



# PRoF

## Alliance

Understanding  
Fetal Alcohol Spectrum Disorders  
(FASD):

*What Care Coordinators  
Need to Know*

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FASD Diagnostic Clinic



# PROF Alliance

Our mission is to prevent fetal alcohol spectrum disorders and to support all impacted throughout Minnesota and beyond.

Our vision is a world in which alcohol is not consumed during pregnancy and people living with fetal alcohol spectrum disorders are identified, supported and valued.

# Learning Objectives

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- Understand the process of FASD diagnosis & subsequent support
- Gain insight on how to effectively support children with FASD
- Learn about resources for youth with FASD and their caregivers



## \* Please Note \*

Proof Alliance acknowledges that not every person who can become pregnant identifies as a woman. While we try to use gender-neutral language as often as possible, much of the current research available currently refers only to “women” when discussing the ability to become pregnant. When citing this research, we refer to the language used in the study. In these cases, “woman” refers to someone who was assigned female at birth.



# What is FASD?

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## Fetal Alcohol Spectrum Disorder

- A group of birth defects that is the result of prenatal alcohol exposure
  - Wide range of symptoms including physical, mental, behavioral, & learning disabilities
  - 100% preventable
  - Prenatal alcohol exposure affects each person differently
  - Permanent disability, lasts a lifetime
  - All people with FASD can be successful
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# 1973

The effects of prenatal alcohol exposure were first recognized in research journals in the early 70s. The effects were referred to as 'fetal alcohol syndrome'



# 1996

In 1996, the Institute of Medicine split this medical condition into five different diagnoses.



# 2000+

The effects of prenatal alcohol exposure are now referred to as a whole spectrum. FASD includes all five diagnoses first identified in 1996.



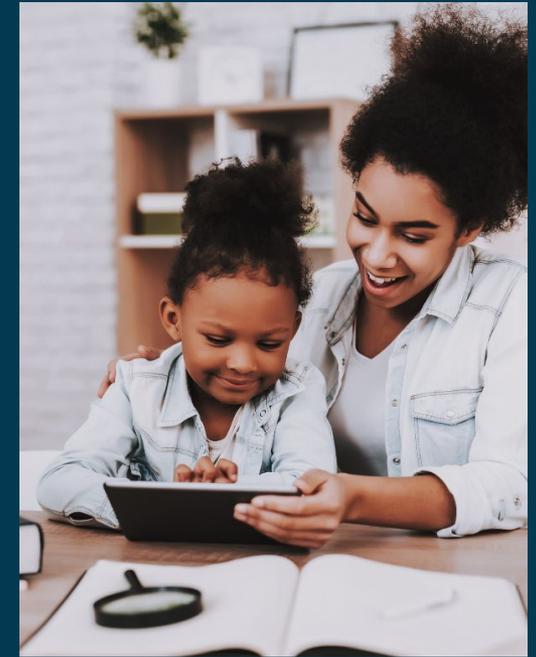
True or false?

FASD is more common than Down Syndrome.



True or false?

FASD is more common than autism.



True or false?

FASD is the leading cause of preventable intellectual disabilities in the U.S.

# Prevalence Study

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Research shows as many as 1 in 20 children  
in the U.S. have an FASD.

# 11.5%

In the United States, 11.5% of women drank alcohol during pregnancy and 4% engaged in binge drinking.



# Why do people drink during pregnancy?

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- Unplanned pregnancy may lead to drinking without the knowledge they are pregnant
- Substance use disorders
- Form of self-medicating or coping mechanism due to external stressors or mental illness
- Binge drinking is generally socially-accepted
- Mixed messages from family, friends, media, etc.
- Doctors implicitly give permission by not discussing alcohol use with their patients or downplaying the risks
- Public still misunderstands risks from drinking and does not recognize the high prevalence of FASD

End the Stigma: FASD is a Complex Public Health Issue

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# Effects of alcohol during pregnancy

**Decades of research have shown:**

- Even low levels of alcohol can affect the fetus
- The risk increases with more alcohol
- The healthiest and safest choice is to avoid drinking any alcohol during pregnancy.



