COVID-19 pandemic required millions of individuals to stay home to avoid risking exposure to the virus or infecting others if they were ill. At the onset of the pandemic, many U.S. hospitals were overwhelmed by a surge in COVID-19 patients, leading to the depletion of hospital beds and resources such as personal protective equipment (PPE) and disinfectants.¹¹² Because of the resulting resource constraints and fear of infection, clinicians and non-COVID-19 patients deferred medical care, including emergency care (e.g., care for immediate life-threatening conditions); urgent care (e.g., care for immediate non-life-threatening conditions); routine medical care (e.g., annual check-ups); and non-urgent visits, evaluations, diagnostics, surgeries, and therapeutics.^{113,114}

In June 2020, the CDC conducted a web-based COVID-19 Outbreak Public Evaluation Initiative, reviewing data gathered from 4,975 adults. Among all respondents, 40.9 percent reported having delayed or avoided any medical care, including urgent or emergency care (12 percent) and routine care (31.5 percent), because of concerns about COVID-19.¹¹⁵ A total of 858 (17.3 percent) were adults ages 65 and older, of whom 33.5 percent reported having deferred any medical care, including urgent or emergency care (30.3 percent) and routine care (4.4 percent).¹¹⁶ Many older adults over the age of 50 (and especially those over the age of 65) have urgent medical needs.

To address the ongoing need for medical treatment during public health emergencies (PHEs), the availability of many health care services has rapidly expanded through outlets like telehealth, which allow physicians and other health care providers to meet with their patients remotely, including in their homes.¹¹⁷ Other organizations, such as national and local public health agencies, developed online educational tools and resources for people seeking guidance on how to access health care and remain safe during a PHE. This scan focused on identifying interventions and strategies that addressed deferral of medical care among older adults by directly providing safe access to health services, or by helping older adults and their caregivers find and make decisions about safe and appropriate care.

Summary of Findings. We identified a total of 29 interventions focused on preventing deferral of medical care among older adults during PHEs, found mainly through grey literature and websites. The interventions were categorized as education (n=20), health care (n=15), and policy and system change (n=2), and were developed for both individuals and groups. While national organizations (e.g., CDC, Consumer Reports, Commonwealth Fund, Alzheimer’s Association, American Hospital Association) developed most educational resources, including guidance for older adults, caregivers, and providers, the majority of health care interventions were developed locally by regional foundations and health care organizations. Further, the scan showed that most resources that help prevent deferral of medical care among older adults as a result of PHEs targeted health systems, health plans, and medical providers (n=18), with fewer resources or interventions directly targeting older adults (n=10). Finally, 19 of the 29

interventions and resources were developed during or after March 2020, with a specific focus on supporting older adults' health care within the context of the COVID-19 pandemic.

Type and format of interventions. We found that the majority of interventions were educational (n=20), focused on delivering guidance and sharing resources for older adults, caregivers, and health care providers to encourage and support health care delivery during the pandemic.

Education. The websites' focuses ranged from resource guides and toolkits for older adults on how and when to access needed care, to guidance for health care providers related to telehealth services and communicating effectively with patients about health care safety protocols implemented during the COVID-19 pandemic. All 20 educational resources were available online in various formats: 17 websites, three webinars, two media campaigns, one podcast, two print resources, and one peer-reviewed journal article. The three webinars targeted a variety of stakeholders (e.g., Area Agencies on Aging, health plan administrators, clinical leadership, health care providers, care coordinators). They covered three topics: tips for promoting flu vaccines for dually eligible beneficiaries during COVID-19, best practices for providing in-person services to people living with dementia during COVID-19, and key approaches to implementing motivational interviewing to increase engagement among older adults during health care and behavioral health visits.^{118,119,120} A podcast developed by the Commonwealth Fund described how the pandemic has changed health care for older Americans.¹²¹ To encourage the public not to postpone care for other concerns outside of COVID-19, the American Hospital Association (AHA) created a Reassurance Communications Toolkit, including videos, editorial content, radio and digital ads, and social media posts.^{122,123} Similarly, the American Heart Association launched a public education and awareness campaign called Don't Die of Doubt™ to encourage people to call 9-1-1 if they experienced symptoms of a heart attack or stroke. Finally, the print resources included the Institute for Healthcare Improvement's Age-Friendly Health System Approach, a conversation guide for providers on how to conduct effective telehealth clinics for older adults, and the International Society of Geriatric Oncology (SIOG)'s consensus of recommendations on the implications of the COVID-19 pandemic on several aspects of cancer care for older adults, including the delay of cancer treatment.^{124,125}

Across all educational resources identified in the environmental scan, one article was developed prior to 2020 and therefore did not address the current COVID-19 pandemic. This resource, *Using Telehealth to Improve Home-Based Care for Older Adults and Family Caregivers*, was developed in May 2018 by the AARP Public Policy Institute; it focused on telehealth strategies that gave older adults with complex health conditions access to high-quality, cost-effective care, in addition to improving support for their caregivers.¹²⁶ Older adults who were avoiding in-person medical care due to COVID-19 were able to use the "home-based primary care for frail older adults" strategy, which joined specialists and primary and community care providers to conduct routine care through virtual visits.

Health Care. Some hospitals and emergency departments (EDs) were focusing efforts on making patients feel more comfortable with seeking medical care when they needed it. These efforts included communicating with patients on websites, through videos, and by email, and redesigning ED workflows and spaces to ensure non-COVID-19 patients were safe and unafraid of potential infection when they

sought care. Specifically, four resources developed by Advisory Board, West Health, Emergency Design Collective, and AHA provided guidance and examples that hospitals and EDs could use to improve outreach and communication strategies for patients and caregivers. They communicated messages offering information about quality and safety protocols, the importance of receiving timely care for urgent and emergent concerns, and advertising new services (e.g., telehealth).^{127,128,129,130} One such resource, the AHA's "Stay Healthy: Don't Delay Care," included materials for hospitals, such as a communications toolkit, videos, talking points, internal checklists and communications plans, a sample op-ed, and a sample public service announcement to help hospitals and health systems address individual and community concerns about seeking care during COVID-19.¹³¹

In addition to suggested messaging, two of the resources described above also provided recommendations for redesigning spaces and workflows to improve patient safety and comfort level. For example, "Emergencies Still Happen in a Pandemic: How to Address Patient Fears in the ER" by the Emergency Design Collective outlined effective strategies carried out in a community hospital in California to address a sudden drop in ED visits after the statewide stay-at-home order. In addition to developing targeted messages for patients and establishing new communication channels across hospital/ED staff and the general public, the resource also provided suggestions for ways EDs could create a physical divide between patients with potential COVID-19 cases and patients seeking care for other concerns. The resource guide also suggested creating a system for rapidly moving patients from the non-COVID-19 side to the COVID-19 side if they started developing symptoms.¹³² West Health developed a resource called "Emergency Care for Older Adults in the COVID-19 Era and Beyond: Proactive, Safe, and Close to Home," which proposed a new paradigm for emergency care for older adults during the pandemic. This resource took a three-pronged approach: 1) conduct proactive and targeted outreach to older adults and high-risk individuals and their caregivers so they know how and when to access needed care, 2) redesign the emergency care response team to provide acute medical care in the home, and 3) ensure that physical environment and processes in EDs are safe and accessible for older adults.¹³³

Direct Services. The environmental scan identified four programs and interventions that provided health care services to individuals both at home and in community-based settings. Developed by health care organizations and health care technology companies, most were technological alternatives (telemedicine, remote patient monitoring, and mobile apps) to in-person care. For example, Tufts University and a tech company, Medically Home, partnered to develop the Tufts-Medically Home® Partnership Program, a remote patient-monitoring program that provided hospital-level care in patients' homes. Eligible patients had to have a safe, stable place to live and a chronic and/or infectious condition such as heart failure, diabetes, pneumonia, or kidney infections. Medically Home provided all the equipment to patients in their home (communications devices, monitors, backup internet, cell signals, and power source) and health care teams monitored each patient 24 hours a day from a "command center" to address complications and questions.¹³⁴ In another example, researchers at Brown University and Johnson & Wales University summarized 15 smartphone apps for older adults to use during the COVID-19 pandemic, including three telemedicine apps and two prescription management apps.¹³⁵

We also identified a program developed by Contra Costa County in California to assist Medicaid beneficiaries most vulnerable to respiratory infections during the statewide shelter-in-place order. Case managers called beneficiaries to address their unmet social and health care needs, connecting them to community resources, scheduling telehealth appointments, and sending messages to primary care providers.¹³⁶ Other health care interventions that encouraged receipt of needed care services during PHEs included mobile medical units that provided needed health services to rural communities and two programs that supported access to needed mental and physical health services for New York City residents in the wake of Hurricane Sandy in 2012.^{137,138} One such intervention focused on the community delivery of streamlined mental health therapy to older adults in New York City impacted by the hurricane. The intervention—Sandy Mobilization, Assessment, Referral, and Treatment for Mental Health (SMART-MH)—involved a brief therapy for late-life depression called “Engage” that could be offered in community settings, such as a congregate meal site, to help decrease depression among a diverse array of older adults impacted by a natural disaster.^{139,140} The other intervention dispensed community health workers and health coaches to engage with vulnerable residents in Rockaway, New York, in the wake of the hurricane through counseling and referrals to a variety of local resources and services including medical care, dental care, and health insurance.¹⁴¹

Size and scope. Of the 29 interventions and resources identified in the environmental scan, 18 were available nationally. A variety of organizations created the resources, including those focused specifically on older adults or health care issues among older adults (e.g., International Society of Geriatric Oncology, American Psychological Association Committee on Aging, AARP Public Policy Institute, Hearing Loss Association of America), and others without a specific focus on older adults (e.g., Consumer Reports, The Commonwealth Fund, The Advisory Board, Mayo Clinic, Institute for Health Care Improvement).

While most of the educational resources we identified were developed by national organizations (e.g., CDC, The Advisory Board, Consumer Reports, Commonwealth Fund), we found one resource guide developed by the Los Angeles County Department of Public Health that highlighted local resources helping older adults access health care services during the pandemic (e.g., pharmacy delivery services).¹⁴² The other locally developed interventions addressed health care (i.e., telehealth, mobile clinics, remote patient monitoring, streamlined mental health therapy, case manager/community health worker outreach programs) created by regional foundations and medical centers.

As described above, the majority of educational resources were available online and applied to older adults, caregivers, and providers across the county in both urban and rural locales. While some of the health care interventions could be adapted for multiple settings (e.g., telehealth services, telemedicine mobile apps), the mobile medical unit targeted rural locales. This remote patient-monitoring program required access to more sophisticated technology for both patients and providers, and proximity to a nearby hospital or command center in case clinicians, services, or medications needed to be dispatched to a patient’s home.^{143,144} Additionally, the SMART-MH program involved mental health screenings and referrals at 31 congregate meal sites in New York City. Such a program could be more challenging to administer in non-urban settings with limited access to congregate meal program sites.¹⁴⁵

Focus on subpopulations. While most of the *educational* resources targeted older adults, most of the *health care* interventions did not specifically target any age group and could benefit adults of all ages who needed alternative ways to access health care services during the pandemic (e.g., mobile apps, telemedicine, remote patient monitoring, mobile clinics). An exception was the SMART-MH program, which was specifically designed for older adults and offered them community delivery of mental health services.¹⁴⁶ We did not identify any interventions specifically targeting racial and ethnic minority populations, but four of the educational resources included some or all of the information in Spanish. For example, the AHA media campaign included a video in Spanish and English for patients and community members that explained how hospitals and health systems were providing safe care and encouraged them not to defer preventive and emergency care.¹⁴⁷ The L.A. County Senior Resource guide was also offered in Spanish and Tagalog. Further, the SMART-MH program, assessments, and therapy were conducted in English, Spanish, Cantonese, and Russian.^{148,149}

One resource focused on cancer care for older adults during the pandemic.^{150,151,152} In addition, some resources focused on preventive care and services for older adults regardless of health condition, while other interventions, such as the remote patient monitoring program developed by Tufts-Medically Home Partnership Program, targeted individuals with a variety of common chronic and infectious conditions including heart failure, diabetes, and pneumonia.¹⁵³ Finally, one resource called COVID-19: Guidelines for Health Care Providers – Video-Based Telehealth Accessibility for Deaf and Hard of Hearing Patients, developed by the Hearing Loss Association of America, aimed to improve telehealth accessibility for all individuals who were deaf and hard of hearing, not exclusively older adults.¹⁵⁴

