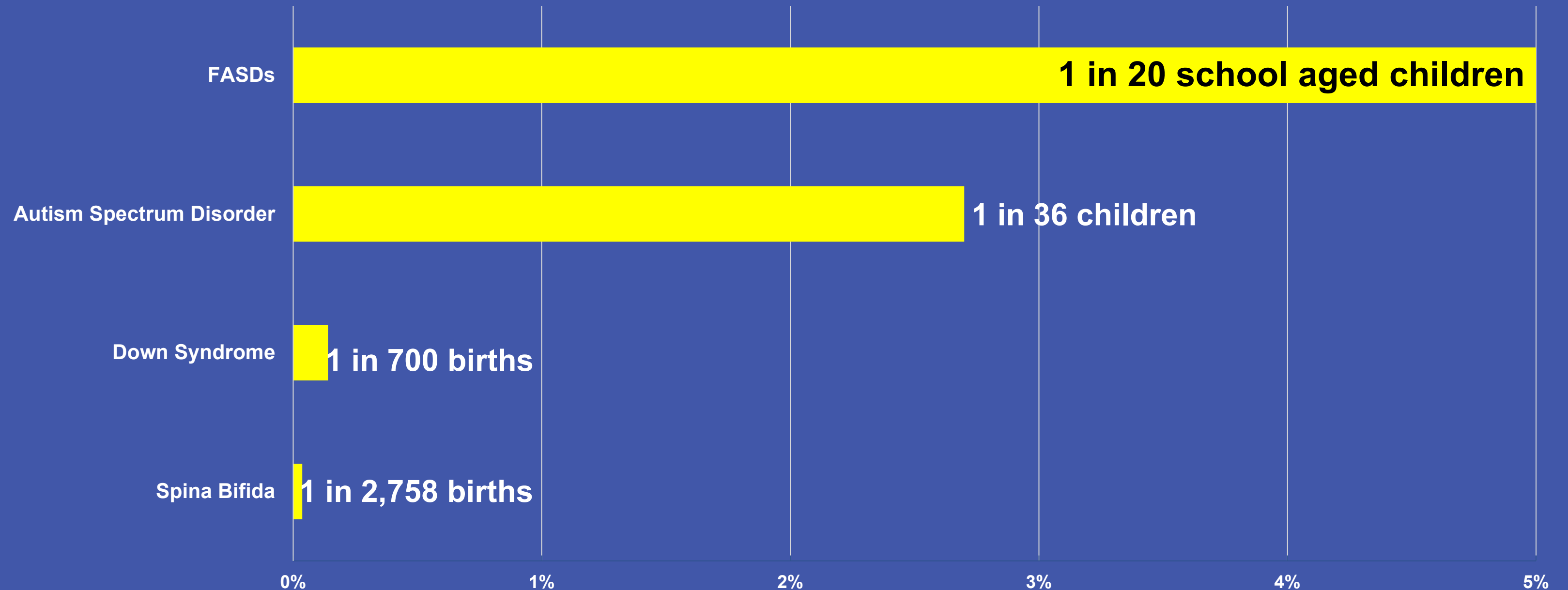




FASD is the most common cause of intellectual disability and birth defects in the U.S.



CDC MMWR March 2023 Autism Prevalence “The data come from 11 communities in the Autism and Developmental Disabilities Monitoring (ADDM) Network and are not representative of the entire United States.”

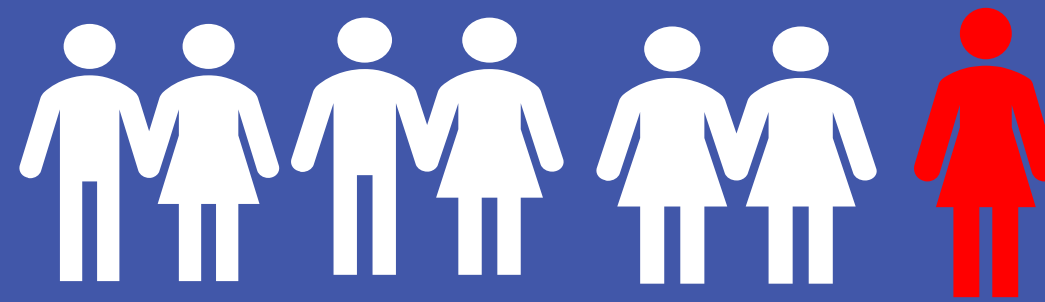
CDC Spina Bifida Data & Statistics <https://www.cdc.gov/ncbddd/spinabifida/data.html>

Mai CT, Isenburg JL, Canfield MA, Meyer RE, Correa A, Alverson CJ, Lupo PJ, Riehle-Colarusso T, Cho SJ, Aggarwal D, Kirby RS. National population-based estimates for major birth defects, 2010–2014. *Birth Defects Research*. 2019; 111(18): 1420-1435

May PA, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *JAMA*. Online February 2, 2018

Alcohol Use in Pregnant Adults U.S.

1 in 7 reported drinking alcohol in the last 30 days



1 in 20 binge drank

(4 or more drinks on one or more occasions)

Alcohol Use in Pregnant Adults

New England

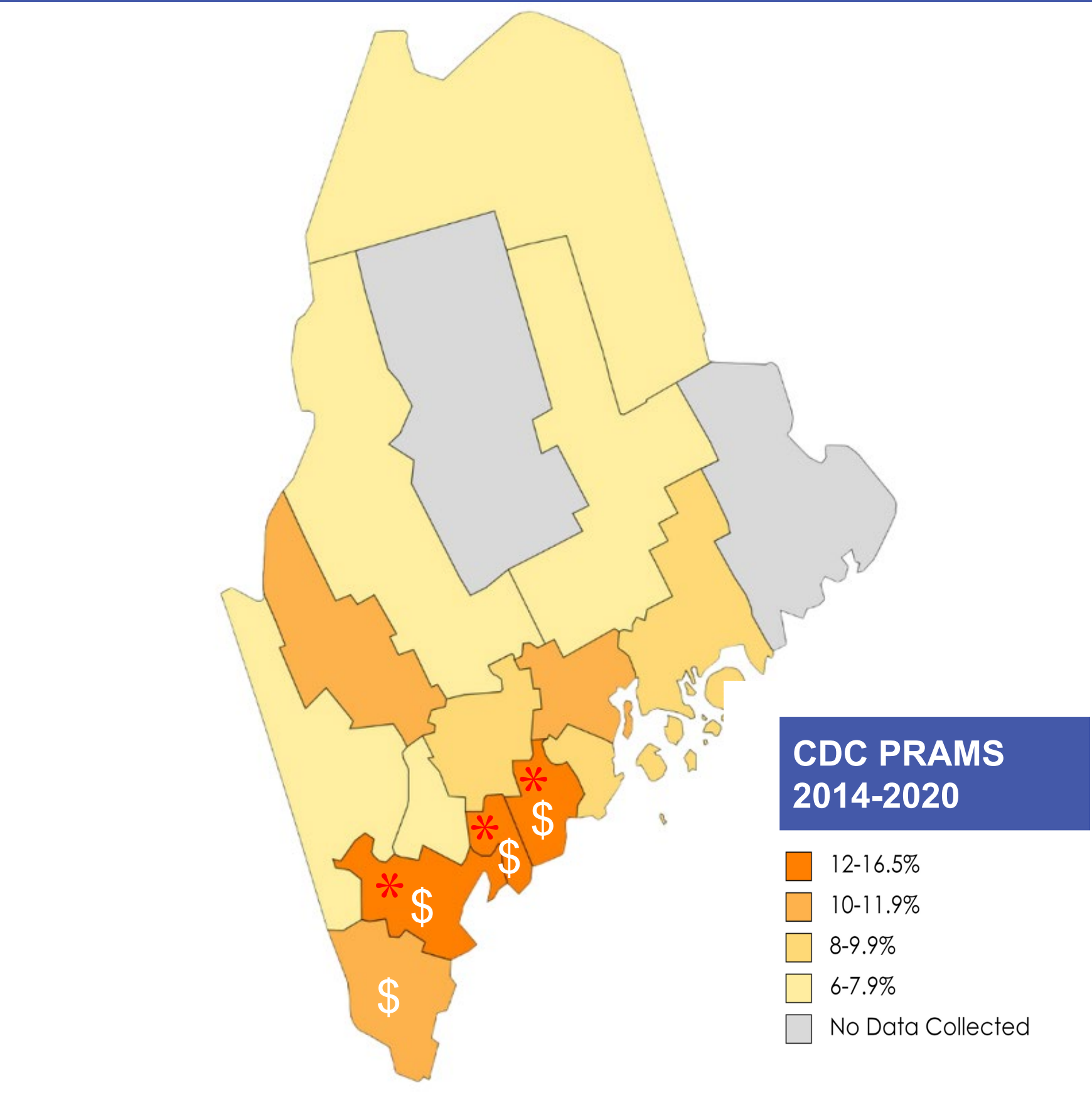
1 in 6 reported drinking alcohol in last 30 days



2nd highest rate of alcohol use among all regions of U.S.

Maine Alcohol Use Rate in Pregnancy

Maine overall	10.2
Cumberland	16.5
Lincoln	14.1
Sagadahoc	12.2
Waldo	11.9
Franklin	11.0
York	10.1
Knox	8.7
Hancock	8.2
Kennebec	8.0
Aroostook	6.4
Somerset	6.4
Androscoggin	6.2
Oxford	6.2
Penobscot	6.2
Piscataquis	ND
Washington	ND








Red Flags for Alcohol Use During Pregnancy

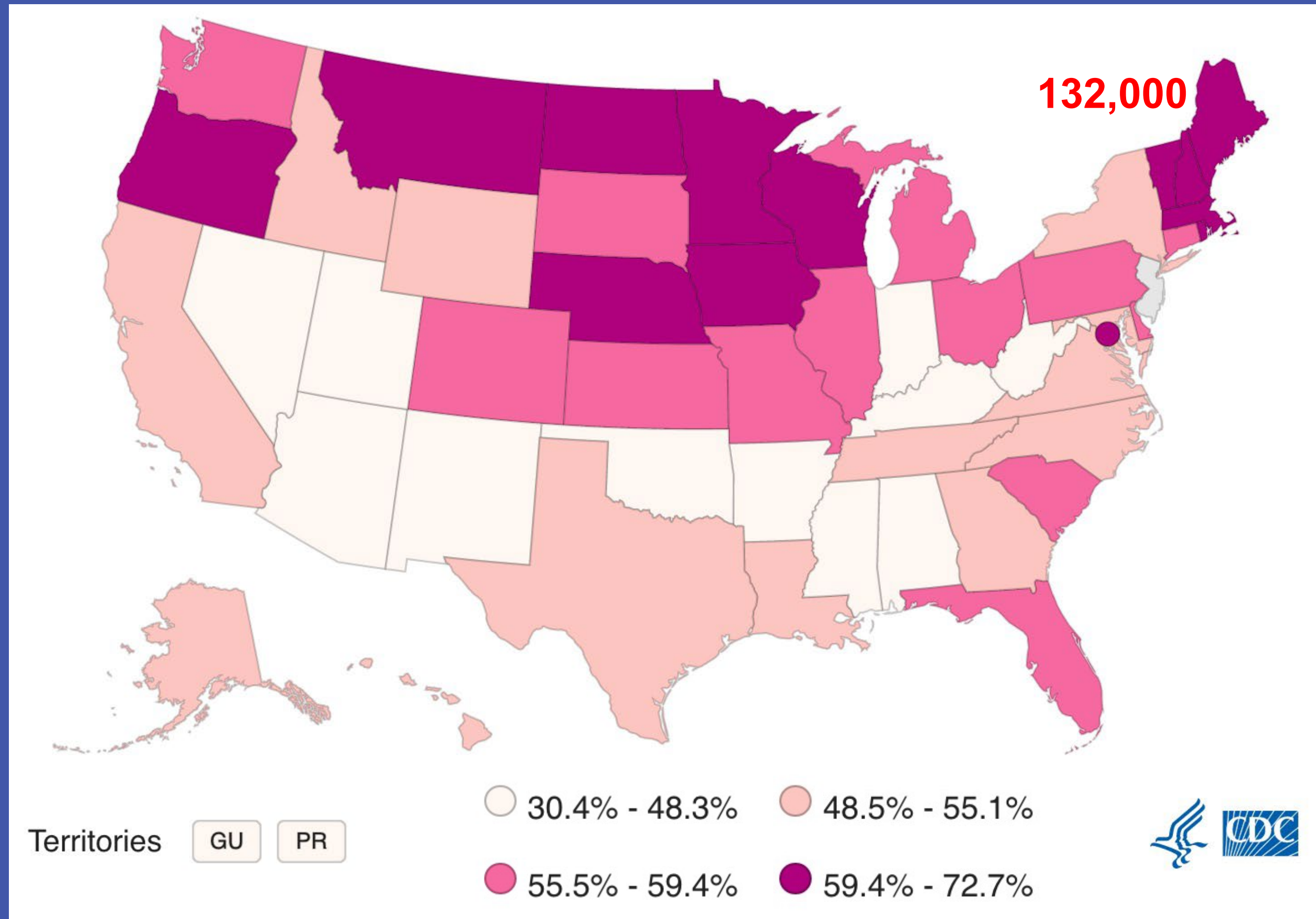
- Drank alcohol before pregnancy 
- Binge drank before pregnancy 
- Tobacco use before pregnancy 
- Any drug/substance use 
- Partner violence, partner drinks 
- 35 yo or older 
- Higher income, higher education 

