**Special Needs Alliance Provides Comments In Support Of Family Caregivers**

In 2017, Congress passed the RAISE Family Caregivers Act creating the Family Caregiving Advisory Council to advise and provide recommendations to the U.S. Department of Health and Human Services (HHS) on supporting family caregivers. In November 2022, the RAISE Family Caregiving Council sought comments on its strategic priorities.

The Special Needs Alliance (SNA) is pleased to have the opportunity to submit comments on behalf of its thousands of family caregiving clients throughout the United States. The 143 members of the SNA have an average of 18 years of relevant legal experience and meet with family caregivers each day struggling to provide care to loved ones with disabilities, with many members also serving as family caregivers of their own loved ones with disabilities.

While we applaud and support the numerous actions presented by the Council, the SNA reported what it sees as some of the highest priorities necessary to support family caregivers:

* **End the compensation bias against family caregivers embedded in Medicaid programs**. Parents, spouses, siblings, and other family members should not be expected to provide extraordinary care out of “love and affection” when those parents, spouses, and other family members are precluded or prevented from working outside the home to ensure the care and safety of their loved ones. Furthermore, any prohibition on the payment of a person who is the natural or legal guardian of an individual who needs care and support must be eliminated.

Antiquated compensation hurdles and roadblocks often presented to or imposed upon family caregivers are irrationally discriminatory and a senseless barrier to meeting the escalating caregiving crisis American families face. Systems to prevent abuse should be applied equally to *all* caregivers and not through presumptive regulations preventing meaningful compensation to family caregivers. In many parts of the country, care plans are developed and even funded, but cannot be utilized because of the lack of available direct support staff. The value of and need for compensated family caregivers to stem this staff shortage cannot be understated.

States should be pressed by the Department of Health and Human Services (HHS) as well as the Centers for Medicare and Medicaid Services (CMS) to allow for compensation of family caregivers through the myriad of 1915(c) waiver programs, regardless of disability type and regardless of family relation. Exceptions made for family caregivers in the public health emergency are a positive start and should be made permanent and expanded upon.

* **Proactively end the reliance on families as a caregiving “crisis” plan**. Currently, crisis planning is virtually non-existent and heavily relies on family caregivers (otherwise known as unpaid natural supports) to step in and address any needs and shortfalls in care. Family caregivers cannot be the presumed crisis plan expected to put their own lives on hold to manage a loved one’s care or housing crisis. The converse is also true in that when family caregivers are the primary care plan, they cannot also be the crisis plan. Crisis planning must be done proactively, preventatively, and enhanced to contemplate family caregivers’ need for support and respite.
* **Improve Caregiving Compensation**. Family caregivers must often disrupt their lives, careers, and aspirations when outside caregivers cannot be found. There can be no higher priority than improving caregiver compensation. A caregiver shortage existed before the public health emergency, and it has only been exacerbated. Record numbers of retirements and only a fractional amount of human capital are entering the workforce to replace them.

Due to the abysmal pay scale, nonprofit disability service organizations cannibalize each other for the same staff. In most of the country, current and prospective caregivers will work for non-caregiving private industry jobs where they can make several more dollars an hour for what is likely an easier, albeit mundane, job. Ensuring a strong workforce to support individuals with disabilities and chronic illnesses of all ages is necessary, and more than lip service must be devoted to making this issue a priority.