

Beyond the Diagnosis: Effective Interventions for Children and Adolescents with Fetal Alcohol Spectrum Disorders



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Disclosure: Julian Davies, MD

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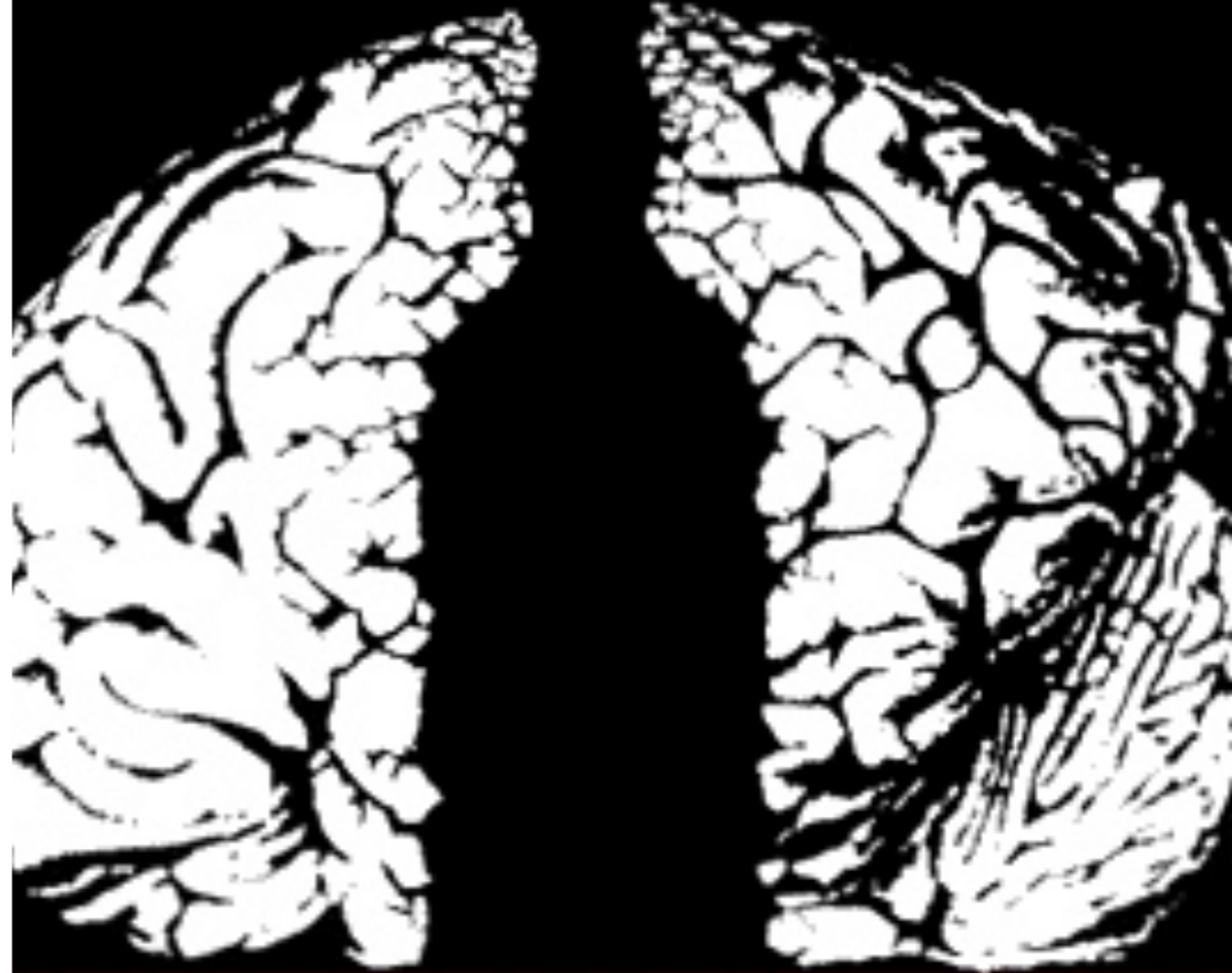


Why this talk? Why me?



