

Creating Success for Patients on the Fetal Alcohol Spectrum

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How did we get here?

- **FASD** is a result the result of some level of drinking alcohol during pregnancy
- **Drinking** is often a result of trauma
- **Trauma** is an experience outside the realm of common human experience
- **Historical trauma** affects indigenous people generationally

Trauma

- An experience outside the realm of common human experience

DSM-IV

- Must have been exposed to a traumatic event or experience involving intense:
 - fear, horror, or helplessness
 - involves a threat of death, serious injury, or threat to physical integrity
 - the event or experience may be to yourself or to others around you.

Trauma

- Duration

- More than one month
- Acute: Symptoms less than 3 months
- Chronic: Symptoms longer than 3 months

Historical Trauma

Impact of the past on the
present

Trauma

- Trauma is worse as a consequence of man-made disasters

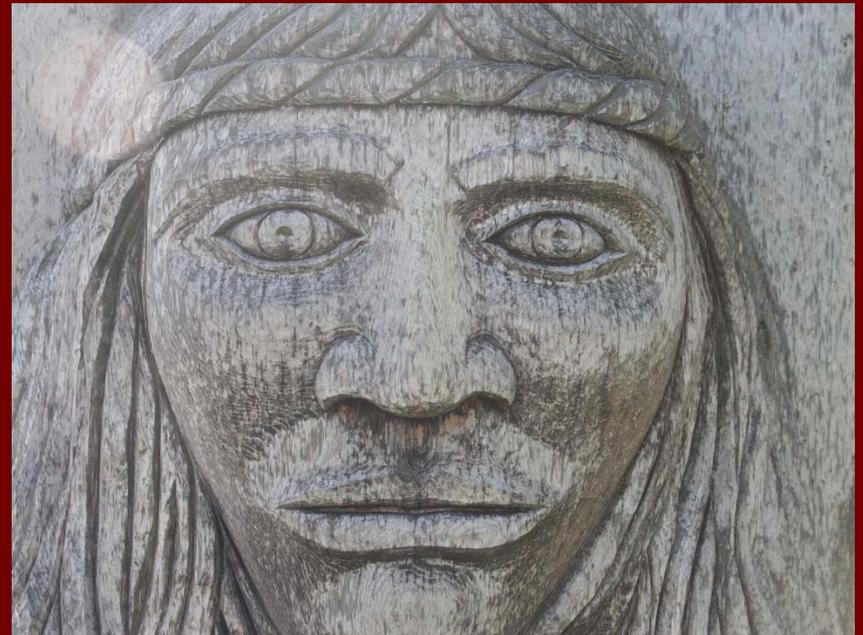
The Effects of Traumatic Stressors on Health Outcomes

- Diagnostic categories such as PTSD fail to capture the complete and utter wounding of the spirit that is caused by such traumas



Soul Wound

- “spirit wounding”
 - the cumulative effect of historical trauma brought on by centuries of colonialism, genocide, and oppression



Common Consequences of Trauma

- Loss of:
 - spiritual beliefs
 - sense of self-efficacy
 - sense of invulnerability
 - sense of proportion
 - connection to others and the world

Commonly Associated Diagnoses

- Anxiety
- Depression
- Borderline Personality Disorder
- Conduct Disorder
- Reactive Attachment Disorder
- Substance Abuse

Effects

- unsettled trauma
- increase of alcohol abuse
- child abuse
- domestic violence

Alcohol is a devastating reality
in our society

Fetal Alcohol Spectrum
Disorders are a consequence
that affects everyone
especially the next seven
generations

Consequences are far ranging and life long

- Individuals
- Families
- Tribes
- Social Services
- Indian Child Welfare
- Medical Services
- Mental Health Services
- Rehab Services
- Justice System
- Education
- Work Force

Incidences of FAS per 10,000 total births for different ethnic groups were as follows:

– Asians 0.3

– Hispanics 0.8

– Whites 0.9

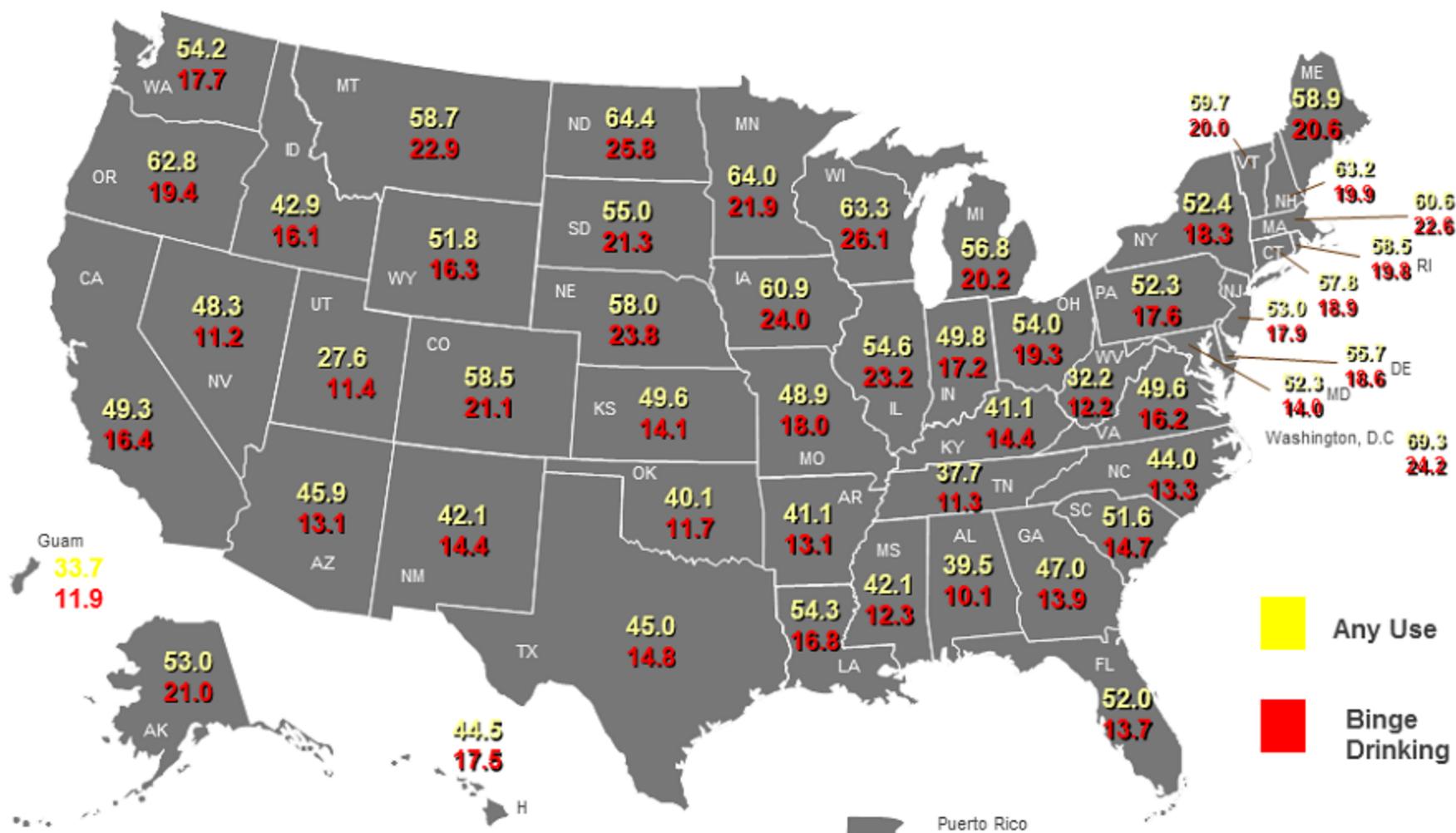
– Blacks 6.0

– Native

Americans 29.9

Journal of the American Medical
Association 261(2):205-209,
1989.]

**Map 1: State-Specific Weighted Prevalence Estimates of Alcohol Use
(Percentage of Any Use* & Binge Drinking†)
Among Women Aged 18 – 44 Years — BRFSS, 2013**



* One or more drinks during the last 30 days
† Four or more drinks on any one occasion during the last 30 days

Prevalence

- Experts are unsure exactly how many individuals in the United States have an FASD. Studies by the Centers for Disease Control and Prevention have reported FAS prevalence rates from 0.2 to 1.5 cases per 1,000 births across various populations.
- Other studies using a variety of methods have produced estimates ranging from 0.5 to 2.0 cases per 1,000 live births. Such rates are comparable with or above other common developmental disabilities such as Down syndrome or spina bifida.

Prevalence

- Some experts estimate that an FASD occurs in 10 in 1,000 live births.
- Thus, of 4 million infants born each year, an estimated 40,000 will be born with an FASD.
- Studies of particularly vulnerable populations yield even higher prevalence estimates. For example, some Native Americans have FAS rates as high as 3 to 5 per 1,000 children.

Maternal Risk Factors for Fetal Alcohol Spectrum Disorders: Not As Simple As It Might Seem

National Institute on Alcohol Abuse and Alcoholism

Philip A. May, Ph.D., and J. Phillip Gossage, Ph.D.

Table 2 Common Risk Factors Associated With Heavy Maternal Drinking, FAS, and ARBD/ ARND

Influential Element	Maternal Risk Factor
Health	<ul style="list-style-type: none"> Older than age 25 when FAS child is born Already has three or more children when FAS child is born Use of other drugs, including tobacco and illicit substances Morbidity or premature mortality from alcohol-related causes
Socioeconomic status (SES)	<ul style="list-style-type: none"> Low SES Social transience Unemployment or marginal employment
Drinking pattern	<ul style="list-style-type: none"> Early age at onset of regular drinking Frequent binge drinking (i. e. , consuming five or more drinks per occasion 2 or more days per week) Frequent drinking (i. e. , every day or every weekend) High blood alcohol concentration No reduction in drinking during pregnancy

Psychological
profile

Low self-esteem
Depression
Sexual dysfunction

Family social
traits

Alcohol misuse in family
Alcohol misuse by the woman's male partner
Tenuous marital status (i. e. , cohabitation,
never married,
separated, or divorced)
Loss of children to foster or adoptive placement

Local culture and
community

Relatively tolerant of heavy drinking

FASD Center for Excellence

- Raises awareness of FASD and provides information and resources for providers and the public.
- Under the previously funded FASD Center for Excellence, SAMHSA developed a number of publications and resources that continue to be available.

FASD Center for Excellence

- The following are intended to assist people affected by FASD and their families, state and local agency administrators, and service providers:

FASD Center for Excellence

- Tools for Success: Working with Youth with Fetal Alcohol Spectrum Disorders (FASD) in the Juvenile Justice System – 2014
 - is a self-paced educational program.
 - It is based on Carlson and Holl's *Tools for Success: Working with Youth with Fetal Alcohol Syndrome and Effects in the Juvenile Justice System Resource Guide* — 2001.
 - The program has been updated to emphasize more recent published literature and terminology.

FASD Center for Excellence

- Curriculum for Addiction Professionals (CAP):
Level 1 – 2007
 - provides guidance on encouraging women in treatment not to consume alcohol during pregnancy.
 - It also helps professionals work with adult and adolescent clients affected by FASD, as well as clients with children affected by FASD.
 - Parents, caregivers, and other family members can also benefit from this information.

