This presentation will cover the following topics:

• Terminology
  • Many different terms have been used to describe individuals who are affected by prenatal exposure to alcohol.
  • In this presentation, we will clarify the most current terminology, and the distinctions among some of the different diagnoses applied to individuals with prenatal alcohol exposure.

• Scope and significance
  • We will review the impact of Fetal Alcohol Spectrum Disorders (FASDs) in order to convey the significance of FASDs as a public health problem.

• Drinking rates
  • This presentation will review the rates of alcohol consumption by women of childbearing age and by pregnant women in the U.S.

• Prevalence and Course of FASDs
  • We will also discuss how common FASDs are in the general U.S. population, as well as their prevalence in certain high-risk populations.

• Course
  • The long-term outcomes for individuals with FASDs will be presented.
  • We will review factors that are associated with better and worse outcomes for alcohol-affected individuals

• Clinical presentation
  • We will describe the physical, neurocognitive, and behavioral manifestations of these disorders

• Evaluation
  • Multi-disciplinary approach
  • Components of an evaluation
  • Assessment of prenatal alcohol use
  • Diagnostic distinction among different disorders that fall under the umbrella of FASDs
Terminology, Scope, and Significance
Fetal Alcohol Syndrome (FAS) is a preventable birth defect that is caused by a woman consuming alcohol during her pregnancy.

FAS is characterized by a particular pattern of physical sequelae, as well as cognitive and behavioral abnormalities.
- Many of these abnormalities are a reflection of the damage that was done to the brain of the developing fetus.

FAS is associated with lifelong impairments.
- Individuals with FAS or another alcohol related condition do not “outgrow” this disorder over time.
  - Long-term studies that have followed individuals with FAS or other alcohol related conditions into adolescence and/or adulthood have found persistent cognitive, behavioral, and physical problems (Steinhausen & Spohr, 1998; Streissguth et al., 2004; Streissguth & O’Malley, 2000).
  - Affected individuals are likely to require services and support throughout the life span.
• Fetal Alcohol Spectrum Disorders (FASDs) is a relatively new term that has come into usage in order to convey the fact that although some individuals with prenatal alcohol exposure will meet the full criteria for a diagnosis of FAS, in fact, the majority of individuals with prenatal alcohol exposure exhibit some but not all of the criteria of FAS (Consensus statement on FASDs issued at FASD Terminology Summit hosted by NOFAS on April 7, 2004).

• The term FASDs is meant to convey that there is a continuum of effects, and that individuals can be mildly affected in one area, but may be moderately or severely affected in another area.

• The term FASDs is not a clinical diagnosis in and of itself, but is an umbrella term intended to include several alcohol related diagnoses, including Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorder (ARND), Alcohol Related Birth Defects (ARBD).

• The latter three diagnostic terms (Partial FAS, ARND, and ARBD) were proposed in the Institute of Medicine’s report, *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment* (Stratton, Howe, & Battaglia, 1996), for individuals who do not meet all the criteria for FAS.

• The term, Fetal Alcohol Effects (FAE), has also been used previously to describe individuals who do not exhibit all the sequelae of FAS (e.g., individual does not exhibit all the characteristic facial features), but still have experienced significant impairments associated with prenatal alcohol exposure. However, this term is used less frequently in the current literature.
• FAS represents the most common known cause of mental retardation, which suggests that the most common known cause of mental retardation is potentially 100% preventable.

• Estimated costs for FAS vary. However:
  • The most recent estimates by NIAAA indicate that FAS costs the U.S. over 4 billion dollars per year. When considering the costs for the entire spectrum of FASDs, the estimates rise to approximately 9.7 billion dollars per year.
  • The average lifetime cost per individual with FAS is estimated to be over 2 million dollars (SAMHSA FASD Center for Excellence), although costs per individual range from $860,000 to 4.2 million (NOFAS)

• Despite the fact that FAS was identified in this country more than 30 years ago (Jones & Smith, 1973), and despite intensive public awareness campaigns, prenatal alcohol exposure continues to be a significant public health concern.

• Public awareness messages (i.e., alcohol warning labels) do not appear to be very effective for women who are moderate or heavy drinkers (Hankin et al., 1996).

• Even when women are relatively knowledgeable about the risks of prenatal alcohol use, this knowledge does not necessarily translate into healthy behavior during pregnancy. A recent study found that women’s pre-pregnancy drinking was a much stronger predictor of their prenatal drinking than was their knowledge regarding the risks of prenatal alcohol use (Chang, McNamara, Orav, & Wilkins-Haug, 2006).

• Approximately 1 in 8 pregnant women (or 500,000 pregnant women) consumes one or more drinks per week. 80,000 of those women are drinking at levels that are associated with significant negative effects on fetal development. Furthermore, more than half of non-pregnant women report drinking alcohol, and 1 in 8 report binge drinking in the prior month. Given that almost half of the pregnancies in this country are unplanned, and that many women are unaware they are pregnant until the sixth week of pregnancy, prenatal alcohol exposure continues to represent a major public health concern (Floyd & Sidhu, 2004).
Alcohol Use and Pregnant Women
Part of the challenge in preventing alcohol-exposed pregnancy stems from the fact that alcohol is a legal drug commonly used by many adults, including women.

