**Fetal Alcohol Syndrome Disorders and Neonatal Abstinence Syndrome: A Guide for Foster Parents**

**Introduction to Fetal Alcohol Syndrome Disorders**

Alcohol is the most used and abused drug in America. Estimates are that 20% of American women drink enough during pregnancy to put their child at risk. Children with alcohol effects face lifelong struggles with physical delays, physical abnormalities, learning disabilities and brain dysfunction. Up to 3 cases for every 1000 births translates to as many as 12,000 cases per year. Other experts estimate that up to 40,000 children yearly are born with FASD. Children with alcohol effects are born into families affected by alcohol and addiction. Many of these children end up in the foster care system.

(Self-Study 2006)

* 20% to 30% of women have reported drinking at some point during pregnancy – most typically during the first trimester
* More than 8% of women have reported binge drinking at some time during pregnancy—most typically during the first trimester
* More than 9% of pregnant women reported drinking alcohol in the previous month
* More than 2% of pregnant women reported binge drinking in the previous month (4 or more drinks per occasion)

(Fetal Alcohol Exposure- National Institute on Alcohol Abuse and Alcoholism and Phung, et al 2011)

**What is Fetal Alcohol Syndrome Disorders (FASD)?**

*[A}n umbrella term describing the range of effects that can occur in an individual whose mother drank during pregnancy. These effects may include physical, mental, behavioral and/or learning disabilities with possible lifelong implications.* (Chasnoff 2011)

**How is FASD different from Fetal Alcohol Syndrome (FAS)**

*Fetal Alcohol Syndrome (FAS) is the original name given to a cluster of physical and mental defects present from birth that is the direct result of a woman’s consuming alcoholic beverages while pregnant.* (Chasnoff 2011)

**Infants with FAS have signs in 3 categories:**

1. Growth Deficiencies

At birth, tend to have lower than normal birthweight. As they grow older they tend to be small for their age falling at or below the 10th percentile for reduced weight or height at any point after birth.

1. Facial Dysmorphology

Changes in facial features consisting of an overall flattening of the middle portion of the face. As a result, children with FAS exhibit

* 1. Extra skin folds coming down around the inner angle of the eye
  2. Small eye openings
  3. No groove or crease running from the bottom of the nose to the top of the lip
  4. Thin upper lip
  5. Small mouth with a high arched palate
  6. Small teeth with poor enamel coating
  7. Low-set ears

1. Central Nervous System Impairment

The average IQ of a child with FAS is 68 compared to 100 for the average child. More importantly, even those with a normal IQ have difficulty with behavioral regulation, impulsivity, social deficits and poor judgement causing problems in the classroom and home.

To make a definitive diagnosis of FAS, medical professionals require a positive history of maternal drinking during pregnancy.

(Chasnoff 2011.)

**Fetal Alcohol Effects (FAE)**

In the past, if a child was born who showed partial or no apparent physical signs of FAS, but whose mother was known to have drank during pregnancy and the child has intellectual, behavior, or emotional development difficulties, they were said to have Fetal Alcohol Effects. The current diagnosis for children who do not meet all three diagnostic categories of FAS are said to have Alcohol-Related Neurodevelopment Disorder (ARND) or Alcohol-Related Birth Defects (ARBD).

(Chasnoff 2011.)

**Diagnosis**

Diagnosis can be very difficult. It is not as straightforward as the terminology implies. It is often unknown if the mother drank during pregnancy particularly with adopted or foster children. Facial changes in children have been the essential component of diagnosis. However new research indicates that growth status may be the primary component.

Without a proper diagnosis, children are not eligible for early intervention and school-based treatment programs, nor will insurance companies pay for related health care interventions.

In 2005, the Centers for Disease Control and Prevention published guidelines. The goal was to clarify diagnosis, but in many respects, made it more difficult. Therefore, foster and adoptive parents are encouraged to:

1. Get as much information as possible about mother’s drinking during pregnancy
2. Get a comprehensive evaluation by an experienced professional
3. Advocate for their child so that they receive early interventions.