Evidence base and outcomes. Because 19 of the 29 identified resources and interventions designed to specifically prevent the deferral of medical care during the COVID-19 pandemic have been developed since March 2020, the majority of interventions were emerging and had not yet been evaluated. Outcomes were available for the two programs developed in the wake of Hurricane Sandy: the SMART-MH program and the health coaching and community health worker program developed for vulnerable Rockaway residents. Older adults who received treatment in the SMART-MH program reported significantly decreased severity of depression over time.¹⁵⁵ Participants in the Rockaway program who engaged with health coaches and community health workers reported significant improvements in health, health care utilization, and confidence managing health issues.¹⁵⁶ In addition, one webinar reported that health workers shared promising practices for promoting flu vaccines for individuals dually eligible for Medicare and Medicaid during the COVID-19 pandemic (e.g., establishing committees, developing effective communication and outreach strategies, partnering with community organizations).¹⁵⁷



Management of Chronic Conditions: Public Health Interventions and Strategies

Chronic diseases are defined broadly as conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both.¹⁵⁸ According to the CDC, 85 percent of older adults in the United States live with a chronic disease and 60 percent live with two or more chronic conditions.^{159,160} Most older adults dwell in communities; only about 7 percent of people ages 85 and older live in nursing facilities.¹⁶¹ A network of state and local public agencies and community-based organizations support independent living for older adults with chronic conditions through self-management programs,¹⁶² fall prevention programs, home repair and handyman programs that address safety hazards and functional barriers, non-emergency transportation for those with limited mobility, and other offerings that often depend on the availability of federal pass-through funding.¹⁶³

Public health emergencies (PHEs) make managing older adults' chronic conditions at home or in community-based settings much harder. Approaches that safely monitor a chronic condition at home become even more crucial when a PHE strikes, for example, when medical equipment requires electricity that is turned off during a wildfire. Losing access to residential power service during an emergency can affect the ability to perform dialysis at home or keep medicines refrigerated. This crisis can be mitigated if there is access to a backup power source. Yet, a recent study conducted by the University of Michigan found that among adults ages 50-80 years who depend on electricity for medical needs, only 25 percent had access to backup power.^{164,165} A recent study under the auspices of the National Center for Disaster Preparedness identified 17 recommendations for state and local public health and clinical stakeholders related to supporting individuals with chronic conditions across the lifespan during emergencies. These recommendations emphasized capacity development at a systems level (for example, through law and policies, stakeholder collaboration, workforce training, and inclusion of non-health-oriented stakeholders such as those focused on infrastructure), as well as development of capabilities among individuals, providers, and organizations (e.g., patient education, special medical needs shelters, alternative sites for care).¹⁶⁶

In 2018, the American Red Cross and the American Academy of Nursing explored the evidence base around disaster preparedness for older adults, conducting a systematic review and convening a national group of experts to consider recommendations across six domains (individuals and caregivers, community services and programs, health care providers and first responders, care institutions and organizations, legislation and policy, and research).¹⁶⁷ A subset of the 25 recommendations directly addressed people with chronic conditions or disabilities who lived in community settings, including the following:

- Encouraging older adults and caregivers to plan for emergencies by considering physical, functional, and health needs if evacuation is required (for example, having appropriate food for those with diabetes or having a ramp to facilitate a quick exit from the home)
- Enrolling in a local emergency response registry to be identified as having specific needs (despite the limitations of such registries due to shortfalls in staffing and resources during emergencies)
- Using alert devices and emergency communication plans to facilitate help for people with visual or hearing impairments
- Keeping an easy-to-find list that describes the person's chronic conditions, medications, durable medical equipment, and other needed supports, as well as health care providers and emergency contacts for health and other decision-making
- Maintaining a 30-day supply of medications
- Securing backup power when electricity is needed to run durable medical equipment or refrigerate medications; may involve joining a backup list maintained by local utilities or installing a backup generator
- Creating and sustaining regular contact with neighbors and others nearby who can get help quickly if a disaster occurs (for persons who live independently), for example, through a neighborhood village that organizes volunteer and mutual self-help such as telephone check-ins and rides to medical appointments¹⁶⁸

The COVID-19 pandemic has put unique pressures on existing interventions and resources designed to support older community-dwelling adults during PHEs. For example, requirements for social distancing to prevent the spread of disease present new challenges to monitoring chronic conditions and identifying and addressing safety issues in the home environment that may interfere with IADLs that would otherwise enable independent living.¹⁶⁹ Starting in January 2020, changes in Medicare regulations and relaxed enforcement of current regulations have supported reimbursement for telehealth delivery for a lot of primary and specialty care, with greater flexibility for sites of care (e.g., home-based) and modalities of care delivery (e.g., telephone calls, synchronous audio-visual appointments).¹⁷⁰ For Medicare Advantage plans that enroll approximately one-third of all Medicare beneficiaries, the Centers for Medicare & Medicaid Services (CMS) approved Special Supplemental Benefits for the Chronically Ill in 2020 that have expanded options for plans to offer nonmedical supports (such as food, delivered meals, nonmedical transportation, help with housing and utility bills and safety updates, programs to address social isolation, and service dogs) and expanded existing supplemental benefits oriented toward long-term services to include a smartphone or tablet for telehealth.¹⁷¹ However, almost all of these changes were time-limited, at least at present, and it is unclear to what degree these enhanced benefits and services were adequately meeting the health and functional needs of community-dwelling older adults across the country.

This scan focused on public health strategies, interventions, and resources that were developed or modified to support older adults and address challenges related to managing chronic conditions around, or as a result of, PHEs. We used the CDC list of chronic diseases for this environmental scan, as follows:

heart disease; cancer; chronic lung disease, including chronic obstructive pulmonary disease (COPD); stroke; Alzheimer’s disease and other dementias; diabetes; and chronic kidney disease, including end-stage renal disease.¹⁷² In addition, disability was a focus, specifically as defined in terms of functioning (mobility, cognition, hearing, vision); self-care; and independent living. The management of chronic conditions refers to the context of managing the condition during a PHE that is distinct from approaches that address access barriers incidental to, or not directly related to, a PHE.^{viii} Approaches developed during nonemergency times but adapted as a result of a PHE were included.

Summary of Findings. We identified a total of 49 public health interventions and strategies related to the management of chronic conditions for older adults during PHEs. We found that many national organizations updated existing program information, guidance, and protocols as a result of COVID-19. We also found that many news sites, national organizations, and local resources were posting similar information on caregiving through educational resources (e.g., fact sheets to support caregivers) or direct services (e.g., counseling for caregiver burden).

Approximately half of the identified interventions focused on individuals with multiple chronic conditions. These were educational materials, including self-management fact sheets, webinars, and websites or direct services provided to older adults with chronic conditions (n=7), such as utility restoration and transportation support. In addition, some resources were developed for use by clinicians serving older adults with multiple or complex chronic conditions, focusing on emergency preparedness planning or disaster response. Examples included tools to map at-risk populations (e.g., emPOWER, GIS mapping) or to support home-based care during PHEs such as COVID-19 (e.g., checklists, telehealth tools).

The other half of the interventions focused on older adults with a specific chronic condition. For example, we found checklists and toolkits for people living with dementia or with COPD, respectively. Typically, these materials were developed by associations or specialty societies that represented patients, caregivers, or providers. Of the condition-specific interventions, most focused on chronic kidney disease (n=8), such as a set of health care recommendations to increase the safety of dialysis centers for patients during PHEs. The scan also identified four interventions for older adults with diabetes, a condition that afflicts 23 percent of people (or 12 million) ages 60 and older in the United States.¹⁷³ These interventions included information for health care professionals on best practices for managing the care of diabetes patients during PHEs, such as guidelines for switching insulin products and educational self-management plans for older adults with diabetes.

Evidence for the efficacy of identified resources and programs was limited or not available. This may reflect the fact that we identified most interventions and resources through the grey literature and websites based on Google searches, rather than in PubMed or Google Scholar. We found six interventions with a level of evidence classified as “effective” or “evidence-based.” Three interventions were classified

^{viii} For this reason, the scan did not include the global literature on refugee health care nor the considerable literature on interventions and programs designed to improve access to care for chronic conditions in the absence of a public health emergency.

as having an “emerging” level of evidence (e.g., fact sheets developed by reputable national organizations or government agencies). We did not identify a published evaluation either of efficacy or of effectiveness (outcomes related to health and functioning) for the remaining 39 interventions. Further, we found that many national organizations and government agencies related to aging services provided similar educational information on preparedness planning for older adults with chronic conditions.

Type and format of interventions. The 49 public health interventions for community-dwelling older adults with chronic conditions were categorized as education (n=23), health care (n=13), direct services (n=18), and policy or system changes (n=3).

Education. Over half of the identified interventions were educational materials and programs that covered topics such as emergency planning while on dialysis (a guide)¹⁷⁴; use of telehealth to support patients with end-stage renal disease (a fact sheet)¹⁷⁵; and disaster planning for people living with dementia (a toolkit).¹⁷⁶ Of these educational interventions, 29 were print materials, six were websites, two were webinars, and the remaining were a smartphone app that stores medical identification information that is readily available during emergencies, a media campaign on health insurance coverage during COVID-19, an educational video on COVID-19 considerations for individuals with disabilities, and an intervention that incorporated both mailed print materials and conference calls.

Most often, the educational materials were produced by national organizations, such as the American Diabetes Association, DaVita Kidney Care, and the COPD Foundation, with each focusing on a specific population. Government agencies, including CMS, the U.S. Food and Drug Administration, and the Administration for Community Living, provided informational materials such as checklists that referenced websites and additional resources for health care providers and individuals living with chronic conditions. One online educational tool, CV19 Checkup, was launched recently by the New York Office for the Aging, a digital technology company called BellAge, Inc., and New York’s network of county Area Agencies on Aging (AAAs).^{177,178} The tool served as a free screening resource that uses artificial intelligence to generate a personalized report with guidance about COVID-related risks and how to manage care for chronic health conditions based on data from the CDC and the World Health Organization (WHO).

Overall, most educational materials directly targeted older adults, providing guidance on how to manage or prepare for managing their chronic conditions during PHEs, including planning for health care treatment options during natural disasters. Stroke was the only condition of interest for which we did not find educational materials, while each of the other conditions had between one to four educational resources. Education materials most often covered multiple chronic conditions (n=12).

Chronic disease self-management programs (CDSMPs) made up a key, evidence-based category of educational interventions adapted for use during PHEs.¹⁷⁹ Developed by a team at Stanford University in the 1990s, CDSMPs have been used with patients and caregivers across a range of diseases and functional disability, with workforce training and licensure through the Self-Management Resource Center. A CDSMP consists of a set of workshop sessions led jointly by a health professional and a peer (typically someone

with the chronic condition that the intervention focuses on), with topics ranging from nutrition and medication management to effective decision-making and self-efficacy.¹⁸⁰ The National Council on Aging supports CDSMP dissemination and implementation. It hosts a CDSMP webpage with links to in-person and virtual resources (e.g., Stanford's Better Choices, Better Health online program) and a listing of CDSMPs that have been modified for virtual delivery (telephone or online) in response to COVID-19, which address behavioral health, diabetes, fall prevention, and managing more than one chronic condition at a time.¹⁸¹ Two North Carolina AAAs, for example, present different approaches to implementing modified CDSMPs during the COVID-19 pandemic: the Centralina AAA moved its CDSMP from in-person to virtual,¹⁸² and the Piedmont Triad Regional Council AAA modified its Living Health at Home with Chronic Conditions program by sending its materials through the mail and then holding conference calls to review the information, rather than holding in-person meetings.¹⁸³

Another group of educational materials were designed for clinicians and tailored to the delivery of health services during PHEs. For example, in response to the expansion of Medicare coverage for telehealth in March 2020, the IPRO ESRD Network of New York developed a fact sheet with tips and regulatory guidelines for providers in New York on how to use telehealth services to conduct visits with patients with end-stage renal disease.¹⁸⁴ To support the Veterans Health Administration's (VHA) Home-based Primary Care Program (HBPC), which serves older veterans with multiple chronic conditions and is described below, the VA developed materials for providers to share with patients on emergency preparedness.¹⁸⁵

Health Care. Thirteen interventions were health care programs and resources in various formats, including webinars, websites, in-person services, and telehealth platforms to provide remote care. Although the formats varied, the overarching settings could be grouped into two categories: community-based programs or modification to services rendered in a health care facility.

