Long-Term Outcomes of Substance Exposure After NAS

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Background and Significance

- Nearly half of all women of childbearing age drink alcohol regularly
- 25% of these women binge drink
- Women 18-25, alcohol consumption 55.8%, binge drinking 31.8%
- Nearly half of all pregnancies in AZ are unplanned
- SAMHSA reported pregnant women ages (15-44)- 9.8% reported drinking alcohol during the past month, 4.1% reported binge use
- 4.3% of pregnant women reported illicit drug use during the past month; ages (15-25) - 8% use, ages (26-44) - 1.6%
Substance Use & NAS in Arizona

• The rate of NAS has increased by 235% from 2008 to 2014 and 27% since 2013
• AHCCCS was the payer in 79% of the NAS cases overall, 2008-2014
• White, non-Hispanics made up 68% of the total number of NAS cases, 2008-2014
• The rate of newborns exposed to narcotics has increased more than 218% since 2008
• AHCCCS was the payer in 76% of the newborns exposed to narcotics from 2008-2014
• White, non-Hispanics made up 52% of the total number of narcotic exposure cases (n=1,707), 2008-2014 and Hispanics composed an additional 28% (n=922) of cases
• The number of newborns exposed to cocaine decreased by 76% between 2008-2014 and by 39% from 2013 to 2014
• The number of newborns with FASD increased by 67% from 2013-2014
• Preliminary data reports an increase of NAS rates from 5.2 to 5.7 in 2015
Newborns with NAS & Drug Exposures in Arizona 2008-2014*

<table>
<thead>
<tr>
<th>Year</th>
<th>NAS</th>
<th>Narcotic</th>
<th>Cocaine</th>
<th>Hallucinogens</th>
<th>Alcohol</th>
<th># of Hospital Births</th>
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<tbody>
<tr>
<td>2008</td>
<td>145</td>
<td>234</td>
<td>161</td>
<td>35</td>
<td>22</td>
<td>95,420</td>
</tr>
<tr>
<td>2009</td>
<td>154</td>
<td>410</td>
<td>99</td>
<td>51</td>
<td>25</td>
<td>89,115</td>
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<tr>
<td>2010</td>
<td>223</td>
<td>414</td>
<td>79</td>
<td>46</td>
<td>15</td>
<td>84,069</td>
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<tr>
<td>2011</td>
<td>300</td>
<td>424</td>
<td>68</td>
<td>46</td>
<td>30</td>
<td>81,988</td>
</tr>
<tr>
<td>2012</td>
<td>304</td>
<td>531</td>
<td>59</td>
<td>47</td>
<td>27</td>
<td>82,905</td>
</tr>
<tr>
<td>2013</td>
<td>339</td>
<td>646</td>
<td>55</td>
<td>68</td>
<td>20</td>
<td>82,338</td>
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<tr>
<td>2014</td>
<td>438</td>
<td>650</td>
<td>34</td>
<td>93</td>
<td>33</td>
<td>83,427</td>
</tr>
<tr>
<td>Total</td>
<td>1,903</td>
<td>3,309</td>
<td>555</td>
<td>386</td>
<td>172</td>
<td>599,262</td>
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</table>

* Some of the cases may be included in multiple categories
Drug/Alcohol Related Birth Defects

- Learning difficulties
- Social/behavioral challenges-violence
- Substance use/abuse
- Mental health challenges
Pregnancy and Fetal Development
Pregnancy Timeline

- Day 1 = Menstruation
- Day 14 = Conception
- Day 15-28 = Pre-implantation/Implantation
  - time when fertilized egg is leaving the ovary and moving down into the uterus to implant
  - No obvious physical changes or signs of pregnancy
  - No pregnancy symptoms
- Week 5-6 = Missed period and positive pregnancy test
- Week 8-12 = Pregnancy confirmation; doctor visit; prenatal care starts
Early Fetal Development

Critical Periods of Development

<table>
<thead>
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<th>Weeks gestation from LMP</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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</table>

Missed Period: 4 weeks
Mean Entry into Prenatal Care: 10 weeks

(CDC)
Fetal Development Timeline

CRITICAL PERIODS OF DEVELOPMENT
(RED DENOTES HIGHLY SENSITIVE PERIODS)

1. period of dividing zygote, implantation & bilaminar embryo
2. C.N.S.
3. heart
4. eye
5. heart
6. eye
7. ear
8. palate
9. ear

embryonic period (in weeks)

fetal period (in weeks) → full term

central nervous system

heart
arms
eyes
legs
teeth
palate
external genitalia
ear

usually not susceptible to teratogens

prenatal death
major morphological abnormalities
physiological defects & minor morphological abnormalities
Poor Pregnancy Outcomes

• The causes of most birth defects remain unknown.