From the  
Institute of Medicine

“Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus resulting in life-long, permanent disorders.”<sup>99</sup>



# Facial Features

- It's a common myth that all people with an FASD have a specific set of facial features.
- The fact is, only a small percentage of people with FASD have these facial features. For the vast majority of individuals with an FASD, their disability is invisible.



# Risk Factors

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- In foster care or raised in adoptive home
- Many mental health diagnoses
- Easily distracted, hyperactive, inattentive, impulsive
- Extreme behavior (aggressive; emotional)
- Poor social skills
- Poor organization and planning
- Difficulty problem-solving
- Difficulty generalizing
- Difficulty completing tasks independently
- Problems with abstract concepts
- May give inconsistent answers to questions
- Difficulty learning. Repeats the same mistakes

# Overlapping Characteristics

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depression	ODD	Trauma
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ
Easily distracted by extraneous stimuli	X	X							
Developmental Dysmaturity	X			X					
Feel Different from other people	X				X				
Often does not follow through on instructions	X	X					X	X	X
Often interrupts/intrudes	X	X	X	X	X		X		
Often engages in activities without considering possible consequences	X	X	X	X	X				
Often has difficulty organizing tasks & activities	X	X		X	X		X		
Difficulty with transitions	X		X	X	X				
No impulse controls, acts hyperactive	X	X	X		X	X			
Sleep Disturbance	X				X		X		X
Indiscriminately affectionate with strangers	X		X		X	X			
Lack of eye contact	X		X	X		X	X		
Not cuddly	X			X		X	X		
Lying about the obvious	X				X	X			
Learning lags: "Won't learn, some can't learn"	X		X			X			X

FASD is commonly undiagnosed or misdiagnosed. It can also be co-occurring with other conditions.

# Let's Talk Brain

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- Most individuals with FASDs look typical on the outside
- Most individuals with FASDs have brains that look structurally normal
- Most individuals with FASDs have functional areas of difficulty
- FASD is a neurobehavioral disability: brain impairment that is reflected in learning and behavioral problems



# FASD Diagnostic Assessment

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**A diagnosis under the FASD umbrella requires both a specialized medical & neuropsychological evaluation**

- Medical: review birth history, growth (birth & current), facial features, and other soft neurological signs
- Neuropsychological: clinical interview with caregiver and child, assessment of cognitive functioning (including learning, memory, executive functions), emotional functioning, and daily living skills.

