



Fetal Alcohol Spectrum Disorders For Educators

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www.adoptmed.org

Disclosure: Julian Davies, MD

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I have a financial relationship with this program.

Objectives

At the end of this presentation, participants will be able to:

1. Know how FASDs are diagnosed, and feel more confident working with or referring to FASD diagnostic clinics.
2. Describe the neurobehavioral impacts of prenatal alcohol exposure in the classroom.
3. Access 3 free FASD for Educators resources online.

Overview

Define Fetal Alcohol Spectrum Disorders

Diagnosis

How the brain is impacted by alcohol

What to do about it

Educator resources



What Is FAS?

Permanent birth defect syndrome caused by maternal alcohol consumption during pregnancy

An FAS diagnosis requires:

- Pre and/or postnatal **growth** deficiency
- Cluster of minor **face** anomalies
- **Brain** dysfunction
- Prenatal **alcohol** exposure



What about FAE, ARBD, ARND, PFAS, ND-PAE?

Fetal Alcohol Effects, Alcohol-Related Birth Defects, Alcohol-Related Neurodevelopmental Disorder, Partial FAS, Static Encephalopathy / Alcohol Exposed, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure ...

Patients missing one or more of the four FAS criteria

“FAE” has been retired; the alternatives aren’t much better

Fetal Alcohol Spectrum Disorders (FASD) - an umbrella term, not a diagnosis

- We have a marker for FAS: “the face”
- We lack a specific neurobehavioral phenotype for FASD

DSM-5 is catching up

Other Specified Neurodevelopmental Disorder (315.8): ND-PAE

A proposed condition for future study:

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure

- A. More than minimal prenatal alcohol exposure
- B. Impaired neurocognitive functioning
- C. Impaired self-regulation
- D. Impairment in adaptive functioning
- E. Onset in childhood
- F. Clinically significant distress or impairment
- G. Not better explained by other medical issues, substance use, neglect

The Current Problem

Leading known cause of mental retardation

- As common as Down Syndrome and spina bifida, catching up on Autism Spectrum Disorders

Incidence of FAS in general population at least 1-3/1,000 live births, similar in Europe

- Alaska Native/American Indians in Alaska: 5-6/1,000
- King County foster care: 10-15/1,000
- Russian specialized orphanage: 140/1,000

\$17,000/yr in medical costs (9x those without)

"Non-dysmorphic" FASD estimated 3-10x FAS

Alcohol Use in Pregnancy & FAS

Alcohol is a teratogen

Timing of use

Dose of alcohol

Pattern of use

Individual risk/protective factors

Прогресс будущего ребенка!



Asking about Alcohol

Confirmed alcohol exposure during pregnancy is required, unless the client has the full face of FAS (only ~10% do)

Maternal self-report, directly witnessed by others, or medicolegal evidence

Prior to pregnancy, before you knew you were pregnant, after you knew?

Typical and maximum consumption, weekday and weekend? Type of alcohol and size of container?

Positively stated questions: “In the month before you knew you were pregnant, how many drinks did you have?”

Alcohol is a possible explanation that opens doors to diagnosis and services

Diagnosing FAS ...



What EVERYONE Agrees On: FASD involves ...

Growth deficiency

Facial anomalies

Organic brain damage

Alcohol exposure

ЭТА
ОВНОВА
МНЕ
К ЛИЦУ...



What Everyone
DISAGREES On:
The DEFINITION of ...

Growth deficiency

Facial anomalies

Organic brain damage

Alcohol exposure

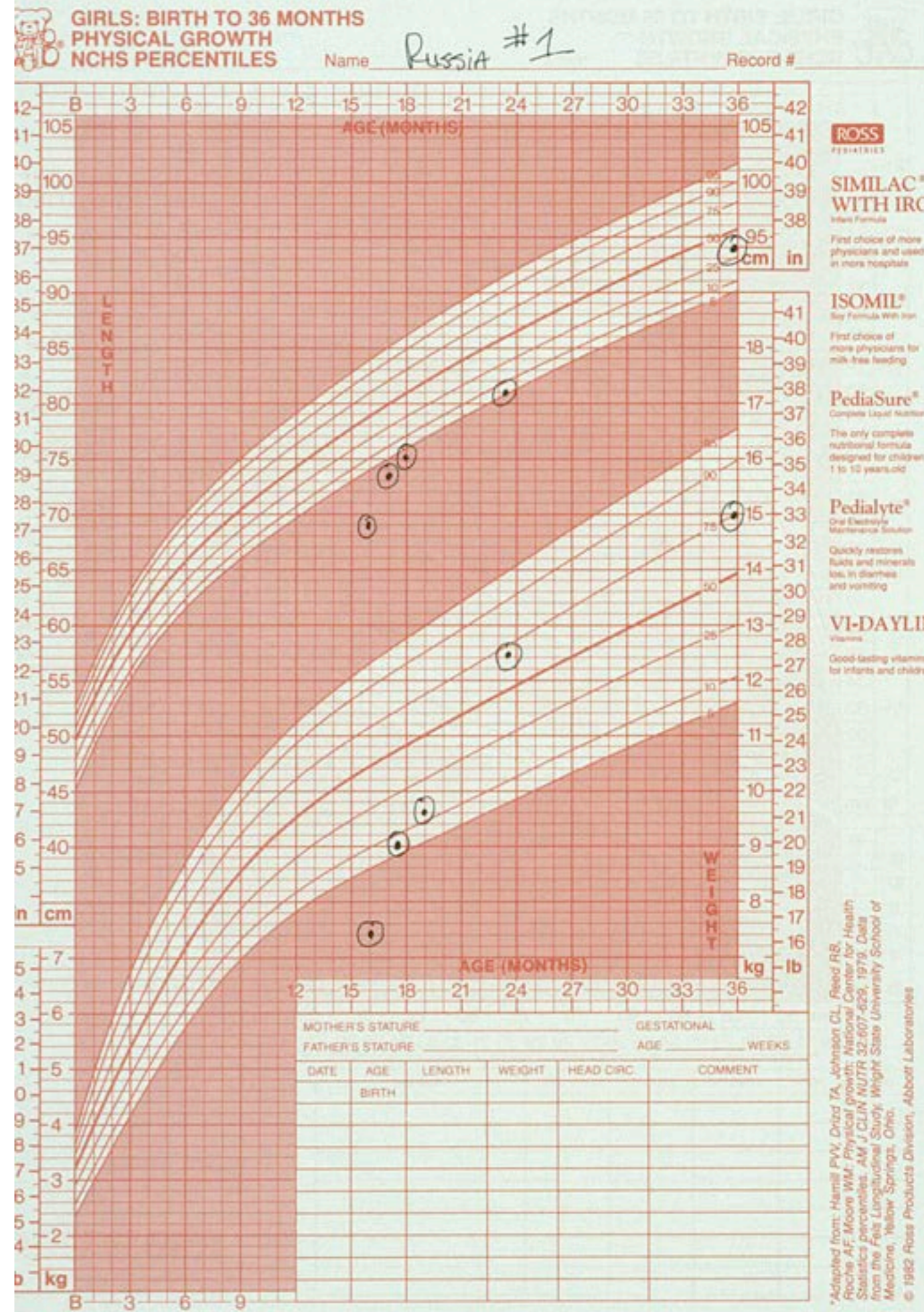


Growth Deficiency

Height deficiency (birth or since)*

Weight deficiency (birth or since)*

*Not better explained by other influences on growth (chronic illness, severe malnutrition, etc.)