In order to appreciate the scope of alcohol use by women in the United States, it can be helpful to look at rates of drinking among both non-pregnant women of childbearing age and pregnant women.

Rates of drinking among non-pregnant women of childbearing age

- Important to look at alcohol use among this group because:
  - Approximately one half of the pregnancies in the U.S. are unplanned (Finer & Henshaw, 2006)
  - Many women do not immediately realize they are pregnant and continue to drink at pre-pregnancy levels until pregnancy is confirmed
    - More alarmingly, one study found that 60% of frequent drinkers were not aware of their pregnancy until after their 4th week of gestation, and 30% were not aware until after their 6th week of gestation (Floyd, Decoufle, & Hungerford, 1999).
  - Drinking status prior to conception is highly predictive of alcohol use during pregnancy

- Among non-pregnant women of childbearing age:
  - Approximately 53% reported alcohol use in the previous month (CDC, 2002)
  - Regarding the number of women who reported binge drinking (> 5 drinks per occasion) in the previous month, estimates range from 12% (CDC, 2002) to 23.3% (SAMHSA, 2005)

- Rates of drinking among non-pregnant women of childbearing age across different ethnic groups
  - Although exact rates vary across different studies, a fairly consistent finding is that Caucasian women report the highest rates of alcohol consumption when compared with any other group (e.g., Caetano, Ramisetty-Mikler, Floyd, and McGrath, 2006). These patterns hold true with regard to both alcohol use without binge drinking and well as binge drinking.
Rates of drinking among pregnant women

- Rates of any alcohol consumption among pregnant women have not increased over the last decade (CDC, 1997; 2002; 2004).
  - The CDC found rates of 12.4% in 1991 and 10.1% in 2002; SAMHSA reports a rate of 12.1% in 2005.
- However rates of binge drinking and frequent drinking among pregnant women have increased over the last decade (CDC, 1997; 2002; 2004):
  - Binge drinking (defined as > 5 drinks per occasion) increased from 0.7% in 1991 to 1.9% in 2002, a 2.7 fold increase.
  - The National Survey on Drug Use and Health, conducted by SAMSHA (2005) found an even higher rate, with 3.9% of pregnant women reporting binge drinking.
  - Frequent drinking (defined as binge drinking or > 7 drinks per week) increased from 0.8% in 1991 to 1.9% in 2002, a 2.4 fold increase.

- Rates of drinking among pregnant women across different ethnic groups
  - Similar to the patterns found among non-pregnant women, Caucasian women report the highest rates of any alcohol use during pregnancy when compared with any other group (SAMHSA, 2003), although some studies have found that Black, Non-Hispanic women report higher rates of frequent alcohol use or binge drinking during pregnancy than White, non-Hispanic or White, Hispanic women (CDC, 1988; Perreira & Cortes, 2006).
Factors Associated with Alcohol Use in Pregnant Women

- Younger age
- Caucasian
- Less education
- Single
- Unemployed
- Past sexual abuse
- Current or past physical abuse
- Using tobacco or other drugs
- Living with or having partners who are substance users
- Higher levels of depressed mood
- Higher tolerance of alcohol
A number of factors may moderate the impact of prenatal alcohol exposure on a developing fetus.
Con contrary to these beliefs, the type of alcohol consumed is irrelevant. It is the amount of absolute alcohol consumed that is relevant with regards to the impact on the developing fetus.

- "Hard liquor would be bad...If it burns going down..." (Branco & Kaskutsas, 2001)
- There appears to be a common misperception among the public and even some health professionals that some types of alcohol are less damaging to the developing fetus than others.
It is not uncommon for individuals to underestimate how much they're actually drinking. Consequently it is important to educate pregnant women and women of childbearing age about how much alcohol they're consuming and what constitutes a standard drink.

Standard Drink Calculations

- 0.60 ounce of absolute alcohol is equivalent to one standard drink
  - To calculate # of standard drinks:
    • (% absolute alcohol x # ounces)/0.60

- Examples:
  - 12 oz Budweiser: (0.05 x 12 oz)/0.60 = 1 stand. drink
  - 40 oz Olde English: (0.075 x 40 oz)/0.60 = 5 stand. drinks
  - Long Island Iced Tea: (0.40 x 2.25 oz)/0.60 = 1½ stand. drinks
The following all contain equivalent amounts of absolute alcohol

- 12 ounce beer
- 5 ounce glass of wine
- 3 ounce glass of fortified wine
- 1.5 ounce shot of hard liquor
Another question commonly asked is, “How much alcohol is it safe to drink during pregnancy?”

In general, there appears to be a dose-response relationship between maternal drinking and fetal outcomes. That is, children who were exposed to higher levels of alcohol in general show more effects than children who were exposed to lower levels of alcohol (Mattson, Schonfeld, & Riley, 2001).

