

Executive Summary

Fetal Alcohol Spectrum Disorder in California

Fetal Alcohol Spectrum Disorder (FASD) is a silent epidemic in California. It is the leading known cause of developmental disability in North America.¹ FASD is a complex, serious, neurodevelopmental disability caused by prenatal alcohol poisoning to the developing brain and body in utero. The result is deficits that occur in thinking, learning, social skills, self-regulation, mental health, adaptive functioning (independent living skills) and physical health that require lifelong support, regardless of IQ.

Fetal Alcohol Spectrum Disorder poses a significant public health risk:

- The disorder is more common than Autism, affecting 2% to 5% of every first grade child in the United States (CDC, 2014)
- For select populations, such as foster care, adoption and juvenile justice, the prevalence is much higher
- Taking the above prevalence figures, 800,000 to 2,000,000 Californians have FASD
- The disability occurs on a spectrum, like Autism; 90% of affected people do not have the better known Fetal Alcohol Syndrome, but instead have an invisible disability that most often goes undiagnosed or misdiagnosed

The cost in dollars and cents to California is staggering. Every system of care is affected: child welfare, education, medical care, mental health/substance use services, developmental disability services, criminal justice and employment. Medicaid spends 9 times the amount for a child in foster care who has Fetal Alcohol Syndrome.² Between 17% to 35% of youth in the criminal justice system have been estimated to have FASD. The estimated annual cost of care for just one person with FASD is \$23,000.³

In California, many areas of the state do not have diagnostic capacity for FASD and services are not available for both affected children and adults. In addition, training of professionals in Fetal Alcohol Spectrum Disorder is not part of the curriculum of training programs. The lack of recognition of the disability has a profound impact on prevention, the well-being of affected people and their families and systems of care across the state.

Adults with FASD can lead successful lives but early diagnosis is critical to that success (Institute of Medicine). Without early diagnosis and treatment, significant adverse life effects include:

¹ Reid, D et al. Fighting for a future: where we were and where we are now. *8th International FASD Conference, University of British Columbia Continuing Education*. 2019; Canada FASD Research Network; Health Canada, 2017.

² Amendah, D, Grosse, SD and Bertrand, J. Medical expenditures of children with fetal alcohol syndrome. *Neurotoxicology and Toxicology*. 2011; 33, 322-324

³ Greenmeyer, JR. et al. A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder. *J Addiction Medicine*. 2018 Nov/Dec; 12(6), 466-473

- 90% plus have a mental illness
- 35% have a substance use disorder, starting at 12 years of age
- 61% will experience school disruption (repeat suspensions, expulsion or drop out)
- Average lifespan is only 34 years
- 60% will have trouble with the law
- 35% of homeless population have FASD⁴

Some states have developed programs for screening, diagnosis and delivery of services for affected children and adults. For example, in Alaska and Minnesota advocacy groups, the university, public agencies and the legislature have cooperated to develop programs for systems of care and public outreach across the state. In Michigan, the legislature mandated an action plan for the prevention, education and provision of service for FASD. California is lacking any plan to address the needs of people affected by FASD.

California can do better. A legislative task force on Fetal Alcohol Spectrum Disorder can inform the legislature as to the effect of FASD on the people of California. Such a task force can also help the legislature formulate an action plan to address the needs created by FASD that impact the state.

- It is essential for the public to be better informed about FASD, not just for prevention, but so affected children and adults can be identified
- The need to train professionals cannot be overemphasized; currently, training in FASD does not occur in medical school or graduate programs in social work, education or mental health
- California can implement pilot programs to screen, diagnose and treat people with FASD, as has been done in other states, Such programs already exist for evidenced-based treatment
- Diagnostic and service centers for FASD must be established in Central and Northern California

The failure to train professionals in FASD results in the failure to identify affected children and adults, leading to a cascade of negative outcomes. The lack of diagnostic capacity in many areas of the state is part of that failure. Right now, people with FASD occur in high numbers in the criminal justice and homeless populations in California. Early diagnosis is critical to better outcome. Treatment and support for this population is specific to the disorder, so training of professionals must occur.

Without an action plan to address Fetal Alcohol Spectrum Disorder the cost in dollars to California is huge. The cost to affected individuals, their families, and communities is immeasurable. It is time for California to develop an action plan to address the most common cause of developmental disabilities in North America.

⁴ Badry, D. et al. The fetal alcohol spectrum disorder and homelessness project: making connections for promising practice. *J Subst Abuse Alcohol*. 2015; 3(1):1027