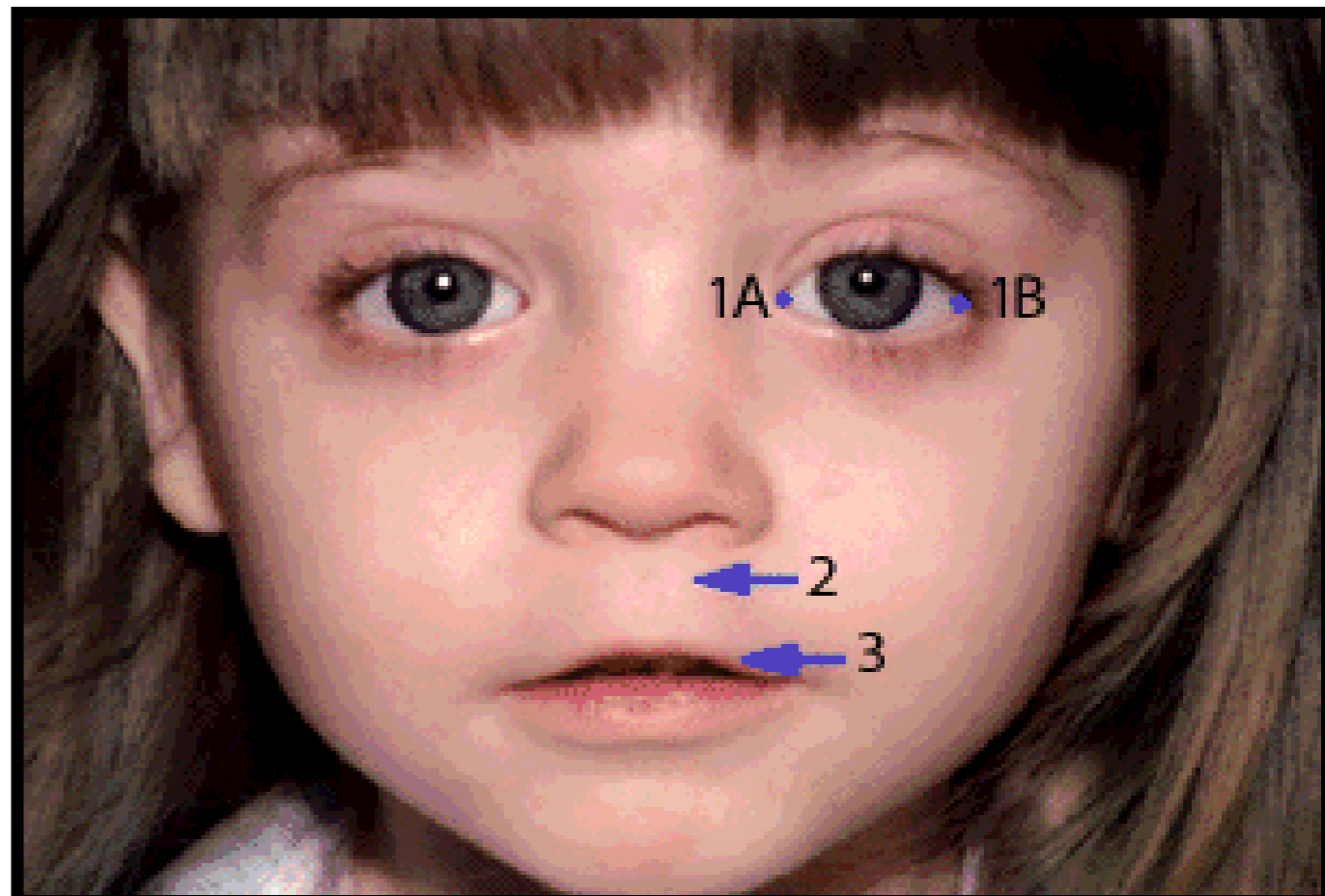


Facial Anomalies

1. Small palpebral fissures
2. Smooth philtrum
3. Thin upper lip

Others are inconsistent and change with age

These probably don't



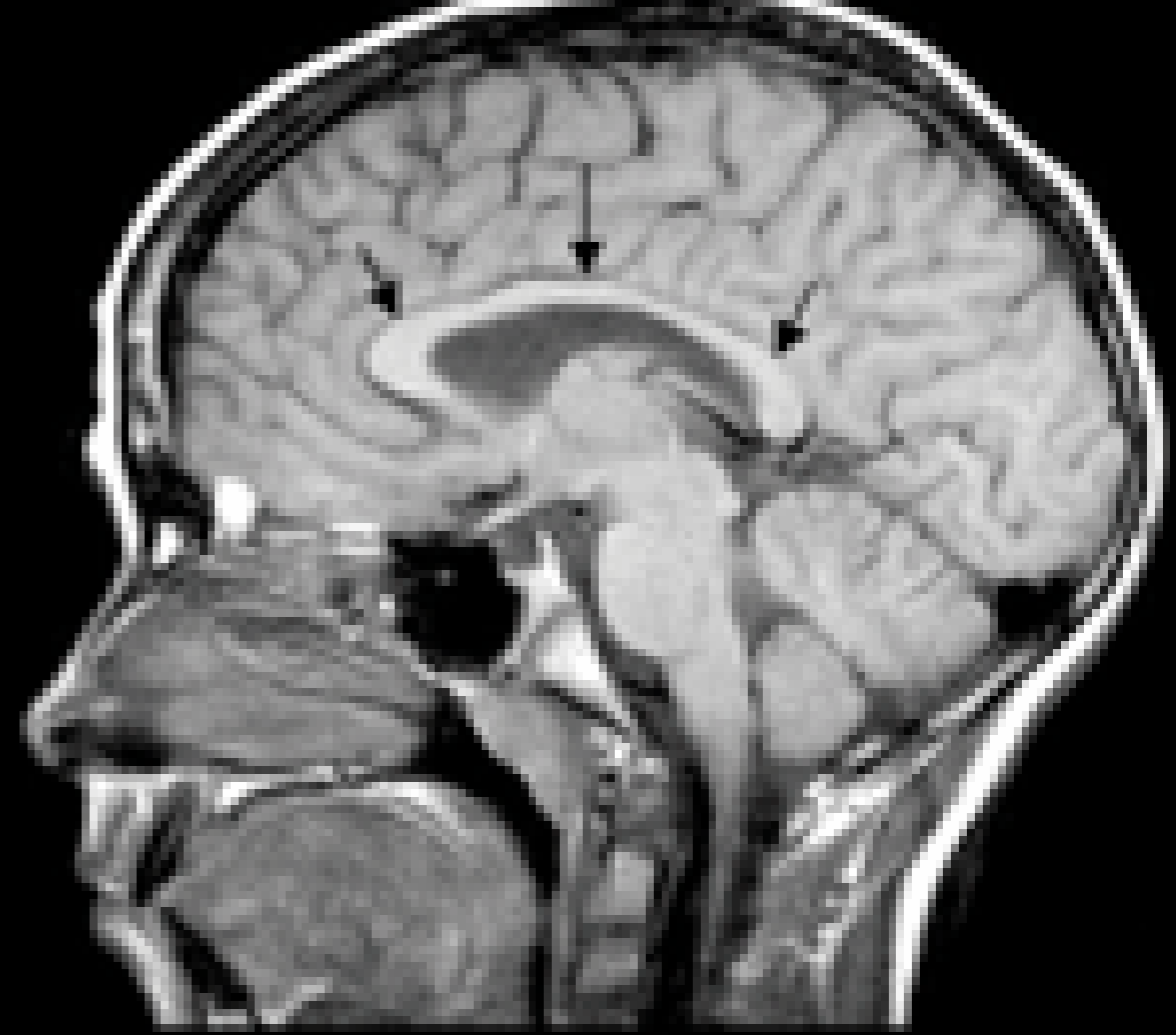
Evidence of Brain Damage

Microcephaly

“Hard” Neurologic signs, e.g. seizures

Functional Evidence of Brain Damage

- “3 strikes” criteria



Main Diagnoses under the FASD Umbrella



Diagnosis		Growth	Face	Brain	Alcohol
FAS	Fetal Alcohol Syndrome	mild-severe	severe	severe	optional
pFAS	Partial FAS		mod-severe	severe	alcohol
SE/AE	Static Encephalopathy / Alcohol Exposed*			severe	alcohol
ND/AE	Neurobehavioral Disorder / Alcohol Exposed*			mild-mod	alcohol

*aka ARND or Neurodevelopmental Disorder Assoc. with Prenatal Alcohol Exposure (ND-PAE)

Other Organ Systems

Eye: Myopia, strabismus, ptosis, optic nerve hypoplasia

ENT: Hearing impairments, clefts, micrognathia, external ear anomalies, recurrent/chronic ear infections

Cardiac: ASD/VSD, PS, PDA, AS, Tet, etc. Septal defects make up most of ARBDs in a recent study

Renal: hydronephrosis, dys/hypoplastic kidneys

Skeletal: clinodactyly, limited ROM, pectus, scoliosis, etc.