(Chasnoff 2011)

**Hidden Disability**

What is important to remember is that these disorders are not a milder form of FAS. “FASD refers to the whole spectrum of alcohol exposure related effects, but there is one that seems constant – impact on brain development. A child may have no physical facial characteristics of alcohol exposure, but may be profoundly impacted because of the damage done to his brain during fetal development.”

Children with FASD have varying degrees of brain dysfunction. FASD may go unnoticed.

(Self-Study 2006)

Hand-out “Common Misconceptions About Fetal Alcohol Spectrum Disorders (FASD)”

**Effects of FASD**

1. Physical Effects
2. Processing Effects
3. Behavioral Effects

See handout: Effects of Prenatal Exposure to Alcohol from Self Study Course: Adolescents with Fetal Alcohol Spectrum Disorder (June 2006).

**Treatment of FASD**

There is no cure for FASD, but many studies indicated that early treatment services can minimize the effects of the child’s prognosis. The treatments include medication, behavior and education therapy, and parent training.

**Supporting Foster Parents of Children with FASD**

* Parents need understandable and practical information about FASD.
* Parents need a substantial amount of support. Children with FASD need a great deal of supervision. (Day care, respite care, and other relief)
* Support network of family, friends and communities
* Experienced and compassionate professionals
* Community resources
* Special education programs
* Income assistance to pay for therapies
* Foster home characteristics should include: parents who are calm and low-key with stable, predictable lives
* Collaboration with school system
* Support groups

(Practice Notes 1997 and Parenting Children with Fetal Alcohol Syndrome Disorders 2011)

**Introduction to Neonatal Abstinence Syndrome (NAS)**

The incidence of Neonatal Abstinence Syndrome (NAS) is increasing rapidly in the United States. In a study from Florida, the number of babies admitted to the Neonatal Intensive Care Unit (NICU) increased 10-fold between 2005 and 2011. These mothers generally lead risky lifestyles and often have multiple social, nutritional, physical and mental health problems. Many of these babies end up in foster care.

(Kocherlakota 2014)

**What is Neonatal Abstinence Syndrome (NAS)**

Technically, NAS is a group of problems that occur in a newborn who was exposed to addictive opiate drugs while in the mother’s womb. These drugs include heroin, codeine, oxycodone, methadone or buprenenorphine. However, withdrawal symptoms may occur in babies exposed to alcohol, benzodiazepines, barbiturates, and SSRI antidepressants. Babies of mothers who use other addictive drugs (nicotine, amphetamines, cocaine, marijuana) may have long-term problems. While there is no clear evidence of NAS for other drugs, they may contribute to the severity of a baby’s NAS symptoms.

(Neonatal Abstinence Syndrome 2015)

**Symptoms**

The signs of NAS are

* High-pitched cries or crankiness
* Stiff arms, legs and back
* Trouble sleeping
* Shaking, jitters, or lots of sucking
* Vomiting due to overeating or crankiness
* Fast breathing and/or stuffy nose
* Sneezing or yawning a lot
* Irritation on diaper area due to loose, watery stools
* Irritation on face, back of head, arms, and/or legs due to restlessness
* Poor weight gain after a few days of life
* Seizures

(Neonatal Abstinence Syndrome: A Guide for Families)

Handout: Parent/Caregiver Education of NAS Symptoms

**In-Hospital Treatment**

NAS babies are usually hospitalized for one to four weeks for withdrawal. Sometimes this can go on for much longer, particularly if the baby was premature.