3 Months Before Pregnancy

Third Trimester

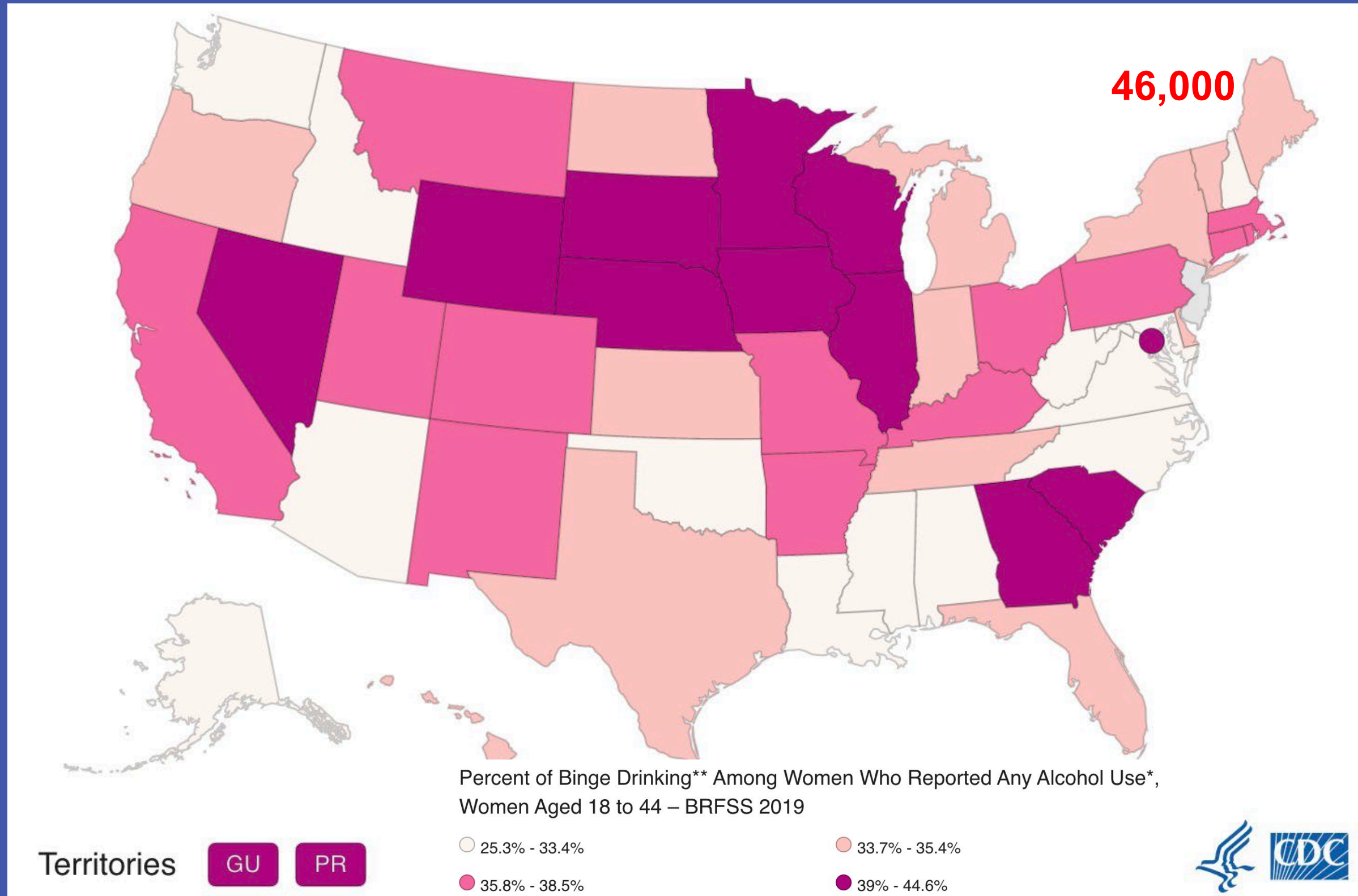
	67.3%	11.3%
	5.4%	ND
	24.6%	11.1%
	19.8%	11.0%
	8.7%	2.8%

Alcohol Use Maine Women 62.26% Age 18-44



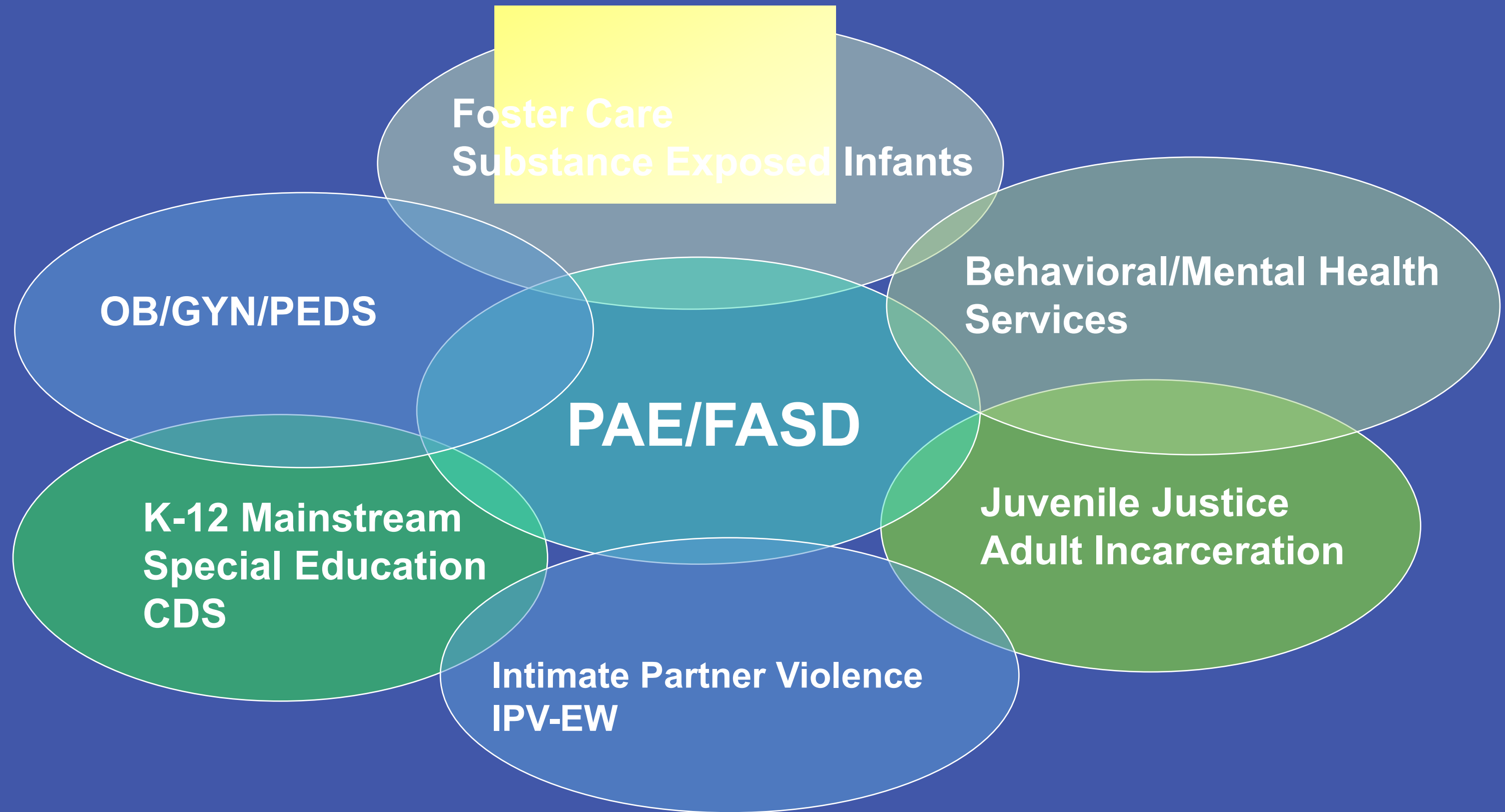
Binge Drinking Maine Women 35.3% Age 18-44

Among those who reported alcohol use



Unintended Pregnancy
Maine 30%
US 41%

Opportunities for Prevention, Diagnosis, Support



Disparities in diagnosis/care of individuals with an FASD

FASD

- Identified at higher rates in Native American, Black, and low-SES communities compared to White and middle/upper class communities.

Autism/ ADHD

- Both diagnoses given to White individuals more frequently than Black, Indigenous, and People of Color (BIPOC).

FASD is prevalent in foster care

- Rates of FASD are 17 to 19 times higher in child welfare systems than in the general population.
- Of 1400 Washington State FASD clinic patients with confirmed PAE: 70% were no longer in the care of their birth parents.*
- On average these children had three out-of-home placements.

