ACL Response to Covid 19
https://acl.gov/COVID-19

ACL launched webpage to provide information in support of older adults and people with disabilities.

Coronavirus Disease 2019 (COVID-19)
As guidance is updated, ACL will post or link to it on this page and share it through the ACL Updates email service.
https://public.govdelivery.com/accounts/USACL/subscriber/new

If you need help finding services in your community, visit the Eldercare Locator web page or call 1-800-677-1116. https://eldercare.acl.gov/

2020 Alzheimer’s Disease Programs Initiative Grant Program

- Grants to States and Communities (HHS-2020-ACL-AOA-ADPI-0379)
- Dementia Capability in Indian Country (HHS-2020-ACL-AOA-ADPI-0418)

Decision packages with ACL leadership. Grant awards anticipated on or before August 1, 2020

RAISE Family Caregiving Advisory Council

The RAISE Council held their fourth meeting on July 16, 2020. A recording of the meeting, which was open to the public, will be posted at https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council.

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Quick Guide to Billing Codes for Dementia Services

Designed to support the many organizations trying to obtain reimbursement through fee-for-service Medicare and other third-party payers. This guide should be available in early Fall of 2020 on the NADRC website. ACL will distribute information on the launch and availability of the guide very broadly.

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UPCOMING WEBINAR

August 27, 2020 2-3 p.m. ET, Navigating the World of Assistive Technology for People Living with Dementia.

Are you caring for a person living with dementia or do you want to broaden your “toolbox” with strategies and solutions for someone living with dementia or Alzheimer’s disease? Discover Assistive Technologies that can benefit people living with dementia.

Additional information about this webinar and the registration link can be found here: https://protect2.fireeye.com/url?k=11823fc9-4dd73619-11820ef6-0cc47a6a52de-a4fd62db411f6db&u=https://www.asaging.org/web-seminars/navigating-world-assistive-technology-people-living-dementia

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2020 WEBINAR SERIES

(Recordings of all webinars are located on the NADRC webpage)

- **January 28, 2020**--Finding the Right Fit: Choosing Dementia Caregiving Programs for your Organization and Community, Presenters: David Bass and Heather Menne (518 participants)
- **February 12, 2020**--Occupational Therapy and Social Work: Offering community-based approaches to support PLWD and their caregivers, Presenters: Stephani Shivers and Jane Gruner (556 participants)
- **April 8, 2020**--LGBTQ Elders and Dementia, Presenters: Awaiting Confirmation (903 participants)
- **May 19, 2020**--Addressing Dementia in Indian Country: Where we are and What comes next, Presenters: Mike Splaine and Tribal Elder (480 participants)
Since January, ASPE has released a number of reports on dementia, caregiving, and long-term care.

**Functional Trajectories at the End of Life for Individuals with Dementia**

Dementia, including Alzheimer’s disease and related disorders, is a neurocognitive condition affecting an individual’s cognitive function and behavior. Dementia is a leading cause of death and is particularly prevalent at the end of life (EOL) in older adults. However, there is limited knowledge regarding the patterns of decline for adults with dementia, who may also have comorbid terminal conditions. This knowledge gap may prevent providers from offering palliative and hospice services, because they may not be able to identify when a dementia patient has entered the terminal phase of illness. It may also limit patients’ and families’ ability and willingness to access palliative services that can improve and complement EOL care.

For this project, we used a sample of decedents from the 2000-2012 Health and Retirement Study to understand the trajectories of functional decline of older adults with dementia near the EOL, and how these trajectories differ from those of people without dementia. In addition, we examined whether and how these trajectories vary by other patient characteristics such as demographics, comorbidities, and access to caregiving. Overall, the findings from the point-in-time analyses indicated that people with dementia have significantly higher levels of functional impairments than do people without dementia up until the last year of life. However, the functional impairment of people with dementia at 2-4 years before death may look similar to people without dementia in the last 6-12 months before death, after controlling for other characteristics.


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Implications of Alternative Methods of Identifying Populations with Dementia: Issue Brief

This study sought to identify the amount of overlap among three methods of identifying people with dementia, and to obtain national estimates of the number of people with dementia. It also explored key characteristics of people identified as having dementia by the various methods, to understand potential causes and implications of differences for policy and practice.


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Individuals’ Awareness of a Dementia Diagnosis: Issue Brief

This study examined the characteristics of people who do not report having a diagnosis of dementia, despite a documented diagnosis by a health care provider, to health understand the factors that may contributed to their lack of awareness or failure to report. Understanding these factors is a key to taking steps to increasing awareness.

