

FASD and Maine

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Paul R. LePage, Governor

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Agenda

- What is FASD?
- What are the National statistics?
- What are Maine statistics?
- What can we do?

FASD

- **Fetal alcohol spectrum disorders (FASDs)** are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. The most severe form of the condition is known as **fetal alcohol syndrome (FAS)**. Other types include **partial fetal alcohol syndrome (pFAS)**, **alcohol-related neurodevelopmental disorder (ARND)** and **alcohol-related birth defects (ARBD)**. Some accept only FAS as a diagnosis, seeing the evidence as inconclusive with respect to other types.

The problem

- More than **3 million** US women are at risk of exposing their developing baby to alcohol.
- **3 in 4** women who want to get pregnant as soon as possible report drinking alcohol.
- **100%** Fetal alcohol spectrum disorders are completely preventable.

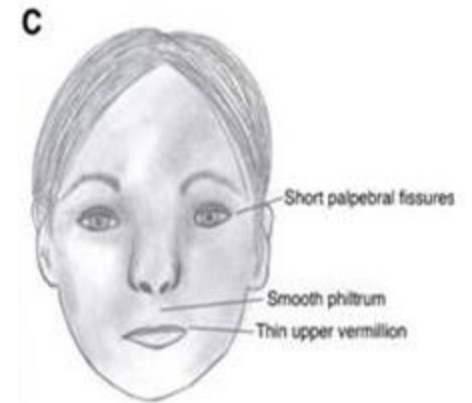
IOM criteria

Table 1: Institute of Medicine diagnostic criteria for fetal alcohol syndrome and alcohol-related effects⁴

Fetal alcohol syndrome (FAS)

1. *FAS with confirmed maternal alcohol exposure**
 - A. Confirmed maternal alcohol exposure*
 - B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum and flat midface)
 - C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportional low weight-to-height ratio
 - D. Evidence of central nervous system neurodevelopmental abnormalities, as in at least one of the following:
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
2. *FAS without confirmed maternal alcohol exposure*
 - B, C, and D as above
3. *Partial FAS with confirmed maternal alcohol exposure*
 - A. Confirmed maternal alcohol exposure*
 - B. Evidence of some components of the pattern of characteristic facial anomalies
Either C or D or E
 - C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportionally low weight-to-height ratio
 - D. Evidence of CNS neurodevelopmental abnormalities, e.g.,
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurologic hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

A picture is worth a thousand words....



- A. Photo of a 4 month old infant with Fetal Alcohol Syndrome
- B. Photo of same child at 5 years of age
- C. Illustration showing major facial characteristics used in the diagnosis of FAS.

Photos courtesy of T. Kellerman/used with permission.
Illustration by Kristen Breit and used with permission

AAP guide

- <http://pediatrics.aappublications.org/content/pediatrics/early/2015/10/13/peds.2015-3113.full.pdf>

Why do we miss it so often?

FASDs frequently are mis/undiagnosed because;

- Physicians are not well-trained in this area
 - and so do not accurately identify FASDs or mistakenly associate some common symptoms of FASD with other disorders.
- Given the place that alcohol has in U.S. culture, illegal drug use during pregnancy is more likely to receive attention than drinking during pregnancy
 - and people may be less inclined to associate behavioral or developmental problems with alcohol.
- Source: Friedmann, Peter D; McCullough, Deirde; Chin, Marshall H.; and Saitz, Richard. "Screening and Intervention for Alcohol Problems." *Journal of General Internal Medicine* 15.2 (2000): 84-91.

Signs and Symptoms

FASDs refer to the whole range of effects that can happen to a person whose mother drank alcohol during pregnancy. These conditions can affect each person in different ways, and can range from mild to severe.

- Abnormal facial features, such as a smooth ridge between the nose and upper lip (philtrum)
- Small head size
- Shorter-than-average height
- Low body weight
- Poor coordination
- Hyperactive behavior
- Difficulty with attention
- Poor memory
- Difficulty in school (especially with math)
- Learning disabilities
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones

FASD

Alcohol use during pregnancy can lead to lifelong effects.

Up to **1 in 20** US school children may have FASDs.



People with FASDs can experience a mix of the following problems:

Physical issues

- low birth weight and growth
- problems with heart, kidneys, and other organs
- damage to parts of the brain



Which leads to...

Behavioral and intellectual disabilities

- learning disabilities and low IQ
- hyperactivity
- difficulty with attention
- poor ability to communicate in social situations
- poor reasoning and judgment skills



These can lead to...

Lifelong issues with

- school and social skills
- living independently
- mental health
- substance use
- keeping a job
- trouble with the law



Drinking while pregnant costs the US **\$5.5 billion** (2010).