# When you Suspect an FASD.....

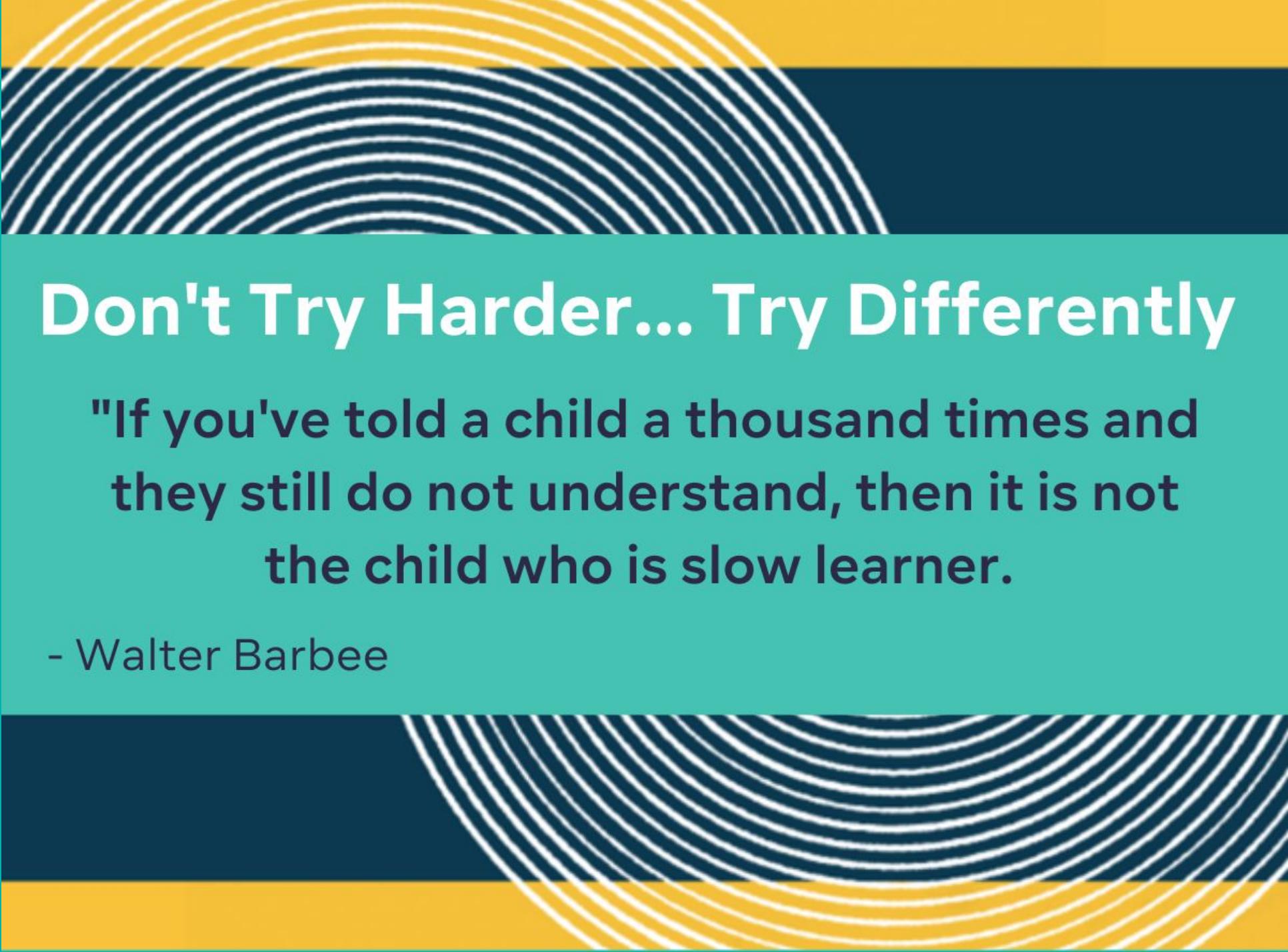
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- Proof Alliance FASD Diagnostic Clinic
    - Referral: Contact Mercedes Rider, Senior Clinic Coordinator at 651-917-2370 or [mercedes.rider@proofalliance.org](mailto:mercedes.rider@proofalliance.org)
  - University of Minnesota – Fetal Alcohol Spectrum Disorders Program
    - Referral: Appointment line at (612) 365-6777
  - See handout for additional diagnostic clinics
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# When You Suspect an FASD...

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- Explain that the purpose of the appointment is to learn more about how the child's strengths and weaknesses, and how they think, learn, and feel.
- Use nonjudgmental language:
  - Many mothers may not have known they were pregnant, may not have known about the risk of drinking alcohol during pregnancy, or may have had their own mental or chemical health struggles.



# Don't Try Harder... Try Differently

**"If you've told a child a thousand times and they still do not understand, then it is not the child who is slow learner.**

- Walter Barbee

# Think “Brain” not “Blame”

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How many of you woke up this morning and thought about your brain function?



