Fetal Alcohol Spectrum Disorder: It's a Developmental Disability

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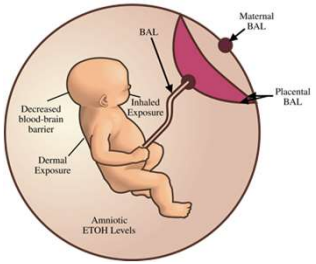
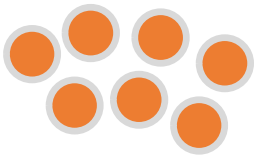
FASD: How Much Does it Take?

Six drinks in a week for 2 separate weeks

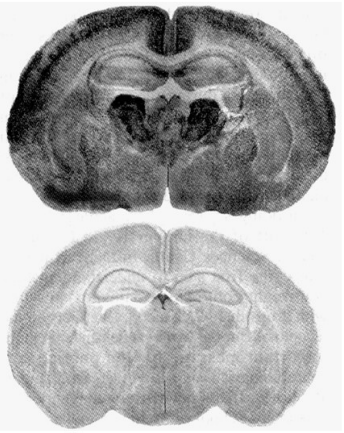
Three drinks at a time on 2 separate occasions


Maternal BAL
BAL
Placental BAL
Inhaled Exposure
Decreased blood-brain barrier
Dermal Exposure
Amniotic ETOH Levels

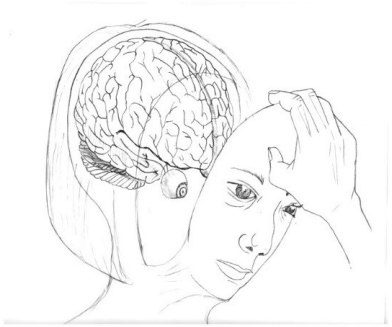


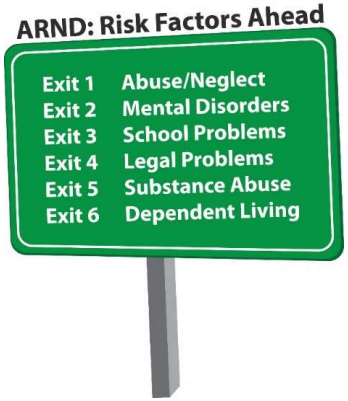
Oocytes

Fetal Alcohol Spectrum Disorders (FASD)



See PAE, Think Impairment





FASD in Arkansas (36,564 births per year)

- Born Each Year

FAS	43
ARND	312
Total FASD	365

That’s one per day - 7 each week

FASD in Arkansas

• Birth -18	6,570
• Adults 19-60	15,330
• Elderly 61-75	5,110
• Total	27,010
• Diagnosed 1%	270
• Diagnosed 5%	1,350

FASD Recurrence in Arkansas

- Annual birth cohort 365
- Recurrent cases 94
- 20-24 will recur in families with multiple affected children.
- **Start Prevention Here**

Cost of FASD in Arkansas

- Cost Per Day $172,173
- Annual Cost $77,704,470
- Annual Cost: Special Education and Juvenile Justice $14,861,280
- 5 year Costs $314,215,950

Costs of FASD

Annual Costs: $22,810 to $24,308 + $14,700 (parents)

26% ADHD

26% higher than autism

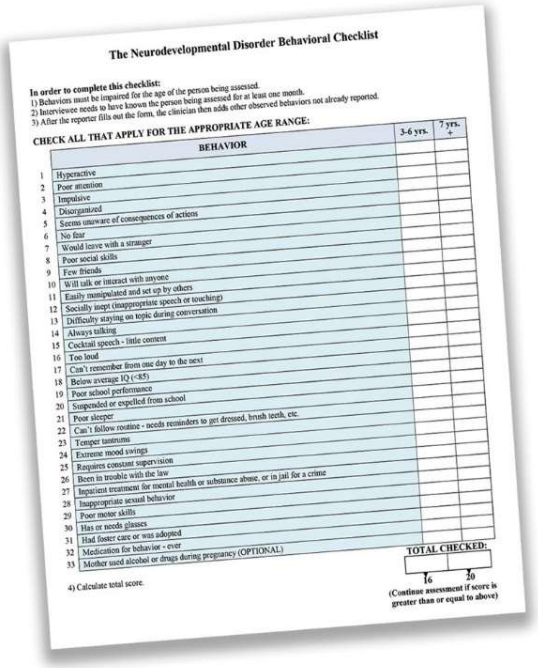
87% higher than asthma

13% higher than diabetes

56% higher than epilepsy

In North Dakota, USA, the annual cost for parents with a child with FAS, is estimated at US $17,400, which includes costs associated with travel, meals and lodging, insurance deductible, vacations and sick leave, child care, and telephone costs. This amount is equal to 36.4% of the median gross household income in North Dakota which was $47,800 in 2009.