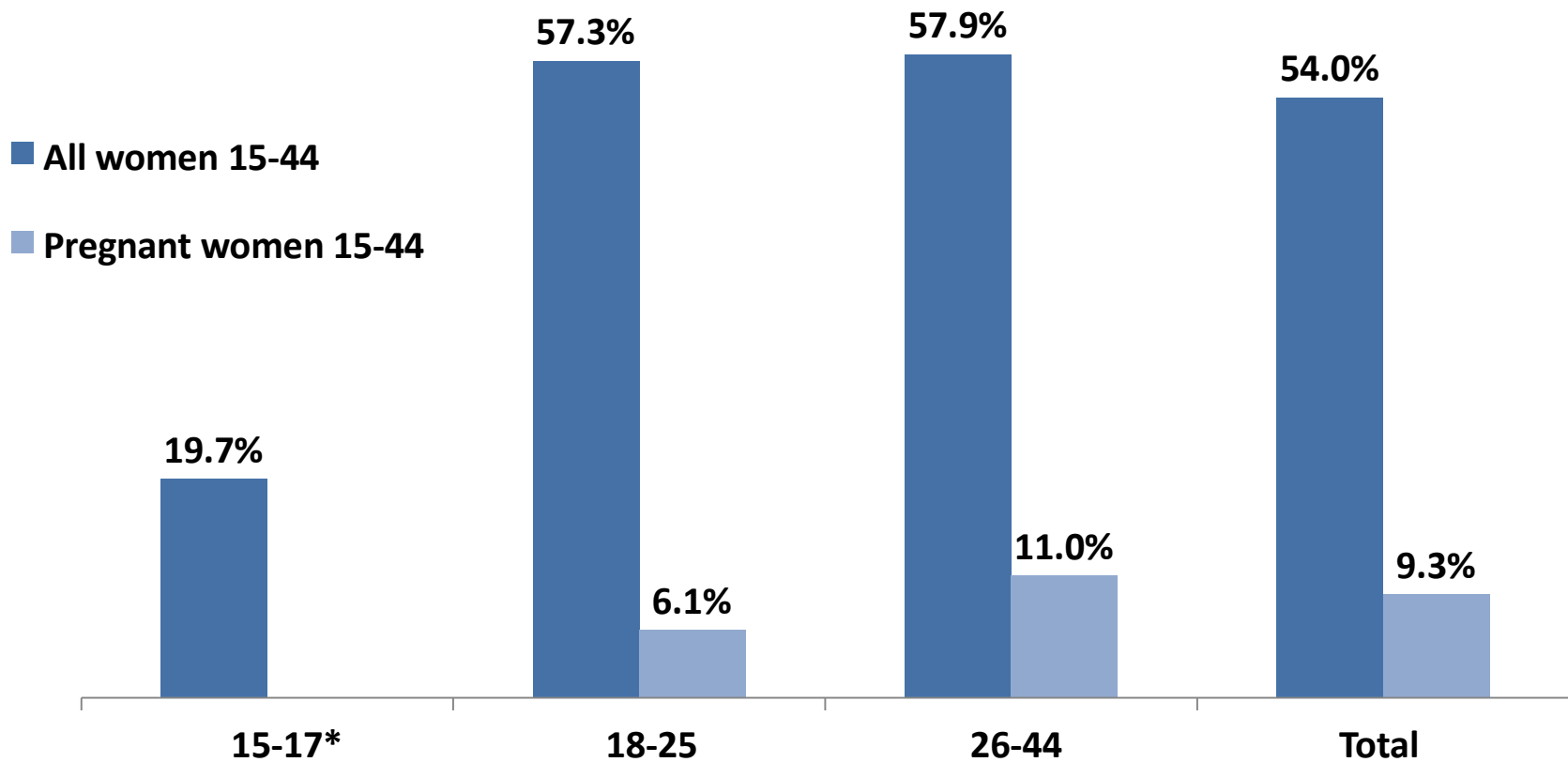
SOURCES: CDC Vital Signs, February 2016. American Journal of Preventive Medicine, November 2015.

Guidance

- <https://www.cdc.gov/ncbddd/fasd/index.html>
- https://www.cdc.gov/ncbddd/fasd/documents/fasd_english.pdf
- <https://www1.maine.gov/dhhs/mecdc/documents/SnuggleME-Project.pdf>

National statistics

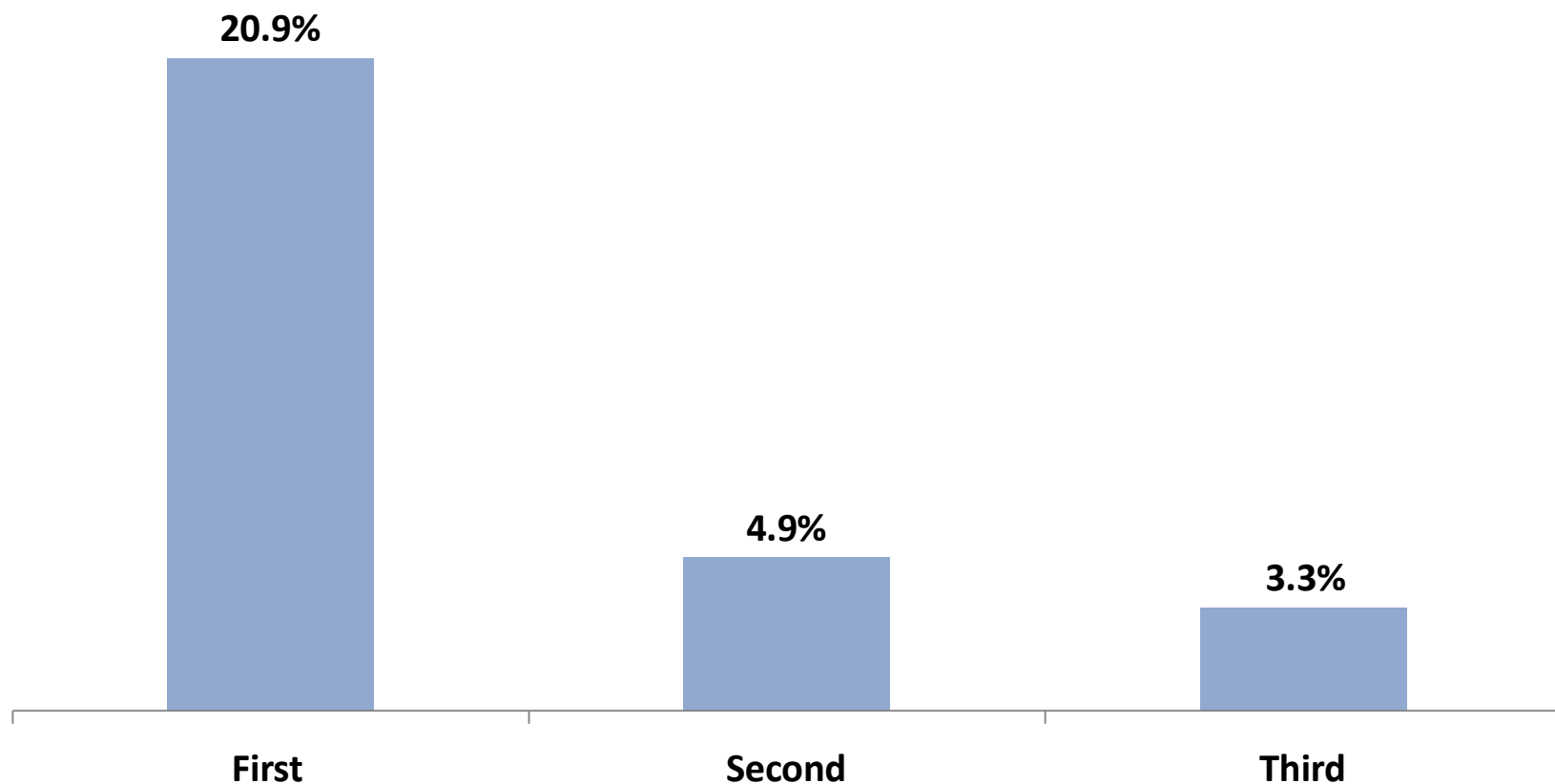
Any alcohol use in the past month among U.S. females 15 to 44, by age group and pregnancy status: 2013-14



