

## **2022 National Strategy to Support Family Caregivers** **Overview for the ARCH Committee for Advancement of Respite Research (CARR)**

The 2022 National Strategy to Support Family Caregivers was created to support family caregivers caring for those of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them and their loved ones. The strategy was developed jointly by the advisory councils created by the [RAISE Family Caregiving Act](#) and the [Supporting Grandparents Raising Grandchildren Act](#), with extensive input from the public, including family caregivers and the people they support. Public comments will be used to help the Advisory Councils identify priorities for future updates of the Strategy.

For more information visit <https://acl.gov/CaregiverStrategy> and for a 2-page infographic visit [https://acl.gov/sites/default/files/RAISE\\_SGRG/NatStrategyFamCaregivers\\_Infographic.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatStrategyFamCaregivers_Infographic.pdf).

Following is a summary of relevant content related to respite research and data collection for the CARR within each of the 4 main documents that are part of the 2022 National Strategy to Support Family Caregivers. A link to the full document is included below the document name for reference. Relevant content is **bolded** and highlighted in the color **orange**, and a page number where content can be found within the document is provided in parentheses.

### **The 2022 National Strategy to Support Family Caregivers**

[https://acl.gov/sites/default/files/RAISE\\_SGRG/NatStrategyToSupportFamilyCaregivers.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatStrategyToSupportFamilyCaregivers.pdf)

This document describes the background, purpose, components, and how to use the strategy. It also provides an overview of the 5 goals.

**\*Note: The word “Respite” is only mentioned 35 times in the 102-page document; the word “research” or “researcher” is mentioned 90 times.**

GOAL 1: Increase awareness of and outreach to family caregivers (p. 30)

- Outcome 1.1: Americans are educated about and understand the experience of family caregiving.
- Outcome 1.2: Caregiver self-identification and knowledge of services is enhanced.
- Outcome 1.3: Outreach to family caregivers is improved.
- Outcome 1.4: Family caregiving—and caregivers—are embedded in federal, state, territorial, tribal, and local planning.
- Outcome 1.5: Public-private partnerships at all levels help drive family caregiver recognition and support.

GOAL 2: Advance partnerships and engagement with family caregivers (p. 43)

- Outcome 2.1 Family caregivers are recognized as essential partners in the care teams of the person(s) to whom they are providing support.

- Outcome 2.2: Where appropriate, identifying services and supports needs for caregivers consistently starts with a review of family caregiver strengths and preferences using evidence-based assessments.
- Outcome 2.3: Where appropriate, family caregivers are included and considered in the development of care recipient's plans of care across a range of settings and circumstances.
- Outcome 2.4: When policies are proposed or revised, the potential impact on family caregivers is anticipated and understood.
- Outcome 2.5: The education curricula of professionals who will potentially work with family caregivers include specific topics and coursework designed to ensure they have the skills to do so effectively.

GOAL 3: Strengthen services and supports for family caregivers (p. 53)

- Outcome 3.1: Person- and family-centered, trauma-informed, and culturally appropriate caregiver services and supports are accessible for all family caregivers.
- **Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs.**
- Outcome 3.3: A range of evidence-based, education, counseling, and peer support services are available to family caregivers.
- Outcome 3.4: Family caregivers and families have safe places to live, nutritious food, and adequate transportation.
- Outcome 3.5: Family caregivers have innovative tools and technology to assist them in their roles.
- Outcome 3.6: Volunteers of all ages and abilities are trained, vetted, and ready to assist family caregivers.
- Outcome 3.7: Family caregivers' and care recipients' needs are a key consideration in emergency response efforts.
- Outcome 3.8: Family caregivers have the skills and tools necessary to prepare for the future needs of the person they support.
- Outcome 3.9: An agile, flexible, and well-trained direct care workforce is available to partner with and support family caregivers.
- Outcome 3.10: Kinship families and grand families are recognized, supported, and valued within the child welfare system.

GOAL 4: Ensure financial and workplace security for family caregivers (p. 70)

- Outcome 4.1: Family caregivers can provide care without negative impacts to their near- and long-term financial health.
- Outcome 4.2: Family caregivers have access to employee-centered flexible workplace policies and practices that support work/life balance and professional performance when personal circumstances change.
- Outcome 4.3: Family caregivers have access to and use of financial education and advance planning tools.

- Outcome 4.4: Long-term services and supports are more affordable, allowing family caregivers to reduce their out-of-pocket costs.

**GOAL 5: Expand data, research, and evidence-based practices to support family caregivers (p. 79)**

- **Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience. (p. 80)**
- **Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and well-being of the family caregiver and the person receiving support. (p. 83)**
- **Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services. (p. 85)**

**Federal Actions**

[https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyFamCaregivers\\_FedActions.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_FedActions.pdf)

This document describes 345 actions that 15 agencies within the federal government will take in the coming three years that are aligned with and support the vision of the Strategy. Items in orange are federal actions related to research and data.

