

Assembly Bill Draft Request AKA “Compelled Caregiving Bill”

BDR Summary: Establishes requirements related to programs for family caregivers.

Background:

In 2000, Congress established the National Family Caregiver Support Program (NFCSP) as part of the reauthorization of the Older Americans Act (OAA), marking the first federal recognition of the critical role families play in the nation’s system of long-term services and supports. The estimates of the prevalence of informal caregiving make it clear that there is a great deal of reliance on family members to provide care to people living in the community.

Family caregivers have stepped into the role of caregiver to meet these long-term support needs without education, training, or an understanding of the sacrifices and tradeoffs they will be required to make. They are compelled by the desires of the recipient of care, family expectations, cultural expectations, social expectations, their own expectation of receiving familial and community support, and the lack of acceptable alternatives for care.

An extensive body of research documents the negative physical, emotional, and financial consequences that caregiving brings. The combination of loss, prolonged distress, the physical demands of caregiving, and any biological vulnerabilities of caregivers may compromise their physiological functioning and increase their own risk for physical health problems, even leading to increased mortality.

Currently, Nevada does not have a system of caregiver assessments to address the health and well-being of family caregivers, even at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers. Family caregivers are the critical link to ensuring that the instructions of medical providers are implemented outside of the physician’s office or hospital.

Because of caregiving pressures and demands, family caregiver regularly need an intermittent break or short-term relief from the day-to-day responsibilities of care. Respite care for the caregiver helps sustain the health and well-being of the caregiver, helps avoid or delay costly out-of-home placements, and reduces the likelihood of abuse and neglect. Unfortunately, the link to respite is not made when it could provide protective and restorative benefits, because the needs of the caregiver are not assessed until the caregiver is in crisis.

In recognition of the pressures and demands of caregiving, there are several national initiatives that emphasize the importance of caregiver assessments.

First, the Centers for Medicaid and Medicaid Services (CMS) final rule for section 1915(i) State Plan HCBS, states in § 441.662 (a)(4) a new requirement for a caregiver assessment. When caregivers are

being relied upon to implement the person-centered service plan, it is important that a caregiver assessment be required, to acknowledge and support the needs of informal family caregivers. Caregivers provide critical care and support that enables individuals to live in their homes and communities. When there is a caregiver involved, an assessment of the caregiver's needs is essential to facilitate the individual's linkage to needed supports. The capacity of primary caregivers to provide for the individual's assessed needs is necessary, as natural supports often have declining capacity, and failing to take this into account leads to unrealistic plans. <https://www.federalregister.gov/d/2014-00487>

Secondly, caregiving issues were of particular interest to policymakers in the 2020 reauthorization of the Older Americans Act. P.L. 116-131 amends the National Family Caregiver Support Program (NFCSP) to include caregiver assessments, allowing Area Agencies on Aging (AAA) to utilize assessments in determination of services to be provided. Caregiver assessment refers to a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to the needs of the care recipient. Administration on Community Living (ACL) provides technical assistance on caregiver assessment, including *"tools and templates, comprehensive assessment protocols, and best practices concerning— (1) conducting caregiver assessments (including reassessments) as needed; (2) implementing such assessments that are consistent across a planning and service area, as appropriate; and (3) implementing caregiver support service plans, including conducting referrals to and coordination of activities with relevant State services."* [Public Law 116 - 131 - Supporting Older Americans Act of 2020 - Content Details - \(govinfo.gov\)](#)

Previous CMS guidance on the Balancing Incentives Program also acknowledged the importance of caregiver assessment. CMS recommended that family caregiver needs be considered as part of best practices, recognizing that *"families and/or caregivers often have needs outside the needs specific to the individual eligible for services. These needs are typically connected to caregiver stress, a need for information and referral, support groups and/or respite care. An assessment process that incorporates components tied to caregiver needs will result in a more well-rounded assessment of the service and support needs of the whole family."*

Since 2018, Medicare and Tricare have reimbursed clinicians for care planning services provided to individuals with cognitive impairment, including Alzheimer's disease and other dementias, mild cognitive impairment, and those individuals without a clinical diagnosis who, in the judgement of the clinician, are cognitively impaired. Under CPT code 99483, physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified nurse midwives can currently bill under this code every 180 days per client. The code includes specific identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, the willingness of caregiver to take on caregiving tasks, and the ability to provide care.

Our recommendation is to propose legislation that establishes a process for hospitals, Medicaid waiver programs, healthcare professionals, and agency programs for Long Term Services and Support (LTSS) that rely on a family caregiver to provide care and support for a person with a disability, terminal illness, cognitive impairment, or chronic healthcare condition (Inclusive of definitions in NRS 449A, NRS 426,

and NRS 427A) to assess caregiver willingness, ability, and needs to provide that care long term, and provide data from the assessments to the Nevada Department of Health & Human Services (DHHS).

This legislation will emphasize caregiver engagement, including the use of evidence-support and culturally sensitive family caregiver assessments, to measure the extent, quality, value, or effect of family caregivers' social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk.

Suggested NRS Provisions

- DHHS to conduct an interim study of caregivers to include: 1) evidence-supported and culturally sensitive family caregiver assessments, to determine the willingness, ability, and needs of a family caregiver to provide long term services and supports to a person with a disability or special healthcare condition, 2) measuring the extent, quality, value, or effect of family caregivers' social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk, 3) the efficacy of referrals linking caregivers to local community resources, and 4) a process for gathering data from assessments for annual reporting.
- Implement a pilot program of the caregiver assessment tools and process developed in the interim study, expanded, based on recommendations from the study, to include other target populations, with an emphasis on strategies to address unmet demand for community resources.
- Report results of the study and pilot program to the Nevada Lifespan Respite Care Coalition, the Commission on Aging, the State Independent Living Council, and the Commission on Services for People with Disabilities annually throughout the biennium.
- DHHS will develop a system for all programs, including subrecipients, to report caregiver assessment data, and require participation as part of grant awards.
- DHHS will publish an annual report of caregiver data to include family caregivers' willingness, ability, and needs to provide long term services and supports, social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk.

Additional Items for Consideration/Research

- Conduct an interim study on the expansion of NRS 449A.324 to include a caregiver assessment, upon hospital discharge, of the caregiver's capacity to provide all necessary aftercare, including any ADLs and IADLs.
 - Require hospitals to report data to DHHS Office of Data Analytics
- Conduct an interim study on the use of CPT Code 99483 to analyze its usage for caregiver assessments in Nevada, specifically identifying caregiver knowledge, caregiver needs, social supports, the willingness of caregiver to take on caregiving tasks, and the ability to provide care.
 - Require practitioners to report data to DHHS Office of Data Analytics