Thanh et al., 2013, J Popul Ther Clin Pharmacol vol 20(1):e63-e66



The Neurodevelopmental Disorder Behavioral Checklist

In order to complete this checklist:
1) Behaviors must be impaired for the age of the person being assessed.
2) Interviewee needs to have known the person being assessed for at least one month.
3) After the reporter fills out the form, the clinician then adds other observed behaviors not already reported.

CHECK ALL THAT APPLY FOR THE APPROPRIATE AGE RANGE:

	BEHAVIOR	3-6 yrs.	7 yrs. +
1	Hyperactive		
2	Poor attention		
3	Impulsive		
4	Disorganized		
5	Seems unaware of consequences of actions		
6	No fear		
7	Would leave with a stranger		
8	Poor social skills		
9	Few friends		
10	Will talk or interact with anyone		
11	Easily manipulated and set up by others		
12	Socially inept (inappropriate speech or touching)		
13	Difficulty staying on topic during conversation		
14	Always talking		
15	Cocktail speech - little content		
16	Too loud		
17	Can't remember from one day to the next		
18	Below average IQ (<85)		
19	Poor school performance		
20	Suspended or expelled from school		
21	Poor sleeper		
22	Can't follow routine - needs reminders to get dressed, brush teeth, etc.		
23	Temper tantrums		
24	Extreme mood swings		
25	Requires constant supervision		
26	Been in trouble with the law		
27	Inpatient treatment for mental health or substance abuse, or in jail for a crime		
28	Inappropriate sexual behavior		
29	Poor motor skills		
30	Has or needs glasses		
31	Had foster care or was adopted		
32	Medication for behavior - ever		
33	Mother used alcohol or drugs during pregnancy (OPTIONAL)		
	TOTAL CHECKED:		
		16	20

4) Calculate total score.

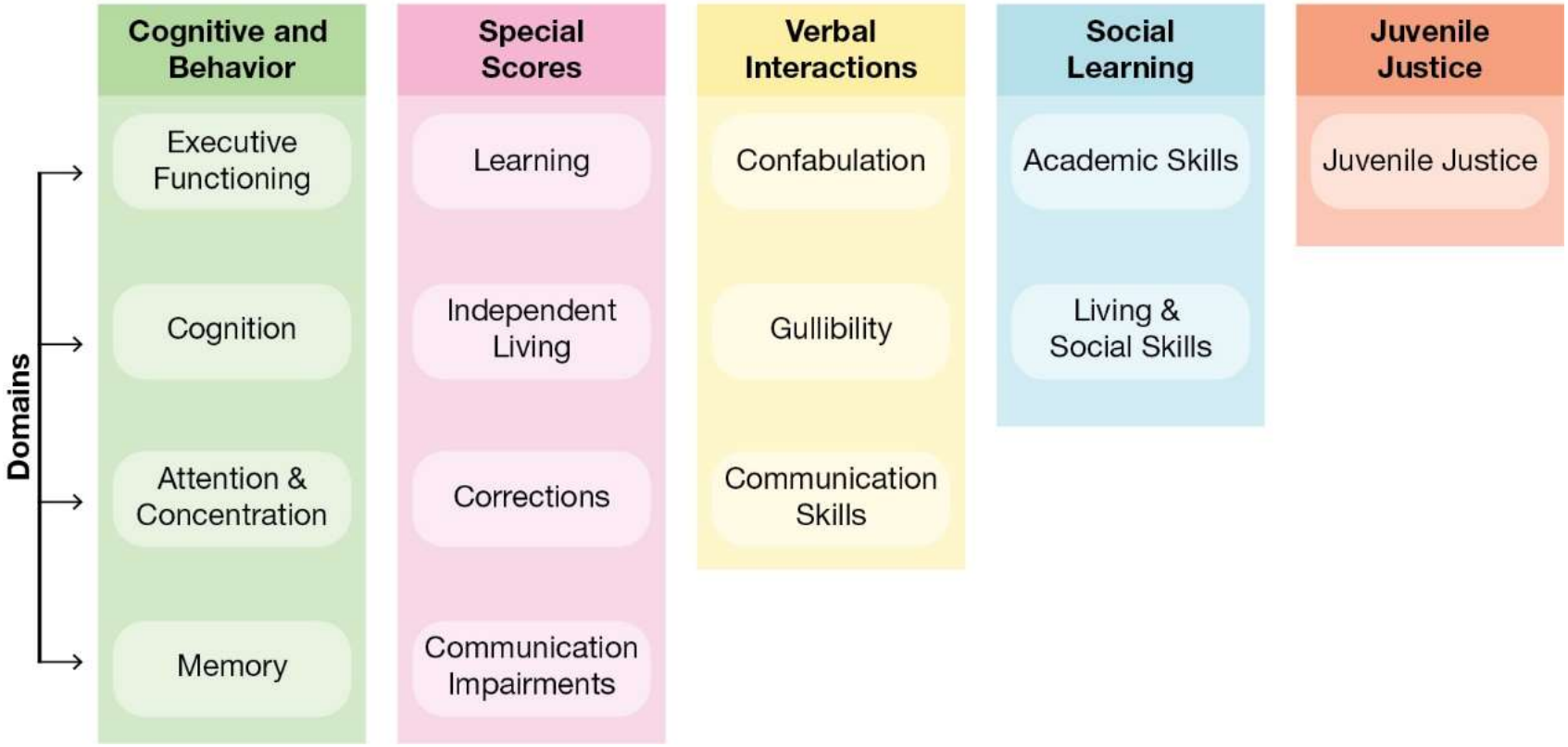
(Continue assessment if score is greater than or equal to above)

