Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure

Improved outcomes through Screening & Diagnosis of ND-PAE in Patients with FASD

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Formed Families Forward Webinar
January 28, 2019
6:30-8 pm
Outline/Topics

What is ND–PAE?
- Why is early diagnosis important?

Science: Teratology & Physiological Wiring
- Consider why they “can’t” vs. “won’t”

4–Domain Treatment Planning Model
- Preventing “Mental Illness”

Positive Parenting for ND Cocooning
- Improving Neuroplasticity & Adaptive Functions
OBJECTIVE:
…to assess the rate of misdiagnosis & missed Dx of FASD in foster and adopted youth from a children's mental health center.

METHODS:
…547 children - comprehensive multidisciplinary diagnostic evaluation (FAS, pFAS, ARND, ARBD).
…Changes in rates of FASD-related diagnoses & co-occurring mental health disorders (pre- and post-assessment).

RESULTS:
156 (28.5%) met criteria for FASD…
…missed Dx rate: 125 (80.1%) had never been diagnosed.
…misdiagnosis rate: of 31 who had been recognized before, 10 (6.4%) needed diagnoses changed.
…accurate diagnosis: 21 (13.5%) diagnoses stayed the same.
…additional co-occurring diagnoses: significant changes in the rate of MH Dx, LDs, communication disorders, and IDD = neurocognitive damage → not recognized in a significant number of children with FASD.

CONCLUSIONS:
…86.5% of youth with FASD never previously diagnosed or misdiagnosed.
…significant implications for intervention and therapeutic services.
The “FASD Iceberg”

ARBD
fewer
very early exposures → physical birth defects

FAS
10–15%
early, binge exposures → dysmorphic

ARND
85–90%
non-dysmorphic = functional BDs

Adapted from Dr. Anne Streissguth, University of Washington at Seattle.
Early “FAS” Diagnosis

...by age 5 predicts better outcome for the child who...

➢ Understands his/her “special needs” → becomes a self-advocate or has advocates → strengths-based approach
  ▪ focus on strengths/interests/abilities = improved self-image
  ▪ realistic expectations of parents/caregivers/school

➢ NDD child w/ “Grieving Parent” vs. “Guilty Parent”
  ▪ knowing early prevents future self-blame
  ▪ Positive versus punitive parenting style

➢ Becomes integrated into an accepting community & cocooned from a harsh world view
  ▪ more work is needed in “community tolerance” and integration of all differences

➢ More likely to get academic/school system supports
  ▪ neurodevelopmental disorder vs. “emotional disorder” or “behavior problem”
“ND–PAE” in DSM–5

“Childhood Mental Disorders” → “Neuro–Develop–Mental” Disorders
(The neurological basis of developing mental disorders?)
Neurobehavioral Disorder associated with Prenatal Alcohol Exposure

In “Conditions for Further Study.”

Neurodevelopmental Disorders = “Functional BD’s”

- Autistic Disorders
- Intellectual Disability
- Learning Disabilities
- Developmental Delays
- Speech/Language Issues
- Sensory/motor problems
- Attention deficits, hyperactivity
- Behavior & mood
- Anxiety & Perceptual Differences
- Schizophrenia
- “Addictive” disorders
ND–PAE (DSM–5 Diagnostic Criteria)

A. More than minimal exposure to alcohol during gestation…

B. Impaired neurocognitive functioning…: (at least one)
   1. …global intellectual performance (i.e., IQ of 70 or below,…)
   2. …executive functioning (poor planning and organization, inflexibility, difficulty with behavioral inhibition)
   3. …specific learning disability
   4. Memory impairment…
   5. …visual-spatial reasoning…

C. Impaired self-regulation…: (at least one)
   1. …mood or behavioral regulation…
   2. …attention deficit…
   3. …impulse control…


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ND–PAE (DSM–5 Diagnostic Criteria)

D. Impairment in **adaptive functioning** …: *(two or more)*
   1. **Communication** deficit…
   2. …**social** communication and interaction…
   3. …**daily living skills**…
   4. …**motor** skills…

E. **Onset** of the disorder (symptoms in Criteria B, C, and D) occurs in **childhood**.

F. The disturbance causes clinically significant **distress or impairment** in **social**, **academic**, **occupational**, or other important areas of functioning.