**GOAL 1: Actions to increase awareness of and outreach to family caregivers:**

- **CDC will annually publish updated infographics for states regarding caregiving using data from the BRFSS Caregiver module. Additionally, these data will be updated annually on the Alzheimer’s Disease and Healthy Aging Data Portal. (Also supports Outcomes 5.2) (p. 9)**
- **CDC will publish updated infographics for states utilizing the BRFSS Caregiving module conducted in 2021 and 2022. These infographics will provide national estimates of prevalence of caregiving and characteristics of the caregiving situation by race/ethnicity, sex, sexual orientation, veteran status, and rurality. (Also supports Outcome 5.1) (p. 9)**
- **CDC will evaluate and revise the BRFSS Caregiving Module to be fielded on the 2024 BRFSS Survey. (Also supports Outcome 5.1) (p. 9)**
- **CDC will submit caregiving questions being fielded on the 2025 BRFSS Survey to other national surveys, such as the National Health and Nutrition Examination Survey (NHANES) or the National Health Interview Survey (NHIS) by 2024. (Also supports Outcome 5.1) (p. 9)**
- **DOL’s Women’s Bureau will expand a section of its website to showcase elements of the most recent American Time Use Survey Leave module. It will include subgroup analysis where possible to better understand how diverse populations responded to the survey in FY22. (Also supports Outcome 5.2) (p. 10)**

- NIA's OCPL will update the NIA-managed Alzheimers.gov Clinical Trials Finder to achieve the goal of recruiting caregivers for clinical trials focused on Dementia Care and Caregiver Interventions (including dementia care and impact of disease) in 2022. (Also supports Outcome 5.3) (p. 11)
- AmeriCorps Seniors may seek to collaborate with one of its federal and/or nonprofit partners with a primary focus on grand families and kinship families to survey its volunteer network to determine the number of volunteer grandparents raising their grandchildren and how AmeriCorps programs might better support them in the future. (Also supports Outcomes 3.6, 5.1) (p. 13)
- CMS's OPOLE, in collaboration with CMS's Office of Communications and regional executives at ACL, will develop localized public messaging and outreach/training materials in 2022 aimed at the caregiver audience to achieve the goal of improving outreach efforts to family caregivers and promoting access to services and supports. Relevant topics include durable medical equipment, respite care, home care services, and hospice. (Also supports Outcome 5.1) (p. 15)
- ACL's Office of Network Advancement (ONA), within CIP, will provide direct funding to 5-7 states to develop plan/strategy to ensure that family caregiver diverse needs, issues and challenges are embedded within a state's No Wrong Door (NWD) Governance structure and part of the NWD state access plan. Promising practices and tools will be shared more broadly for all states to replicate by FY23. (Also supports Outcome 5.3) (p. 18)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh in 2022 to analyze sociodemographic and health correlates of current non-caregivers' perceptions of the likelihood of becoming a family caregiver using nationally representative BRFSS data to inform a caregiver education strategy. (Also supports Outcome 1.1) (p. 18)
- IHS will collaborate with the CDC-funded New York University BOLD Center of Excellence on Early Detection of Dementia on the adaptation of an early recognition toolkit for use in IHS, Tribal, and Urban Indian Health Programs with the goal of improving early detection of dementia and identification of caregivers in 2022. (Also supports Outcome 1.3) (p. 19)
- VA's CSP in partnership with the Veteran Experience Office will develop a survey tool to conduct a needs assessment to help identify and bridge gaps in services and resources. (Also supports Outcome 5.3) (p. 19)

**GOAL 2: Actions to advance partnerships and engagement with family caregivers:**

- HHS' ASPE will use multiple data sources and sophisticated econometric techniques to project the future risk of disability, need for support, and use of family caregiving or paid LTSS. Using the Urban Institute's dynamic microsimulation of income model (DYNASIM4), ASPE is able to incorporate future population characteristics, project financial resources, disability status, cognitive status and use of caregiving. In 2022, ASPE will release four reports to inform policies that support older adults:

- Future Changes in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults with Needs for Long-Term Services and Supports at Present and in the Future.
- The Economic Value of Unpaid Care Provided to Older Adults Who Need Long-Term Services and Supports.
- Diversity in Caregiving Needs and Networks: Differences by Race-Ethnicity in the Care Older Adults Receive.
- Change in Caregiving Networks Over the Course of Disability (p. 20)
- NIA will solicit new research focused on policy and payment models, health insurance, and/or the ability of people and families to pay for and access needed services and support to achieve the goal of addressing the impact of policy and payment models and insurance on persons living with dementia, their care partners, and health care systems as well as economic and organizational factors associated with uptake of health care services by 2022 (See: NOT-AG-21-046/NOT-AG-21-047:NOSI: Dementia Care Research: Programs and services for persons with dementia). (p. 21)
- NIA will develop research initiatives with the goal of supporting research on the ethical implications of inclusion of the care partner in the care team for the person living with AD/ABRD, dependent upon sufficiently successful applications and our future appropriations by 2025 contingent upon National Institutes of Health (NIH) appropriations and the submission of a sufficient number of meritorious applications.(Also supports Outcome 5.2) (p. 21)
- NIA will continue to solicit and fund research on early-stage intervention development to achieve the goal of addressing the care needs and promote the health, function, and well-being of persons with Alzheimer’s disease (AD) and Alzheimer’s disease-related dementias (ABRD) and of those providing their care in 2022 (See: PAR-21-307: Dementia Care and Caregiver Support Intervention Research), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications.(Also supports Outcome 5.2) (p. 21)
- Outcome 2.2: Where appropriate, identifying services and supports for caregivers consistently starts with a review of family caregiver strengths, needs, and preferences using evidence-based assessments. (p. 21)
- IHS will work through the IHS Health Information Technology (HIT) Modernization initiative in 2022 to identify family and kin caregivers in structured fields in the HER of individuals receiving care. (Also supports Outcome 5.1) (p. 22)
- ACL’s NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh in collaboration with UPMC Hillman Cancer Center to implement an evidence-based family caregiver assessment whose responses are linked to a determination of caregiver risk of poor outcomes and recommendations for strategies to mitigate risk by 2023. The assessment and risk determination will achieve the goal of engaging family caregivers using evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support. (p. 23)

- DOL's ODEP, through its technical assistance (TA) centers, may conduct research, convene think tanks, and provide TA on career ladders, training, and retaining direct care workers to achieve the goal of expanding the availability and stability of direct care for family caregivers in FY 22-25. (p. 25)
- NIH will continue to solicit and fund meritorious career development applications that propose research and training activities focused on caregiving, -to achieve the goal of building capacity of medical and other professionals in the issues and needs of family caregivers and the development and implementation of strategies to support caregiver engagement in clinical encounters, contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 26)

**GOAL 3: Actions to strengthen services and supports for family caregivers:**

- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to begin national dissemination of evidence-based family caregiver guides and resources through a national advocacy organization to meet the goal of increasing access to meaningful and culturally relevant information, services, and supports for family caregivers by 2023.(Also supports Outcome 5.3) (p. 27)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to complete analyses of nationally representative survey data on family caregivers, including caregiving context; activities and stressors; and physical, mental, social, and financial health outcomes across the caregiver lifespan to inform profiles of caregivers most in need of services and supports. These profiles of caregivers will inform interventions to meet the goal of increasing access to meaningful and culturally relevant information, services, and supports for family caregivers by 2023. (Also supports Outcome 5.1) (p. 27)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh will develop adaptive mHealth caregiving apps containing culturally appropriate education materials tailored to different caregiver populations to increase access to information, services, and supports by 2024. (Also supports Outcome 1.3) (p. 28)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to create guidelines and develop technologies that can enhance communications between extended families to meet the goal of enhancing meaningful and culturally relevant supports for family caregivers by 2024.(Also supports Outcome 3.5) (p. 28)
- ACL's NIDILRR will fund the RESILIENCE RRTC at Johns Hopkins School of Nursing to develop and disseminate a caregiver adaptation to achieve the goal of increasing access to relevant information and caregiver-centric support services for family caregivers of older adults with functional disabilities by 2025. (p. 28)
- ACL's NIDILRR will fund the RESILIENCE RRTC at Johns Hopkins School of Nursing to develop and disseminate a caregiver adaptation to achieve the goal of increasing access to meaningful and culturally relevant information and support services for family caregivers of children with social, emotional, or behavioral disabilities by 2025. (p. 28)

- ACL's NIDILRR will fund the RESILIENCE RRTC at Johns Hopkins School of Nursing to develop and disseminate a caregiver adaptation to achieve the goal of increasing access to relevant information and support services for caregivers with functional and/or sensory disabilities by 2025. (p. 28)
- Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs. (p. 31)
- ACL's Office of Supportive and Caregiver Services (OSCS), within AoA, launched a new grant program within the Alzheimer's Disease Program Initiative (ADPI) in FY2022. *Innovations in Dementia-Specific Respite* will assess the current landscape of dementia-care respite options and pilot new respite services in states and communities. (Also supports Outcome 5.3) (p. 31)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to address the goals of unpaid care partners of older adults through an adaptation of the Community Aging in Place-Advancing Better Living for Elders (CAPABLE) by 2024. Pittsburgh Area Agencies on Aging piloted CAPABLE to meet the goal of increasing the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities. (p. 31)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to address the goals of unpaid care partners of older adults through an adaptation of the Community Aging in Place-Advancing Better Living for Elders (CAPABLE) piloted with Pittsburgh Area Agencies on Aging to meet the goal of increasing the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities by 2024. (p. 32)
- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh by 2024 to: a) Create and disseminate a policy brief leveraging the insights from analyses of large national datasets to inform relevant policy related to encouraging and expanding the use of technology, including assistive technology, as a means of supporting family caregivers; b) Develop digital interventions targeting both caregivers and care recipients with cross-cutting modules agnostic to care recipient diagnosis and templates for adapting disease-specific modules to meet the goal of expanding the use of technology as a means of supporting family caregivers; c) Develop caregiver risk assessment apps for dissemination to the public through app stores to meet the goal of expanding the use of technology as a means of supporting family caregivers. (p. 34)
- The National Institute on Minority Health and Health Disparities (NIMHD), NIA, and NCI, will solicit caregiving research in 2022 that examines the impact of leveraging health information technology (HIT) to reduce disparities in access to and utilization of health care services, patient-clinician communication, and health outcomes for populations that experience health disparities in the U.S. basic and/or methodological research projects that seek to illuminate or measure independent and interdependent health-related effects within caregiver and care-partner dyads(See: PAR-22-145: Leveraging Health Information Technology (HIT) to Address and Reduce Health Care