CAP

- CAP Level 1 is organized into six competencies with content that includes:
 - An historical overview of alcohol use by pregnant women
 - Identification and diagnosis of FASD
 - Prevention strategies to address FASD
 - Treatment strategies to address FASD
 - Continuing care for families affected by FASD
 - Legal issues affecting pregnant women and people affected by FASD

FASD Center for Excellence

- Treatment Improvement Protocol (TIP) 58: Addressing Fetal Alcohol Spectrum Disorders (FASD) – 2013

- reviews alcohol screening tools and interventions for use with pregnant women and women of childbearing age to prevent FASD.
- It also outlines methods for identifying people affected by FASD and modifying treatment accordingly.

Alcohol produces by far the most serious neurobehavioral effects in the fetus. Only alcohol can produce all of the noted problems. Combinations of substances (e.g., alcohol and tobacco) can produce more serious effects than either substance alone. Many women use multiple substances.

	Alcohol	Tobacco	Opioids	Amphetamines	Cocaine	Marijuana	PCP
Growth deficiency	X	X	X	X	X	X	X
Behavior problems	X	X	X		X	X	X
Cognitive problems	X	X	X			X	X
Motor deficits	X	X					X
Developmental delays	X				X		
Facial anomalies	X						X
Physical defects	X			X	X		X

Comparative Effects of Alcohol and Other Substances on the Developing Fetus Commonly abused substances include:

- Only alcohol can produce all of the noted problems.
- In addition, combinations of substances (e.g., alcohol and tobacco) can produce more serious effects than either substance alone.
- Many women use multiple substances.

Prenatal methamphetamine exposure and childhood behavior problems at 3 and 5 years of age.

RESULTS:

- MA exposure was associated with increased emotional reactivity and anxious/depressed problems at both ages and externalizing and attention-deficit/hyperactivity disorder problems by age 5 years.
- Heavy exposure was related to attention problems and withdrawn behavior at both ages. There were no effects of MA on the internalizing or total behavior problems scales.

CONCLUSIONS:

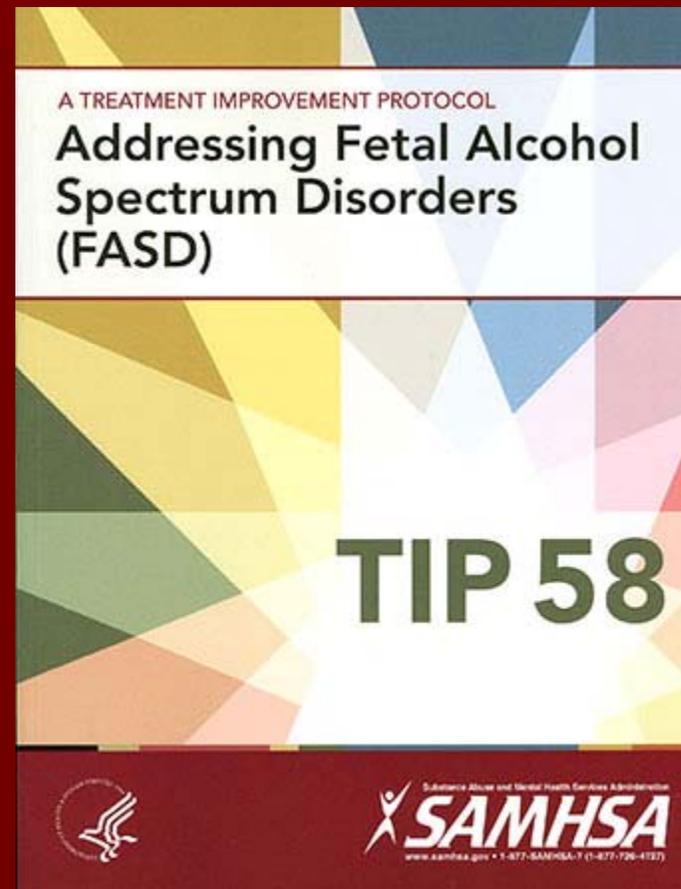
- This first report of behavior problems in patients as young as 3 years associated with MA exposure identifies an important public health problem.
- Continued follow-up can inform the development of preventive intervention programs.

PubMed Commons [Pediatrics](#). 2012 Apr;129(4):681-8. doi: 10.1542/peds.2011-2209. Epub 2012 Mar 19.

[LaGasse LL](#)¹, [Derauf C](#), [Smith LM](#), [Newman E](#), [Shah R](#), [Neal C](#), [Arria A](#), [Huestis MA](#), [DellaGrotta S](#), [Lin H](#), [Dansereau LM](#), [Lester BM](#).

TIP

- Price: **FREE** (shipping charges may apply)
Reviews alcohol screening tools and interventions for use with pregnant women and women of childbearing age to prevent fetal alcohol spectrum disorders (FASD). Also, outlines methods for identifying individuals with FASD and modifying treatment accordingly.



The Chicken or The Egg

Fetal Alcohol Spectrum Disorders,
Mental Health and Addiction

Fetal Alcohol Spectrum Disorders

- The umbrella term FASD includes a diverse set of mental and behavioral phenotypes that are often misdiagnosed and ill-treated, causing individuals and families to endure undue social, emotional and financial costs.

What are Fetal Alcohol Spectrum Disorders ?

- FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy
- The term FASD is not intended for use as a clinical diagnosis

Fetal Alcohol Spectrum Disorders, Mental Health and Addiction

■ The Brain

- Alcohol's affect in utero
 - What is FASD?
 - How is behavior impacted by brain damage from alcohol?
- Mental health issues
 - Born with
 - Onset in adolescence and adulthood
- Origin of addiction
 - Nature or nurture?

FASD and Other Disorders

- Those with a fetal alcohol spectrum disorder frequently have other disorders
 - Some may be co-occurring disorders
 - Some may be misdiagnosed
 - Accurate diagnosis of all disorders is essential

FASD and Other Disorders

- A thorough diagnostic work-up must be done
 - Medical
 - Family history
 - Mental health
 - Developmental disabilities
 - Neuropsychological testing
 - Adaptive functioning testing

Fetal Alcohol Spectrum Disorders As Co-occurring Disorders

- People with mental illness frequently use substances
 - Estimates are at least 50% have co-occurring disorders
 - The percentage is as high as 70% in corrections

Fetal Alcohol Spectrum Disorders As Co-occurring Disorders

- Substance use disorders may have a genetic component leading to vulnerabilities in offspring
- Therefore, the risk of giving birth to a child with a FASD and vulnerabilities for mental illness and substance use is higher than in the general population

Epigenetics And Fetal Alcohol Spectrum Disorders

- Increasing evidence indicates that both genetic and epigenetic mechanisms may play a role in mediating the broad range of effects reported in children with FASD.

Michael S. Kobor, Ph.D., and Joanne Weinberg, Ph.D., NIAAA, Alcohol Research & Health, Volume 34, Issue Number 1

Fetal Alcohol Spectrum Disorders As Co-occurring Disorders

- It has been shown that stressors can exacerbate underlying disorders
- Individuals with fetal alcohol spectrum disorders experience multiple stressors in their lives
- Substance use disorder is significant

Fetal Alcohol Spectrum Disorders As Co-occurring Disorders

- Therefore, the likelihood that a person with a fetal alcohol spectrum disorder and these underlying vulnerabilities would have a co-occurring mental illness and/or substance use disorder is significant

Fetal Alcohol Spectrum Disorders As Co-occurring Disorders

- The possibility that a person with a mental illness and a co-occurring substance use disorder, from a family with these histories, would also have a FASD is significant
 - The possibility of prenatal exposure needs to be addressed

Likely Co-occurring Disorders

- Attention-Deficit/Hyperactivity Disorder
- Substance use disorders
- Schizophrenia
- Major depressive disorder
- Bipolar disorder

Likely Co-occurring Disorders

- Anxiety disorder
 - Separation anxiety disorder
- Reactive attachment disorder
- Posttraumatic stress disorder
- Traumatic brain injury
- Conduct or Oppositional Defiant disorder

Profile of 80 Birth Mothers of Children with FAS (Astley et al 2000)

- 100% had alcohol use histories
- 96% had one to ten mental health disorders
 - 77%: PTSD
 - 59%: Major depressive episode
 - 34%: Generalized anxiety disorder
 - 22%: Manic episode/Bipolar disorder
 - 7%: Schizophrenia

Profile of 80 Birth Mothers of Children with FAS (Astley et al 2000)

- 95% had been physically or sexually abused during their lifetime
- 79% reported having a birth parent with an alcohol problem

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- Optimal outcomes in the treatment of co-occurring disorders occur when all are accurately diagnosed and treated simultaneously
 - If one or more co-occurring disorders is not recognized, treatment will not be “successful”

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- Secondary disabilities can increase when co-occurring disorders are not recognized and treated

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- The cognitive impairments in FASD can interfere with the ability to be successful with typical treatment approaches
 - Literal thinking
 - Inability to respond to point or level systems that require a sense of historical time and future time

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- Difficulty with multiple directions
- Difficulty following through with multiple treatment plans
- Difficulty with treatment based on verbal receptive language skills (i.e., most of our treatment modalities)
- Difficulty with treatment based on processing information outside sessions

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- When a fetal alcohol spectrum disorder is not recognized:
 - These individuals often fail in our traditional treatment programs
 - They say they know what they need to do but don't follow through
 - Many have mental health problems

The Importance of Recognizing a Co-occurring Fetal Alcohol Spectrum Disorder

- Care givers with unrecognized FASD are often labeled as non-compliant, uncooperative, uninvolved, or sabotaging
 - They don't follow through on multiple instructions

The Possibility of Misdiagnosis

- Since fetal alcohol spectrum disorders are not psychiatric diagnoses, they are often not recognized by mental health professionals
- The symptom presentation of individuals with an FASD is similar to that of a number of psychiatric disorders

The Possibility of Misdiagnosis

- The possibility of prenatal alcohol exposure causing some of the symptoms is often not considered
- Even if a fetal alcohol spectrum disorder is recognized, another diagnosis may be used in order to provide services and treatment

FASD in the DSM-IV

- The most accurate place in a mental health (DSM-IV) diagnosis to identify FAS was on Axis III as it is a medical diagnosis (760.71)

An End to Alphabet Soup: FASD and Changes in the DSM5

Ira J. Chasnoff, MD, Psychology Today

Posted March 3, 2014

Neurodevelopmental Disorder-Prenatal Alcohol Exposure (ND-PAE).

- There's bad news and good news. The bad news is that ND-PAE failed to be listed in the DSM 5, although it is included in the appendix as conditions needing further study (page 798).
- The good news is that ND-PAE is used as an example for "Other Specified Neurodevelopmental Disorder," code 315.8 (page 86).

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) will appear in the DSM V *Appendix*.

- Criteria established are based upon over 35 years of research.
- Our goal now is to see if these criteria discriminate between individuals with PAE and those without PAE but with other psychiatric disorders.
- We will be using not only behavioral and clinical information but also information based upon imaging studies.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Rather, diagnosis focuses on behavior in three functional domains.
 - The first domain is self-regulation of one's attention, mood, behavior, and impulses.
 - The second domain is neurocognitive - in other words, the person's IQ, executive functioning, memory, visual-spatial reasoning skills and their ability to learn.
 - The third domain is the patient's adaptive functioning in communication, daily living skills, motor skills, and social skills.

