

# **A Pragmatic Approach to Supporting FASD Individuals and Their Families**

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# FASD Facts

There is a significant **overrepresentation of FASD** children in adoption/foster care.

There is a significant over-representation of FASD adults in **U.S. prisons**

FASD is **often undiagnosed**; (hardly ever diagnosed prior to adoptive/foster care placement)

Too many families struggle with their FASD children due to **lack of education** around FASD

# Brain Damage

There are too many FASD people **facing unrealistic societal expectations** to be who they cannot be, and do what they are incapable of doing.

There are too many families trying to raise FASD children **without any or proper support or resources.**

Fetal Alcohol Syndrome is irreversible brain damage.

# Reframing FASD

Gentle reminder to anyone working or living with anyone who has or may have an FASD:

Rather than saying a person “**Won’t**” do something,  
say  
that the person “**Can’t**” do something.

# Time to Write!

Please take a few minutes to write down anything you know about **successful FASD management** or interventions that work.

Are you **raising or working with a child/teen/adult** who you think has FASD but has **not been diagnosed**? If yes, and if no diagnosis, why no diagnosis?

Write down whatever you wish to share!

# FASD 101

- There is no safe amount of alcohol consumption during pregnancy
- Alcohol is a known teratogen
- The first trimester is the most important for long-term brain development
- **The first trimester is when most women are least likely to know they are pregnant.**

# FASD 101

## Types of FASD Diagnosis

- Fetal Alcohol Syndrome (FAS) - **1970s – FAS** meant growth failure, intellectual disability, and characteristic changes in facial structure.
- **Fetal Alcohol Effect (FAE)** For children with behavioral/cognitive functioning affected by in utero alcohol exposure, but growth/facial features, and global cognitive functioning did not meet specific deficits.

# FASD 101

- The CDC came up with terms FAS and Partial FAS (for FAS with normal growth), then ...
- Alcohol Related Neurodevelopmental Disorder (ARND), and Alcohol Related Birth Defects (ARBD).
- In 2004 the CDC introduced Fetal Alcohol Spectrum Disorders (FASD) for all individuals along broad continuum of clinical deficits



# FASD 101

More terms!

The Federal Gov't came up with Neurodevelopmental Disorder - Prenatal Alcohol Exposure (ND-PAE)

In the most recent DSM 5, ND-PAE **was not listed**, but is included in the appendix and is used as an example for **“Other Specified Mental Neurodevelopmental Disorder”** **(Code 315.8)** which means there is a diagnostic code.