Source: National Drug Use and Health Survey

*Precision is too low for estimates among pregnant women 15 to 17. Maine Center for Disease Control and Prevention

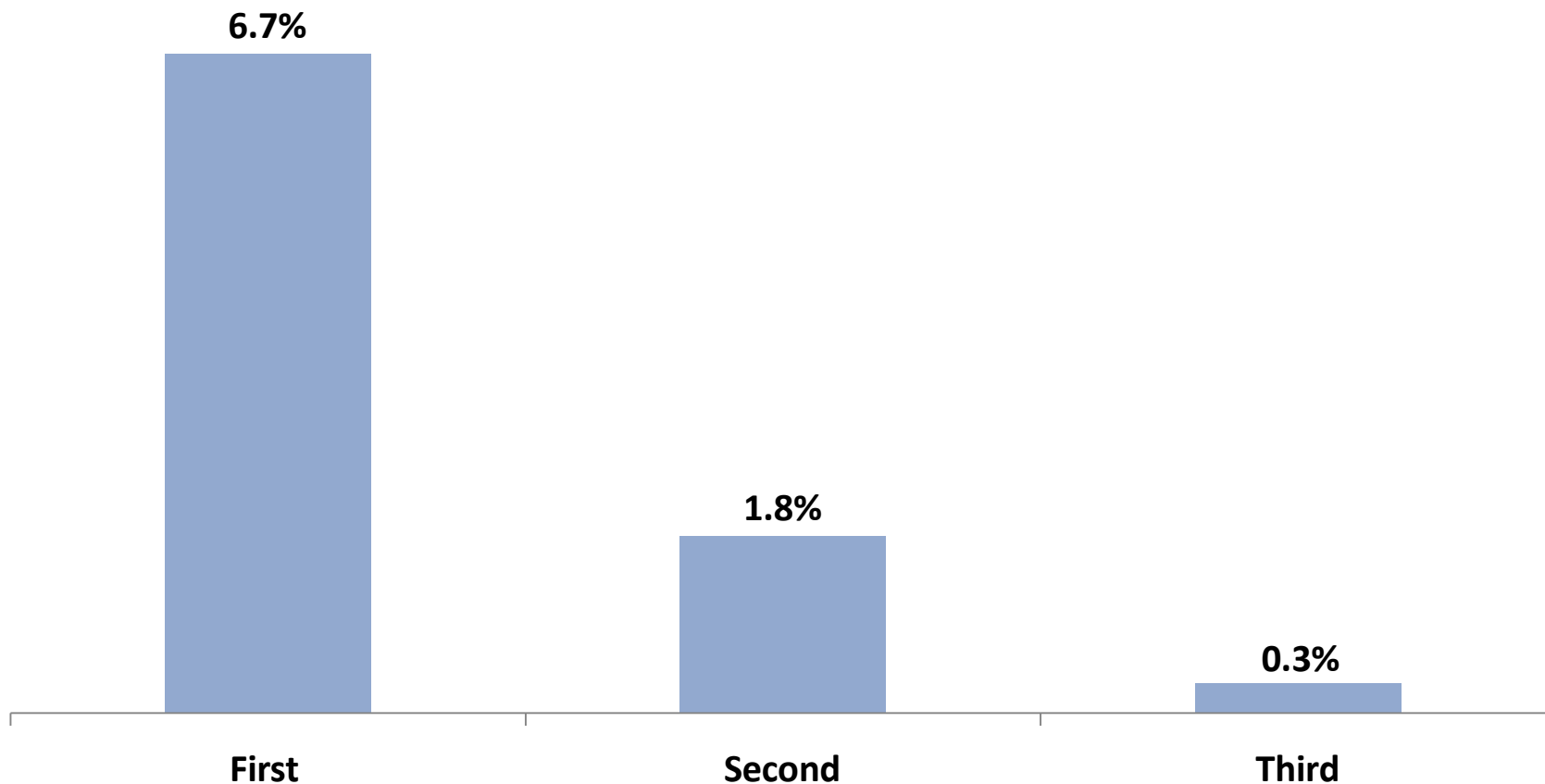
Any alcohol use within the past month among U.S. pregnant females 15 to 44, by trimester: 2013-13