Tenenbaum, A., Mandel, A., Dor, T. *et al.* Fetal alcohol spectrum disorder among pre-adopted and foster children. *BMC Pediatr* **20**, 275 (2020)

Popova S, Lange S, Shield K, Burd L, Rehm J. Prevalence of fetal alcohol spectrum disorder among special sub-populations: a systematic review and meta-analysis. *Addict*. 2019

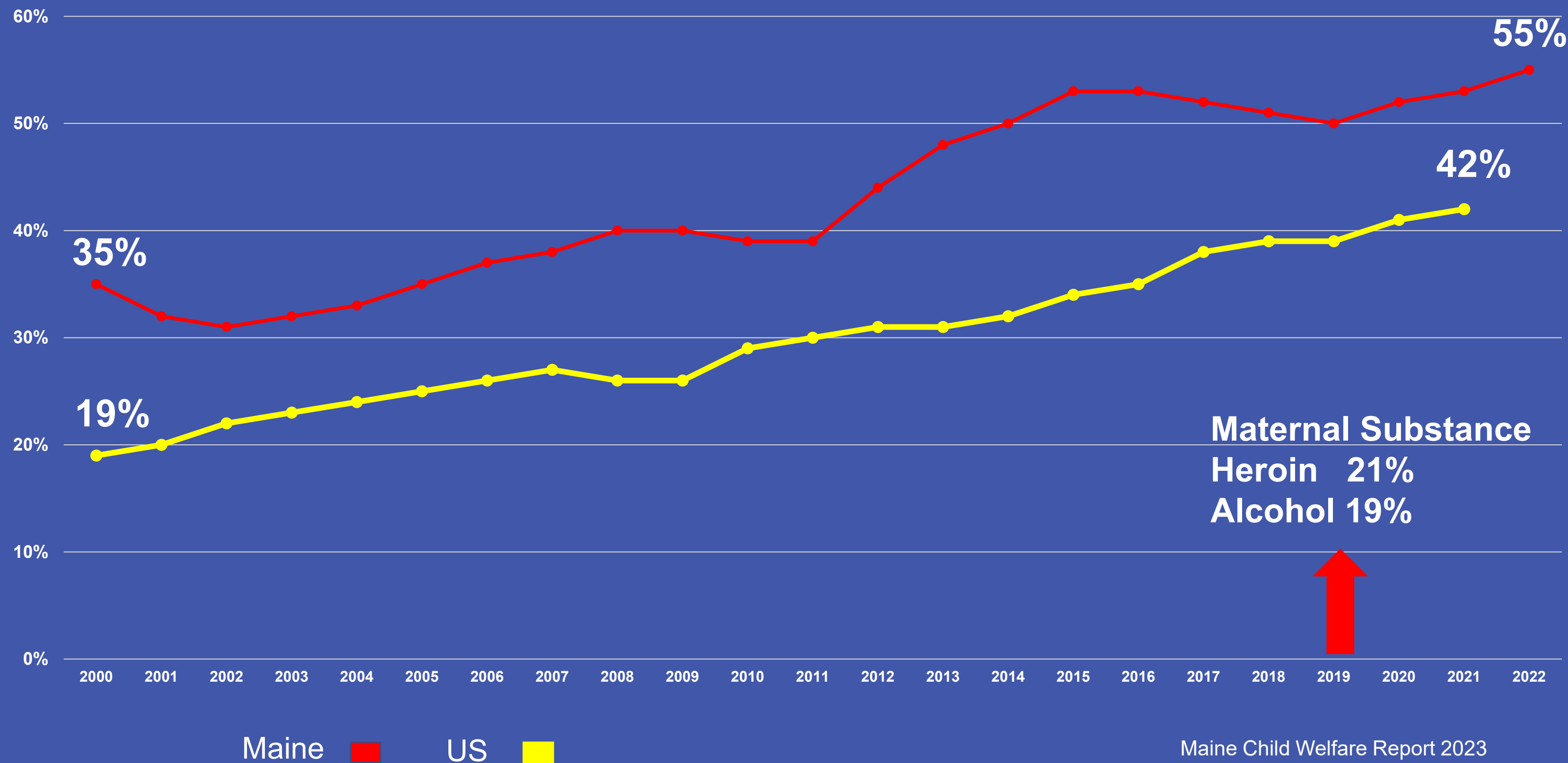
Petrenko, Christie, et al. "I'm doing my part, I just need help from the community." Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD. *Journal of Family Nursing*. 2019;25(2):314-347

Chasnoff, Ira J., et al. Misdiagnosis and Missed Diagnosis in Foster and Adopted Children with Prenatal Alcohol Exposure. *Pediatrics* 2015; 135(2):264-270

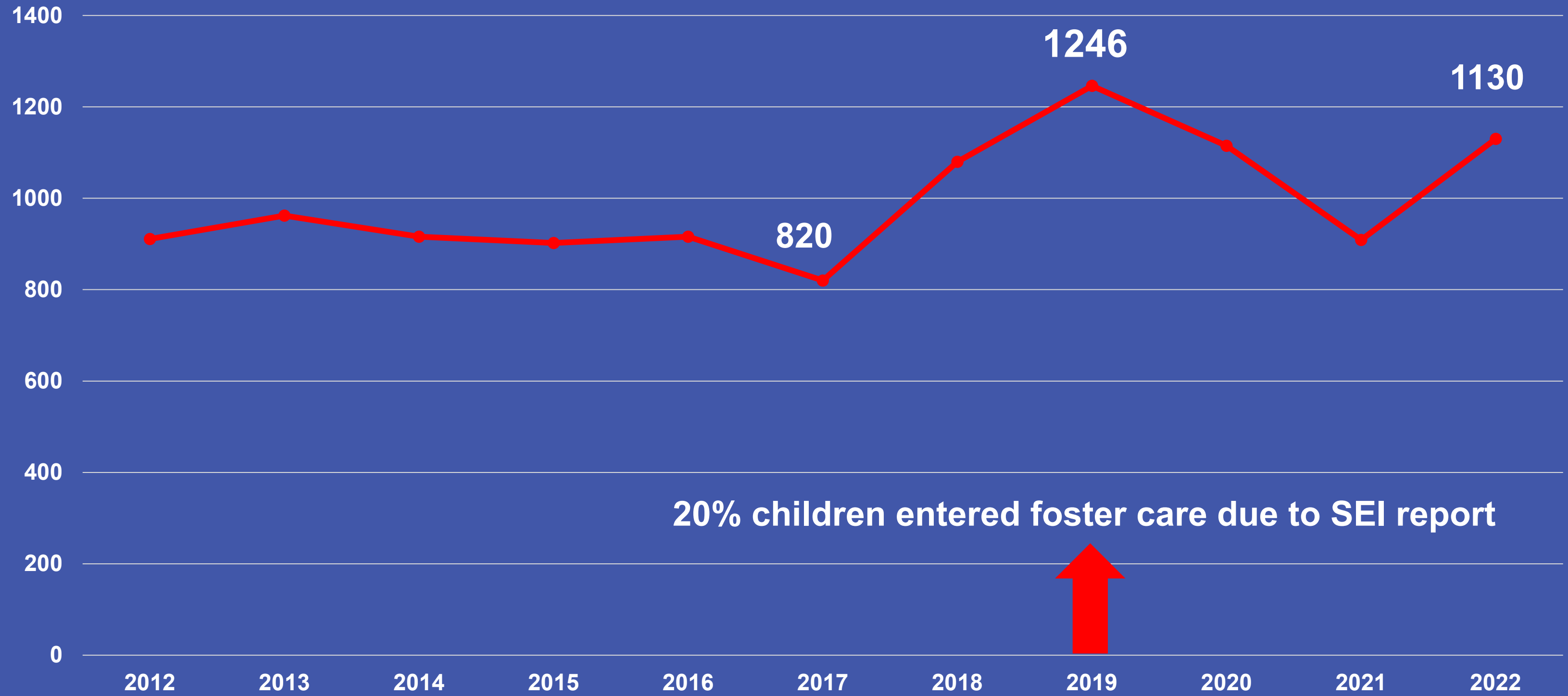
Lange, Shannon, et al. Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. *Pediatrics* 132.4 (2013): e980-e995

Astley, S. J. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*. Winter 2010;17(1), e132-e164*

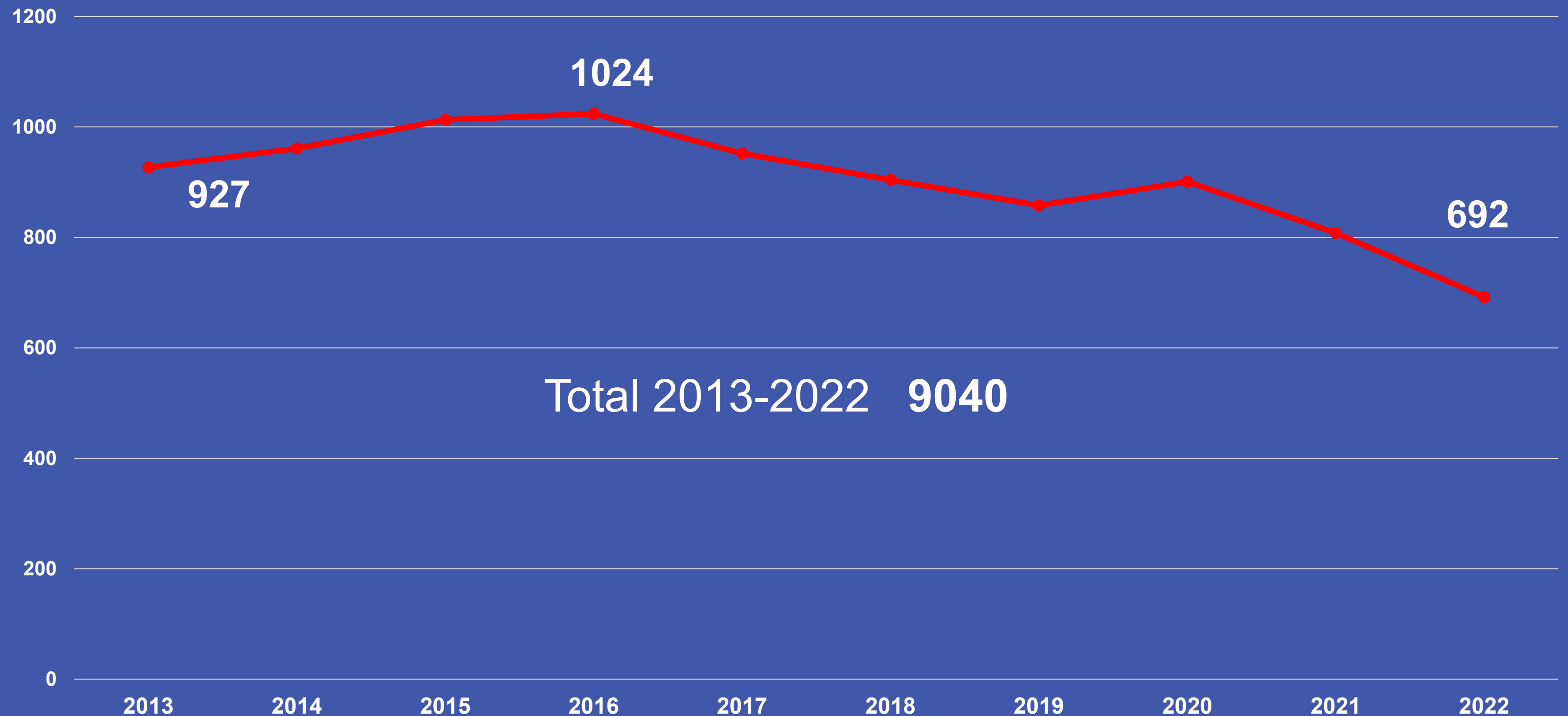
Parental Substance Use Factor



Entered Maine Foster Care Each Year



Reported Substance Exposed Infants



Special Ed and FASD

Under federal IDEA:

- FASD does not have its own category (e.g., Autism)
- FASD is not a “named condition” under any IDEA category. (e.g., ADHD under “Other Health Impairment”)
- California and Alaska are the only states that include FASD as a named condition, under Other Health Impairment (OHI).