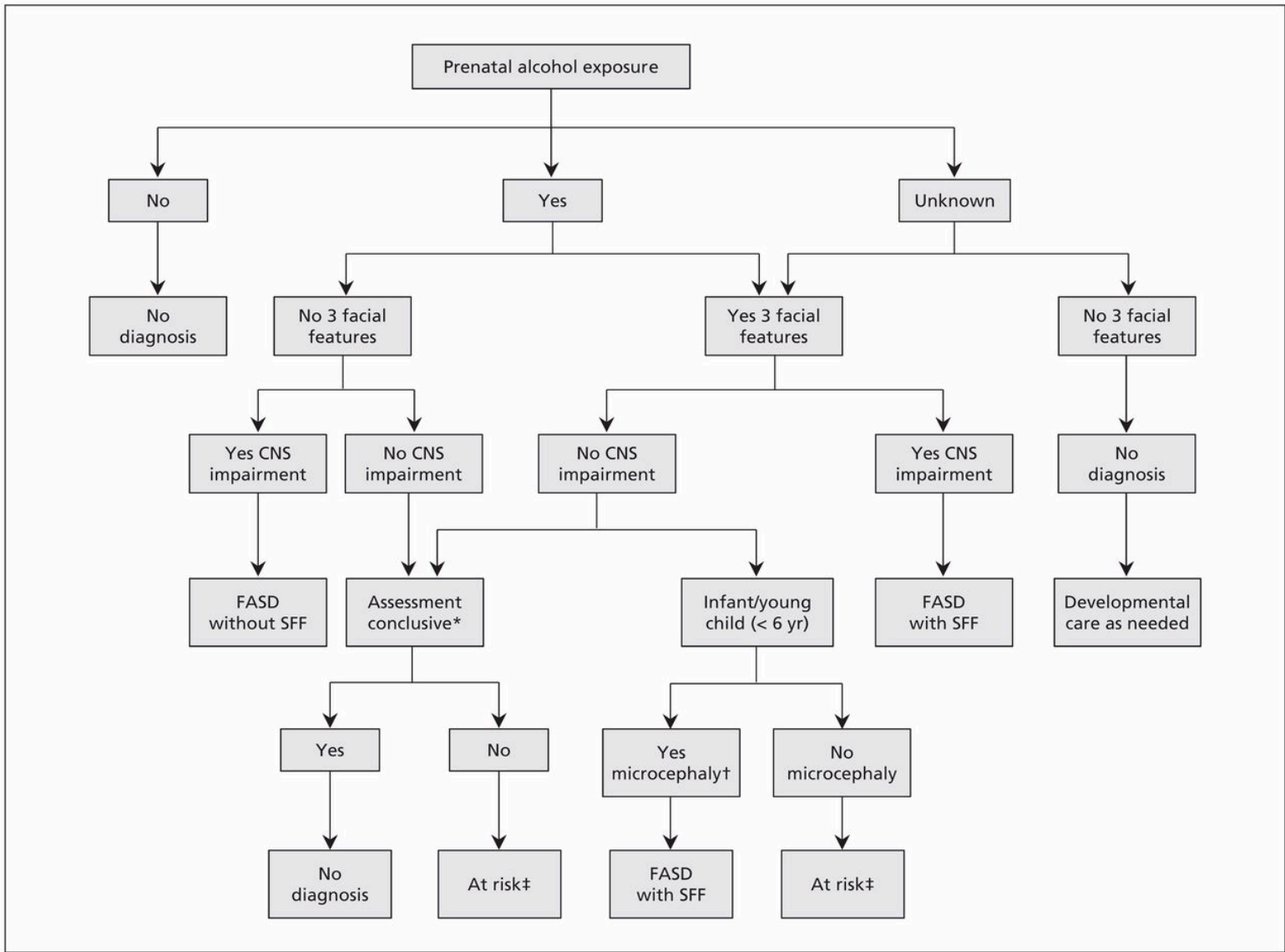
**That is good news!**

# Diagnostic Tools

- The Canada Fetal Alcohol Spectrum Disorder Research Group – CanFASD

The CanFASD's new standard recommends a **multidisciplinary approach and diagnosis**

<http://www.cmaj.ca/content/188/3/191>



# Diagnostic Tools

- University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network

The UW FASDPN recommends a multidisciplinary approach and diagnosis.

Free downloadable diagnostic handbook (123 pp.)

<http://depts.washington.edu/fasdpm/pdfs/guide04.pdf>

# University of Washington

## 4-Digit Diagnostic Code TM

One Example of FAS

significant	significant	definite	4		X	X	X	4	high risk
moderate	moderate	probable	3	X				3	some risk
mild	mild	possible	2					2	unknown
none	none	unlikely	1					1	no risk
<b>Growth Deficiency</b>	<b>FAS Facial Features</b>	<b>CNS Damage</b>		<b>Growth</b>	<b>Face</b>	<b>CNS</b>	<b>Alcohol</b>		<b>Prenatal Alcohol</b>

# The University of Washington Diagnostic Chart

- This chart is provided for reference only and should not be used by non-experts to diagnose.
- A rating of 1 on any scale means a finding within the normal range;
- a 4 represents a finding that corresponds with accepted cases of FAS.
- A 2 or 3 defines intermediate steps between clearly typical and atypical.
- FAS applies to children with all “4”s or two “4”s and two “3”s

# Diagnostic and Statistical Manual of Mental Disorders

## DSM 5

- The DSM is not designed as a multidisciplinary tool, and is not reliant on cut-offs.