G. The disorder is **not better explained by** the **postnatal use** of a substance…, a general medical condition…, other known teratogen, a genetic condition, or environmental neglect.

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND–PAE)

History of more than minimal levels of PAE

ND-PAE

1. Neurocognitive
   - IQ < 70 (IDD)
   - Executive Dysfunction
   - Learning Disabilities
   - Memory deficits
   - Faulty visual spatial reasoning

2. Self-Regulation
   - Mood or behavioral Dysregulation
   - Attention deficits
   - Communication deficit*
   - Social impairment*

3. Adaptive Functions
   - Deficient ADLs
   - Motor/Coordination
   - Sensory Disintegration

Sarah Mattson, PhD. 2014; AACAP, San Diego.

Intellectual Disability Disorder (IDD) Adaptive Functions & IQ Score = IDD

Adaptive Function Deficits + IQ Score ≤ 75 = IDD

IDD

AFDs

Conceptual

• Learning Disabilities
• Applied Academics (money, time mgt., etc.)

Social

• Pragmatics
• Speech/language
• Reciprocity
• Communication
• Nuances
• Gullibility

Practical

• Activities of Daily Living (hygiene, self-care, chores)
• Household Mgt.
• Child Care Responsibilities
• Transportation
• Vocational Skills

Types of Birth Defects

**Physical BDs**
- “Birth Defects” id’ed @ birth
- Heart, lungs, liver, kidneys, other organ damage
- Legs, arms, hands, feet, fingers, toes
- Visible damage to eyes, ears, nose
- Cleft lip and palate

**Functional BDs**
- “Neurodevelopmental”
- Damage to the brain and nervous system
- Results in cognitive & behavior problems
- Often not diagnosed until the child is older
<table>
<thead>
<tr>
<th>Disability</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Delay</td>
<td>1,086</td>
<td>1.05%</td>
</tr>
<tr>
<td>Multiple Health Impaired</td>
<td>4,335</td>
<td>4.18%</td>
</tr>
<tr>
<td>Intellectually Disabled</td>
<td>5,290</td>
<td>5.10%</td>
</tr>
<tr>
<td>Emotional Disability</td>
<td>6,635</td>
<td>6.39%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>8,102</td>
<td>7.81%</td>
</tr>
<tr>
<td>Autism</td>
<td>10,211</td>
<td>9.84%</td>
</tr>
<tr>
<td>Other Health Impaired</td>
<td>16,984</td>
<td>16.37%</td>
</tr>
<tr>
<td>Speech/Language</td>
<td>18,344</td>
<td>17.68%</td>
</tr>
</tbody>
</table>

Most Vulnerable Period of Embryo Development

Menses Begins

2 weeks post-LMP

FERTILIZATION

IMPLANTATION

GASTRULATION

NEURULATION

BEGIN NEURAL TUBE CLOSURE

END NT CLOSURE

2^{nd} Missed period (“Yikes!!!”)

FETAL PERIOD BEGINS

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The FAS Face:
Late 3rd Week to Early 4th Week of Human Development

Narrow forehead
Short palpebral fissures
Small nose
Small midface
Long upper lip with deficient (flat) philtrum

Courtesy of Kathleen K. Sulik, PhD
University of North Carolina Science; 1981
A Critical Point of Vulnerability
in embryos only 3-4 weeks old

22 day old human embryo
(about 3 mm. long, the length of the ear on the US dime)
Midline Brain Defects

(Mouse embryo at early 4th week
Human equivalent)

• Pregnant mouse dams exposed in one binge episode in the late 3rd week/early 4th week equivalent (4-5 servings of alcohol)

• Pups harvested 12 hours later

• Nile blue stain indicates areas of apoptosis (cell death) not seen in control pups

Courtesy of Kathleen K. Sulik, PhD
University of North Carolina Science; 1981

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EPIGENETICS

A mechanism for regulating gene activity independent of DNA sequence that determines which genes are turned on or off:

- in a particular cell type
- in different disease states
- in response to a physiological stimulus
Largest portion of the brain, including the cerebral hemispheres (cerebral cortex and basal ganglia); involved in controlling consciousness and voluntary processes.