Community-based programs. Examples of interventions designed to provide care to individuals who live independently include:

- **Blood pressure measurement:** CDC's [Million Hearts](#) initiative highlighted self-measured blood pressure monitoring on a regular basis as an evidence-based intervention to lower and control hypertension.¹⁸⁶ The Million Hearts website offered an array of training materials for patients and clinicians; resource briefs tailored for different audiences (public health, clinicians, and patients and their caregivers); information about validated blood pressure measurement devices; and links to evidence-based recommendations issued by the U.S. Community Preventive Services Task Force, the U.S. Preventive Services Task Force, and the CDC's 6|18 Initiative, as well as a comparative effectiveness review published by the Agency for Healthcare Research and Quality (AHRQ). A recent policy statement published by the American Heart Association and the American Medical Association advocated for the expanded use of self-measured blood pressure monitoring as a cost-effective intervention; in interviews accompanying release of the statement, co-authors spoke about the importance of self-measured blood pressure monitoring for managing heart disease and its risk factors during COVID-19.¹⁸⁷

- **Medication management:** Rural communities face challenges to accessing sufficient care due to the time and distance to health care providers; PHEs exacerbate these challenges. As a response to COVID-19, a rural Florida community implemented a pharmacist-led chronic care management program. The Florida Agricultural and Mechanical University College of Pharmacy and Pharmaceutical Sciences, Institute of Public Health (FAMU CoPPS, IPH) used two ambulatory care pharmacist faculty members from the federally qualified health center in Pensacola, Florida, to provide medication-related recommendations and counseling to a cohort of patients to improve their outcomes. They also established a medication therapy management (MTM) program that focuses on cardiovascular disease and stroke prevention among the medically underserved population.¹⁸⁸ The goal is to ensure that patients will become more comfortable and empowered with regular MTM appointments, which will ideally improve medication adherence and health outcomes.
- **Long-term services and supports:** The VHA developed a Home-based Care During Hurricanes intervention to provide interdisciplinary care to older veterans with chronic conditions, focusing on preparedness planning, post-hurricane phone calls, and in-home visits. We provide more information on this program in the subpopulations section below.¹⁸⁹
- **Care coordination and integration:** The Program of All-Inclusive Care for the Elderly (PACE) is an integrated care model for community-dwelling older adults and people living with a disability, designed to address health care (including behavioral health), long-term services and supports, and some social needs through the use of interdisciplinary care teams and day center programming. PACE began as a demonstration to keep older adults dually eligible for Medicare and Medicaid who were nursing-home eligible at home in their communities. PACE programs in at least four states (Colorado, Massachusetts, Michigan, and North Carolina) have modified their operations in light of COVID-19, shifting from in person to telehealth for needs assessments, care planning, monitoring, and day programming such as exercise and mental health check-ins; transporting clinicians, meals, durable medical equipment, medications, and other supports to participants at home rather than bringing participants to a PACE Center; and using PACE Centers as dedicated sites to care for participants with COVID-19 or who need respite care.¹⁹⁰

Facility-based programs. Several interventions represented modifications of services typically delivered at health care facilities:

- **Telehealth** was identified in three interventions, two of which were actual telehealth services providing care to community-dwelling patients, while the third was a webinar providing tips to health care providers on how to conduct effective telemedicine visits for patients with end-stage renal disease.¹⁹¹ One of the telehealth interventions, TV-AssistDem, which operated in Spain, used the platform to provide health and social support care to its patients with dementia living at home.¹⁹² The second telehealth intervention was the Telestroke ED program, operated out of Mayo Clinic.¹⁹³ This existing program studied the change in transfer rates from the rural spoke hospitals (community hospitals) to large hospital facilities during COVID-19. With limited hospital capacities during peak COVID-19 infection rates, the study found a 50 percent reduction in stroke transfers after the WHO classified COVID-19 as an official pandemic.

- **Discharging patients back home** after a hospital admission was a routine practice with standardized guidelines, such as the U.S. Department of Health and Human Services (HHS) Communication, Maintaining Health, Independence, Support and Safety, and Transportation (CMIST) Framework.¹⁹⁴ For individuals with disabilities discharged during a PHE, considerations can be more complicated. As a result of COVID-19, HHS developed the Discharge Planning and Care Coordination during the COVID-19 Pandemic Tool to support nurses, social workers, case managers, and others conducting effective discharge planning and care coordination for adults with disabilities who 1) received care or treatment for COVID-19 illness in an acute care setting, 2) were no longer COVID-19 positive, and 3) required continuation or reconnection to supports and services. These tips included using a suggested framework such as the CMIST Framework, as well as an overview of state-level programs, national resource centers, and federal contacts to support discharge planning and care coordination.
- **Workflow redesign** was another way facilities could alter practices during PHEs. As a way to mitigate the transmission of COVID-19 during necessary in-person treatment, DaVita Care Clinics began categorizing patients into cohorts based on risk and/or COVID-19 diagnosis.¹⁹⁵
- PHEs could require patients to alter their **medication plans**, which could be challenging without prior planning. Due to the time-sensitive nature of insulin administration for individuals with diabetes, the American Diabetes Association developed a fact-sheet for health care professionals to use when managing diabetes patients during a disaster, in the event that patients were not on their usual schedule. It includes insulin storage notes and interchange recommendations.¹⁹⁶

Direct Services. Eighteen interventions were services provided to older adults with chronic conditions by providers, government agencies, or community-based organizations. These interventions focused more on social determinants of health than health care-specific needs such as utilities, exercise programs, and meal and nutritional services. Examples included:

- **Addressing power outages.** The emPOWER Map, operated by HHS, gave every public health official, emergency manager, hospital, first responder, electric company, and community member the ability to collect data on the electricity-dependent Medicare beneficiaries in their state, territory, county, and ZIP Code. The goal was to quickly identify older adults in need of immediate power reconnection after a natural disaster, to better support their medical needs and prevent catastrophic health impacts.¹⁹⁷
- **Providing transportation.** Mountain Empire in Virginia operated a call center to triage transportation needs of older adults with chronic conditions separate from rides they provided to the general public. The intervention, which included scheduling and providing transportation to older adults, aimed to minimize the spread of COVID-19 among this vulnerable population by increasing their sanitization practices, so they could continue to offer the service.

Size and scope. Thirty of the identified interventions were available nationally, meaning that the intervention could be implemented or used across the country and was not specific to a certain region, state, or tribal community. Twelve of these national interventions were print resources (e.g., toolkits, fact sheets) published by government or organizations on aging, while six were websites with lists of

resources and three were webinars that focused on informing viewers of special considerations during COVID-19 for individuals with specific chronic conditions, and offering tips on using telemedicine during the pandemic. We identified 14 state-specific (n=8) or local (n=6) interventions. For example, in California, a major public utility (PG&E) and the California Foundation for Independent Living Centers established a pilot disaster readiness program, implemented at local independent living centers, to provide qualifying customers who use electrical medical devices with access to backup portable batteries. In addition, the Washington State Emergency Management Division's Public Education Program developed a neighborhood preparedness program. The program trained a lead organizer who lived in the neighborhood to conduct a meeting to identify neighbors who would need additional assistance to evacuate the home (e.g., individuals with disabilities, older adults, those with chronic conditions); sources of potential hazardous materials; and communication plans.

Few interventions focused on specific geographic areas (rural, suburban, or urban), as most interventions were available nationally through websites or print-based materials available online. Four interventions were designed for rural populations, including the Mountain Empire Older Citizens' transportation service call center in Virginia, which modified their standard practices to increase safety for riders,¹⁹⁸ and a telestroke emergency department program operated by the Mayo Clinic that included rural spoke hospitals.¹⁹⁹

Focus on subpopulations. Some interventions were designed to support specific groups with chronic conditions:

Individuals with disabilities. A total of 18 interventions either partially or fully focused on assisting individuals with disabilities. Most focused on community-dwelling older adults with both chronic conditions and disabilities, and did not focus on specific types of disabilities. Fifteen of these interventions referenced multiple chronic conditions or chronic conditions broadly; eight of them were print resources, while ten interventions provided a direct service. Further, only one intervention to support individuals with disabilities focused on a specific type of disability (mobility) while the others referenced the population broadly.

In addition, we identified one intervention that included additional translation materials, such as Braille or American Sign Language accessibility. The one intervention with a Braille option was developed and implemented internationally.²⁰⁰

Tribal communities. While many tribal organizations provided resources and programs for their respective communities, the scan identified four interventions specifically focused on older adults with chronic conditions during a PHE. Both were print resources developed by a state and national organization, respectively. The National Indian Health Board developed a clearinghouse website for tribal communities to reference for tools, including fact sheets, infographics, and videos, to educate older adults, their caregivers, and providers about the COVID-19 pandemic.²⁰¹ In a second example, the Seattle Indian Health Board released a two-page handout (i.e., The COVID-19 Information for High-Risk Individuals) that provided tribal communities with information on COVID-19 symptoms and

transmission, including particular considerations for high-risk individuals such as older adults and members with chronic conditions.

LGBT. The scan identified a guidebook developed by the Fenway Institute that gives LGBT older adults specific information about COVID-19 transmission and concerns for people living with HIV/AIDS or chronic conditions.²⁰²

Veterans. The scan identified three interventions implemented by the VA that focused on assisting older veterans with chronic conditions. Both interventions were developed from an existing Veterans Health Administration HBPC program that provided care to veterans with complex health needs in their homes.²⁰³ The first was a Patient Assessment Tool for Disaster Planning, comprising a checklist administered by clinicians during home visits to identify the veteran's gaps in disaster preparedness. A team led by VA researchers field-tested the tool during hurricanes and a wildfire, documenting the ease of use and relevance of the checklist, and how using it contributed to preparedness for clients. A counterpart intervention was the development of a GIS Mapping Project, piloted with 30 HBPC sites to assess how mapping could be used to identify at-risk patients.²⁰⁴

Individuals with Limited English Proficiency. While searching for interventions, we noted which interventions included resources for individuals with LEP. The scan identified 10 such interventions for Spanish speakers, which included a mix of educational materials, direct services, and health care interventions. The Management of Chronic Conditions table in the Environmental Scan Interventions Tables attachment notes when materials are available in Spanish.

Evidence base and outcomes. Most of the interventions, programs, and resources identified were emerging and had yet to be evaluated. For tools and interventions developed in the context of disaster preparedness and response, the exceptions were case studies and process evaluations of some of the registry and mapping tools, to assess efficacy of implementation rather than impact on the health of older adults.

- The following examples were national interventions that would be characterized as emerging in terms of an evidence base for outcomes. The [Kidney Community Emergency Response \(KCER\)](#) was a website clearinghouse hosted by CMS to support kidney transplant and dialysis patients and their caregivers with educational materials. KCER also offered technical assistance to providers and payers, organized through the ESRD Network Program.²⁰⁵ For example, during the California wildfires in 2020, CMS supported regional activation of the KCER program, including operating dialysis centers, helping evacuated patients gain access to care, and educating patients on preparedness.²⁰⁶ The website appeared to be 508-accessible, and selected parts were available in Spanish.
- As noted above, the VA's [Home-Based Primary Care \(HBPC\) Program](#) field-tested a short emergency preparedness toolkit/checklist, used by members of their multidisciplinary home-visiting team to educate patients and their caregivers about preparedness, identify gaps where services or resources may be needed, and communicate effectively with first responders if needed.²⁰⁷ Another component of the HBPC has been a GIS mapping tool that facilitates preparedness planning by clinical teams; the mapping

tool was piloted in response to wildfires in Northern California and to Hurricane Irma in Florida.²⁰⁸ The GIS mapping tool appears to be inspired by [emPOWER](#), a preparedness mapping tool developed by HHS to identify Medicare beneficiaries with electricity-dependent durable medical equipment.²⁰⁹



Elder Abuse and Neglect: Public Health Interventions and Strategies

According to the CDC, elder abuse is “an intentional act or failure to act that causes or creates a risk of harm to an older adult.”²¹⁰ A complex phenomenon characterized by multiple, interrelated risk factors, elder abuse encompasses at least five, often co-occurring forms of mistreatment, including physical, sexual, or verbal/psychological abuse, financial exploitation, and neglect.^{ix} In the United States, one in 10 adults age 60 years and older is estimated to be a victim of abuse each year. Despite the wide prevalence of elder mistreatment, however, only one in 24 cases of elder abuse is reported to social service or legal authorities.²¹¹ Identification of elder financial abuse is even rarer, with just one in 44 cases of financial exploitation ever being reported.²¹² Although elder abuse was already recognized as a significant public health and human rights issue prior to the pandemic, the conditions created by the public health emergency (PHE) are expected to only further increase the incidence, if not reporting, of elder mistreatment.