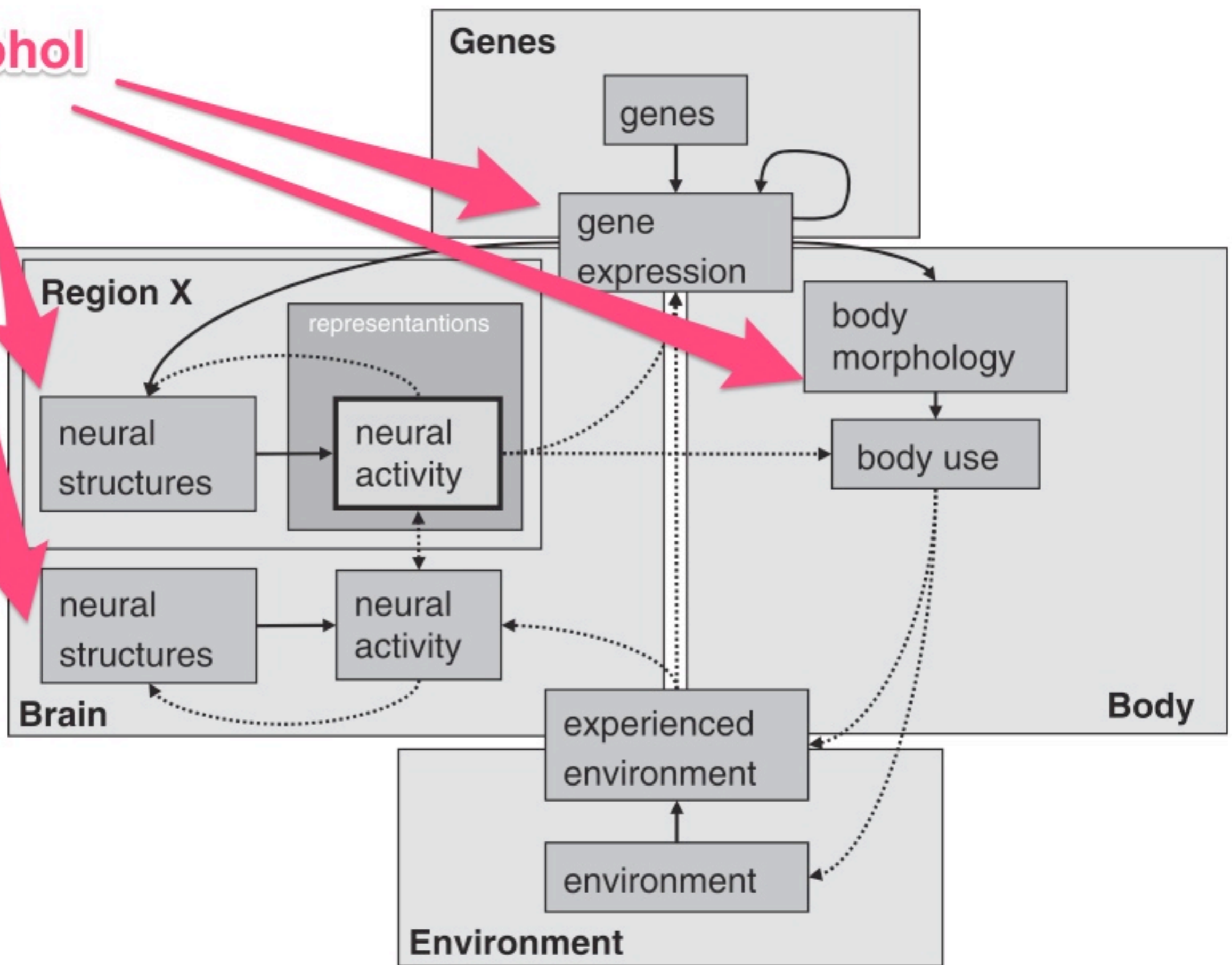
Making this work for you and yours

How does prenatal alcohol exposure damage the brain?



АЛКОГОЛЬ - ВРАГ РАЗУМА

Alcohol



How can alcohol impact the child/adolescent brain?

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?)