Issue brief: https://aspe.hhs.gov/basic-report/individuals-awareness-dementia-diagnosis-issue-brief

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Economic Impacts of Programs to Support Caregivers: Final Report

As the nation ages and more individuals live longer with chronic illness and disabilities, the need for long-term services and supports (LTSS) will rise. Roughly 9.8 million Americans ages 65 and older living in settings other than nursing homes need care and help with personal activities, with 2.7 million requiring assistance with at least three basic activities of daily living, such as bathing, dressing, or eating. Ninety-five percent of older adults with LTSS needs living in a community setting received help and care from unpaid caregivers. These caregiving activities clearly benefit the economy. Older adults with LTSS needs are more likely to enter nursing facilities, for example, if they do not receive family care than if they receive unpaid help from caregivers. Government programs, such as Medicaid, would have to cover some of the costs of additional paid LTSS, using state and federal funds.

Although family caregivers are not generally paid for their services, spending time helping family and friends with LTSS needs may be costly. Some caregivers may have to reduce their work hours when they provide care, switch to part-time work, or temporarily drop out of the labor force. Government programs to support family caregivers could potentially limit some deleterious effects of caregiving. Programs that provide caregivers with training, counseling,
information, and respite care or that provide care recipients with some paid help could relieve family caregivers, help them provide care more effectively, and perhaps enable them to increase their paid work hours. Support programs that enable caregivers to work more could in turn raise government tax revenue, partly offsetting part program costs.

However, our results show that relatively few caregivers provide intensive care, although these intensive caregivers are most likely to experience significant caregiver burdens and conflict between employment and care responsibilities. We conclude that the macroeconomic benefits of caregiver supports on employment and subsequent economic feedback (through tax revenue) would likely be quite limited. Nearly one-third of family caregivers, and nearly one-half of family caregivers who provide intensive care without help from others, are ages 65 and older, and thus unlikely to work if they did not serve as family caregivers. The available empirical evidence suggests that relatively few younger caregivers would increase their labor supply much if they did not provide care. We found that the increase in earnings and tax revenue that might result from caregiver support programs would fall far short of the cost of providing those services.


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Impacts of Minimum Wage Increases on Nursing Homes

Nursing homes employ large proportions of their workforce at the minimum wage. This project sought to understand the potential impacts of federal minimum wage increases on nursing staffing and labor costs of nursing homes. We found that an increase of the federal minimum wage would result in large proportions of nursing assistants gaining a wage increase, thereby increasing direct labor costs to nursing homes. These results are based on national estimates.


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Analysis of State Efforts to Comply with Fair Labor Standards Act Protections to Home Care Workers

The purpose of this study is to describe and document changes states have made to their Medicaid or other publicly-funded consumer directed home care programs for seniors and individuals with disabilities to comply with the 2013 update to Fair Labor Standards Act (FLSA) regulations. This report provides an overview of early implementation activities at the state level and perspectives from various stakeholder groups. After introducing the study methods, we describe issues that emerged from interviews conducted with stakeholder group
representatives. We then present findings from an environmental scan of state policies and procedures conducted in all U.S. states, including the District of Columbia. Finally, to illustrate both state variations in FLSA implementation and promising practices, we present examples of select case study states with well-documented hardship exceptions policies: California, Massachusetts, Wisconsin, and Ohio; and provide insights from all case studies. This report, prepared by ASPE staff, synthesizes and expands upon key study findings from several reports prepared by Mission Analytics.

The fiscal year (FY) 2020 Coronavirus Aid, Relief and Economic Security Act, P.L. 116-136, (CARES Act) appropriated funds to the Public Health and Social Services Emergency Fund (PHSSEF) to prevent, prepare for, and respond to coronavirus, including through telehealth access and infrastructure. The Health Resources and Services Administration (HRSA), using CARES Act funding, is supporting the Geriatrics Workforce Enhancement Program (GWEP) in preventing, preparing for, and responding to coronavirus disease 2019 (COVID-19). GWEP grant recipients may use funding to:

- Educate and train students and clinicians on providing telehealth-enabled COVID-19 referral for screening and testing, case management and outpatient care; and/or
- Maintain primary care functionality away from physical sites, especially for COVID-19 positive, quarantined, elderly and individuals at a higher risk of severe illness.

https://www.congress.gov/116/bills/hr748/BILLS-116hr748enr.pdf
Nursing Homes

- In April CMS announced a COVID-19 transparency effort to keep nursing home residents safer
- The regulatory requirements in the May 8, 2020 Federal Register (CMS-5531 IFC) require nursing homes to inform residents, their families and representatives of COVID-19 cases in their facilities
- The measure augments longstanding reporting of infectious disease to State and local health departments
- CMS also now requires nursing homes to publically report cases of COVID-19 to the CDC
- On June 4 CMS published the underlying CDC-collected data at a link from Nursing Home Compare so the public can view information about how COVID-19 has impacted nursing homes, and all 15,000 are reporting this data


