

A Series on Adoption and Foster Care Issues

Acquired Substance Abuse Disorders Fetal Alcohol Syndrome Fetal Alcohol Effects Fetal Exposure to Cocaine

OBJECTIVES:

- Discuss the nature and scope of children affected by maternal substance abuse.
- Provide data on Fetal Alcohol Syndrome (FAS) in comparison to Fetal Alcohol Effects (FAE).
- Present the often complex nature of cocaine abuse and its effect on children who were exposed to cocaine in utero.
- Consider frequently asked questions regarding maternal substance abuse and its effects on their children.
- Provide an Action Plan for caregivers of children with acquired substance abuse disorders.
- List references of books, articles and websites for further information.

OVERVIEW:

SCOPE AND NATURE OF THE PROBLEM

While the numbers in different studies vary widely, the National Institute on Drug Abuse (NIDA) estimates that as many as one in every 10 newborns in the United States is exposed to one or more drugs in utero. In major urban areas the number of drug-exposed children is estimated to be as high as 20%.

The NIDA estimates that about 15% of women between the ages of 14 to 44 years (childbearing age) are current substance abusers.

The drugs that women of childbearing age abuse include alcohol, cigarettes, marijuana, cocaine, heroin, methadone, amphetamines, PCP and more. Currently, researchers estimate as many as 375,000 infants per year may be affected by their mothers' drug use.

While the methods for assessing maternal drug use remain flawed, the number of infants affected by their mothers' drug use is clearly on the rise. The NIDA estimated a 339% increase in drug-affected newborns between 1979 and 1987.

Because alcohol abuse often occurs alone (not accompanied by the abuse of other substances) and maternal abuse of alcohol produces recognizable characteristics, the effects of alcohol on infants are well documented. When the effects from alcohol are clear-cut, the infant is diagnosed with Fetal Alcohol Syndrome (FAS); infants exhibiting

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more subtle effects from alcohol (e.g., they may have many of the characteristics but lack the typical facial features) are diagnosed with Fetal Alcohol Effects (FAE).

The effects of maternal cocaine use on an infant are less well known for a number of reasons:

1. Many cocaine users are considered “polydrug” substance abusers, i.e., they often take other drugs, such as alcohol, tobacco, marijuana, PCP, etc., in conjunction with cocaine.
2. Studies on the effects of cocaine in newborns are relatively recent (most of the studies didn’t emerge until 1989). Consequently, there aren’t enough studies to conclude accurately just what the effects of cocaine are on infants and there has not been enough time to conduct long-range studies that would show the effects on cocaine-exposed infants as they grow into childhood and adolescence.
3. It’s often difficult to accurately determine whether the mother did abuse cocaine. The urine screen detects cocaine for up to 72 hours; a mother in labor may not have used cocaine for over that period and would consequently have a clear urine screen. Further, many mothers, fearing censure or punishment, will deny using cocaine.
4. Because cocaine is extremely expensive, the lifestyle that often accompanies cocaine use (such as prostitution or engaging in other forms of crime) also affects the infant’s outcome. If the infant is receiving substandard care before and after birth, it becomes harder to determine whether the environment or the cocaine itself contributed to the infant’s distress.

WHAT ARE THE KNOWN EFFECTS ON THE NEW BORN CHILD?

The National Organization on Fetal Alcohol Syndrome (NOFAS) offers a number of provocative statistics regarding FAS and FAE:

1. FAS is the leading known cause of mental retardation (even exceeding Spina Bifida and Down Syndrome).
2. Although alcohol use is considered more “socially acceptable” than most other drug use, alcohol produces more serious effects in the fetus than heroin, cocaine or marijuana.
3. The Centers for Disease Control and Prevention reported that the percentage of babies born with FAS has increased sixfold in the past fifteen years.

4. Perhaps because alcohol use is considered more socially acceptable and alcohol is more readily available, three times as many women use alcohol during pregnancy than any other (harmful) drug.
5. In 1992 approximately 5,000 babies were identified with FAS. The number of babies showing evidence of FAE (Fetal Alcohol Effects), however, was over 50,000.
6. To date, no cure for FAS or FAE has been found; the effects are irreversible.

WHAT ARE THE CHARACTERISTICS OF FAS AND HOW DOES IT DIFFER FROM FAE?