Elder Abuse and COVID-19 Pandemic. Since the emergence of confirmed COVID-19 cases in the United States in early 2020, public health policies and recommendations have focused on measures that limit personal interaction to slow the progression of the virus. Over the course of the pandemic, these evolving measures have included social distancing; stay-at-home or shelter-in-place orders; travel and entry restrictions; closures of daycares, schools, and nonessential businesses; and restricted visitations to long-term care facilities, including residential care communities. While initially enacted in a small number of cities and states that were acutely affected by the pandemic, every state and the District of Columbia progressively adopted these and other safeguards as the virus spread across the United States.

Increased Risk of Abuse for Victims and Perpetrators. The very preventive measures designed to protect the public and keep them physically safe from the virus, however, have also created conditions that are likely to place older adults at higher risk for abuse and neglect. Current strategies to reduce interpersonal contact—as well as financial stresses generated by the national economic downturn—have heightened older adults’ vulnerability to known risk factors for elder mistreatment, including social isolation, depression, anxiety, financial hardship, and dependence on others for care. Other increased risk factors relate to the perpetrator, of whom the majority are family members, spouses, and caregivers.^{213,214} The personal and financial stress (e.g., unemployment); increased substance abuse; and change in living

^{ix} Definitions of elder abuse (and how they are collected by Adult Protective Services) vary across states and across programs, and can include additional types of abuse (such as abandonment). Neglect includes both caretaker neglect and self-neglect. While the CDC definition of elder abuse does not include self-neglect, longstanding programs such as Adult Protective Services and the Long-Term Care Ombudsman Program address both caretaker neglect and self-neglect. Newer web resources identified do not define neglect.

conditions resulting from the pandemic may make family members and caregivers more likely to commit abuse. Among existing abusive relationships, advocates have learned of perpetrators exploiting the virus and social isolation to misinform and threaten victims.

Decreased Ability to Detect Abuse. In addition to elevating abuse risk factors for both victims and perpetrators, social distancing measures have inhibited the ability of communities to detect elder mistreatment. Because elder abuse is often hidden from view, family and friends as well as the health care system serve an important monitoring function. Although dramatic variation exists, state mandatory reporting laws require selected individuals and professionals such as doctors and nurses to report suspected abuse (other mandatory reporters may include social service providers, clergy members, and employees of financial institutions, among others). At the same time that older adults experience difficulties accessing health care during the pandemic (whether due to fears of exposure to the virus or financial barriers), physicians, emergency department staff, home care agencies, and other health care providers are hindered in their ability to detect and report potential abuse to the appropriate authorities.

Similarly, federal and state policies restricting visitations to long-term care facilities have disrupted the sentinel function of long-term care ombudsmen. In addition to strict guidelines issued by the Centers for Medicare & Medicaid Services (CMS) preventing visits to nursing homes, state health officials have also limited visits to assisted living facilities and other adult care facilities where community dwelling-older adults reside. By prohibiting entry, older adults remain out of sight of long-term care ombudsmen who would normally serve as the eyes and ears of the community to prevent and respond to elder abuse. Staff shortages and stresses related to caring for a high-risk population also make older adults in facilities especially susceptible to neglect.

Increased Opportunities for Fraud Victimization. Further exacerbating these vulnerabilities in risk and detection are fraud schemes that typically proliferate during PHEs to exploit public fears and undermine relief efforts. In the case of COVID-19, scammers have preyed on vulnerabilities related to the pandemic. Through telemarketing calls, text messages, email phishing attempts, social media platforms, and door-to-door visits, they have spread misinformation about contact tracing, coronavirus testing, medical treatments, charities, and personal protective equipment (PPE). Various scams that specifically target older adults include grandparent scams (where scammers pose as a grandchild asking for money to fund a coronavirus emergency); medical fraud (fraudulent treatment for infections); contact tracing fraud (posing as COVID-19 contact tracers seeking personal information); Social Security Administration fraud; and personal care fraud (claiming to run errands for the older person). Actors in these various fraud schemes pose as authorities from the CDC, World Health Organization, Internal Revenue Service, Treasury Department, and Social Security Administration, among others.

Reports of Abuse Since the Emergence of the Pandemic. Although official statistics on elder abuse in the United States since the pandemic do not yet exist, anecdotal evidence by researchers suggests a massive uptick in reports of elder abuse.²¹⁵ Thus far, nine large metropolitan police departments have shared data showing a double-digit percentage increase in domestic violence cases in March 2020 compared to either March 2019 or January and February 2020. For example, Boston and Seattle

experienced a 22 percent and 21 percent increase, respectively, in domestic violence reports in March 2020 compared to March 2019.²¹⁶ At the same time, some direct service providers are seeing a decline in calls for assistance, largely due to the drop in reports from the health care system described earlier. With respect to financial exploitation, the Federal Trade Commission received 91,000 coronavirus-related fraud complaints between January 1 and June 8, 2020.

Elsewhere in the world, a national seniors advocacy group in Canada known as CanAge observed a tenfold increase in calls from people concerned about elder abuse,²¹⁷ while the international advocacy nonprofit HelpAge reported sharp rises in call volume to their violence helplines about elder abuse in Nepal, the Democratic Republic of Congo, Jordan, and Kyrgyzstan. Similarly, the French government reported increases between 32 and 36 percent in police reports of domestic violence after instituting a nationwide lockdown on March 17, 2020, and has begun contracting with hotels to accommodate abuse victims.²¹⁸ Evidence is also emerging from other countries that domestic violence is climbing due to pandemic-related safety measures.

U.S. Response to COVID-19 Pandemic. In response to this unprecedented crisis, federal, state, and local agencies and programs, as well as various nongovernmental organizations dedicated to preventing and addressing elder abuse, are now called upon to re-envision how to protect and intervene on behalf of vulnerable older adults in the context of the pandemic. In this ongoing process, social services, the criminal justice system, and other advocates have undertaken new initiatives and adapted traditional service delivery, particularly for essential frontline professionals, including Adult Protective Services and the Long-Term Care Ombudsman Program. These strategies continue to evolve as new information and guidance as well as lessons learned are shared. Helping to shore up these efforts is the Promoting Alzheimer’s Awareness to Prevent Elder Abuse Act, recently introduced by the Special Senate Committee on Aging, which highlighted the urgency of such services in light of the pandemic. The legislation will require the U.S. Department of Justice to develop training materials to assist professionals in engaging with older adults living with dementia to protect them from abuse.

Environmental Scan on Elder Abuse. The purpose of this scan is to identify public health strategies and interventions available in the United States that address elder abuse and neglect for community-dwelling older adults and caregivers during PHEs such as COVID-19. Based on an extensive review of the peer-reviewed and grey literature as well as websites, our environmental scan focuses on strategies, interventions, resources, and tools that local and national organizations developed or modified since 2017.

Relevance of Related Environmental Scans. It should be noted that although this scan is limited to interventions that directly address elder abuse and neglect, the five other topics of interest to CDC Foundation and CDC (social isolation, chronic conditions, deconditioning, deferral of medical care, and caregiving) are also relevant for reducing the risk of elder mistreatment, whether as a risk factor or as a monitoring function. Because social isolation; cognitive impairment/dementia (as one type of chronic condition); and diminished physical functioning that can result from deconditioning are key risk factors for elder abuse, any efforts to support older adults in these areas will also help lower the risk for elder

abuse, albeit to varying degrees. Social isolation, in particular, is a major risk factor for all forms of abuse, and the presence of social support in the lives of older adults has been found to mitigate its adverse effects.²¹⁹ Meanwhile, interventions that address the deferral of medical care are critical for identifying elder abuse. As described earlier, when older adults defer or forgo medical care, the monitoring function provided by the health care system is interrupted. A reduction or loss of care is especially detrimental for older adults who are vulnerable to neglect. Lastly, interventions that support caregivers broadly are important for giving them the tools and resources necessary to cope with the changing dynamics and stressors brought on by the pandemic. The support they receive can help minimize the risks associated with elder abuse for older adults in their care. We discuss each of these topics in further detail in other sections of the report.

Summary of Findings. We identified 16 interventions addressing elder abuse, neglect, or financial exploitation, the majority of which were identified through grey literature and websites, rather than peer-reviewed articles. We found that many federal agencies and national organizations also have dedicated COVID-19 webpages compiling resources to educate and empower the public to obtain help. These include AARP, Administration for Community Living, Center for Advocacy for the Rights & Interests of the Elderly, Consumer Finance Protection Bureau, Consumer Reports, Department of Justice, Financial Trade Commission, National Alliance for Caregiving, National Center on Elder Abuse, National Council on Aging, National Indian Council on Aging, National Clearinghouse on Abuse in Later Life, and the National Resource Center for Reaching Victims. Posted resources encompassed checklists, hotlines, tip sheets, research publications, webinars, and contact information for Eldercare Locator, social services and law enforcement agencies, district attorney's offices, as well as links to other relevant organizations. While some organizations simply compiled resources, others developed and disseminated or implemented them (the latter being the focus of this scan). The audience for these resources included older adults (n=10), and, to a lesser extent, caregivers (n=4) and direct service providers/advocates (n=8). Most of the resources for older adults and caregivers focused on educating consumers about detecting signs of abuse and fraud, how to report incidents to relevant authorities, and how to seek assistance. Resources for advocates and direct service providers centered on sharing strategies and program adaptations for adoption. Lastly, the majority of interventions identified did not include an evaluative component or data collected during the pandemic.

Type and format of interventions. The 16 interventions developed or adapted for older adults, caregivers, and direct service providers/advocates were related to education or focused on modifying direct services.

Education. The majority of education interventions (n=12) identified focus on preventing or responding to financial abuse or fraud prevention. Resources addressing older adult financial exploitation and fraud prevention were created by large national organizations or programs (e.g., Federal Trade Commission, Senior Medicare Patrol, Consumer Finance Protection Bureau, AARP) as well as other groups (e.g., Seniors Blue Book, Institute on Aging). All six resources focused on preventing fraud or financial abuse were available online, though the resource or intervention format varies and some resources were offered in multiple formats: one video, three printable resources, and six websites. Additionally, one of the web

resources included a telephone helpline (AARP's Fraud Watch²²⁰). Most commonly, these resources shared tips on avoiding fraud particular to COVID-19, such as contact tracing or phishing scams. Generally, these resources were intended to share information (e.g., Federal Trade Commission's Consumer Information Blog, Seniors Blue Book's Stay Savvy Against COVID-19 Scams page, Consumer Finance Protection Bureau's Resources for Older Adults and Their Family Members page), or to give older adults a forum to monitor incidence nationally, share information, and report scams directly (i.e., AARP's Fraud Watch Network). Four printable and video resources also offered tips for older adults to avoid COVID-19 scams (e.g., Institute on Aging's COVID-19 Related Scams, Senior Medicare Patrol's Protect Yourself from COVID-19 Medicare Scams! video). Finally, one online resource also shared statistics and data reports demonstrating that adults 60 years and older are particularly vulnerable to fraud (Federal Trade Commission's Consumer Information Blog).²²¹

Three of the interventions for caregivers developed to prevent or mitigate older adult financial exploitation, fraud, and scams were exclusively online resources (e.g., Federal Trade Commission's COVID-19 Fraud Blog entries, and Consumer Finance Protection Bureau's Resources for Older adults and Their Families" and Tips for Financial Caregivers during the Coronavirus Pandemic). These websites functioned as repositories for information about common fraud schemes unique to COVID-19 and tips for caregivers and family members to identify and avoid scams.

Two online resources offered guidance on recognizing, preventing, and reporting any type of elder abuse (not exclusive to financial exploitation). One resource drew lessons from the 2008 financial crisis, wherein elder abuse rates soared after adult children facing economic hardships moved back in with their parents. The National Center on Elder Abuse developed a checklist to reduce tensions and potential abuse within families resulting from similar living arrangements created by the pandemic. The resource included tips for preventing physical, emotional, and financial abuse (e.g., discussing whether funds will be pooled and how expenses will be allocated) and a conversation checklist for family members to use prior to living together to help establish boundaries and support a healthy living environment (e.g., discussing how to maintain respectful communication, allocation of household chores, etc.).²²² In terms of caregivers, the Consumer Finance Protection Bureau and National Alliance for Caregiving co-hosted a webinar on October 20, 2020, to share findings from National Alliance for Caregiving's joint study with AARP on caregivers, including information on how financial strain can affect caregivers and their older adult care recipients. As part of this event, Consumer Finance Protection Bureau shared money management tips and resources that financial caregivers of older adults can use during the pandemic.