All of this manifests during childhood and causes extensive and significant impairment or distress in multiple areas of functioning (Brown, Grant, & Clarren, 2014).

For ND-PAE, the patient's outward physical appearance is irrelevant.

- According to the CDC (2011), a person with an FASD might have any of the following or a combination thereof:
 - abnormal facial features, such as a smooth ridge between the nose and upper lip (the ridge called the philtrum)
 - small head size
 - shorter-than-average height
 - low body weight
 - poor coordination

For ND-PAE, the patient's outward physical appearance is irrelevant.

- poor memory
- difficulty in school (especially with mathematics)
- 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

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Affected children typically exhibit considerable difficulty with nearly all aspects of their behavior ranging from learning and remembering things to applying what they have learned to everyday experiences, paying attention, and controlling their emotions and urges.

■ (Brown, Grant, & Clarren, 2014).

For ND-PAE, the patient's outward physical appearance is irrelevant.

- The DSM-5 explains that the brain damage in ND-PAE affects everything about the way the developing child functions.
- Because brain damage is irreparable and permanent, putting legal intervention into context requires recognition of the signs of ND-PAE and providing external supports in a structured environment to compensate for the individual's deficits.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Principal neurocognitive deficits specific to ND-PAE include:
 - learning problems that not only impede academic achievement but also impair the child's ability to learn routines and social rules in both the home and in the community

■ (Brown, Grant, & Clarren, 2014).

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Because of attention and memory deficits, affected youth have considerable difficulty remembering multistep instructions.
- Coping with change is difficult for children with ND-PAE because each new context requires new behavioral routines that are unknown.
- In these settings, the child with ND-PAE becomes overwhelmed, cognitively speaking.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Children with FASD often compensate for their learning deficits by mimicking what they observe around them, and this characteristic must be kept in mind vis-à-vis placement and legal disposition.
- Self-regulation deficits among children with FASD involve their ability to control their emotions, moods, and urges along with their behaviors.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- It is common for children with ND-PAE to have an over-sensitivity to stimuli (internal and external) and these children may become upset, angry, and frustrated with little provocation, thereby resulting in overreaction.
- Among very young children, these overreactions may look like a tantrum.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- During late childhood, overreactions may manifest in aggressive behavior toward oneself or others.
- The DSM-5 states that FASD children have difficulty foreseeing consequences and appreciating the effect of their behavior on themselves, as well as others.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Therefore, making mid-course corrections is virtually impossible for FASD individuals. Behavioral self-regulation problems can include one's inability to delay gratification, resulting in boundary violations.
- Theft is commonplace, and so is sexually inappropriate behavior once the child enters puberty.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Because of the multiple cognitive deficits, children with ND-PAE tend to be developmentally delayed in adaptive functioning, including social, practical, and language skills.
- In addition, attention, language, memory, and executive function deficits may negatively impact legal competencies.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- The DSM-5 explains that the social development delays common to ND-PAE make it difficult for these individuals to establish and maintain relationships.
- Developmental delays in socialization affect moral maturity.

For ND-PAE, the patient's outward physical appearance is irrelevant.

- Most adults with FASD operate socially and emotionally as though they were very young children, particularly in unfamiliar situations where appropriate conduct has not been practiced and well learned.

Likely Misdiagnoses for Individuals with an FASD

- ADHD
- Oppositional Defiant Disorder
- Conduct Disorder
- Intermittent Explosive Disorder
- Major Depressive Disorder
 - Especially in adolescents

Likely Misdiagnoses for Individuals with an FASD

- Bipolar Disorder
- Psychotic disorders
- Autism
- Asperger's syndrome
- Antisocial Personality Disorder
- Borderline Personality Disorder

Comparing FASD, ADHD and Oppositional Defiant Disorder

FASD	ADHD	Oppositional Defiant Disorder
Do not complete tasks	Do not complete tasks	Do not complete tasks
<ul style="list-style-type: none"> -may or may not take in information -cannot recall information when needed -cannot remember what to do 	<ul style="list-style-type: none"> -takes in information -can recall information when needed -get distracted 	<ul style="list-style-type: none"> -takes in information -can recall information when needed -choose not to do what they are told
Provide one direction at a time	Limit stimuli and provide cues	Provide positive sense of control; limits & consequences

Comparing FASD, ADHD and Conduct Disorder

FASD	ADHD	Conduct Disorder
May hit others	May hit others	May hit others
<ul style="list-style-type: none"> -someone told them to -misinterpret intentions of others -may sense bump as attack -may respond from history of abuse 	<ul style="list-style-type: none"> -frequently an impulsive act 	<ul style="list-style-type: none"> -plan to hurt others -misinterpret intentions of others as attack or impending attack
Deal with misinterpretations at the time; 1-to-1 support	Behavioral approaches to address impulsivity	Consequences; cognitive behavioral approaches

Comparing FASD, ADHD and Conduct Disorder

FASD	ADHD	Conduct Disorder
Take risks	Take risks	Take risks
-do not perceive danger	-act impulsively	-push the envelope; feel omnipotent
Provide mentor; utilize a lot of repeated role playing	Utilize behavioral approaches (e.g., stop and count to 10)	Psychotherapy to address issues; protect from harm

Risks of Not Recognizing and Appropriately Treating an FASD

- Inaccurate diagnosis
- Mislabeled
- Inappropriate treatment
- Unemployment
- Psychiatric hospitalization

Risks of Not Recognizing and Appropriately Treating an FASD

- Loss of family
- Homelessness
- Jail
- Death
 - Suicide, accident, murder, untreated physical illness

Benefits of Identification and Diagnosis of an FASD

- The individual is recognized as having a disability
 - May decrease anger and frustration on the part of the individual, the family, providers, and the community

Benefits of Identification and Diagnosis of an FASD

- The individual may feel relieved that s/he is not just “lazy” or “a bad person”
- We can focus on why the person is not succeeding in a program and how we can help them succeed
 - Address the need to define “success” for each individual

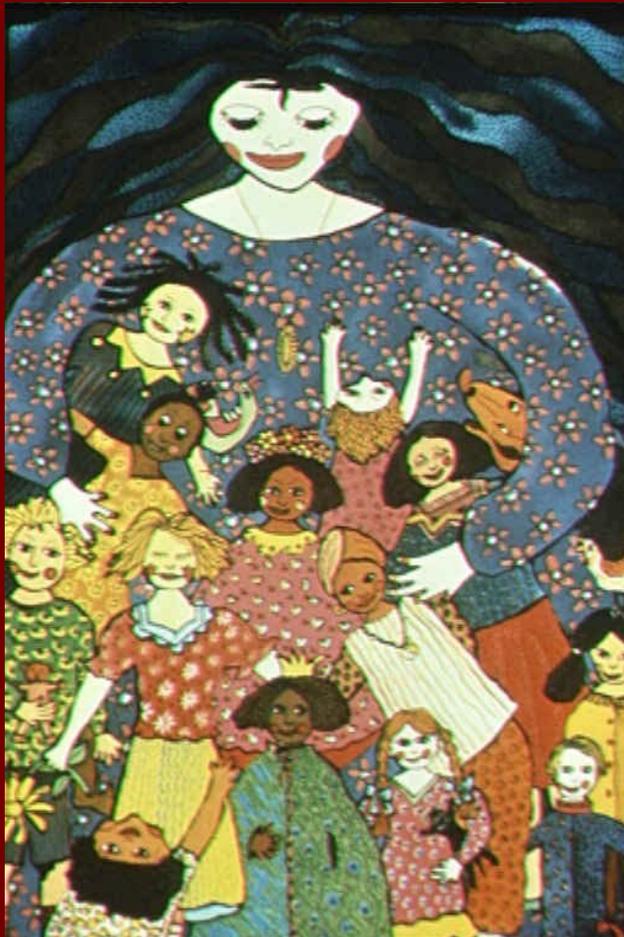
Benefits of Identification and Diagnosis of an FASD

- If we recognize an FASD, we can improve treatment outcomes
- Those at highest risk of giving birth to a child with a fetal alcohol spectrum disorder are women who have already given birth to a child with a fetal alcohol spectrum disorder

Benefits of Identification and Diagnosis of an FASD

- Therefore, an essential prevention approach is the recognition of, and *successful* treatment for, these women
 - Some of them may have a fetal alcohol spectrum disorder