FIVE BROAD AREAS

Domains

Cognitive and Behavior	Special Scores	Verbal Interactions	Social Learning	Juvenile Justice
Executive Functioning	Learning	Confabulation	Academic Skills	Juvenile Justice
Cognition	Independent Living	Gullibility	Living & Social Skills	
Attention & Concentration	Corrections	Communication Skills		
Memory	Communication Impairments			

FIVE BROAD AREAS



Birth to Three Screen

FASD Screening Birth to 3 – Brief Screen

Name _____ DOB _____ Sex M___ F___

or

ID _____ Age _____ Date _____

_____/_____/_____

Height Weight Head Circumference

Findings That Suggest Increased Risk of FASD

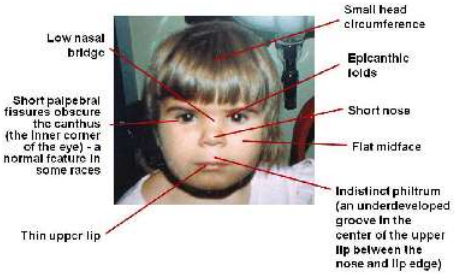
(circle all that apply)

		Score
1.	Child is adopted or in foster care	1
2.	Child has attention deficit hyperactivity disorder (ADHD)	1
3.	Child has head circumference < 20th percentile now or at birth (small head)	1
4.	Child is below 20th percentile for weight now.	1
5.	Child has midface hypoplasia (flat midface)	1
6.	Red raised birthmark now or in the past	1
7.	Child has altered palmar creases	1
8.	Child has a smooth philtrum (ridge under nose flat)	1

Total Score = _____

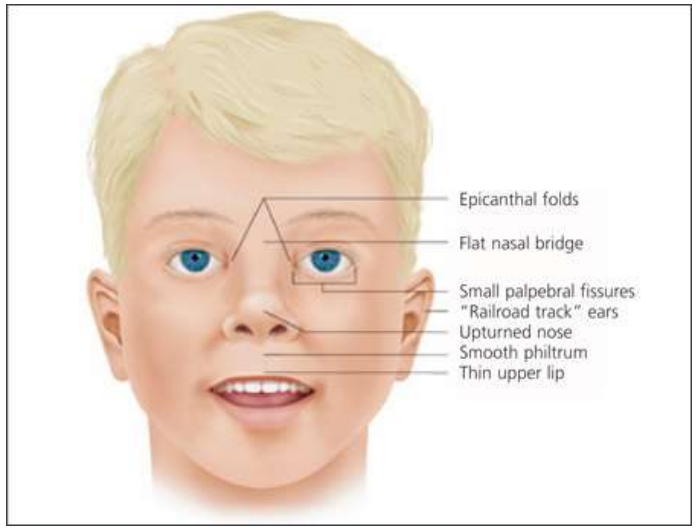
Score of 4 or more consider FAS referral
83.8% accuracy, 93.8% sensitivity, 51% specificity

Facial Features



Nuthun Special About Me

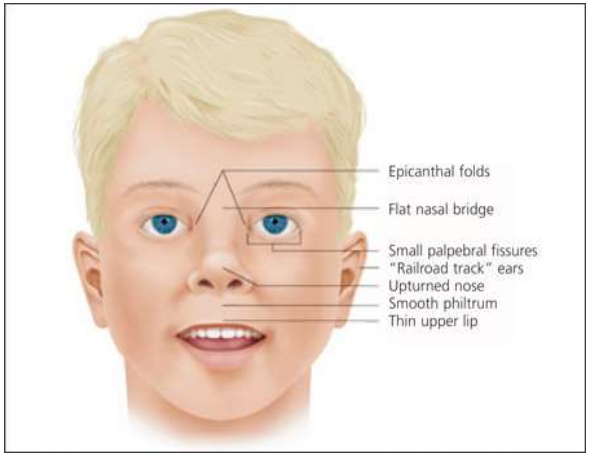
		RR
• Stillbirth		4
• SIDS		10.2
• Infectious Illness		13.7
• Mortality Risk		5.3
• Sibling Risk		5
• Maternal Mortality		(33-44)
• Head Injury		15%
• Juvenile Corrections	x	19
• Foster Care	x	25
• Residential Care	x	25
• Independent Living		15%



FASD

THE Leading Identifiable Cause of:

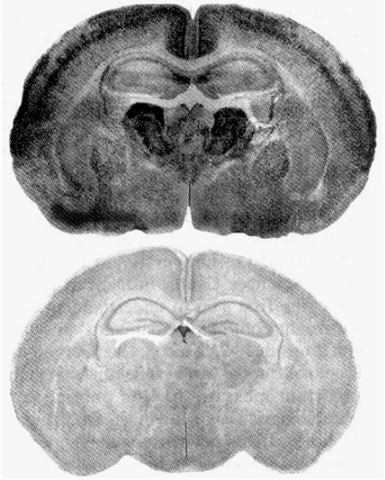
- Intellectual Disability
- Mental Disorders in Children
- Attention Deficit Hyperactivity Disorder
- Residential Care
- Juvenile Corrections
- Developmental Disability
- Learning Disabilities



FASD: A Leading Identifiable Cause of:

- Placement in foster care
- ADHD
- Childhood mortality
- Outpatient mental health
- Inpatient psychiatric hospitalizations
- Special education placement
- Visual impairment
- Impaired adaptive behavior

Could we prevent much of this?



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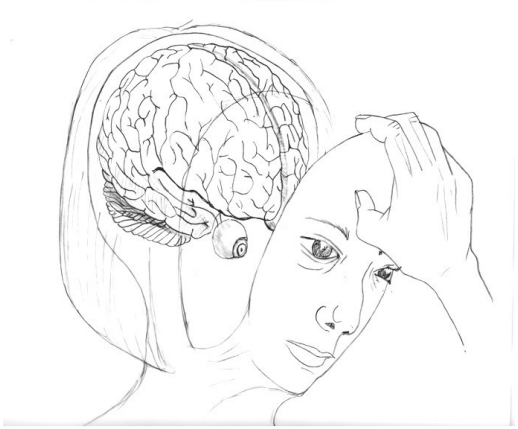
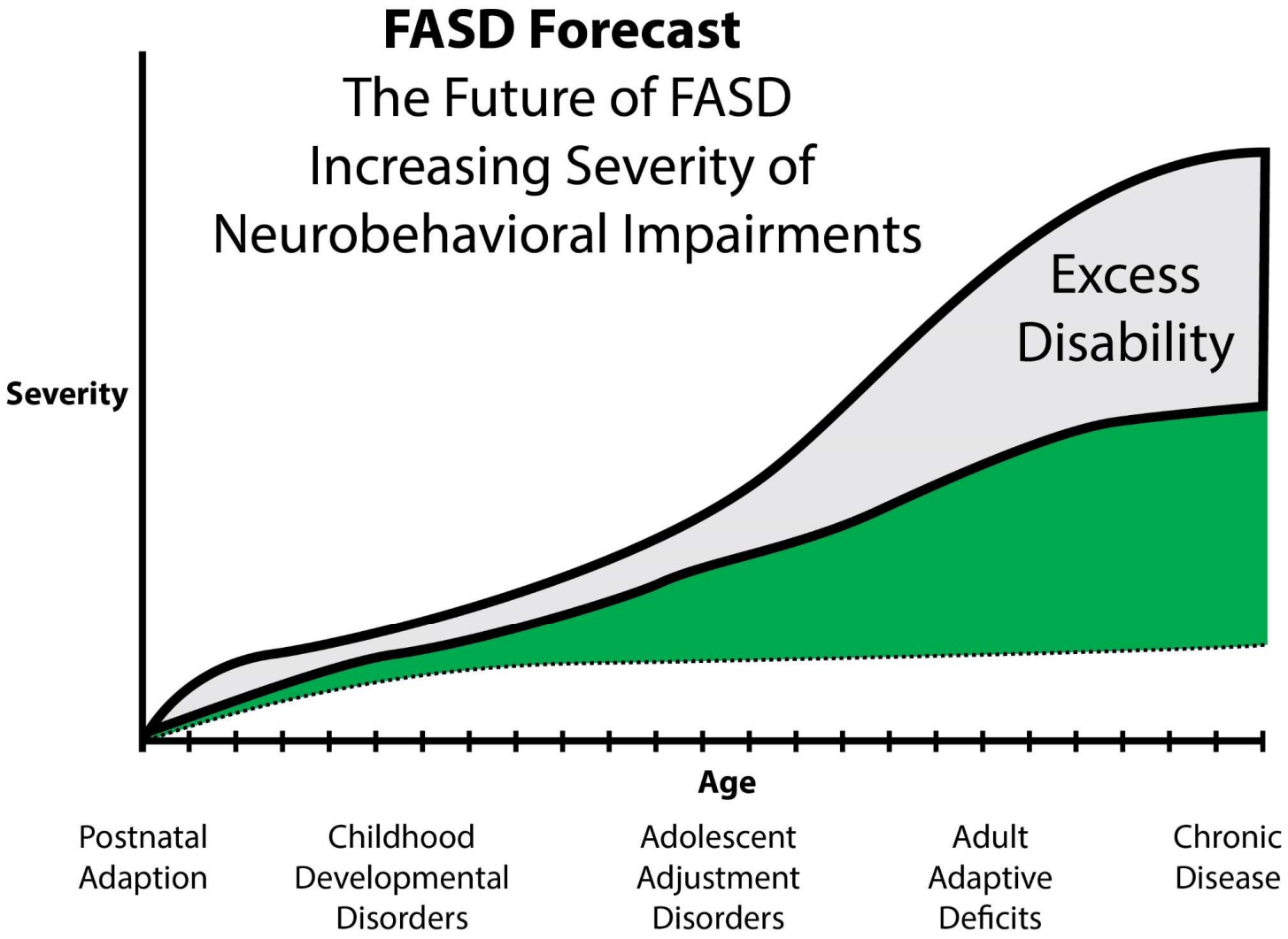