Other resources were developed for faith-based communities, advocates, and local service providers. With respect to the former, because older adults often trust and turn to faith leaders and faith communities when experiencing abuse, faith leaders can play a critical role in responding to elder mistreatment and in some states, are also mandatory reporters. In partnership with Safe Havens Interfaith Partnership Against Domestic Violence and Elder Abuse, the National Clearinghouse on Abuse in Later Life drafted an open letter on April 23, 2020, encouraging faith community leaders to raise awareness of elder abuse and support victims during the pandemic. Thus far the letter has been endorsed by 22 national organizations and continues to be shared with additional faith leaders.²²³

Also in April 2020, the National Resource Center for Reaching Victims hosted a listening session (video recorded with an American Sign Language interpreter) for advocates in the field of crime victims services on the challenges facing older adult survivors during the pandemic, and offered strategies for sustaining services to respond to their needs. In addition to the recording, a PowerPoint slide and printable document were also made available. Lastly, the National Council on Aging hosted a webinar on March 30, 2020, to educate organizations on popular technological platforms and applications (such as Facebook Live and Google Hangouts) that are available to support remote service delivery. Entitled “Tools for Reaching a Remote Audience: Webinar and Tips,” the webinar included an overview of each tool and its advantages, disadvantages, and links to additional resources (PowerPoint slides and printable document were also posted on the website for download).

With respect to resources for advocates and direct service providers, the scan identified a research article in the *Journal of Applied Gerontology* in which advocates from New York City, one of the first epicenters of the virus, shared initial lessons in combatting the COVID-19 pandemic to help provide guidance to other communities facing the crisis.²²⁴ The authors described the various remote meetings that were facilitated to bring together stakeholders in the community. These meetings helped keep providers informed of service disruptions, new guidelines, and updates on policy and programmatic changes, created opportunities for service collaboration and provided emotional support. Sharing information with stakeholders via standing remote meetings can support the many organizations across sectors that protect vulnerable older adults and promote greater system-wide coordination. Their work also highlighted the importance of attending to the needs of frontline workers, who often face secondary trauma and fears about contracting the virus as they protect others. Although vulnerable older adults are of primary concern, the ability of frontline staff to safely perform their vital roles can only be sustained if they, too, are supported and properly trained.

Direct Services. The environmental scan identified seven programs and organizations that adapted service delivery to safely address challenges presented by the pandemic: Adult Protective Services, JASA’s Legal Social Work Elder Abuse Program, Long-Term Care Ombudsman Program, Lifespan, and Minnesota Elder Justice Center. For example, because many Adult Protective Services program staff have had to alter their home visits due to COVID-19 restrictions, Adult Protective Services created additional educational resources, such as a webcast led by Adult Protective Services program leaders experienced in managing Long-Term Care Ombudsman Program workers as guidance for programs navigating the adjustment to virtual client support. Similarly, the Long-Term Care Ombudsman Program has encouraged the use of PPE for essential onsite facility visits and remote platforms for communicating with facility residents directly (i.e., telephone, video conference, email, Facebook). As part of this adaptation, the Long-Term Care Ombudsman Program shared National Council on Aging’s webinar (Tools for Reaching a Remote Audience) described earlier that reviews remote communication options.²²⁵ Additionally, the Legal Social Work Elder Abuse Program transitioned their in-person group meetings for elder abuse and neglect survivors to telephone support groups to adapt their mutual aid model to the local pandemic regulations.²²⁶

Although videoconferencing platforms were invaluable for connecting with health care professionals, remote solutions could not assure frontline staff that older adults were alone when engaging in these virtual meetings. A key component of programs designed to monitor and respond to elder abuse was the ability to see vulnerable older adults in person, whether in their home, community, or health care setting. With in-person appointments, for example, doctors administered elder abuse screening tools by first requesting caregivers who accompany the patient on the visit leave the room. This ensures the patient had the privacy to safely answer sensitive questions. This was also true for other frontline professionals such as Adult Protective Services staff and long-term care ombudsmen. Remote delivery can complicate the identification of abuse.

Strategies other than transitioning services to remote delivery used by advocates and direct service providers included making calls to existing clients/known victims of abuse, and forging relationships with local organizations and programs that still offered in-person access to older adults (e.g., Meals on Wheels) to help expand their reach to older adults. For example, the Update Elder Abuse Center at Lifespan, which typically received referrals from frontline workers, was contacting all clients they had worked with over the past six months to increase vigilance, given that many people were avoiding health systems as a result of COVID-19 safety measures.²²⁷ To help continue providing advocacy services to vulnerable older adults, Minnesota Elder Justice Center was partnering with Meals on Wheels because of their ability to check in on older adults in their homes.²²⁸

Size and scope. Of the 16 interventions and resources identified in the environmental scan, 12 were available nationally through websites. These resources were created by a variety of organizations, including those focused specifically on older adults and/or elder abuse (e.g., National Center on Elder Abuse, National Council on Aging, AARP, Seniors Blue Book) and others without a particular focus on elder abuse or older adults more generally (e.g., Federal Trade Commission, Consumer Finance Protection Bureau). Given that most were online resources and primarily educational, the audience was limited to older adults, family members, caregivers, and advocates/service providers with internet access. Two programs, Long-Term Care Ombudsman Program and Adult Protective Services, provided services nationally, but programs were administered at the state/local level. For this reason, implementation of national organizations' guidance may have varied slightly among local partners based on local regulations and response to COVID-19. Four programs were administered by a local or state organization and served populations within a defined geographic area. These included Legal Social Work Elder Abuse Program (Brooklyn, Queens, and Manhattan); Lifespan (Greater Rochester, NY); Minnesota Elder Justice Center; and Institute on Aging²²⁹ (California's Bay Area and surrounding counties).

Focus on subpopulations. The scan did not identify any interventions designed specifically for subpopulations to prevent elder abuse or neglect in the context of PHEs. However, it should be noted that the service population for Adult Protective Services and the Long-Term Care Ombudsman Program included individuals with disabilities. With respect to language accessibility, eight of the identified interventions were also available in Spanish. Further, of those eight resources, Institute on Aging's and Consumer Finance Protection Bureau's resources and tips for older adults to avoid coronavirus-related scams were available in several additional languages. Institute on Aging's resources were available in

Mandarin, Russian, and Vietnamese. Consumer Finance Protection Bureau’s two online resources were also available in numerous additional languages (Mandarin, Cantonese, Vietnamese, Korean, and Tagalog). In addition, National Resource Center for Reaching Victims’ listening session video recording included an American Sign Language interpreter, making this resource available to deaf and hard-of-hearing older adults.

Evidence base and outcomes. The majority of identified elder abuse interventions were emerging and had not yet been evaluated. Some programs, however, were established long before the pandemic and had been previously evaluated. However, because modifications to their service delivery represented a significant change to typical program activities, we could not apply earlier study findings to current operations. Given the newness of program modifications, furthermore, these adaptations had not yet been evaluated. For example, while Adult Protective Services has been widely studied,²³⁰ the impact of the shift to virtual services on the effectiveness of Adult Protective Services programs has yet to be assessed. However, research has found that adoption of virtual services (i.e., videoconferencing) has been successfully incorporated into Adult Protective Services’ assessment protocols in some remote areas.²³¹



Informal or Unpaid Caregivers: Public Health Interventions and Strategies

Informal or unpaid caregivers are family or friends who provide assistance with an older adult's social or health needs, either in the home or from a distance. This may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation; emotional support; and help with managing a chronic disease or disability.²³² Caregivers also provide support in alleviating feelings of loneliness and social isolation, as well as financial support. Caregiving responsibilities can increase and change as the care recipient's needs increase, which may result in additional strain on the caregiver.

In 2015, the Family Caregiver Alliance estimated there were approximately 43.5 million people who had provided unpaid care to an adult or child in the last 12 months.²³³ More recently, the Associated Press-NORC Center for Public Affairs Research found that nearly 20 percent of the U.S. population in 2020 provides ongoing living assistance to a family member or friend.²³⁴ With the outbreak of COVID-19 and the ongoing pandemic, however, caregivers who were providing in-home care for loved ones have been forced to suspend or cancel their usual care and make new arrangements to keep their older adult family members or friends safe. As families adjust to these new realities, caregivers as young as 18 years of age have been taking on greater responsibility to provide safe care for their family members at greater risk for COVID-19. These safer alternatives have included meal and grocery delivery, transportation to medical appointments, help with telehealth medical appointments, and checking in on their loved ones through video chat technology.

Unpaid or informal caregiving may result in what is referred to in the literature as “caregiver burden.” Caregivers experience stress in their capacity and ability to provide adequate care for their loved ones, while simultaneously trying to manage their own needs, including their job, family, and health. The stress of this dual role has a disproportionately negative impact on all areas of caregivers' lives, including emotional, financial, physical, social, and spiritual.²³⁵ Although the problem of caregiver burden is not new, its focus and potential solutions are timely, given how COVID-19 has exacerbated the burden for the one in five Americans currently caring for a family member or friend.

Support for caregivers included education and skills training, environmental modifications to keep the care recipient living safely and independently, care management, and mental health and emotional counseling. Results from randomized clinical trials identified at least three characteristics of successful caregiver support interventions: assessments of caregiver risks and needs, custom interventions to address the caregiver's specific needs and preferences, and engagement of the caregiver in skills training to teach proper techniques to care for their care recipient.²³⁶

The purpose of this environmental scan is to synthesize what is known about interventions to support caregiving for the older adult population. We have placed an emphasis on identifying a comprehensive

landscape of interventions to support caregivers across a variety of subpopulations with a diversity of needs. In doing so, our research across populations found gaps, or “shallow areas,” where there was a scarcity of resources for particular populations. These gaps in knowledge and resources can be used to guide future research and policymaking to support caregiving. Our research focused on interventions and policies at the local, state, and national level to support caregivers’ own physical and mental health needs, as well as interventions and policies that help support caregivers’ ability to provide care for older adults.

Summary of Findings. We identified 75 interventions addressing caregivers for older adults. Of the 70 national interventions, the implementing organizations included those focusing specifically on caregivers or older adults (e.g., Family Care Alliance,²³⁷ SAGE USA,²³⁸ Caregiver Action Network,²³⁹ Department of Veterans Affairs,²⁴⁰ Cancer Support Community,²⁴¹ AARP,²⁴² Roslyn Carter Institute for Caregiving,²⁴³ Family Eldercare,²⁴⁴ Institute on Aging,²⁴⁵ ARCH National Respite Network and Resource Center²⁴⁶) and organizations without a particular focus on caregivers or older adults (e.g., PillPack,²⁴⁷ Alarm,²⁴⁸ American Psychological Association,²⁴⁹ American Red Cross²⁵⁰). We segmented the list of 75 interventions by caregiver versus the person who receives care. For the purposes of this study, we refer to the person who received caregiver support as the “care recipient.”²⁵¹ The designation was determined by the sponsor of the care intervention. Intervention or resources that supported the caregiver’s own physical, emotional, and/or mental health needs were referred to as “caregiver-focused” resources, while those interventions that supported the caregiver’s ability to assist their care recipient were referred to as “care recipient-focused” resources. Both types of interventions were designed with the caregiver in mind. We found that of the 75 interventions identified, 59 were “caregiver-focused” while the other 16 were “care recipient-focused.”

Type and format of interventions. Many interventions were available to support caregivers of older adults in the context of PHEs such as the COVID-19 pandemic. Most of these interventions were available before COVID-19 but were adapted to address the increase in the number of caregivers, as well as *where* they were providing care—either in the caregiver’s home, the care recipient’s home, or remotely through video technology, home sensors, and other remote monitoring technology.

Most resources addressing interventions for caregivers were curated from large national organizations such as the Family Caregiver Alliance,²⁵² the National Council on Aging,²⁵³ AARP,²⁵⁴ and ARCH National Respite Network and Resource Center.²⁵⁵ However, many interventions originated from private-sector organizations that had identified a gap in resources for caregivers, while some resources were created by national and state public policy. For each broad category of intervention, we synthesized the findings to describe common themes or subtypes of interventions; the section below also includes select examples of resources that meet the criteria for each intervention type. Of the 5 broad intervention types—educational, direct services, health care, and policy and system change—the greatest proportion of resources are educational (33), direct services (35), and policy and systems change (7).