Anyone who drinks during pregnancy can have a child with a FASD

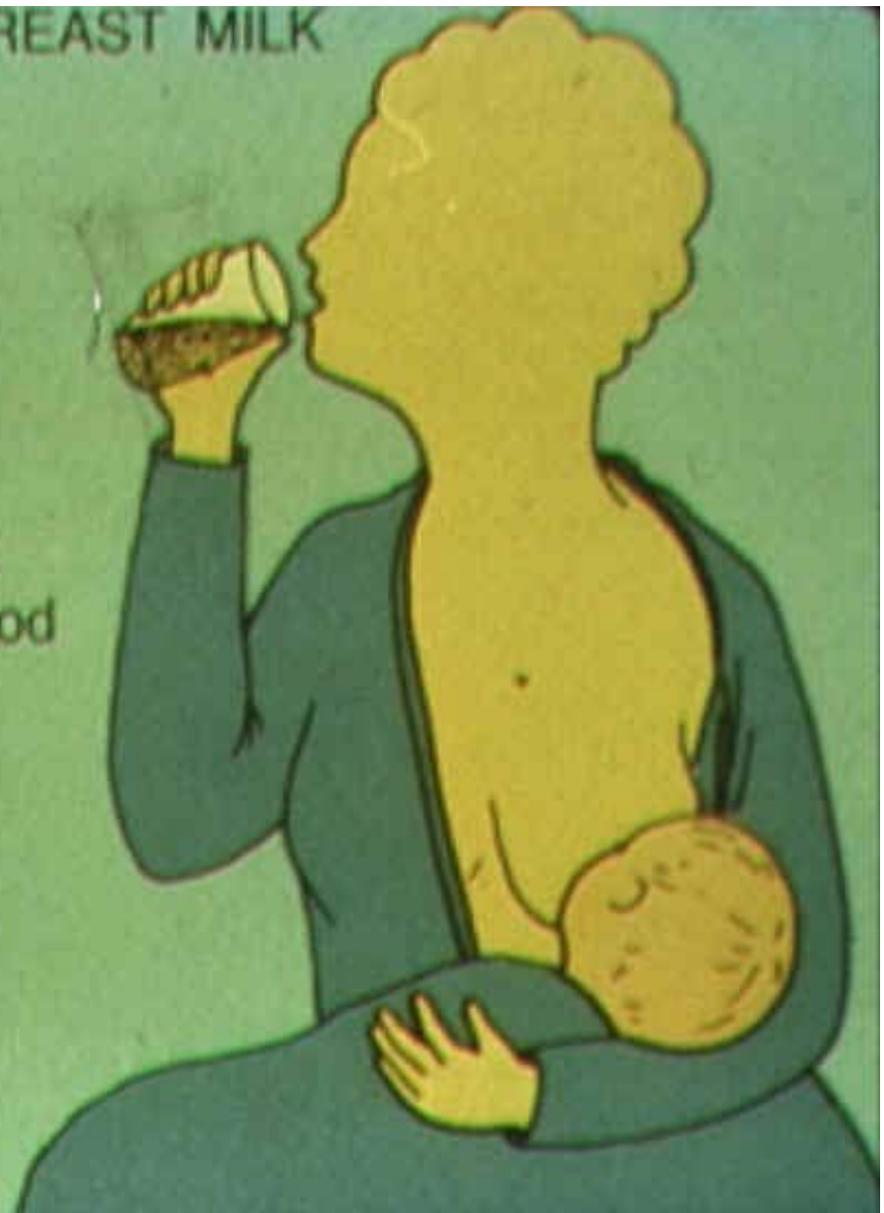


**THERE IS NO SAFE
AMOUNT OF
ALCOHOL USE
DURING PREGNANCY**

**One ounce in a week can
cause damage to a fetus**

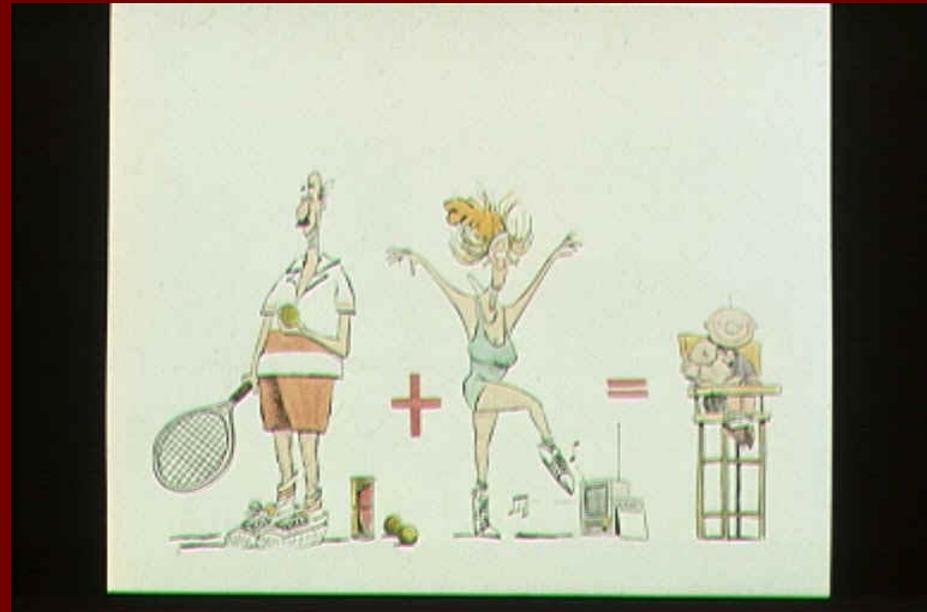
ETHANOL ENTERS BREAST MILK

Concentration of ETOH in milk
 \approx concentration in maternal blood





- **Women and men do not drink to harm their unborn children**



Implications of brain damage

- Mental Health
- Addiction

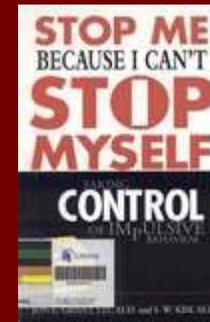
Developmental manifestations
of
Behavioral characteristics
and
Cognitive processing

Behaviors

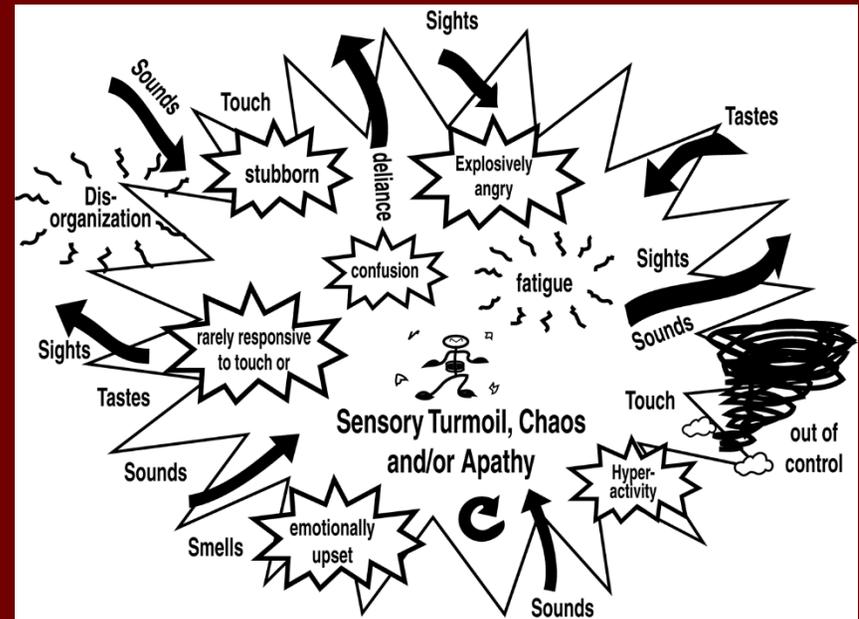
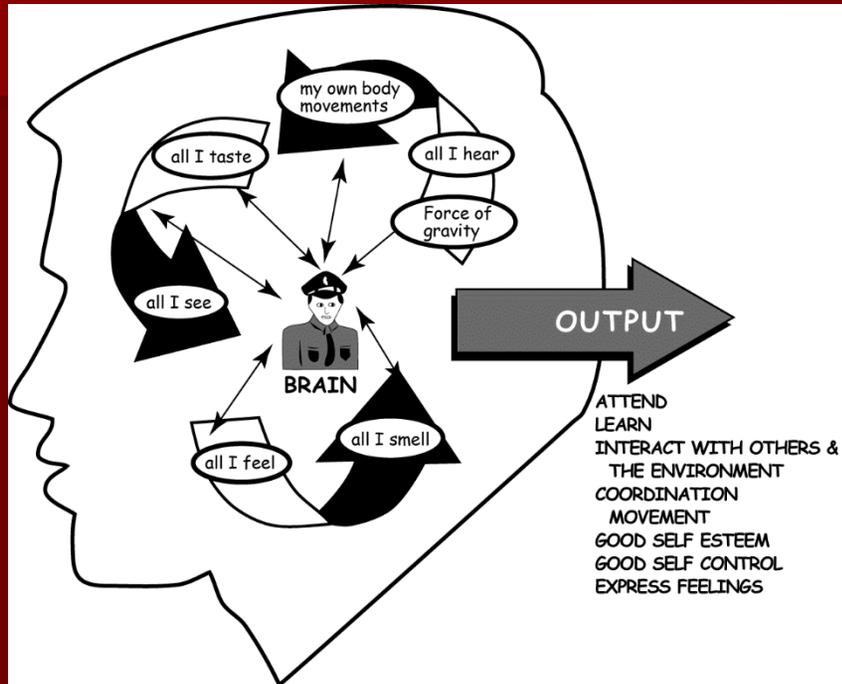
- Ability to connect cause and affect impaired
- Poor reality testing
- Poor memory
- Difficulty learning from mistakes

Impulse control

- Over stimulated
- Overwhelmed
- In the moment
- Easily influenced



Poor Auditory Processing

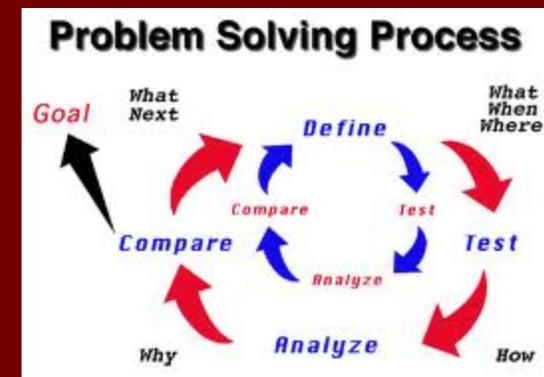
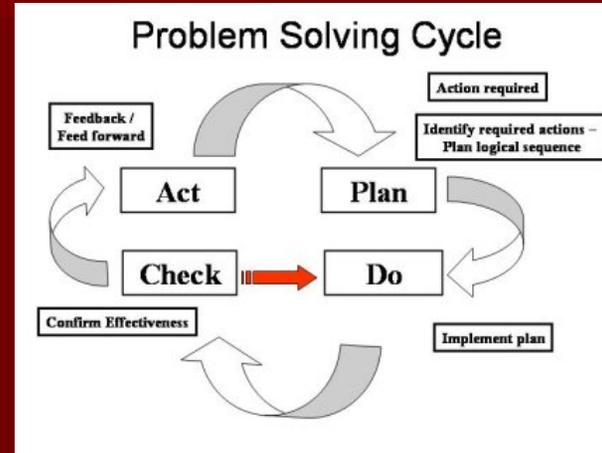


Difficulty Transitioning



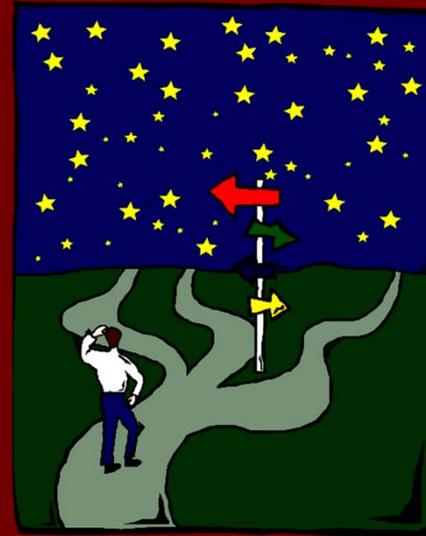
Difficulty Processing Information

- Input
- Integration
- Memory
- Output



Abstract vs Concrete

Concrete Processing



"This is not my street."