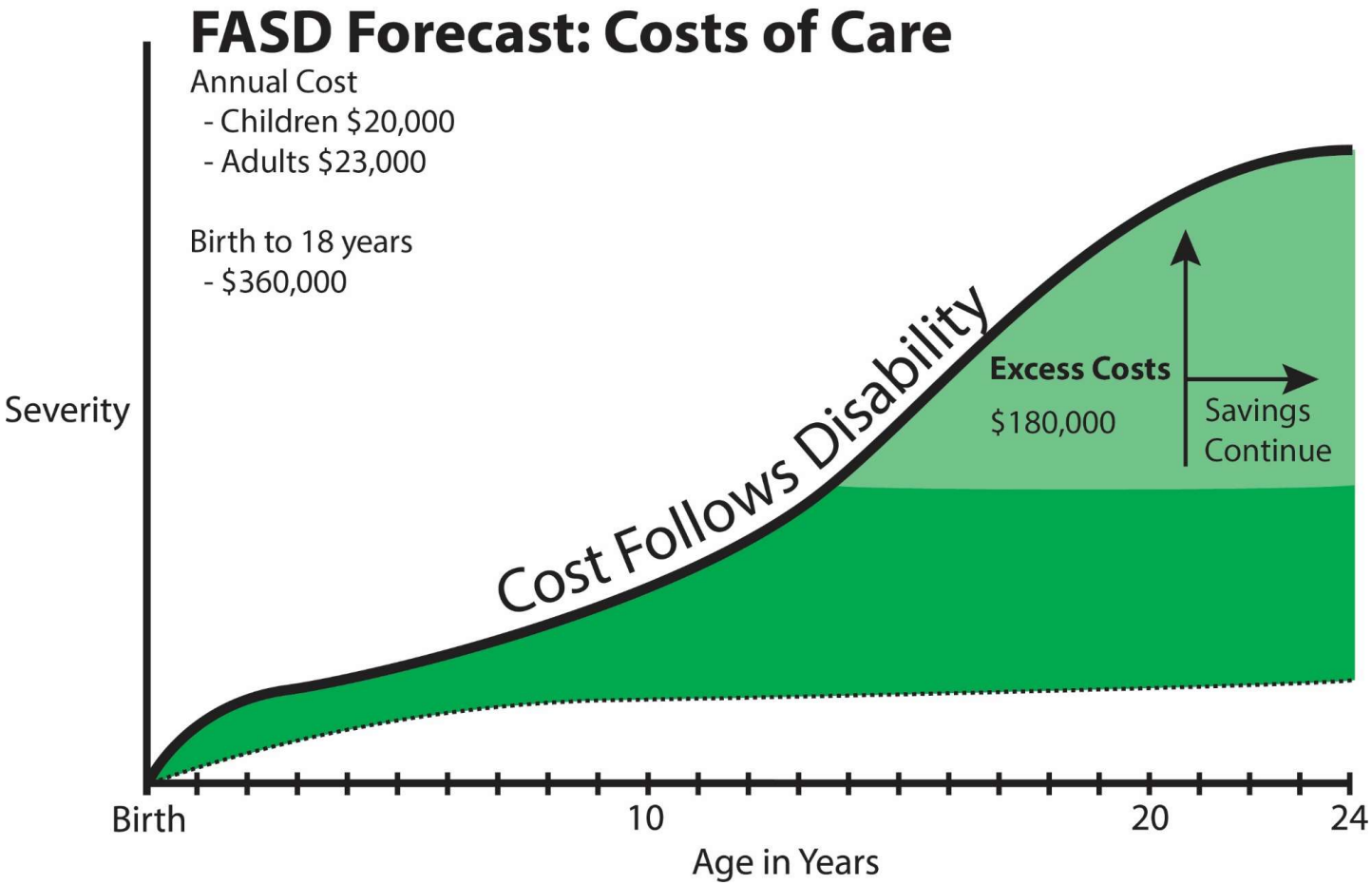



FASD Forecast
The Future of FASD
Increasing Severity of
Neurobehavioral Impairments
Excess
Disability
Severity
Age
Postnatal
Adaption
Childhood
Developmental
Disorders
Adolescent
Adjustment
Disorders
Adult
Adaptive
Deficits
Chronic
Disease


FASD Forecast: Costs of Care
Annual Cost
- Children $20,000
- Adults $23,000
Birth to 18 years
- $360,000
Severity
Cost Follows Disability
Excess Costs
$180,000
Savings
Continue
Birth
10
20
24
Age in Years

Incarceration Risk For FASD

- In Canada youth 12-18 years of age with FASD have a 19 fold increase risk of incarceration.

