

Louisiana Developmental Disabilities Council

SELF-DETERMINATION ♦ INDEPENDENCE ♦ PRODUCTIVITY ♦ INTEGRATION ♦ INCLUSION

February 11, 2020

Mary Lazare, Principal Deputy Administrator
Administration on Community Living
U.S. Department of Health and Human Services
330 C St. SW
Washington, DC 20201

Re: Reconsideration of Developmental Disabilities Councils membership eligibility of family members of individuals with developmental disabilities who are recently deceased

Dear Mrs. Lazare,

The Louisiana Developmental Disabilities Council (Council) requests the Administration on Community Living (ACL) reconsider the determination defining a family member of an individual with a developmental disability for purposes of Council membership to not exclude family members of individuals with developmental disabilities who are recently deceased.

The Council was aware of the decision issued on September 14, 2016 by then Commissioner of the Administration on Disabilities, Aaron Bishop to similar requests by other State Councils on Developmental Disabilities to the Administration on Intellectual and Developmental Disabilities (AIDD). Specifically, the AIDD believes that the intent of the DD Act is for the family member role to be filled by a family member of living individuals with developmental disabilities to be represented on the DD Council.

The Council believes there are multiple reasons to consider having Council members whose immediate family member with developmental disabilities is deceased. First and foremost, children with the most significant disabilities need a more comprehensive array of services and would more likely have a higher probability of mortality at a young age than other children, even among other children with developmental disabilities, albeit less involved medically complex or significant disabilities. Unfortunately, the voice of parents of some of the most involved children tends to be underrepresented due to these parents being consumed with providing life-supporting care for their children while they are alive. Parents of children with some of the most significant disabilities may also have the ultimate experience of failures in the service delivery system. These parents' passion for change has only been fueled by their continued love for their children.

As it relates to systems change, parents of children who are recently deceased are clearly seeking to serve the community at large. While these parents may not have an individual child who will be impacted by any policy or programmatic changes, they do have a vested interest and desire to ensure changes are made to ensure parents who

February 11, 2020

Page 2 of 2

are too busy with caring for their children will have access to needed and appropriate supports and services.

The Council hopes ACL will reconsider its position on this issue and allow family members of individuals with developmental disabilities who are deceased to serve on State DD Councils.

Thank you again for your leadership and commitment to improving the lives of people with developmental disabilities.

Respectfully,

A handwritten signature in black ink that reads "April Dunn". The signature is written in a cursive, flowing style.

April Dunn

AD:spf