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Commission on Safety and Quality in Nursing Homes

- The Commission began meeting in early July; it is tasked with conducting a comprehensive assessment of the nursing home response to the COVID-19 Public Health Emergency (PHE) in order to inform current efforts to safeguard the health and quality of life of nursing home residents, and prepare for future threats to resident safety and public health.
- Through July 17 members of the public had the opportunity to provide their perspectives based on their experience with nursing homes


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Waivers During the COVID-19 PHE

- Section 1135 waivers waiving of various administrative requirements to increase access to medical services during an disaster or emergency, and a declared PHE
- Flexibilities address telehealth and phone delivery options, verbal orders, certain reporting requirements, discharge planning, advance directives, transfer, and others – for a range of facility and provider types


- Medicaid Waivers During the PHE
- The Medicaid program has certain flexibilities through additional statutory authorities including section 1115 demonstration waivers, section 1915(c) waivers (Appendix K), Disaster State Plan Amendments, and managed care options


(Strategy 2.H)

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Resources for Integrated Care Webinar

- In June CMS sponsored a webinar entitled “Navigating COVID-19: Supporting Individuals with Dementia and their Caregivers”
- The agenda included how COVID-19 might present in people with dementia, unique challenges during the Public Health Emergency (PHE) in dementia care, and offered strategies for caregiver support, including how to plan ahead for illness
- About 2,000 people attended on-line, with more on the phone

Information at: https://www.resourcesforintegratedcare.com/Older_Adults/2020_Webinar/COVID-19_Supporting_Individuals_with_Dementia_and_Caregivers

(Strategy 2.H)

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NCAPPS Resource

- The National Center on Advancing Person-Centered Practices and Systems, an initiative between CMS and ACL to implement person-centered practices, issued a new tool, the Health Care Person-Centered Profile
The template includes essential health information and a format for outlining what is important to the person who may be hospitalized and unable to communicate.

Information at: https://ncapps.acl.gov/covid-19-resources.html
(Strategy 2.F)

NIA is also excited to support the launch of Rapid Acceleration of Diagnostics [https://www.nih.gov/research-training/medical-research-initiatives/radx], or RADx, to catalyze the scientific community to improve COVID-19 testing technologies, capacity, and accessibility. As one of the four RADx components, RADx-Underserved Populations (RADx-UP) will establish a network of community-engaged projects to improve access to and acceptance of testing in underserved and vulnerable populations.

As part of the RADx-UP initiative, NIH has released four funding opportunities [https://www.nih.gov/research-training/medical-research-initiatives/radx/funding] for research on COVID-19 testing among underserved and/or vulnerable populations to both understand and close the disparity gap. NIA has signed on to participate in all four of these initiatives. These funding opportunities include:

- Emergency competitive revision applications to existing awards for large consortia, multi-site trials, centers, and other current networks [https://www.nih.gov/research-training/medical-research-initiatives/radx/funding] which have the capacity, infrastructure, and established community-engaged relationships to support large-scale testing interventions.
- A complementary emergency competitive revision opportunity which shifts eligibility to individual research awards, including community collaborations and partnerships [https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-120.html].
- Emergency competitive revisions to solicit research on the social, ethical, and behavioral implications of COVID-19 testing within underserved and vulnerable populations [https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-119.html].
- And lastly, an award for a coordination and data collection center [https://grants.nih.gov/grants/guide/rfa-files/RFA-OD-20-013.html], which will support the broader goals of the RADx-UP initiative.

In response to the COVID-19 emergency, NIA recently released an article on government COVID-19 resources for older adults. Included are resources on health and safety amid the crisis, caregiving, financial matters, housing, employment, considerations for veterans, and much more. Please consult the article today [https://www.nia.nih.gov/health/government-covid-19].
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resources-older-adults), and please feel free to share these resources widely, including on social media platforms such as Twitter and Facebook.

2020 Dementia Care Summit Update: NIA, in conjunction with the Department of Health and Human Services, and as part of the National Alzheimer’s Project Act, planned to host the second National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers on March 24-25, 2020. The event was canceled per COVID-19 physical distancing guidance. In lieu of hosting an in-person event, the NIA is hosting a 2020 Dementia Care, Caregiving, and Services Research Summit Virtual Meeting Series in Summer 2020.