BUT - inconsistent definitions of FAS, no controlling for other risks, many not found in recent survey (overall, ARBDs 4x more likely in heavy 1st trimester PAE)

Bottom line: Hearing & vision eval, watch for heart & ENT issues

Consultation for Diagnosis

FASD team, neurodevelopmental clinic, neurology, genetics for medical aspects

Early intervention teams, psychologists, educational teams for brain function

Endocrine or growth workup for unusually severe/persistent growth problems

Neurology with imaging for microcephaly or “hard” signs, with EEG if seizures suspected

Dysmorphologist/genetics if diagnosis is uncertain

CGH Array for atypical FAS, FASD with intellectual disability?

МАТОВОЕ
ВУТРИННЕЕ
СОДЕРЖАНИЕ

FASD and the Brain

We hope to better understand the structural, cognitive, and behavioral features of FASDs



Brain injuries often go undiagnosed & unserved

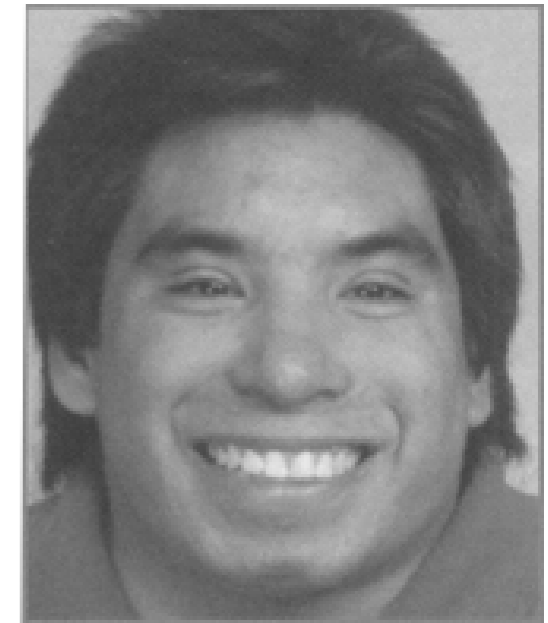
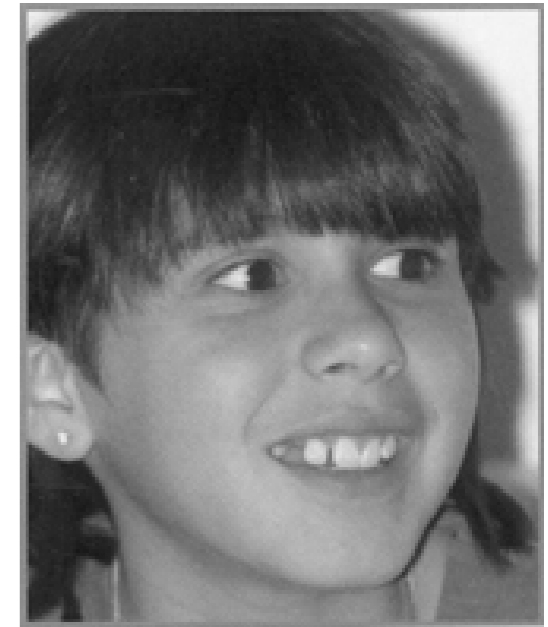
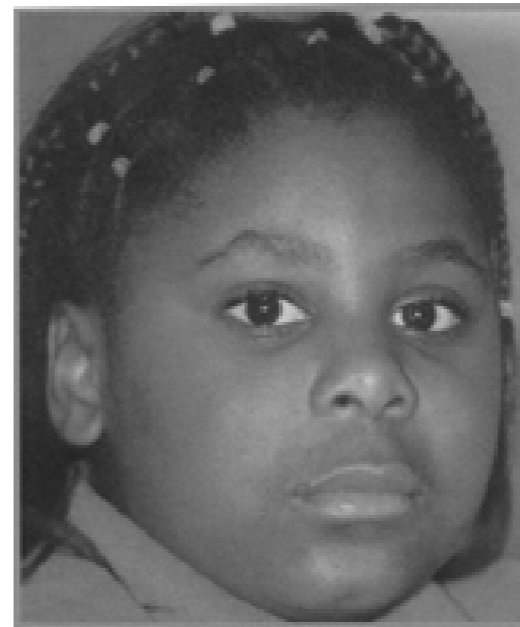
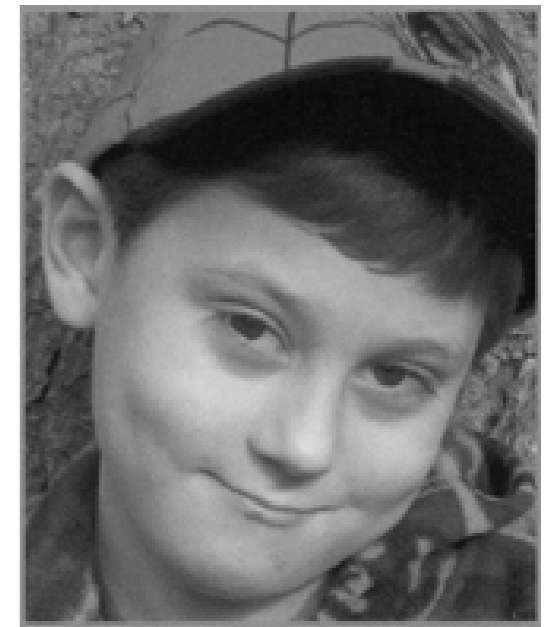
It's not the face that needs services

FASD is often an “invisible” disability

Children often fail to qualify for services until later school years – too late!