Concrete Processing



Good or Bad
Black or White
no
Grey

Time



Money



Emotional Rollercoaster



Ability to predict what will happen next is compromised



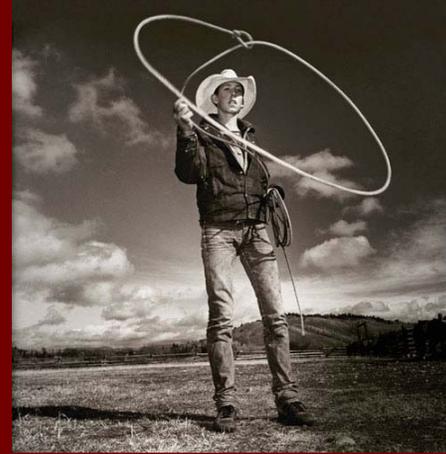
Difficulty generalizing information

**Inductive Reasoning
(specific to general)**

**Deductive reasoning
(general to specific)**

Uneven Learning/Performance

- May perform even above average in some areas
- Same person may perform well below average in others



Lack of judgment



Extremely social

Cuddly

Clinging



Credulous

Confused

Compliant

Unfortunately, this is one
thing FAS doesn't diminish





Feelings of failure



**depression, mental health
and substance issues**

**Frustrated
communication**



**tantrum, "oppositional
defiant disorder"**

**Difficulties in
processing,
memory and cognition**



**involvement in
corrections school and
job failure**

**Need for social
reinforcement and
physical
reinforcement**



**inappropriate sexual
behaviors**

FAS is the leading cause of mental retardation in the Western World

**Most people with a FASD
have I.Q.s above 70**

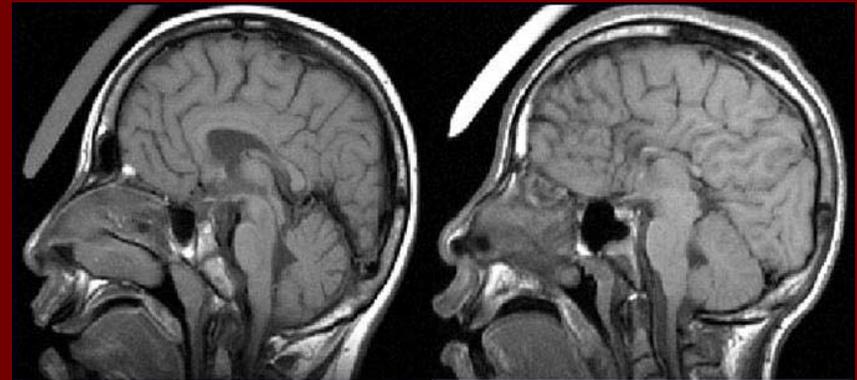
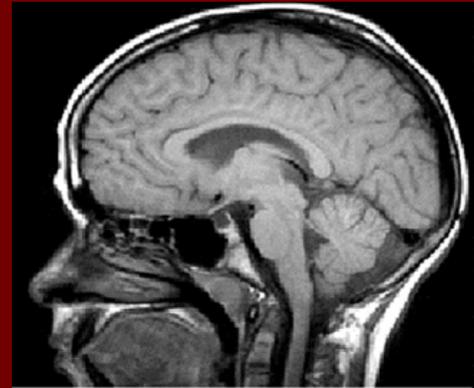
Corpus Callosum Abnormalities

- Most affected people have an IQ between 75 and 95 The complete IQ range is from 30 to 130



Corpus Callosum Abnormalities

- Average level of adaptive living skills 7 years
- Median age: 16 years



**Fetal Alcohol
Syndrome/Fetal Alcohol
Effects
Secondary Disabilities and
Mental Health Approaches**

**by Ann P. Streissguth, Ph.D. and
Kieran D. O'Malley, M.D.**

Secondary Disabilities

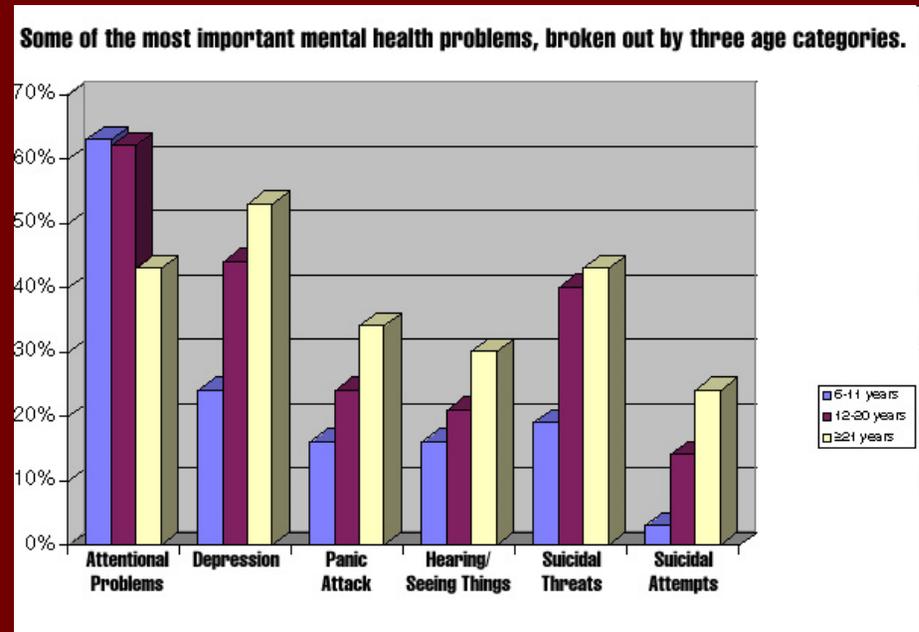
- Research has revealed that almost all such patients are seen at some point in their lives by mental health specialists -- psychiatrists, psychologists, social workers -- to whom they are referred for mental health problems.
- Understanding that such patients may actually have a dual diagnosis (FAS or FAE and a DSM-IV diagnosis) can facilitate more effective treatment.

Secondary Disabilities

- Understanding these are secondary disabilities and recognizing the linkages between the secondary and primary disabilities are important first steps in effective treatment.
- A critical key in this process is obtaining information about prenatal alcohol exposure and possible maternal alcohol abuse at the intake interview for any mental health assessment or treatment.

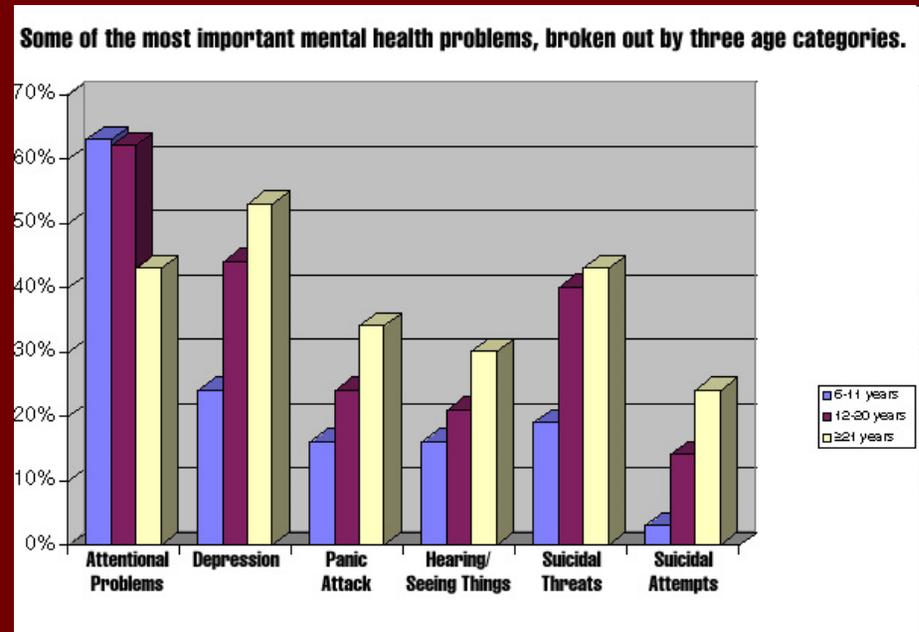
Six of the mental health problems identified

- All six of the mental health problems identified have practical clinical relevance in the treatment of patients with FAS and FAE.



Six of the mental health problems identified

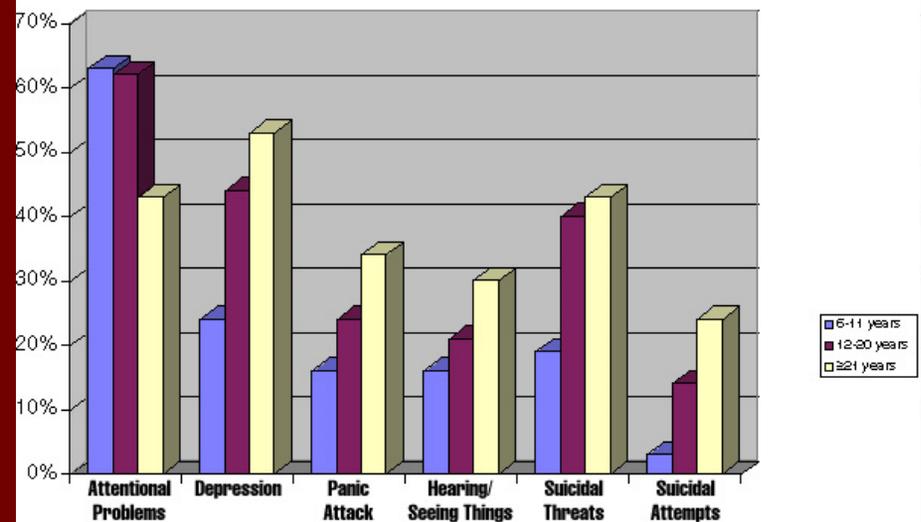
- Depression, suicidal threats and attempts, attention deficit problems, panic attacks and auditory and visual hallucinations were all present in this patient population.



Six of the mental health problems identified

- With the exception of attention deficit problems, all of these problems increased with age.

Some of the most important mental health problems, broken out by three age categories.



Issues Related to Professional Values and Ethics

- The role of the counselor in addiction treatment is to provide support and education.
- Addiction professionals also need to use treatment approaches that help women move from unhealthy, self-defeating, self-devaluing behaviors to healthy, self-enhancing, and self-nurturing behaviors.
- The counselor needs to understand the roots of alcohol abuse among women, as well as symptoms, motivation, problems, and issues to enhance engagement and treatment effectiveness.
- It is important for the addiction professional to know and believe that women do not try to hurt their babies.

Issues Related to Professional Values and Ethics

- Cases of women drinking to induce a miscarriage or harm the baby are very rare.
- Most women want healthy babies, but some cannot stop drinking, even when they are pregnant.
- Addiction professionals can provide needed support and understanding as women go through the difficult process of recovery.
- Clients often feel a great deal of shame associated with their addictive behaviors.

Issues Related to Professional Values and Ethics

- Some clients may learn about FASD and realize that their children might have an FASD.
- This discovery can increase their guilt and shame when they realize they have harmed their children permanently.
- Alcohol problems already carry a tremendous stigma in our society, particularly when women drink.
- To help resolve those feelings of shame and guilt, the counselor should encourage the client to speak honestly about her addictive behaviors and respond to the client with honesty, gentleness, and care.

Practical Implications for Professionals

- **The management of FAS/FAE patients involves an appreciation of the impact on the patient of the social environment, as well as the organic brain damage.**
- **This requires a sensitivity of the mental health professional to the clinical presentation of a combination of developmental disability with mental health problems.**

Practical Implications for Professionals

- It is not sufficient to see these patients as solely organically brain damaged or as solely emotionally disturbed.
- It is essential to understand that patients with FASD often present a dual diagnosis.

University of Washington study showed:

- Over 90 percent of the patients with FAS/FAE had mental health problems.
- It is wiser to begin treatment by attempting to look at areas of stress in the environment than to plunge into the use of medication.

University of Washington study showed:

- Patients with FAS/FAE who have attentional problems often respond to simple changes in the physical environment:
 - decreasing visual and auditory distractions
 - using clear concise directions
 - setting realistic expectations

University of Washington study showed:

- **Also, depression and suicidal gestures should always be taken seriously no matter what age the patient is.**
- **They are a cry for help and may necessitate an examination of environmental conditions through coordination with caretakers and teachers.**

Important for the clinician to remember:

- **These patients have organic brain damage as an etiological factor, there are often complex family systems that can also contribute to psychopathology in the child.**

Important for the clinician to remember:

- **Treatment must involve a multi-modal approach.**
 - Family therapy, special education, cognitive testing and psychopharmaco-therapy are all important considerations in therapy.
 - At the moment, however, there are no controlled studies of medications to show their efficacy in FAS/FAE patients, and safety is an issue because of A.R.B.D (alcohol-related birth defects).
 - Deficiencies in nutritional elements such as zinc, magnesium, iron folate and B12 need further study.