Popova L., Am J Epidemiol ,2012

43% of juveniles in corrections with FASD had given at least one false confession, two-thirds of which resulted in charges

McLachlan and collaborator Ron Roesch

FASD IS A CONCERN AT VIRTUALLY ALL LEVELS OF THE LEGAL SYSTEM

Pre-arrest

"We need to figure this out so you can go home."

Parole and probation

The impairments from FASD increase problems in keeping scheduled meetings, completing forms and meeting day to day requirements in these systems. A diagnosis and diagnosis dependent accommodations are crucial to maximize likelihood of success.

Incarceration

People with FASD often become victims of crime while being detained or serving a sentence in jail or prison.

People with FASD have brain damage which affects their ability to:

- understand
- communicate
- appreciate adversarial hearings
- assist their attorney
- accurately recount events
- understand complex explanations

They also:

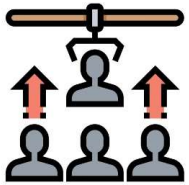
- have memory deficits which they compensate for by filling in missing information
- have problems attending to what's going on in court
- often agree without understanding
- are susceptible to victimization
- are disinhibited
- are gullible

Sentencing

All Judges must consider FASD as a mitigating factor. For example, in Alaska all judges must consider FASD at time of sentencing. FASD should be considered as a mitigating factor because people with FASD do not understand cause and effect of their behavior and it relates to the state of mind at the time of the crime.

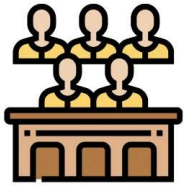
Interrogation room

People with FASD have an array of cognitive, social and neurobehavioral deficits that could lead to false confessions and inaccurate testimony, often from suggestibility and gullibility.



Court proceedings:

People with FASD are often unable to form a working relationship with their attorney, provide relevant facts about their arrest and often cannot provide witness information relevant to their arrest. FASD produces brain damage which leads to problems with executive functioning, short and long term memory, processing information and long term planning. ALL these factors must be considered when evaluating competency to stand trial for people with FASD.



ADAPTIVE BEHAVIOR	Assesses daily living skills, essential abilities for age appropriate independent functioning.
Socialization	Assesses ability to relate to others or function in groups. Socially odd (no or few friends).
Communication	Ability to communicate in age appropriate independent situations. Difficulty asking for help or clarifying misunderstandings.
Self-Care	Ability to function at age level. Cooking, laundry, showering other areas of personal care or hygiene.
Gullibility, Naivety, Credulity	Inadequate caution in all steps of the legal process often occurs with poor social skills (desire to fit in) and decreased IQ. Simplistic view or appreciation of consequences of decision making or uncritical acceptance of statements by others especially authority figures.
Suggestibility	Often comorbid with decreased IQ, memory deficits and anxiety. Easily led or influenced. Increases risk of victimization.
Confabulation	Very serious problem in legal settings. Exacerbated if anxiety is present. Very often occurs with memory impairments. Often includes in descriptions of events or actions information acquired during interviews, from TV or other unrelated situations. Anxiety increases susceptibility to confabulation. memory deficits suggestibility commonly co-occur

The 11 keys to Incarnation in FASD
1. Undiagnosed FASD

- *Gullibility
- *Naivety
- *Credulity
- *Suggestibility
- *Confabulation

- Anxiety
- Borderline IQ (71-90)
- Impulsivity
- Comprehension Deficits
- Memory deficits

- * Neurolinguistic disorder

ENVIRONMENTAL FACTORS	
Adverse childhood experiences (ACEs)- exposure to trauma	Children and adolescents in foster care or juvenile services have much higher rates of exposure to multiple ACEs. Trauma and PTSD lead to loss of train of thought, impaired sustained attention and explosive episodes,
Multiple Foster Home placements	Often occurs when services are limited or when overall neuropsychological severity is increasing.
Victimization/Exploitation	Shares money, housing, sexual favors for others, can lead to theft or aggression to get keep friends.
MENTAL HEALTH	
Anxiety	Increases desire to escape stressful situations and impairs thoughtful decision making. When comorbid with impulsivity adverse outcomes increased.

How I Feel...Depression?

(Circle the number that best describes how you have felt in the last month.)

