

**THE RECOGNIZE, ASSIST,
INCLUDE, SUPPORT, AND ENGAGE (RAISE)
FAMILY CAREGIVERS ACT COUNCIL**

REFERENCE MATERIALS



The John A. Hartford
Foundation



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National Family Caregiver Organizations			
	Organization	Mission	Core Constituencies
1	AARP	"Empower people to choose how they live as they age."	Seniors
2	ARCH National Respite Network	"Assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums."	Caregivers and professionals who are seeking respite and crisis care programs in their community
3	Family Caregiver Alliance	"Improve the quality of life for family caregivers and the people who receive their care."	Family caregivers of adults with physical and cognitive impairments, such as Parkinson's, stroke, Alzheimer's and other types of dementia Family caregivers in the San Francisco Bay Area counties of: San Francisco, San Mateo, Santa Clara, Alameda, Contra Costa and Marin.
4	National Alliance for Caregiving	"Advancing family caregiving through research, innovation, and advocacy."	A national network of caregiving coalitions representing nearly 30 states and localities in the United States 4A Member Group includes national organizations who are leaders in the field of caregiving
5	Caregiver Action Network	"Promote resourcefulness and respect for the more than 90 million family caregivers across the country."	Family caregivers across the country Caregivers who are taking care of people with cancer and rare diseases Organizations who employ those providing family caregiving services and want to provide them with more resource

6	American Association of Caregiving Youth	"To increase awareness and provide support services for youth caregivers and their families by connecting them with healthcare, education and community resources."	Children & adolescents <18 years of age who provide significant assistance to relatives or household members who need help
7	Caring From a Distance	Assist "long-distance caregivers organize for the task" of long-distance caregiving "and identify public and private service providers to help [their] loved one[s]."	Long-distance caregivers
8	N4A	"Build the capacity of our members so they can help older adults and people with disabilities live with dignity and choices in their homes and communities for as long as possible."	America's national network of 622 Area Agencies on Aging The more than 250 Title VI Native American aging programs *N4A is a membership organization*
9	SAGE	"SAGE operates at the intersection of LGBT and aging experiences. [Its] work ensures that all LGBT older people have just and fair access to the opportunities they deserve and are free from ageism."	LGBTQ older adults and their caregivers
10	National Indian Council on Aging	"To advocate for improved comprehensive health, social services, and economic wellbeing for American Indian and Alaska Native Elders."	American Indian and Alaska Native Elders 55+ *services are available to paying members and non-members*
11	National Hispanic Council on Aging	"To improve the lives of Hispanic older adults, their families, and caregivers."	Hispanic older adults, their families, and their caregivers

12	National Caucus and Center on Black Aging, Inc.	“To enhance the quality of life for aging, and aged blacks, by providing a comprehensive program of education, information gathering and dissemination, and coordinating consulting services to the public and private sectors.”	African American and low-income minority seniors
13	Diverse Elders Coalition	“[A]dvocates for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaskan Natives; and lesbian, gay, bisexual and/or transgender people.”	Diverse Elders, including LGBTQ elders, Black elders, Hispanic elders, American Native and Alaskan Native elders, and Asian American and Pacific Islander elders
14	Rosalynn Carter Institute for Caregiving	“The Rosalynn Carter Institute for Caregiving establishes local, state, national, and international partnerships committed to building quality, long-term, home and community-based services. We believe this begins with providing caregivers with effective supports to promote caregiver health, skills and resilience. We also believe strongly in the need to provide greater recognition for professional and family caregivers. We focus on helping caregivers coping with chronic illness and disability across the lifespan.”	Caregivers coping with chronic illness and disability across the lifespan

Key Terms and Definitions

Key Terms and Definitions			
	Key Term	Acronym	Definitions
(Definitions are from <i>Families Caring for an Aging America</i> Acronyms and Glossary)			
1	Activity of Daily Living	ADL	A series of basic activities performed by individuals on a daily basis necessary for independent living at home or in the community.
2	Care Recipient		Adults aged 65 or older, who need help from others due to functional or cognitive limitations, or a serious health condition.
3	Caregiver Assessment		The process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the caregiver, and their ability to contribute to the needs of the care recipient.
4	Caregiver		Relatives, partners, friends, or neighbors who assist an older adult who needs help due to physical, mental, cognitive, or functional limitations.
5	Family Leave		A period of time away from a job for family reasons such as to care for a spouse, child, or parent who has a serious health condition.
6	High-Need Care Recipients		Older adults who suffer from dementia or need help with at least two self-care activities (i.e., bathing, dressing, eating, and getting in and out of bed).
7	Home and Community-Based Services	HCBS	Provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings.
8	Instrumental Activity of Daily Living		Instrumental activities of daily living are the skills and abilities needed to perform certain day-to-day tasks associated with an independent lifestyle.
9	Intellectual and Developmental Disabilities	IDD	Disorders that are usually present at birth and negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development.

