

# Family Caregiver Assessment – Pilot

SFY2024 Annual Report | Assembly Bill 100 (2023)

## Introduction

Family caregivers are an integral part of the long-term service and support systems and are vital to supporting older adults and people with disabilities remain in their homes and communities for as long as they wish. Supporting family caregivers in this role through identification, training, and support is critical to helping family caregivers maintain their own health and well-being.

The Nevada Aging and Disability Services Division (ADSD) has been working to build a system of respite support for family caregivers since 2009. These efforts have resulted in training, expanded services, and pilot programs testing different models of respite. Throughout this time, it has become evident that the one gap that continues to be a challenge is data specific to the caregivers themselves. Caregivers are often recognized as part of an individual's support system, however data regarding the types of care, the number of care recipients, the burden of care, or the need of the caregiver is not collected. In the rare instances where caregiver data is collected (such as through Nevada Care Connection Resource Centers), there is not a data system available to easily extract and analyze the data.

Often, respite is seen as a service for the care recipient, rather than a service for the caregiver. There is a need for a shift in perspective to recognize that often there can be two individuals that need support – the care recipient and the family caregiver.

In the 2023 Legislative Session, the Legislature passed Assembly Bill 100 (AB100) requiring ADSD to research and pilot an evidence-based caregiver assessment that measures five core areas:

- (1) The willingness and ability of family caregivers to provide long-term services and supports to a person with a disability or health condition.
- (2) The extent, quality, value, and effect of social determinants of health, specific risk factors related to stress and depression, as well as environmental and cultural barriers on family caregivers.
- (3) The efficacy of referrals linking family caregivers to local community resources.
- (4) Capacity of each family caregiver to provide all necessary care, including activities of daily living and instrumental activities of daily living.
- (5) Identify the knowledge and needs of family caregivers to undertake caregiving tasks

This legislation is in line with recommendations from the National Family Caregiver Strategy developed by the Family Caregiving Advisory Council established through the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act in 2018.

## Pilot Program Status

In previous years, ADSD has piloted a caregiver support program from the Benjamin Rose Institute (BRI) called Care Consultation. This program provides telephone support to family caregivers, including ongoing 1:1 support calls. Today, this program is sustained by two community organizations specializing in caregiver support, without ongoing support from ADSD. It is not available statewide.

In State Fiscal Year (SFY) 2023, ADSD explored another evidence-based program known as T-Care. This program includes assessment, training, and data collection. In SFY 2024, ADSD has also looked at additional evidence-based programs including Trualta and Archangels, which have similar offerings of T-Care. All three of these evidence-based options have strong merits, with slightly different focus and the shared challenge of sustainability.

Outside of the exploration of evidence-based programs, ADSD began collecting existing assessments that are used by current community partners within Nevada as well as assessments that are used across respite programs in other states.

In SFY 2019, ADSD implemented a caregiver intake assessment within the Nevada Care Connection Resource Centers. This assessment collects demographic information about the care recipient and caregiver, as well as asks questions related to the caregiver's role, the impact of caregiving on areas such as housing, mental well-being, and their needs. Currently, the use of this tool is limited and there is no mechanism for the resource centers to report the data to ADSD.

The goal during this state fiscal year was to start a workgroup that could help assess the various tools collected (or previously implemented) to determine an appropriate course of action including choosing between the develop an informal assessment that captures all required data from AB100 or utilize an evidence-based which would have an ongoing financial investment.

Due to staff turnover, the workgroup was not started. ADSD is negotiating with a vendor under the statewide contract for consulting, marketing, and education services to help support this pilot as part of work in existing federal Lifespan Respite Care programs. ADSD anticipates being able to continue efforts to implement a pilot that has broader support in state fiscal year 2025, with a current goal of piloting an assessment by January 2025 (pending finalization of a contract and Board of Examiner approval).

## Conclusion

The identification and support of family caregivers is essential to the health and well-being of care recipients as an investment in long-term services and support. Providing support to family caregivers not only helps prevent or delay institutionalization for older adults and people with disabilities, but it also improves the health outcomes of the caregivers themselves. The previous investments made through federal funding from the Lifespan Respite Care Program have demonstrated the value of caregiver support and respite. This pilot is an opportunity to build upon the lessons learned, while also gaining broader support and implementation to sustain efforts long-term.