However, it is important to remember that there is no established safe level of maternal alcohol consumption during pregnancy.

- Cognitive and growth effects have been found with ½ drink three times per week (Day et al., 2002; Day & Richardson, 2004).
- Recent animal studies (e.g., Young & Olney, 2006) suggest that brief, low-dose exposure may be enough to kill developing brain cells, suggesting that there is no known safe level of alcohol consumption during pregnancy.
- The peak blood alcohol concentration (BAC) to which the embryo or fetus is exposed is a key factor that affects fetal brain development—that is, higher BAC levels are associated with more severe fetal brain injury (Maier & West, 2001).
  - Women vary in their ability to metabolize alcohol for a number of reasons (e.g., age, genetics), and thus two women may drink the same amount of alcohol and have very different BAC levels. Thus, it is impossible to predict with any certainty what level of alcohol might lead to a very low BAC for one woman and what level might lead to a very high BAC for another woman.
- Although there is no established safe level of maternal alcohol consumption during pregnancy, a woman’s pattern of drinking may have an impact on the likelihood and severity of fetal brain damage.
  - Binge drinking appears to be particularly harmful to the developing fetus, probably because it’s associated with higher blood alcohol concentrations
  - Animal studies demonstrate that:
    - If the same total dose of alcohol is administered in two patterns: continuous exposure (24 hours per day) or condensed exposure (12 hours per day), the group with condensed exposure has higher BAC levels and lower brain weights than the group with continuous exposure (Price & West, 1986).
    - A lower dose of alcohol can result in higher BAC levels and greater damage to the developing brain than a higher dose of alcohol, if the lower dose is administered in a more condensed pattern (e.g., over a 4 or 6 hour period), and the higher dose is administered in a more continuous pattern (e.g., over a 24 period) (Bonthius & West, 1990).

- Human studies
  - Binge drinking has been found to be a stronger predictor of neurobehavioral deficits, including problems with attention, memory and cognitive processing than other more commonly used measures of prenatal alcohol consumption, including average amount per day and frequency of drinking (Streissguth, Barr, & Sampson, 1990).
• Timing of Exposure
  • Alcohol has different effects on developing fetus depending on when the exposure occurs
    • **1st trimester**
      • Major morphological/structural abnormalities
        • Facial features
        • Because organogenesis occurs 2-8 weeks, exposure during this time may result in cardiac or renal malformations
    • **2nd trimester**
      • Increased risk of spontaneous abortion
    • **3rd trimester**
      • Growth retardation
      • Particularly vulnerable period for brain development
        • However, because central nervous system development occurs throughout pregnancy, *again there is no safe period during pregnancy for alcohol consumption*
Prevalence, Course, and Clinical Presentation of FASDs
Rates for FASDs

- Birth prevalence of FAS: .5 - 2/1000 births
- All alcohol related disorders (FASDs): at least 10/1000 births
- Approximately 40,000 children born with FAS or a related disorder per year
- More common than some other more well-known birth defects

- Most recent studies (May & Gossage, 2001) suggests that the overall prevalence of FAS in the United States is between .5 and 2 per 1,000 births
  - If we include the full spectrum (e.g., ARBD, ARND), at least 1 in 100 (10 in 1,000)
  - This estimate translates into approximately 40,000 children every year born with FAS or another alcohol related disorder.

- Studies in other countries reveal considerable variation in the prevalence of FAS and FASDs
  - In a study of a random sample of schools in Italy, Ceccanti et al. (2007) found a rate of 12% for FASDs (2% for FAS, 9% for Partial FAS, 1% for ARND).
  - In a study conducted in Western Cape Province in South Africa (Viljoen et al., 2005), the prevalence for FAS was estimated to be 65.2-74.2 per 1,000.
    - Risk factors in the South African study included living in rural areas and being a farm worker. In South Africa, many of the workers were traditionally paid in alcohol. Although this system has since been outlawed, it has left a legacy of heavy, frequent alcohol consumption among farm workers.

- Studies in high-risk populations
  - A recent study of consecutive admissions to a child psychiatric inpatient unit found 30% of the patients had documented prenatal alcohol exposure and, within the exposed group, 26% met full criteria for FAS (or 8% of the entire group) (O’Connor, McCracken, & Best, 2006)
  - Foster care (Astley, Stachowiak, Clarren, & Clausen, 2002)
    - Found rates of 10-15/1,000, which is 10-15 times higher than in general population

- Notably, FASDs are more common than other more well-known birth defects, such as Down syndrome, with an estimated prevalence of 1 in 800, and autism, with an estimated prevalence of 1 in 500 to 1 in 167.
A number of studies (Famy, Streissguth, & Unis, 1998; Steinhausen & Spohr, 1998; Streissguth et al., 2004; Streissguth, Barr, Kogan & Bookstein, 1996; Streissguth & O’Malley, 2000) have demonstrated that individuals with FASDs are vulnerable to a broad array of negative psychological, social, and behavioral outcomes.