10	Long-Term Services and Supports	LTSS	A variety of personal care, healthcare, and social services provided to people of all ages with chronic conditions and with functional limitations. Services can include personal care, help with medication management, paying bills, transportation, meal preparation, and health maintenance tasks. Services can be provided in a variety of settings such as nursing homes, residential care facilities, and individual homes.
11	Palliative Care		Care that provides relief from pain and other symptoms, supports quality of life, and is focused on people with serious advanced illness and their families.
12	Patient-Centered Care		Health care that establishes a partnership among practitioners and patients to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.
13	Person-and-Family Centered Care		An approach to the planning and delivery of care across settings and time that is centered in collaborative partnerships among individuals, their defined family, and providers of care.
14	Resources for Enhancing Alzheimer's Caregiver Health	REACH	Multisite caregiver intervention study that compared a variety of interventions for dementia caregivers to control conditions.
15	Respite Care		Services designed to allow family caregivers to have time away from their caregiving role. Respite can be provided at home, through adult day services in the community, or by short-term stays in a facility or retreat setting.
16	Skilled Nursing Facility		A special facility or part of a hospital that provides medically necessary professional services from nurses, physical and occupational therapists, speech pathologists, and audiologists.
17	State Unit on Aging	SUA	State-level agencies that are responsible for developing and administering multi-year state plans that advocate for and provide assistance to older residents, their families, and adults with physical disabilities.

Major Federal Family Caregiving Legislation

	Legislation	Acronym	Overview
1	Family and Medical Leave Act	FMLA	Entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.
2	Older Americans Act	OAA	Originally passed in 1965, this legislation authorized grants to states for the creation of new or improved programs for community planning and services, and for training, through research, development, or training project grants in the field of aging. The OAA was amended in 1978 to include Title VI, which currently provides caregiver support services, in addition to nutrition and other supportive services, to American Indians, Alaska Natives, and Native Hawaiians.
3	Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act	RAISE	Directs the Department of Health and Human Services (HHS) to develop and make publicly available a National Family Caregiving Strategy that identifies recommended actions for recognizing and supporting family caregivers in a manner that reflects their diverse needs. Calls for HHS to convene a Family Caregiving Advisory Council to advise the department on recognizing and supporting family caregivers.

Key Federal Family Caregiving Programs			
	Legislation	Acronym	Overview
1	Lifespan Respite Care Program		<ul style="list-style-type: none"> • Offers respite care services for family caregivers of children and adults of all ages with special needs. • Aims to “improve the delivery and quality of respite services available through the following objectives: <ul style="list-style-type: none"> ○ Expand and enhance respite services in the states; ○ Improve coordination and dissemination of respite services; ○ Streamline access to programs; ○ Fill gaps in service where necessary; and ○ Improve the overall quality of the respite services currently available.”
2	National Family Caregiver Support Program	NFCSP	<p>“Provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible. NFCSP grantees provide five types of services:</p> <ul style="list-style-type: none"> ○ Information to caregivers about available services; ○ Assistance to caregivers in accessing supportive services; ○ Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles; ○ Respite care to temporarily relieve caregivers from their responsibilities; and, ○ Supplemental services, on a limited basis, to complement the care provided by caregivers.”
3	Native American Caregiver Support Services		<p>“Grants assist American Indian, Alaskan Native, and Native Hawaiian families caring for older relatives with chronic illness or disability, and grandparents caring for grandchildren. The program offers a variety of services that meet a range of caregivers’ needs, including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services.”</p>
4	VA Caregiver Support Program		<p>“Caregivers play an important role in the health and well-being of Veterans. The Caregiver Support Program offers training, educational resources, and multiple tools to help [caregivers] succeed.”</p>
5	The National Network of University Centers for Excellence in Developmental Disabilities	UCEDD	<p>“A nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. Discretionary grants are awarded to interdisciplinary education, research, and public service units of universities and public or nonprofit entities associated with universities.”</p>

	Education, Research, and Service		
6	Federal Medicaid Authorities		Medicaid is the major source of funding for long-term services and supports (LTSS), which include home and community-based services (HCBS). “Medicaid HCBS include four types of state plan benefits and two types of waivers. State plan HCBS include home health; personal care; Section 1915 (i), which authorizes HCBS targeted to a particular population with functional needs that are less than an institutional level of care; and CFC attendant services and supports. HCBS waivers include Section 1915 (c) and Section 1115, both of which allow states to expand financial eligibility and offer HCBS to seniors and people with disabilities who would otherwise qualify for an institutional level of care, while limiting enrollment.”
7	Family Support Research and Training Center	FSRTC	“The FSRTC is a collaboration of researchers and organizations who are focused on synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course.”

Key Federal Agencies

	Legislation/Program	Acronym	Overview
1	Administration for Community Living	ACL	“Brings together the efforts and achievements of the Administration on Aging (AoA), the Administration on Intellectual and Developmental Disabilities (AIDD), and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.”
2	Administration on Aging	AoA	The agency designated by the Department of Health and Human Services “to carry out the provisions of the Older Americans Act (OAA).” The AoA has provided home and community-based services to millions of older persons through the programs funded under the OAA.
3	Health Resources and Services Administration	HRSA	“The primary federal agency for improving health care to people who are geographically isolated, economically, or medically vulnerable.”
4	Veterans Health Administration	VHA	“The largest integrated health care system in the U.S., providing care at 1,255 health care facilities... to over 9 million Veterans enrolled in the VA health care program.”