Disparities), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 35)

- The National Institute on Nursing Research (NINR) will continue in 2022 to solicit and fund research in 2022 that will develop and test technology tools to achieve the goal of addressing caregiver symptoms and quality of life, including assistive medical devices, remote communication and monitoring tools, sensors (wearables, in-home devices), mobile technologies, alert systems (See: PA-19-024/ PA-19-023: Addressing Caregiver Symptoms through Technological Tools), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 35)
- ACL's OSCS, within AoA, will issue, in 2024, pending the availability of federal funding, a notice of funding opportunity to continue developing the Community Care Corps Program. The Community Care Corps program works at the community level to foster innovative models that leverage volunteer engagement to support caregivers and provide older adults and people with disabilities with non-medical care. (p. 36)
- NIA will solicit research applications in 2022 that focus on (1) how economic and policy factors and demands as well as features of the work environment drive the composition and quality of the dementia care workforce; (2) demographic and familial factors that influence demand for and supply of dementia care workers; (3) training and certification effects on quality and retention of dementia care workers; and (4) the development of data resources required to study these issues, to achieve the goal of promoting behavioral and social research on the dementia care workforce and the impact of workforce factors on outcomes for persons living with AD or ADRD and their families. (See: NOT-AG-21-049: NOSI: Dementia Care Workforce for Those Living with Alzheimer's Disease (AD) and Alzheimer's Disease-Related Dementias (ADRD)), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 39)

GOAL 4: Actions to ensure financial and workplace security for family caregivers:

- ACL's NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to complete analyses of nationally representative survey data of family caregivers, including income, employment, out-of-pocket spending, and health care utilization; caregiving context; activities and stressors; and physical, mental, social, and financial health outcomes across the caregiver lifespan to inform profiles of caregivers at high risk for negative financial impacts. These profiles will inform the development of interventions to meet the goal of decreasing the negative financial impacts for family caregivers on both a short- and long-term basis. (p. 40)

GOAL 5: Actions to expand data, research, and evidence-based practices:

- Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience. (p. 43)

- ACL’s Office of Performance and Evaluation (OPE) will pilot test the addition of anew question as part of the redesign of the 2023 National Survey of OAA Participants. It will ask if recipients of OAA services such as congregate meals, home-delivered meals, transportation services, case management, and homemaker services are also caregivers. (p. 44)
- ACL’s NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh to summarize the measurement approaches and the strengths and weaknesses of existing nationally representative datasets and will make recommendations for a standard set of caregiving questions to address family support across the lifespan that should be included in all national surveys to achieve the goal of establishing a national caregiving data infrastructure by 2023. (p. 44)
- CDC will support robust data collection from the Caregiver Module of the BRFSS across US states and territories in 2021 & 2022. (p. 44)
- CDC will evaluate and revise the BRFSS Caregiving Module to be fielded on the 2024 BRFSS Survey by 2024. (p. 45)
- CDC will submit caregiving questions being fielded on the 2025 BRFSS Survey to other national surveys, such as the National Health and Nutrition Examination Survey (NHANES) or the National Health Interview Survey (NHIS) by 2024. (p. 45)
- NIA will initiate at least one public-private partnership to support the development of AD/ADRD data and clinical infrastructure and harmonization processes that can allow for the integration of AD/ADRD data and clinical infrastructure and harmonization processes that allow for the integration of health care, formal and informal caregiving, and other care-related data from multiple sources (e.g., EHR, claims, surveys, patient-reported outcomes) to achieve the goals of enabling analyses of care disparities among diverse populations, making such infrastructure resources available to the research community, and incentivizing its use, contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications by 2025. (p. 45)
- NIA will support the development of methods and measures for capturing expanded definitions of “family” and related concepts relevant to informal caregiving for people living with AD/ADRD, and the he testing of these measures in populations underrepresented in AD/ADRD research and implementation of these measures in new and existing studies by 2023, contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications (see: RFA-AG-23-022/RFA-AG-23-023: Measures and Methods for Research on Family Caregivers for People Living with Alzheimer’s Disease (AD) and Related Dementias (ADRD) (R01Clinical Trial Not Allowed). (p. 45)
- NIA will support the establishment of standard protocols for harmonizable data collection to achieve the goal of establishing data infrastructure for the