Variability is the rule

- For the fetal alcohol spectrum and for the child



Cognitive/Behavioral Phenotype?

Not yet (or ever?), but FASDs seem to involve:

a generalized deficit in processing complex information

(such as diminished intellectual function, slow processing, relative difficulty with complex tasks)

variability

(for the child and the spectrum)

adaptive gaps that widen with age

(can the gaps close with intervention?)

A problem has been detected and windows has been shut down to prevent damage to your computer.

BAD_POOL_HEADER

If this is the first time you've seen this stop error screen, restart your computer. If this screen appears again, follow these steps:

check to make sure any new hardware or software is properly installed. If this is a new installation, ask your hardware or software manufacturer for any windows updates you might need.

If problems continue, disable or remove any newly installed hardware or software. Disable BIOS memory options such as caching or shadowing. If you need to use safe Mode to remove or disable components, restart your computer, press F8 to select Advanced startup options, and then select safe Mode.

Technical information:

*** STOP: 0x00000019 (0x00000020, 0xA8EBB8B0, 0xA8EBC008, 0xA8EBB8B0)

*** csatdi.sys - Address A8EBB8B0 base at A8E8A000, DateStamp 444947b7
*** csatdi.sys - Address A8EBC008 base at A8E8A000, DateStamp 444947b7
*** csatdi.sys - Address A8EBB8B0 base at A8E8A000, DateStamp 444947b7

Beginning dump of physical memory

Physical memory dump complete.

Contact your system administrator or technical support group for further assistance.

TOSHIBA

The Old Laptop

Stress, Neglect & Maltreatment

Before we blame it all on drink & drugs ... don't forget other influences, like complex trauma

Prenatal stress and anxiety may also affect postnatal stress response, IQ, ADHD, sleep

Early childhood trauma can impact amygdala, hippocampus, corpus callosum, frontal lobes, cerebellar vermis

These are the same areas damaged by prenatal alcohol



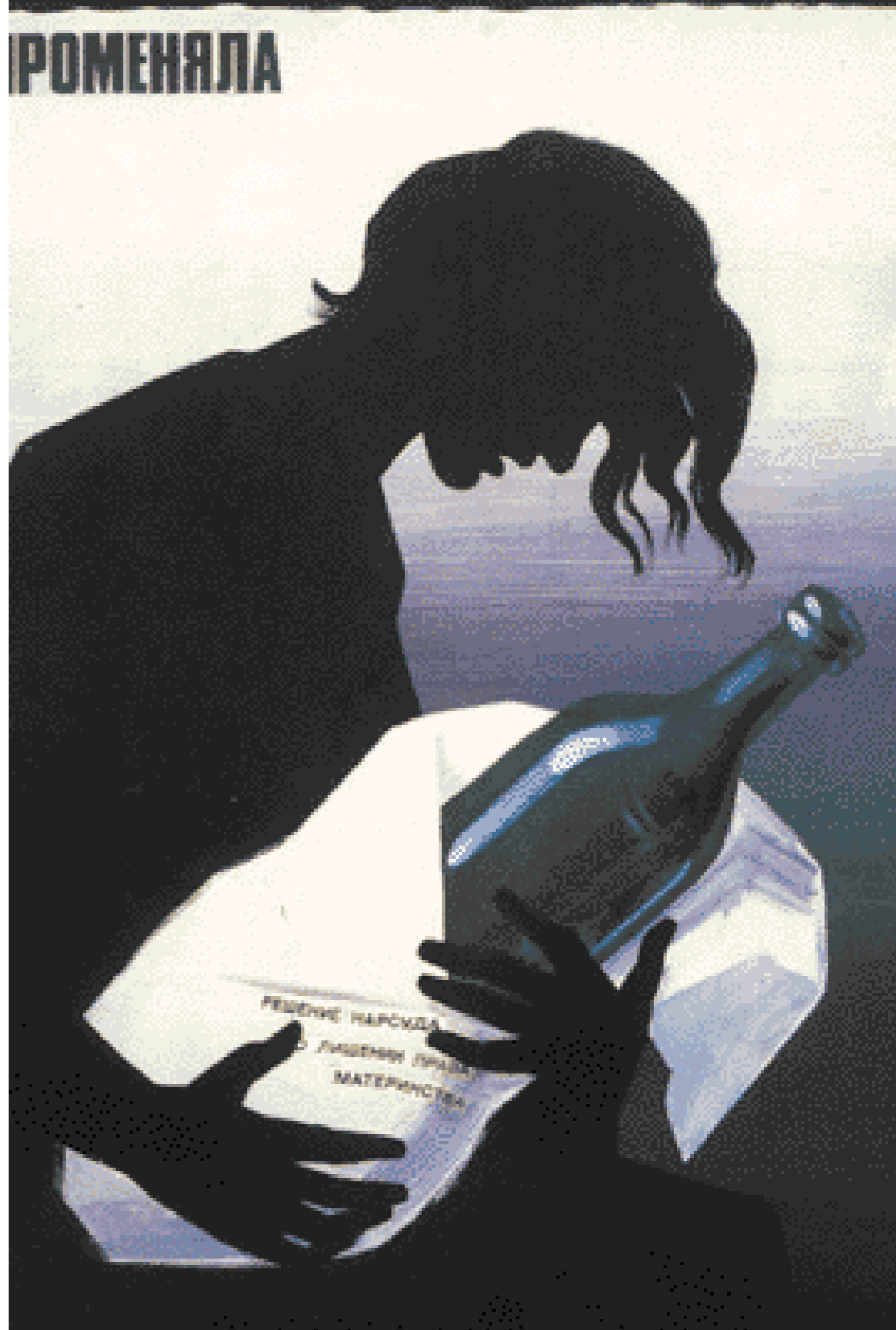
Newborns with FAS

Small, microcephalic?

Facial features present but trickier to assess

Often with poor state regulation, irritability, disturbed sleep, feeding difficulties, disorganized attachment