• The causes of most cases of cognitive disabilities remain unknown.

• The causes of most behavior disorders are unknown.

(Many are felt to be a combination of genetic and environmental factors).
Children who are exposed to alcohol, drugs, and/or other substances in utero can experience a variety of health problems:

• Physical
• Developmental
• Cognitive
• Behavioral
Substance Exposed
Pregnancies: The Basics
Alcohol during pregnancy is the leading preventable cause of birth defects, cognitive disabilities, and neurobehavioral disorders.

The only factor that causes FAS and FASD is alcohol consumption.
The sole cause of FASD is women drinking alcoholic beverages during pregnancy.

Alcohol is a teratogen.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996
Drinking alcohol during pregnancy puts a woman at risk for having a baby with:

- fetal alcohol syndrome (FAS),
- an alcohol-related neurodevelopmental disorder (ARND),
- alcohol-related birth defects (ARBD).

Collectively, these syndromes, disorders, and defects are referred to as Fetal Alcohol Spectrum Disorders (FASD).
Research shows...

• There is no safe time for a pregnant woman to drink alcohol.
• There is no safe amount of alcohol for a pregnant woman to drink.
• Alcohol affects whatever organ or system that is currently growing, including:
  • Brain, heart, bones, kidneys, eyes, ears, face
• The brain grows and/or develops every day during pregnancy.
Development and Damage
Structural Damage

• Most structural damage occurs between weeks 2-10 (after LMP)
  • FAS facial features
  • Cleft disorders (common with alcohol exposure); occur by week 12
Facial Features of FAS
Develop between weeks 2-10 after LMP
Structural Damage

- Most CNS and heart malformations occur early in the first trimester of pregnancy. Damage may continue to occur through the 16th week.
- CNS and heart defects both occur more frequently with alcohol exposure.
Not just about Structural Damage

• Weeks 16-40, maturation and development continue.

• Organ function and ability to perform are affected.

Remember:
Alcohol affects whatever organ and/or system currently growing; the brain grows and/or develops every day during pregnancy.
Many FASD characteristics are related to brain development and maturation, not structure.

- FAS social, behavioral, and developmental issues:
  - lower IQ’s, learning disabilities, decreased adaptive functioning, balance and coordination impairments, sensory deficits or sensitivities, trouble with information processing and decision making.

- Growth restriction at birth and throughout life are common with FAS/FASD

Many women think it’s okay to have “a drink or two” later in pregnancy. But...
How many drinks would you give a newborn?
Diagnosing for Services

• **FAS** is a medical condition, therefore treatment and services, are generally covered.

• Only 15% of people with **FASD** qualify for developmental disability services.

• Screening and proper diagnosis are essential.
Diagnosis of FAS

- Abnormal facial features (e.g., smooth ridge between nose and upper lip)
- Lower-than-average height, weight, or both
- Central nervous system problems (e.g., small head size, problems with attention and hyperactivity, poor coordination)
- Prenatal alcohol exposure; although confirmation is not required to make a diagnosis

Can be difficult to accurately diagnose.
Often not diagnosed until age 3-5.

Diagnosis of FAS by age 6 is a strong protective factor for future success.
Centers for Disease Control Guidelines for FAS Diagnosis and Referral

**Caregiver-initiated Provider Contact**
- Child presents for office visit.
- Triggers emerge from contact, i.e., developmental problems, facial abnormalities associated with FAS, growth delay, or maternal alcohol use.