- study of dementia caregiving by 2025, contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 45)
  - SAMHSA will explore adding “*are you a caregiver,*” “*are you a grandparent caregiver*” to the agency’s Government Performance and Results Act (GPRA) performance monitoring data collection tool, across all SAMHSA programs. (p. 45)
- Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and well-being of the family caregiver and the person receiving support. (p. 46)
  - ACL’s OSCS, within AoA, will institute new performance reporting for the Lifespan Respite Care Program grantees beginning in 2024 and pending approval. This new reporting framework will provide ACL and the field of respite care with critical information on the numbers of family caregivers served by the program as well as advancements being made by grantees in the development of state Lifespan Respite systems. (p. 46)
  - ACL will partner with the DOL and ED to provide grants for colleges and universities that offer studies in gerontology and family services to encourage research and expand those programs to increase the number of professionals in the aging network in/by FY 2024. (p. 46)
  - ACL will require state grants for BRFSS to include the Caregiving module as an ongoing mandatory module, with related funding by FY24. States will review modules and add any questions that will give better outcome data on use of supportive caregiver interventions. (p. 47)
  - ACL’s OPE will analyze data from the COVID-19 module of the 2021 National Survey of Older Americans Act Participants to better understand how the pandemic has disrupted and changed service delivery for OAA clients including caregiver support clients in fall 2022. The findings from this study will be presented in a final report to ACL leadership to support ongoing work and to facilitate discussion on potential new research, demonstration, and evaluation opportunities. (p. 47)
  - ACL’s NIDILRR will fund the RRTC on Family Support at the University of Pittsburgh in collaboration with established community and academic partners for a completed data collection, analysis and dissemination of all center-based projects focused on increasing family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and care recipient by 2024. (p. 47)
  - ACL’s NIDILRR will fund the RESILIENCE RRTC at Johns Hopkins School of Nursing to train early career scientists on best practices for designing interventions or technologies for supporting family caregivers that are person-centered, effective, and scalable (Building for Scale Scholars Program) to achieve the goal of increasing family caregiver research that support and enhance the health and well-being of caregivers by 2025. (p. 47)

- CDC will publish peer-reviewed studies examining the current landscape of dementia caregiving in the United States focusing on the health and well-being of caregivers by 2024. (p. 47)
- DOL's ODEP and its technical assistance centers will expand its research on workplace mental health considering COVID to include family caregiving, to achieve the goal of identifying best practices to support the mental health and well-being of family caregivers in the workplace in FY22. (p. 47)
- DOL's Women's Bureau will release in FY22 research contracted through the Urban Institute on the opportunity costs and economic effects of caregiving in order to update understanding of the lifetime effects of providing family care to account for current data and trends with additional analysis by race and ethnicity. (p. 48)
- NIA will continue to solicit research applications focused on dementia care and caregiver support intervention development research to achieve the goal of laying the groundwork for the implementation of AD/ABRD care and caregiving interventions that can be delivered with fidelity in the real world.(See: PAR-21-307: Dementia Care and Caregiver Support intervention Research and that can produce results that can be directly adopted by healthcare providers, patients, or caregivers for rapid dissemination and implementation (See: PAR-21-308: Pragmatic Trials for Dementia Care and Caregiver Support, contingent upon NIH appropriations- and the submission of a sufficient number of meritorious applications in 2022. (p. 48)
- NIA will continue to solicit and fund research applications focused on high-priority Alzheimer's disease (AD) and AD-related dementias (ABRD) care partner/caregiver research areas as set forth by the NIA's Division of Behavioral and Social Research to achieve the goals of funding research that can inform the development of successful interventions for caregivers and that can address priority areas guided by the AD/ABRD research implementation milestones, expert discussions from the NIH2020 Dementia Care Summit, and recommendations from the National Academies of Sciences, Engineering, and Medicine (NASEM) Decadal Survey of Behavioral and Social Science Research on AD/ABRD (see: NOT-AG-21-047: Notice of Special Interest (NOSI): Behavioral and Social Science Priority Areas in Dementia Care. Partner/Caregiver Research), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications by 2024. (p. 48)
- VA's CSP in partnership with VA CARES will conduct research on programs and services targeted to enhance the health and well-being of the veteran and caregiver. Research topics will be identified based on assessment of needs reported by veteran and caregivers through surveys, listening sessions, etc. (p. 48)