Colorado https://www.cde.state.co.us/cdesped/guidance_determiningeligibility_sped_students_ohi

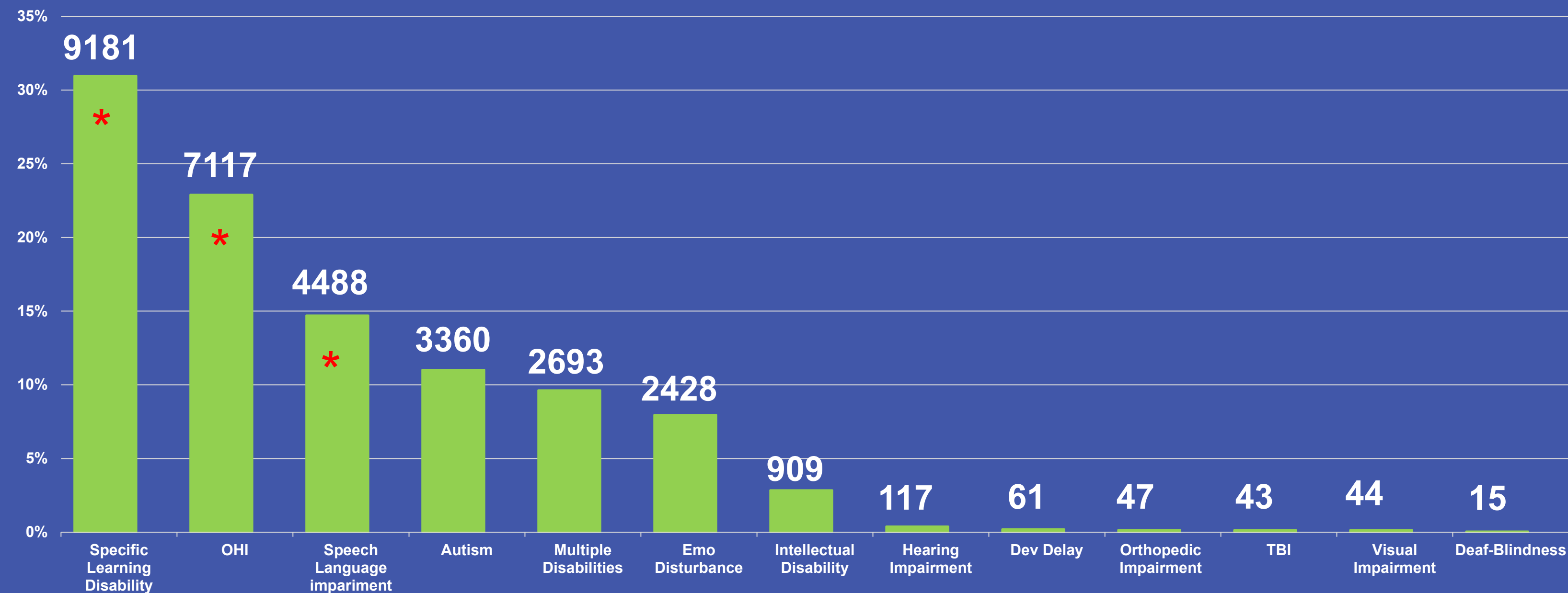
Minnesota <https://education.mn.gov/MDE/dse/sped/cat/ohd/info/059855>

California <https://www.calhealthreport.org/2022/12/20/theres-a-new-pathway-to-special-education-for-up-to-300000-california-children/>

Alaska https://education.alaska.gov/Media/Default/static/covid/AK_SPED_Handbook.pdf

Maine Special Education by IDEA Category

(Total 30,503 20%)



FASD co-occurring disabilities

Other Health Impairment (OHI)

- ADHD (most common diagnosis in this category)

Specific Learning Disabilities

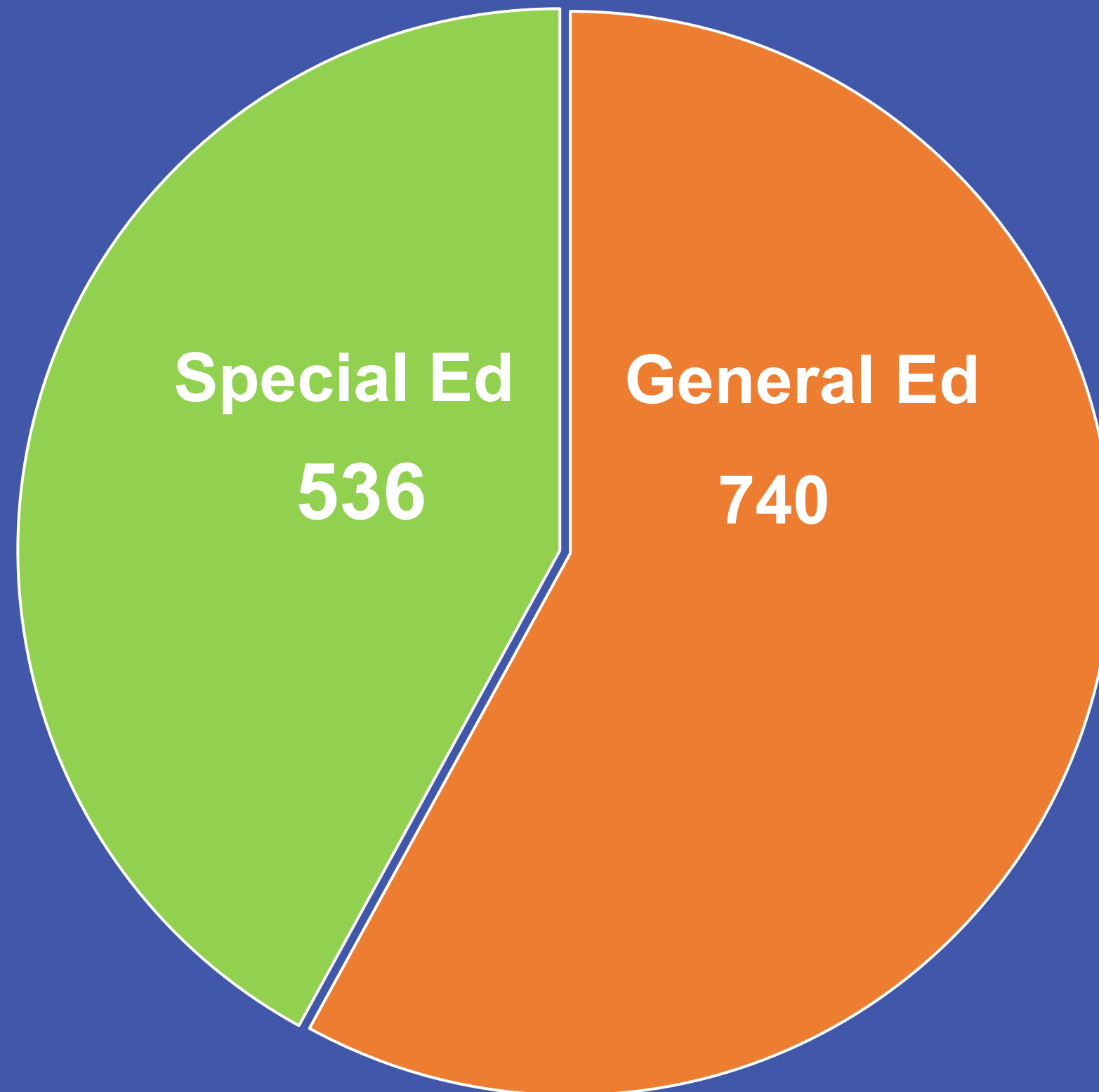
- Auditory Processing Disorder
- Dyscalculia (Math Disorder)
- Dysgraphia