Source: National Drug Use and Health Survey

Maine Center for Disease Control and Prevention

Binge alcohol use within the past month among U.S. pregnant females 15 to 44, by trimester: 2012-13



Source: National Drug Use and Health Survey

Female binge drinking = four or more drinks in one sitting

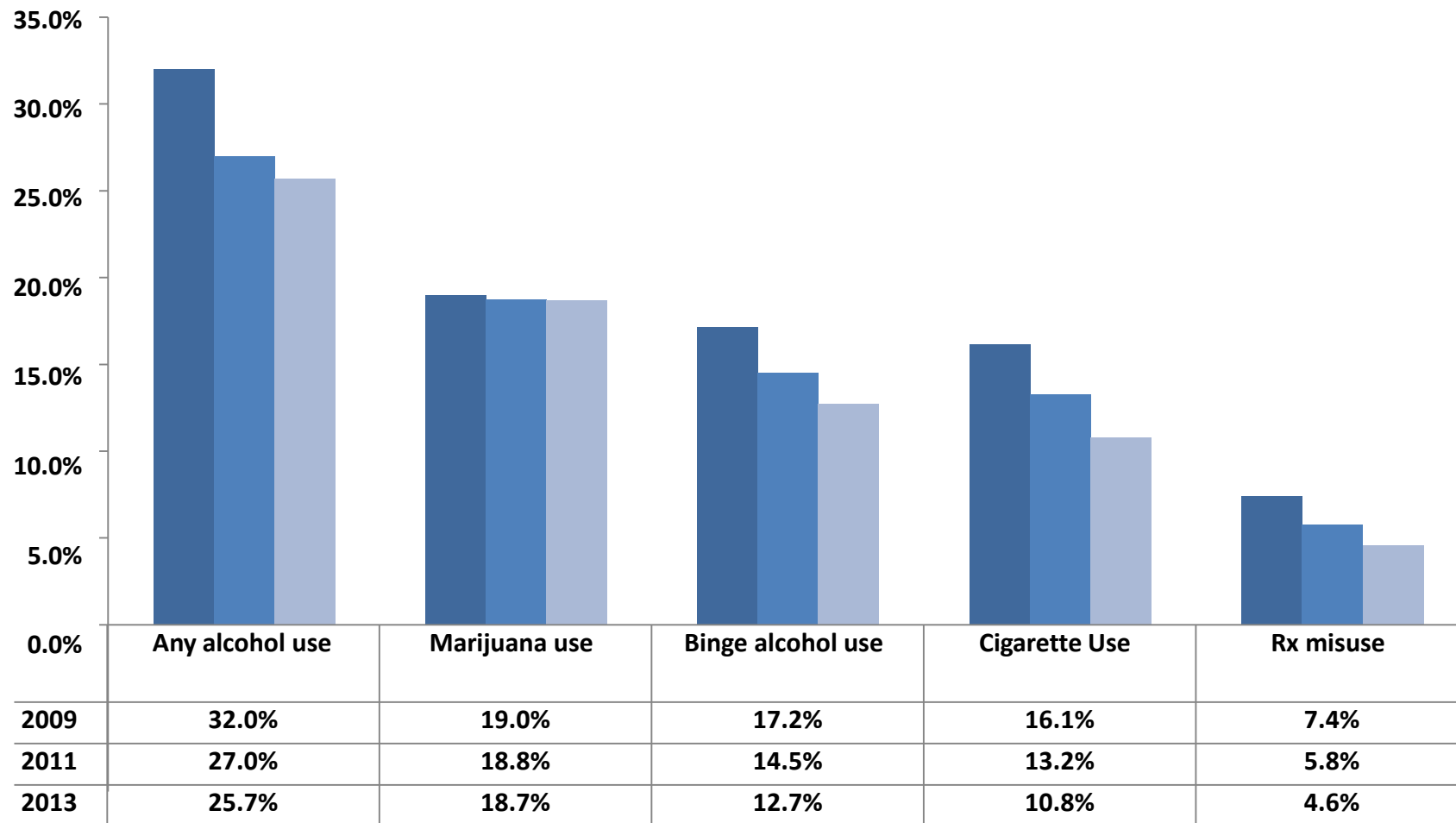
Maine Center for Disease Control and Prevention