# DSM 5 Diagnosis

“Neuro Developmental Disorder - Prenatal alcohol exposure.”

To have FAS must have

- 1) Prenatal alcohol exposure, and
- 2) One or more of the following:
  - i. Facial abnormalities
  - ii. Growth deficit
  - iii. CNS abnormalities (structural, neurological, or functional)



# FAS Diagnosis

Presence of all three (3) of following are required:

1. Documentation of all three (3) facial abnormalities

**Smooth philtrum** (vertical groove)

**Thin vermilion border** (lip and normal skin)

**Small palpebral fissures** (between corners of eye opening)

# FAS Diagnosis

2. Documentation of growth deficits
3. Documentation of CNS abnormalities (structural, neurological or functional or combo of all)

**Confirmed prenatal alcohol use can strengthen evidence but is not necessary for diagnosis.**

# pFAS (partial FAS)

A diagnosis of pFAS would require:

1. A confirmed history of prenatal alcohol exposure
2. CNS abnormalities

Note that individuals with pFAS may or may not have the FAS growth deficiencies, may “look” less like typical FAS.

THE FACE OF FAS CARRIES A FAS WITH BRAIN FUNCTION



**CONTROL**

D-Score = - 2.4

ABC-Score = AAA

4-Digit Facial Rank = 1

**FAS**

D-Score = + 3.2

ABC-Score = CCC

4-Digit Facial Rank = 4

# American Family Physician

V96, N 8, p. 516 10/15/2017

Documented prenatal alcohol exposure	Facial dysmorphism	Growth deficiency	CNS dysfunctions	Neuro-behavioral impairments	Diagnosis
+	+	+	+	+	FAS
-	+	+	+	+	FAS
+	+	+	-	+	PFAS
+	+	-	+	+	PFAS
+	+	-	-	+	PFAS
-	+	+	-	+	PFAS
-	+	-	+	+	PFAS
+	-	-	-	+	ARND

# Misunderstood

Often, **primary disabilities** are mistaken for **behavior problems** but the underlying CNS damage (brain damage) **is the originating source of a functional difficulty.**

- Brain. Damage.

# Early Intervention

**Early (diagnosis) and intervention** is important for managing and **potentially minimizing** secondary behavioral challenges.

The longer someone lives with undiagnosed FASD, the more likely they are to get into **harmful situations**.

# Secondary FAS

- **Mental health disorders** – depression and suicidal ideation
- **Disrupted** school and employment experience
- **Trouble** with the law
- **Inappropriate** sexual behavior and involvement in the sex trade
- **Addictions**



# Multidisciplinary Team

- Audiologist
- Cardiologist
- Developmental Pediatrician
- Developmental Therapist
- Family Therapist
- Nephrologist
- Occupational Therapist
- Ophthalmologist
- Physical Therapist
- Play Therapist
- Primary Care Physician
- Psychiatrist
- Psychotherapist
- Sensory integration Therapist
- Social worker
- Special Education Teachers
- Speech-language pathologist

# The Ten Brain Domains

- In an attempt to **standardize assessment across** North America, the Ten Brain Domains encompasses aspects of the four top diagnostic systems.
- The system is based on **empirical data** and provides clear definitions of brain dysfunction, defines intervention considerations that intend to avoid common secondary disabilities.