Corpus Callosum
A bundle of fibers connecting the brain’s hemispheres.

Hippocampus
Part of the limbic system, which is involved in emotional aspects of survival behavior; also plays a role in memory.

Basal Ganglia
A group of structures lying deep in the brain involved in movement and cognition.

Cerebellum
Involved in maintenance of posture, balance, and coordination.

Cortext
Outer layer of gray matter covering the surface of the cerebrum and the cerebellum.

Neocortex
Outermost portion of the cerebral cortex that contains the most structurally complex brain tissue.

Diencephalon
- Septal area—related to the limbic system, which is involved in emotional aspects of survival behavior.
- Thalamus—a communication center that relays information to the cerebral cortex.
- Hypothalamus—important in maintaining the body’s internal environment, or homeostasis, through the receipt of sensory and chemical input.

Figure 1 Areas of the brain that can be damaged in utero by maternal alcohol consumption.
Brain Abnormalities on MRI
in adolescents with FASD/ND-PAE

Mattson, et al., 1994; Mattson & Riley, 1995; Riley et al., 1995
Neurotypical Human Brain Wiring Continues from Early Childhood into Adulthood

Prefrontal Cortex: “Executive Control Center”

- Attention
- Impulse control
- Working memory (reflection)
- Anticipation
- Prioritizing
- Strategizing
- Sequencing
- Organization
- Second thought
- Modulating mood
- Response flexibility
- Judgment
- Goal-directed behavior

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O’Malley K and Rich SD; Clinical Implications of a Link Between Fetal Alcohol Spectrum Disorders (FASD) and Autism or Asperger’s Disorder – A Neurodevelopmental Frame for Helping Understanding and Management; March 6, 2013; Chapter 20; “Recent Advances in Autism Spectrum Disorders – Volume I”, book edited by Michael Fitzgerald
4-DOMAIN EVALUATION OF ND-PAE

✓ NEUROCOGNITIVE
   “Intellect” = Cognitive (IQ) & Executive Functions (EF) = working memory, processing speed, organization, planning, “filing,” scheduling, inhibitory control, attention/focus, detail-oriented, consequential thinking, gullibility

✓ SOCIAL COMMUNICATION & PERCEPTION (SQ)
   “Social intellect” = expressive/receptive language, social skills, empathy, reciprocity, dyadic relations, semantics, nuances, V/NV cues, pragmatics; cognitive flexibility

✓ EMOTIONAL (EQ)/MOOD REGULATION & AUTONOMIC AROUSAL
   “Emotional intellect” = “fight, flight, freeze, avoid;” sympathetic vs. parasympathetic (involuntary control), reactivity; rage = “limbic seizure” (AKA: fainting goats…myoclonic seizure)

✓ SENSORY & MOTOR
   Sensorium: multi-sensory, “sensory integration disorder,” hyper/hyposensitivities, temperature, texture, pressure preferences

   Kinaesthetic Abilities: fine/gross motor, coordination, balance, clumsy, oral–motor issues, affinity for hard physical contact.

   7 Senses: Sight, Hearing, Smelling, Taste, Touch, Proprioception, Interoception (hyposensitivity to sharp pain fibers → cutting behaviors)

❖ All influence Adaptive Functioning

A Key Deficit in FASD: 
Executive Dysfunction *(not low IQ)*

- impaired attention/mood/impulse control,
- poor self-/other-awareness,
- impaired working memory (e.g., reflection, prioritizing, strategizing, sequencing),
- poor judgment/problem-solving (e.g., trouble-shooting, shifting strategies),
- inability to link cause-and-effect/foresee consequences,
- inability to learn from experience & generalize
- emotional/social immaturity.