National maps

<https://www.cdc.gov/ncbddd/fasd/data-maps.html>

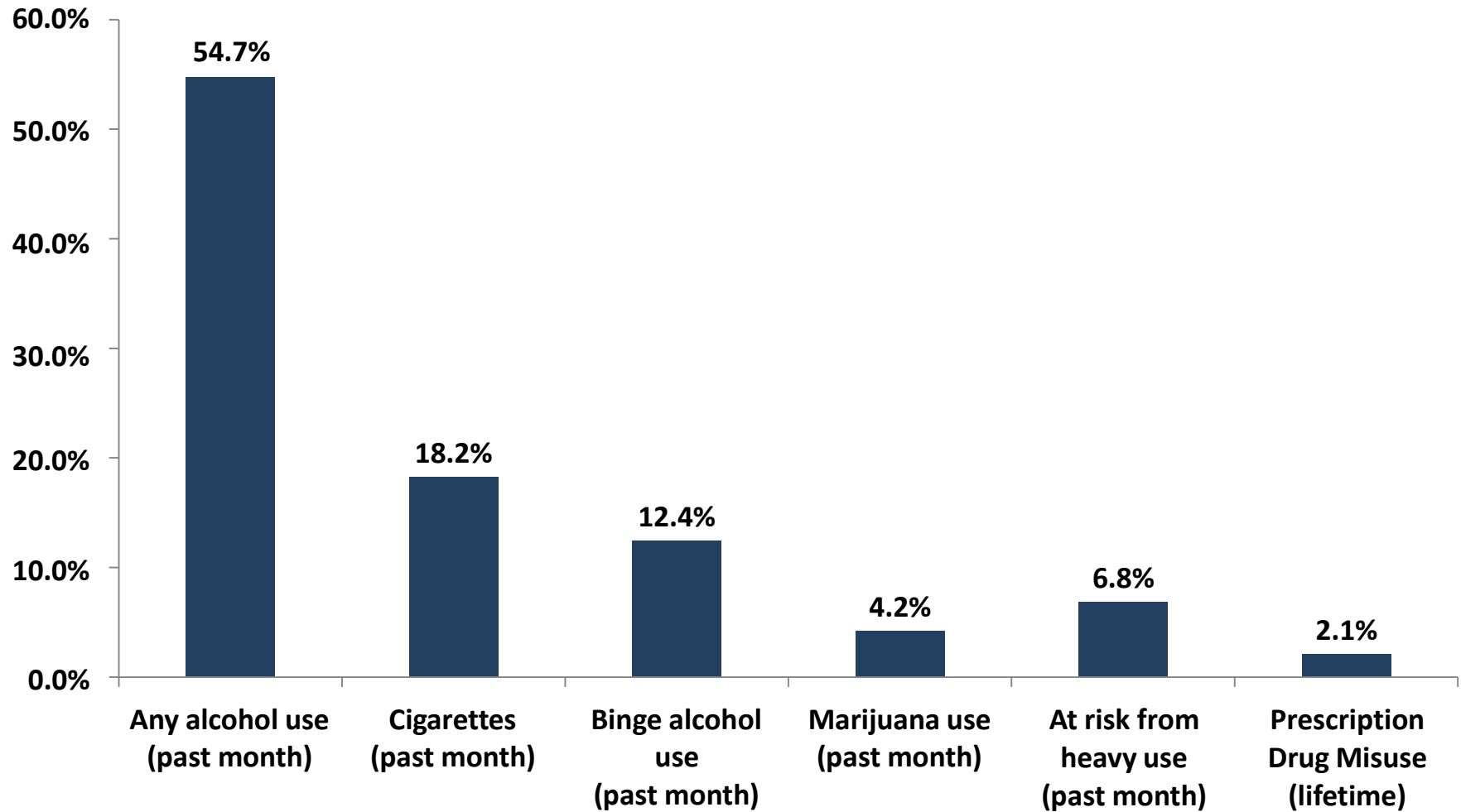
Maine statistics

Past month substance use among Maine high school students, by substance type: 2011-2013



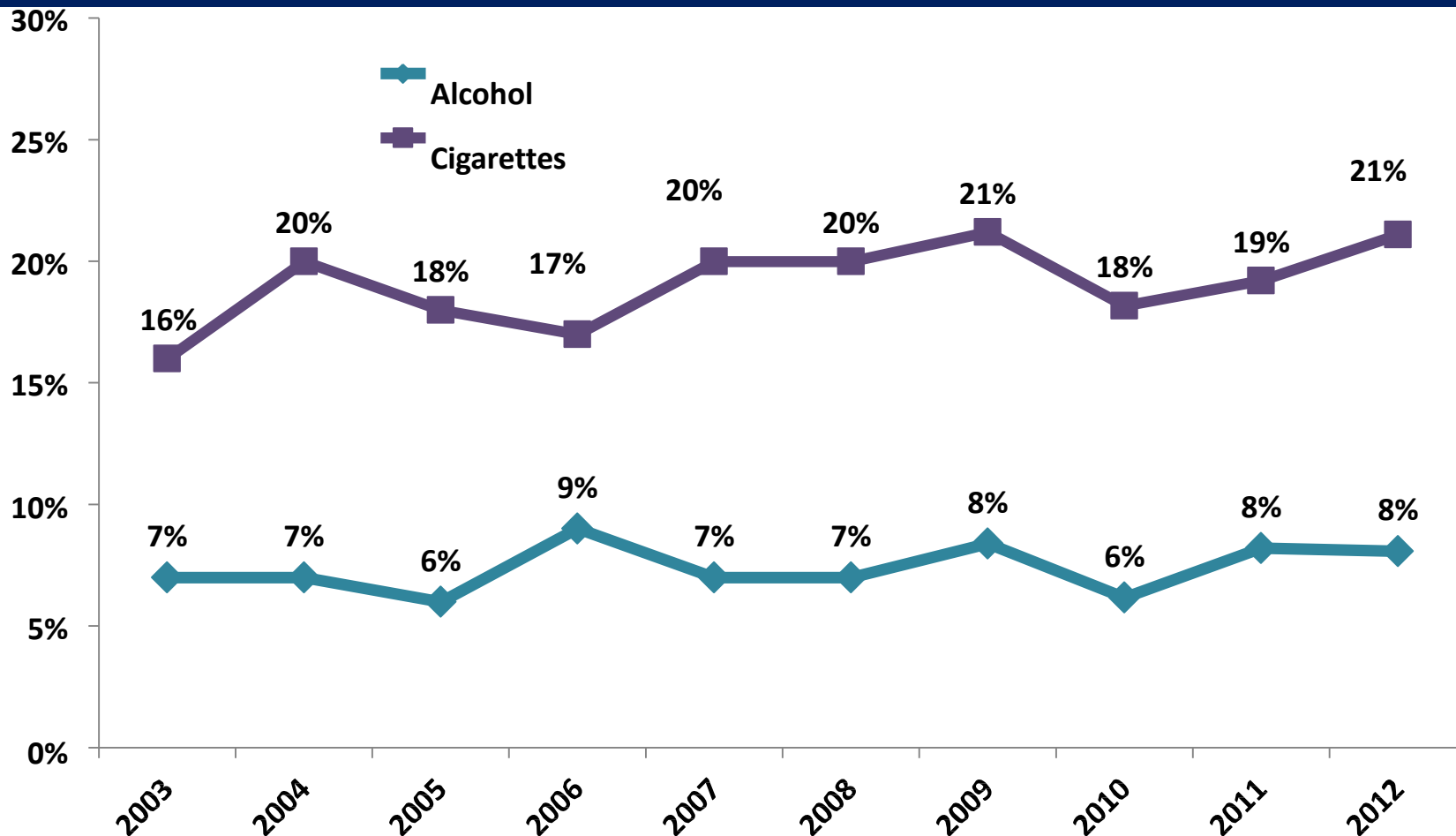
Source: Maine Integrated Youth Health Survey