Longitudinal research has also identified risk factors that have been found to increase the risk for negative outcomes among individuals with FASDs (Streissguth et al., 2004).

- Being diagnosed with FAS or another alcohol related disorder after age 12
- Living a lower percent of one’s life in a nurturing, stable, living environment
- Living a higher percent of one’s life with someone who is abusing alcohol and/or drugs
- Being a victim of physical or sexual or domestic violence
- Being a male
- Being diagnosed with Fetal Alcohol Effects rather than Fetal Alcohol Syndrome
- Having an IQ > 70

It is notable that individuals who do not meet the full criteria for FAS, but instead are diagnosed with Fetal Alcohol Effects and those with IQ’s above 70 are at greater risk for adverse outcomes, including disrupted school experiences and alcohol/drug problems (for both groups) and for trouble with the law (for individuals diagnosed with FAE). It seems likely that these individuals may be at increased risk because they may be less readily identified as needing services, and are less likely to qualify for and receive services than either individuals who meet full criteria for FAS or those with IQs below 70.
Growth Deficiency

- Prenatal and/or postnatal growth deficiency
- May see growth problems in height, weight, or both
- Growth deficits may persist in many alcohol-exposed individuals, although may see some catch up in adolescence, more often in weight than in height.

Clinical Presentation: Growth Deficiency

- Growth Deficiency
  - There is evidence from both animal and human studies that prenatal exposure to alcohol is associated with growth deficits with respect to both height and weight, and these deficits are apparent at birth and in early infancy (Day & Richardson, 2004) and persist into childhood (Klug, Burd, Martsolf, & Ebertowski, 2003) and adolescence (Day et al., 2002).
  - The relationship between prenatal alcohol exposure and growth deficiency appears to be linear, with effects documented even at relatively low levels of exposure (Day & Richardson, 2004). Additionally, the time of exposure may also determine the level of growth effects (Day et al., 1989; Streissguth, Martin, Martin, & Barr, 1981).
    - Not surprisingly, however, the most significant growth deficits appear to be associated with continuous and heavy drinking throughout the pregnancy (Smith, Coles, Lancaster, Fernhoof, & Falek, 1986).
  - These growth effects may persist in many, but not all, individuals exposed to alcohol in utero. Such variations may be a function of interactions between the individual's prenatal exposure and postnatal environment, with growth effects more likely to persist among individuals from less advantaged backgrounds (Day & Richardson, 2004).
• The photograph on the left provides an example of facial malformations in a child who was exposed to alcohol in utero.

• The photograph on the right depicts facial malformations produced in mice by in utero exposure to alcohol.

  • This study demonstrated that brief exposure (on gestational day 7) to two doses of ethanol was sufficient to produce the major facial dysmorphism observable in the alcohol-exposed mouse on the left. For comparison, the mouse on the far right was not exposed to alcohol.

  • Eye malformations were common, including growth deficiency of the eye (as indicated by decreased length of the palpebral fissures), as well as coloboma of the iris (defect in the structure of the iris), microphthalmia (one or both eyes are abnormally small) and anophthalmia (absence of one or both eyes).

  • Malformations in the nasal and upper lip regions can also be observed, including a small nose, and a reduced or absent philtrum, and a long, but thin upper lip.
The child in this photo exhibits the three essential facial features characteristic of FAS:

- Short palpebral fissures
- Smooth philtrum
- Thin upper lip
Brain damage resulting from prenatal alcohol exposure

Photo: Sterling Clarren, University of Washington, 1986

• Comparison of the brain of a baby with heavy prenatal alcohol exposure on the left, to the brain of a baby of similar age with no prenatal alcohol exposure on the right.
Among individuals with prenatal alcohol exposure, a wealth of studies have documented structural brain abnormalities, including:

- Smaller overall brain volume
  - In addition to reductions in brain volume, white matter density appears to be reduced, but gray matter density is increased in certain regions
  - The cerebellum, which plays a role in movement, especially balance and coordination, as well as attentional abilities has been found to be smaller, and characterized by abnormalities, particularly in the anterior regions of the vermis
  - The corpus callosum has been found to be smaller, thinning or completely absent (agenesis)
    - Agenesis is present in approximately 0.3% of the general population and about 2.3% in developmentally disabled populations. Although the true incidence among FAS populations is unknown, it is has been suggested that FAS may be the most common cause of agenesis of the corpus callosum.
    - Reduction in size appears specific to the splenium.
    - In addition to decreased size, abnormalities in shape and location have been documented.
    - Imaging studies have also documented white matter anomalies in the corpus callosum. A recent study utilizing diffusion tensor and T1-weighted magnetic resonance imaging to examine white matter integrity in children and adolescents with FASDs found that compared to controls, individuals with FASDs exhibited decreased fractional anisotropy in the right lateral temporal lobe and bilaterally in the lateral aspects of the splenium of the corpus callosum.
- The basal ganglia, which governs voluntary movement, and some cognitive functions, such as ability to shift from task to another, inhibition of inappropriate behavior, and spatial memory, has been found to be smaller, primarily due to reduced size of the caudate
• Although FAS is the most common known cause of mental retardation, most children with FASDs do not qualify for a diagnosis of mental retardation.
  • The cognitive abilities of individuals affected by prenatal alcohol exposure can vary widely, with studies of this population documenting IQ's ranging from the severe range of mental retardation to the above average range of intellectual functioning.
  • In general, individuals with Fetal Alcohol Spectrum Disorders exhibit lower overall intellectual functioning compared with the general population (May et al., 2006; Streissguth & O’Malley, 2001).
    • For example, Streissguth et al. (2004) found in a sample of 415 adolescents and adults a mean IQ of 80 for patients diagnosed with FAS and a mean IQ of 88 for those diagnosed with Fetal Alcohol Effects (FAE).
    • In a sample of children with prenatal alcohol exposure, Mattson, Riley, Gramling, Delis, and Jones (1997) found a mean IQ of 74.4 among those who met full criteria for FAS, and a mean IQ of 83.6 for those who did not exhibit the physical features of FAS.