Impacted Brain Domains in FASD

Cognition

Memory

Language

Visual-motor

Executive function

ADHD

Academics



Sensory

Motor

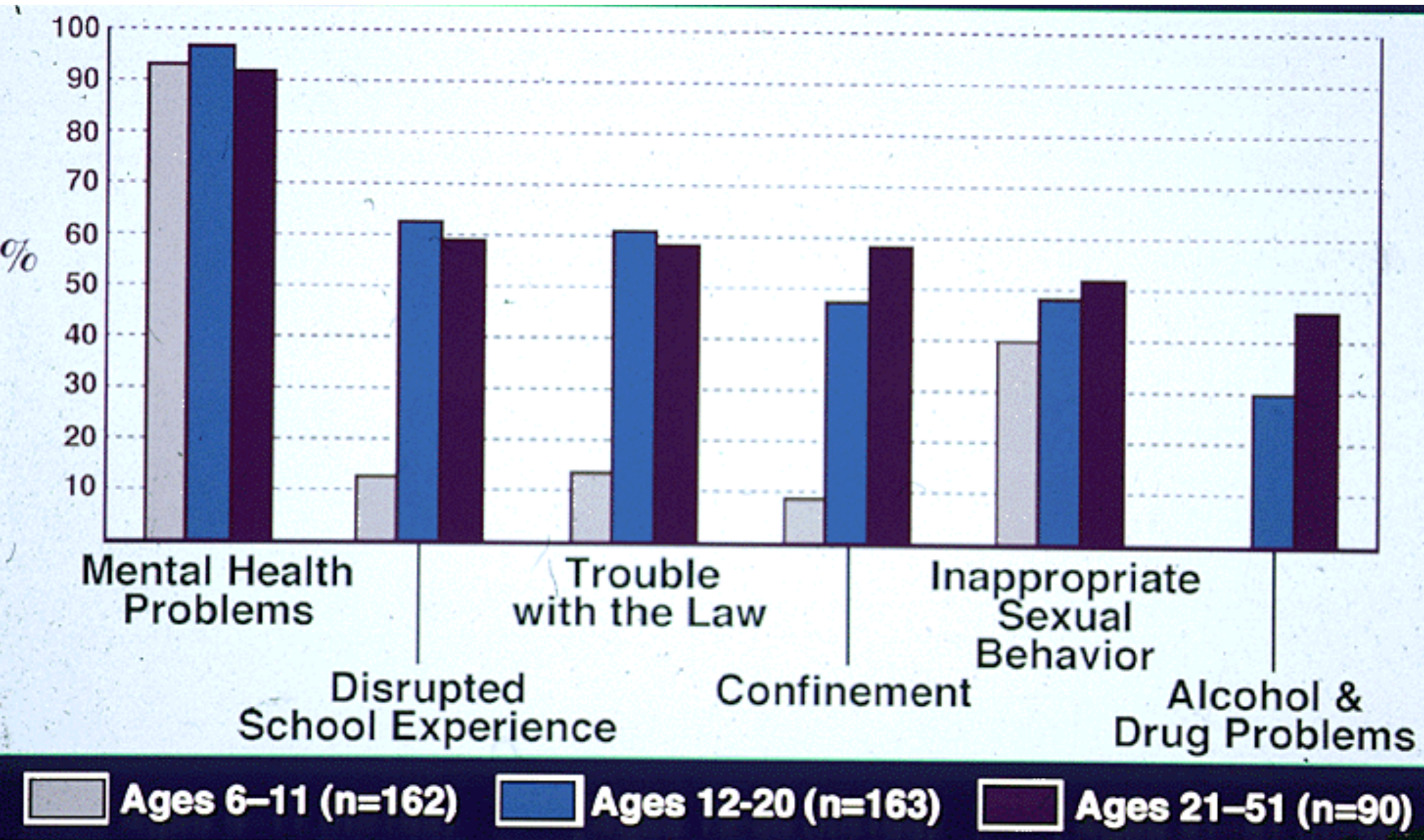
Behavior

Social Skills

Adaptive

Sleep





Secondary Disabilities from Streissguth et al, 1996

FASD Interventions



FASD Challenges

Uneven
Complex
Life-Long
Stressful



Key Concepts

Leverage

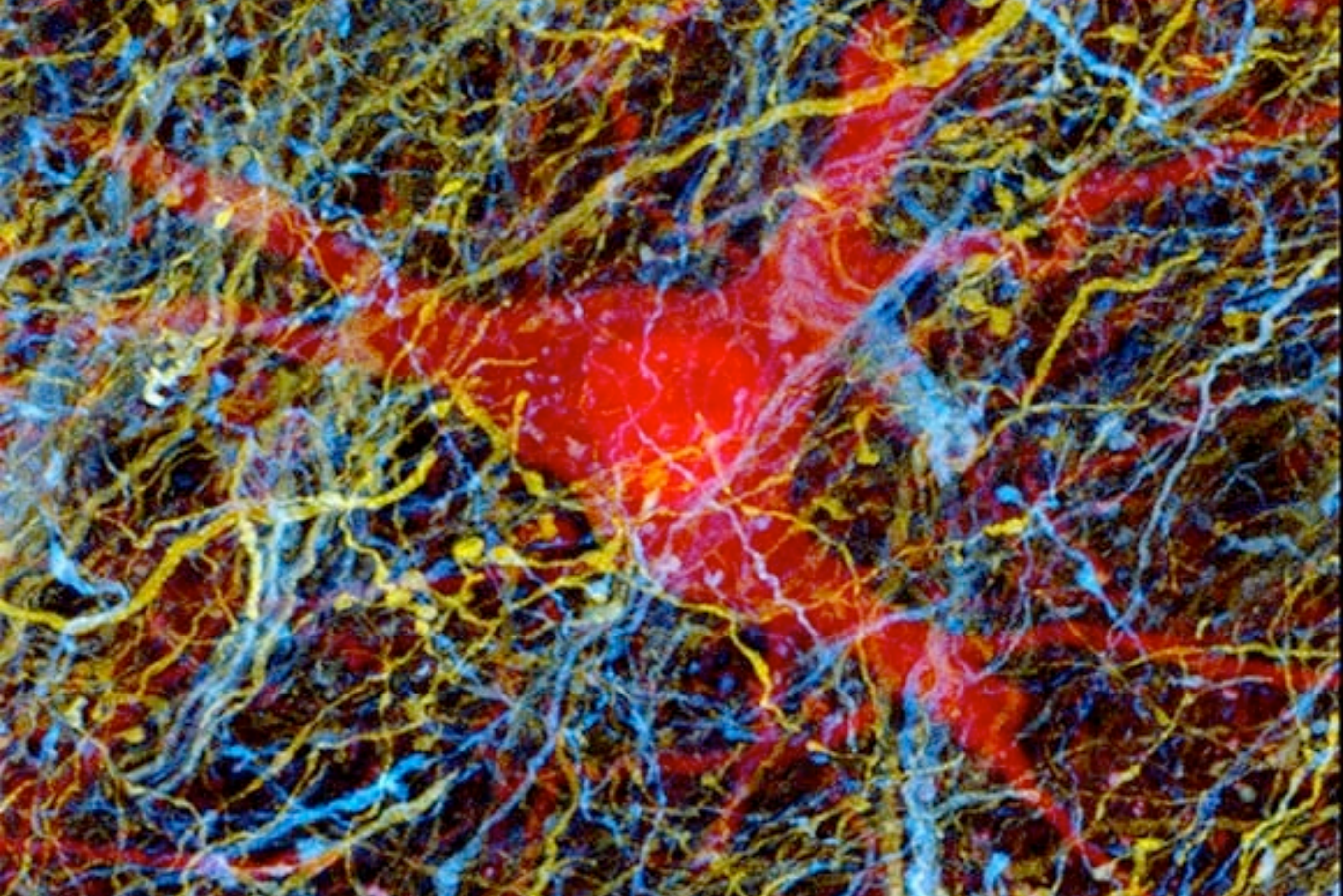
Turning Points

Invisible Disabilities

Reframing

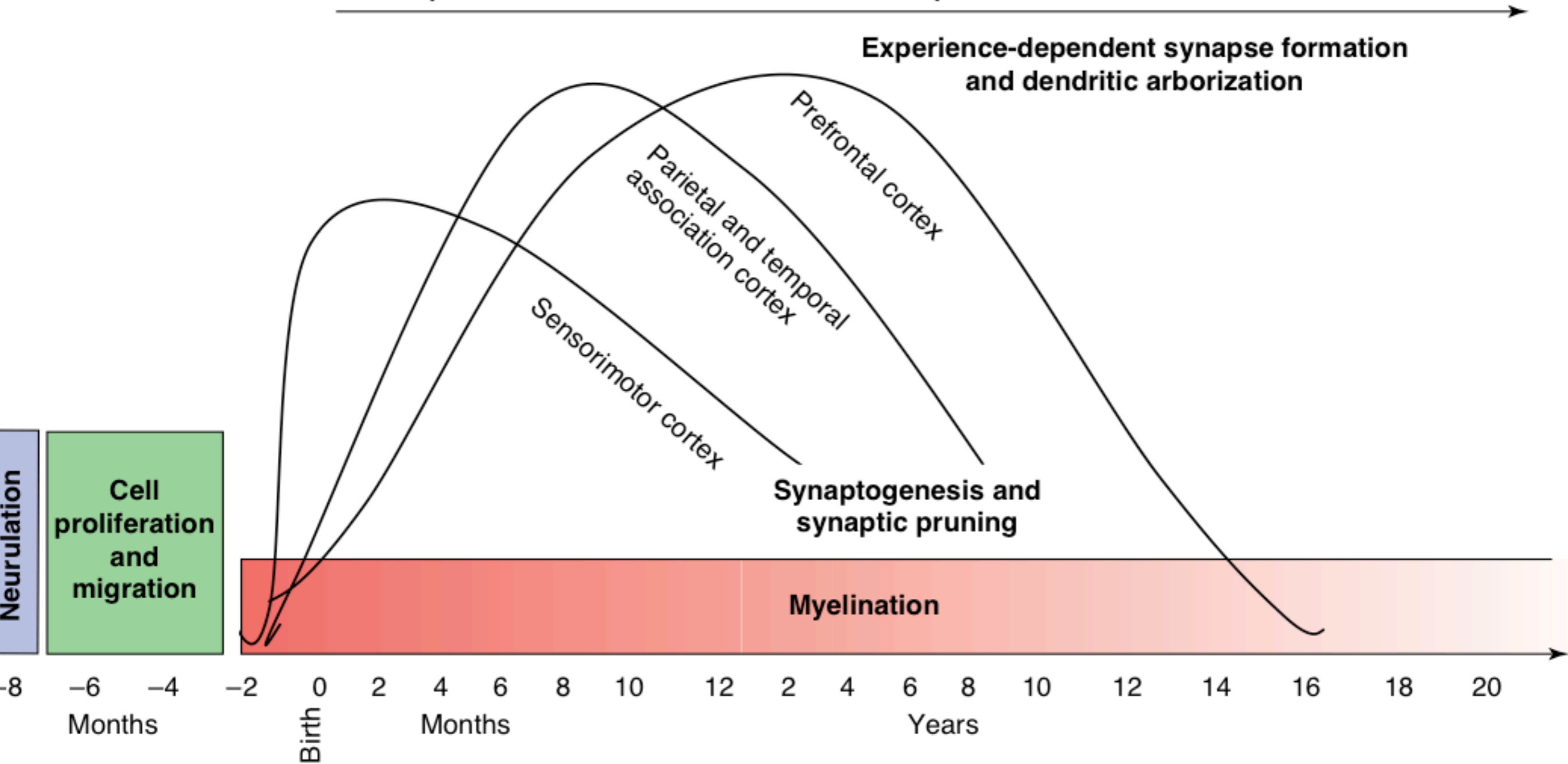
Scaffolding





Mixing Metaphors

Developmental course of human brain development



Brain Development Timeline

Casey, 2005



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

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

[Adapted from Streissguth et al., 1996]

Recent FASD Intervention Research Projects

Self-Regulation & Sensory Strategies

- The Alert Program (Children's Research Triangle)

Learning How to Learn - "Cognitive Habilitation"

- Math Interactive Learning Program (Marcus Institute)

Social Skills Interventions

- Children's Friendship Training (UCLA)

Behavioral Support

- Families Moving Forward (UW research)

PCIT vs Parent Support and Management

- University of Oklahoma

Pillars of Parenting Kids with FASD

Structure
Supervision
Simplicity
Steps in sequence
Situational



Pillars of Parenting, Part I

Map your 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.

Pillars of Parenting, 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.