Substance use among Maine adults (18+) 2013

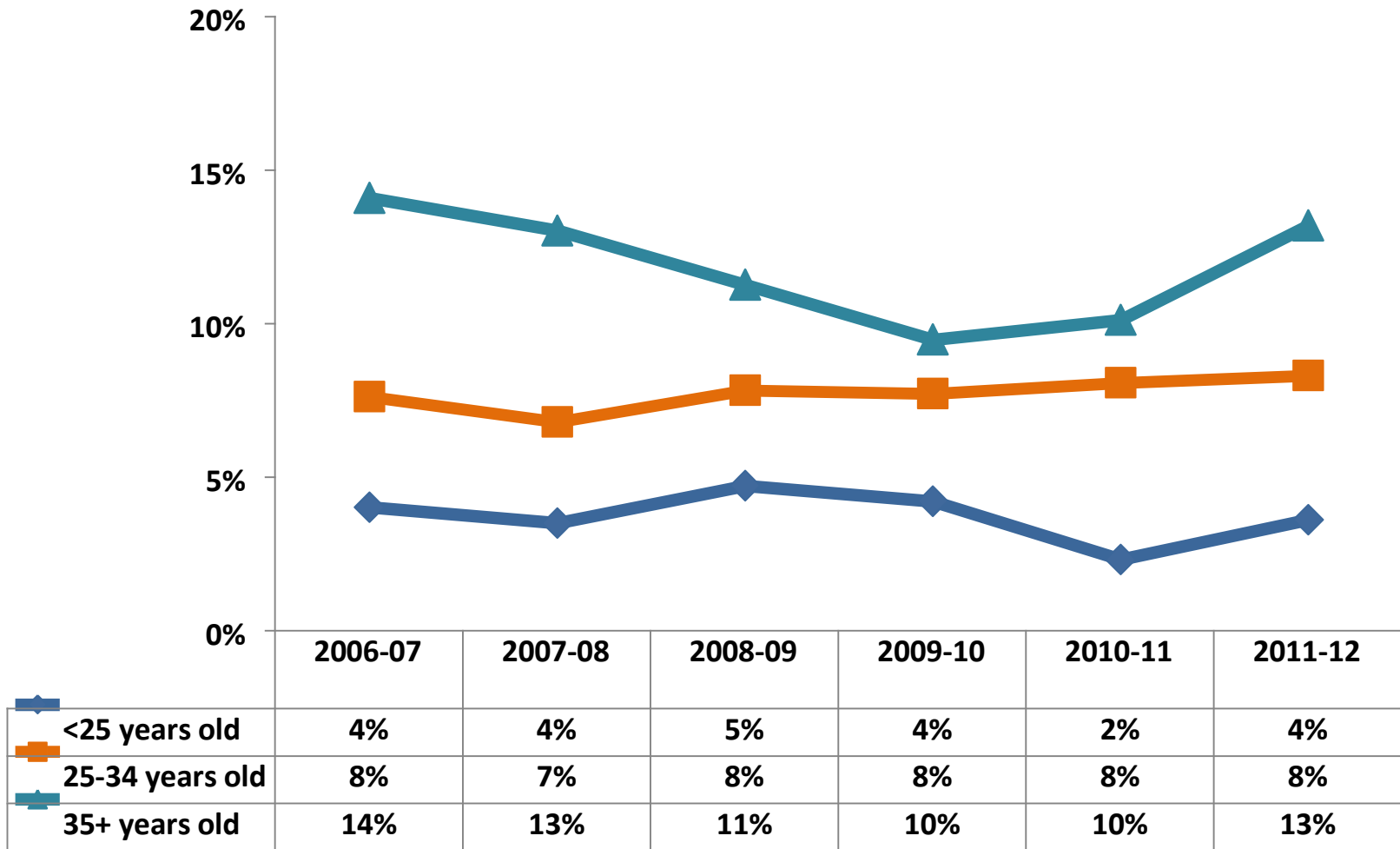


Source: Behavioral Risk Factor Surveillance System

Percent of Maine women reporting alcohol and/or cigarette use during last three months of pregnancy 2008-2012