Education. The majority of educational interventions were in the form of websites that included fact sheets, guides, or PowerPoint slides. They explained the role of the caregiver, how to maintain their own health and well-being particularly during this pandemic, and provided caregivers with information on

supporting the health and well-being of their loved ones. The materials included education on stress management techniques, suggestions to improve communication between the caregiver and care recipient on sensitive topics, caregiver depression, and financial management skills for the caregiver. Seven of the 33 resources were COVID-specific, providing information to the caregiver on best approaches to keep both the caregiver and care recipient safe during COVID-19. The COVID-related materials included resources like a comprehensive FAQ page for caregivers of older adults, and ideas on how to manage the chronic care needs of the care recipient during a pandemic.

- **Mental and emotional well-being of the caregiver:** One of the most common themes that arose in the educational interventions was how to support the mental and emotional well-being of the caregiver. Fourteen resources focused on the caregiver's mental health, and 4 of the 14 focused primarily on reducing caregiver stress and coping with depression. For example, the Family Caregiver Alliance²⁵⁶ created fact sheets and guidelines on symptoms of stress and depression, resources, and treatment options for caregivers who may be suffering from caregiver burden. As part of its Resources for Integrated Care (RIC) initiative,²⁵⁷ the Centers for Medicare & Medicaid Services (CMS) Medicare-Medicaid Coordination Office hosted a webinar and developed a resource guide focusing on supports for caregivers during times of stress and social isolation. The webinar highlighted strategies for supporting caregivers of older adults with depression; assisting caregivers who live apart from their loved ones who need care, including those in rural areas; addressing caregiver grief; and strategies for engaging caregivers virtually. The intended audience for these resources included care managers, care coordinators, providers, and other staff at health plans and provider organizations.²⁵⁸
- **Supporting the diverse needs of caregivers of Alzheimer's disease/dementia:** On average, a caregiver providing primary, informal care to a loved one with dementia will spend 69 to 117 hours per week on caregiving tasks.²⁵⁹ Often, the time needed to provide care to others leaves little time for caregivers to take care of themselves. Seven of the 49 educational interventions focused on supporting caregivers of older adults with neurodegenerative disorders. Six of the 7 interventions were in the form of tip sheets, fact sheets, and guides. The Family Caregiver Alliance created three fact sheets on topics such as how to remain calm and gain cooperation when caring for someone with Alzheimer's disease or dementia, and similarly how to provide care to people with cognitive disorders or other chronic conditions.²⁶⁰ The MIT AgeLab partnered with The Hartford Center for Mature Market Excellence® to develop a guide to help support caregivers for older adults with dementia to prepare for a natural disaster.²⁶¹

Direct Services. Groups ranging from local, community-based organizations to technology companies, as well as large national organizations and the Department of Veterans Affairs, had resources targeting caregivers of older adults. These programs included social or peer support to the caregiver, technologies to help coordinate care between family caregivers or remotely monitor the care recipient's well-being, and resources to support caregivers of veterans.²⁶²

- **Social or peer support for the caregiver:** The primary objective of peer support groups is to support the needs of the caregiver. Social support groups such as Daughterhood²⁶³ were created with a mission to support people who are managing their parents' care. Daughterhood social support

groups (known as “Circles”) are located in large U.S. cities such as San Diego, San Francisco, Atlanta, Chicago, Boise, Tucson, and Houston. The Daughterhood Circles give women opportunities to gather and discuss openly their feelings and share experiences in their caregiver journey. Daughterhood Circles have adapted to virtual Zoom calls during COVID-19 to ensure caregivers can continue participation in their social support group during this challenging time. The Daughterhood blog, website, and social media page connect the caregiver to resources to navigate the health system for older adults. Minnesota Senior Linkage Line,²⁶⁴ Well Connected,²⁶⁵ and the AARP’s Community Connections²⁶⁶ are also platforms that allow caregivers to talk to each other through virtual peer support groups. Each intervention has a list of resources for caregivers on protecting their own mental and physical health while caring for loved ones.

- **Caregiver well-being screening tools:** Amid the COVID-19 global outbreak, caregivers have been experiencing a high degree of “moral distress, burnout, and harm.”²⁶⁷ Screening tools are one way that health providers or community-based organizations can assess the physical and mental health well-being of caregivers. The Zarit Burden Interview is a common caregiver self-report measure used by many Area Agencies on Aging (AAAs) for caregivers of people with dementia. The interview assessment tool includes 22 items and scores that were found to be significantly positively correlated with depression scores in caregivers, as measured by the Center for Epidemiological Studies Depression Scale.²⁶⁸
- **Coordinating and monitoring care for caregivers and their care recipients:** Over the past few years, technology-based interventions have emerged to support informal care for older adults.²⁶⁹ These technological advancements have brought about a category called telehomecare. Defined as “the use of telehealth in the home,” telehomecare enables the remote monitoring and communication of older adults and can provide information on overall trends and detect cases where an additional, care-recipient focused intervention may be needed. COVID-19 has only hastened the need to adequately provide care or monitor care remotely between family caregivers and their care recipients.²⁷⁰ The programs have a variety of functions and benefits, including coordinating informal care across family members, delivering groceries to older adults who are at high risk of COVID-19, and connecting over the phone or through video chat technology to reduce feelings of social isolation. For example, Papa²⁷¹ is an on-demand assistance program that pairs older adults or families with “Papa Pals.” In response to COVID-19, Papa launched their virtual companionship program in which Papa-pals can sign up to provide companionship via telephone to give emotional support to older adults, even during a pandemic.²⁷² Papa Pals can also perform other helpful tasks like grocery shopping and delivery, transportation to medical appointments, completing household needs, or running other errands.

Other care coordination and remote monitoring interventions have included CaringBridge,²⁷³ which allows caregivers to stay connected during a care recipient’s health care event (such as a hospitalization or hospice episode) and Alarm.com Wellness,²⁷⁴ which places discreet wireless sensors throughout the care recipient’s living area. The sensors track activity and give caregivers real-time insight into their care recipient’s well-being and notify the caregiver of a potential emergency.

MedMinder²⁷⁵ is another example of an innovative technology that assists caregivers to remotely monitor their care recipient's health needs, using an internet-connected automated pill dispenser called MedMinder Maya. MedMinder Maya comes with a built-in SIM card that connects the device to MedMinder's website. This connection allows the caregiver to remotely manage Maya's schedule and monitor when the pills have been removed in the correct dosage.

- **Support for caregivers of veterans:** Seventy-five percent of veterans within the Veteran Administration (VA) system have a functional impairment that necessitates daily care for support and health management. This puts caregivers of military veterans at a greater risk of burnout, which endangers a key component of the veteran care system.²⁷⁶ The VA has developed numerous programs to support caregivers. The VA's Caregiver Support Program provides resources and services available to both the caregiver and the Veteran, including online education courses such as Taking Care of Yourself, Problem Solving, Mood Management, Asking for Help, and Stress Management, as well as telephone peer support and opportunities to connect telephonically with licensed mental health professionals.²⁷⁷ Another online opportunity is Building Better Caregivers-Online Mode,²⁷⁸ a psycho-educational training workshop program developed for caregivers of veterans and veterans who serve as caregivers for individuals with dementia or any other serious injury or illness. The intervention consists of six weekly self-paced lessons, an online workshop, guidance, group support, and alumni access. The education sessions focus on techniques for reducing stress, action planning, problem-solving, and decision-making.

Policy and System Change. We identified seven interventions characterized as either policy or system changes. Of these, three interventions are state-focused policies or programs, three are federal policy such as the CARES Act and recent changes to Supplemental Benefits under Medicare Advantage (MA) that allow support for caregivers of MA enrollees, and the remaining four are considered system change and relate to how groups such as health care organizations can change their practices to include more caregiver-related resources.

- **State Medicaid programs to support caregivers:** Many of the policy-based interventions are being implemented at the state level through waivers to expand caregiver benefits, or through multistate initiatives to identify and test programs that directly benefit caregivers. As a result of COVID-19, every state has made at least one change to its Medicaid program, using various available Medicaid authorities such as the 1135 waiver, Appendix K waiver, and the Disaster Relief and Disaster Response waivers to expand their authority on Home & Community Based Services (HCBS). These Medicaid flexibilities enable more older adults to receive HCBS during COVID-19—improving access to coverage and care, helping people access care while social distancing, and ensuring financial stability for providers so they can keep their doors open and serve their communities.²⁷⁹ Thirty-seven states are using Appendix K waivers to address three main functions: expand the use of telehealth and technology, expand the HCBS workforce, and change payment policy. Notably for caregivers, Appendix K waivers permit states to expand paid family caregiver limits and temporarily allow family or legally responsible relatives to serve as paid caregivers, if not already permitted under the state's

waiver.²⁸⁰ Appendix K waivers are temporary authorizations (ranging from 3 to 12 months) and vary widely across states in terms of duration and the authority.

- **Multistate initiatives to support family caregivers.** A variety of multistate initiatives are exploring promising opportunities for states to better support family caregivers. Six states—Alabama, Idaho, Iowa, New Hampshire, South Carolina, and Virginia—are testing new strategies to ramp up family caregiving supports through the Center for Health Care Strategies’ Helping States Support Families Caring for an Aging America initiative.²⁸¹ Over a two-year period (2018-2020), participating states received tailored one-on-one technical assistance, as well as peer-to-peer information sharing, convening, and learning opportunities. In a subsequent phase (2020-2022), an additional six states will be added to the cohort to address four main objectives: 1) strengthen family caregiver capacity through new technologies, increased access to respite care, and formalized training for family caregivers; 2) establish data collection strategies to better identify caregiver support needs and to inform program or policy reform for caregivers (e.g., family caregiver needs assessments, surveys of program effectiveness); 3) build cross-sector state teams comprising community and private organizations (e.g., aging, housing, transportation, health plans); and 4) connect aging initiatives and family caregiving programs in more formal ways to prioritize family caregiving.
- **Medicare Advantage expanded caregiver supports:** Beginning in 2019, CMS allowed Medicare Advantage (MA) plans to expand their definition of services that could count as part of plans’ Supplemental Benefits. New Supplemental Benefits could include in-home support services (e.g., help with laundry, preparing meals); respite care to relieve a primary caregiver; and others.²⁸² A recent AARP Public Policy Institute analysis of the 2019 MA Landscape Source Files found that 13 percent of MA plans offered caregiver support such as respite care, counseling, and skills training.²⁸³ The study found that caregiver supports were the second most common new category of supplemental benefit offered that year.²⁸⁴

Size and scope. Most interventions identified were available nationally. Eight of these national interventions were websites and webinars that focused on informing the viewers of special considerations during COVID-19 for care recipients with a specific chronic conditions or tips on using telemedicine during the pandemic, while three were telephone and telehealth options with lists of resources.

We identified 10 state-level programs or policies including CMS changes to state Medicaid policy and programs at the state government level (e.g., Colorado Department of Human Resources, Iowa Department on Aging). For example, Iowa’s Department on Aging compiled a list of national and state resources to help caregivers find the necessary supports to stay healthy physically and mentally as they navigate their caregiving role. Florida’s Department of Elder Affairs, in collaboration with the Alzheimer’s Association, developed an initiative called Project: VITAL (Virtual Inclusive Technology for All), which supports the well-being of older adults, their families, and caregivers by allowing them to remain virtually engaged and connected. Project: VITAL uses best practices developed by the Alzheimer’s Association to provide support, care, education, and awareness to all those who are dealing with the effects of social

isolation during the public health crisis of COVID-19. Implementation of national programs' guidance may vary slightly among local partners based on local regulations and response to COVID-19.²⁸⁵

Focus on subpopulations. Some interventions were designed to support specific populations with chronic conditions, as discussed below.