**Complete initial evaluation to gather specific data related to the four FAS criteria: facial malformations, growth abnormalities, neurodevelopmental concerns, and maternal alcohol use.**

**Diagnosis**
- Refer to Specialist for further assessment
  - **FAS Diagnosis confirmed using dysmorphic and anthropometric assessment procedures along with appropriate neurodevelopmental evaluation data.**
  - **An Intervention plan is developed using a multidisciplinary team approach.**

**Services**
- The Intervention plan is communicated to frontline providers, caregivers, and child with ongoing exchange with the intervention team.
- A case management plan is initiated at the community level based on recommendations from the intervention team (i.e., specialty services, community and educational resources.)
Identifying an FASD

• Only trained professionals can diagnose an FASD. Ideally, diagnosis is done by a team that may include:
  • Geneticists
  • Developmental pediatricians
  • Neurologists
  • Dysmorphologists (physicians specializing in birth defects)
  • Teachers and education consultants
  • Psychologists, psychiatrists, and social workers
  • Occupational therapists
  • Speech and language specialists
  • Parents and other caregivers
Signs of FASD
(signify need for formal screening)

Signs that may suggest the need for FASD assessment include:

• Small head or facial or dental irregularities
• Heart defects or other organ dysfunction
• Deformities of joints, limbs, and fingers
• Slow physical growth before or after birth
• Vision or hearing problems
• Sleeping, breathing, or feeding problems
• Intellectual impairments and/or delayed development
• Behavior problems
• Maternal alcohol use; paternal alcohol abuse
More Signs
(not automatically associated with FASD)

• Lack of eye contact during infancy
• Does not like to be cuddled as a baby
• General behavior management techniques are not very effective
• Makes the same mistakes over and over, despite consequences
• Ever suspended from school or kicked out of a program due to behavior issues
Alcohol During Pregnancy Can Create a Lifelong Brain That:

- Can’t read the emotions or body language of other people
- Thinks like the brain of someone much younger
- Forgets information
- Has trouble moving information from one situation to another
- Responds slowly
- Has difficulty with time and money
- Can’t link cause and effect
- Thinks in a disorganized way
- Uses poor judgment
- Responds slowly
Common Mental and Behavioral Outcomes Associated with FASD

• Poor coordination
• Developmental delays
• Distractible
• Learning problems
• (especially arithmetic)
• Attention and memory problems
• Uninhibited/impulsive
• Lack of organizational skills
Common Mental and Behavioral Outcomes Associated with FASD

• Continued sleep problems
• Trouble making and keeping friends
• Trouble reading and understanding social cues
• Trouble understanding boundary issues
• Easily frustrated
• Trouble understanding cause/effect relationships
Potential “Secondary Disabilities”

• Early school drop-out
• Alcohol and drug abuse problems
• Unable to care for their children
• Joblessness
• Trouble with law
• Mental health problems
• Premature death
Clinical Implications for Adolescents & Adults with FASD

- Poor judgment...easily victimized
- Attention deficits....easily distractible
- Arithmetic disability...can’t handle money
- Memory problems...doesn’t learn from experience
- Difficultly abstracting...doesn’t understand consequences
- Disoriented in time and space...fails to perceive social cues
- Poor frustration tolerance...quick to anger
Signs of FASD in Adults

- History of alcohol abuse in birth family
- Multiple home placements
- Special education classes in school
- Suspended or dropped out from school
- History of depression/ADHD
- History of abuse and/or neglect
- Trouble maintaining jobs
- Trouble managing money
- Trouble with time management
- Unusual or inappropriate peer groups
## Other Substance Exposure

<table>
<thead>
<tr>
<th>Cocaine</th>
<th>Ecstasy, Methamphetamine and Other Club Drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marijuana</td>
<td>Opioids (Rx &amp; illegal)</td>
</tr>
</tbody>
</table>
Cocaine

*Preterm birth
*Placental abruption
*Decreased birth weight
*Neonatal abstinence syndrome
*Cleft defects; some evidence suggests increased risk of brain, skull, face, eyes, heart, and limb defects
*Attention and behavior problems
Ecstasy, Methamphetamine and Other Club Drugs

* Preterm birth
* Placental abruption
* Decreased birth weight
* Neonatal abstinence syndrome
* Increased risk of SIDS
* Breathing issues
* Hearing and vision problems
* Learning Disabilities
Marijuana

