

November 21, 2022

Comments to ACL proposal to support family caregivers

Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 characters)

- 1) Family caregivers need support that is comprehensive and consistent. Support needs range from financial planning information and guidance to funding trained employees to provide relief for caregivers.
- 2) Long-term services and support should be funded so services are readily available and minimize or eliminate wait lists for all types of residential needs and for short-term emergency needs. Every beneficiary has unique medical requirements. If they have an available family member caregiver, they too have individualized capabilities and constraints. ACL should prioritize equitably supporting programs to ensure that the entire continuum of this community has the best quality care available at all times.
- 3) Prioritize data collection that reveals nuances in federal benefits so that it can assist with the above. The data could allow policymakers to continue or establish programs that recognize that not all beneficiaries have guardians available, capable, or willing to assist in providing for all or some of their needs. Federal funding should work in parallel with data and policy to ensure timely support for the entire spectrum of needs.
By reducing wait times for emergency, short-term, and long-term care needs, ACL will have a positive impact on caregivers' financial, emotional, and physical burdens.

Are there issues that are not covered in this component that should be addressed in future updates? (1500 characters)

Direct Support Professionals (DSPs) are in crisis. It is imperative that all federal agencies working in this space prioritize ensuring that individuals with I/DD have the care necessary to keep them safe.

To provide a long-term solution, VOR urges establishing an HCBS Family Caregiver Support Program based on the successful Veterans Affairs Program of Comprehensive Assistance for Family Caregivers (PCAFC).

The family caregiver would complete a training program for certified nursing assistants (CNAs), and then would be employed by a home health agency. This would enable the caregiver to receive competitive compensation and earn Social Security benefits for work done. This also would enable state and federal governments to receive tax revenue from additional employees in the workforce, and such caregivers could receive healthcare benefits through their employer -- all of which would improve the care provided to the beneficiary, address the quality of life for the caregiver, and reduce strain on state and federal governments.

Support for the caregiver would include direct oversight from the supervising nurse case manager of the home health agency (as traditional CNAs do). Data collection would improve as the family caregiver

would be reporting data as other CNAs do. This would address the common hurdle of adjusting government programs to best fit the needs of those it serves while being fiscally mindful of taxpayer funds.

If you have additional comments on any aspect of the Strategy, please provide them below. (500 characters)

The I/DD system must maximize and protect choice. Healthcare needs for I/DD patients are continually evolving. Medical and behavioral needs ebb and flow during a patient's life. Also, the ability of guardians to continue as caregivers may change. Residential care choices should be comprehensive and readily available. Best policies allow for the fluidity of medical care and residential settings - recognizing ever-changing patient needs and respecting patient and guardian choice.