Important for the clinician to remember:

- **Mental health professionals should not be intimidated by the presumptive diagnosis of FAS/FAE**
- **Take the opportunity to inform themselves of the epidemiological data in order to be better able to anticipate the risk factors in FASD and facilitate the protective factors in this unique and challenging condition.**

Important for the clinician to remember:

- **Mental health professionals have an essential role in advocating for the needs of patients with a FASD, who often do not have the cognitive or social skills to advocate for themselves, and in advocating for their families or caregivers, who are often overwhelmed by the patients' primary and secondary disabilities.**

Resources

- **"Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE),"**
 - A final report on the secondary disabilities study
 - Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).
- **"The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities"**
 - Streissguth, A.P., & Kanter, J. (Eds.), Seattle: University of Washington Press, (1997). a volume of selected papers on treatment and community responses to FAS/FAE secondary disabilities
- **"Fetal Alcohol Syndrome: A Guide for Families and Communities"**
 - Baltimore, MD: Paul H. Brookes Publishing Co., (1997 a book on FAS/FAE are available for further information on this topic. Streissguth, A.P.,)

Behavior is communication

**When we change,
they change**

Building Blocks for Successful Prevention and Intervention Strategies

- **Observe**
- **Identify strengths**
- **Show not tell**
- **Create calm structure**
- **Be consistent**
- **Lead to desired behavior**

Building Blocks

- Understand ramifications of concrete processing
- Beware of “ceilings” of expectation and “never” statements
- Assist in generalization
- Have and identify realistic expectations
- Know that it is never too “late” to provide successful strategies and preventions

Building Positive, Strength Based Addictions



Build from Strengths

- **Flexibility**
- **Love of Learning**
- **Self-Motivation**
- **Competence - is "good at something"**
- **Self-Worth - self-confident**
- **Spirituality**
- **Perseverance**
- **Creativity**

- **Positive View of Personal Future - optimistic**
- **Flexibility**
- **Love of Learning**
- **Self-Motivation**
- **Competence - is "good at something"**
- **Self-Worth - self-confident**
- **Spirituality**
- **Perseverance**
- **Creativity**

Strengths

- Energetic
- Friendly/want to please
- Creative
- Forgiving
- Loving
- Loyal
- Generous
- Compassionate
- Selfless

Behaviour

Misinterpretation

Accurate

Debra Evenson

Noncompliance	<ul style="list-style-type: none">■ Willful misconduct■ Attention seeking■ Stubborn	<ul style="list-style-type: none">■ Difficulty translating verbal directions into action■ Doesn't understand
Repeatedly making the same mistakes	<ul style="list-style-type: none">■ Willful misconduct■ Manipulative	<ul style="list-style-type: none">■ Cannot link cause to effect■ Cannot see similarities■ Difficulty generalizing
Often late	<ul style="list-style-type: none">■ Seeking attention■ Bothering others■ Willful misconduct	<ul style="list-style-type: none">■ Neurologically based need to move while learning■ Sensory overload

Behaviour	Misinterpretation Debra Evenson	Accurate
Not sitting still	<ul style="list-style-type: none"> ■ Seeking attention ■ Bothering others ■ Willful misconduct 	<ul style="list-style-type: none"> ■ Neurologically based need to move while learning ■ Sensory overload
Poor social judgment	<ul style="list-style-type: none"> ■ Poor parenting ■ Willful misconduct ■ Abused child 	<ul style="list-style-type: none"> ■ Not able to interpret social cues from peers ■ Does not know what to do
Overly physical	<ul style="list-style-type: none"> ■ Willful misconduct ■ Deviancy 	<ul style="list-style-type: none"> ■ Hyper or hypo-sensitive to touch ■ Does not understand social cues regarding boundaries ■ Does not work independently ■ Willful misconduct ■ Poor parenting ■ Chronic health

Behaviour

Misinterpretation

Accurate

Debra Evenson

Overly physical	<ul style="list-style-type: none">■ Willful misconduct■ Deviancy	<ul style="list-style-type: none">■ Hyper or hypo-sensitive to touch■ Does not understand social cues regarding boundaries
Does not work independently	<ul style="list-style-type: none">■ Willful misconduct■ Poor parenting	<ul style="list-style-type: none">■ Chronic health problems■ Cannot translate verbal directions into action

Brain/Body and Physical Environment

- **Calm**
- **Uncluttered**
- **Low level of stimulation**
- **Neutral colors**
- **Clothing**
- **Reduce transitions**

Structure

- **Consistency**
 - Schedules
 - Language
 - Environment
- **Don't say don't, say what you want them to do**

**Global implications of FASD
across all service provider
and community settings**

NAMI SUBMITS COMMENTS ON UPCOMING SAMHSA REPORT ON CO-OCCURRING MENTAL ILLNESS AND SUBSTANCE ABUSE DISORDERS

- **NAMI's comments are focused primarily on the issue of "integrated treatment" as a proven evidence-based model of service delivery for persons with co-occurring disorders and the importance of "blended" funding from the separate public mental health and substance abuse treatment and service systems.**

NAMI SUBMITS COMMENTS ON UPCOMING SAMHSA REPORT ON CO-OCCURRING MENTAL ILLNESS AND SUBSTANCE ABUSE DISORDERS

- **National studies commissioned by the federal government estimate that 10 million to 12 million Americans have co-occurring mental and addictive disorders.**
- **The prevailing research confirms that integrated treatment for co-occurring disorders is much more effective than treating these illnesses separately.**

Circle of Collaborative Care

- **Comprehensive Team approach includes:**
 - Treatment and mental health providers
 - social workers or case managers
 - other social service agencies should be involved also because the client's needs extend beyond the treatment environment, into the home and community

Circle of Collaborative Care

- counseling may have to be arranged by the case manager, and the counselor will then need to be included on the team

Assessment Information

- For example, assessment information on client's ability to understand:
 - abstract concepts
 - use language to negotiate peer interactions
 - process auditory and visual information
 - understand and remember directions
 - problem solve in novel situations

Assessment Information

- Results will provide the intervention team with important information for developing goals and objectives in all program areas
- Without the proper assessment information, goals and expectations set by intervention teams might be set too high, too low, or focused on inappropriate areas, such as those not needing intervention

Screening, Assessment and Diagnosis

- **Developmental**
- **speech and language
social/behavioral inventories**
- **drug and alcohol assessments**
- **diagnostic multidisciplinary team**

Services are most successful when:

1) Embedded in a culturally congruent context that is neither stigmatic or punitive in response to need or delivery of support strategies

2) Family-focused and multi-generational with extended family strengths identified and used as the foundation for holistic interventions

**3) Provider partnership
delivery and service
integration are “co-located”
in the ecologic context of
“natural” community settings**

4) Providers are knowledgeable about the special parenting challenges of parents who themselves have special needs

Keys to prevention

- Identifying women at risk for having a child with a FASD
- Community working together to encourage healthy pregnancy
- Pregnancy planning
- Communities that view each pregnancy as a welcome addition

Keys to successful intervention

- Appropriate diagnosis
- Holistic team approach
- Appropriate structures for each child's needs
- Individualized education plans
- Family and school working together
- Culturally relevant programs
- Consistency
- Patience

Fetal Alcohol Syndrome



THE DIAGNOSTIC CHARACTERISTICS OF FAS

- HISTORY OF ALCOHOL EXPOSURE IN UTERO
- A UNIQUE SET OF FACIAL FEATURES
- CENTRAL NERVOUS SYSTEM DAMAGE
- GROWTH DEFICIENCY