Speech or Language Impairment

- Expressive and receptive language

Foster Children in Maine Schools **1276**

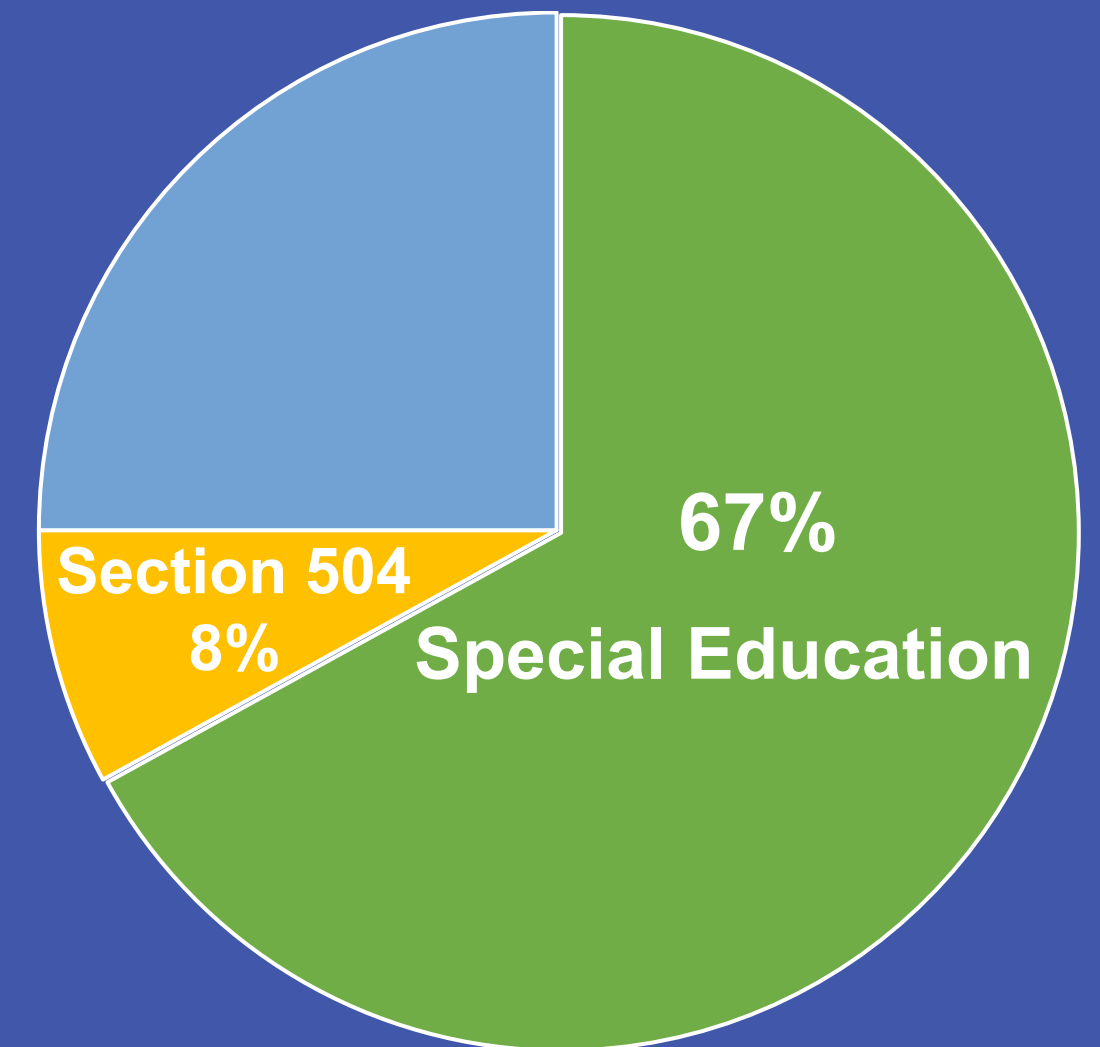
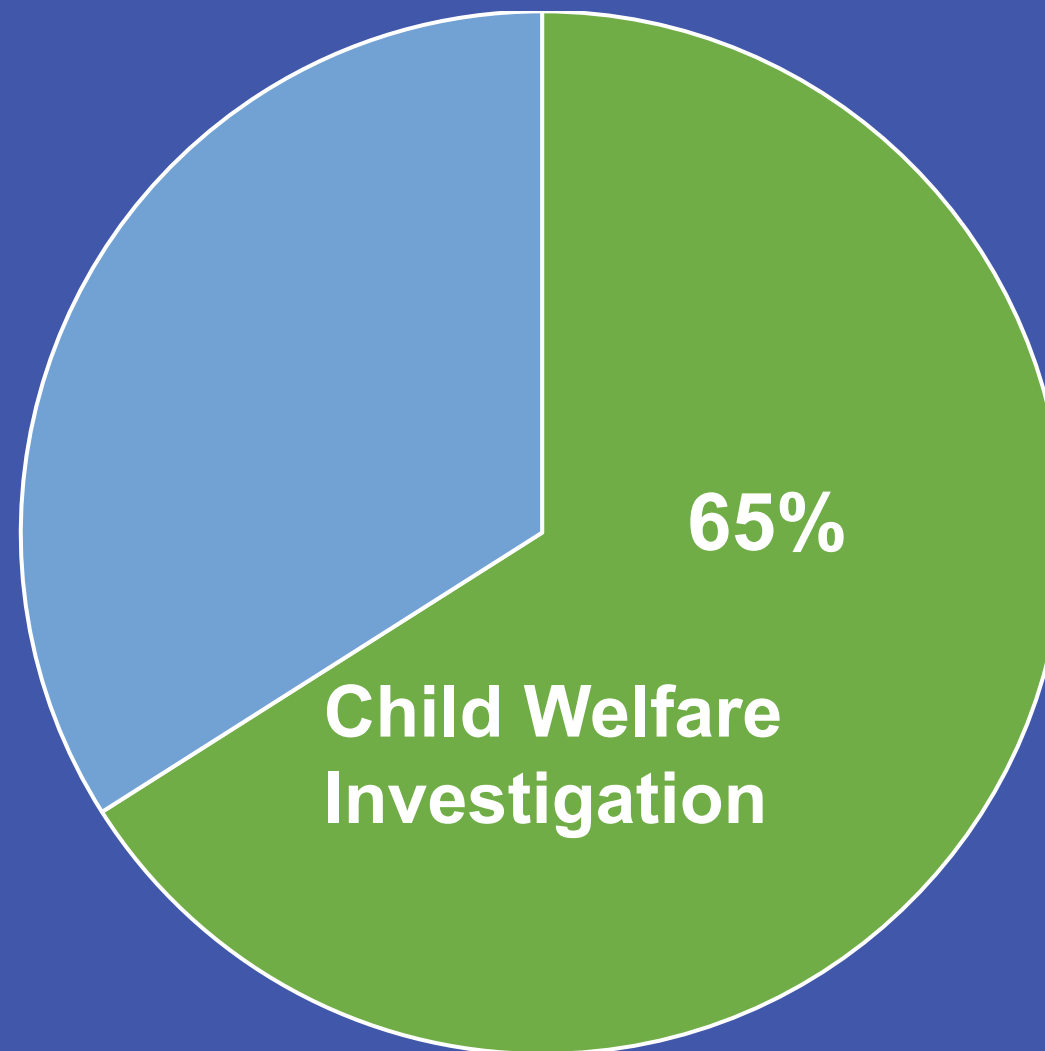
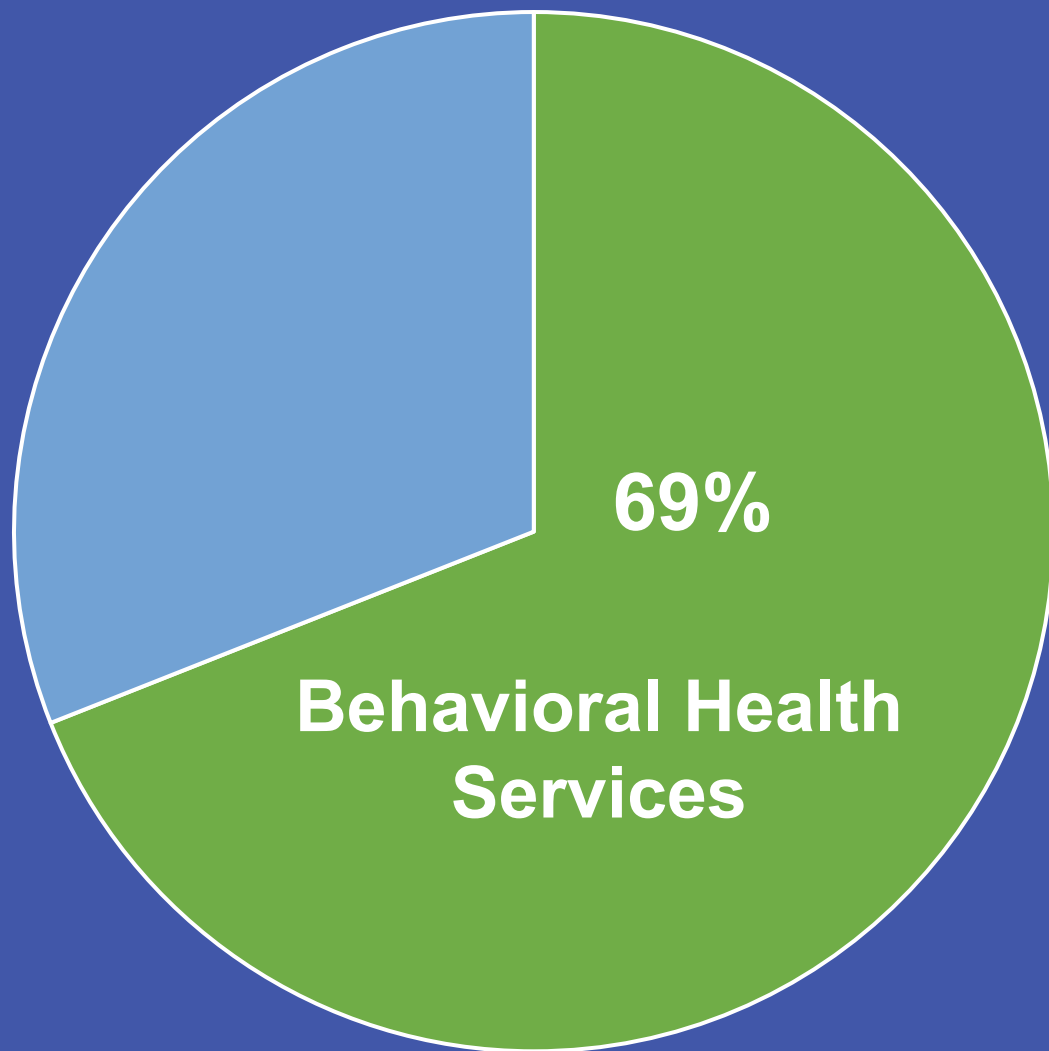
Special Education **42%**



CCLP 2020 Investigation Report on Long Creek Recommendations

“In addition, there is growing evidence that the prevalence of Fetal Alcohol Spectrum Disorders (FASD) is pronounced among incarcerated youth... Thus, in addition to screening youth for TBI, youth should also *be screened for FASD at all entry points into the behavioral health and juvenile justice systems.*”(p.58)

Long Creek Youth



Mental Health Diagnoses at Commitment

Most common mental health diagnoses:

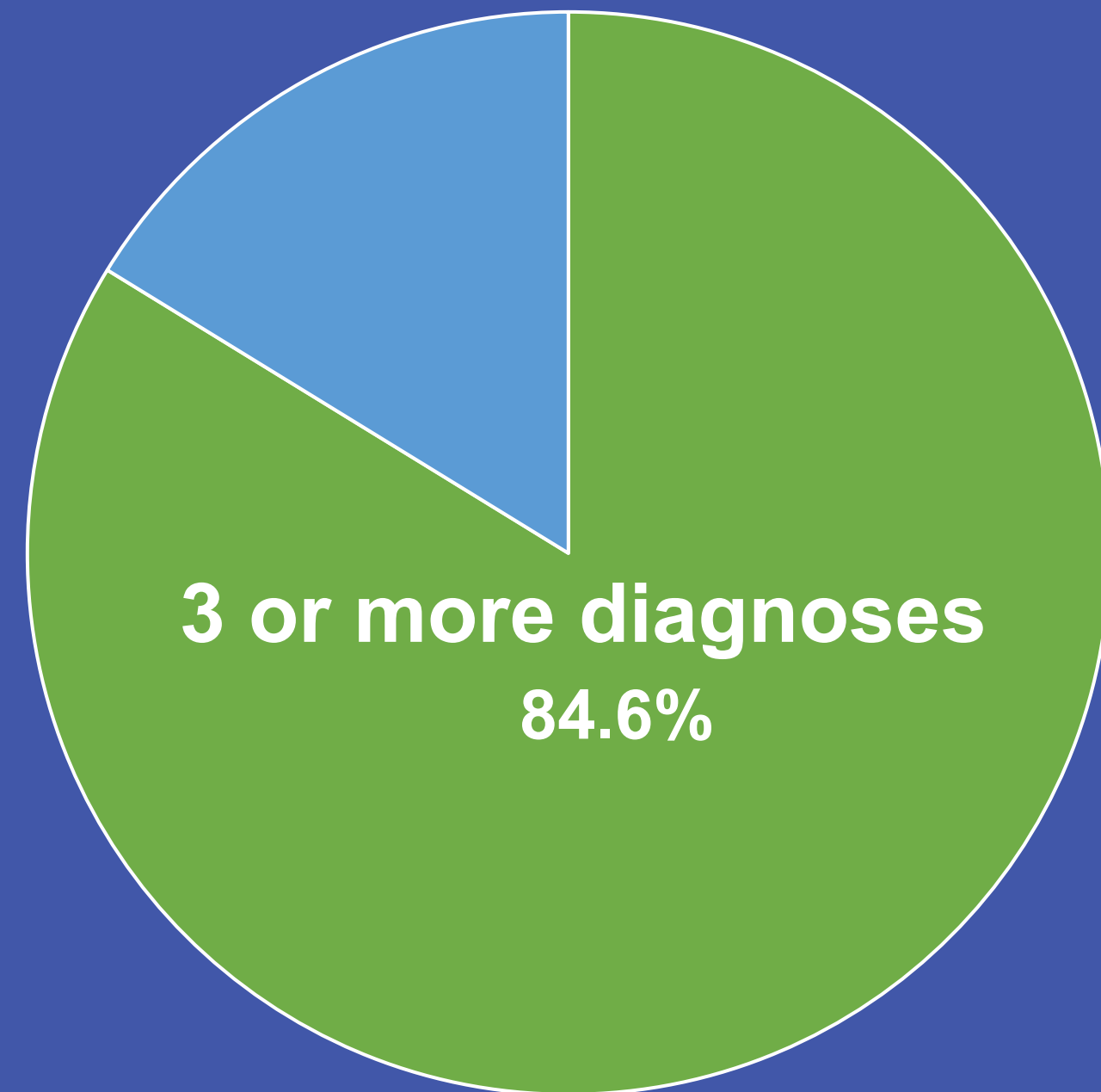
Females

- PTSD
- Mood Disorder
- ADHD

Males

- ADHD
- Mood Disorder
- PTSD/DD

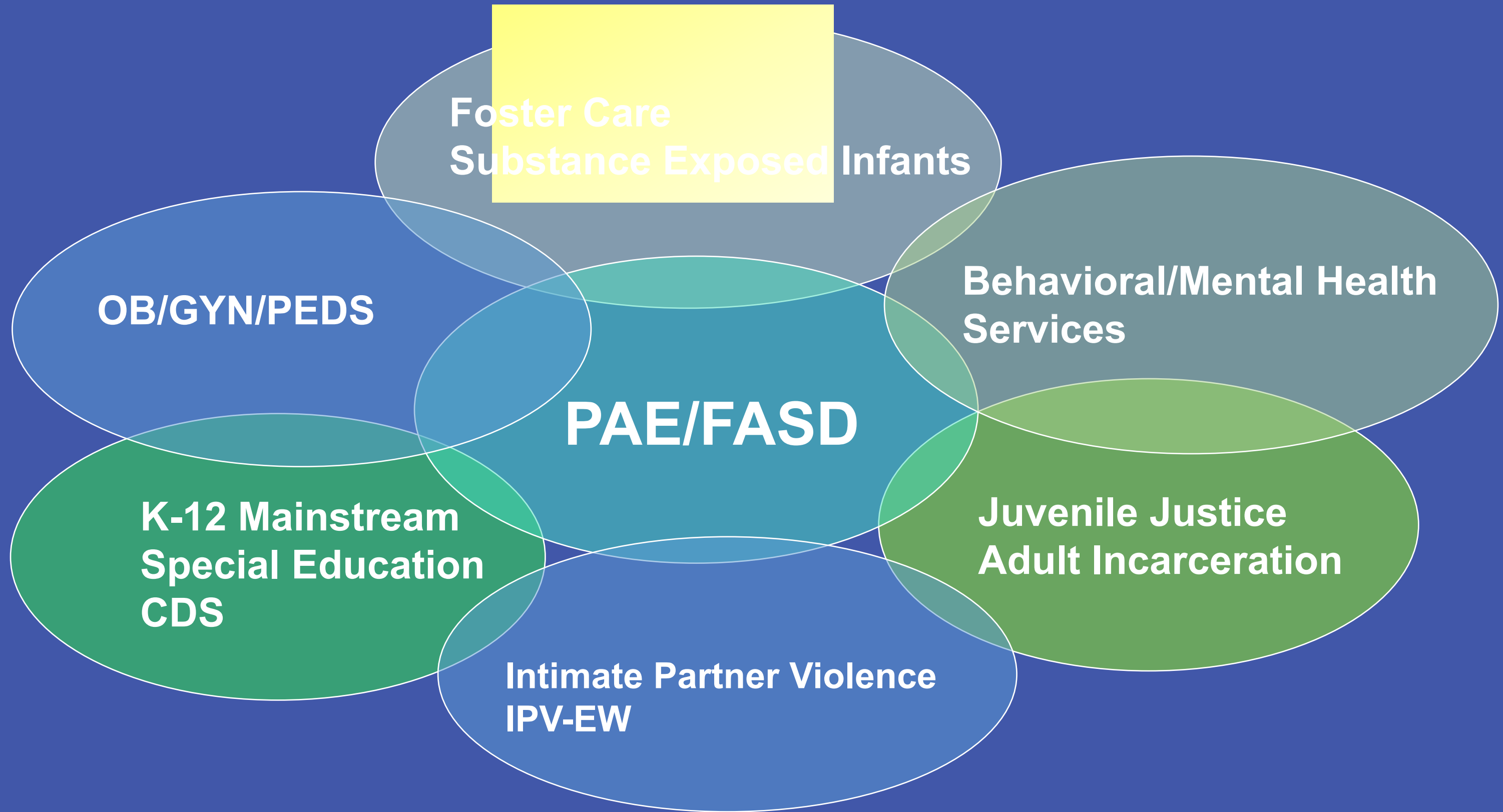
(Excluding conduct disorders)



Types of Behavioral Health Services Received Year Prior to Commitment



Opportunities for Prevention, Diagnosis, Support



What is FASD?

And Why Does It Matter??



Lynn Cole, RN, DNP
Associate Division Chief
Division of Developmental & Behavioral Pediatrics
University of Rochester Medical Center

An illustration of an iceberg floating in a teal ocean under a teal sky with stylized clouds. The visible tip of the iceberg is pink and jagged, while the submerged portion is a much larger, dark blue structure, symbolizing the hidden nature of FASD.

Fetal Alcohol Spectrum Disorders

- Fetal alcohol syndrome (FAS) = “tip of the iceberg”
- Most people with FASD do NOT have facial features

**All experience neurobehavioral impact,
including some combination of difficulty in :**

- Learning
- Memory
- Executive Function
- Emotion Regulation
- Adaptive Functioning
- Social Skills
- Sensory processing



Developmental Unfolding



FASD is one of the
most prevalent
developmental
disabilities

1.1 to 5% of
general population

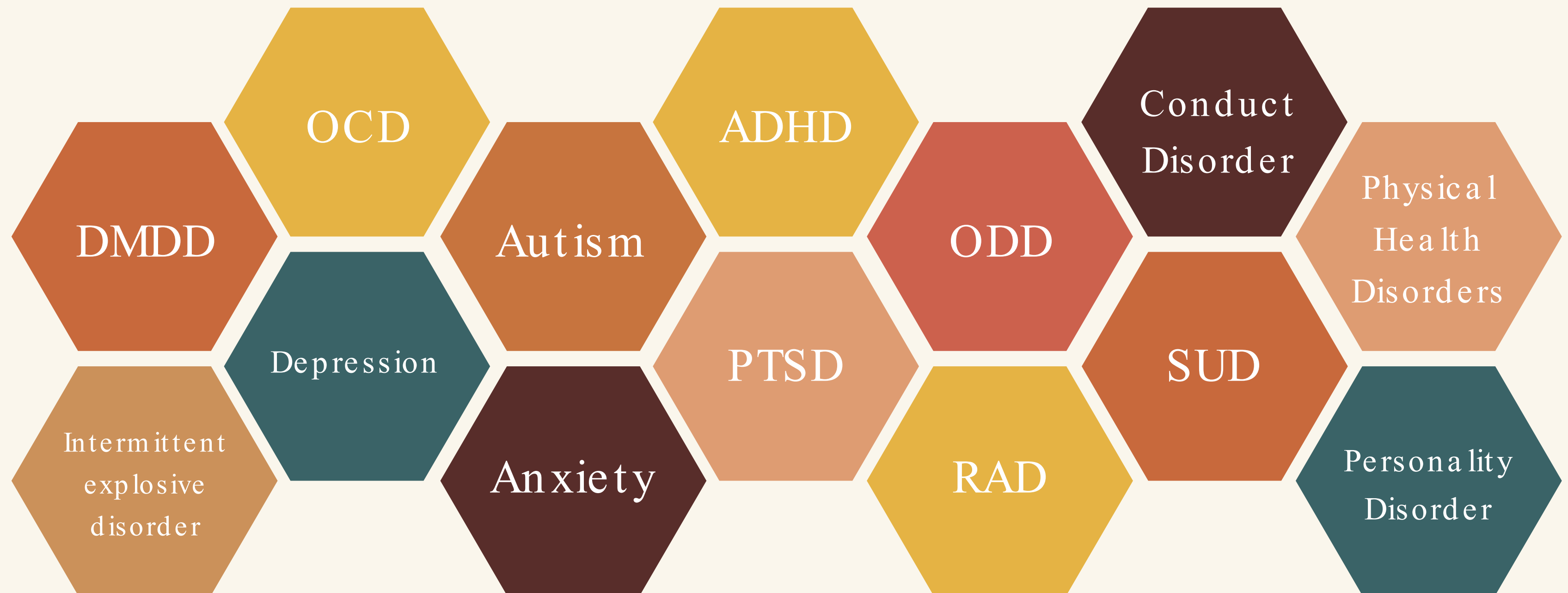


Rates of FASD are even
higher in
special populations

6 to 17% in child
welfare or mental
health settings



FASD is Often Missed or Misdiagnosed



Why?

FASD is not
included in
provider
education

Prenatal
alcohol
exposure not
assessed

Limited
diagnostic
capacity

Stigma

How does this
impact
families?



How Does an FASD Diagnosis Help?



Clinical Benefits of an FASD Diagnosis

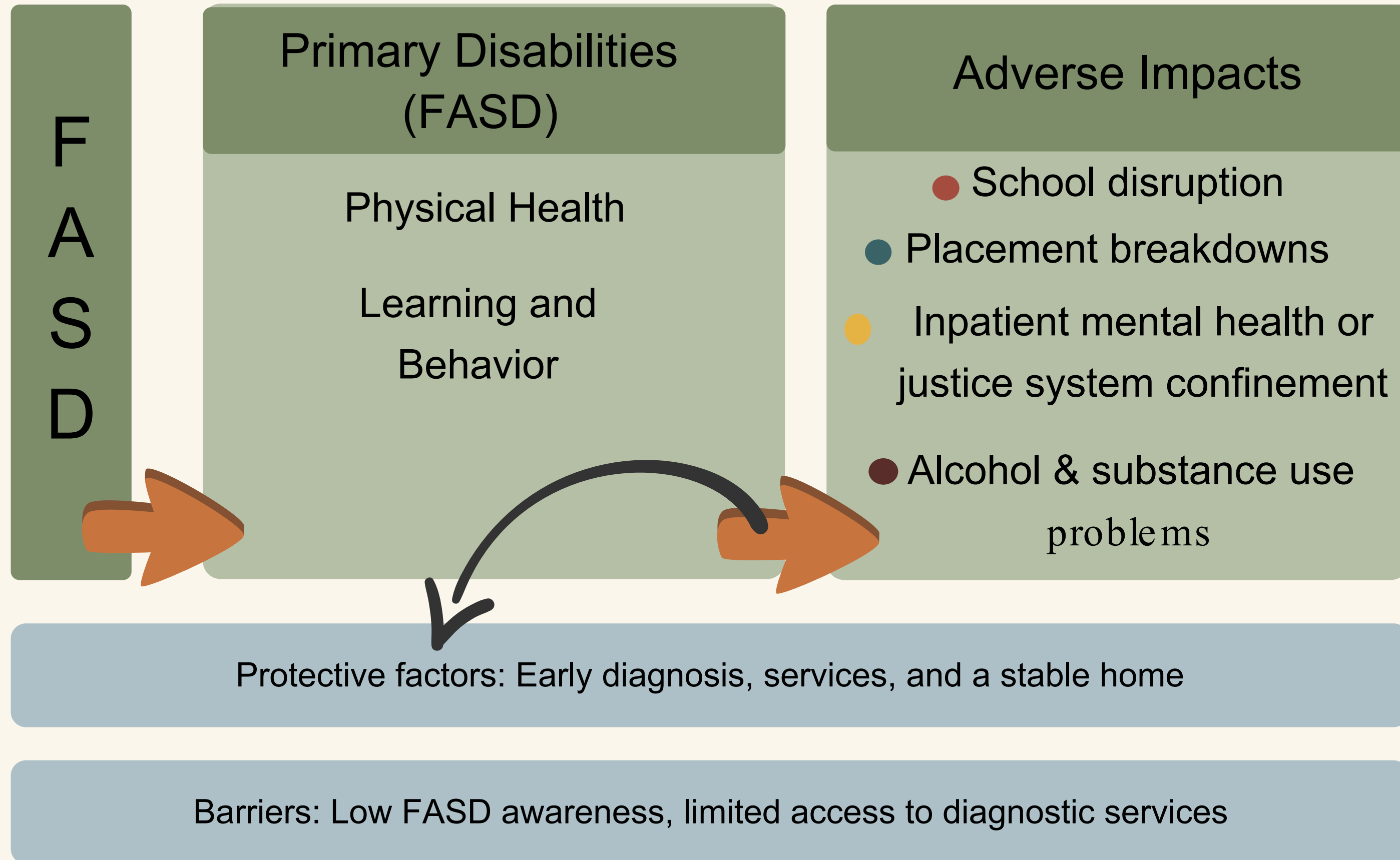
- 1 Provides an understanding for confusing symptoms
- 2 Helps the child and family get the right treatment
- 3 Offers opportunity to connect with others in the FASD community