Fetal Alcohol Syndrome (FAS) is a pattern of mental and physical defects that develops in some unborn babies when the mother drinks too much alcohol during pregnancy (note: what amount of alcohol is “too much” is not known and differs from person to person). The characteristics of FAS may be categorized into the following clusters:

Prenatal and Postnatal Growth Retardation:

1. Small body size and weight.
2. Slower than normal physical development and failure to catch up.
3. Skeletal deformities; e.g., deformed ribs and sternum, curved spine, hip dislocations, bent, fused, webbed or missing fingers or toes, limited movement of joints, small head.

Facial Abnormalities:

1. Small eye openings.
2. Skin webbing between eyes and base of nose.
3. Drooping eyelids.
4. Near-sightedness.
5. Failure of eyes to move in the same direction.
6. Short, upturned nose.
7. Sunken nasal bridge.
8. Flat or absent groove between nose and upper lip.
9. Thin upper lip.
10. Opening in roof of mouth (fistula or cleft).
11. Small jaw.
12. Low-set or poorly-formed ears.

(Note: While the facial characteristics described above may sound unusual, children demonstrating FAS facial characteristics are often described as “cute” or “elfin” in their appearance.)

Central Nervous System Dysfunction:

1. Small brain/head.
2. Faulty arrangement of brain cells and connective tissue.
3. Mental retardation (usually mild to moderate from sometimes severe).
4. Learning disabilities.
5. Short attention span.
6. Irritability-particularly in infancy.
7. Hyperactivity in childhood.
8. Poor body, hand and finger coordination.
9. Poor judgment and impulsive behavior.

Other Birth Defects (these might occur):

1. Cleft palate.
2. Heart defects and heart murmurs.
3. Genital malformations.
4. Kidney and urinary defects.

Fetal Alcohol Effects (FAE) usually refers to infants who demonstrate two or more of the FAS cluster of characteristics. Commonly, infants and children with FAE, rather than FAS, do not have the characteristic facial features. Because FAE presents more subtly and is thus harder to diagnose, it can often be mistaken for other problems such as Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Conduct Disorder, etc. Further, since alcohol use in pregnancy may be under-reported or considered too “minimal” to mention, FAE may not even be suspected. FAE is known to be at least five to ten times more common than FAS; given the difficulty in diagnosing FAE reliably, that number may be much higher.

WHAT ARE SOME OF THE COMMON CHARACTERISTICS MY CHILD WITH FAS WILL DEMONSTRATE AS SHE OR HE GETS OLDER?

Newborns/Babies

A newborn child with FAS might undergo a syndrome of alcohol withdrawal in addition to the growth deficiencies and birth defects that make up FAS/FAE. The infant's alcohol withdrawal

reaction might include epileptic seizures and these seizures and unusual brain activity can persist into adulthood. The infant also might be extremely jittery, have poor muscle tone and be unable to suck adequately. The infant with FAS often startles easily and is difficult to console. Developmentally, infants with FAS will generally be delayed.

Early Childhood

Young children with FAS might have surprisingly large vocabularies but very small “social” vocabularies. That is, they will not understand how to behave with or talk to other children and often do not understand the causes of their actions. For example, a child with FAS can hear what the teacher is saying but might not understand the teacher's purpose. When looking at a picture or a picture sequence, the child might focus only on a segment or part of the picture and, when asked, be unable to describe what is occurring in the picture or sequence.

Children with FAS may also struggle with the ability to reason. A child with FAS may only be able to partially understand the thoughts and feelings of another child or adult. Consequently, because a child with FAS may not be able to empathize, his or her actions may sometimes seem cruel.

Adolescence

By adolescence, children with FAS may become isolated and depressed. Without intervention, they may continue to exhibit poor judgment and seem unable to appreciate the consequences of their actions. They may be unable to look ahead to make plans or look back and learn from their experiences.

Because they can be very impulsive, adolescents with FAS may act fearlessly and even recklessly. In their desire for body contact, they may become too rough or aggressive. Extremely depressed adolescents may turn to petty crime, inappropriate sexual behavior, drug abuse and alcoholism.

WHAT IS KNOWN ABOUT THE EFFECTS OF PRENATAL EXPOSURE TO COCAINE?