Racial/ethnic minorities. In review of the interventions, we identified six interventions with participants representing various racial/ethnic backgrounds. Of these six, two interventions serve the Latinx community, another two serve the Black/African-American community, and one intervention references "persons of color" broadly. Most interventions are educational resources offered in multiple formats (i.e., in person or virtual, and online for self-pacing). All of the interventions are offered nationally, not targeting any specific geographic location. Resources for Enhancing Alzheimer's Caregiver Health (REACH) II was designed to address the needs of ethnically diverse caregivers of care recipients with dementia. This includes White, Hispanic, and African-American caregivers.²⁸⁶ REACH II uses an initial assessment that includes a variety of strategies designated to address caregivers' individualized needs. These intervention strategies include "educational information, skills training, problem solving, role playing, stress management, and telephone support."²⁸⁷

Individuals with Disabilities. A total of 27 interventions either partially or fully focus on assisting caregivers of individuals with disabilities, including cognitive and functional impairments. This includes caregiver interventions that help individuals with disabilities to live safely and independently. Of the 27 interventions, 11 resources address caregivers of individuals with cognitive impairment, seven relate specifically to independent living, and four relate to unspecified disabilities. The type of resources for caregivers of people living with disabilities varies, and includes fact sheets about caregiving for people with dementia, remote monitoring to ensure a safe home setting, and respite programs for caregivers. Although these interventions do not discuss COVID-specific adaptations, the resources will support people's ability to live in the community independently and safely during the PHE. As families and caregivers are making decisions about whether to use nursing homes and other institutional settings during the pandemic, many families have decided to keep their loved ones in their own homes to avoid potential outbreaks or to mitigate the risk of social isolation if family members are unable to physically visit their loved ones. Remote monitoring technologies like GrandCare,²⁸⁸ a large, easy-to-use touch screen placed in the care recipient's residence that uses wireless remote activity monitoring and telehealth sensors to alert designated caregivers for further action, is one example of solutions that give caregivers alternatives to nursing homes and other congregate living arrangements.

Tribal Communities. We identified two programs focusing on caregivers in tribal communities.²⁸⁹

The University of North Dakota and The Elders Advisory Group of the Spirit Lake Dakota Tribe developed the Native Elder Caregiver Curriculum to help people in tribal communities better prepare to care for their elders. The Native Elder Caregiver Curriculum can be offered by local health professionals, especially nurses, who have had experience with providing direct care for older adults. It can be adapted to the specific learning needs of caregivers and can be used flexibly to meet training schedules for any

given caregiver group. Due to COVID-19, the full curriculum and presentation slides can be downloaded from the National Resource Center on Native American Aging website.²⁹⁰ The National Minority Aging Organization Technical Assistance Center for the Development of Dementia Care Resources for American Indians and Alaska Natives at the National Indian Council on Aging developed a manual for trainers implementing the Savvy Caregiver evidence-based psycho-educational training program for caregivers with American Indian and Alaska Native populations.^{291, 292}

LGBT. We identified three resources for LBGT caregivers or caregivers of LGBT older adults created by SAGE,²⁹³ a nonprofit organization dedicated to meeting the needs of LGBT older adults. The resources include a guidebook, which provides information on common issues facing LGBT caregivers, along with best practices to engage and support LGBT caregivers through programming, an educational tip sheet, and a help hotline for LGBT peer support and resources.

Limited English Proficient Populations. We found several interventions that provided resources for non-English Spanish speakers that include a mix of educational materials, trainings, and telephone hotlines. The scan also identified five interventions that provide resources in other languages in addition to Spanish. For example, the European project INNOVAGE created a web-based platform with information resources translated into the study participants' national official language.²⁹⁴

Evidence base and outcomes. Almost a quarter of the total identified interventions are evidence-based; however, more than half of the evidence-based interventions have been adapted for the COVID-19 pandemic (i.e., shifted to virtual), and evidence is not available on the adapted version of the programs. Evidence-based interventions have demonstrated results on outcomes measures such as caregivers' objective burden (i.e., number of potentially negative experiences) and subjective burden (i.e., caregiver's reported distress in response to those experiences). Early research on these interventions found improvement in self-reported physical, mental, and emotional health; levels of depression; amount of sleep; reactions to behavioral problems; and memory issues.²⁹⁵ The following are examples of evidence-based caregiver interventions:

- **African-American Alzheimer's Caregiver Training and Support Project 2:** The African-American Alzheimer's Caregiver Training and Support Project 2 consists of 12 telephone sessions for African-American caregivers of persons with dementia, focusing on skills-building, spiritual support, self-care, and improving the relationship with the person living with dementia. Studies have found post-intervention improvements in depression, health status, and severity of caregiving and self-care concerns.²⁹⁶ The research showed that caregiver self-empowerment through connection between community care centers and mainstream providers appears to drive positive outcomes. Because this program is telephone-based, it has been able to continue through the COVID-19 pandemic.
- **TCARE® (Tailored Caregiver Assessment and Referral®):** TCARE® is a CMS 1115-approved & ACL-accredited solution to prevent family caregiver burnout through supporting AAA capabilities to support family caregivers.²⁹⁷ In response to the COVID-19 pandemic and in recognition that health care organizations and their consumers need to increase and support both patients and their

caregivers, TCARE® partnered with CareSignal to “bring COVID-19 programs to communities, patients, and frontline health care staff across the country.”²⁹⁸ The partnership enables TCARE®'s family caregiver support program to leverage CareSignal's COVID-19 Suite of three internet-accessible programs.

- **Resources for Enhancing Alzheimer’s Caregivers in the Community (REACH):** REACH Community, a multisite program sponsored by the National Institute on Aging and the National Institute on Nursing Research, was designed specifically for dementia caregiving. The program uses trained coaches to provide caregivers with the information, tools, and skills needed to understand and meet their specific caregiving challenges and demands and, thus, reduce caregiver burden. The REACH framework reduces caregiver burden based on a theoretical framework consistent with basic health-stress models, with the goal to modify and reduce specific stressors (problematic caregiver recipient behavior). This can include understanding illnesses, managing stress, and planning care. Reduction in caregiver burden was measured using the RMBPC Burden score; the higher the score, the greater the perceived upset or burden by the caregiver. The REACH Community program is a result of the original REACH study, “a multi-site national study funded by the NIH to identify and test a behavioral intervention for caregivers.”²⁹⁹ After the success of the pilot program, in 2016, the VA launched REACH Community and since then, the agency has supported dissemination of the program to agencies and organizations across the country. In response to COVID-19, the VA adapted the program so that all coaching sessions are now conducted telephonically, rather than in-person. REACH Community can provide a caregiver with COVID-19 safety precaution through four one-hour sessions to “identify their specific challenges and figure out solutions.”³⁰⁰

Environmental Scan: Key Findings

- National, state and local agencies, organizations, and advocates that are dedicated to promoting the health and well-being of older adults and caregivers developed the majority of the interventions. While many stakeholder organizations addressed multiple areas of interest, including areas unrelated to those of this project, other organizations focused on one individual topic area, given their jurisdiction and specific area of expertise (such as elder abuse). These agencies and organizations included but were not limited to: AARP, Administration for Community Living, Alzheimer’s Association, ARCH National Respite Network and Resource Center, American Red Cross, Caregiver Action Network, CDC, Center for Advocacy for the Rights & Interests of the Elderly, Centers for Medicare & Medicaid Services (CMS), Consumer Finance and Protection Bureau, Department of Veteran Affairs, Family Care Alliance, Institute on Aging, National Association of Area Agencies on Aging, National Council on Aging, National Institute on Aging, The Commonwealth Fund, and the World Health Organization.
- **The majority of interventions developed in response to the pandemic are educational resources and are available online.** Government agencies and national and local organizations had dedicated COVID-19 webpages presenting a list of resources to educate and empower the public to obtain help. These included blogs, toolkits, checklists, infographics, tip sheets, fact sheets, FAQs, PowerPoint slides, videos, webinars, research publications, contact information for social service agencies, and links to other relevant organizations. These online materials were widely accessible to anyone with broadband services.
- **Relatively few interventions are available for older adults for public health emergencies (PHEs) outside of COVID-19 (e.g., natural disasters).** However, there are several innovative interventions. For example, the U.S. Department of Health and Human Services emPOWER program provides data on the electricity-dependent Medicare beneficiaries by state, territory, county, and ZIP Code to quickly identify older adults in need of immediate power reconnection after a natural disaster, to better support their medical needs and prevent catastrophic health impacts.³⁰¹ The Department of Veterans Affairs developed a Home-based Care During Hurricanes intervention to provide interdisciplinary care to older veterans with chronic conditions, focusing on preparedness planning, post-hurricane phone calls, and in-home visits.
- **Across topic areas, the audience for interventions includes older adults, caregivers, direct service providers, and other stakeholders (e.g., advocates, local chapters of national**

organizations, researchers). Most interventions were targeted at older adults or caregivers and, to a lesser extent, advocates and direct service providers. While the majority of resources developed for older adults and caregivers focused on education, resources for direct service providers and advocates centered on sharing alternative solutions to service delivery (including interactions and communicating with older adults, workflow redesigns, and use of technology) and relevant research and literature reviews on evidence-based practices.

- **Organizations have adapted existing interventions, largely by transitioning to remote delivery, where possible.** In particular, telehealth and other digital health technology use has increased during the COVID-19 pandemic, and many interventions have adjusted components of their interventions to suit remote capabilities for older adults. These formats were particularly promising for reaching older adults and caregivers in rural areas.
- **To a lesser extent, existing interventions have adapted components of service delivery to increase vigilance as well as patient safety and comfort levels by redesigning workflows, making wellness calls, and fostering partnerships to expand outreach to, and check in on, older adults.** These modifications focused on ensuring regular contact through periodic telephone calls or fostering partnerships to expand or gain direct access to older adults. This included coordinating with local service providers, such as Area Agencies on Aging and Meals on Wheels, as well as developing public-private partnerships (e.g., Project Enhance).
- **Few interventions for older adults addressed systems and policy level changes. Most that were identified focused on caregivers.** For caregivers, several federal and state policies and programs (such as waivers) were implemented to expand benefits or enhance support. For older adults, a small number of interventions focused on coordinating efforts or advancing policy, while the majority targeted individual education or service delivery.
- **Evidence-based interventions addressing chronic disease management, deconditioning, social isolation, and caregivers have been adapted for the COVID-19 pandemic.** We identified a number of evidence-based interventions to address chronic disease management, deconditioning, and caregiver support that were applicable to the COVID-19 pandemic because they were delivered remotely or adapted for remote delivery. For interventions that have been adapted, modifications to service delivery represented such a significant change to typical program activities that earlier study findings could not be applied to current operations. Notably, evaluations of a small number of adapted interventions addressing social isolation or loneliness were underway but not yet complete (e.g., PEARLS, Social Support Action Team).
- **With the exception of selected resources for caregivers and older adults with chronic conditions, few interventions targeted specific subgroups (e.g., racial/ethnic groups, individuals with disabilities).** Most interventions that focused on specific subpopulations were developed for caregiving and managing chronic conditions, and to a lesser extent, for addressing social isolation and deconditioning. These interventions were designed to assist individuals with

disabilities; tribal elders; LGBT older adults; Hispanic or Latino immigrants with LEP; veterans; older adults with vision difficulties, functional impairments, or Parkinson's; and digitally excluded older adults. By contrast, we identified no interventions related to the deferral of medical care and elder abuse among specific groups. At most, resources were offered in languages other than English, including Spanish, Cantonese, Mandarin, Russian, Vietnamese, Korean, and Tagalog, among others.

Conclusions



Conclusions

The COVID-19 pandemic is an unprecedented public health emergency (PHE) that has severely impacted older adults and informal or unpaid caregivers in the United States. This report, which summarizes findings from our environmental scan and needs assessment, has produced important insights about the pandemic's effect on these populations. Specifically, it describes the major needs and concerns of older adults and caregivers during PHEs such as COVID-19, and the range of public health strategies and interventions that are available in the United States to support their physical and mental well-being.

Our analysis is based on an environmental scan and six complementary formative research activities conducted in September and October 2020 (see Exhibit 4). Next, we explore key themes from our exploration of these two related topics, and discuss the implications of these findings for the CDC Foundation and CDC.

Needs and Concerns of Older Adults and Caregivers

Older adults had five major areas of concern relative to the COVID-19 PHE. Older adults were concerned about social isolation; transmitting and contracting the virus; having access to and using technology; obtaining household supplies and other necessities; and the financial and economic impact of COVID-19. These needs and concerns were similar across all older adults, but some issues were particularly acute among subgroups. For example, mental health and financial stress were concerns among racial and ethnic minority populations. Older adults living in rural and tribal communities had concerns about the lack of broadband internet access. Older adults with low socioeconomic status were concerned about getting basic household supplies, a lack of access to health care, finances, transportation, and affordability of technology. Older adults with limited English proficiency experienced social isolation, concerns about managing their chronic conditions, and concerns about using technology. Finally, older adults with disabilities expressed concerns about their lack of access to medications and supplies, getting food, getting health care, obtaining in-home help, and transportation.

Older adults had several unmet needs, and half received some type of assistance during the COVID-19 PHE. Older adults expressed the need for three key types of assistance during the pandemic: food delivery services, help with technology, and accurate information about COVID-19. These needs differed by subpopulation. For example, older adults with low socioeconomic status needed help with getting household supplies; paying for basic expenses such as rent, food, or health care; prescription drugs; and home energy costs. Older adults with disabilities needed assistance with exercise options, in-home care, and cleaning.