Lived Experience Perspective

Morgan, age 19

Research Evidence

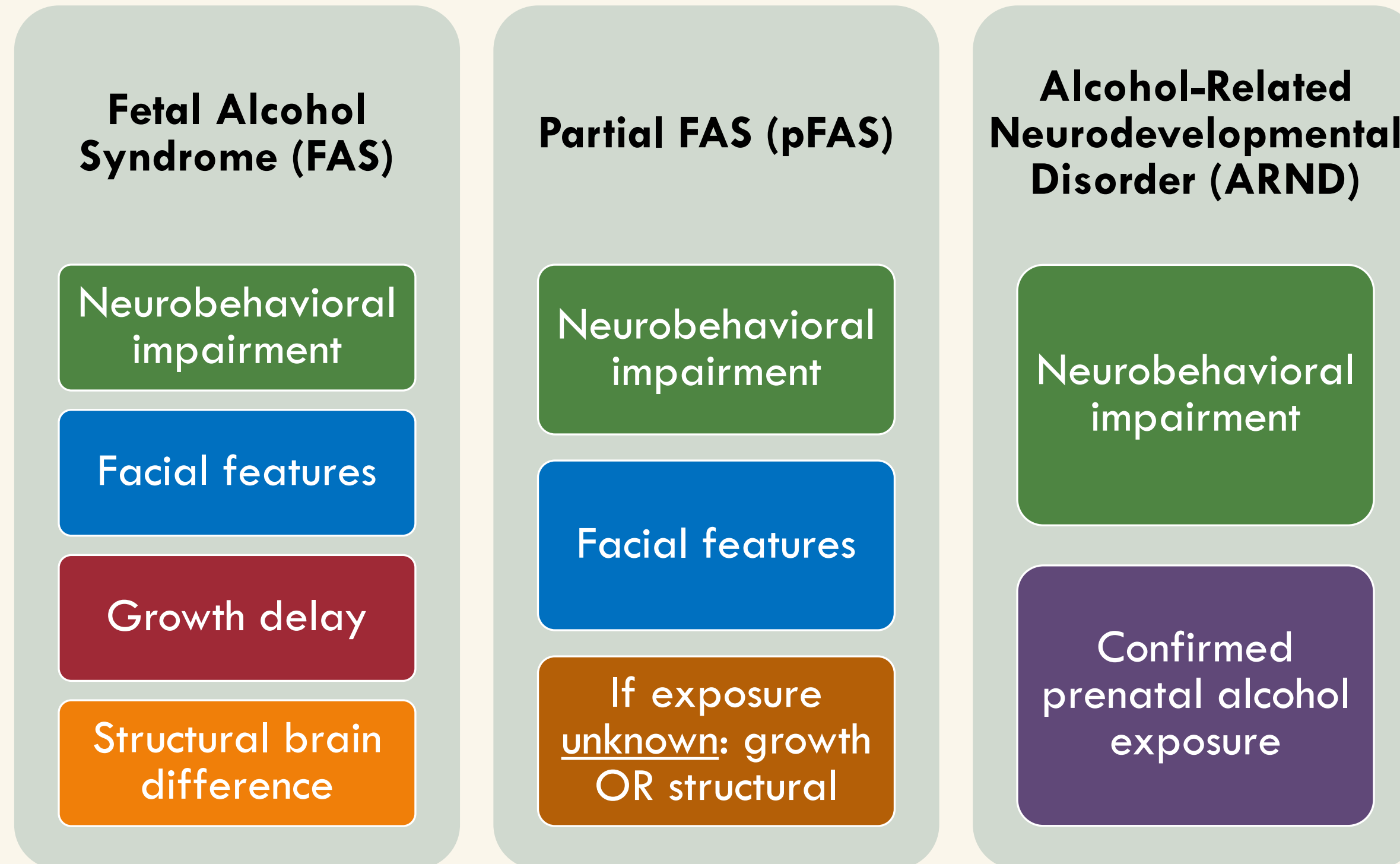


Diagnosis

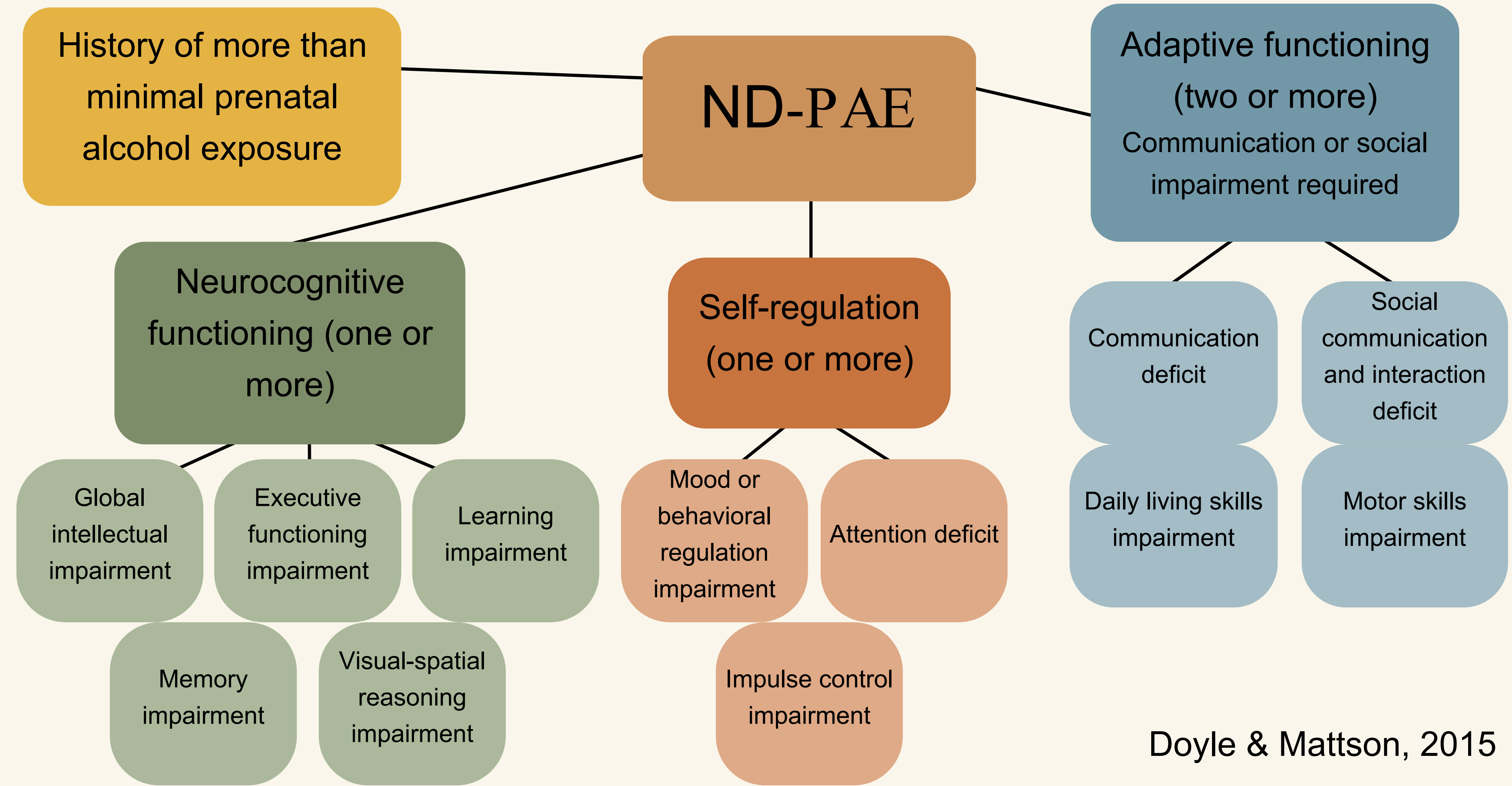
- Alcohol Exposure
- Facial Features
- Growth
- Brain abnormality
- Neurobehavioral Features



IOM/HOYME CRITERIA – MEDICAL PROVIDERS



DSM-5 – Mental Health OR Medical Providers



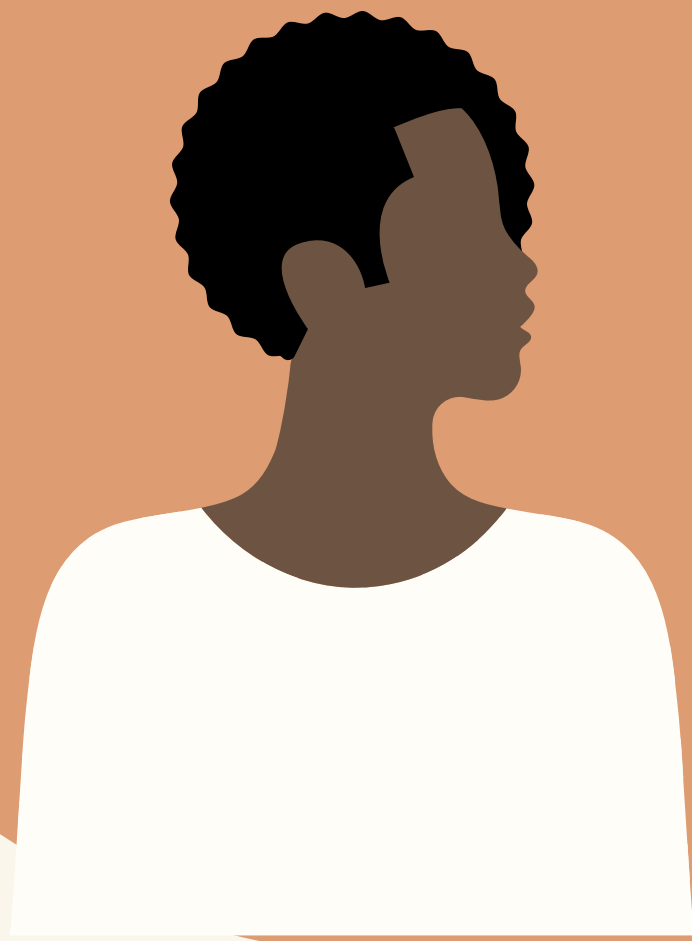
We have a diagnosis...
Now what?

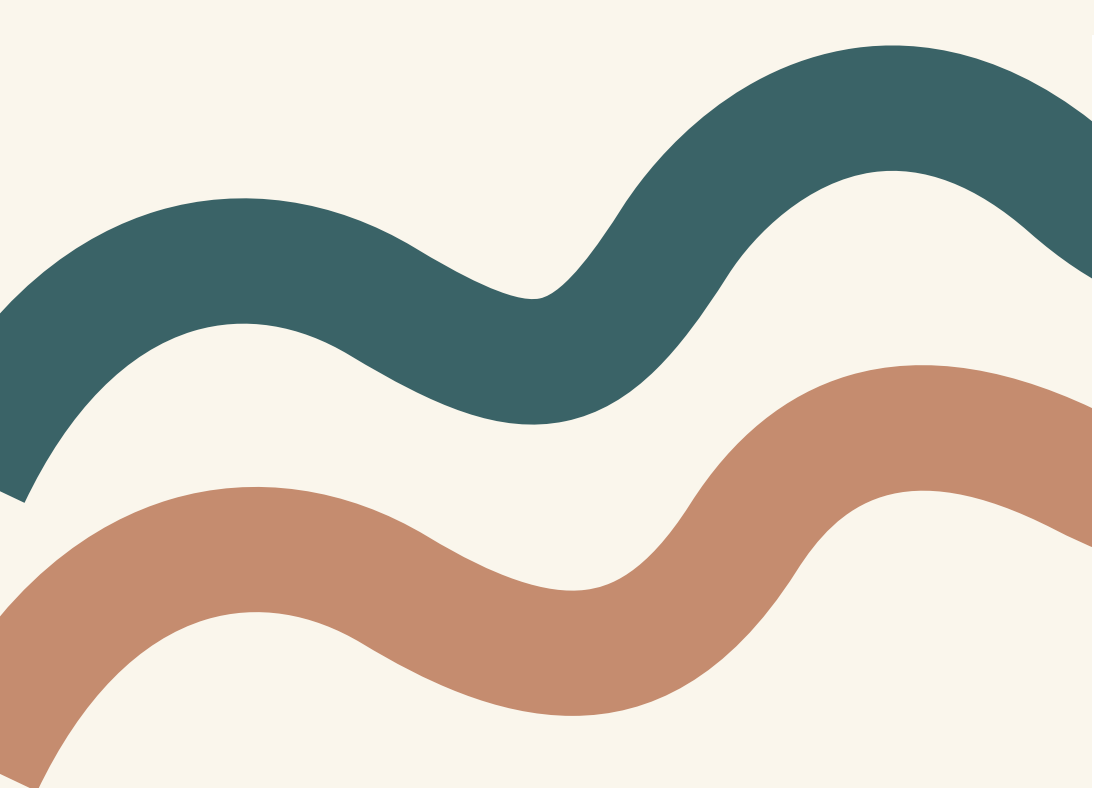


Can't I just do what I already know?

FASD is more than the sum of its "parts."

GOOD NEWS: You can apply some straight
forward principles to adapt your approach
for FASD!