# Consider "Fit"

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## Characteristic

Visual Learner

Processes Slower

Needs External Support

Difficulty Organizing

Concrete



## Strategy/Expectation

Verbal Instruction

Fast Paced

Work Independently

Organize, Prioritize

Abstract

## Characteristic

Visual Learner

Processes Slower

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Concrete



## Strategy/Expectation

Provide Visual Cues

Allow Adequate Time

Provide Supports

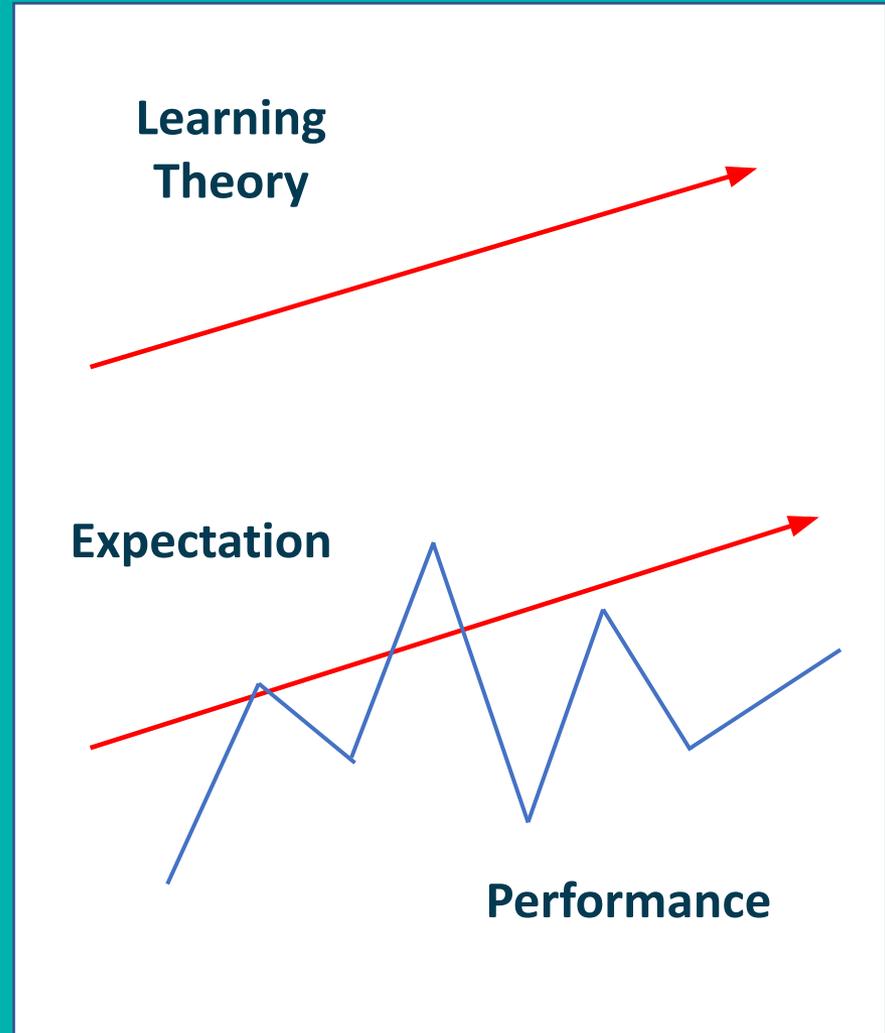
Provide Structure

Teach Experientially

# How to Help Yourself “Think Brain”

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- Stop fighting
- Depersonalize, step back
- Ask: What if?
- Think younger
- Give time and then more time
- Accept the need to reteach
- Breathe
- Be gentle with yourself