Can be a terrible “fit” – impaired parent with a very difficult infant



FASD in Preschool

Often missed, unserved at this stage

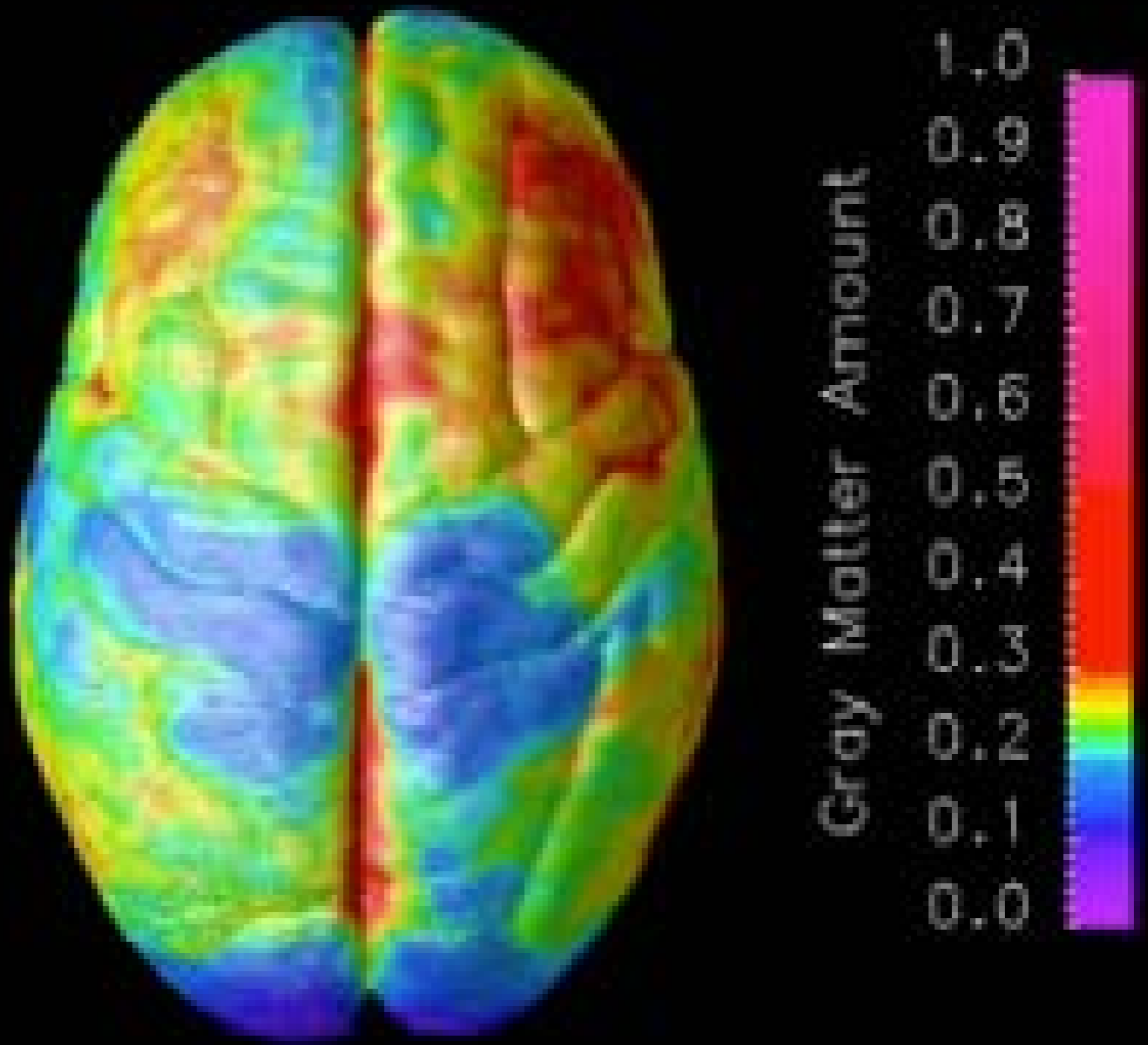
Language, adaptive, gross and fine motor delays

Difficulty regulating emotions and behavior; extreme tantrums

Overactive, impulsive, inattentive

Slow to learn social boundaries





FASD in School and Beyond ...

Impacted Brain Domains in FASD

Cognition

Memory

Language

Visual-motor

Executive function

ADHD

Academics



Sensory

Motor

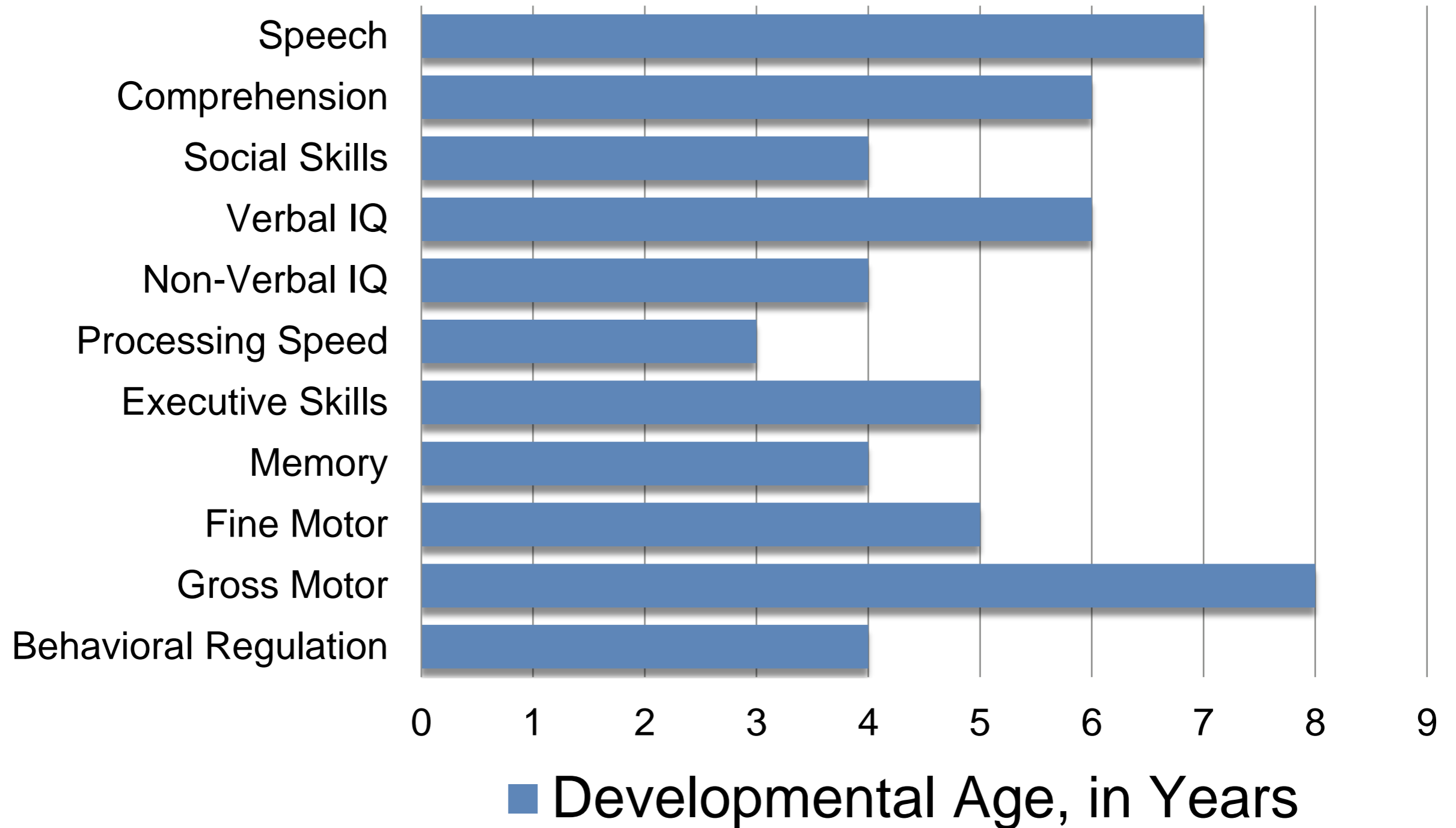
Behavior

Social Skills

Adaptive

Sleep

A Developmental Map



Overall Cognition

STRENGTHS

Tested intelligence is usually not in retarded range

This can also be a liability, services-wise

WEAKNESSES

IQ scores lower than expected based on genetic potential

- FAS mean IQ – 66 to 80 in various studies
- FASD more variable

Lots of sub-test variability, verbal IQ vs performance IQ “splits”