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Social Communication in ND-PAE

- **Better expressive** than receptive language
  - Leads to misunderstanding that “they should know better” or “they understand what I am saying”

- **Impairment in social interaction**, social perception, social cognition & social communication
  - Misread and misinterpret social nuances, cues, facial expressions, body posture
  - “Neutral face” may seem threatening

Sifneos, 1974; Coggins et al., 1998, 2008; Kapp & O’Malley, 2001; O’Malley and Nanson, 2002; Sullivan 2008
Mood Dysregulation & Autonomic Arousal
(“faulty emotional thermostat & rheostat”)

hyperactivity
aggression*
hyper-reactivity
low frustration tolerance*
heightened stress response
intense, immediate reactions to stimuli
act before they think
easily triggered, provoked, instigated*

*also influenced by environmental mediators
Problems articulating emotions (emotional language)
  ▪ Lack words to express feelings

Inaccurately sense or perceive emotions
  ▪ Difficulty “knowing” the feelings/motivations of others
  ▪ Appear unconcerned or dispassionate
  ▪ Misunderstood as callous/unemotional

Acts out emotions in physical expression

Sifneos, 1974; Coggins et al., 1998, 2008; Kapp & O’Malley, 2001; O’Malley and Nanson, 2002; Sullivan 2008
Autonomic Nervous System
Alexithymia Deficit Model

➢ “psycho-somatic” (mind-body) symptoms result from:
  ▪ physiological shunting of “arousal”
  ▪ into the endocrine/metabolic system & involuntary nervous system.

➢ have limited psychological processes
  ▪ the average person would use to overcome stressors

➢ lack resiliency in times of stress
  ▪ we need to limit the stress on their nervous systems

Campbell, 1996
Seven (7) Senses – Hypo/Hypersensitivities

1. Smell: olfactory nerve (I)
2. Sight: optic nerve (II)
3. Hearing: vestibulocochlear nerve (VIII)
4. Touch: somato-sensory nerves from the skin
5. Taste: hypoglossal nerve (XII).

Any of the senses can be affected by PAE.
Sense #7 = Interoception

**Interoception:**
→ interpret internal signals from the body and internal organs
→ sensory processing and prediction of internal bodily states.
→ signals are transmitted to the brain via multiple neuronal pathways including:
  (1) the lamina/spinothalamic pathway  
  (2) the classical viscerosensory pathway  
  (3) the vagus nerve and glossopharyngeal nerve  
  (4) chemosensory pathways in the blood  
  (5) somatosensory pathways from the skin.
Secondary Disabilities Study of FAS & FAE/ND-PAE

- Mental Health problems 90%
- Disrupted school experience 61%
- Trouble with the law 60%
- Confinement: hospital, alcohol rehab., jail 50%
- Repeated inappropriate sexual behaviors 49%
- Alcohol /drug problems 35%

Sample n=415, 6 to 51 years old, median IQ 86 (self-report)

Streissguth, et al., 1996
Why So much “Mental Illness” in PAE?

Theory of Mind:

- Alexithymia
- Misperceive, misread & misinterpret social/non-verbal cues
- Cognitive disconnect to consequences

“Faulty Emotional Rheostat” = Limbic Seizures

- Poor frustration tolerance
- “rage episodes”
- Epileptiform discharges
- Leads to more damage to neural networks

Sifneos, 1974; Coggins et al., 1998, 2008; Kapp & O’Malley, 2001; O’Malley and Nanson, 2002; Sullivan 2008
Lack Resiliency:
✓ Maladaptive attachment behaviors
✓ Over-reactive to minimal provocation
✓ Neurocognitive deficits → academic problems
✓ Difficulty learning a trade without early supports
✓ Socially disenfranchised (appear odd)

Maladaptive Behaviors → High Risk of Abuse
→ Perceived misbehavior due to clumsiness/impulsivity
→ lack of consequential thinking
→ Negative caregiver response
→ faulty attachments
→ reactive attachment disorder or oppositionality

Sifneos, 1974; Coggins et al., 1998, 2008; Kapp & O'Malley, 2001; O'Malley and Nanson, 2002; Sullivan 2008
Defective Wiring in Interoceptive Signals

→ **Misrepresentations of internal states**
  A disconnect between the body's signals and the brain's interpretation and prediction of those signals

→ **Suggested to underlie some mental disorders:**
  - Autism spectrum disorders
  - Anxiety, panic, PTSD, OCD, illness anxiety disorder
  - Somatic symptom disorders
  - Eating disorders: anorexia nervosa, bulimia nervosa.
  - Depressive disorders.

