

The Invisible Developmental Disability

Fetal Alcohol Spectrum Disorders (FASD) in Massachusetts



FASD is Common, but Misunderstood.



1 in 20:

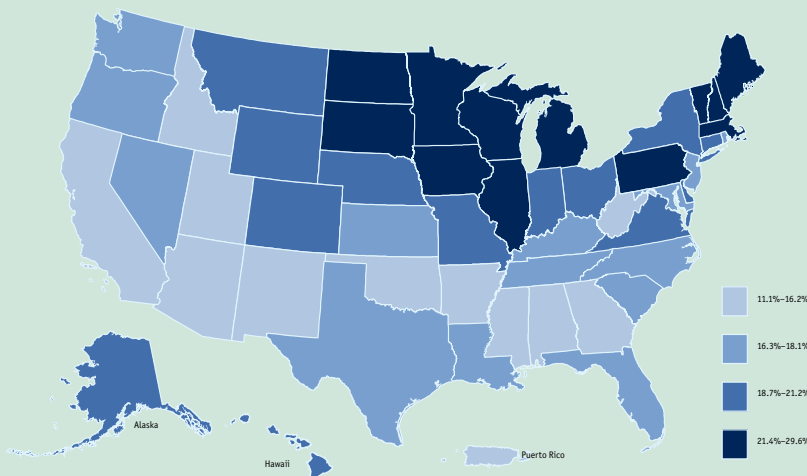
That's more common than autism.

There is an urgent need in Massachusetts to recognize this developmental disability and to develop strategies to support youth and adults on the spectrum. In spite of this high prevalence, FASD is often an invisible disability.

May, P.A., Chambers, C.D., Kalberg, W., Zellner, J., Feldman, H., Buckley, D., ... Hoyme, H.E. (2018) Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA* 319(5): 474-482. doi: 10.1001/jama.2017.21896

Weighted Prevalence Estimates

Binge Drinking* Among Women Aged 18-44 (BRFSS, 2016)



*Four or more drinks on any one occasion during the last 30 days.



FASD is a medical condition that encompasses a range of conditions caused by prenatal alcohol exposure.



FASD is a lifelong condition. While there is no cure, early treatment and adaptive approaches can impact individual and societal outcomes.



FASD-related brain injuries have major implications for individuals and families. Supportive state and community resources are crucial for best outcomes.

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No alcohol during pregnancy is the safest choice.

Neuropsych Testing Results for DCF-Involved Parent

22 year-old with an FASD.

IQ scores should not be used as a predictor of capabilities; those with an FASD often appear more capable than they are.

Full scale IQ	68, i.e. low normal
Math calculation	Grade 8
Reading	Grade 4
Receptive language	8 year-old
Personal daily living skills	22 year-old

For example, a 25 year-old, DCF-involved parent with an average IQ may function as a 14 year-old.

Everyone Deserves a Bright Future:

FASD Matters in Massachusetts

Of adults with an FASD:¹

- 94% also have a diagnosable mental illness (FASD is a rule/out at DMH)
- 13% of young adults ever held an "ordinary" job, despite 69% having at least preparatory job training
- 70% are unemployed and dependent
- 80% require assistance with daily living
- 67% live in dependent-living or institutional setting
- 16% live with a partner or had their own family
- 81% required greater than minimal care although only 34% have an intellectual disability

With FASD-informed services and supports, people with an FASD can be contributing members of society.

Early and Ongoing Interventions make a big difference!²

- Early Identification
- Educational & Cognitive Training
- Parent Training
- Adaptive Skills Training
- Service Coordination and Mentorship
- Life Skills training
- Life/Job Coach (ongoing)
- Supportive Living
- FASD-Informed School Social Programs
- In-Home Continuum Family Therapeutic Services

¹Moore, E.M. & Riley, E.P. (2015) what happens when children with fetal alcohol spectrum disorders become adults? *Curr Dev Disord Rep* 2(3), 219-227. doi:10.1007/s40474-015-0053-7

²Blair, P. & O'Connor, M.J. (2009). Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management. *Developmental Disabilities Research Reviews*, 15(3), 258-267.

³Chasnoff, I.J., Wells, A.M. & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2) 264-270. doi: 10.1542/peds.2014-2171

FASD is an Invisible Disability

Of a total of 547 adoptive/foster children in Illinois who were referred to a children's mental health center for assessment, 86.5% of youth with FASD had never been previously diagnosed or had been misdiagnosed.³

Secondary disabilities can occur when FASD-affected people, frustrated by being misdiagnosed repeatedly and receiving interventions that don't improve their lives, turn to negative coping strategies. Without appropriate intervention and support networks, demands on costly supports such as:

- Court system
- Correctional Facilities
- Hospitals
- Child Welfare
- Substance Use Disorder Treatment programs
- Mental Health services
- Homeless shelters



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Be a massFAS advocate!

Check out massFAS on Facebook and massfas.org on the web for updates on our legislative advocacy.