Slower information processing

Nonverbal abstract reasoning

Memory

STRENGTHS

Recall of single word vocabulary and categorical labels

Recall of visual and kinesthetic patterns

Often capable of retaining verbal information (especially if words are in a rhythm or song)

WEAKNESSES

Impaired verbal learning

Auditory sequential memory

Limited working memory span

Integration and retrieval of information and concepts

Speech & Language

STRENGTHS

Superficial conversational speech – talkative and fluent

Ability to learn vocabulary and comprehend single words

WEAKNESSES

Comprehension in complicated discussions and explanations
(especially out of context)

Language less complex, more superficial, more literal than peers

Comprehension scores less than expressive in some studies

Understanding directions

Social communication deficits

Visual Motor Skills

STRENGTHS

Use of color

Sculptural abilities

Ability to make direct copies,
especially of simple shapes

WEAKNESSES

Visual spatial organization

Making creative, complex drawings

Handwriting



Executive Functions

The brain's CEO and executive secretary

Executive function (EF) underlies many realms of adaptive behavior

Independent of intelligence

EF develops later, and continues to mature into early adulthood ...

This is good and bad

MEMORY	EXECUTIVE FUNCTION	PERCENTILE RANK
		100
		95
		90
		85
		80
		75
		70
		65
		60
		55
		50
		45
		40
		35
		30
		25
X		20
		15
	X	10
		5
MEMORY	EXECUTIVE FUNCTION	PERCENTILE RANK

FASD Executive Functioning Deficits

SELF-REGULATION

The ability to stay in control of emotions (“hot EF”); awareness of how others perceive you; use of self-talk strategies to monitor self and behavior

SEQUENCING OF BEHAVIOR

Knowing when and how to start an activity, keeping track of what to do next, initiating tasks

FLEXIBILITY

The ability to shift tasks smoothly, accept change, deal with transitions appropriately, absence of rigidity

Executive Functioning Deficits (continued)

RESPONSE INHIBITION

Lack of impulsivity, ability to inhibit first “knee-jerk” response to difficult situations and think before acting

PLANNING

The ability to use mental and action steps to complete tasks, to anticipate what is needed to complete tasks, related to sequencing of behavior

ORGANIZATION

The ability to keep one’s self and materials organized, in order, predictable, etc.

Attention and Behavior

Behavior regulation/mood swings

Easily overwhelmed by stimulation

Obsessive and perseverative features

Problems with visual and auditory attention

Variations on ADHD – many will receive the diagnosis, but response to meds is variable

Risk of ADHD goes up with increasing alcohol exposure (50% if Rank 4, 30% Rank 3, 15% rank 2 in several FAS clinics ... Bhatara et al.)

Academic Skills

STRENGTHS

Decoding words and oral reading

Spelling skills

WEAKNESSES

Reading comprehension

Story, essay and report writing

Arithmetic skills

Math reasoning

Organization and study skills

Academic achievement lower than IQ would predict

ATTENDING SCHOOL		Report of <u>HAZEL</u>	
Promoted by promotion		Grade.....	
8th Month	9th Month	REPORTS	
		Reading	1
		Arithmetic	C+
		Writing	C
		Language	B
		Phonics	C+
		Spelling	C+
		Geography	B
		History	C+
		Hygiene	D+
		Agriculture	B-
		Civics	B
		Art	B
		Department	B
		1/2 Days Absent	0
		Times Tardy	0
		Teacher <u>Mills</u>	

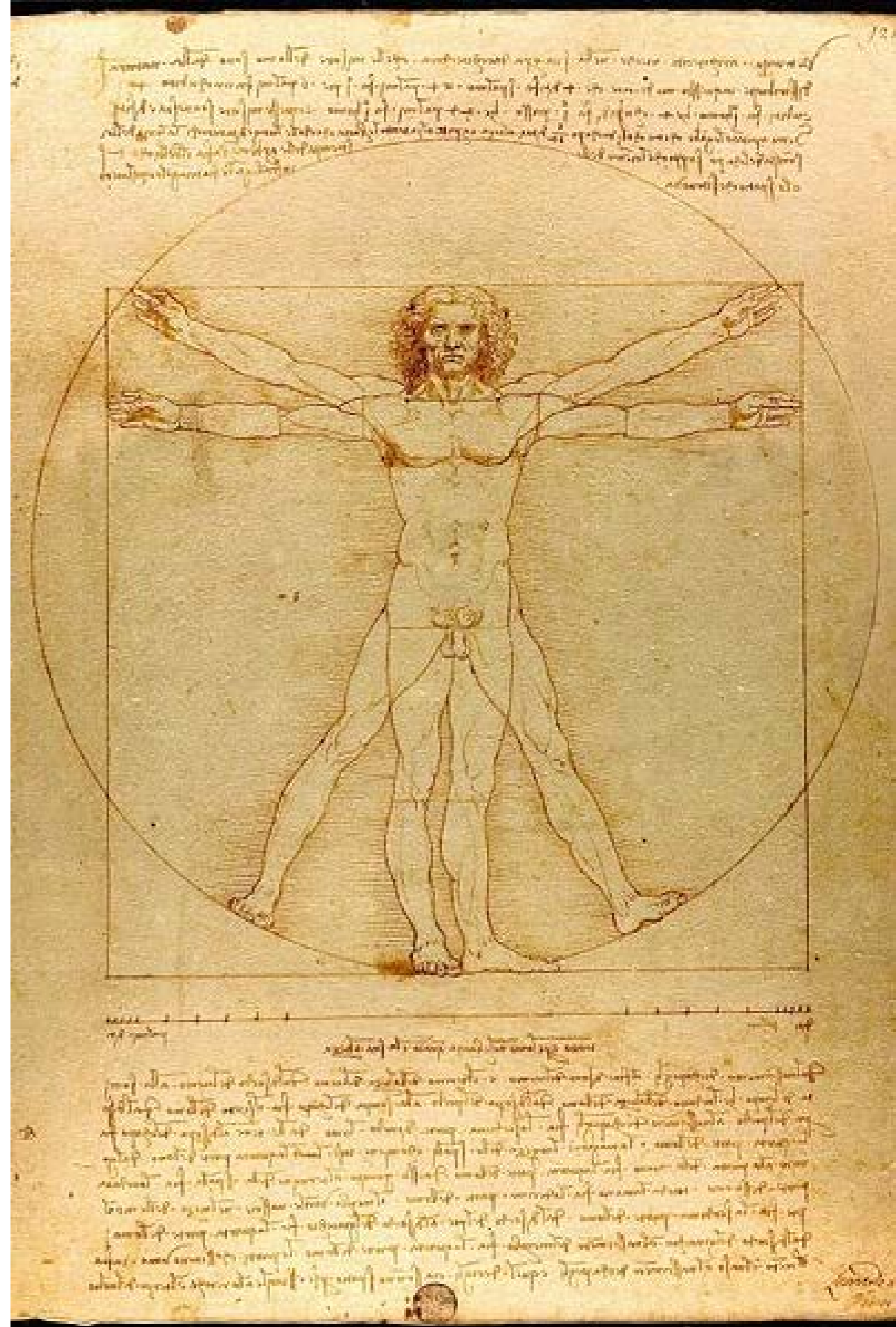
Sensory and Motor

Poor balance and coordination

Other “soft neurologic signs”