Nonpharmacological Care is the first option and involves:

* Gentle handling
* Demand feeding
* Careful avoidance of waking the sleeping infant
* Swaddling lessens stimulation, decreases crying times, and promotes sleep that is more sustained.
* Continuous minimal stimulation practices with dim light and low noise must be implemented.
* High-calorie formula and thickened feeds to meet nutritional and metabolic demands.
* Kangaroo care.
* Water beds (but not rocking beds)
* Pacifiers
* Music therapy
* Holding, cuddling, and manual rocking

Pharmacological Care is used when nonpharmacological methods fail to control the signs and symptoms, withdrawal scores remain high, serious signs such as seizures are observed, severe dehydration. 27% to 91% of babies with NAS will need drug intervention.

Morphine is the most commonly used medication. Methadone and Buprenorphine are also used. For nonopiate NAS, phenobarbital is the drug of choice. Clonidine may also be used.

(Kocherlakota 2014)

**Discharge**

Discharge from the hospital occurs when the baby shows no major signs of withdrawal, is sleeping well, gaining weight and maintaining good scores with minimal medication support. The baby will need a safe, stable home environment and continue the nonpharmacological care.

(Kocherlakota 2014)

**Follow-Up for NAS**

The baby needs

* Assessments to identify motor deficits, cognitive delays, brain size
* Psycho-behavioral assessments to identify hyperactivity, impulsivity, attention-deficit
* Assessments for vision problems
* Growth and nutritional assessments
* Family support assessments

(Kocherlakota 2014)

**What to Expect When the Baby Leaves the Hospital**

* Problems feeding
* Slow weight gain
* Crankiness
* Sleep Problems
* Sneezing, stuffy nose, and trouble breathing

Babies with NAS tend to cry more often and easily. To comfort the baby

* Settle into a quiet, low lit room for feedings
* Gently rock or sway the baby to calm but not during feedings
* If you get upset, walk away and take deep breaths for a few minutes
* Never shake your baby or put anything over the baby’s face to quiet the baby
* Call somebody if you feel upset, angry, scared or need help.

**How to Support and Care for Your Baby**

* Make the baby comfortable by setting up a routine
* Let few people visit
* Talk softly
* Keep room quiet and dim
* Let baby sleep as long as needed without being woken suddenly
* Make feeding time quiet and calm
* Burp your baby often
* Learn to spot “I am upset” signs
* When baby is upset, stop what you are doing, hold your baby skin-to-skin or gently swaddle him or her in a blanket on your chest.
* Gently and slowly introduce new things to your baby, one at a time
* As your baby becomes calmer for longer periods, start checking to seek if they might like to have the swaddling loosened.
* No daycare for two months

(Neonatal Abstinence Syndrome: A Guide For Families)

**Long Term Effects of NAS**

There are few studies looking at the long term effects of NAS. However, mothers abusing opioids often abuse other substances including alcohol for which we do know the effects. It is likely that NAS babies will have lifelong disabilities.

(Kocherlakota 2014)

**Tips for Foster and Adoptive Parents**

1. Work with informed professionals in quality adoption agencies.
2. Explore your feelings about alcohol and drug abuse, particularly among pregnant women
3. Discuss the child’s background with your social worker so that you have a realist picture of the birth parents’ substance use and related lifestyle.
4. Ask for written summaries of the child’s diagnoses, medical complications, treatment services, and necessary followup care
5. Ask for information on services and resources to meet the child’s needs, including eligibility for adoption subsidies and Medicaid.
6. Find out how to reduce the impact of the child’s biological risks by providing a nurturing, responsive, and healthy caring environment.
7. Recognize that you must be prepared for and able to tolerate the uncertainties that are part of adopting a child prenatally exposed to drugs or alcohol.
8. Resist negative stereotypes of children prenatally exposed to drugs or alcohol, which ignore the individuality of each child and the role of a healthy environment.
9. Recognize the importance of timely identification of problems and early intervention.

(Adopting and Fostering Children with Fetal Alcohol Spectrum Disorders 2007.)

