

June 20, 2024

President Joseph R. Biden  
The White House  
1600 Pennsylvania Ave, NW  
Washington, DC 20500

Dear President Biden:

There are 53 million American family caregivers providing care to someone who is aging, ill, or disabled. Family caregivers provide an estimated economic value of \$600 billion in unpaid care a year.<sup>1</sup> As a champion for caregivers throughout your career, you know well how critical this invisible frontline of our healthcare system is for the health and economic strength of our nation.

The 167 undersigned organizations represent family caregivers, individuals with disabilities and chronic illnesses and conditions and the providers who care for them and understand their essential role. We greatly appreciate your accomplishments for family caregivers, including your Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers. **As we move beyond its one-year anniversary, we need to build upon that historic action and maximize the existing caregiver resources and programs within the federal government with the creation of an Office of Caregiver Health.**

To elevate and focus unprecedented federal representation, investment, and coordination of caregiver support across federal agencies, the late former First Lady Rosalynn Carter believed that the establishment of a new Office of Caregiver Health at the Department of Health and Human Services would ensure that family caregivers are represented in health policy, regulation, program, and budget negotiations across HHS. A centralized office can dismantle silos that are barriers to progress by creating ways to consider the universal needs of caregivers, regardless of their care recipient's condition or payor.

Caregivers experience disproportionate physical, emotional, and financial strain and social isolation because of their caregiving responsibilities. Caregivers span every generation from youth to elderly, come from all backgrounds and lived experiences, and care for individuals with a wide array of conditions covered by varying payors.

Despite a wide array of caregiver support programs across the federal government, our experience clearly indicates that caregivers struggle daily to navigate the systems, fail to qualify for the types of benefits they seek, and often find that the resources available to them are not sufficient to meet their specific needs.

Caregivers must be recognized as a population rather than segmenting them by the conditions or diagnosis of care recipients. Moreover, we should redesign structures and systems to proactively center caregiver health and wellbeing, and not to add to their caregiving tasks by requiring caregivers to self-identify or seek out supports without assistance.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 National Strategy to Support Family Caregivers released in 2022 highlights the need for policy coordination and prioritization. The RAISE Strategy provides long overdue visibility on commitments to caregivers yet

includes 345 commitments across 15 agencies. Further, the FY 2024 Department of Health and Human Services Budget does not have funds at the required scale for cross-agency implementation.

The RAISE strategy provides great momentum to establish a federal Office of Caregiver Health. We envision the office working in close collaboration with the Assistant Secretary for Aging at the ACL and other agencies and departments to accelerate the strategy's cross-sector implementation.

The office's mission would be to advance the health and well-being of family caregivers across the nation through coordinating federal services, support, research, and education. Key functions of the office would include:

- Ensuring caregivers are understood and monitored as a population with their own needs.
- Ensuring that the needs of caregivers are considered in all federal programs and policies.
- Leveraging research and ensuring effective program evaluation and delivery across federal agencies to recommend policy and regulatory reforms to mitigate and prevent adverse outcomes from caregiving.

Further, this office would define caregivers and assess their needs, identify all existing programs and policies that may impact them and coordinate access to a streamlined system with a centralized resource entry point to locate the appropriate supports and resources.

We are extremely appreciative of the many investments in family caregivers made by your Administration. At the April 11 White House Caregiver Convening, Neera Tanden said "We are so close, so close, to transforming our economy and transforming families and communities by finally stepping up and giving them the support they need but more importantly the support they deserve from their government". We agree and strongly believe they need and deserve an Office of Caregiver Health. We look forward to your action on this request to improve the efficiency and effectiveness of federal programs for family caregivers. Thank you in advance for your consideration of taking immediate action to establish an Office of Caregiver Health within the Office of the Secretary at the Department of Health and Human Services.

For further information or questions, please contact Diana Felner, Senior Director of Caregiver and Mental Health Policy at the Rosalynn Carter Institute for Caregivers, at [diana@rosalynncarter.org](mailto:diana@rosalynncarter.org).

Sincerely,

Rosalynn Carter Institute for Caregivers

The Carter Center

AARP

ACCSES – The Voice of Disability Service Providers

ADvancing States

Alliance for Aging Research

ALS Network

ALS Northwest

Alter

Alzheimer's Association

Alzheimer's Foundation of America

Alzheimer's Impact Movement  
Alzheimer's Los Angeles  
Alzheimer's Orange County  
Alzheimer's San Diego  
Alzheimer's Tennessee  
American Academy of Addiction Psychiatry  
American Academy of Child and Adolescent Psychiatry  
American Academy of Pediatrics  
American Association for Marriage and Family Therapy  
American Association of Caregiving Youth  
American Association of Nurse Practitioners (AANP)  
American Brain Coalition  
American College of Rheumatology  
American Foundation for Suicide Prevention  
American Geriatrics Society  
American Kidney Fund  
American Mental Health Counselors Association  
American Parkinson Disease Association  
American Psychiatric Association  
Amyloidosis Support Groups Inc.  
Angelman Syndrome Foundation  
Anxiety and Depression Association of America  
Arthritis Foundation  
Association of American Indian Physicians  
Association of Maternal & Child Health Programs  
Asthma and Allergy Foundation of America  
Autism Society of America  
Autism Speaks  
BAGS-Being a Grandparent Support  
Barth Syndrome Foundation  
Benjamin Rose Institute on Aging  
Biomarker Collaborative  
Blue Star Families  
Brain Injury Association of America  
CancerCare  
Cancer Support Community  
Caregiver Action Network  
Caring Across Generations  
CaringKind