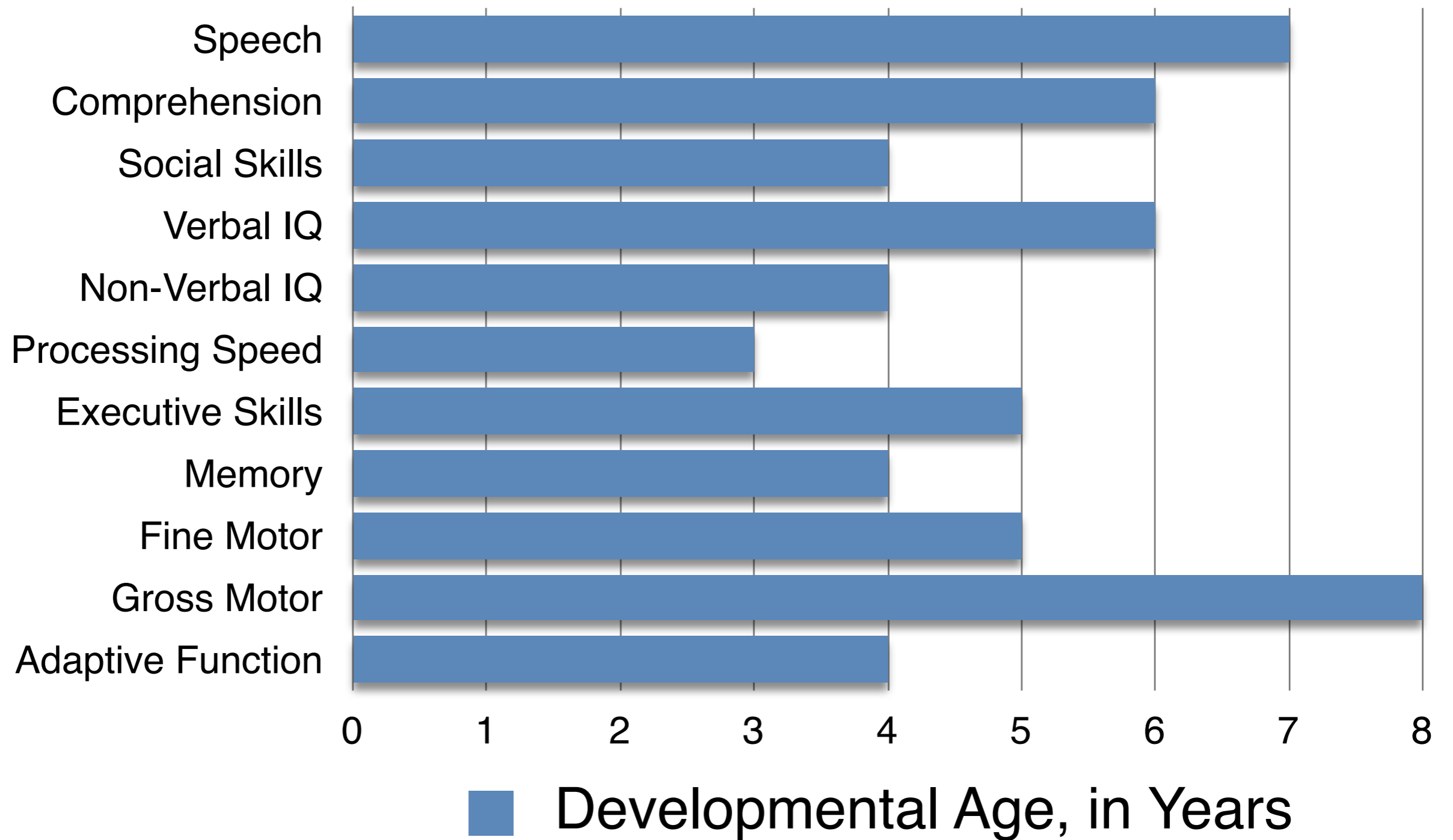
Use positive behavior support strategies, finding ways to prevent problem behaviors, and ways to respond that don't reinforce them.

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

Practice self-advocacy with your child.

Parental support and self-care is not optional.





Map, and re-map, their developmental profile

Brain Bucket



Be their “external brain” ...

Model and support
self-regulation.

Daily practice,
grasshopper.



Use sensory strategies





Use scaffolding for lagging skills

Learning
Relearning
Learning to learn





Reframe challenging behaviors

Behavior

DIDN'T FOLLOW DIRECTIONS

My client is willfully disobedient

Interpretation

Directions were too complex, abstract, for my client's ability

Punish, scold, give warnings

Response/
Accommodation

Reduce complexity of directions, provide visual support, teach how to ask for help/clarification

Confused, frustrated, angry, unfairly treated

Individual Feels

Understood, less confused, calmer, respected, willing to try

Risk of secondary disabilities, avoiding, blaming, ignoring

Possible Outcome

Increased effort, success, more positive self-image



Behavior

WON'T STOP WATCHING TV TO START CHORES

My client is willfully disobedient, only does what he wants

Interpretation

My client has difficulty with transitions, poor impulse control

Punish, scold, give warnings

Response/
Accommodation

Give him a "heads up" or warning that a change is coming to give him time to adjust