• An extremely important point to note is that many alcohol-affected individuals with normal IQs still exhibit significant deficits in other domains. For example,
  • Deficits in executive functioning have been found to be greater in exposed individuals than what would be expected based on IQ scores (Connor et al., 2000); other studies have demonstrated that problems with executive functioning are still apparent even when controlling for IQ (Kodituwakku et al., 2001; Schonfeld et al., 2001).
  • Similarly, the adaptive functioning (the ability to carry out developmentally expected tasks of everyday functioning) of alcohol-affected individuals is often well below what would be expected given their IQs.
Attentional problems

- Individuals with FASDs commonly present with clinical symptoms consistent with a diagnosis of ADHD.
- Individuals with FASDs are most frequently diagnosed as the inattentive subtype of ADHD as defined by the DSM-IV (Kapp and O’Malley, 2001).
- Prevalence rates of ADHD increase significantly with increasing levels of prenatal alcohol exposure (Bhatara, Loudenberg, & Ellis, 2006).
- ADHD symptoms are particularly evident in childhood and early adolescence (Nanson and Hiscock, 1990; Streissguth et al., 1994) and the proposed link between FASDs and ADHD is based on the premise that the teratogenic effects of ethanol exposure disturb the neurochemical and structural development of the fetal brain.
- There may be differences in the types of attentional problems exhibited by individuals with FASDs as compared to non-alcohol exposed individuals with ADHD.
  - In a study examining different aspects of attention, children with FAS or FAE performed most poorly on measures of encoding (the ability to learn and manipulate new information) and shifting attention; in contrast, non-exposed children with ADHD performed most poorly on measures of focused and sustained attention (Coles et al., 1997). However, it is important to note that children with FASDs also show deficits in focused and sustained attention when compared to non-exposed, non-psychiatric controls (see Jacobson & Jacobson, 2002).

Learning and memory problems

- Verbal learning problems
  - Individuals with prenatal alcohol exposure appear to have difficulties acquiring new verbal information (Mattson, Riley, Delis, Stern, & Jones, 1996)
- Memory problems
  - Impairments in both visual and auditory memory (Carmichael Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998) have been observed.
- Difficulties learning from experience
  - Clinical reports frequently describe individuals with prenatal alcohol exposure as being unable to predict that the same behavior will produce the same result no matter how many learning trials they have, and as unable to learn from negative consequences.
• **Speech and language problems**
  - Individuals with FASDs can often be quite talkative, and may appear to have good language skills at a superficial level. However, when their communication skills are examined at a more meaningful level, impairments in several areas emerge, including:
    - Speech disorders, such as articulation problems (Church, Eldis, Blakley, & Bawle, 1997)
    - Receptive language deficits (Mattson & Riley, 1998; May et al., 2006)
    - Expressive language deficits (Church et al., 1997)
    - Poor semantics and syntax (Abkarian, 1992)
    - Poor pragmatics (Abkarian, 1992)

• **Executive functioning**
  - Individuals with prenatal alcohol exposure (including both those that meet full criteria for FAS and those who do not) show impairments in several aspects of executive functioning (for reviews, see Kodituwakku, 2007; Rasmussen, 2005), including:
    - Working memory (Burden, Jacobson, Sokol, Jacobson, 2005; Jacobson et al., 1998; Kodituwakku et al., 1995; Streissguth et al., 1990)
    - Planning (Kodituwakku et al., 1995; Mattson et al., 1999)
    - Verbal and nonverbal fluency (Schonfeld et al., 2001)
    - Concept formation and verbal reasoning (Mattson et al., 1999)
    - Abstract and practical reasoning
    - Nonverbal reasoning (May et al., 2006)
    - Cognitive flexibility (Kodituwakku et al., 1995; Mattson et al., 1999; Schonfeld et al., 2001)
    - Response inhibition (Mattson et al., 1999; Schonfeld et al., 2001)
**CNS Dysfunction**