0 1 2 3 4 5 6 7 8 9 10

No problems
Feel great

- Sleep well
- Good energy
- Enjoy life

I have depression

- Difficulty sleeping
- Low energy
- Unhappy

- Troubled sleeping
- Anxious
- Worried
- Sad

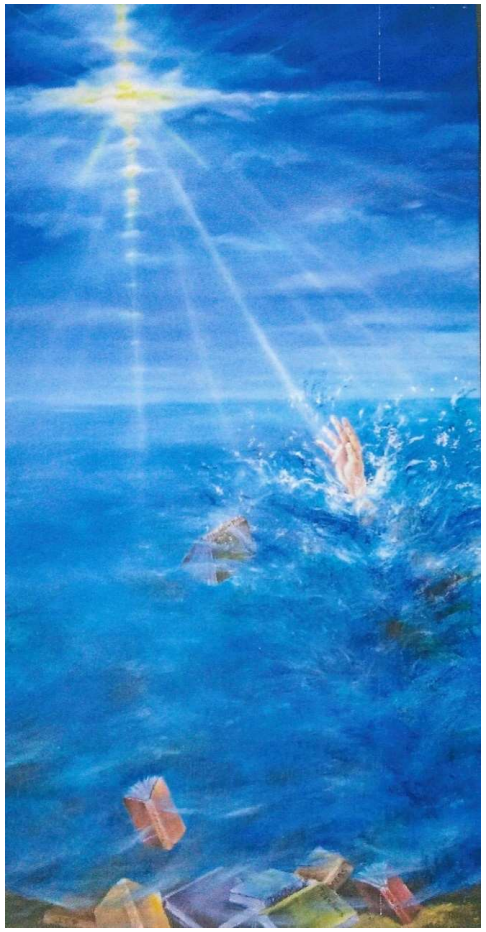
Severe depression

- Life is not worth it
- Suicide thoughts
- Cry or feel like crying often

Benefits of Diagnosis

- **Mothers**
- Huge risk for premature mortality.
- Greatly increased risk for another alcohol exposed pregnancy
- Since FASD is both generational and familial we have an opportunity to determine if mother or other children have an FASD.
- If mother has reduced prenatal exposure we can encourage and assist in maintaining the Quit or reduction (Don't Quit the Quit) especially between pregnancies.
- Opportunity to establish an ongoing relationship with a woman needing supportive intervention.
- **Children**
- Prevention of exposure to ACEs
- Reduce development of secondary disabilities,
- Reduce costs of care for children and adolescents
- Begin diagnosis-informed care
- Long term plan

Parenting and FASD



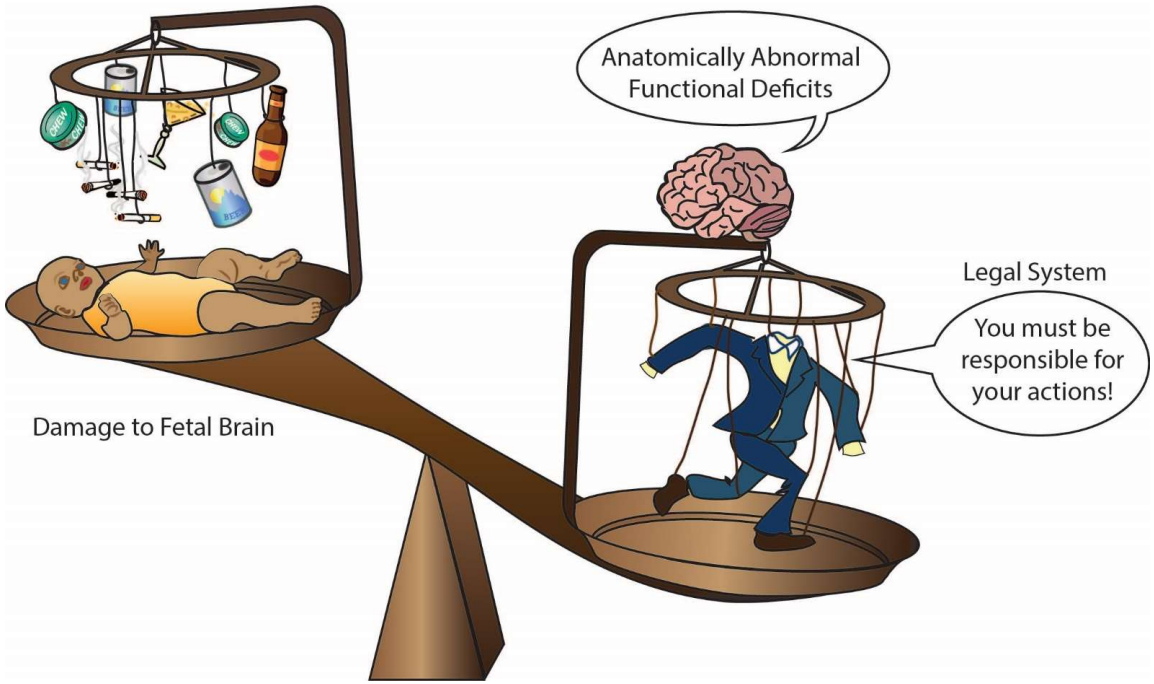
Children With FASD-Difficult to Parent

- High rates of
  - Sleep disorders
  - Eating problems
  - Toilet training difficulties
  - Temper Tantrums
  - Developmental disorders-needing therapy
  - School problems
  - Homework problems
  - Increasing severity of phenotype