(The FASD Elephant )

# The Ten Brain Domains

- Achievement
- Adaptive Behavior
- Attention
- Cognition
- Executive Functioning
- Language
- Memory
- Motor Skills
- Multisensory Integration
- Social Communication

# What can be impaired

## “The (FASD) 10”

- **Achievement** – learning disabilities
- **Adaptive Behavior** – Poor impulse control, can't see personal boundaries, anger management, intrusive, poor daily living habits, too friendly, developmental delays.
- **Attention** – ADHD

# What can be impaired

## “The FASD 10”

- **Cognition** – Intellectual disability, confusion under pressure, poor abstract skills, slower cognitive skills, can't discern between fantasy and reality.
- **Executive Functioning** – Poor judgment, poor cause and effect reasoning, inconsistent at linking words to actions, can't generalize

# What can be impaired

## “The FASD 10”

- **Language** – Lack understanding of metaphor, idioms, sarcasm; grasps parts but not whole concepts, expressive or receptive language disorder
- **Memory** – Poor short-term memory
- **Motor Skills** – Delayed/poor fine motor skills

# What can be impaired

## “The FASD 10”

- **Multisensory Integration** – Sensory processing disorder
- **Social Communication** – Intrude into conversations, can't easily read social cues

# The Brain

- From Dr. Jeanette Lang's proposed book *The Broken Chord*.
- In a healthy brain - millions of neurons develop and then migrate outward, **forming the circuits and structures** of the brain
- Brain circuits and structures are genetically programmed to develop in an **organized fashion to produce orderly communication** among the brain structures
- This genetic organization of communication among brain circuits and structures **allows normal human functioning** and behavior



# The FASD Brain

- Prenatal alcohol exposure **kills neurons, disrupts neuron migration, and prunes dendritic connections**, which results in permanently malformed brain circuits and structures
- Malformed brain circuits and structures **cannot communicate** and signal each other in a normal, adaptive, predictable way
- These structural defects in brain formation and brain circuit communication **allow lapses and errors in brain functioning**
- This is the essence of permanent brain damage, which results in **unpredictable and troublesome functional behaviors**

# The Life of an FASD Family

- Super cute and charismatic kids
- Some agencies started using photos with dots
- Many families unknowingly adopted FASD children in the 1990s and early 2000s.
- Families struggle, fall apart, many children were “re-homed”
- Stories of families with children from former CIS

# Not Easy

Many families of FASD children **feel incapable** of raising their FASD children and seek respite care or full-time residential treatment.

Families are **surprised to learn** that they cannot rely on state child-welfare systems to step in and take over or strongly lead in the care of their children.

Families “**try everything**”, spin their wheels, run out of options.

# Treatment Centers

- Ranch for Kids in Montana
- FASDD Communities in Wisconsin

Both started by moms who adopted (undiagnosed) FASD kids from Russia.

# The Life of an FASD Family

- Who adopts/fosters FASD children?

Most families **lack education** when making the decision to adopt/foster a child

Many families experience **pressure from agencies**

Often prospective children are **undiagnosed** at time of placement

Parents believe they can “fix” **everything with love**

Parents are **exhausted** by years of childlessness and the desire to become a family

# Without support, families fall apart

Many families with FASD children report they feel that **no one understands their struggle.**

In many cases families are **unable** to find professional help, are left to figure out how to help their children navigate a system that is ultimately unable to help them.

# FASD kids in care

Per capita, children with FASD are over-represented in adoptive and foster families.

80% of children with FASD are **not raised in their birth families**

70% of children in U.S. **foster care system** have FASD

Too often, the behaviors of children with FASD are inappropriately attributed to their challenging family histories

# Criminal Justice System and FASD

- Criminal activity from the non-criminal FASD mind.
- FASD teens and adults are over-represented in the criminal justice system
  - 35% of individuals with FASD have been in prison or jail at some point. More than half have been in trouble with the law.
  - Few systems screen for FASD so percentages may be higher



# The Criminal Justice System

- Lack of impulse control
- Inability to think ahead, understand cause and effect or future consequences to actions
- High rate of recidivism due to lack of ability to control and or understand consequences

# Criminal Life

People with FASD are more likely to have criminal involvement, because they have:

- Difficulty planning
- Difficulty empathizing
- Difficulty taking responsibility
- Difficulty making good judgment
- Difficulty delaying gratification
- Difficulty saying no to peer pressure