FOUR DIGIT CODE

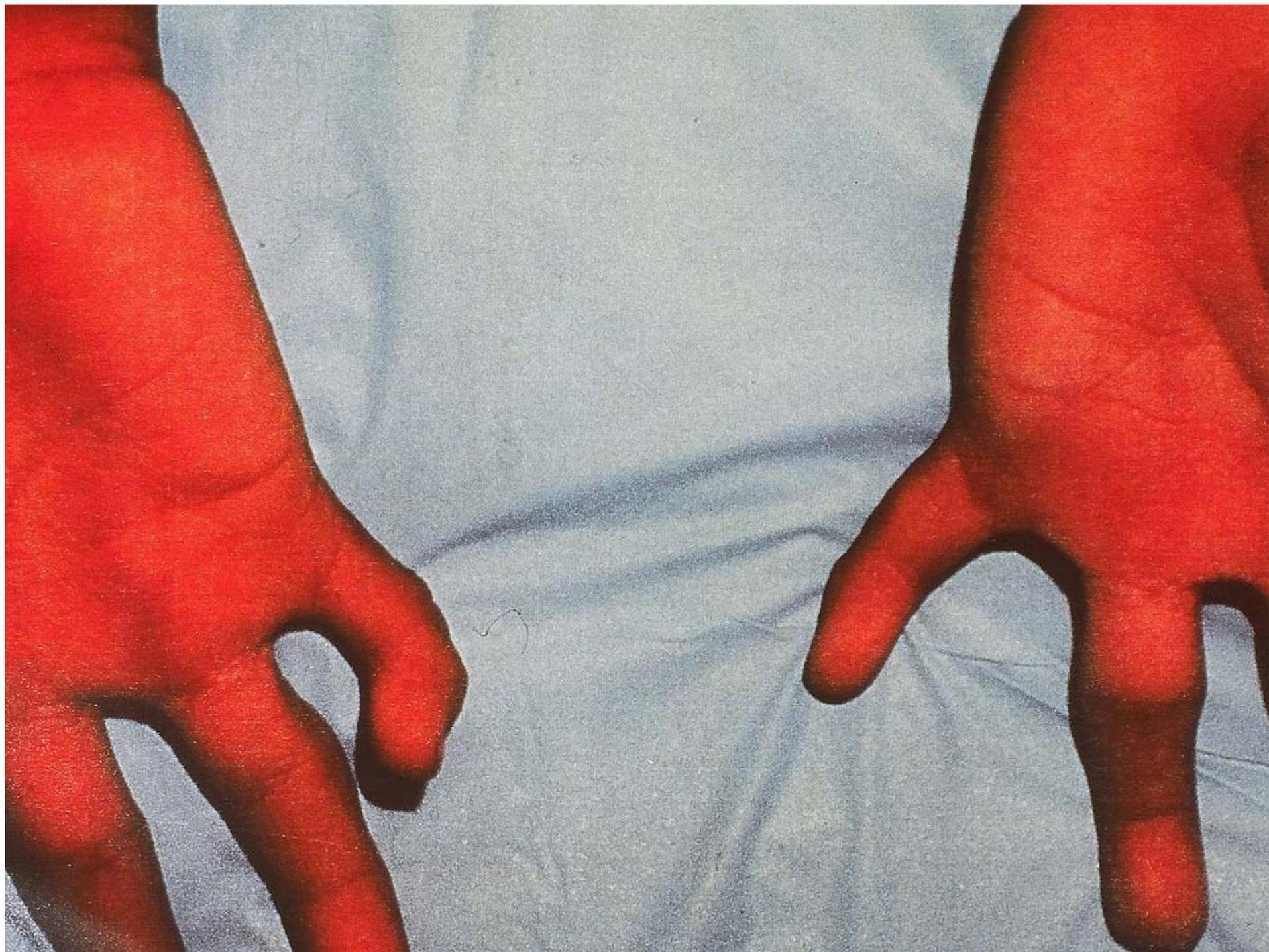
4233

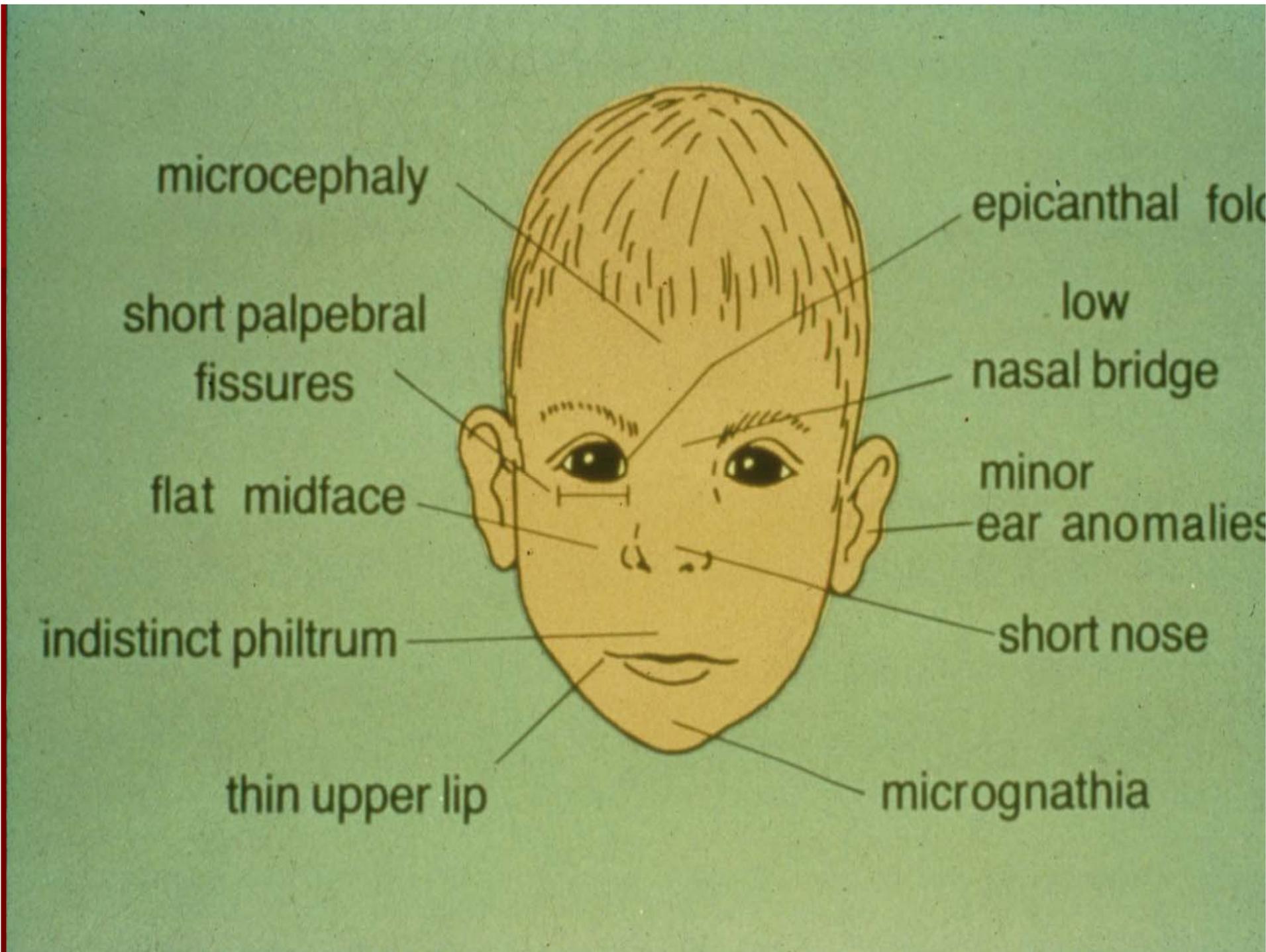
X			
		X	X
	X		
FACE	GROWTH	BRAIN	ALCOHOL

HOW MANY FOUR DIGIT CODES ARE THERE?

- There are 256 combinations ranging from 1111 to 4444
- Each 4-digit code falls into one of 22 categories