* Preterm birth
* Low birthweight
* Stillbirth (2x as likely)
* Neonatal abstinence syndrome
* Slightly increased risk of gastroschisis; possible increased risk of congenital heart defects
* Mild long term behavioral and memory/learning problems
Prescription Opioids During Pregnancy

* Decreased birth weight
* Preterm birth
* Stillbirth
* Neonatal abstinence syndrome
* Slightly increased risk of congenital heart defects
* Long term behavioral problems
* Risks vary greatly depending on dose and frequency of drug use
Limitations of Studies
(“Other Substances” and Alcohol)

• Limited research on outcomes of prenatal exposure to other substances
  • Controversial
  • Unknown or uncontrolled doses
  • Time
  • Multiple drug exposures/co-occurring use

• Drug and Alcohol study limitations
  • Reporting bias by patients and/or researchers
  • Unknown or uncontrolled doses
  • Co-occurring use
  • Confounding factors (poor nutrition, low SES, no/poor prenatal care, abusive homes, family history of neurobehavioral problems, etc.)

• Long-term follow-up is expensive and difficult to conduct

• Genetics vs. environment

*Much more confirmed research on alcohol effects, but there are still limitations*
Perinatal Factors That May Affect Long-term Outcomes

• Duration of in utero drug/alcohol exposure
• Dose-effect relationship
• Maternal polydrug use (legal, other RX, illegal)
• Withdrawal symptoms versus drug effects
• Severity of withdrawal manifestations
• Continuing drug exposure from postnatal treatment
  • Type of drug, duration of postnatal treatment
• Family, environmental factors
The Newborn With Prenatal Drug Exposure Including Opiates

• Low birth weight
• Small head circumference
• Congenital malformations (over reported)
• Signs of drug effects
  • Abnormal tone may persist for months
• Seizures & abnormal EEG pattern; abnormal sleep patterns
• Signs of withdrawal (drug dependency)
Prenatal Exposure & Brain Development

• All legal & illegal drugs/alcohol will affect brain development; effects depend on stage of gestation the fetus had exposure

• Various stages of brain development
  • Doral induction (3-4 weeks)
  • Ventral induction (5-6 weeks)
  • Neuronal proliferation (2-4 months)
  • Migration (3-5 months)
  • Organization (6 months-years postnatal)
  • Myelination (birth to years postnatal)
Prenatal Exposure & Brain Development Continued

• Behavior Teratology Framework: Vulnerability of the CNS to injury extends beyond fetal, neonatal and infancy stage.
  • Most frequent manifestations of injury to the developing CNS do not result in nervous system malformation but in functional abnormalities that may not be detected at birth but later in childhood, adolescence, or adulthood.

• Related to Barker hypothesis: Any perturbation during fetal development may have enduring effects on later behavior.
Maternal & Family Factors

• Maternal age
• Co-morbidities (psychological/psychiatric disorders)
  • Depression, anxiety disorders, PTSD, etc.
• Pregnancy complications
• Sexually transmitted diseases (increasing prevalence of Hepatitis C)
• Hospitalizations (due to violence)
• Parenting
• High-risk lifestyle
• DCS reporting and involvement
• Discharge placement: biological parent, kinship care, non-kinship care
Individual, Maternal, & Family Factors

• Polydrug or Other Drug Use (rarely single drug use) affecting fetal brain development

• Maternal, family/caretaker, and community have influences on child development
Adverse Neurodevelopmental Outcomes of Infants Exposed to Opiates In-utero

Olofsson, et al. 1983
N=89 (methadone, morphine, heroin)
• 25% normal physical, mental, and behavior
• 56% hyperactive, aggressive, with lack of concentration and social inhibition
• 10% severe psychomotor impairment
• 11% moderate psychomotor impairment
Effects of Prenatal Opiate From Caretaker & Teacher Reports (13 y/o)

• Children with prenatal opiate exposure did not start out with high problem scores at early ages

• From caretaker report: behavior problem scores: worse with time.
  • Internalizing Behavioral Problems
  • Total problems
  • Attention problems

• From teacher report
  • Attention Problem Scores worse with time

Long-Term Follow-up of Opiate Exposed Children (After 3 years)