Confused, frustrated, angry, unfairly treated, defensive

Individual Feels

Unsurprised, calmer, more willing, more in control

Risk of secondary disabilities, avoiding, yelling, ignoring

Possible Outcome

Increased effort, greater compliance, more adaptable

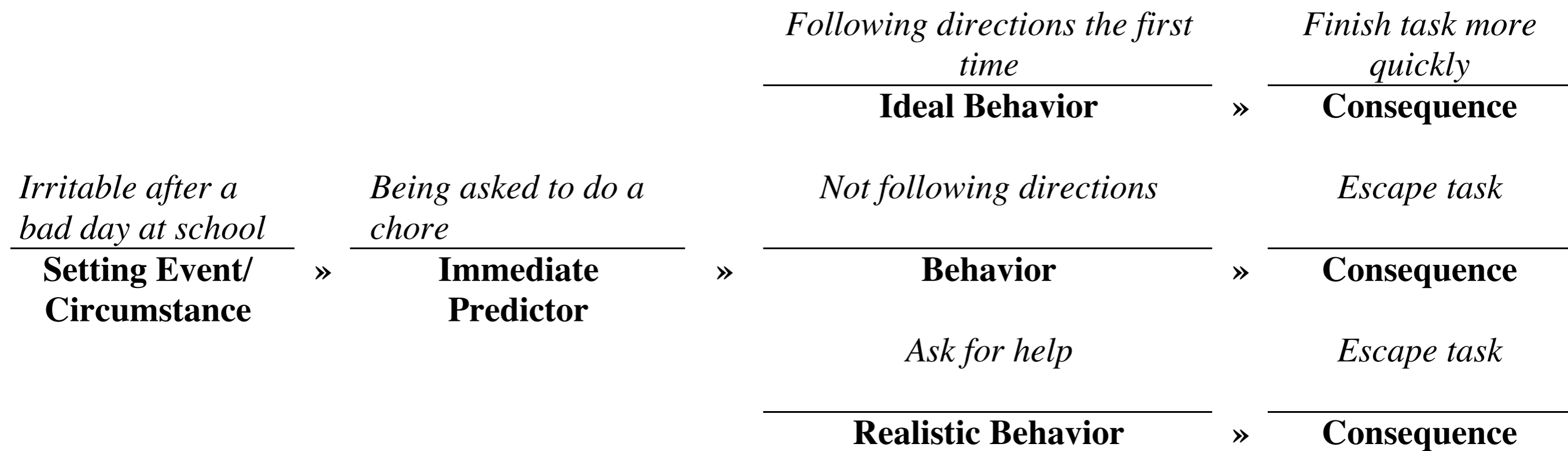


Change the
environment and
expectations





Use positive behavior support strategies ...



Antecedents, Behaviors, Consequences (FBA, BIP)



The ABCDs? The D is for Dance ...



