



FAMILY CAREGIVING ADVISORY COUNCIL
FINAL RECOMMENDATIONS
Adopted November 18, 2020

On November 18, 2020, the Family Caregiving Advisory Council adopted twenty-six recommendations aimed at establishing a national approach to addressing the needs of family caregivers of all ages and circumstance. The following recommendations grew out of months of discussion, examination of relevant data and information and the input of family caregivers and stakeholders alike. They address critical priority areas including awareness and outreach to family caregivers and their engagement as key partners in healthcare delivery and long-term services and supports; strengthening community-based supports for family caregivers; ensuring workplace and financial security for family caregivers; and greater focus on data, research and the development of evidence-informed supports for family caregivers.

These recommendations will be included in the Council's initial Report to Congress in 2021 and serve as the foundation for the National Family Caregiving Strategy that will begin development next year. The Strategy will outline critical actions that can be taken at the federal, state levels, by local communities as well as health, long-term services providers and others to better support family caregivers in ways that reflect their diverse needs. The Strategy will focus on areas such as person and family-centered care; assessment and service planning; information, education and training supports; respite options; and financial and workplace security issues. The Strategy will provide a roadmap for the nation to strengthen its support and recognition of the critical role family caregivers' play in our healthcare and long-term support systems.

Awareness and Outreach for Family Caregivers

Goal 1: Family caregivers' physical, emotional, and financial well-being will improve as a result of expanded awareness, outreach, and education.

Recommendation 1.1: Increase public awareness and recognition of the diverse needs, issues, and challenges family caregivers face and of the importance of recognizing and supporting them.

Recommendation 1.2: Increase family caregivers' self-identification and awareness of, and access to, information, services, and supports across a range of topics.

Recommendation 1.3 Improve outreach efforts to family caregivers to ensure early identification and access to services and supports.

Recommendation 1.4: Support the development, or revision of, state, territorial, Tribal and local planning that focuses specifically on recognizing, including, and supporting family caregivers of all ages and is aligned with the National Family Caregiving Strategy.

Recommendation 1.5: Promote the expansion and role of public/private partnerships at all levels that recognize, assist, include, support and engage family caregivers.

Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports

Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of healthcare and long-term services and supports.

Recommendation 2.1: Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in healthcare systems.

Recommendation 2.2: Identify and include family caregivers as essential members and partners in the care recipient's care team.

Recommendation 2.3: Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.

Recommendation 2.4: Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and care recipient.

Recommendation 2.5: Strengthen the training of healthcare, social service, and allied professionals to maximize family caregiver engagement and referrals to services in the community.

Services and Supports for Family Caregivers

Goal 3: Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.

Recommendation 3.1: Increase access to meaningful and culturally relevant information, services, and supports for family caregivers.

Recommendation 3.2: Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.

Recommendation 3.3: Increase the availability of diverse counseling, training, peer support, and education opportunities for family caregivers, including evidence-informed interventions.

Recommendation 3.4: Expand caregiver support programs and services that maintain the health and independence of families by increasing access to housing, safe living accommodations, food, and transportation, and by reducing social isolation.

Recommendation 3.5: Encourage use of technology solutions as a means of supporting family caregivers.

Recommendation 3.6: Expand the use of vetted volunteers and volunteerism as a means of supporting family caregivers.

Recommendation 3.7: Improve the support of family caregivers during emergencies (e.g., pandemics, natural/manmade disasters).

Recommendation 3.8: Increase the prevalence and use of future planning as a means for ensuring family members have the needed supports in place throughout the care recipient's life.

Recommendation 3.9: Increase and strengthen the paid LTSS and direct support workforce.

Financial and Workplace Security for Family Caregivers

Goal 4: Family caregivers' lifetime financial and employment security is protected and enhanced.

Recommendation 4.1: Decrease the negative financial impacts for family caregivers on both a short- and long-term basis.

Recommendation 4.2- Advance the development and broad adoption of employee-centered flexible workplace policies and practices that support work/life balance and maintain performance when personal circumstances change.

Recommendation 4.3: Increase the availability, and use of, financial education and planning tools for family caregivers.

Recommendation 4.4: Improve the affordability of long-term services and supports and reduce out-of-pocket costs for families through public and private payers.

Research, Data, and Evidence-Informed Practices

Goal 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

Recommendation 5.1: Establish a national infrastructure using standardized data, questions, and a definition of “family caregiver” for obtaining, analyzing, and disseminating information about caregivers and their experiences.

Recommendation 5.2: Increase 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.

Recommendation 5.3: Increase the promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of healthcare and long-term services and supports.