**Global Comment for all Four Components**

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

Compensation. Meaningful compensation to family caregivers regardless of family relation or the nature of the disability. Parents, spouses, 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. Any prohibition on the payment of a person who is the natural or legal guardian of an individual who needs care and support needs to be eliminated. Hurdles and roadblocks to give the appearance of conflict avoidance and limitation on system abuses, without providing any meaningful benefit to the individuals who need support, also need to be eliminated.

Crisis Planning. 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 the provision of care. Family caregivers cannot be the presumed crisis plan. Crisis planning needs to be done proactively, preventatively, and enhanced to contemplate the need for family caregivers to have support and respite.

Demographics and economics. A caregiver shortage existed prior to the public health emergency, and it has only been exacerbated. Record numbers of retirements and only a fractional amount of human capital entering the workforce to replace them. The nation is at the front end of the need for family caregivers, this trend will increase, and increase rapidly over the next five to ten years. The value of and need for family caregivers, and the need to compensate those caregivers, cannot be understated.

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

The 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) waver programs, regardless of disability type and regardless of family relation. Specifically, many states do not permit parents or legal guardians to be compensated through their waiver programs that support individuals with intellectual and developmental disabilities, leaving families without paid support. In many parts of the country care plans are developed and even funded, but they cannot be utilized because of the lack of available direct support staff. Most person-centered planning requires a significant amount of advocacy and oversight by family caregivers who are not compensated for their time, in a system that gains additional complexity with each passing year. Housing options for the intellectual and developmental disability population is also limited resulting in more and more adults with intellectual and developmental disabilities living with their families well into adulthood with no financial support and limited if any community support.

Due to the abysmal pay scale, not for profit disability service organizations are cannibalizing each other for the same staff (also happening in hospitals and nursing homes), and in many locations those would be staff are going to 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 there is a strong workforce to support individuals with disabilities and chronic illnesses of all ages is a necessity and more than lip service needs to be devoted to making this issue a priority.