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Alliance



**Roxanne King,**

CHW

Program Manager for  
Caregiver Services

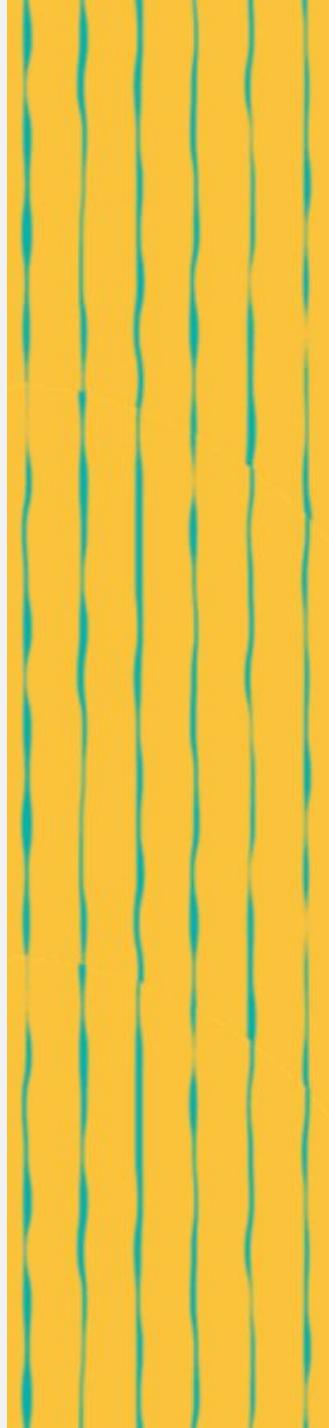
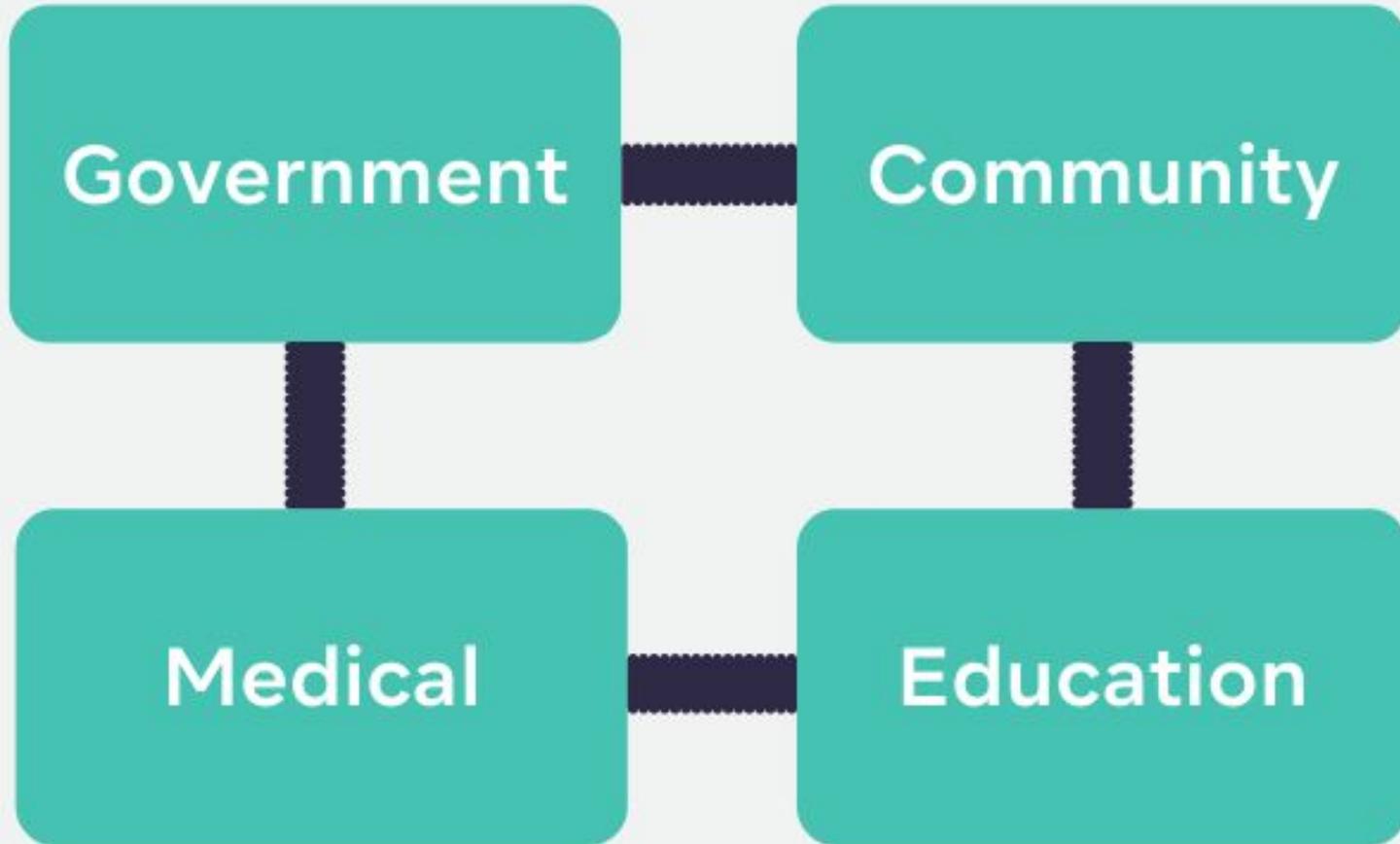
# What are the needs?