Actually, we don't know too much. Or, to state this more accurately, we know quite a bit about the immediate effects of cocaine on a baby but we do not know a great deal about the long-term effects of prenatal cocaine exposure. Furthermore, it's often very difficult to determine just what effects may be attributed to cocaine when there are often other factors at work, e.g., concomitant or “polydrug” use and/or a challenging environment such as one that includes poverty or crime. Also, most of the studies done about cocaine are recent; 90% of all the studies date from 1989 or later.

Despite all the publicity regarding “crack babies” (the term used to describe infants exposed to cocaine) and the assumption that these children were doomed forever, more recent studies suggest that the effects of cocaine may be reversible by the time a child reaches the age of two. It becomes particularly important, therefore, to differentiate between the immediate effects of cocaine versus what may (or may not be) long-term effects of cocaine.

What is known, or theorized, about the prenatal effects on children may be divided into three stages: infancy, early childhood and late childhood/adolescence.

Prenatal/Infancy:

Women who use cocaine during pregnancy are three times more likely to have a premature baby; some miscarry early in their pregnancy.

Because cocaine cuts down the flow of nutrients and oxygen to the baby, cocaine-exposed infants tend to be smaller and have smaller heads.

Most cocaine-exposed babies are born too soon or too small. Babies with a birth weight below 5.5 pounds (like many of these infants) are 40 times more likely to die in their first month than babies of normal weight. The risks faced by low-weight, premature infants include mental retardation, cerebral palsy, visual and hearing impairment.

Many cocaine-exposed babies go through experiences similar to “withdrawal” from the drug. Many are very jittery and irritable, and startle and cry easily. These babies can be extremely hard to comfort and are often described as withdrawn or unresponsive.

Cocaine may cause disorders in what is known as the “four A’s of infancy”:

- Attention, the ability for babies to be aware of their surroundings.
- Arousal, the ability for babies to control their behavioral states from one activity to another (e.g., from sleeping to waking) and to show a wide range of behaviors in response to different stimuli.
- Affect, the ability for babies to respond to social interaction.
- Action, the ability for babies to use age-appropriate motor function.

Due to the various stresses a cocaine-exposed infant might endure, the bonding process may be difficult and create later problems with attachment.

Early Childhood:

Although lower IQs and permanent learning disabilities have been theorized as a long-term effect of prenatal cocaine exposure, no studies exist as yet to prove these theories.

Recently studies have indicated instead that cocaine-exposed infants “catch up” (developmentally) by the age of two. It has to

be stressed, however, that there have not been enough long-term studies to be certain.

Areas that may remain affected throughout early childhood include central nervous system functions, such as poor visual recognition memory, and other neurodevelopmental impairments. If cocaine-exposed children, for example, have difficulty in shifting from one task to another, this disorder could hamper their later school performance.

Later Childhood/Adolescence:

Given how little is known about the effects of cocaine in early childhood, it isn’t surprising that even less is known about how prenatal exposure to cocaine affects older children. Most of the studies that are old enough to comment on adolescents were not studies of cocaine exposure exclusively.

While some studies suggested that cocaine-exposed infants might be at higher risk for behavioral and academic problems in late childhood and adolescence, too many variables were present to posit this risk conclusively.

FREQUENTLY ASKED QUESTIONS REGARDING SUBSTANCE ABUSE & ITS EFFECTS ON CHILDREN

In order to prevent FAS or FAE, how much alcohol during pregnancy is “too much”? Is there a safe amount?

At present, experts agree there is no safe amount of alcohol pregnant women can drink. While FAS is nearly always caused by “heavy” drinking, any amount of drinking may cause Fetal Alcohol Effects. Furthermore, because women metabolize alcohol differently, relatively small amounts of alcohol may have a much more harmful effect in one situation than in another.

If a mother is already drinking during the pregnancy does it do any good to stop before the baby is born?

Yes. While any damage that has been done may be permanent, stopping will minimize the damage.

How is FAS/FAE diagnosed?

In an older child not previously diagnosed with FAS/FAE, the diagnosis would probably involve the child’s teacher, physician and psychologist. The teacher would provide information about how the child was performing at school, including both academic and behavioral difficulties.