- Quantitative and numerical concepts
  - Poor arithmetic skills (Aronson & Hagberg, 1998; Streissguth et al., 1991)
  - Clinical reports suggest that individuals with FASDs have difficulties with the concepts of time and money

- Visual-spatial skills

- Motor
  - Fine motor deficits (Barr, Streissguth, Darby, Sampson, 1990; Kalberg et al., 2006)
  - Gross motor deficits (Barr et al., 1990)
  - Impairments in balance (Barr et al., 1990; Roebuck, Simmons, Mattson, & Riley, 1998)
  - Poor coordination (Jones, Smith, Ulleland, & Streissguth, 1973)
The effects of prenatal alcohol exposure are evident from infancy in both animals (Schneider, Roughton, & Lubach, 1997) and humans (e.g., Smith et al., 1986; Streissguth, Barr, & Martin, 1983). Researchers have demonstrated that in infancy, prenatal alcohol exposure is associated with:

• Increased negative affect and higher rates of insecure attachment behavior (O’Connor, 2001; O’Connor, Sigman, & Kasari, 1992)
• Poorer habituation (Streissguth et al., 1983)
• Poorer orientation, specifically difficulty attending to auditory and visual stimuli (Smith et al., 1986)
• Problems with state regulation (Streissguth, 1983)
  • Difficulty maintaining good alert state or good sleep state (instead, frequent alternation)
• Sleep disturbances (shorter duration of sleep, poorer quality of quiet sleep, more restless, and more body movements)
• Poorer autonomic regulation (Smith et al., 1986)
• Increased post-stress cortisol levels (Jacobson, Bihun, & Chiodo, 1999)
• Less mature motor behavior and increased level of activity (Coles et al., 1985)
• Poor sucking and decreased ability to suck, including taking longer to initiate sucking, and decreased intensity of sucking pressure (Ouellette et al., 1977; Martin et al., 1979)
• Feeding difficulties are not uncommon
  • Infants with prenatal alcohol exposure may present in medical settings with failure to thrive (Stratton, Howe, & Battaglia, 1996; Streissguth, 1997).
As children with FASDs enter their preschool years, problems that may have been initially attributed to temperamental difficulties become of increasing concern to parents and other caregivers.

Behavioral disturbances, including problems with inattention, hyperactivity, and impulsivity (Nanson & Hiscock, 1990) may become especially salient as alcohol-affected children have to function in more structured settings, such as preschool or kindergarten.

These children may also be more prone to dysregulation, irritability, temper outbursts; they may also exhibit difficulty dealing with transitions and adapting to change (Streissguth, 1997).

They may have difficulty following instructions, perhaps because of impairments in comprehension and/or executive functioning.

Parents of young children with FASDs have also reported concerns about a failure to perceive danger.
• School problems
  • Increased rates of learning disorders have been reported in children with FAS (Burd et al., 2003)
  • Many alcohol-affected children end up in special education (Aronson & Hagberg, 1998)
  • High rates of externalizing behavior and attentional problems (Bhatara et al., 2006; Sood et al., 2001), are likely to interfere significantly with their school performance.
  • The child may be bringing home poor grades, having difficulty completing homework, and getting into trouble for impulsive or disruptive behavior in class.
  • Parents may hear complaints from teachers regarding the child’s apparent mastery of a skill one day, and complete inability to perform that same skill the following day.
  • The child’s difficulty following directions may sometimes be viewed as willful noncompliance rather than as a reflection of cognitive or executive functioning problems.

• Emotional/behavioral problems
  • Although perhaps less likely to attract the notice of parents and teachers, the emergence of internalizing problems and mood disorders has also been observed in children with prenatal alcohol exposure during this period (O’Connor et al., 2002; O’Connor & Paley, 2005).

• Social problems
  • Prenatally exposed children have shown maladaptive behaviors such as failure to consider the consequences of their actions, difficulty understanding social cues, indiscriminant social behavior, and difficulty communicating in social contexts (Carmichael Olson et al., 1998a; 1998b; Streissguth, 1997; Streissguth et al., 1991).
  • Rated by both their caregivers (Roebuck et al., 1999) and teachers (Brown et al., 1991) as having poorer social skills than unexposed children.
  • When compared to unexposed children with similar deficits in verbal IQ, children with prenatal exposure were more impaired interpersonally than the unexposed group, suggesting that social deficits in these children cannot be explained by low IQ scores alone (Thomas et al., 1998).
  • Parents, however, may mistake their children’s excessive friendliness as an indicator of good social functioning, and may not recognize that their children can be viewed as intrusive or annoying.

• Poor judgment
  • Alcohol-affected children may be easily influenced by others, making them especially vulnerable to exploitation by older, savvier peers, or even adults.
During adolescence, many alcohol-affected individuals can begin to engage in numerous risky behaviors. Parents of adolescents with FASDs may begin to worry about victimization, high-risk behavior, and delinquency (Carmichael Olson & Clarren, 1996), and seemingly with good reason.