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Handout – from Self-Study Course: Fetal Alcohol Spectrum Disorder: An Introduction for Foster Parents. Alaska Center for Resource Families (Revised June, 2006)

**Common Misconceptions About Fetal Alcohol**

**Spectrum Disorders (FASD)**

*This list has been adapted and modified from the original listing by Ann P. Streissguth, Ph.D.*

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*MISCONCEPTION #1:* **FASD means mental retardation.**

*IN FACT:* -Some people with FASD are mentally retarded, others have normal

intelligence.

-They are brain damaged and have specific areas of strengths and

weakness. It’s similar to people who have sustained brain injury from an

auto accident.

*MISCONCEPTION #2:* **The behavior problems associated with FASD are all the result of**

**poor parenting or a bad environment.**

*IN FACT:* -Being brain damaged can lead to behavior problems because brain

damaged people don't process information the same ways that

other people do, so they don't always behave like others expect them to.

-Brain damaged children are hard to raise in the best environments.

Parents need help, not criticism.

*MISCONCEPTION #3:* **Children will outgrow it when they grow up.**

*IN FACT:* -FASD lasts a lifetime. The type of problems will change with each age.

-It takes a longer period of sheltered living for FAS children to grow up.

*MISCONCEPTION #4:* **To admit children are brain damaged is to give up on them.**

*IN FACT:* -Have we given up on children with other birth defects?

*MISCONCEPTION #5:* **Diagnosing children with FASD will brand them for life.**

*IN FACT:* -A diagnosis tells you what the problem is, helps you figure out how to

treat the problem and relieves the person of having to meet unrealistic

expectations.

*MISCONCEPTION #6:* **We now know how to solve the problem of FASD.**

*IN FACT:* -Research is desperately needed. The magnitude of the problem

necessitates more research.

*MISCONCEPTION #7:* **Mothers of these children had an easy choice not to drink during**

**pregnancy. Through callous indifference, these mothers**

**permanently damaged their children.**

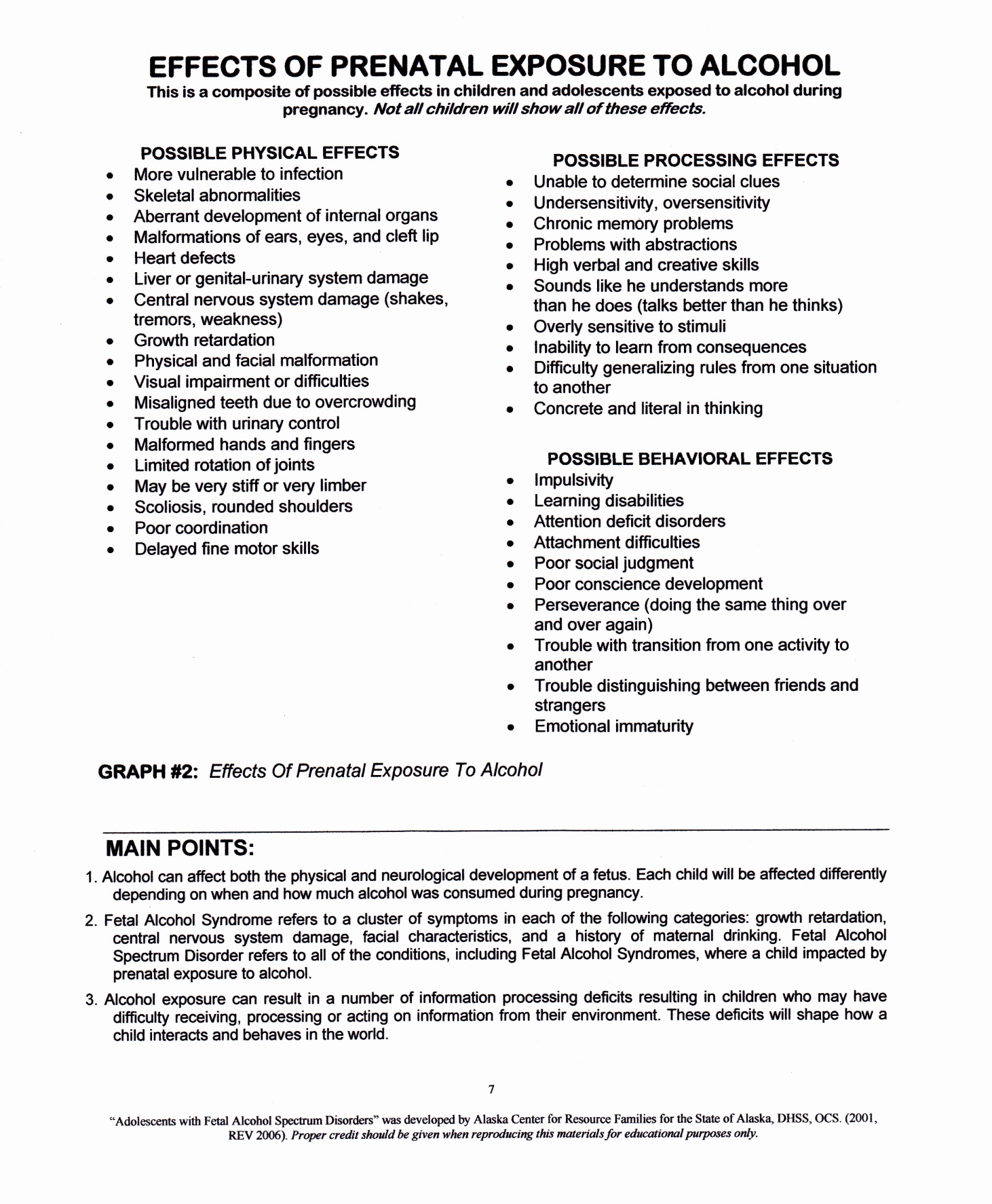
*IN FACT:* -Birth mothers of children with FASD need help with their alcoholism

