

MEMORANDUM IN SUPPORT**Bill: A.2297 (Clark)/S.1866 (Brouk)****Subject: AN ACT to amend the mental hygiene law, in relation to adding fetal alcohol spectrum disorders to the definition of developmental disability.****Date: January 31, 2023**

The University of Rochester strongly supports legislation (A.2297/S.1866), which would add fetal alcohol spectrum disorders, including fetal alcohol syndrome, partial fetal alcohol syndrome (pFAS), and alcohol-related neurodevelopmental disorder (ARND), into the definition of developmental disabilities ensuring that people with this disorder can receive state funded services and aid through agencies such as Office for People With Developmental Disabilities (OPWDD).

Fetal Alcohol Spectrum Disorders (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 the condition 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 secondary conditions, 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 through Mt. Hope Family Center and Developmental and Behavioral Pediatrics at Golisano Children's Hospital within the University of Rochester Medical Center. The University of Rochester clinic currently serves children and adolescents from infancy through age 16 years old. Services available include FASD diagnostic evaluations and neuropsychological assessments to identify the child or adolescent's strengths and weaknesses to aid in treatment planning. The University of Rochester's FASD clinic has the capacity to see 220 children each year and draws families from across the state but also from neighboring states.

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 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.

For the reasons stated above, the University of Rochester urges the Legislature to consider and pass A.2297/S.1866.