

From Knowledge to Action: Addressing the FASD Implementation Gap

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BACKGROUND ON FASD

What is FASD?

Fetal alcohol spectrum disorders (FASDs) are a group of conditions associated with prenatal alcohol exposure that can result in lifelong behavioral, learning, and physical effects. FASD is an umbrella term encompassing several diagnoses rather than a specific clinical diagnosis. (CDC, 2025)

A. Established Causes, Signs, Diagnosis, Treatment, and Prevention

Causes, signs, diagnosis, treatment and prevention measures for FASD are well documented (CDC, 2025). However, researchers and service providers may emphasize different aspects of FASD prevention, identification, and response.

B. Far-Reaching Impacts and Comorbidities

We also know that the impacts of FASD are far-reaching, with many people with FASD experiencing comorbidities related to metabolism; body composition; cardio-renal, immune, and/or reproductive health; as well as hearing, vision, and sleep difficulties (Vanderpeet et al., 2025; Hyland et al., 2023; Flannigan et al., 2022). High rates of ADHD, anxiety, depression, PTSD, intellectual disability, suicidality, and substance use have also been documented among individuals with FASD (Attell et al., 2025).

C. Alcohol Use During Pregnancy

Several studies have sought to measure the prevalence of FASD in U.S. communities. Active case ascertainment studies suggest substantially higher prevalence than administrative identification, indicating that routine systems may miss many affected children (May et al., 2018). Alcohol use

during pregnancy also remains common. Most recently, 15.2% of pregnant women in the United States reported current alcohol use during 2021–2024, compared with estimates ranging from approximately 7.6% to 13.5% in earlier surveillance periods (Thomas et al., 2026; CDC, 2012; Tan et al., 2015; Denny et al., 2019; Gosdin et al., 2022). However, alcohol use during pregnancy may also be underreported, due in part to stigma. Recent studies have also found that among adults, alcohol use has increased among women but not men, and that alcohol-related mortality has increased more rapidly among women than among men (White, 2020; Karaye et al., 2023).

D. Professional Knowledge and System Gaps

Much of the literature has also focused on the resources, knowledge, and supports needed by professionals and systems to identify and respond to individuals with FASD, highlighting the need for professionals across systems to have access to practical, evidence-informed tools, training, referral pathways, and service models (Olson et al., 2023; McCormack et al., 2022; Stubbs et al., 2024). Within educational settings, studies have similarly identified gaps in the availability of practical resources for educators and the need for greater FASD knowledge, training, and support (Lees et al., 2022; Reedman et al., 2024). Additionally, similar concerns have been identified in child welfare, where practitioners report difficulty recognizing FASD, accessing diagnostic pathways, and determining appropriate supports (Petrenko et al., 2014; Richards et al., 2023; Gardner, 2023; Curran, 2026).

Taken together, this literature demonstrates that considerable knowledge already exists regarding the causes and consequences of FASD, the populations affected, and many of the resources and supports needed to improve identification and care. Yet substantial questions remain regarding the extent to which this knowledge has been translated into routine practice and systems of care.

LOOK FOR
THE 3 RS



Resources
A BUDGET



Results
A SCORECARD



Relationships
A TABLE

HISTORICAL CONTEXT: NATIONAL RECOMMENDATIONS AND GAPS

A. The 2009 Call to Action

In 2004, the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect — coordinated by the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities — established a working group committed to addressing the needs of individuals living with FASD. Their work resulted in the 2009 Call to Action: Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders, which highlighted ten recommendations to improve and expand efforts related to early identification, diagnostic services, and quality research on interventions for individuals with FASD and their families (Carmichael-Olson et al., 2009). More than 15 years later, substantial needs remain.

B. Recent Findings: FASD Now and Current Priorities

Many of the recommendations identified in 2009 continue to be reflected in more recent discussions of FASD priorities. Three key outcomes from the 2024 FASD Symposium included: (1) enhancing FASD screening and diagnosis, including through universal screening; (2) promoting a comprehensive and accessible continuum of care for individuals with FASD; and (3) enhancing federal agency collaboration through a national framework that promotes shared leadership and coordinated efforts to integrate FASD awareness and support into policies, education, and community resources across states.

Notably, these priorities echo many of the recommendations made more than a decade earlier. This suggests that the challenge is no longer simply identifying what should be done but also understanding why recommended practices and systems have not been implemented consistently and what is needed to move from recommendations to action.

The Problem: Silence, Omission, Ignorance, and Avoidance

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A. Systemic Invisibility

Thus, FASD remains largely absent from maternal and child health agendas, early childhood conferences, and policy guidance. Silence and omission are now recognized as active drivers of harm. "*Omission becomes a decision.*" (Gardner, 2023; Gardner, Personal Communication, 2026).

B. Ignorance vs Deliberate Avoidance

Systems fail to address FASD due to both lack of knowledge and deliberate avoidance tied to stigma, autonomy, reproductive rights, and discomfort

discussing alcohol use in pregnancy. "*Ignorance is very different from deliberate avoidance.*" (Gardner, Personal Communication, 2026).

C. What Is Not Happening

In understanding the near invisibility of FASD, what is not happening is what must come under the closest possible scrutiny. A subject affecting millions of children and adults with neurodevelopmental impairments is frequently left out of conference agendas, reviews of maternal and child health, guidance for early childhood policy, and much more.

Questions during prenatal health care which are rarely asked with empathy and validated screening tools, as professionally recommended by national organizations, are critical omissions. Numbers of cases are rarely aggregated from surveys or developmental assessments. Omission becomes a decision.

That silence tells us what is missing, but the challenge remains deciding whether ignorance or avoidance is the primary cause of the silence and the omissions. Developing policy responses to each of these possible causes requires further assessment of what professionals and service providers do, what they do not do, and why.

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