# Criminal Life

- Tendency towards explosive behaviors
- Difficulty in communicating their intentions
- Impulse control challenges: I see what I like, I want it, I take it
- Inability to read social cues: Touching others out of innocent intention, crossing socially appropriate boundaries

## How the Criminal Justice System Can Help The FASD Population

- Punitive approach **does not work**.
- FASD individuals **will repeat without remorse** or awareness or malice.
- **Family support**, job training, in some cases, medication will help.
- Better systemic understanding of FASD
  - Bright lights can cause stress and result in attempts to flee police
  - Desire to please may result in waiving rights by signing forms they do not understand

## How the Criminal Justice System Can Help The FASD Population

- Desire to please may result in FASD person taking the blame for a friend
- Being easily manipulated into doing something wrong
- Training prison and criminal justice staff about FASD is crucial
- Having a family member assist with following probation requirements

# Medical Issues in FASD

- Average life expectancy of a person with FASD is 35 years.
- This is 42% of that of the average population
- 44% of the deaths were caused by “external causes” such as suicide (15%), accidents (14%), drugs/alcohol (14%).

# Alcohol Related Birth Defects (ARBD)

- Heart
- Kidney
- Bones (spine)
- Hearing
- Vision

# Treatments

## From the MAYO Clinic

- There's no cure or specific treatment for FASD
- Physical and mental deficiencies persist for a lifetime
- Early intervention services may help reduce some of the effects of FASD and may prevent secondary disabilities.



# Treatment

## Support team may include:

- Special ed teacher, speech therapist, phys and occupational therapists, psychologist
- Early intervention to help with walking/talking/social
- Special services in school to help with learning and behavioral issues
- Medical care for health abnormalities (vision/heart)

# Treatments

- Vocational and life skills training
- Counseling for parents/family in dealing with child's behavioral problems

# Treatments

## Recommended parent training:

- Recognizing child's strengths and weaknesses
- Implementing daily routines
- Creating and enforcing simple rules and limits
- Keeping things simple by using concrete specific language
- Using repetition to reinforce learning
- Teaching skills for daily life and social interactions

# Treatment Programs

## Parents and Children Together (PACT)

Neurocognitive habilitation program to improve self-regulation and executive functioning

- 12 week program for parents and children addressing behavior regulation and executive functioning. Teaches children awareness of their current behavioral state and specific techniques for optimizing.

# Treatment Programs

## Families Moving Forward (FMF)

- Provides support for families dealing with FASD
- Most appropriate for children with severe, clinically significant behavioral problems using positive support techniques.
- For parent/caregiver and child
- Nine to 11 months, every other week, 90 minute sessions

# Treatment Programs

## Good Buddies

- A children's friendship training to teach individuals with an FASD appropriate social skills
  - Addresses difficulties of FASD children to learn subtle social cues.
  - Address how to join groups, appropriate sharing, dealing with teasing.
  - Group format, over 12 weekly parent/child sessions. Goal includes child hosting a play date with a classmate.

# Treatments

“The 2C2R4S Key”

Concrete

Consistent

Repetition

Routine

Simplicity

Specific

Structure

Supervision

# FASD Medications

No medication has been approved to specifically treat **FASD**. Several are used to improve some of the symptoms of FASD.

- **Stimulants** – to treat hyperactivity, poor impulse control, problems paying attention
- **Antidepressants** – to treat sad mood, loss of interest, sleep issues, school disruption, anti-social behaviors, etc.



# FASD Medications

- **Neuroleptics** - Used to treat symptoms such as aggression, anxiety, other behavior problems.
- **Anti-anxiety drugs** – Used for anxiety.

# Never Stop Advocating

The squeaky wheel gets the oil.

If you have an FASD child **prepare for a lot of hard work** to educate and convince others of your child's needs.