Half of older adults received help from family, friends, neighbors, or programs (including government, community-based, and faith-based programs). Older adults who received assistance most commonly received check-ins, assistance with delivering basic supplies, and transportation from family, friends, or neighbors. Black and Hispanic older adults were more likely than White older adults to report having received assistance from family, friends, or neighbors. They were also more likely to report having received assistance from health care providers, or other community programs since the start of the pandemic.

Caregivers had four major needs during the COVID-19 PHE. Caregivers' needs and concerns included their own physical and mental health, the care recipient's physical and mental health, financial concerns, and the need for respite care to give them temporary relief from caregiving responsibilities. For example, during our focus groups, caregivers described the challenges of balancing work and caregiver duties—and many of these issues were amplified among caregivers of people with disabilities, cognitive impairment, or limited English proficiency.

COVID-19 has exacerbated longstanding issues and created a ripple effect on older adults and caregivers. Our environmental scan focused on five key areas of interest: deconditioning, deferral of medical care, management of chronic conditions, social isolation, and elder abuse and neglect. The scan found that these areas can have a cascading, deleterious effect on older adults and caregivers during the COVID-19 pandemic. Social distancing and stay-at-home orders, for example, have increased social isolation among older adults, which can lead to deconditioning and require more help from caregivers with activities of daily living. Caregivers have experienced heightened levels of stress from the additional demands. Social isolation has become problematic for older adults who must manage chronic conditions, given perceived threats of contracting the virus if they visit a health care setting or hospital. Misconceptions about COVID-19 and financial hardships resulting from the economic recession may motivate older adults to defer or forgo medical care. A reduction or loss of medical care for older adults—especially those with multiple chronic conditions—may result in negative long-term health consequences. Caregivers, too, face social isolation and financial stressors resulting from the pandemic, and the COVID-19 PHE has severely compromised their ability to effectively provide care for older adults as well as themselves.

Older adults and caregivers sought information about the pandemic from a variety of sources, ranging from family and friends to social media. News media and the internet were perceived as important resources for older adults seeking COVID-19 information, although these findings differed among subpopulations. For example, Hispanic older adults were less likely than White older adults to rely on the internet for information about COVID-19. Older adults in the youngest age cohort (50-64) were more likely to use social media for information. Beyond media, many older adults also relied on people they knew, including health care providers, friends, and family members, for information about COVID-19. Similar to older adults, caregivers turned to the internet as a primary source of information.

Available Public Health Strategies and Interventions for Older Adults and Caregivers in the United States

A range of public health interventions and strategies were available to serve older adults and caregivers. The most common interventions and strategies we identified were programs and resources focused on educating older adults (i.e., informative materials/campaign/media); 2) direct services (i.e., support groups, counseling, direct/social services pertaining to legal/financial/housing assistance); 3) health care (i.e., telehealth/telemedicine); and 4) policy and system change (i.e., organizations pushing policy efforts and working with local, state, and national authorities to develop and strengthen one of the five areas of interest among older adults and caregivers). The majority of interventions developed in response to the pandemic were online educational resources. Government agencies and national and local organizations have dedicated COVID-19 webpages that present resources to educate and empower the public.

National, state and local agencies, national organizations, and advocates dedicated to promoting the health and well-being of older adults and caregivers developed the majority of interventions. Although many stakeholder organizations addressed more than one area of interest to the CDC Foundation and CDC, others focused on an individual topic, given their jurisdiction and specific area of expertise (such as elder abuse). These agencies and organizations included but were not limited to: AARP, Administration for Community Living, Alzheimer's Association, ARCH National Respite Network and Resource Center, American Red Cross, Caregiver Action Network, CDC, Center for Advocacy for the Rights & Interests of the Elderly, Centers for Medicare & Medicaid Services, Consumer Finance and Protection Bureau, Department of Veteran Affairs, Family Care Alliance, Institute on Aging, National Association of Area Agencies on Aging, National Council on Aging, National Institute on Aging, The Commonwealth Fund, and the World Health Organization.

The target audiences for these interventions were broad and diverse. The audiences for interventions included older adults, caregivers, community-based organizations, Area Agencies on Aging, health care providers, and other stakeholders (e.g., advocates, local chapters of national organizations, researchers). Most interventions were targeted directly at older adults or caregivers and, to a lesser extent, advocates and direct service providers. Although the majority of resources developed for older adults and caregivers focused on education, resources for direct service providers and advocates centered on sharing alternative solutions to service delivery (including interacting and communicating with older adults, workflow redesigns, and use of technology), as well as relevant research and literature reviews of evidence-based practices. Use of telehealth and other digital health technology has increased during the COVID-19 pandemic, and many interventions have adjusted their components to suit remote capabilities for older adults. These formats may be promising for reaching older adults and caregivers residing in rural areas, though internet access is a challenge.

The evidence base for COVID-19 interventions for older adults and caregivers was still emerging. Nearly all newly launched efforts and adaptations to existing interventions were evidence-informed or emerging in nature. Because of the recent and ongoing nature of the COVID-19 pandemic in the United States, the majority of interventions have yet to be fully evaluated. Some evidence-based interventions were applicable during the COVID-19 pandemic, because they were already provided virtually or had a virtual option. Other existing evidence-based interventions were adapted to the circumstances surrounding the pandemic. Even if these interventions were previously evaluated, the modifications to service delivery represented such a significant change to typical program activities that we cannot apply earlier study findings to current operations. Evaluations of a small number of interventions that addressed social isolation or loneliness were underway but not yet complete (e.g., PEARLS, Social Support Action Team).

Gaps in strategies and interventions persisted for key subpopulations. With the exception of selected resources for caregivers and older adults with chronic conditions, few interventions targeted specific subgroups (e.g., racial and ethnic minorities, individuals with disabilities). Interventions focusing on specific subpopulations tended to be developed for caregiving and managing chronic conditions, and to a lesser extent, for addressing social isolation and deconditioning. These interventions were designed to assist individuals with disabilities; tribal elders; LGBT older adults; Hispanic or Latino older adults with limited English proficiencies; veterans; older adults with vision difficulties, functional impairments, or Parkinson's Disease; and digitally excluded older adults. By contrast, we did not identify any interventions targeting specific groups related to the deferral of medical care and elder abuse. Some resources were offered in languages other than English, including Spanish, Cantonese, Mandarin, Russian, Vietnamese, Korean, and Tagalog, among others.

Methodological Strengths and Limitations

Our needs assessment and environmental scan used a rigorous, mixed-methods study design. To understand the needs and concerns of older adults and caregivers during COVID-19, the needs assessment consisted of six concurrent activities: a nationally representative survey of older adults; focus groups of older adults and caregivers; stakeholder interviews; a stakeholder survey; secondary data analysis; and social data listening. All primary data were collected and analyzed during October 2020. We triangulated findings across data sources to identify the themes for this report. For the environmental scan, we identified and categorized interventions related to five distinct topics of concern facing older adults and caregivers. To our knowledge, this is the first effort to identify both older adults and caregivers' needs and concerns, and the types of interventions available to support these populations during PHEs like COVID-19.

However, readers should consider the following limitations when interpreting findings. First, the focus group participants were selected through convenience sampling in partnership with community-based partners and a recruitment firm. Therefore, focus group findings are not generalizable to the experiences of all older adults and caregivers. Second, we did not conduct a comprehensive scan of every public health

strategy and intervention available at the national, state, and local levels, as this was beyond the scope of this study.

Final Considerations

Taken together, findings from the needs assessment and environmental scan offer salient lessons that could inform the CDC Foundation and CDC's efforts to further address the unmet needs of older adults and caregivers during PHEs like COVID-19. There is a marked need to raise awareness of the many interventions, strategies, and resources available to support older adults and empower caregivers in their role. The public health interventions and strategies that have been developed in response to the COVID-19 pandemic rely heavily on internet use and broadband access as well as remote delivery of services. In addition, relatively little attention has been paid to developing resources for specific subpopulations.

We describe the implications of these approaches and the gaps in services that they create, as well as potential solutions, as follows:

- 1. Develop approaches that address the lack of broadband or high-speed internet services for many older adults in the United States.** Although the use of online resources and the shift to telehealth/telemedicine enables older adults to access help across geographic locations, these approaches also exclude older adults who lack broadband services. Further, we identified only one intervention addressing deconditioning among older adults with limited access to the internet or other technologies. While posting resources online is not only an appropriate and efficient means of dissemination for direct service providers and advocates, this method of information-sharing and health care provision may be less effective for reaching older adults and their caregivers. According to the Pew Research Center, in 2019, 73 percent of U.S. adults ages 65 and over used the Internet and 59 percent had home broadband access.³⁰² Older adults with lower levels of education and household income were also more likely to lack online access.³⁰³ This means that over one quarter of older adults—many of whom are the most vulnerable—may be unable to learn about or access intervention services. We did not identify other media such as public service announcements through television, radio, and print (newspaper, etc.), but they may complement existing channels of support and direct the populations with the greatest need to these resources. The nature of this environmental scan may have omitted other relevant media (e.g., television, radio) that were deployed during the pandemic. Because older adults and caregivers rely on a range of sources for information about PHEs, there is a need for a multipronged communication strategy to ensure broad reach of PHE interventions and information to older adults and caregivers.
- 2. Invest in programs that improve technology literacy among older adults.** Remote delivery of services presents challenges to older adults who are not “digital natives”— meaning they did not grow up with this technology.³⁰⁴ Use of videoconferencing platforms may discourage older adults from connecting with health care providers or accessing interventions online. In a 2017 Pew Research study, approximately one third of older adults ages 65 and over reported that they were only “a little” or “not at all” confident in their ability to use computers, smartphones, or other electronic devices to

do necessary online activities.³⁰⁵ The percentage was much lower for other age groups (17 percent for those 50-64; 11 percent for those 30-49; and 5 percent for those 18-29). Older adults ages 65 and over were also far more likely to report needing someone else to set up their electronic devices, compared to all other age groups.³⁰⁶ According to the Department of Justice, older adults are more likely to report losses due to technical support scams than younger people.³⁰⁷ Our review identified few interventions that educate older adults on how to use various technologies (e.g., Zoom, iPhones, MacBooks) to connect with others. Although older adults are increasingly embracing digital technology during the pandemic, efforts to expand their technology literacy (as a component of or supplemental to interventions) would help support fuller participation in PHE services.

- 3. Focus attention on assisting specific subpopulations of older adults in the United States.** In this study, we also explored the needs of other specific subpopulations, and the interventions available to them. Interventions developed for racial and ethnic minorities and tribal communities were largely limited to caregivers and older adults managing chronic conditions. Few, if any, resources were developed for addressing social isolation, deconditioning, the deferral of medical care, and elder abuse. There are opportunities for national organizations that support older adults to invest in new interventions that can support specific subpopulations (e.g., racial and ethnic minority populations, individuals with disabilities, rural communities, tribal communities). There are also opportunities for national organizations to establish partnerships with trusted local organizations (e.g., community- and faith-based organizations) to spread and scale existing interventions.

This scan also identified few interventions that addressed accessibility for individuals who are deaf and hard of hearing (not exclusively older adults). Guidance on interacting with and enhancing the environment of older adults with hearing loss could help providers across the range of intervention services effectively communicate verbally and nonverbally. For individuals with hearing and vision impairments, making resources and information available in Braille and American Sign Language, as appropriate, would increase accessibility. Access to written materials can also be promoted by ensuring that resources are accessible for screen readers, for example through adherence to compliance standards under Section 508 of the Rehabilitation Act of 1973.³⁰⁸

- 4. Identify approaches to support caregivers in getting respite care during PHEs.** Interventions are needed to fill gaps in respite care for caregivers. The need for respite care among caregivers is not new or unique to the COVID-19 PHE. However, this issue has gained urgency during the public health crisis because many organizations that have typically offered respite care (e.g., volunteer organizations, support groups, senior living communities) have closed or offer limited services. The Family Caregiver Alliance and the ARCH National Respite Network and Resource Center provide educational interventions, such as fact sheets and other resources, to support caregivers' mental and emotional well-being. Additionally, some PACE centers have offered respite care services during the COVID-19 PHE.³⁰⁹ HHS is also working to identify best practices in respite care for caregivers.³¹⁰ Approaches to supporting caregivers with temporary relief from their responsibilities are critical during PHEs, so that caregivers can balance caregiving with family and employment responsibilities.

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