February X, 2023

Hon. Andrea Stewart-Cousins Hon. Carl Heastie

President Pro Tempore and Majority Leader Speaker

NYS Senate NYS Assembly

Legislative Office Building Legislative Office Building

Room 907 Room 932

Albany, NY 12247 Albany, NY 12248

Hon. Liz Krueger Hon. Helene Weinstein

Chair, Finance Committee Chair, Ways and Means Committee

Capitol Building Legislative Office Building

Room 416 Room 923

Albany, NY 12247 Albany, NY 12248

Dear Leader Stewart-Cousins, Speaker Heastie, Chair Krueger, and Chair Weinstein:

I XXXXXXXX (example: parent, educator, community advocate, etc) write to you today to urge you to include language in the FY 2023-24 budget that that would **add fetal alcohol spectrum disorders (FASDs), including fetal alcohol syndrome, partial fetal alcohol syndrome, and alcohol-related neurodevelopmental disorder, to the definition of “developmental disability”.**

FASD is a pressing public health problem with the National Institutes of Health estimating

that 1 to 5 percent of Americans may have FASD, making FASD more prevalent than previously

recognized. And yet, it is often missed. Children and adults with FASD struggle with life-long

learning and behavioral problems. Without appropriate supports, individuals with FASD are at high

risk for adverse life experiences, such as mental health problems, trouble with the law, school

disruption, and substance abuse. An early diagnosis and appropriate services can help prevent these

secondary problems.

In New York state, there are only two FASD Clinics: one in New York City, consisting of a

single provider; and the other, the University of Rochester’s FASD Diagnostic and Evaluation Clinic,

which is a multidisciplinary clinic created in partnership with Mt. Hope Family Center and

Developmental and Behavioral Pediatrics at Golisano Children’s Hospital within the University of

Rochester Medical Center.

Currently, FASD is not considered a developmental disability under OPWDD. This lack of

definitional inclusion has prevented patients with FASD from receiving services from OPWDD such

as family services (i.e. in-home behavioral supports), recreation and socialization services

(specialized recreational camps), and employment assistance from OPWDD (i.e. job training and

coaches). Additionally, OPWDD can provide needed assistive technology such as an electronic

communication device that allows individuals with varying communication abilities to be able to

connect with other individuals. Lastly, many individuals with FASD need extra support to learn the

skills to live independently while others want to remain in their family home but require support to

do that. For children, OPWDD can provide supports that can help them live at home more safely.

OPWDD has indicated that they believe this change in the statute will have a fiscal cost

associated with it, which is why we are urging you to include this legislative language in the FY 2023-24 budget. However, it is important to also note that the cost will not be great to the state,

as money spent in the OPWDD system will likely reduce expenditures on individuals with FASD in

other systems of care such as the mental health and justice systems. In addition, as noted above, there

are only two clinics in NYS that provide FASD diagnosis, with a yearly FASD diagnosis totaling

less than 150 people per year. Inclusion of FASD into law as an identified disability category (or qualifying condition) would ensure that those who need support from OPWDD finally receive it.

INCLUDE PERSONAL NOTE ON IMPACT TO YOU

Thank you for your consideration and again I urge you to include language that would add fetal alcohol spectrum disorders (FASDs) to the definition of “developmental disability” in the FY 2023-24 budget.

Sincerely,