• Lower IQ scores than non-exposed children (8-15 point differences)
  • Considering that normal IQ is mean (SD)=100 (15); a 10-point lower mean IQ in exposed children translates to a probability of an increase in the number of children in the below average range from 16% to 36%

• Poor Language development

• Behavior and school problems: 1 out of 4 children
Summary: Prenatal Opiate Drug Exposure & Outcomes at Late Childhood

• 8-15 point difference (lower) in IQ scores after prenatal opiate exposure compared to non-exposed children
• Lower Language scores in exposed children
• Maternal opioid replacement treatment was not associated with improved cognitive development in exposed children
• Higher rates of behavioral problems that become worse with time.
Summary: Prenatal Opiate Drug Exposure & Outcomes at Late Childhood Continued

• Need more research on the appropriate treatment of infants with NAS, RX that will not continue or aggravate the effects of in-utero exposure

• These prenatal & postnatal drug exposure effects and other factors could have implications for antisocial behavior, child mental health, and school functioning.

• More research to mitigate behavior problems in exposed children
Problem Behaviors

• Externalizing Behavior Problems
  • Delinquent Behaviors
  • Aggressive Behaviors

• Internalizing Behavior Problems
  • Withdrawn
  • Somatic complaints
  • Anxious/depressed

• Total Behavior Problems
  • Externalizing, internalizing, social problems, thought problems, attention problems, sex problems
Long-Term Outcomes of Prenatal Opiate Exposure-Summary

- Prenatal opiate exposure often occurs in the context of polydrug exposure.
- High incidence of withdrawal (NAS) in illegal opiate use, with maternal medical replacement therapy (methadone or buprenorphine), or prescription opioids.
- Increase in likelihood of adverse effects noted at later childhood or adolescence.
- Lower IQ, lower language scores, higher rate of behavior problems among exposed children.
Long-Term Outcomes of Prenatal Opiate Exposure-Summary

• Adverse outcomes are noted even with maternal opioid treatment during pregnancy; therefore focus much needed to treatment of NAS and on child development

• Prenatal exposure effects can be aggravated by environmental risks but can also be mitigated by protective factors (at individual, family, and community levels)

• Need to explore interventions to minimize the adverse effects of prenatal drug exposure

• We need to address maternal treatment, child treatment and development
Treatment/Prevention/Intervention

• There is no single program or plan that works for all persons with FASD or drug exposure

• Each plan needs to be individualized according to the person’s needs
Protective Factors
(Keys to Success)

• Early diagnosis

• Involvement in special education and social services

• Absence of violence and substance abuse

• Loving, nurturing, and stable home environment
Intervention

• For both the birth mother and the person with FASD, or drug exposure it is important to remember that it is more about support and intervention than a “cure.”

• Helpful guidelines:
  • Clear understanding
  • Realistic expectations
  • Creative problem solving
  • Patience
Infant Intervention

- Swaddling
- Soft clothing
- Frequent naps
- Frequent feedings
- Alternate positioning for breastfeeding
- Facing away during bottle feeding
- Avoid chaos and over-stimulation
- White noise or gentle music
- Sensory integration therapy
Infant Intervention Guidelines: SCREAMS Model

- Structure: routine, easy steps, ABC Rules
- Cues: for meds, appointments, manners
- Role models: TV, movies, friends, family
- Environment: avoid chaos, stimulation
- Attitude: understand FASD and drug exposure
- Meds and diet: restore balance and control
- Supervision: many need 24/7
“Crossover” Interventions

• Much of the SCREAMS model can be applied to adolescents and adults with FASD and drug exposure

• Also appropriate for children with exposure to other substances

• Avoid overstimulation

• Find and focus on strengths
Substance Exposed Newborn Treatments

• Medical care
• Medication
• Behavior and education therapy
• Developmental care/therapy
• Parent/partner/caregiver training
• Alternative approaches
Prevention is Best

• Educate and inform
• Start early
• “Preconception Health” paradigm shift
  • Every woman every time; not just pregnancy health
• Ideals:
  • If pregnancy is possible, avoid alcohol and other substances, especially binge consumption.
  • If a pregnancy may have occurred, abstain from any exposure to alcohol and other drugs.
Resources
Mothertobaby.org
Arizona FAS Resources http://www.nofas.org/state-resources-for-arizona/

FAS Arizona
Tucson, AZ
www.fasarizona.com/
FAS Arizona is a source for information, support, events, and resources in Arizona for Fetal Alcohol Syndrome (FAS) and Fetal Alcohol.