Make “invisible disabilities” visible

Practice self-advocacy





Parent support and self-care is not optional

Sleep

Impact on child & family

Entrenched habits

Consistency and routine

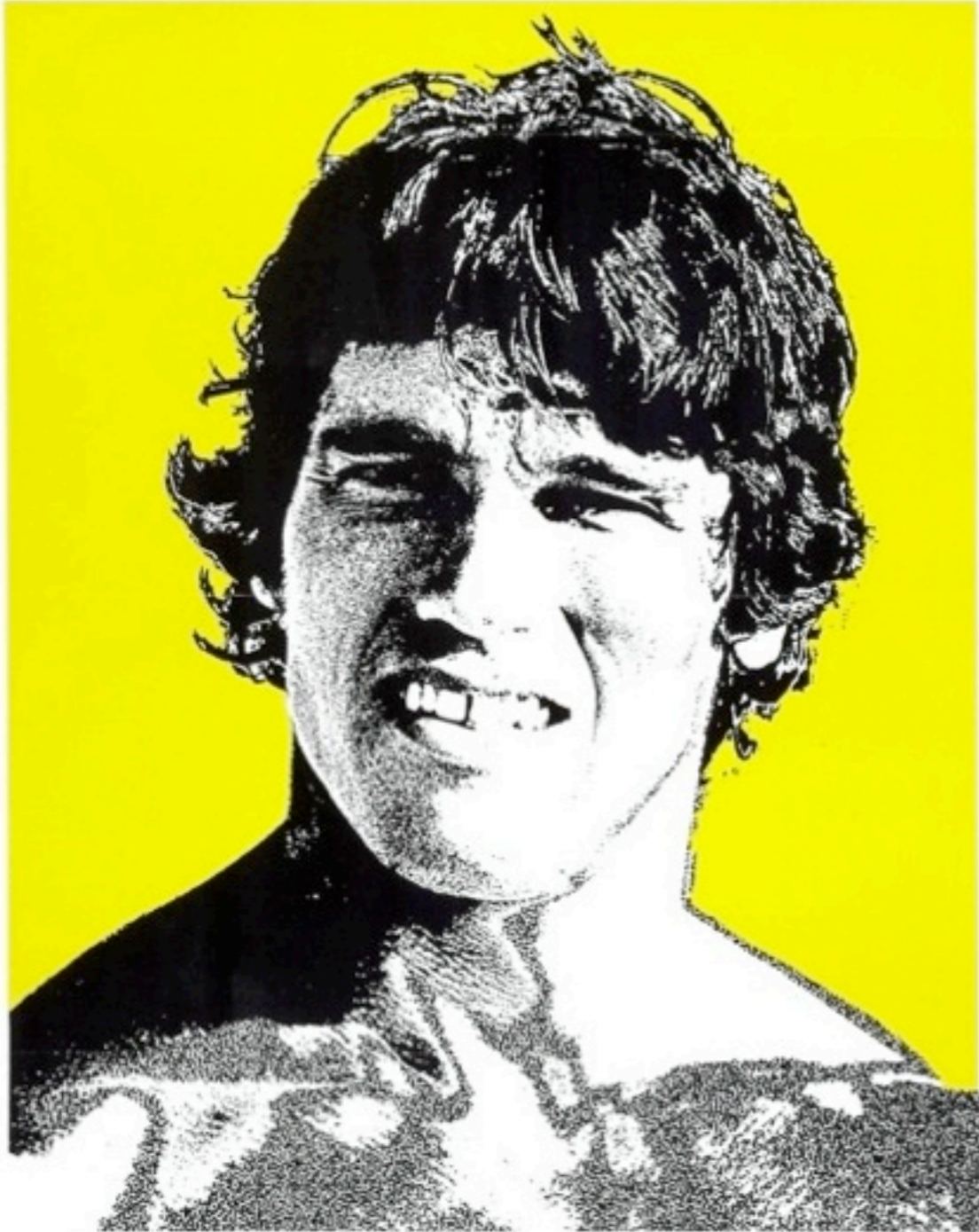
Sleep associations

Safety

Diagnoses

Sleep specialists





Arnold Schwarzenegger in
Pumping Iron PG

Nutrition and Feeding



Other Problem Areas

Social Skills & Bullying
Safety
Sexuality
Substances





FASD Parenting Ages & Stages

Ideal School?



Tools of the Mind

A promising preschool



Advocating for School Needs

Birth-to-3, then Child Find

504 Plan vs IEP

Develop an ally/advocate

IEP Meetings

- Check your own pulse
- Stack the deck in your favor
- Build a succession of YES's
- Make the bureaucracy work for you

If things still aren't going well ...

NICHCY.org



POOH CORNER Rx



Patient: Winnie the Pooh
Symptoms: Binge Eating
Prescription: Sibutrex ®



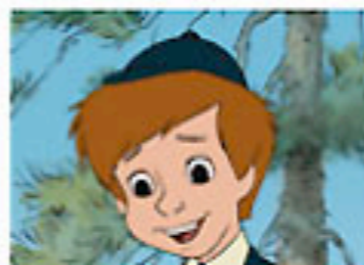
Patient: Piglet
Symptoms: Anxiety
Prescription: Cymbalta ®



Patient: Eeyore
Symptoms: Depression
Prescription: Zoloft ®



Patient: Tigger
Symptoms: ADHD
Prescription: Ritalin ®



Patient: Christopher Robin
Symptoms: Hallucinations
Prescription: Clozaril ®



Medications?

Stimulants

Alpha-agonists

SSRIs

Mood stabilizers

Atypical anti-psychotics

BIG Cautions

Treatments of the future?

Nootropics

Choline

Thyroid

L1 adhesion targets

Neurofeedback

Executive skills training

Newer medications

**Most of these are far from
proven**



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

Key Points for Caregivers 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

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

FASD Resources

UW Publications, Diagnostic Tools, Guides and Training:

fasdnpn.org

(including an online course in 4-Digit Code)

adoptmed.org/fas

Other Online Resources

cdc.gov/fasd/

fasdcenter.samhsa.gov

nofas.org/ (with national resource directory)

More Resources

Sleep

chroniccare4sleep.org

adoptmed.org/topics/sleep-and-adoption.html

Feeding

www.feedingdoctor.com

adoptionnutrition.org

School

education.alberta.ca/admin/supportingstudent/diverselearning/fasd.aspx

nichcy.org

Native American FASD Resources

Online Resources

fasdcenter.samhsa.gov/nativeinitiative/resources.aspx

[ihs.gov/headstart/documents/
FetalAlcoholSpectrumDisordersAmongNativeAmericans.p
df](https://ihs.gov/headstart/documents/FetalAlcoholSpectrumDisordersAmongNativeAmericans.pdf)

comingoftheblessing.com (prevention booklet)

Journey Through the Healing Circle Video Series

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

Gifts from the Sacred Circle (parenting curriculum)

Thank You!

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Allison Brooks, PhD

The FAS Clinic Team

Our Clinic and Study
Families

Maria's Children (artwork)