- **Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services.**
  - **ACL will offer grant opportunities by FY 2023 for researching the effectiveness of evidence-supported practices to support family caregivers and the aging network. (p. 49)**
  - **ACL's OPE will analyze data in late 2022 on caregivers from the National Survey of Older Americans Act Participants to examine the prevalence of health disparities that impact access to care and services for many groups, including racial and ethnic minorities and people living in rural communities. The findings from this study will be submitted to a peer-reviewed journal with the goal of building a greater understanding of caregivers' differing needs and providing insights that may help increase the development and delivery of programs and services that support and enhance the health and well-being of the caregivers and care recipients. (p. 49)**
  - **ACL's NIDILRR will fund the Shepherd Center to produce scientific evidence regarding the comparative effectiveness of two interventions that offer support to caregivers of patients with acquired brain injury (ABI) during the transition home from inpatient rehabilitation by 2023. This project examines two interventions, Building Better Caregivers (BBC) and Problem-Solving Training (PST), and measures their impact on (1) caregiver stress/burden and depression, (2) caregiver self-efficacy in their ability to manage their loved-one's care needs, and (3) health care utilization(i.e., hospitalization, emergency room, and doctor office visits) by patients and caregivers in the first six months after discharge from the rehabilitation hospital. It supports Goal 1 by providing evidence of best practices for improving family caregiver physical and emotional well-being. (p. 49)**
  - **ACL's NIDILRR will fund RRTC on Family Support at the University of Pittsburgh will host a national biennial State of the Science on Family Caregiving Research Conference to meet the goal of increasing promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of health care and LTSS by 2022. (p. 49)**
  - **ACL's NIDILRR will fund RESILIENCE RRTC at Johns Hopkins School of Nursing will promote, translate, and disseminate promising practices and approaches for scaling evidence-based programs to support caregivers and care recipients in the delivery of health care and LTSS by 2025. (p. 50)**
  - **NIA will solicit and fund research grants in 2022 and 2023 to support pragmatic trials to achieve the goals of addressing practical comparative questions faced by AD/ABD patients, clinicians, and caregivers (both paid and unpaid) from broad and diverse populations; improving the quality of life for persons with dementia and their informal caregivers, delivering more patient-focused, cost-effective care across multiple settings; and/or reducing disparities in dementia care (See: PAR-21-308: Pragmatic Trials for Dementia Care and Caregiver Support [R61/R33 – Clinical Trial Required]), contingent upon NIH**

appropriations and the submission of a sufficient number of meritorious applications. (p. 50)

- NIA and NIMHD will solicit caregiver-relevant applications in 2022 to conduct efficient, large-scale pragmatic or implementation trials to improve health and care delivery, with a particular focus on health care systems (HCS) with less historical involvement in research studies focused on improving health outcomes for US patient populations (See: RFA-AT-22-001: NIH Health Care Systems Research Collaboratory - Pragmatic and Implementation Trials of Embedded Interventions (UG3/UH3, Clinical Trials Optional), contingent upon NIH appropriations and the submission of a sufficient number of meritorious applications. (p. 51)

### **Actions for States, Communities, and Others**

[https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyFamCaregivers\\_ActionsSCO.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_ActionsSCO.pdf)

This document contains more than 150 suggested actions that states, communities, and other public and private stakeholders can take to holistically recognize, assist, include, support, and engage family caregivers in support of the Strategy.

GOAL 1: Actions to increase awareness of and outreach to family caregivers:

- **Researchers, academic institutions, and funders can invest in research and education to better understand how cultural beliefs about caregiving affect caregiver identification and to identify the best ways to train and educate diverse family caregivers to prepare them for the role. (Also supports Goal 3). (p. 6)**

GOAL 2: Actions to advance partnerships and engagement with family caregivers:

- **Collect data to determine the real-world return on investment of integrating family caregivers into the care team. (Also supports Goal 5). (p. 10)**
- **Providers can implement evidence-based practices for including caregiver supports at all points of health care delivery (inpatient, outpatient, LTSS, etc.) and transitions, including care coordination when care needs change and when caregivers relocate. (Also supports Outcome 5.3) (p. 12)**

GOAL 3: Actions to strengthen services and supports for family caregivers:

- **Collaborate with the federal government and other states to collect consistent data on outcomes of existing workforce efforts. (Also supports Goal 5). (p. 19)**
- **Participate in national data collection efforts to more fully understand the issues affecting the direct care workforce at the state and local levels. (Also supports Goal 5). (p. 20)**

GOAL 4: Actions to ensure financial and workplace security for family caregivers:

- States can conduct assessments to better understand how many caregivers in the state have access to paid leave either through public or private programs. (Also supports Outcome 5.1) (p. 23)

GOAL 5: Actions to expand data, research, and evidence-based practices:

- Consistent Definitions and Data Sets (p. 28 – 31)
  - Researchers can develop a core set of standardized family caregiver questions that to add to national surveys.
  - States can ensure their definitions of “family caregiver” are flexible and broad enough to encompass populations that are often missed or undercounted (e.g., grandchild caring for a sick grandparent) and are inclusive of terminology used to describe caregiving activities in other cultures.
  - National, state, regional, and local philanthropic organizations and research institutions can improve quality of LTSS by funding or otherwise encouraging coordinated and consistent measurement development for HCBS and family experiences of care, especially for caregivers of people with Alzheimer’s disease or other cognitive or intellectual disabilities.
  - All states can administer the optional Caregiver Module of the Behavioral Risk Factor Surveillance System (BRFSS), a system of health-related telephone surveys from the CDC that collect state data about health-related risk behaviors, chronic health conditions, and use of preventive services.
  - State agencies and CBOs can collaborate to collect data at a single point of entry to save administrative costs and reduce the risk of data entry errors and inconsistencies.
  - National, state, regional, and local philanthropic organizations; research institutions; business leaders; and others can work together to establish a set of standards for data collection to enable researchers and other key stakeholders to better evaluate research results.
  - Private sector leaders (such as large employers) who have embraced caregiver friendly policies (e.g., paid family leave) and business coalitions can advocate for widespread adoption of standardized metrics for evaluating the efficacy “caregiver friendly” workplace programs. Such efforts have the potential to ensure that smaller employers and those just beginning to offer caregiver programs can easily align their efforts with other companies and/or research initiatives, reducing information silos and encouraging the sharing of success stories.
  - State agencies and CBOs can support the expansion of research using national caregiving-related data sets.
  - National, state, regional, and local philanthropic organizations; research institutions; and CBOs can create a caregiver data repository that caregivers can opt into to share data with researchers. The University of Southern California Family Caregiver Support Center provides a model.
  - Business coalitions can encourage private-sector entities to use standardized data collection tools, forms, and definitions of terms.

- Philanthropic organizations, researchers, CBOs, and other stakeholders, such as standards development organizations (SDOs), terminologists, and family caregiving interest groups can partner to:
  - Encourage widespread adoption of a core minimum data set with standardized data (including standardized caregiver definitions, and data attributes).
  - Educate stakeholders about the value of a coordinated approach to data collection about caregiving. (Also supports Outcome 1.1)
- States can adopt standardized, evidence-based or evidence-informed family caregiver assessments and use the results to develop person-centered and family centered care plans. Tracking outcomes from those plans can help identify information that organizations can use to determine future resource needs and identify programming gaps.
- Researchers can make available to other researchers in-progress caregiver research via social networking sites for scientists and researchers. (See above Goal 1).
- Researchers and states can collaborate to collect more data on interactions between family caregivers and the long-term care workforce and share that information with other states. (Also supports Outcome 5.3)
- State agencies, health care systems, insurance payers, and CBOs can adopt interoperative and flexible technologies that allow public and private programs to streamline their efforts and collaborate with each another. For example, they can:
  - Build internet-based interfaces that can be shared by multiple agencies. These systems can host application and identification forms that enable family caregivers to provide information for use on several forms and applications. This can reduce the risk of inconsistent or incomplete reporting.
  - Adopt tools and processes for reducing risks associated with handling of Personally Identifiable Information (PII). Examples include data-anonymizing techniques (such as character shuffling, encryption, or term substitution) and tools that reduce the risk of data breaches (such as fillable forms that do not store information in a database).
- State agencies, health care systems, insurance payers, and CBOs should embrace and participate fully in data collection efforts of the federal government that can facilitate future support to caregivers. For example, they can:
  - Proactively seek opportunities to participate in the development, testing and deployment of new data collection and research efforts.
  - Set aside fiscal resources for data collection and reporting efforts.
  - Explore ways to participate in efforts to increase broadband speed and access data in communities with low access rate. (Also supports Outcome 3.5)

- Encourage local health departments to commit to adopting and using the Behavioral Risk Factor Surveillance System (BRFSS) questions as part of their data collection programming.
- Private philanthropy can include adequate funding for administrative costs to provide incentives for CBOs to include data collection and research learning as a part of their programs and services.
- Funders can also provide CBOs with the administrative and operational support to effectively build and standardize the evidence base for improved services and supports.
- States can collaborate to establish data-collection methods that jointly support understanding the economic value, and opportunity costs, of family caregiving.
- States can work with managed care plans and researchers to convene a community of practice/learning collaborative and create a collection of vetted best practices for different purposes at the state Medicaid level.
- States can implement evidence-informed programs for family caregivers and collect data on those programs to assist researchers with translation and adaptations.
- States can develop state evaluations of family caregiving programs to identify programs that warrant additional study and adaptation.
- CBOs can partner and utilize the Best Practice Caregiving Database as a model to create databases of in-kind community-tested programs to facilitate program and service development, delivery, and use.
- CBOs and/or research institutions can translate identified best practices for culturally competent use with diverse populations, including kin and grandparent caregivers.
- States can collaborate with managed care plans and researchers to create evidence-based trainings for staff of participating plans.
- State legislatures can include evidence-based approaches to service delivery in state-funded caregiver support programs.
- States and organizations can build partnerships with universities and academic institutions to expand research and funding for evidence-supported family caregiving. Best practices include:
  - Developing standardized language for funding announcements to facilitate collaboration across research entities and sectors using the outcome data.
  - Presenting findings at the national level, including to the Advisory Councils and at major conferences, so that evidence-based practices have the best chance of being adopted nationwide.
  - Sharing data on academic research and evidence-based outcomes with other states.
  - Ensuring evidence-based approaches identified in research are communicated to policy makers for implementation.
- Caregiving stakeholder organizations can develop a model like pivotal ventures investments and incubation to advance evidence-based and evidence-informed