Sense #7 = Interoception
Prenatal Alcohol Exposure

Poor social and academic performance

School Failure

ACEs
Witnessing or Experiencing Abuse

NOT RESILIENT

Neurodevelopmental Disorders

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3-HIT MODEL OF NEURODEVELOPMENTAL DAMAGE

FIRST HIT
Prenatal [Alcohol] Exposure

SECOND HIT
ACEs

THIRD HIT
Alcohol, tobacco, other drug abuse


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Children with FASD who experience Adverse Childhood Experiences are significantly more impaired than neurotypical children who are traumatized.
A 4-DIMENSIONAL PERSPECTIVE

The Individual with ND–PAE in the context of his/her Caregiving Environment

External Factors Influence Thoughts, Regulation, Functioning

Touch
Taste
Texture
Temperature

Sounds
Smells

Tone
Rhythm
Vibration

Cues
Facial
Expressions

Situation
Transitions
Social Nuances

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Heterotopies ➔ Seizure Disorders

- PAE at GD7
- without observable faces
See: “Dispelling Myths about Alcohol-related Birth Defects” https://www.youtube.com/watch?v=3TnYC7KtM34
MEDICAL HISTORY
Common Medical Problems/ARBD

in Newborns, Infants, & Toddlers w/ FASD:

- **ocular defects**
  - strabismus
  - ptosis
  - short palpebral fissures
  - other ophthalmologic issues

- **recurrent otitis media**
  - resultant S/L delays &/or sensori-neural hearing loss

- **failure to thrive**
  - Prenatal: LBW/Prematurity
  - nutritional deficiencies
  - poor gastrointestinal absorption?
  - reflux
Role of the FAMILY in achieving Maslow’s Hierarchy of Needs
Rethinking Parenting

Achieve Maslow’s Hierarchy

✓ Food, clothing, “home”
  = safe, supportive housing/apartment

✓ Safety & Security = Lifelong Supports

✓ Love/Belonging/Community = “Tribe”

✓ Meaning & Purpose = Meaningful Employment, recreational activities; farm/gardening, low stress environments.
FORMULATION of Patients with ND-PAE

- Identify adaptive & maladaptive functioning
- Healthy understanding of Strengths & Challenges
  - Foster self-confidence
  - Limit self-esteem issues
  - Provide a broader fund of knowledge with focused areas of interest/ability

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In teaching...“You can’t do the Bloom stuff until you take care of the Maslow stuff.”

Alan E. Beck
Self-Esteem
(industry, identity, purpose, vocation)

Love & Belonging
(Family, Caregiving, Relationships)

Safety and Security
(Trust, Forgiveness)

Air, Food, Water, Clothing, Shelter

Self-actualization
Transendence
Mechanisms by which Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan

- Adverse Childhood Experiences
- Disrupted Neurodevelopment
- Social, Emotional and Cognitive Impairment
- Adoption of Health-risk Behaviors
- Disease, Disability, and Social Problems
- Early Death
Rethinking Parenting → “Positive Parenting”

- Always Breathe Calmly (“channel your inner Buddha”) – deep, cleansing breaths for a positive & peaceful perspective.
- Simplify, Structure, Schedule, and Supervise.
- Floor Time, Child Directed Play, and Free Play.
- Chores and Responsibilities.
- Preview, Review, and Remind.
- Roleplay, Replay and Reframe.
- During their “outbursts” and frustration, bring your emotional furnace to room temperature.
- Try to set a calm, gentle tempo from infancy onward → use a gentle voice versus “trash talk”
“Positive Parenting” Techniques

➢ The tone and pitch of your voice has a lot to do with how your children respond.
  ➢ Remember “misperception” and “over-activation”
➢ Yelling switches “on” the panic button (amygdala) → fight – flight kicks in → then the child cannot respond → like a seizure episode.
➢ If you’re feeling stressed (by them or for another reason), breathe in and out gently through the nose to calm your “fight or flight” reaction.

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One of the main reasons children will act out is to call you back to being present with them.