Emily Anderson Family Learning Center
1919 East Thomas Road
Phoenix, AZ 85016
Phone: (602) 546-1400 Fax: (602) 546-1409
www.phoenixchildrens.com/health-information/the-emily-center/
The Emily Center is a library that is free and open to the public. All the materials are about child health, injury and illness. They have books, videotapes and articles on FAS and other conditions.

Raising Special Kids
5025 East Washington Street
Suite #200
Phoenix, AZ 85034
Phone: (602) 242-4366 Fax: (602) 242-4306 Toll Free: (800) 237-3007
www.raising specialists.org/
Raising Special Kids is a non-profit organization serving families of children with disabilities and special health care needs in central and northern Arizona. All programs and services are provided to families free of charge.

Native American Community Health Center
4520 North Central Avenue
Suite 620
Phoenix, AZ 85012
Phone: (602) 279-5262
www.nativehealthphoenix.org/
NATIVE HEALTH currently provides a wide range of programs including primary medical, dental, WIC, health promotion and prevention, wellness programs and behavioral health programs.

Native American Connections Inc, Guiding Star Lodge
3424 E Van Buren
Phoenix, AZ 85008
Phone: (602) 254-5805
www.nativeconnections.org/about/locations/guiding-star
Outpatient and Inpatient Services at Guiding Star and Indian Rehabilitation for Substance use disorders and co-occurring mental health disorders. Specialty services for pregnant, post partum, and parenting women.

The Arc of Arizona
PO Box 90714
Phoenix, AZ 85066
Phone: (602) 234-2721
www.arcarizona.org/
The Arc is the nation’s leading advocate for all people with intellectual and developmental disabilities and their families and the premier provider of the supports and services people want and need.
The FAS Community Resource Center provides a wealth of information and resources for parents and professionals. There is information on support, training, and advocacy as well as many printed materials, videos, posters, brochures, and presentations.

Pilot Parents provides a wide variety of programs and services that support families of children with disabilities including peer to peer support, parent training, and a resource library.

The members of the Genetics Section see children with birth defects, with unexplained mental retardation or failure to thrive—widely diagnosed conditions that sometimes are genetic, and with known genetic disorders (about 5,000 different ones). They are expert about potential teratogen (chemical or medication) exposures to the fetus and the causes of mutations.

March of Dimes is dedicated to improving the health of babies by preventing birth defects, premature birth and infant mortality. They carry out their mission through research, services, education and advocacy.
Parker Indian Health Service Hospital
12033 Agency Road
Parker, AZ 85344
Phone: (520) 669-2137
U. S. Public Health Service Indian Hospital is a general medical and surgical hospital in Parker, AZ, with 20 beds.

NAFACES
77 West Forest Ave, Suite 110
Flagstaff, AZ 86001
For more information contact:
Jean Richmond-Bowman (928)214-3747
Cindy Beckett (928)773-2307

Resource Center
Flagstaff Medical Center
2nd Floor - PICU/Pediatric Conference Room
(928)214-3747

Arizona Department of Health, Office of Women’s and Children’s Health
150 North 18th Ave.
Suite 320
Phoenix, AZ 85008
Phone: (602) 364-1400 Fax: (602) 364-1495 Toll Free: (602) 542-1200
www.azdhs.gov/phs/owch/
The Office of Women’s and Children’s Health (OWCH) supports efforts to improve the health of Arizona women and children. Activities focus on assessment of health status and identification of health issues, development of partnerships and planning to address health issues, and provision of “safety net” services. High risk perinatal program for pregnant women. Has developed guides for identifying substance exposed newborns.
References


References


• Teresa Kellerman, Presentation Fetal Alcohol Spectrum Disorders Screening and Intervention Strategies (2013).

Healthy Pregnancies = Healthier Babies

Questions?
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