Center for Health and Social Care Integration at RUSH  
Center for Healthy Aging, Nevada  
Center for the Advanced Study of Aging Services  
Center to Advance Palliative Care  
Cerebral Palsy Foundation  
Child Neurology Foundation  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Christopher & Dana Reeve Foundation  
CLOVES Syndrome Community  
Clusterbusters, Inc  
Coalition of Wisconsin Aging and Health Groups  
Coalition to Transform Advanced Care (CTAC)  
Creutzfeldt-Jakob Disease Foundation, Inc.  
CurePSP  
Cure VCP Disease  
DEFEAT MSA ALLIANCE, DEFEAT MULTIPLE SYSTEM ATROPHY ALLIANCE  
DEFEAT MSA AWARENESS SHOE  
Dementia Alliance of North Carolina  
Dementia Society of America  
Dravet Syndrome Foundation  
Dreamsickle Kids Foundation  
Duke Health  
Dystonia Medical Research Foundation  
Easterseals, Inc.  
Elizabeth Dole Foundation  
Emory University  
Epilepsy Foundation  
EveryLife Foundation for Rare Diseases  
Exon 20 Group  
Family Caregiver Alliance  
Fanconi Cancer Foundation  
Foundation for Angelman Syndrome Therapeutics  
FOXG1 Research Foundation  
Gaucher Community Alliance  
Georgia First  
Georgia Parent Support Network  
Gerontological Advanced Practice Nurses Association (GAPNA)  
Gerontological Society of America  
Glut1 Deficiency Foundation

Guide Dog Foundation  
Hawaii Family Caregiver Coalition  
HealthyWomen  
Hemophilia Federation of America  
Hilarity for Charity  
Huntington's Disease Society of America  
Hydrocephalus Association  
I AM ALS  
ICAN International Cancer Advocacy Network  
Immune Deficiency Foundation  
Inseparable  
International Association for Indigenous Aging  
International Autoimmune Encephalitis Society  
International OCD Foundation  
ITSAN  
Justice in Aging  
Latino Alzheimer's & Memory Disorders Alliance  
LEAD Coalition (Leaders Engaged on Alzheimer's Disease)  
Live Like Lou Foundation  
Lupus and Allied Diseases Association, Inc.  
Meadows Mental Health Policy Institute  
MET Crusaders  
Mission MSA  
MSA UNITED INTERNATIONAL RESEARCH CONSORTIUM  
Myasthenia Gravis Association  
Myasthenia Gravis Foundation of America (MGFA)  
National Alliance for Caregiving  
National Alliance for Hispanic Health  
National Alliance on Mental Illness  
National Association for Homecare & Hospice (NAHC)  
National Association of Social Workers  
National Council for Mental Wellbeing  
National Council on Aging  
National Eating Disorders Association (NEDA)  
National Headache Foundation  
National Health Council  
National Hispanic Medical Association  
National Kidney Foundation  
National Minority Quality Forum

National Multiple Sclerosis Society  
National Rehabilitation Research & Training Center on Family Support  
National Respite Coalition  
National Task Group on Intellectual Disabilities and Dementia Practices  
Ohio Council for Cognitive Health  
One Family Foundation  
Organic Acidemia Association  
PA Education Association  
PDL1 Amplifieds  
Parent Project Muscular Dystrophy  
Parkinson's Foundation  
Prader-Willi Syndrome Association | USA  
Prader Willi Florida Chapter  
Prader-Willi Syndrome Association of Minnesota  
Prader-Willi Syndrome Nebraska  
Prevent Blindness  
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)  
Remember The Girls  
Schizophrenia & Psychosis Action Alliance  
Society for Women's Health Research  
Spina Bifida Association  
SYNGAP1 Foundation  
Texas Prader-Willi Association  
The ALS Association  
The Association for Frontotemporal Degeneration  
The Cute Syndrome Foundation  
The Global Foundation for Peroxisomal Disorders  
The Michael J. Fox Foundation for Parkinson's Research  
The VEO-IBD Foundation  
Tourette Association of America  
Tragedy Assistance Program for Survivors (TAPS)  
United Mitochondrial Disease Foundation  
United MSD Foundation  
United Spinal Association  
UsAgainstAlzheimer's  
USAging  
Utah Prader-Willi Syndrome Association  
Voices of Alzheimer's  
Wounded Warrior Project

cc: The Honorable Xavier Becerra, Secretary, Department of Health and Human Services  
Neera Tanden, Assistant to the President and Domestic Policy Advisor