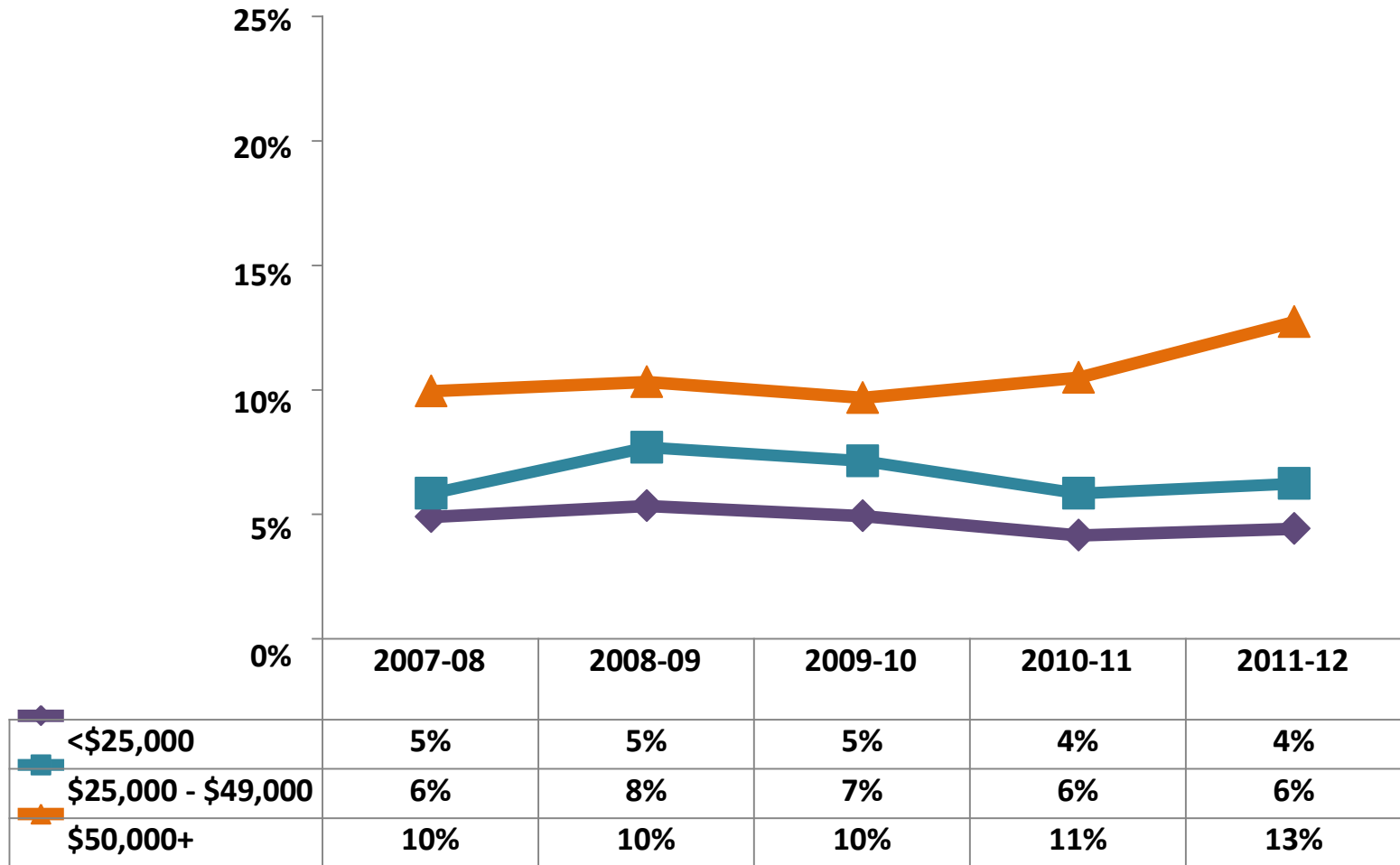


Percentage of Maine women who reported drinking alcohol during last three months of pregnancy by age group 2006-2012



Source: Pregnancy Risk Assessment Monitoring System

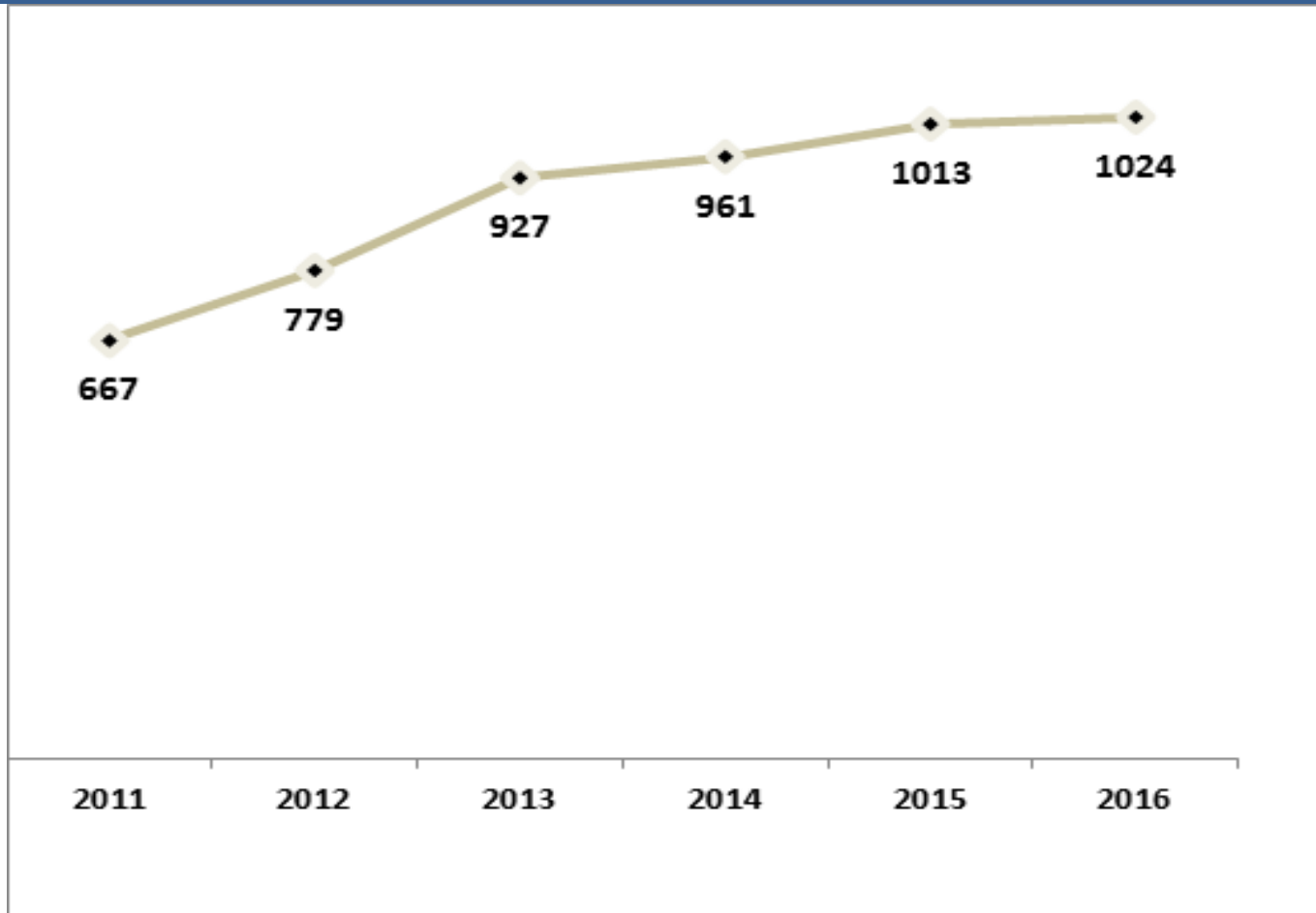
Percent of Maine women who reported drinking alcohol during last three months of pregnancy, by income 2007-2012