microcephaly

epicanthal fold

short palpebral
fissures

low

nasal bridge

flat midface

minor
ear anomalies

indistinct philtrum

short nose

thin upper lip

micrognathia

FACIAL FEATURES

- Thin upper lip
- Absent philtrum
- Short eye slits



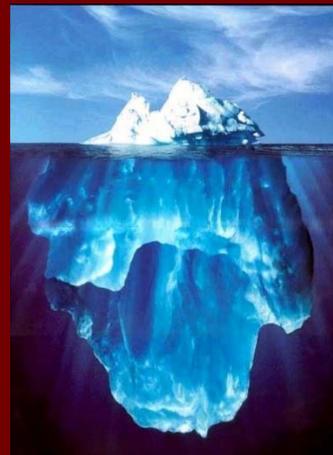






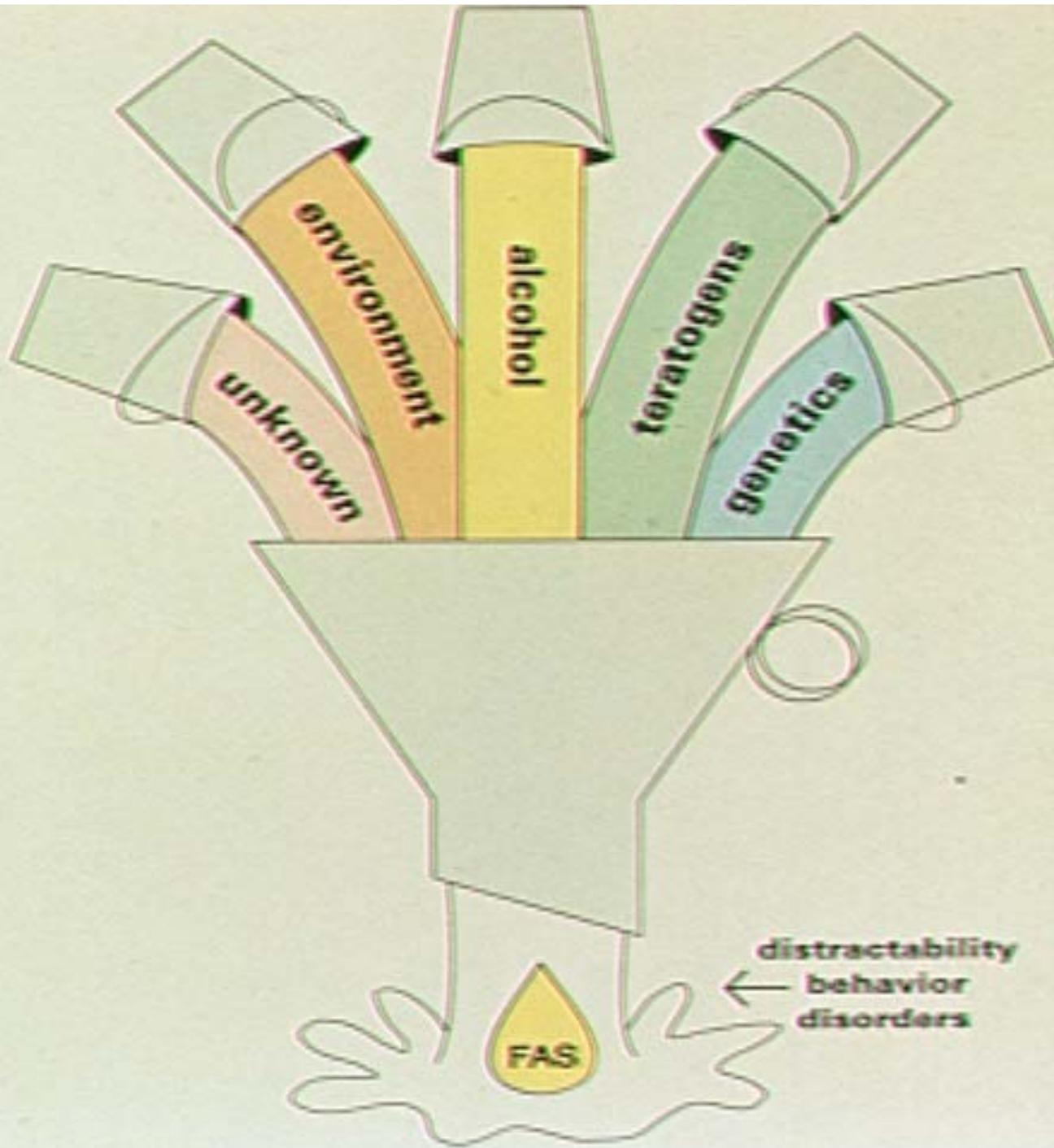
FAS is only the tip of the iceberg

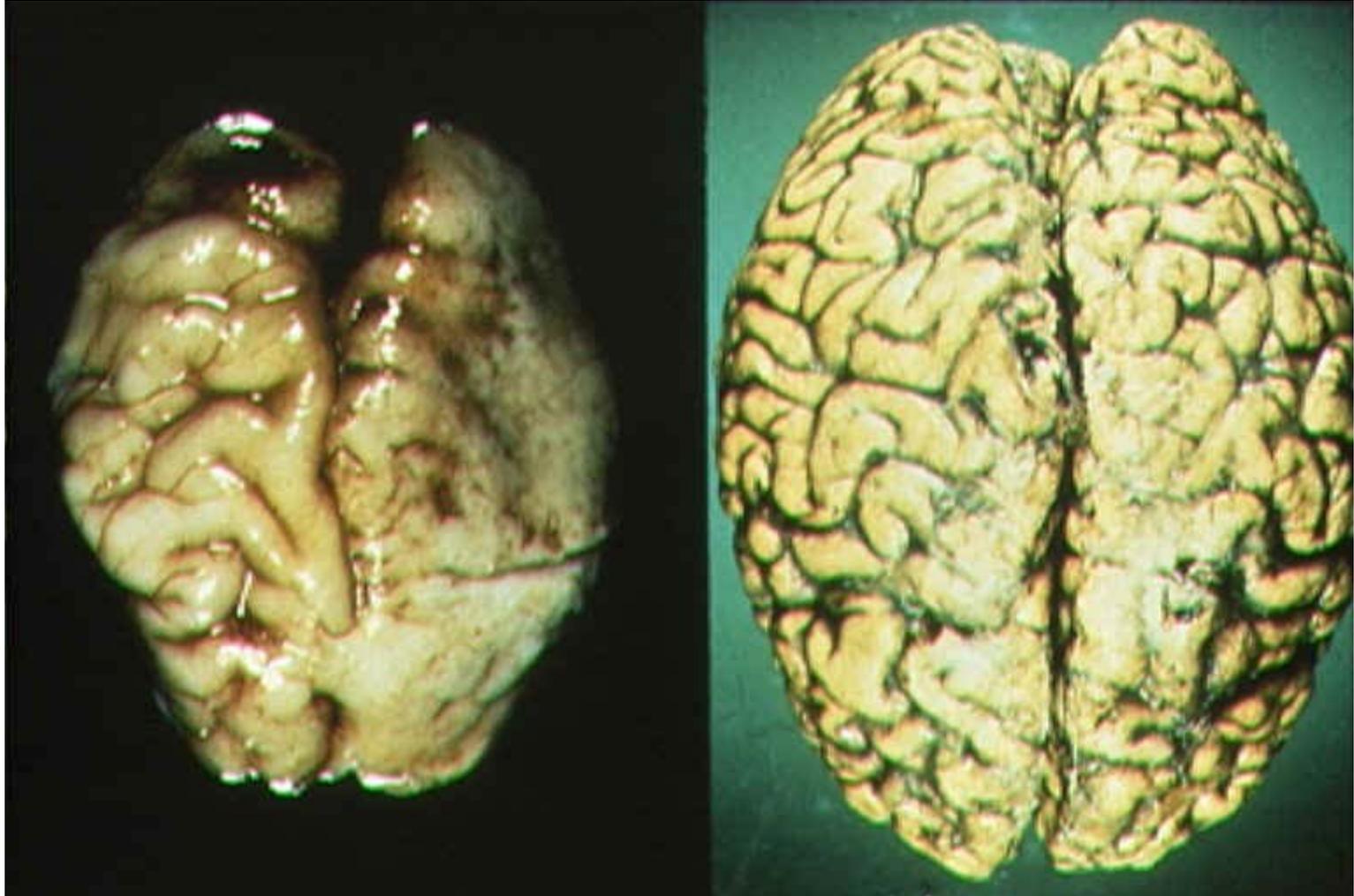
- Clinically suspect or abnormal
- Apparently normal but unable to meet potential

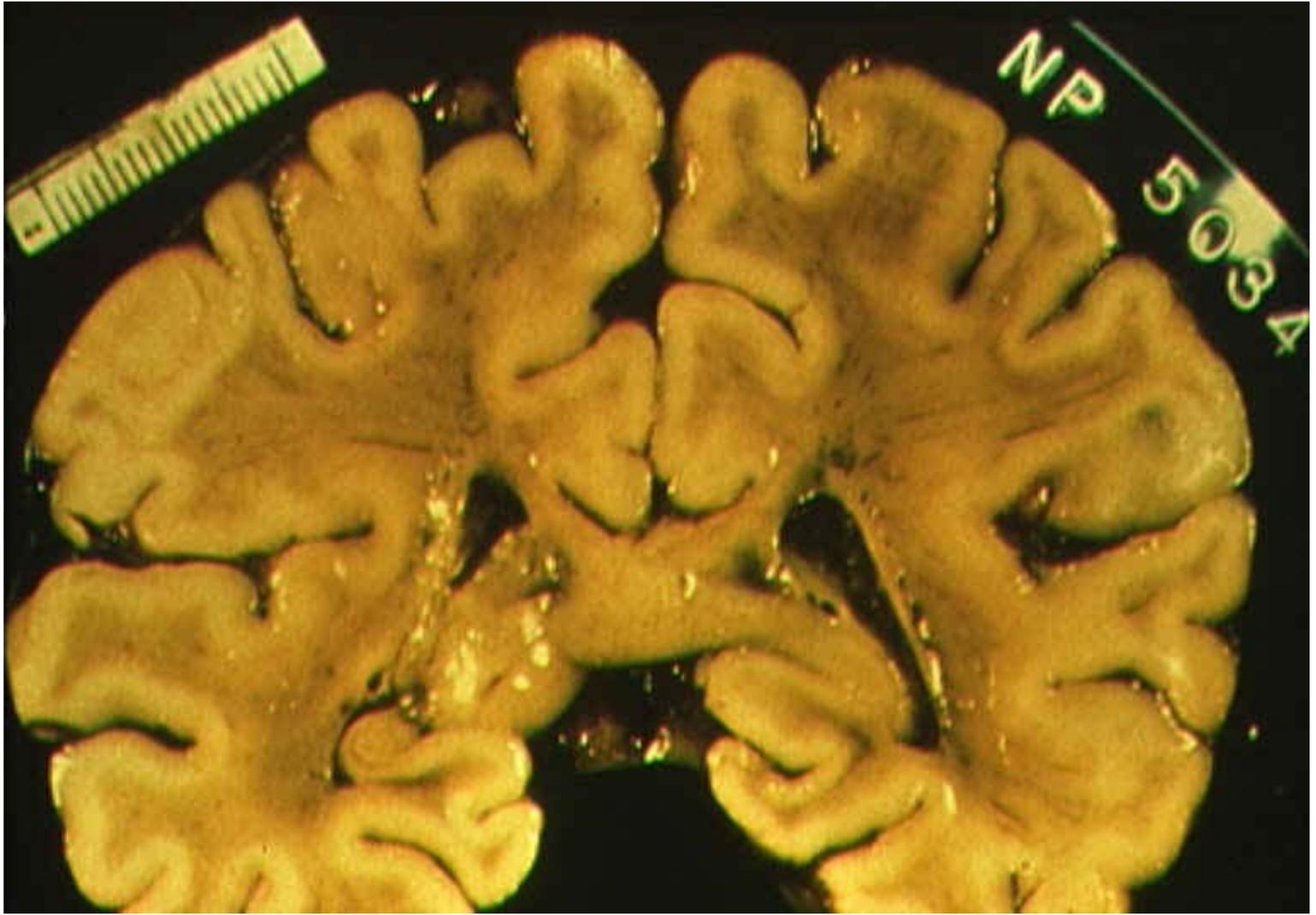


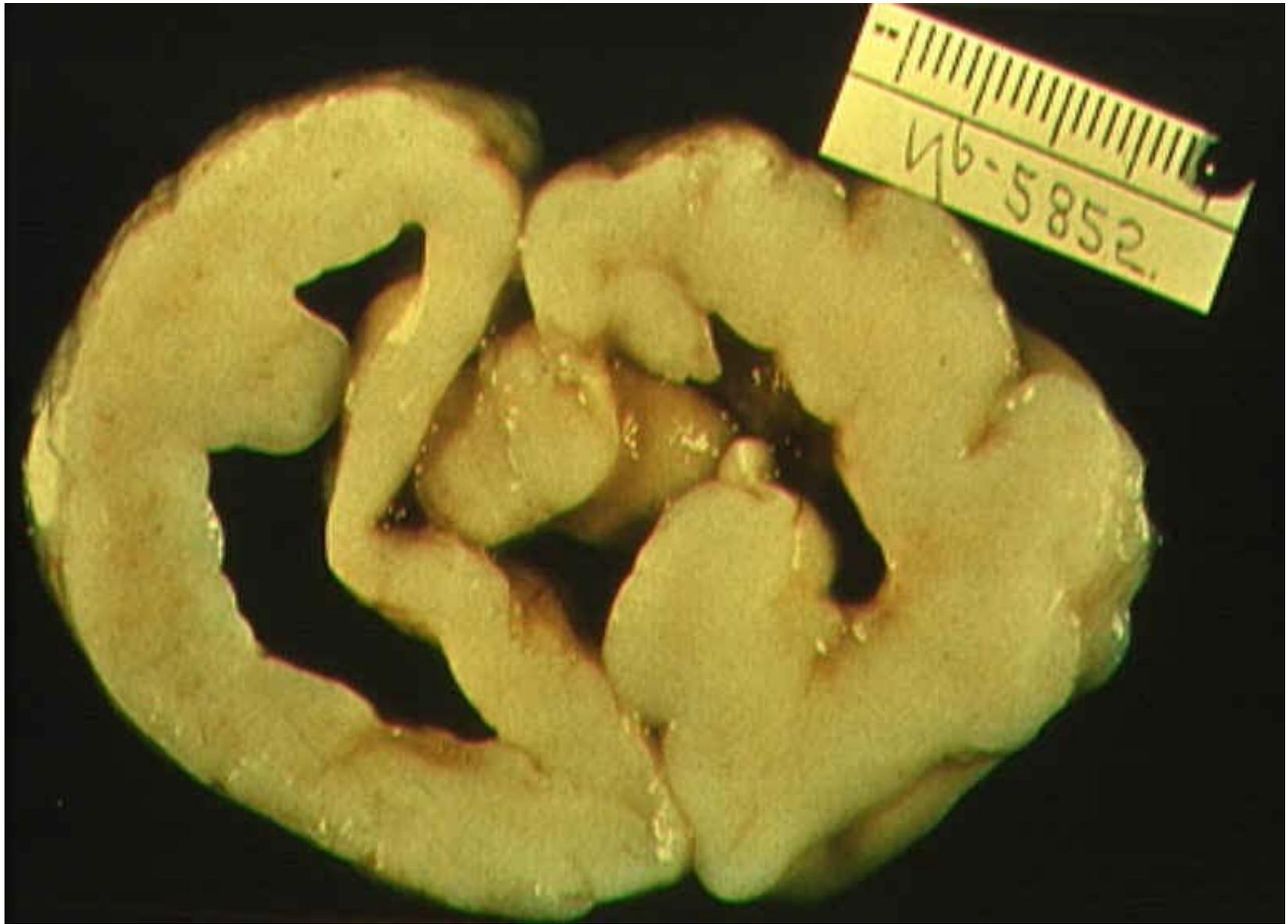
FASD

- The number of people without the characteristics of FAS may be more than 6 times as many as people with FAS









Consequences are far ranging and life long

- Individuals
- Families
- Tribes
- Communities
- Social Services
- Medical Services
- Mental Health Services
- Treatment Services
- Justice System
- Work Force
- Education
- Relationships

Fetal Alcohol Spectrum Disorders Issues

- Anger
- Blame
- Denial
- Shame
- Grief
- Pain
- Loss
- Guilt
- Hopelessness

**The journey of alcohol
through our communities
is generational and so are
the consequences**



Barriers

- **FASD is taboo, multigenerational and often people are misdiagnosed.**
- **Resources are focused on this issue but may not be affective because of denial and shame.**

Barriers

- **Case management is usually unavailable and not collaborative.**
- **Patient tracking does not tie the Health Care systems with the patient.**

Needs

- **Providers need to be empowered and funded to make services available.**
- **Community health centers and other service providers need training.**
- **Primary health care providers need to be educated.**

Needs

- Funding must be available for long periods of time and not subject to cuts.
- Continuum of care – this is life long

**WHAT DO OUR
COMMUNITIES NEED?**

HEALING

Healthy communities have healthy members

- Educated
- Drug and alcohol free
- Proud, honor culture and traditions
- Have a spiritual path
- Part of intact families
- Have high expectations of their children
- Have meaningful work
- Feel part of something bigger
- Nurture all of their children

THE PATH TO HEALING

- Awareness
- Acknowledgement of problem
- Acknowledgement of fear
- Education
- Acceptance
- Understanding
- Compassion
- Forgiveness

Healing can draw
from the diversity
and knowledge in our
communities

**Where does
healing begin?**

YOU