Where does the family need additional supports?

- Respite
- Information
- Guidance
- Education advocacy
- Healthcare services
- Therapy
- Emotional support
- Financial aid
- Sense of community

# Four Areas of Support

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# Navigating Services

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- County and other government programs
  - SSI/SSDI
  - Waiver Programs
- FASD-informed programs and services
  - Therapy and other healthcare needs
- Education
  - School consultation and support
  - Connect with specialized agencies
  - Training referrals
- Community
  - Proof Alliance family engagement and support
  - Connect with community programs



# Resources

- Resource Directory — an online listing by region of agencies that are “FASD friendly”<sup>99</sup>
- Proof Alliance diagnostic clinic and diagnostic consortium
- Financial assistance
- Factsheets and on-demand content
- Virtual Family Center



[www.proofalliance.org](http://www.proofalliance.org)



## Virtual Family Center

“It’s nice to know that this forum is just for parents of children with FASD. It will be nice to share with others that understand, sometimes nothing is going to work yet we wake up in the morning, ready to try something new yet again!”

— *New VFC Mom raising children on the spectrum*

<https://www.facebook.com/groups/ProofAllianceVFC/>

# Caregiver Education

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- Caregiver Monthly Webinar Series
- Hand in Hand Parent and Caregiver Training
- ProofCON 2021 - Caregiver Scholarships (MN residents only)

