

THE INVISIBLE DISABILITY

FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

Presented by: Fetal Alcohol Spectrum Disorders New Hampshire (FASD NH)
www.fasd-nh.org

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THE INVISIBLE DISABILITY: FASD

AGENDA

- What is FASD?
- FASD by the Numbers
- FASD Through the Lifespan
- Diagnosis and Co-occurring Disorders
- FASD Informed Approach

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WHAT IS FASD?¹

- Fetal Alcohol Spectrum Disorder (FASD) - diagnostic term; describes impacts on the brain and body of individuals prenatally exposed to alcohol.
- Brain based disability resulting in a range of behavioral, cognitive and social difficulties
- Invisibility of FASD contributes to social & systemic challenges
- Severity varies considerably among individuals
 - Amount, frequency, and timing of alcohol consumption
 - Health, wellness, nutritional status, during and prior to pregnancy
 - Genetic make-up, other teratogens, environmental factors

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ALCOHOL AND PREGNANCY DON'T MIX

BRAIN DEVELOPMENT CAN BE AFFECTED BY ALCOHOL AT ANY TIME DURING PREGNANCY

Teratogens are substances that can cause abnormal fetal development.

Alcohol is a powerful teratogen that targets the brain.

The disabilities caused by alcohol exposure during pregnancy are called fetal alcohol spectrum disorders (FASDs) and last a lifetime.

For more information, please visit www.fasd-nh.org

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WHAT IS FASD?

FASD Umbrella:

- Fetal Alcohol Syndrome (FAS)
- Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
- Alcohol-Related Neurodevelopmental Disorder (ARND)

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WHAT IS FASD?

- Lifelong disability with challenges in daily living,
- May need support with learning, memory, attention, communication, emotional regulation, and social skills.
- Each individual with FASD is unique and has areas of both strengths and challenges.
- #1 cause of developmental disabilities – 100% preventable⁸

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PREVENTION



No amount of alcohol consumption can be considered safe during pregnancy.

Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows she is pregnant.

The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are lifelong.

Alcohol-related birth defects are 100% preventable.

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FASD BY THE NUMBERS

- 40,000 babies born with FASD yearly⁵
- 50% of pregnancies are unplanned⁵
 - 1 in 10 pregnant woman self-reported alcohol use in the past 30 days⁵
 - 1 in 33 reported binge drinking in the past month⁵
- 1 in 13 women who consume alcohol during pregnancy will deliver a child with FASD⁵
- 90% have no observable facial features

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FASD BY THE NUMBERS¹

Mother's whose children were diagnosed with FASD:

- 50% of the women had FASD
- 95% of the women had experienced physical, emotional or sexual abuse
- 80% of the women had a major unaddressed mental illness
- 75% of the women had PTSD

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FASD BY THE NUMBERS

Prevalence rates

- 1 in 20 first graders¹
- 1 in 4 children in foster care³
- 1 in 12 students in special education³
- 1 in 12 patients in the psychiatric population³

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FASD BY THE NUMBERS

Compared to the general population, people with FASD:

- 5 times more likely to mis-use alcohol and drugs⁹
- 22 times higher intellectual disabilities³
- 11 times higher anxiety disorders³
- 24.5 times higher psychosis³
- 2 times high learning disabilities³
- 10 times higher ADHD³
- 4.9 times higher Oppositional Defiant Disorder³

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FASD BY THE NUMBERS

- 15 times more likely to be a victim of crime, witness or suspect²
- 12.8 average age individuals with FASD begin having trouble with law enforcement^{1,2}
- Make up as much as 40% of the prison population²
- IQ range of 29 to 142^{7*}

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FASD BY THE NUMBERS

- IQ range of 29 to 142⁷

IQ	IQ
Verbal Comprehension	116
Perceptual Reasoning	102
Working Memory	77
Processing Speed	97

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“Whether we know it or not, community service providers are often working with people who have an FASD.”

Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD, Deborah Rueman

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FASD THROUGH THE LIFESPAN

Primary and Secondary Challenges

- Primary – impaired mental functioning due to Prenatal Alcohol Exposure
- Secondary – can be prevented with proper interventions and understanding of the primary behaviors associated with FASD

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FASD THROUGH THE LIFESPAN¹⁰

Primary – impaired mental functioning due to PAE

- Cognition - Executive function and memory
- Social skills – verbal and non-verbal communication
- Adaptive behavior – problem solving, decision making, daily living skills
- Learning deficits
- Abstract reasoning difficulty
- Poor judgement, Impulsivity, risk taking

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FASD THROUGH THE LIFESPAN¹⁰

Secondary Challenges - made less severe through understanding and intervention

- Aggression
- Mental health issues - Depression
- Running away
- School and employment issues
- Legal issues
- Drug and alcohol mis-use
- Inappropriate sexual behaviors
- Problems with parenting

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FASD THROUGH THE LIFESPAN

Secondary Challenges - Protective Factors

- Early diagnosis⁸
- Access to services⁹
- Living in a stable, nurturing environment¹⁰
- Absence of violence¹⁰
- Education on FASD⁸
- Reframing thinking¹⁰

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FASD THROUGH THE LIFESPAN

Information Processing –brain stores, organizes, recalls, uses information

- Difficulty completing tasks or chores – following multiple directions
- Do not ask questions - want to fit in, don't know question to ask
- Trouble with changes in routines
- Say they understand when they do not
- "I don't know" common response
- Difficulty operationalize what they've memorized (e.g., multiplication tables, questions that appear different than memorized)
- Misinterpret others' words or actions,

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FASD THROUGH THE LIFESPAN

Executive Function – planning and problem solving ability

- Do not remember the rules
- Misunderstanding of cause & effect
- Tend not to learn from mistakes or natural consequences
- Frequently do no respond to reward systems
- Naïve, gullible, vulnerable to manipulation & coercion
- Difficulty with assessment, judgment & reasoning
- Overly friendly

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FASD THROUGH THE LIFESPAN

Adaptive Functioning – ability to meet everyday demands

- Communication deficits
- Impaired social skills
- Abstract reasoning difficulties - time, money, laws, etc.
- Concept formation

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FASD THROUGH THE LIFESPAN



Self-esteem and Personal Issues

- Do well one day and not the next - feel "stupid" or like a failure
- Told they're not trying hard enough - lazy, uncooperative, and unmotivated
- May have hygiene problems
- Aware they're "different" from others
- May grow up experiencing multiple losses

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FASD THROUGH THE LIFESPAN INFANCY AND PRESCHOOL



- Difficult to soothe
- Sleep difficulties
- Mild developmental delays
- Distractibility and hyperactivity
- Difficulty adapting to change
- Difficulty following directions
- Sensory

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FASD THROUGH THE LIFESPAN MIDDLE CHILDHOOD



- Academic difficulties/behavior - ADHD
- Concrete thinking may frustrate relationships
- Difficulty predicting and/or understanding consequences
- Difficulty with memory may bring negative feedback
- Poor comprehension of social rules/expectations
- Maladaptive coping skills from feeling misunderstood

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FASD THROUGH THE LIFESPAN ADOLESCENCE

- Poor adaptive functioning – “10 second kid in 1 second world”
- Confabulation—lying or stealing often without malice
- Faulty logic
- Low self-image and motivation
- Increased academic difficulty i.e. math
- Inappropriate sexual behavior & substance mis-use



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FASD THROUGH THE LIFESPAN ADULTHOOD

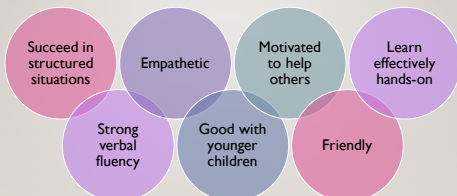
- May seem more capable than they really are
- Secondary disabilities may predominate
- Natural support network may fall away
- Available services may be crisis oriented
- Employment failure possible



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FASD THROUGH THE LIFESPAN POSITIVE TRAITS AND STRENGTHS



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FASD DIAGNOSIS⁷

Why is a diagnosis of FASD important?