Remember to always encourage children with loving words.

Tell them exactly what it is you like about them or their accomplishment; be specific.

Be present and aware of your self expression as they are watching and modeling you.

- By speaking to your child with respect, you are role modeling how you desire to be spoken to.
- Having a private ‘code word’ to share when emotions are getting high is a great tactic and a fun way to help shift stressful energy and avoid blowups.
- Be comfortable saying “I’m sorry for how I made you feel…”
Steps for Resilient, Successful Child Development

Acceptance & Realistic Expectations

Attunement to Baby/Child's Rhythms, Tone, Vibrations, Frequency

Adaptive Functioning
Programming Geared toward Abilities & NDs

Allow Opportunities for Maslow's Hierarchy of Needs (esp. Meaning & Purpose)

Awareness of NDs, Abilities, Interests, & Strengths
Gearing Family Systems
for Resilient, Successful Child Development

- AWARENESS
- ATTUNEMENT
- ACCEPTANCE
- ADAPTIVE FUNCTIONING PROGRAMMING
- ALLOW MEANING & PURPOSE

Happy, Confident, Hopeful Child
Integrated Family System
for Resilient, Successful Child Development

- Awareness of NDs, Interests, & Abilities
- Acceptance & Realistic Expectations
- Allow Opportunities for Meaning & Purpose
- Attunement to Baby/Child
- Adaptive Functioning Programming

allowing opportunities for meaning & purpose
Goals of FASD/ND-PAE Treatment

✓ **Create healthy attachments** for successful, cohesive family ties and social bonds (safety, love/belonging/community)

✓ **Develop adaptive functions** to transition adolescents into meaning and purposeful lives (food/clothing/shelter, self-actualization)
Why So much “Mental Illness” in PAE?

Cultural Norms vs. Parenting Styles?
Childhood → Adolescence → Adulthood

- **Goal: High Standards**
  - Alcohol/tobacco/other drug-free
  - Uphold the law
  - Work in a trade, vocation, or profession
  - Graduate high school pregnancy-free

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**Multidisciplinary Treatment**

**Continuity of Care & Transition Planning**

*Childhood ➔ Adolescence ➔ Adulthood*

- "Low Expectations" ➔ Decreased Stress ➔ Will allow adolescent to achieve their own level of success by having their own aspirations

- Special Education ➔ “Vocational Track”

- Appropriate, realistic expectations by school, care givers, community programs

- Early involvement in areas of interest
  - e.g., learning about nature/animals
  - child care/development
  - extreme sports
  - music/arts, etc.

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Family Support
- family systems model
- therapy for siblings &/or parents
- respite care and improved supports
- appropriate education & community resources

Parent Empowerment
- parent guidance & link w/ support groups
- link with NOFAS (www.NOFAS.org)
MULTIDISCIPLINARY TREATMENT
Continuity of Care & Transition Planning

Childhood $\rightarrow$ Adolescence $\rightarrow$ Adulthood

- **Wrap-around Services for High Acuity**
  - ✔ Patient Self-Advocacy
  - ✔ Parent Guidance and Advocacy
  - ✔ In-home Services
  - ✔ Case Management
  - ✔ Supportive Housing
  - ✔ Job Coaching, Staff/Supervisor Training

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TREATMENT PLANNING SUMMARY

DSM-5 diagnosis of ND-PAE to develop a clinically-relevant, life-course neurodevelopmental treatment plan:

✓ Infant screening with CDC Milestone Tracker App: https://www.cdc.gov/ncbddd/actearly/milestones-app.html
✓ Referral of PARENTS for counseling/treatment/parent guidance
✓ Early childhood intervention: Infants & Toddlers Programs
✓ 3-6 Years & School aged: Individualized Education Plans
✓ Adolescents: Special Education Services for “Multiply Impaired”
✓ Transitional Age Youth: Consider Guardianship, SSI, Disability Services, Special Needs Housing, Vocational Assistance
✓ Young Adults’ Goal: Achieve Meaning and Purpose
The Silent Epidemic
A Child Psychiatrist’s Journey beyond Death Row

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www.prenatalalcoholexposure.com