## Caregiver Support Groups

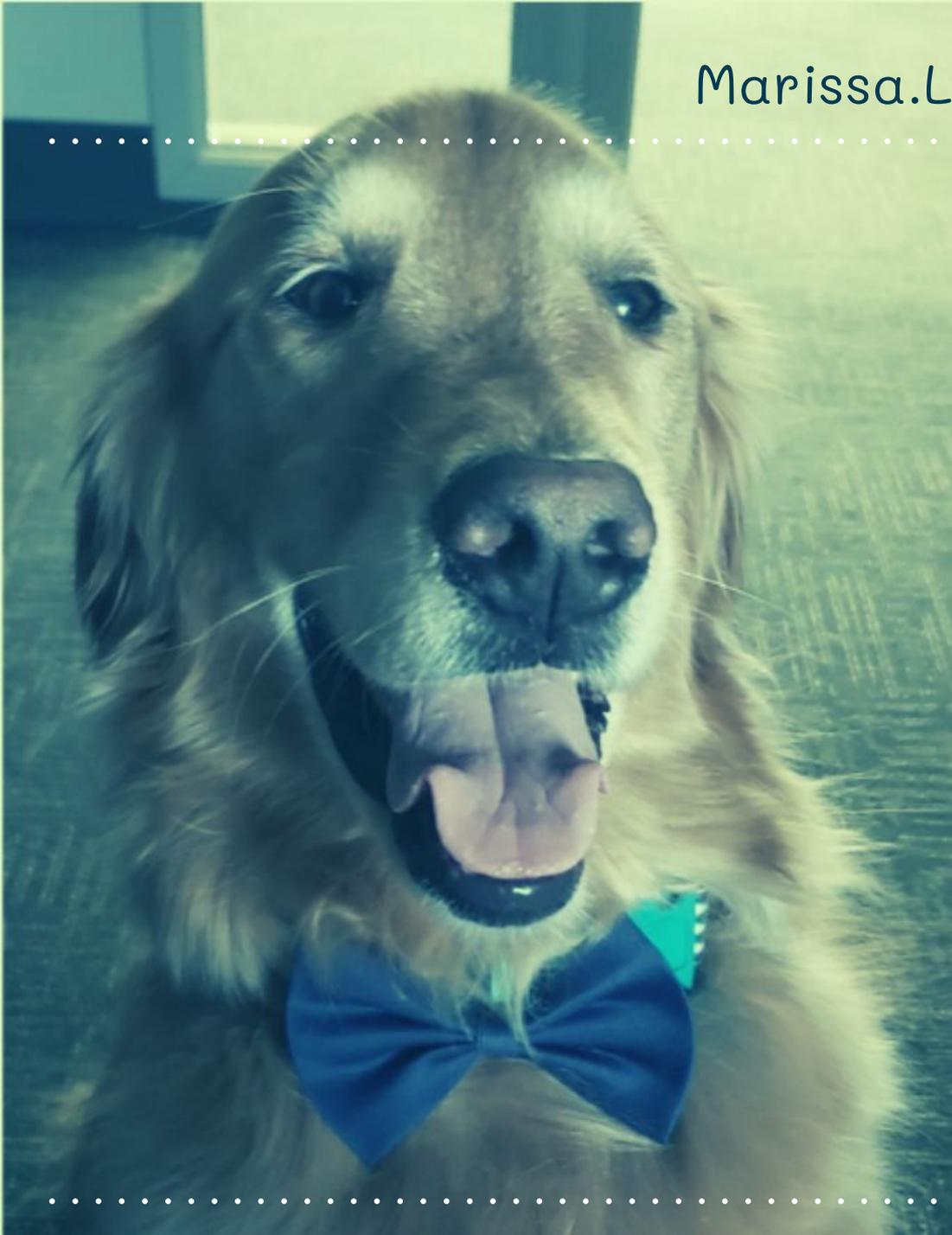
- Alone but Together: Caregiver Virtual Support Group
- Caregivers Connect Support Group
- Peer on Peer During Sensory Group: Caregiver Support Group

## Family and Caregiver Social Events

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- Family retreat
- Caregiver retreat
- Trunk n' Treat
- Winter Gathering
- And more...





Marissa.Lang@proofalliance.org

## Youth Supports

- Support Groups
  - Baxter's Support Group
  - Youth Mentor Group
- Youth Advocacy Group
- One-on-one support (up to 24 years old)

David.Peeples@proofalliance.org

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# Circle of Hope Birth Mother Network

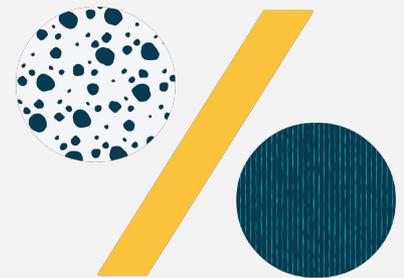
- Changing Course
- Circle of Hope Support Group
- Birth Mother Panels



# Proof Alliance Resources

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- Public awareness and prevention
- Community grants and partners
- Family engagement and support
- Diagnostic clinic and screening
- Youth and young adult program
- Public policy work
- Professional education
- Proof Alliance website resources





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## Alliance

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