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INFORMATIONAL LETTER

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To:	Executive Directors of Voluntary Provider Agencies Executive Directors of Care Coordination Organizations Developmental Disabilities State Operations Offices (DDSOO) Directors Developmental Disabilities Regional Offices (DDRO) Directors
Issuing OPWDD Office:	Division of Statewide Services
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Subject:	Fetal Alcohol Spectrum Disorder (FASD)
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Attachments:	N/A

Related ADMs/INFs	Releases Cancelled	Regulatory Authority	MHL & Other Statutory Authority	Records Retention
23-ADM-02		14 NYCRR 629	MHL §§ 1.03; 13.01; 13.07; 13.09	

PURPOSE

OPWDD is responsible for determining whether someone meets OPWDD eligibility. To be eligible for OPWDD services, the person must meet the qualifications outlined in statute, regulation, and guidance. OPWDD eligibility requires the presence of a qualifying diagnosis, onset prior to age 22, likelihood of indefinite continuation, and substantial impact on the person's ability to care for themselves (i.e., the condition results in a "substantial handicap").

The purpose of this informational letter is to describe the current state of research and understanding of Fetal Alcohol Spectrum Disorder (FASD), the leading preventable cause of intellectual disability, and to describe FASD in the context of OPWDD eligibility criteria.
This Informational Letter will review what FASD is, how the diagnosis is made, risk factors for FASD, prevalence of the condition, and OPWDD eligibility considerations for a FASD diagnosis.

DISCUSSION

A. About Fetal Alcohol Spectrum Disorder

Alcohol consumed during pregnancy can damage the developing fetus. A range of physical and mental effects may be seen, including intellectual disability, depending on the timing and amount of exposure to alcohol. No level of alcohol consumption is considered safe during pregnancy.

Fetal Alcohol Spectrum Disorder (FASD) is a non-diagnostic umbrella term that refers to identifiable consequences of prenatal alcohol exposure including adverse impacts on learning, behavior, and/or physical health. Disorders and terms that fall under the umbrella term of FASD include Fetal Alcohol Syndrome (FAS), Partial FAS (pFAS), Fetal Alcohol Effects (FAE), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD).

Fetal Alcohol Syndrome (FAS) is usually considered to be the most severe form of FASD and is characterized by growth deficiency, facial dysmorphisms (abnormalities), and central nervous system damage.

B. Diagnosis

The diagnosis of an FASD involves gathering information about possible fetal alcohol exposure, looking for characteristic physical findings, and reviewing information related to developmental, cognitive, and behavioral concerns. There is no medical test (e.g., blood test) to determine if someone has FASD. This can be complicated, because other disorders can have some similar symptoms (e.g., Attention-Deficit/Hyperactivity Disorder) and Williams syndrome) (Center for Disease Control; CDC).

The specific diagnosis identified may vary depending on the diagnostic classification system used. Currently, there are at least 4 different diagnostic classification systems used in North America. Discrepancies between diagnostic tools and classification systems can lead to variability in research findings. From a clinical perspective, such discrepancies can also lead to misdiagnoses and missed diagnoses (Brown et. al, 2019). Ongoing efforts towards identification of a single research classification system have been reported (Mooney, Petrenko, Hamre, & Brigman, 2022).

The impact that alcohol can have on a developing fetus range from minimal/no effects to a diagnosis of Fetal Alcohol Syndrome (FAS). Research has not yet determined absolute dose (i.e., how much alcohol consumed) or timing (i.e., when during the pregnancy) thresholds related to alcohol exposure that clearly demarcate when or how much damage may occur. There appears to be a great deal of variability between mothers and fetuses, metabolism, genetics, and interactions of environmental factors, that may influence susceptibility to prenatal alcohol exposure (Canada FASD Research Network). For example, a recent study of fraternal twins found that virtually identical prenatal alcohol exposures led to markedly different fetal alcohol spectrum disorder outcomes, suggesting that genetic vulnerability plays a significant part in susceptibility to adverse outcomes related to prenatal exposure to alcohol (Hemingway et. al, 2018).

C. Risk Factors

Consumption of alcohol during pregnancy is the cause of FASDs and is the leading cause of *preventable* intellectual disability. Maternal alcohol consumption during pregnancy, however, still occurs.

Recent self-report data indicates that 13.5% of pregnant adults reported current drinking and 5.2% reported binge drinking (defined as 4 or more drinks on an occasion) within the past 30 days (Gosdin et al., 2022). Considering that nearly half of all pregnancies in the United States are unplanned and that there is often a delay between the time of conception and the time that a person discovers that they are pregnant, the person may also unknowingly expose the fetus to alcohol by drinking before they realize they are pregnant. One researcher recently estimated that 54% of pregnancies that result in a live birth in the United States have been exposed to alcohol at some point in the pregnancy (Yaesoubi et al., 2022).

Not all pre-natal exposures to alcohol will result in FASD. The consistent recommendations, however, are that people who might become pregnant should avoid alcohol, there should be no alcohol consumption during pregnancy, and that it is never too late to stop alcohol consumption and related exposure that may be occurring.

D. Prevalence

The exact prevalence of FASDs is difficult to precisely determine given that different classification systems yield different results. In one study, conservative estimates of the prevalence of FASD in the United States (using the Hoyme, et. al, 2016 criteria), ranged from 1.1% to 5.0% (May et. al, 2018). Using 2021 population estimate for NY State (19.84 million), this means that between 218,240 and 1,944,320 New Yorkers could be affected by FASD.

E. FASD and OPWDD Eligibility

OPWDD eligibility requires the presence of a qualifying diagnosis, onset prior to age 22, likelihood of indefinite continuation, and substantial impact on the person's ability to care for themselves (condition results in a "substantial handicap").

Having FASD does not make someone automatically eligible for OPWDD services. However, prenatal exposure to alcohol can result in intellectual disability and/or

demonstrable central nervous system damage. Therefore, some people who have been exposed to alcohol in utero may meet OPWDD eligibility criteria. Full details of OPWDD eligibility criteria and the process to apply can be found on the OPWDD.ny.gov website (https://opwdd.ny.gov/eligibility).

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