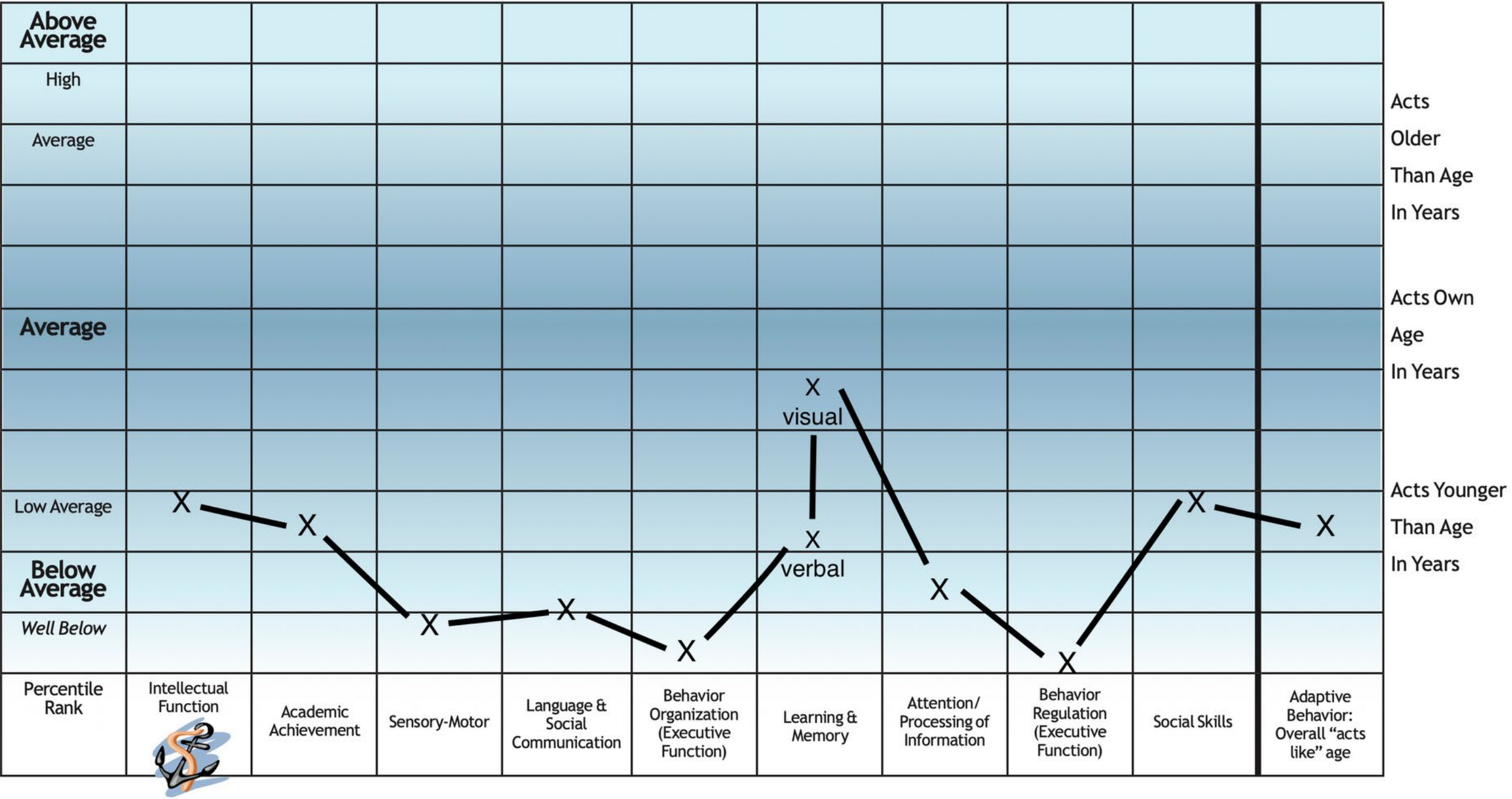
Uneven Profiles



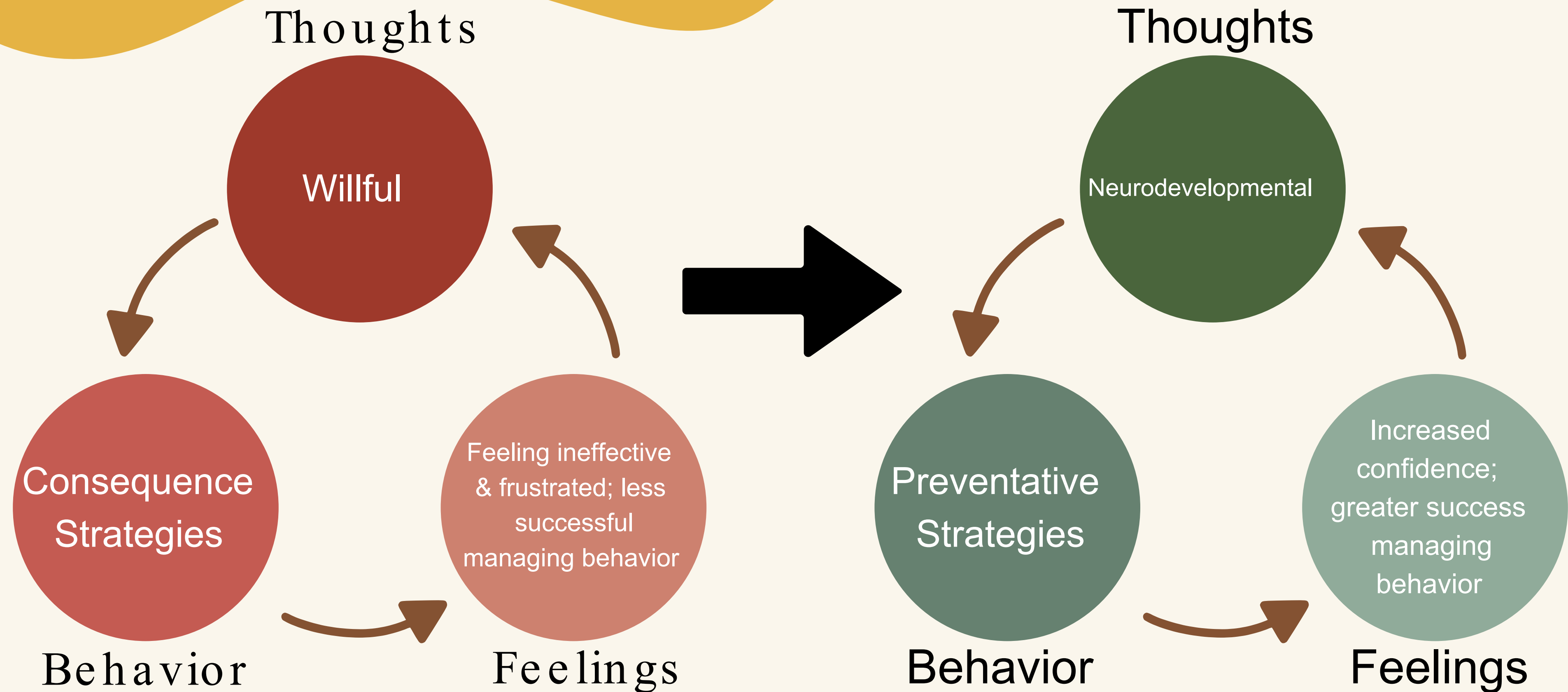
Families Moving Forward Worksheet

Child Profile Graph Based on Careful Observations

Child Profile Graph for: Shade Date: Age 8

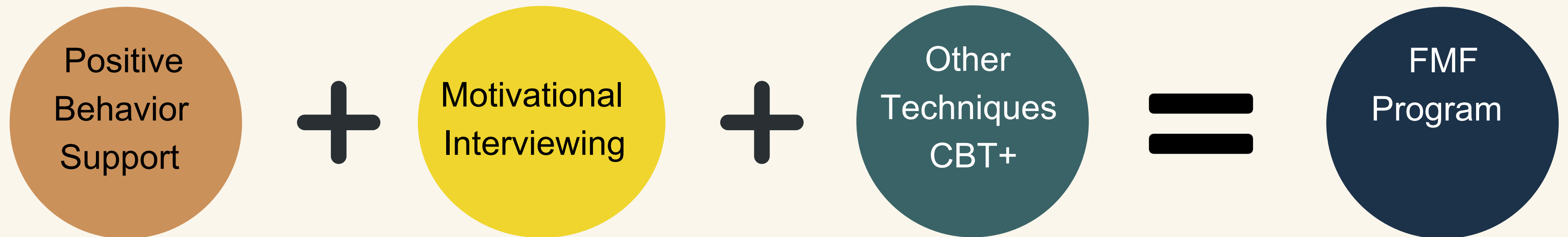


Benefits of Reframing!



Families Moving Forward (FMF) Program

- Evidence-based positive parenting program for FASD
- Incorporates essential elements of FASD-informed care



Making FASD-Informed Care More Accessible

FMF Connect app
for caregivers of
children with FASD
ages 3-12



Here to Help



FASD United

Family Navigator

Go to www.FASDUnited.org/family-navigator or

Call (800) 666-6327

9AM-10PM Eastern, Monday-Friday

No Referral Necessary



FASD Collaborative Project

Creating connection and community
through informed partnerships.

www.fasdcollaborative.com

Progress in Maine!

- SAFEST Choice National Learning Collaborative since 2021 February 2025
safestchoice@bmc.org September 2025
- Maine AAP Foster Care Committee 2021
- Maine DOE CDS 2021- 2022
- Sweetser Diagnosing and Supporting FASD 2022, 2023, 2024
- Maine Association of School Psychologists MASP 2023, 2024
- MaineHealth Psychiatry Grand Rounds 2023 Douglas Waite MD March 11, 2025
- Northern Light OB Grand Rounds ACOG FASD Champion Erin Bradley MD 2022
- RSU 1 MSAD 75 School Clinical Staff 2023

SAFEST Choice Learning Collaborative

Thank you to Maine Participants

The **SAFEST Choice Learning Collaborative** aims to reduce the incidence of prenatal alcohol exposure (PAE) and improve outcomes in children with suspected or diagnosed fetal alcohol spectrum disorders (FASDs).

Boston Medical Center and **Proof Alliance** are partners in this ECHO® virtual FASD training for community health centers (CHCs) and tribal health centers in New England and the Upper Midwest.

- The Prenatal Cohort learns how to screen for and counsel patients about the risks of alcohol use during pregnancy.
- The Pediatric Cohort learns how to identify and care for children and adolescents with suspected or diagnosed FASD.
- Participation in both cohorts provides a streamlined approach for healthcare teams to address prevention of FASD and management of individuals with an FASD across the lifespan.

FASD Maine is grateful to Maine's SAFEST Choice participants for improving access to early FASD diagnosis and intervention for Maine families.

We welcome Dr. Alyssa Goodwin to the 2023-2024 Pediatric Cohort.

The SAFEST Choice Learning Collaborative Participants

2021-2022

Janice Small NP
St. Croix Regional Family Health Center
Princeton - 207-796-5503

2022-2023

Dr. Andrea Tracy MD
Edmund Ervin Pediatric Center
Augusta -207-872-4303

Dr. Sunee Lovely MD
Passamaquoddy Health Center
Princeton - 207-796-2321

Dr. Deborah Hagler MD
Mid Coast Pediatrics
Brunswick - 207-721-8333

2023-2024

Alyssa Goodwin MD
Stellar Pediatrics
9 Bowdoin Mill Island
Topsham
207-406-4462



Pediatric Cohort February 2025
Prenatal Cohort September 2025
Contact: safestchoice@bmc.org

Resources

- fasdmaine.org
- fasdunited.org
- Families Moving Forward familiesmovingforwardprogram.org
- Maine Children's Alliance mekids.org
- SAFEST Choice Learning Collaborative Boston Medical Center
- AAP FASD Toolkit
- AUDIT-US Audit 1-3 Alcohol Use Screening Tool
- CDC Collaborative for Alcohol-Free Pregnancy
- “Trying Differently Rather than Harder” Diane Malbin MSW