The medical assessment of FAS involves a number of steps. The physician must do a careful physical because of the wide-ranging effects of FAS. The physical would include comparing the child’s weight and height against expected standards as well as precise facial measurements to see if the child exhibits the common FAS facial characteristics. If the adoptive parents know the birth mother’s drinking history, that information would be gathered. Also, the doctor would assess the child’s

developmental history in terms of both motor and language skills. A psychologist would use a number of tests including an IQ test, an achievement test and possibly an adaptive measure (to see if the child has the skills needed for independence).

If not much is known regarding the long-effects of cocaine, what measures can be taken to help a cocaine-exposed child?

Although it isn't clear, yet, what long-term effects cocaine causes in children, many of the strategies used for drug-exposed children in general, such as children with FAS/FAE, are applicable. Also, many studies cite behaviors in cocaine-exposed children that are very similar to the behaviors that children with Attention Deficit Hyperactivity Disorder (ADHD) exhibit. Consequently, the strategies (excluding medication) that help ADHD may also help children who were prenatally exposed to cocaine.

My friends/neighbors/relatives know that the child we've adopted was exposed prenatally to cocaine. How can we avoid the label "crack baby"?

As one writer suggested when he entitled his essay "Crack Babies Not Broken," you need to educate the people who will come in contact with your child so they understand that many of the effects of acquired substance abuse are reversible or manageable. In any event, your child, like any other special needs (or ordinary needs!) child, needs their love and understanding rather than negativity. No child should be made to feel like damaged goods. Ask them for their help in making your child feel valued and loved.

ACTION PLAN

Since these children usually have poor organizational skills, you can help to improve their organization by using verbal cues (e.g., a certain word to remind your child when it's time to stop a behavior), clear visual demonstrations, physical cues or songs which could remind your child of things to do (it's time to clean up).

To help your child comprehend abstract ideas or concepts more readily (children with FAS have trouble understanding abstract ideas), try to avoid speaking abstractly (or use visual cues when you do have to), use simple language and use concrete examples from your child's environment to help clarify an idea.

Try to not take misbehaviors personally. Children with FAS are often unable to understand what another person may be feeling and consequently often act in a manner that seems deliberately thoughtless or cruel. Try to remember that your child may need to learn how to empathize and may not be able to realize the consequences of his/her actions.

Try to speak literally. Children with FAS tend not to understand abstract speaking patterns any better than abstract ideas. Consequently, avoid using irony, idioms or sarcasm (even if done playfully) since your child is likely to interpret your words literally.

Teach skills a step at a time. Since these children often have difficulty acquiring a skill, patience is the key. It is helpful to break the skill into smaller steps, to present the skill in more than one way (e.g., visually and verbally), to use concrete examples to explain the skill, to use simple language and to teach the skill in the appropriate environment (e.g., if you're trying to teach your child how to clean the kitchen, show the steps in the kitchen rather than just talking about it).

To help children understand the consequences of their behavior in advance, have them role-play. For example, describe a situation and then ask your child, "What would happen if. . . ?"

Children with FAS, and it is theorized, children who were exposed to cocaine, need help learning how to adapt to sudden changes. To help your child learn these adaptive skills, make it into a game such as Red Light/Green Light.

Since many substance-exposed children have difficulty controlling their impulses because they have no "internalized language" (to provide direction), encourage them to use "self-talk" such as "If I take this money without asking, then the following things are going to happen . . ."

Establish a verbal and visual sequence of "STOP-CALM-THINK" to help your child remember to think (e.g., a picture could be a stop sign, a calm scene and a light bulb or some other picture that represents thought).

To help children become more decisive and organized, encourage them to make choices and decisions. Rather than always telling them what to do, select a couple of options and let them choose (it's better to select a few appropriate options than to keep it open-ended).

Help your child's organizational skills, and make going to school a more positive experience, by having your child get ready for school (clothes, homework, supplies, etc.) before he/she goes to bed.

These children need a great deal of structure and all the security that implies. Try to establish a regular routine and stick to it. If you need to make a major change in the routine, try to prepare your child ahead of time. If possible, keep a large calendar visible so that your child can anticipate daily events.

Even though these children do not always understand why their actions are wrong, it's important to give them clear explanations and to set limits that are followed consistently. Remember to review and repeat consequences of behaviors; make sure your child understands the consequences by having him/her tell you.