Visual-spatial motor skill
difficulties

Sensory over-sensitivities and
sensation-seeking



Athletic Skills

STRENGTHS

Individual sports requiring strength and endurance

WEAKNESSES

Team sports with demands to listen, follow directions, understand rules, and sequences and memorize procedures



Social and Behavioral Skills

STRENGTHS

Likable, friendly, engaging and often kind

Not necessarily “syndromic” in appearance

WEAKNESSES

Poor impulse control

Emotionally labile

Lack of understanding of personal boundaries

Naïve, gullible - often become a “victim”

Social/Adaptive Functioning

Social and adaptive skills often delayed, and may be half their chronologic age

This gap **WIDENS** in middle childhood, before it narrows

Perform better in small, highly structured environments, with range of ages

Big public high schools – OY

SAFETY! Easily victimized ...

Sleep and FASDs

30-50% of our patients have problems with sleep

Rate of sleep disorders goes up with alcohol exposure

Alcohol affects circadian rhythms, the body clock

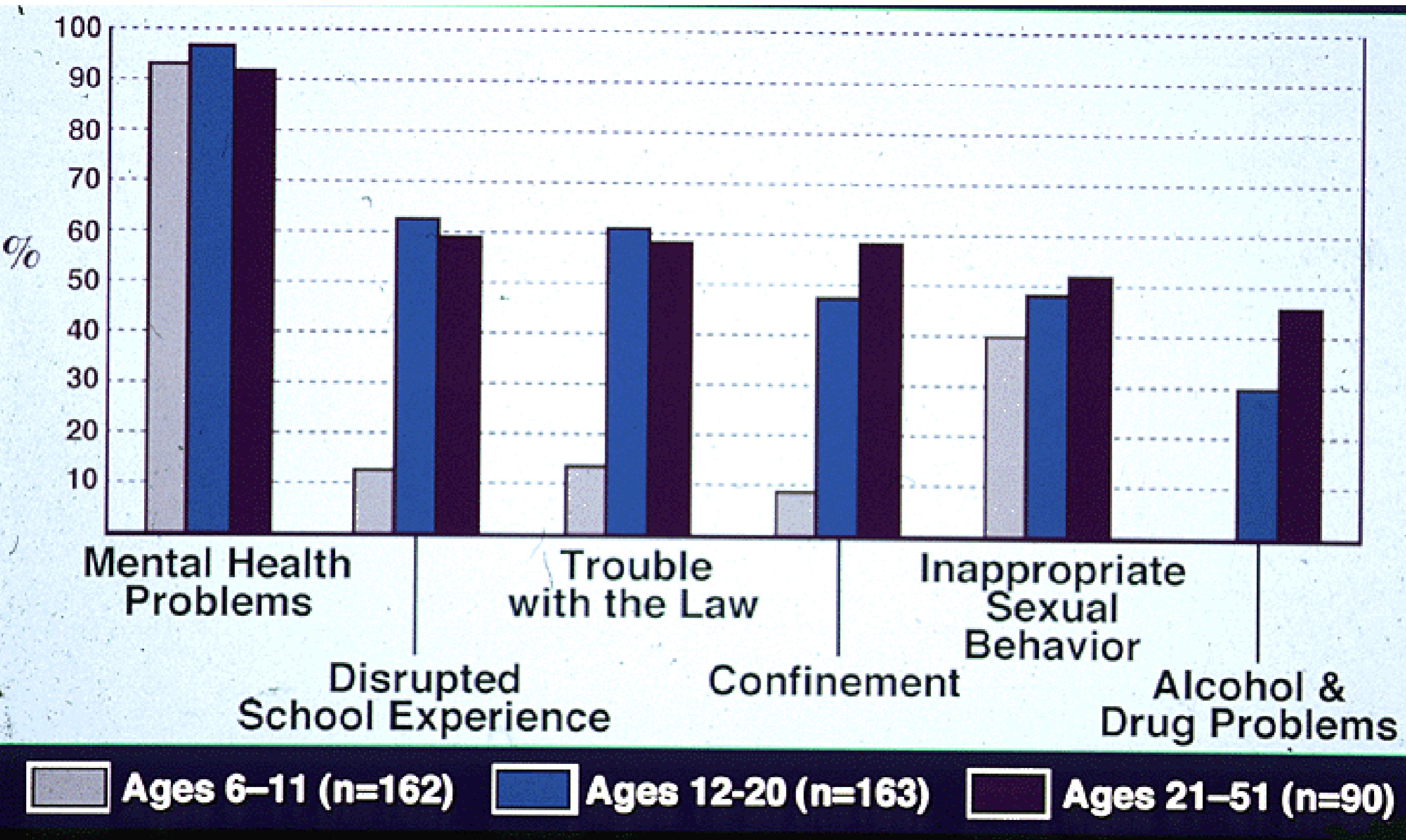
Facial anomalies and low tone make them high risk for obstructive sleep apnea

The midline cerebellum controls response to cardiorespiratory stressors

We see disturbed sleep architecture, less REM sleep

Poor sleep can mimic or worsen ADHD and other daytime cognitive and behavioral issues

Have a low threshold for sleep clinic referral



Secondary Disabilities from Streissguth et al, 1996

FASD Interventions



Protective Factors Against Development of Secondary Disabilities

Early diagnosis and intervention

A caregiving environment (in middle childhood) that is:

