



www.HaystackProject.org

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NOTE: This RFI is a fillable form located here: <https://acl.gov/CaregiverStrategy/Comments>
Responses will need to be copy/pasted into the form. The form has strict length limits. The responses have been drafted to respond to the questions presented in the form and within the length requirements.

Which component of the strategy are you addressing with your comment?

The 2022 National Strategy to Support Family Caregivers narrative

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 max)

Haystack Project is a 501(c)(3) non-profit organization enabling its 120 rare and ultra-rare disease advocacy organizations to amplify the patient and caregiver voice in disease states with unique sets of caregiver needs. Challenges start with symptom emergence, continue through protracted diagnostic journeys, and increase as caregivers struggle with accessing specialists and treatments. Haystack urges the Advisory Councils to focus on:

1. The actions listed in Table 1. Legislative and Other Policy Changes to Support Family Caregivers. In undertaking these initiatives, we urge consideration of the rare and ultra-rare disease community's unique care and caregiver needs.
2. Outcome 3.2: "Family Caregivers can obtain respite services that meet their unique needs." Families caring for an individual with an ultra-rare disorder have respite care needs that may be unique to the specific condition and diverge from respite care associated with elder care. We urge initiatives that are patient- and caregiver-centered, accessible to underserved communities, and sufficiently flexible to ensure that the rareness of a condition does not impede access to needed respite services.
3. Expanding the set of stakeholders involved in developing, prioritizing, and implementing the Strategy to include rare and ultra-rare disease patient advocates. Haystack Project, for example, engages its 120 patient organizations on key policy initiatives to ensure robust participation that captures the patient and caregiver voice in prioritizing high-value access-to-care and support services.

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

Unfortunately, the strategy does not consider the unique caregiver challenges with rare and ultra-rare diseases. As 50% of the people affected by rare diseases are children, rare disease issues are fundamentally caregiver issues.

We ask that Table 1. Legislative and Other Policy Changes to Support Family Caregivers, include:

- Creation of an CMS/HHS Ombudsman for rare and ultra-rare diseases to improve caregiver navigation of resources that may be particularly helpful and identify resource gaps that can be addressed as caregiver initiatives are developed and implemented
- Ensuring that robust newborn screening (including genetic testing) is available in all states and includes testing for rare and ultra-rare conditions that can be identified and addressed through treatments as well as those for which families will likely benefit from caregiver resources.
- Reducing caregiver burdens associated with participation in clinical trials. Families caring for an individual with a rare or ultra-rare disorder wait and hope for advances in research. Many families are unaware of clinical trials, and those that are aware can face significant financial and logistic burdens in accessing promising therapies through clinical trial participation.

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

We also urge policy makers to consider the use of technologies to enable meaningful telemedicine services (greater access to broadband internet) as well as coverage mechanisms that enable caregivers to maximize the benefit of remote monitoring services, including the use of wearables and other items that can track patient progress, communicate data to clinicians, and enable caregivers to recognize symptoms or symptom changes requiring medical care and/or emergency services.

Which component of the strategy are you addressing with your comment?

First Principles: Cross-Cutting Considerations for Family Caregiver Support.

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 max)

Haystack Project enables its 120 ultra-rare disease advocacy organizations to amplify the patient and caregiver voice. Families facing an ultra-rare condition have unique needs that start with symptom emergence, continue through a protracted diagnostic journey, and increase with the struggle to access specialists and treatments. We urge focus on:

- “Advancing Equity, Accessibility, and Inclusion” Rare and ultra-rare disease caregivers should be connected to disease-specific advocacy organizations through the Family Caregiving Information Platform. Our member organizations offer resources to families that include discussion and support forums, recommendations on specialists, summaries of treatments, including clinical trials, and even patient registries. These organizations reduce the potential that caregivers feel “alone” as they face a condition that may be unknown in their community. Broader inclusion

within underserved populations will both enhance the caregiver experience and potentially lead to increased diversity in patient registries and clinical trials. Federal support for ultra-rare disease organizations will maximize the reach of existing resources for the caregiver community.

- “Elevating Direct Care Workers as Family Caregiving Partners” – Low reimbursement rates for direct care workers significantly reduces the available workforce and shifts the burden of reimbursable services from the health system to family caregivers. Medically necessary home nursing care, for example, is unavailable in many areas due to insufficient payment.

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

The principle of “Placing the Family and Person at the Center of All Interactions” is extremely important to the rare and ultra-rare disease caregiver community and we urge that initiatives are implemented in a manner that is sufficiently flexible to accommodate the unique needs associated with low-prevalence conditions. As 50% of the people affected by rare diseases are children, rare disease issues are fundamentally caregiver issues. Parents, grandparents and other caregivers are the ones responsible for navigating the diagnostic odyssey, coordinating out-of-state care, fighting for coverage of off-label pharmaceuticals on top of providing physical and emotional support for their child. Sets of resources developed to support families collaborating on care of a parent with dementia would be inadequate – quantitatively and qualitatively – for families struggling to maximize the opportunity for their child to live a happy, productive life despite their ultra-rare condition.

Haystack urges the Council to prioritize caregiver resources to navigate coverage eligibility. Caregivers are often forced to spend time and energy fighting for coverage of specific providers, specific drugs or even eligibility for Medicare, Medicaid and CHIP programs rather than providing direct care for their dependent. Easing the burden of navigating the healthcare system would be a considerable step in reducing the overall caregiver burden, regardless of the type of patient or caregiver.

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

We also urge policy makers to consider the challenges faced by patients who must travel across state lines to access the limited pool of expert and knowledgeable providers for their condition. It is important not only to cover and coordinate these necessary acute services for children with medically complex conditions, but it is also important to integrate/coordinate that care locally to ensure these individuals receive optimal, timely, and efficient ongoing care.