and/or with birth control.

-Pregnancy is an excellent time for alcohol abusing mothers to stop

drinking by they need help.

Hand-Out From: Self-Study Course: Adolescents with Fetal Alcohol Spectrum Disorder. (June 2006)

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What is Neonatal Abstinence Syndrome (NAS)?

**When will my baby show signs of NAS?**

Most babies show signs of withdrawal, or NAS, between 1 and 5 days after birth. The time it takes for signs to show can depend on how much and what kind of medicine or drug the baby’s mother took and for how long. It also can depend on whether or not the baby’s mother used other kinds of substances as well, such as alcohol, tobacco, or additional medicines.

**It is very important to tell your nurse and your baby’s doctors about all medicines and drugs used during your pregnancy.** This will help them treat your baby.

**What will happen if my baby is in withdrawal?**

Beginning soon after your baby’s birth, nurses will check for certain signs in your baby and give him or her a “score” depending on which NAS signs are present or not. Your baby will be scored every few hours until he or she is ready to go home. The scoring helps doctors decide which types of treatment your baby needs to get better. The nurses will explain the scoring to you. If something is not clear, please ask for more information until your questions are answered.

**What are the signs of NAS?**

High-pitched cries or crankiness

Stiff arms, legs, and back

Trouble sleeping

Shaking, jitters, or lots of sucking

Not eating well or problems sucking

Vomiting due to overeating or crankiness

Fast breathing and/or stuffy nose

Sneezing or yawning a lot

Irritation on diaper area due to loose, watery stools

Irritation on face, back of head, arms, and/or legs due to restlessness

Poor weight gain after a few days of life

Seizures (Also called convulsions, they are hard to spot and can last seconds or minutes. Your baby may suddenly start jerking his or her arms and legs or may go stiff. You may also see eye rolling, staring, lip smacking, sucking, or a change in skin color.) Seizures are a late sign of NAS.

Handout: Neonatal Abstinence Syndrome: A Guide for Families. NAS Project, Ohio Department of Medicaid. <http://www.sstar.org>