Interventions

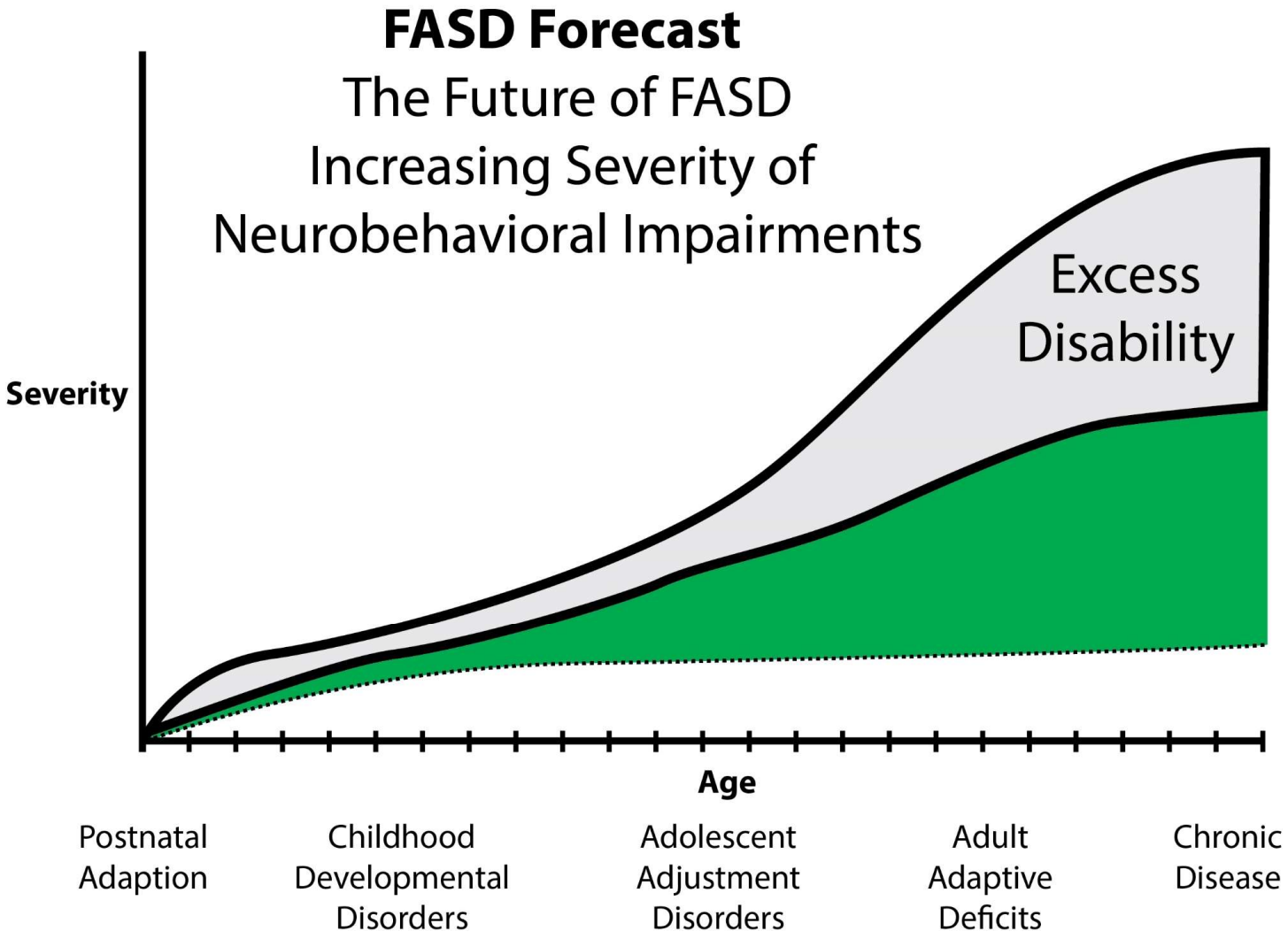
- Understand FASD
- Slow pace
- Picture schedules
- Decrease memory burden
- Manage anxiety
- Positive behavior management – less escalation
- Understand effects of comorbidity
- Comorbidity and future risk reduction
- Respite care for caretakers

The Responsibility Scale



Why Such Poor Outcomes?

- 3 GENERATIONS OF EXPOSURE
- ANTICIPATION (Generational and Familial)
- BRAIN DAMAGE
- INCREASED COMORBIDITY
- LATE IDENTIFICATION
- IMPAIRMENT NOT BEHAVIOR
- FALIURE TO CONTINUE SERVICES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