The Summit Virtual Meetings Series presents the original Summit agenda in three meetings. The first took place on Friday, July 10; the final two will occur on Thursday, July 21; and Tuesday, August 13. For more details on the meeting agendas, instructions on how to register, and an opportunity to provide input (via a Request for Information), please visit the NIA website: https://www.nia.nih.gov/2020-dementia-care-summit.

Alzheimer’s Disease and Related Dementias Clinical Trials Update: NIA is currently supporting 233 active clinical trials on Alzheimer’s disease and related dementias (AD/ADRD). These prevention and intervention trials are diverse with respect to the drug and mechanistic targets as well as the stages of AD/ADRD that are addressed. NIA’s active trials include: early-stage clinical drug development, late-stage clinical drug development, non-pharmacological interventions, clinical therapy development for neuropsychiatric symptoms of dementia, and care and caregiver interventions. The full list of trials was updated in April 2020 and is available here: https://www.nia.nih.gov/research/ongoing-AD-trials.

Care and Caregiving Evidence Review: In 2018, NIA asked the Agency for Healthcare Research and Quality (AHRQ), in conjunction with their Evidence-based Practice Centers (EPC) program, to conduct a rigorous systematic review of the evidence for care and caregiving interventions for people living with dementia (PLWD) and their caregivers, and to assess the potential for broad dissemination and implementation of that evidence. A draft of the report was made available for comment earlier this year and the final version of the AHRQ-EPC report will be posted online soon at this website (https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd).

In parallel, NIA asked the National Academies of Sciences, Engineering, and Medicine (NASEM) to establish an expert committee that would assess the AHRQ systematic evidence review findings (in additional to other relevant sources) and develop a set of recommendations on the readiness of these interventions for broad dissemination and implementation, and research gaps that need to be addressed. More information on NASEM activities is available here (https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers#sectionWebFriendly), and the NASEM committee’s report will be published in 2021.

Data Sharing Resources: NIA recently launched a new data sharing resources page for researchers (https://www.nia.nih.gov/research/data-sharing-resources-researchers). This new page compiles a variety of data sharing policies, considerations, and guidance, as well as links to related NIA-funded initiatives and repositories, both for Alzheimer’s disease and other aging
research. These resources are intended to support researchers in safely and efficiently sharing data from their studies.

**Alzheimer’s Disease and Related Dementias Researchers**: In June 2020, NIA staff released an analysis of researcher trends in the field of Alzheimer’s disease and related dementias from 2015 to 2018. This report, entitled “Attracting New Investigators to Alzheimer’s Disease Research: Outcomes of Increased Funding and Outreach,” was published in *The Gerontologist* and is available here (https://academic.oup.com/gerontologist/article/doi/10.1093/geront/gnaa056/5859850).

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**National Institute on of Neurological Disorders and Stroke (NINDS)**

**Upcoming NINDS FY20-21 ADRD Funding Opportunities**: As highlighted in the June 2020 NINDS Director’s Message (https://www.ninds.nih.gov/News-Events/Directors-Messages/All-Directors-Messages/NINDS-Contributions-ADRD-Research-Activities), the 2019 ADRD Research Summit (https://www.ninds.nih.gov/sites/default/files/2019_adrd_summit_recommendations_508c.pdf) resulted in the establishment of 47 new or refined ADRD research recommendations to be integrated as implementation milestones within the National Plan. Since the first ADRD Research Summit in 2013, NINDS has issued 37 AD/ADRD funding announcements, including 8 in FY2020, inviting grant applications to fill critical research needs. Responsive to several ADRD Summit recommendations, the National Advisory Neurological Disorders and Stroke Council recently approved potential ADRD funding announcements for future release in FY20 and FY21, including:

- **Mechanisms of Selective Vulnerability in LBD and FTD**—to increase basic and clinical research on why certain brain regions are more vulnerable to abnormal protein accumulation and damage.
- **Mechanisms of Pathological Spread of Abnormal Proteins in LBD and FTD**—to increase basic and clinical research on how abnormal proteins spread in the nervous system of LBD and FTD patients.
- **Connecting Pre-mortem Clinical Information with Post-mortem Brain Analysis in LBD**—to increase the linkage of comprehensive pre-mortem clinical information with gold standard post-mortem diagnostic analysis in patients with LBD.
- **Treatments for LBD-Exploratory Clinical Trial**—to encourage exploratory clinical trials (Phase I or II) testing either new or repurposed drugs or devices to treat patients with LBD.
- **Center Without Walls for Molecular Mechanisms of Neurodegeneration in FTD**—to continue support for interdisciplinary team science aimed at elucidating the molecular mechanisms underlying neurodegeneration in FTD, with a focus on examining the role of tau, TDP-43 or FUS pathogenesis, and specific genetic causes and risks factors.
- **Small Vessel VCID Biomarker Validation for Clinical Trials and Coordinating Center**—to continue support for a consortium (currently implemented as MarkVCID) to develop and validate high-quality small vessel VCID biomarkers ready for use in clinical
trials, and for generating scientific breakthroughs in the understanding and treatment of VCID.