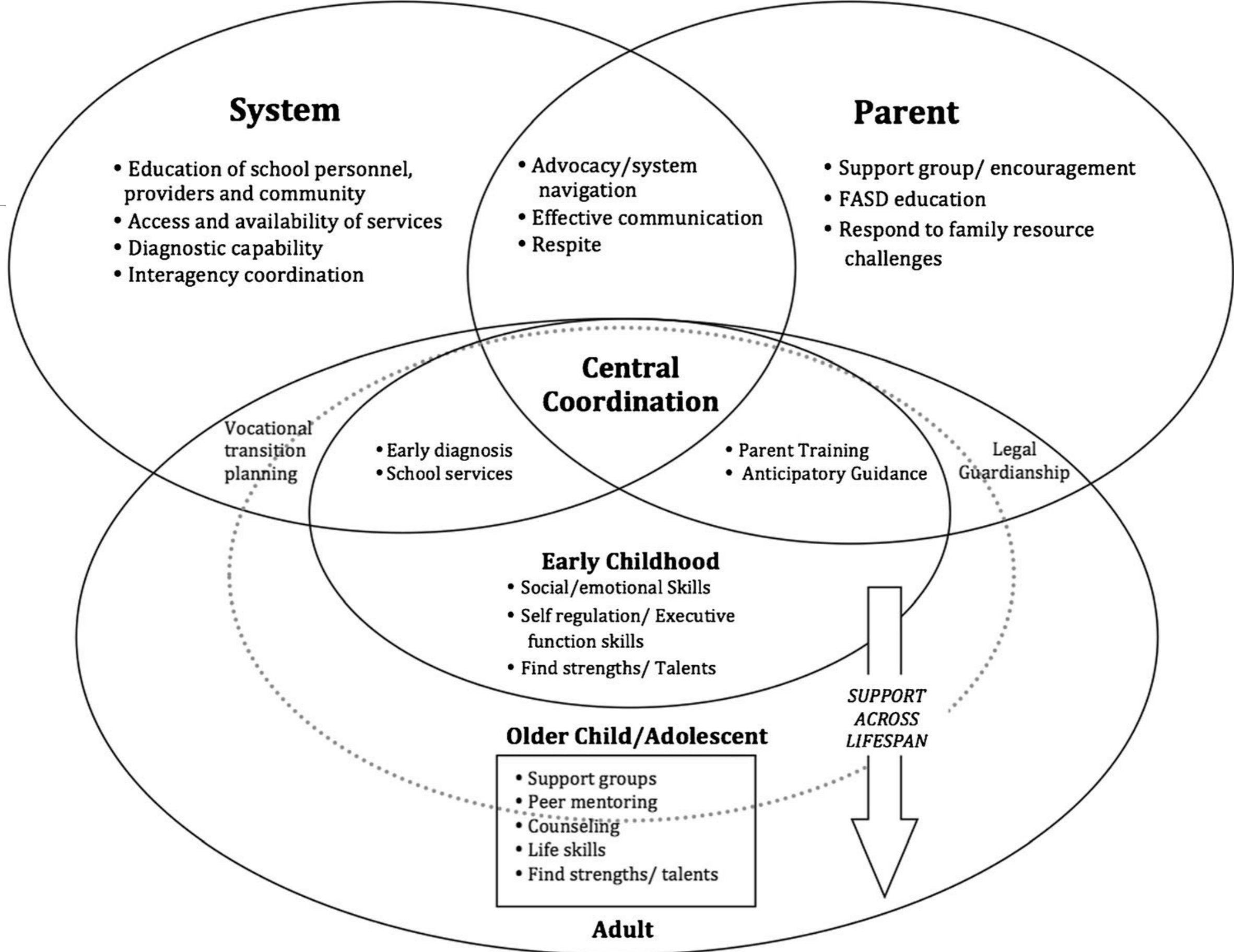
- Nurturing, stable
- Appropriately structured & stimulating
- Geared to the child's developmental needs
- Free from caregiver substance abuse
- Safe from violence

Appropriate social services

FASD Challenges

Uneven
Complex
Life-Long
Stressful





Example FASD Intervention Research Projects

Self-Regulation & Sensory Strategies

- The Alert Program and PACT (Children's Research Triangle)

Learning How to Learn - "Cognitive Habilitation"

- Math Interactive Learning Program (Marcus Institute)

Social Skills Interventions

- Children's Friendship Training / "Good Buddies" (UCLA)

Parent & Behavioral Support

- Families Moving Forward (UW research)

PCIT vs Parent Support and Management

- University of Oklahoma

Key Concepts

Leverage

Turning Points

Invisible Disabilities

Reframing

Scaffolding



Supports for FASDs

Structure

Supervision

Simplicity

Steps in sequence

Situational



Supports for FASDs, Part I

Map the child's strengths and weaknesses. Start early, and repeat as they grow, as new gaps may emerge.

Be their "external brain" in areas of challenge, for as long as they need it.

Model and support self-regulation, self-calming.

Use sensory strategies to help kids maintain focus and an even keel.

Provide "scaffolding" for lagging skills.

Learning may require a lot more repetition, and since learning may not generalize to a new environment or situation, relearning may be necessary.

Supports for FASDs, Part II

Reframe challenging behaviors as “can’t” (yet) vs “won’t”.

Change the environment, when you can’t change the child. Provide accommodations at home and school that reduce stress, sensory overload, help children regulate their behavior, and support their learning styles.

Use positive behavior support strategies, finding ways to prevent problem behaviors, and ways to respond that don't reinforce them.

Make “invisible disabilities” visible to teachers and other caregivers.

Practice self-advocacy.

Parental support and self-care is not optional.



Learning
Relearning
Learning to learn





Use positive behavior support strategies ...

Consultation for Treatment

FASD team or neurodevelopmental clinic for “developmental home”?

PT, OT, and SLPs are frequently involved in assessment and treatment

School-based or private psychologists and behavioral specialists/therapists can be invaluable

Psychiatrists for med management

Social skills groups, Special Olympics, etc.

Online and local support groups for caregivers

Infants and Toddlers

Child–Parent Psychotherapy (CPP)

Mindful Parenting Education (MPE)

Breaking the Cycle (BTC)

Strategies for Enhancing Early Development
Success -Infants and Toddlers (SEEDS-IT)

Parent-Child Assistance Program (PCAP)



Zarnegar 2016
Petrenko 2015

Tools of the Mind

A promising preschool



School-Age Interventions

Parenting Skills and Support

Attention and Self-Regulation

Social Skills

Other Specific Skills

Math, literacy, learning, safety

Adolescent Substance Use

Reid 2016
Petrenko 2016



Ideal School?



Key Points for Educators and Professionals

FASDs are too often an “invisible disability”

Refer alcohol-exposed kids for early evaluation

Thorough testing is so important

Expect deficits in complexity, integration - with VARIABILITY

Individualized, longterm interventions

- Reframe behaviors, adjust expectations and child’s environment
- Behavioral consultation, self-regulation, social, learning to learn
- Targeted medication evaluations
- Anticipate adolescent and adult transitions

Caregiver education, support groups, linkage, school advocacy, respite

General FASD Resources

UW Publications, Diagnostic Tools, Guides and Training Programs:

- www.fasdpn.org (including an online course in 4-Digit Code)
- www.adoptmed.org/fas

Other Online Resources

- www.cdc.gov/fasd/
- <https://www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center>
- www.ihs.gov/womenshealth/maternalchildhealth/fasd/
- www.nofas.org/ (with national resource directory)

FAS – A Guide for Living: Parenting Children with FASD

FASD Resources for Educators

Teaching Students with FASD – Alberta Schools:

<https://education.alberta.ca/media/385139/teaching-students-with-fasd-2004.pdf>

SAMSHA Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders (FASD):

<http://store.samhsa.gov/product/Reach-to-Teach-Educating-Elementary-and-Middle-School-Children-with-Fetal-Alcohol-Spectrum-Disorders-FASD-/SMA07-4222>

USD FASD Educational Strategies Handbook:

www.usd.edu/medicine/center-for-disabilities/fetal-alcohol-spectrum-disorders/guides-and-handbooks

Native American FASD Resources

Online Resources

- <https://www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center>
- www.ihs.gov/headstart/documents/FetalAlcoholSpectrumDisordersAmongNativeAmericans.pdf
- www.comingoftheblessing.com prevention booklet)

Journey Through the Healing Circle Series

- www.dshs.wa.gov/ca/fosterparents/journey.asp

Gifts from the Sacred Circle (parenting curriculum)

Thank You!

Susan Astley, PhD

Julia Bledsoe, MD

Julie Gelo

Heather Olson, PhD

Allison Brooks, PhD

The FAS Clinic Team

Our Clinic and Study Families

Maria's Children (artwork)