Source: Pregnancy Risk Assessment Monitoring System

Department of Health and Human Services

Number of Maine drug affected baby notifications 2011-2016



Source: Office of Child and Family Services (OCFS),
Maine Automated Child Welfare Information System (MACWIS).

Maine statute re: FASD

- <http://legislature.maine.gov/statutes/19-a/title19-asec652.html>
- <http://www.mainelegislature.org/legis/statutes/22/title22sec4004-B.html>

What can we do?

Doctors, nurses, or other health professionals should screen* every adult patient, including pregnant women, and counsel those who drink too much. Providers can help women avoid drinking too much, including avoiding alcohol during pregnancy, in 5 steps.

1 Assess a woman's drinking.

- Use a validated screener (e.g., AUDIT {US}*).
- Take 6-15 minutes to explain results and provide counseling to women who are drinking too much.
- Advise her not to drink at all if she is pregnant or might be pregnant.
- Come up with a plan together.

2 Recommend birth control if a woman is having sex (if appropriate), not planning to get pregnant, and is drinking alcohol.

- Review risk for pregnancy and importance of birth control use.
- Discuss full range of methods available.
- Encourage her to always use condoms to reduce risk of sexually transmitted diseases.

"The best advice is to stop drinking alcohol when you start trying to get pregnant."



3 Advise a woman to stop drinking if she is trying to get pregnant or not using birth control with sex.

- Discuss the reasons to stop alcohol use before the woman realizes she is pregnant.

4 Refer for additional services if a woman cannot stop drinking on her own.

- Provide information on local programs or go to SAMHSA treatment locator. www.findtreatment.samhsa.gov
- Consider referral to treatment or recommend Alcoholics Anonymous. www.aa.org

5 Follow up yearly or more often, as needed.

- Set a time for return appointment.
- Continue support at follow-up.

*Learn how to do alcohol screening and counseling at www.cdc.gov/ncbddd/fasd/alcohol-screening.html.

SOURCE: Adapted from American College of Obstetricians and Gynecologists. www.acog.org/alcohol.

What can we do?

There is no direct cure for FASD

- There are many different types of treatment available, including
 - medications and dietary supplements to help with symptoms
 - behavioral therapy
 - and parent training.
- Treatment options vary depending on the child and what works best for him/her.

Many “protective factors” have proven to help reduce the effects of FASD, such as:

- Early diagnosis
- Special education and social services
- A loving and nurturing environment the absence of violence

For more information, consult your doctor and refer to the [Tools for Parents and Caregivers](#) page; there are many resources available there.

Source: “Treatments.” *Fetal Alcohol Spectrum Disorders (FASDs)*. CDC. (2010)

What can we do?

- <https://www.cdc.gov/ncbddd/fasd/documents/sg-advisory.pdf>
- https://www.cdc.gov/ncbddd/fasd/documents/fasdbrochure_final.pdf
- <https://www.cdc.gov/ncbddd/fasd/freematerials.html>
- <https://www.cdc.gov/ncbddd/fasd/documents/AlcoholSBIImplementationGuide.pdf>

State Initiatives

- **State Steering Committee (Meeting Monthly):** charged with macro level oversight of SEI work
 - SAMHS, Maine CDC programs, MaineCare
- **Community SEI Task Force (Meeting Bi-Monthly):** charged with local level implementation of SEI work.
 - Social service agencies, public health nursing, home visitors, medical professionals, etc..

Strategies

- Annual SEI conference and other workforce development opportunities.
- Clearinghouse of materials
- Online ads-targeting population using keywords and social media.
- Creation of PSA's
- Collaboration with 2-1-1
- Website development-information dissemination.
- Promotion of the use of screening, brief intervention, referral to treatment.
- SnuggleMe Guidelines.
- Developed Maine specific resource guide housed with NOFAS.
- Pregnant women population focus through Maine Prevention Services contracts.

Questions?

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