- Help explain how an individual learns
- Helps us understand behaviors (fight or flight)
- Tailored therapeutic interventions improve long-term outcomes
- Identifying and building on strengths improves life outcomes
- Individual understands they learn differently due to how their brain works – not because lazy or unmotivated

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FASD INFORMED APPROACH¹³

Responding to an Individual with FASD

- Concrete – Avoid sarcasm, figurative language, abstract terms, metaphors. Gauge understanding by asking to repeat back what they heard
- Consistency – Actions need to be predictable and consistent
- Repetition – Multiple reminders
- Routines – set routine that rarely changes

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FASD INFORMED APPROACH¹³


Responding to an Individual with FASD

- Simplicity – keep interactions as simple as possible. Eliminate distractions - turn down radio, turn off patrol lights
- Specific – Step by step directions
- Structure – provide structure, helps individual with FASD to better understand what to expect from their environment
- Supervision/Coach/Mentor – encourage

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“Their learning style might not “fit” into many programs designed to address some of the presenting difficulties. For instance, most risk-reduction programs designed to address sexual assault or drug use are based on learning theory models for students who are not learning disabled. A student with an FASD, who is a concrete thinker, might not benefit from a model that is based on intellect and common-sense approaches to safety. Programs must be adapted to consider brain differences of students with FASDs.”

Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD, Deborah Rutman



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FROM	TO
Won't	Can't
Lazy	Trying hard
Lies	Confabulates, fills in
Resisting	Doesn't understand
Attention seeking	Needs contact and support
Changing people	Changing environment
Is a problem	Struggles

FASD INFORMED APPROACH

CHANGING OUR LENS

Trying Differently Rather Than Harder: Fetal Alcohol Spectrum Disorders by Diane Malbin

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FETAL ALCOHOL SPECTRUM DISORDER RESOURCES

- FASD NH www.fasd-nh.org FASD NH Facebook page
- The FASD Project www.thefasdproject.org
- Proof Alliance www.proofalliance.org
- ABA Resolution 112B FASD
- FASD Implications for Juvenile & Family Court Judges NCJFCJ FASD Guide (nih.gov)

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CONTACT INFORMATION FOR FASD NH/NOFAS NH

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REFERENCES

1. Becoming FASD Informed: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4861453/>
2. Policing and Fetal Alcohol Spectrum Disorder (mydigitalpublication.com)
3. Kambaitz, C., Klug, M.G., Greenmyer, J. et al. Association of adverse childhood experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls. *BMC Pediatr* 19, 498 (2019). <https://doi.org/10.1186/s12887-019-1878-8>
4. Neurobehavioral Profiles of Individuals with FASD <https://www.child-encyclopedia.com/fetal-alcohol-spectrum-disorders-fasd/according-experts/neurobehavioural-profiles-individuals-fetal>
5. B Smart Podcast Boston Medical https://mcusercontent.com/de478651d78dec4ded211e727/files/af06291f-5e9d-4b35-be1a-ec205b5c6e5/Music_Test1_AudioTrimmer.com_.mp3
6. May, P.A., Chambers C.D., Kalberg, W.O., et al. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA*. 2018;319(5):474–482. doi:10.1001/jama.2017.21896

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REFERENCES

7. COMMON Myths About FASD <https://www.aucd.org/docs/webinars/FASD%20Common%20Myths.pdf>
8. Petrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). Prevention of secondary conditions in fetal alcohol spectrum disorders: identification of systems-level barriers. *Maternal and child health journal*, 18(6), 1496–1505. <https://doi.org/10.1007/s10995-013-1390-y>
9. Conry, J, Fast, D. Mental Health Issues for People With Fetal Alcohol Spectrum Disorders in the Criminal Justice System. <https://www.cjcmh.com/doi/pdf/10.7870/cjcmh-2010-0022>
10. Brown J, Trnka A, Harr D, et al. Fetal alcohol spectrum disorder (FASD): A beginner's guide for mental health professionals. *J Neurol Clin Neurosci*. 2018;2(1):13-19.
11. Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A., Mukherjee, R., Bekmuradov, D., Rehm, J. (2016) Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet*, 2016; DOI: 10.1016/S0140-6736(15)01345-86.
12. Proof Alliance (2015). FASD and the criminal justice system. <https://www.proofalliance.org/2014/05/fasd-and-the-criminal-justice-system/>
13. FASD and the Criminal Justice System: A Poor Fit <https://johnhowardbc.ca/wp-content/uploads/2019/11/Resources-jhsbc-factsheet-fasd.pdf>

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