Adoption Resources of Wisconsin maintains an extensive lending library. Contact: 1-800-762-8063, 414-475-1246 or visit our website at www.wiadopt.org to see if we have the following materials available.

RESOURCES:

Suggested Resources Available to Increase Your Knowledge and Understanding of This Topic

RECOMMENDED READING:

- **Outcome of Children Prenatally Exposed to Cocaine and Other Drugs: A Path Analysis of Three-Year Data.** Pediatrics 92 (3): 396-402, 1993. Azuma, S.D., and Chasnoff, I.J.
- **The Clearinghouse for Drug Exposed Children Newsletter.** Division of Behavioral and Developmental Pediatrics. University of California, San Francisco.
- **Working with FAS Children: A Handbook for Caregivers of FAS/FAE Children.** Cornish, Jean.
- **Maternal Cocaine Use Pregnancy: Effect on the Newborn Infant.** Pediatrics 84:205-210, 1989. Hadeed, A.J. and Siegel, S.R.
- **The Effect of Prenatal Cocaine Exposure and Child Outcome: Lessons from the Past.** Infant Mental Health Journal 15(2): 107-120, 1994. Lester, B.M., and Tronick E.
- **The Problem of Prenatal Cocaine Exposure: A Rush to Judgment.** JAMA 267: 406-408, 1992. Mayes, L.C.; Granger, R.H.; Bornstein, M.H.; and Zuckerman, B.
- **Fantastic Antone Succeeds: Experiences in Educating Children with FAS.** National Organization on Fetal Alcohol Syndrome.
- **Effect of Cocaine Use on the Fetus.** Mechanisms Dis 327(6):399-407, 1992. Volpe, J.J.

AUDIOVISUAL MATERIALS:

- **Children Exposed to Crack and Cocaine.** (audiocassette) Van Bremen, Jane.
- **Fetal Alcohol Syndrome: What We Need to Know.** (audiocassette) DeVries, Jocie and Collins, Vincent.
- **Issues in Parenting Children With Fetal Alcohol Syndrome.** (audiocassette) Krippner, Pat.
- **Broken Cord (fetal alcohol).** (video) Dorris, Michael.

SUPPORT GROUPS & WEBSITES:

- **Adoption Resources of Wisconsin ...** www.wiadopt.org
- **Family Empowerment Network: Supporting Families Affected by FAS/FAE ...** gwilton@facstaff.wisc.edu.
- **The FAS Family Resource Institute ...** P. O. Box 2525, Lynwood, WA 98036; or call (206) 778-4048.
- **NOFAS. National Organization on Fetal Alcohol Syndrome ...** www.nofas.org
- **Prevention Primer: Birth Defects and Adverse Birth Outcomes ...** www.health.org/govpubs/phd627/birthdef.htm

Services of Adoption Resources of Wisconsin Include:

- Resource for Adoption Information
- Pre-Adoption Information & Referral
- Training for Foster & Adoptive Families
- Advocacy for Children & Families
- Family Resource Center
- Post Adoption Services

ACTION PLAN CONTINUED ...

When possible, try to "redirect" behavior. If you see your child becoming angry over something trivial, you can try to redirect him/her by mentioning something of interest or suggesting a new activity.

Since many of these children have difficulty controlling their impulses and tend to overreact to stimuli, try to limit or forbid situations where your child will become over-stimulated (e.g., a horror movie or a particularly crowded mall).

Try to avoid power struggles; no one wins and your child will only become resentful. Whenever possible, have your child participate in problem-solving, e.g., "Your room needs to be cleaned before this weekend. What is your solution?"

Make sure to educate as many people in contact with your child as possible. If these people understand why your child acts in a certain way they are more likely to become your child's ally than enemy.

Expect your child to show some developmental delays. Your child may always be a few years behind schedule. For example, one study suggests that people with FAS do not experience significant integration (e.g., being able to live independently) until they are between the ages of 25-30 rather than 18-22.

Provide positive feedback. Whenever possible, notice and comment on your child's progress. Your child is likely to get more than enough negative feedback so let your home be a place where he/she can feel valued.

Help your child realize that your love is unconditional. Let him/her know that despite misbehaviors your love will remain constant.

Make these concepts your watchwords: Structure, Consistency, Brevity, Persistence and Love.



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