

Congress of the United States

Washington, DC 20515

November 14, 2019

Lance Robertson
Administrator and Assistant Secretary for Aging
Administration for Community Living
330 C Street S.W.
Washington, D.C. 20201

Dear Mr. Robertson:

As Members of Congress, we commend the Administration for Community Living and the newly constituted Family Caregiving Advisory Council for its work in supporting family caregivers. We appreciate that the Council held its first meetings in August 2019 to identify and coordinate resources and best practices to support family caregivers. However, we write to express our concern that the Advisory Council is not considering the needs of youth caregivers and does not currently have representation from child caregivers on its Advisory Board.

The RAISE Family Caregivers Act, which became law on January 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. This strategy is intended to identify actions that communities, providers, governments, and others may take to recognize and support family caregivers. To support the development and execution of this strategy, the RAISE Act establishes the Family Caregiving Advisory Council. This Council is charged with providing recommendations to the Secretary of Health and Human Services on effective models of family caregiving, as well as appropriate supports for family caregivers.

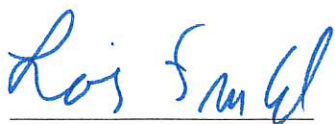
The RAISE Act defines family caregiver as “an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.” In addition, the Act specifically directs that the Council include up to 15 voting members who reflect the diversity of family caregivers and people who receive support for caregiving. Nothing in the statute indicates an intent to exclude youth caregivers. Yet, to date, none of the Council’s Advisory Board members are experts on youth caregiving.

This is an unfortunate oversight. There are at least 1.3 million caregiving youth in the United States ages 8-18 years old. These youth provide significant assistance, sometimes alone, to relatives or family members who need support because of chronic or terminal health conditions associated with aging, disabilities, addiction, and other conditions. The care they provide mirrors the care that adult caregivers give. However, the academic, physical, developmental, and emotional impact of caregiving on youth is often hidden behind closed doors. As a result, they lack the support they need to succeed.

As Members of Congress we must ensure caregiving youth have the support and resources they need to thrive. Therefore, we ask that the Administration for Community Living and the new Family Caregiving Advisory Council consult with experts on youth caregiving and thoroughly consider the needs and perspectives of youth caregivers at future meetings.

Thank you for considering our request, and we look forward to your response.

Sincerely,



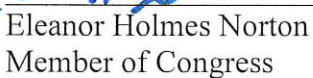
Lois Frankel
Member of Congress



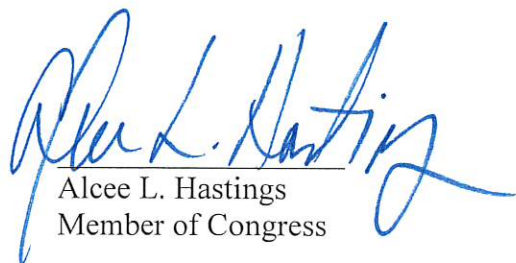
Kathy Castor
Member of Congress



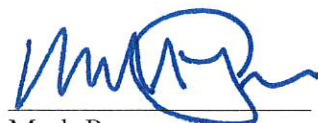
Sheila Jackson Lee
Member of Congress



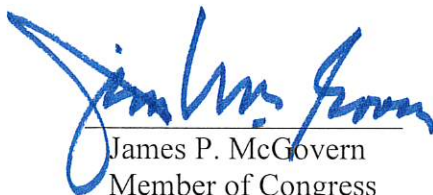
Eleanor Holmes Norton
Member of Congress



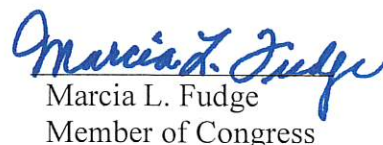
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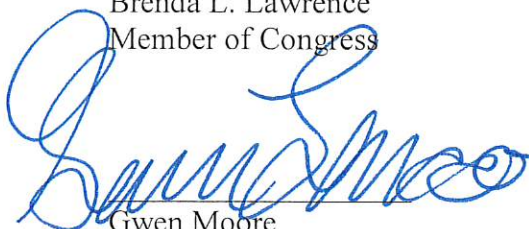
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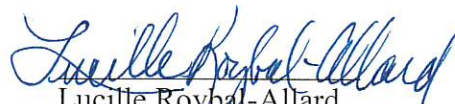
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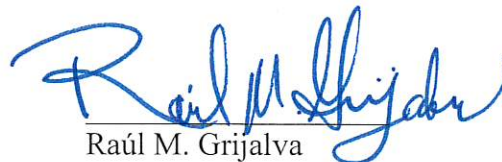
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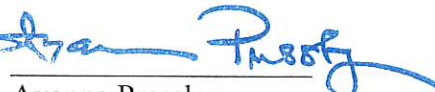
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