Federal Caregiver Legislation in the 116th Congress

	Chamber	Title	Sponsor	Co-Sponsors	Date Introduced	Latest Action	Overview
1	House	<u>Supporting Family Caregivers Act of 2019</u>	Rep. Andy Levin (D-MI)	Rep. Elise Stefanik (R-NY) and Rep. Brian Fitzpatrick (R-PA)	July 16, 2019	Referred to Education and Labor Committee	To amend the Older Americans Act of 1965 to support family caregivers.
2	House	<u>Credit for Caring Act of 2019</u>	Rep. Linda Sanchez (D-CA)	Rep. Tom Reed (R-NY)	May 14, 2019	Referred to House Ways and Means Committee	This bill allows an eligible caregiver a tax credit of up to \$3,000 for 30% of the cost of long-term care expenses that exceed \$2,000 in a taxable year. The bill defines "eligible caregiver" as an individual who has earned income for the taxable year in excess of \$7,500 and pays or incurs expenses for providing care to a spouse or other dependent relative with long-term care needs.
3	Senate	<u>Supporting America's Caregivers and Families Act</u>	Sen. Dick Durbin (IL)	Sen. Tim Kaine (D-VA)	April 3, 2019	Referred to HELP Committee	To amend the Older Americans Act of 1965 in order to address the needs of caregivers, and for other purposes.
4	Senate	<u>Supporting Veteran Caregivers Act of 2019</u>	Sen. Robert Casey (D-PA)	Sen. Jon Tester (D-MT) and Sen. Patty Murray (D-WA)	May 23, 2019	Referred to Veterans' Affairs Committee	To reinstate and compensate family caregivers who were improperly removed from the family caregiver program of the Department of Veterans Affairs or whose benefits were reduced and to ensure all veteran caregivers receive the support and assistance to which they are eligible in a fair and consistent manner, and for other purposes.

5	Senate	<u>TEAM Veteran Caregivers Act</u>	Sen. Gary Peters (D-MI)	Sen. Marsha Blackburn (R-TN)	July 23, 2019	Referred to Veterans' Affairs Committee	To require the Secretary of Veterans Affairs to formally recognize caregivers of veterans, notify veterans and caregivers of clinical determinations relating to eligibility for caregiver programs, and temporarily extend benefits for veterans who are determined ineligible for the family caregiver program, and for other purposes.
6	Senate	<u>Supporting Caregivers Act</u>	Sen. Robert Casey (D-PA)	Sen. Susan Collins (R-ME)	April 11, 2019	Referred to HELP Committee	To amend the Older Americans Act of 1965 to require the Assistant Secretary for Aging to identify and disseminate best practices for the National Family Caregiver Support program, and for other purposes.
7	Senate	<u>Credit for Caring Act of 2019</u>	Sen. Joni Ernst (R-IA)	Sen. Michael Bennet (D-CO), Sen. Shelley Moore Capito (R-WV), Sen. Elizabeth Warren (D-MA), Sen. Tammy Baldwin (D-WI), Sen. Angus King (I-ME), Sen. Richard Blumenthal (D-CT), Sen. Jon Tester (D-MT), and Sen. Chris Coons (D-DE)	May 14, 2019	Referred to Finance Committee	This bill allows an eligible caregiver a tax credit of up to \$3,000 for 30% of the cost of long-term care expenses that exceed \$2,000 in a taxable year. The bill defines "eligible caregiver" as an individual who has earned income for the taxable year in excess of \$7,500 and pays or incurs expenses for providing care to a spouse or other dependent relative with long-term care needs.

8	Senate	<u>Lifespan Respite Care Reauthorization Act of 2019</u>	Sen. Susan Collins (R-ME)	Sen. Tammy Baldwin (D-WI)	April 2, 2019	Referred to HELP Committee	The Lifespan Respite Care Act of 2006 was originally enacted to improve the delivery and quality of respite care services available to families across all age and disability groups by establishing coordinated lifespan respite systems. Currently, thirty-seven States and the District of Columbia have received grants under the Lifespan Respite Care Act of 2006 to improve the availability and quality of respite services across the lifespan.
9	Senate	<u>FAMILY Act</u>	Sen. Kirsten Gillibrand (D-NY)	34 Co-Sponsors; 32 Democrats and 2 Independents	February 12, 2019	Referred to Finance Committee	To provide paid family and medical leave benefits to certain individuals, and for other purposes.
10	Senate	<u>Geriatrics Workforce Improvement Act</u>	Sen. Susan Collins (R-ME)	Sen. Robert Casey (D-PA) and Sen. Richard Blumenthal (D-CT)	January 31, 2019	Referred to HELP Committee	To amend title VII of the Public Health Service Act to reauthorize programs that support interprofessional geriatric education and training to develop a geriatric-capable workforce, improving health outcomes for a growing and diverse aging American population and their families, and for other purposes.