School problems are also likely to continue to be a major concern:
- In a longitudinal study of individuals with prenatal alcohol exposure, Streissguth et al. (2004) found that approximately 53% of adolescents with FAS or FAE had been suspended, 29% had been expelled, and 25% had dropped out of school.

Delinquency:
- Schonfeld et al. (2005) reported increased rates of delinquency among adolescents with prenatal alcohol exposure in comparison to non-exposed adolescents.
  - Moreover, in this study individuals with ARND were at greater risk for delinquency than individuals who met the full criteria for FAS, perhaps because the former group may be less readily identified as in need of services.
  - FASDs appear to be overrepresented (Fast, Conry, & Loock, 1999), yet often underidentified (Burd, Selfridge, Klug, & Bakko, 2004) in juvenile detention and correctional settings, further highlighting the need to identify and treat individuals affected by prenatal alcohol exposure.

Inappropriate sexual behavior:
- Difficulties with maintaining appropriate physical boundaries and navigating peer and romantic relationships may become particularly salient among adolescents with FASDs.
  - Streissguth et al. (2004) found that that 58% of adolescents with FAS or FAE had trouble getting along with peers, 48% had engaged in inappropriate sexual behavior, most commonly promiscuity and inappropriate sexual advances.

Alcohol/substance use problems:
- Individuals with FASDs may be especially vulnerable to experimentation with alcohol or illegal drugs. Streissguth et al. (2004) found that that 29% of adolescents with FAS or FAE/ARND had alcohol or drug problems.

If the adolescent has never received a diagnosis of FAS (or related condition), such a diagnosis might not only help redirect intervention in a more productive manner, but may also play an important role in educational planning meetings and even legal proceedings.
  - For example, a diagnosis of FAS may lead school personnel to view an adolescent who is on the verge of being expelled for behavioral problems in a different manner.
• For many affected adults, basic tasks of daily living, such as maintaining steady employment, managing money, and obtaining medical care present major challenges (Streissguth, 1997).

• Furthermore, Carmichael Olson and Clarren (1996) have noted that parents of alcohol-exposed adults “are dealing with their own mortality and the accumulation of secondary disabilities in their adult child” (p. 3) such as trouble with the law and long-term psychiatric disabilities.

• Such concerns do not appear to be unfounded given the poor long-term outcomes documented among adults with prenatal exposure to alcohol.

• Individuals with FASDs also experience significant work problems, and are much less likely to be able live independently (Streissguth & O’Malley, 2000).

  • In their longitudinal study, Streissguth et al. (2004) found that 80% of adults with FAS or FAE could not live independently and 80% had major problems with employment.

  • Executive function deficits in alcohol-affected individuals suggest that even if they have the cognitive capacity to carry out the tasks in a job, they may lack the organizational and planning skills required to perform successfully in many jobs.

• Using structured diagnostic interviews, Famy et al. (1998) found high rates of psychiatric disorders among adults with prenatal exposure to alcohol, including alcohol or drug dependence, depression, psychotic disorders, and various personality disorders.

• Streissguth et al. (2004) reported that 60% of adults with FAS or FAE/ARND had problems with the law, and 50% had either been incarcerated or hospitalized in a psychiatric facility.
Given continued high-risk drinking among pregnant women, there is a compelling need for medical and allied health professionals working with pre-conceptional and pregnant women to be trained to provide screening and counseling in order to prevent FASDs.

- For instance, in a survey of obstetrician-gynecologists in the United States, although 97% stated that they asked their pregnant patients about alcohol consumption, 70% felt unprepared to accurately assess for alcohol use and 65% cited the need for additional training (Diekman et al., 2000). Alarmingly, 56% of physicians thought that some alcohol consumption posed no risk for the fetus.
- Although many well-standardized screening tools are available, research suggests that most physicians are unaware of these tools and do not use them regularly (Diekman et al., 2000; Floyd, O’Connor, Sokol, Bertrand, & Cordero, 2005; Nevin et al., 2002).
- In a recent survey, 45% of pediatricians reported that they never discuss the risks of prenatal alcohol use with adolescent female patients (Gahagan et al., 2006), a population that would be especially important to target with respect to preventing alcohol-exposed pregnancies.
- Furthermore, one study found that 40% of ethnic minority economically disadvantaged women did not receive advice regarding the risks of prenatal drinking and continued to drink during pregnancy (O’Connor & Whaley, 2006).

Improved training in the identification and diagnosis of FASDs is also needed.

- Nevin et al. (2002) found that only 8% of family physicians could identify the three most important features associated with FAS, whereas Elliott et al. (2006) found that only 19% of pediatricians could identify all of the essential features for diagnosing FAS.
- Caley et al. (2008) found in a sample of human service professionals (e.g., child protective services and foster care workers) that almost 50% did not know what facial features might be indicative of FAS. Particularly concerning was the finding that 90% of these respondents indicated that they had not cared for any children with FAS, a surprising figure given the over-representation of prenatally exposed children in foster care and child protective services (Astley, Stachowiak, Clarren, & Clausen, 2002).