# The Pragmatic Approach

Without a diagnosis it will be difficult to advocate for your child/partner/client. **Make the diagnosis your first goal.**

Approach life the way the airlines tell you to. **Put on your own oxygen mask before helping your child.** Parents/partners of special needs folks run the risk of harming themselves through lack of self-care. You will think and behave more efficiently when you are as healthy as possible.

Also, **FASD means permanent brain injury.** Your goal is to find ways to manage; curing is not an option.

# The Pragmatic Approach

- Throw out the Traditional Parenting Rule Book
- Remind yourself: Her self-sabotaging habits are not designed to destroy you, in fact, **they have nothing to do with you.**
- Many people in your life will **not know about FASD** or will not know much about it.
- People may say your child's challenging behaviors could be better controlled if you would parent better.

# The Pragmatic Approach

- Cutting out sugar and gluten from your child's diet **will not regrow the part of her brain that has been permanently damaged.**
- Forcing your child to remain in a traditional school setting, or deciding that she should complete high school may be **a battle you cannot win.**
- Your child's happiness and safety can be an excellent goal on which to focus.

# The Pragmatic Approach

- Find a therapist who can help you... and your child.
- Determine to set up the most organized, low-stim, nurturing, consistent, home life possible, **then find a way to keep going when nothing goes according to plan, ever.**
- Saying something one hundred times doesn't matter: **Saying it every time it's needed, does.**
- Protect your child by reducing opportunities for failure.

# The World Outside Home

- Meet with your child's school counselor and as many other important school staff as possible.
- Find out how much they know about FASD and what, if anything, they have done to assist other FASD kids in the school.
- Offer to bring in a specialist or present FASD educational materials yourself
- Be prepared to remind regularly, that your child has irreversible brain damage.

# The World Outside Home

- Remind your child's school that your child's educational goals may need to be very different than those of other students.
- Consider the idea that your child may not be able to achieve the academic level you'd hoped.
- Look for areas in which your child thrives, support activities which make your child happy.



# The World Outside Home

- Try to get your child diagnosed. If you cannot find anyone in your area, travel outside your area.
- A diagnosis will open doors and give support people the ability to look at behaviors and expectations differently, more realistically.
- Don't give up.

# Review Time

Please hand back your comment cards if you have not already.

We will review feedback from cards and discuss as time permits.

# Mahalo

- Thank you for your time and interest in FASD.
- Please go out and advocate as much as you can, bringing needed awareness to the issues of FASD.

# FASD Resources

- Free downloadable diagnostic handbook (123 pp.)  
<http://depts.washington.edu/fasdnpn/pdfs/guide04.pdf>
- The Canada Fetal Alcohol Spectrum Disorder Research Group – CanFASD – findings  
<http://www.cmaj.ca/content/188/3/191>
- Proof Alliance (formerly known as MOFAS)  
<https://www.proofalliance.org/>
- <https://www.bestbuddies.org/>

# FASD Resources

- The FASD Elephant Podcast and Blog with Dr. Michael Harris <https://fasdelephant.com/>
- Families Moving Forward with FASD <http://depts.washington.edu/fmffasd/>
- Families Affected by Fetal Alcohol Spectrum Disorder (FAFASD) <https://fafasd.org>
- The Best I Can Be: Living with Fetal Alcohol Syndrome or Effects by Liz Kulp

# FASD Resources

- Fetal Alcohol Spectrum Disorder – The Canadian Guidelines for Diagnosis  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC557121/>
- Dr. Jeanette Lang – FASD Wheel, Chapter two of proposed book, the Broken Cord  
[http://www.fasdwheel.com/images/Chapter\\_Two\\_Mending\\_the\\_Broken\\_Cord\\_.pdf](http://www.fasdwheel.com/images/Chapter_Two_Mending_the_Broken_Cord_.pdf)
- FAS Diagnosis in Hawaii  
<http://health.hawaii.gov/fasd/home/getting-a-diagnosis/>