- “incubator projects” that have promising societal impact for family caregivers and care recipients within the public domain.
- College and university research programs can consider opportunities to expand and obtain funding for research into evidence-based interventions to support caregiving families.
- CBOs and schools can disseminate kin and grandparent caregiver-specific evidence-based programs and evidence-informed practices through non-traditional places such as libraries, recreation/daycare centers, and afterschool programs. (Also supports Outcome 1.3)
- Researchers can expand and standardize information collected from family caregivers including demographics, prevalence and nature, costs of care, health status, specific needs of diverse/multicultural caregivers, and level of unmet need.
- State Medicaid programs can incorporate caregiver feedback as part of quality assurance for state Medicaid programs.
- Researchers can design studies to include family caregivers across racial and ethnic populations by oversampling underrepresented groups as well as examining and comparing their outcomes across groups.
- Academics, business leaders, and national, state, and regional philanthropic organizations can work to gather consistent data that builds the business case for workplace supports and encourages more businesses to adopt such supports. (Also supports Goal 4)
- **Research Topics for Future Consideration (p. 31 – 33)**
  - Assess the effects on caregivers when individuals with disabilities (particularly those with high support needs) are integrated into the workforce through competitive, integrated employment practices.
  - Assess availability, use, and impact of paid leave on caregivers in the state.
  - Evaluate best practices for direct care worker (DCW) workforce training, recruitment, and retention.
  - Explore the roles of entities such as health care systems, insurance companies, FBOs, and tribal communities in expanding research and gathering data about family caregivers.
  - Investigate and determine:
    - Number of children in kin and grandparent-led families who encounter the child welfare system and their outcomes.
    - Outcomes of caregiver assessments over time.
    - The return on investment for supporting family caregivers across all domains: training, support, employment, financial assistance, etc.
    - Person-centered outcomes, especially the totality of outcomes that truly reflect the end users’ or the caregivers’ perceived value of a particular intervention, not only the financial incentive.
    - Capability of local direct care workforces to meet the needs of the state.
    - Testing existing evidence-based practices in multiple modes of delivery, such as in person, by mail, video, and/or phone.

- Expand evidence-based research on respite that can be disseminated to the appropriate populations or groups.
- Collect data to show who may need services but doesn't meet current eligibility requirements.
- Translate clinical-based interventions or care coordination models into more human services or social service settings.
- Translate and adapt other evidence-based approaches (not developed specifically for caregiving) for use by family caregivers.
- Develop a family caregiver study program that uses an interdisciplinary track of courses from multiple academic disciplines.
- Identify which care events trigger an assessment update and/or contingency plans.
- Determine where and how cultural expectations and caregiving competencies intersect and interact.
- Collect statistical data on how many people are providing care, their demographics, and the context in which care is provided.
- Determine the commonalities regarding the role of the family caregiver across all populations.
- Conduct longitudinal studies that research family caregiving over time to identify and document the health-related changes related to caregiving.
- Begin studies about caregiving populations and groups that have not yet been the subject of research.
- Conduct environmental scans to develop an understanding of what currently exists that could be implemented; analyze data to figure out why the evidence-based practices are not being used.

### **First Principles: Cross-cutting Considerations for Family Caregiver Support**

This document empowers communities, agencies, and other stakeholder groups to select actions for implementation, based on community and family caregiver needs and preferences and in consideration of existing supports already in place, resource constraints, and other factors. The Advisory Councils noted that the four issues below must be considered and addressed to achieve success in efforts to support family caregivers.

[https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyFamCaregivers\\_FirstPrinciples.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_FirstPrinciples.pdf)

#### Cross-cutting Considerations and Essential Practices

1. Placing the Family and Person at the Center of All Interactions
2. Addressing Trauma and its Impact on Families
3. Advancing Equity, Accessibility, and Inclusion for Family Caregivers in Underserved Communities
  - **Develop programming, research, and policy for caregivers in Indian Country in collaboration with tribes and tribal communities, including their internal review boards and tribal governments. (p. 13)**

- **Amend data collection, project assessments, and reporting requirements in legislation to ensure that all racial and ethnic groups, American Indians/Alaska Natives, as well as LGBTQIA+ older adults, are represented and provided the opportunity to participate in research. (p. 13)**
  - **Collect data in a way that builds trust with caregivers by providing education about its purpose and use. (p. 13)**
4. Elevating Direct Care Workers as Family Caregiving Partners

*Prepared by Dr. Kim Whitmore, Marquette University College of Nursing, on behalf of the ARCH National Respite Network and Resource Center for the Committee for Advancement of Respite Research.*

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