The next ADRD Research Summit will be held in 2022.

Recently Launched ADRD Research Programs:

- **DISCOVERY (Determinants of Incident Stroke Cognitive Outcomes and Vascular Effects on Recovery)**—NINDS’s most recent ADRD program, this 6-year prospective clinical research study aims to determine the specific subsets of stroke events that cause and do not cause cognitive impairment and dementia in post-stroke populations. The study includes a special focus on race and ethnic populations that experience dementia health disparities, as well as elucidating what additional clinical factors and comorbidities synergize with stroke to result in cognitive impairment and dementia outcomes. [https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=14E9C1084E88CEDF7598B8961CAA4A01A2FFCEB8861BF](https://projectreporter.nih.gov/Reporter_Viewsh.cfm?sl=14E9C1084E88CEDF7598B8961CAA4A01A2FFCEB8861BF)

- **ALLFTD (FTD Natural History, Biomarker, and Genetics Studies)**—NINDS and NIA co-manage this integrated consortium conducting detailed natural history studies of FTD, ultimately aimed at developing sensitive clinical assessments and biomarker tools for future use in FTD clinical trials. [https://www.allftd.org/](https://www.allftd.org/)

**ADRD Research Roundtable:** On June 30, NINDS and NIA co-hosted a “ADRD Research Roundtable” with several ADRD focused nonprofit organizations/NGOs. The Institutes provided updates on ADRD funding, research programs, and progress on addressing priorities of the National Plan. Discussion topics also included updates from nonprofits (e.g., new initiatives & opportunities for collaboration); COVID-19’s impact on AD/ADRD research, practice, and patients; addressing health disparities/promoting health equity; enhancing research workforce diversity; public health messaging; NIA’s 2020 AD Care Summit/webinar series; and the ADRD Research Summits.
Awardee Announcements

COMING SOON!

BOLD

HEALTHY BRAIN INITIATIVE
“Social isolation was associated with a 50% increased risk for dementia.”

— National Academies of Engineering and Medicine 2020

MAY
Older Adults Month

- Loneliness and Social Isolation
- Soledad y aislamiento social vinculados a afecciones graves

JUNE
Brain Health Awareness Month

- Healthy Body, Heathier Brain
- Cuerno sano, cerebro más sano

8 healthy behaviors may also reduce risk for subjective cognitive decline.
AD+HAP COVID-19
Webpage Launched
Traffic up 369%
Nearly 400K page views since March
Mobile traffic doubled
Return visits up 15%

https://www.cdc.gov/aging/index.html

Communications Center Launched

AGING & HEALTH MATTERS

Infographics
Resources and Publications
Web Features
Podcasts (Podcast) and Videos

https://www.cdc.gov/aging/communications/index.html
Resources and Publications Launched

- Aging and Health in America Data Briefs
- Reports on Aging
- Journal Articles
- Mental Health and Aging in America (MAHA)

https://www.cdc.gov/aging/publications/index.htm

Products and Publications
MMWR Characteristics and Health Status of Informal Unpaid Caregivers: 44 States, DC and PR, 2015-2017 BRFSS

https://www.cdc.gov/mmwr/volumes/69/ww/mm6907a2.htm#cid=mm6907a2_w

Recent Article Comorbid Chronic Conditions Among Older Adults with Subjective Cognitive Decline, United States, 2015–2017

Available online at no cost
Recent Article The Public Health Road Map to Respond to the Growing Dementia Crisis

Available online at no cost

$290 Billion Annually
Alzheimer's Association, 2019

The Most Costly Chronic Medical Condition in America

www.ruralhealth.info.org
Getting lost in a familiar place like driving to the grocery store is not a normal part of aging.

https://www.youtube.com/watch?v=YhT5B5sQrA&deliveryName=FCP_10_DM10886

**PODCAST SERIES**

What's New?

- Loneliness Puts Older Adults at Risk for Serious Medical Problems with DPH Director, Dr. Craig Thomas
- What About the Caregivers?
Animated Video: 2 minutes When Brain Health Meets Public Health
ASTHO

NEW! Data Brief
Chronic Diseases and Cognitive Health – A Public Health Issue
NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Charting health, monitoring progress.