Many health care professionals also do not utilize tools that could potentially assist in more accurate diagnosis of individuals with prenatal alcohol exposure, either because they are unaware of their existence or are unsure how to use them.

- Gahagan et al. (2006) found that only 13% of pediatricians relied on standardized criteria for diagnosing FAS in their clinical practice. Furthermore, 77% of pediatricians perceived lack of training as a barrier to making a diagnosis of FAS, whereas only 29% believed it was due to lack of time.
- These gaps in knowledge and skills may explain why some health care professionals may not assess for or detect FASDs, even when a child presents with a history of prenatal alcohol exposure and evidence of prenatal alcohol effects (Stoler & Holmes, 1999).

Obtaining accurate information regarding prenatal alcohol exposure may be challenging sometimes

- Some professionals may be uncomfortable asking biological mothers about their use of alcohol during pregnancy
- Biological mothers may be reluctant to acknowledge prenatal alcohol use, particularly if they are asked in a manner that feels judgmental or blaming
- Foster/adoptive parents often don’t have information about prenatal history

- There can be reluctance on the part of professionals to making a diagnosis because they are concerned it may engender guilt in the mother, or that a diagnosis will stigmatize child and the family
• Early identification is one of the strongest predictors of better outcomes for individuals affected by prenatal alcohol exposure
  
  • Individuals who do not meet full criteria for FAS, but are nonetheless affected by prenatal alcohol exposure, are a particularly important group to identify and treat, as they are at even greater risk for adverse outcomes, such as delinquency, school failure, and alcohol and drug problems.

• Although individuals with FASDs often come to the attention of mental health and medical professionals, they often receive diagnoses that do not take into account their history of prenatal alcohol exposure (e.g., conduct disorder).

  • However, it is essential that this history of prenatal alcohol exposure, along with the attendant cognitive and behavioral deficits be taken into consideration when developing a treatment plan for these individuals.
• This finding highlights the importance of identifying FASDs, in order to educate families and prevent additional alcohol exposed pregnancies.
Multidisciplinary Approach

- These individuals are typically impacted across multiple domains of functioning
- Functioning in one domain often affects functioning in other domains
- Enhances both diagnostic and treatment planning process

• Multidisciplinary Approach
  • Individuals impacted by prenatal alcohol exposure often present with challenges in multiple domains of functioning, and thus can benefit from working with a team of professionals who possess expertise across those various domains.
  • An integrated approach is particularly important because impairments in one domain of functioning (e.g., behavior, language) might often interfere with functioning in another domain (e.g., social, academic), and affected individuals are done a disservice when care is not coordinated across different specialists.
  • Such an approach is likely to lead to more accurate diagnostic decisions and to more comprehensive treatment plans.
  • By capitalizing on the expertise and skills of each of its members, a multidisciplinary team can provide an integrative, detailed assessment of an alcohol-affected individual’s primary areas of difficulty, as well as his or her strengths and resources, and recommend interventions that target the individual's and his or her family’s specific areas of need.
  • Such a team might include physicians, psychologists, social workers, speech and language therapists, educational therapists, occupational therapists, physical therapists, public health nurses, advocates, as well as others.
Components of FASD Evaluation

- Physical examination, including dysmorphology exam
- Standardized diagnostic protocols will increase validity and reliability of diagnosis. Two examples of standardized diagnostic approaches are:

- Note that facial features change with development, and may be easier or more difficult to diagnose FAS depending on individuals age (opinions vary, but early to middle childhood may be easiest time to recognize facial dysmorphology)

- Also note that what is normative for various facial features can differ across ethnic groups, so it is important to use tools that take into account those normative variations. For example, Astley (2004) provides different lip/philtrum guides for Caucasians and African Americans, and is developing additional guides for individuals of Hispanic and Asian descent.

- A comprehensive history should include a thorough review of birth records, medical records, records from social service agencies, school records, as well as interviews with current and past caregivers (to the extent possible). See Paley, Schonfeld, & O'Connor (in press) for an extensive discussion of conducting clinical interviews with parents or caregivers of individuals with prenatal alcohol exposure.

- When evaluating individuals with prenatal alcohol exposure, a comprehensive battery that includes measures of cognitive, neuropsychological (including measures of executive function), academic assessment, adaptive, behavioral, social, and emotional functioning is optimal.

- Such an assessment battery should include measures that have been standardized and normed on diverse samples. Testing results should be interpreted in light of relevant cultural factors, language issues, and environmental experiences.

For an extensive discussion of how to conduct a multidisciplinary evaluation of individuals with FASDs, please see:


• Non-blaming, non-judgmental approach
  • Medical and/or mental health professionals may sometimes have negative feelings towards women who use alcohol (or other substances) during pregnancy that may impact the way in which they ask about alcohol use
  • It is important to examine one’s own biases in order to become more comfortable asking these questions
  • Asking questions about prenatal alcohol use in a neutral, non-blaming manner will likely elicit more forthcoming responses
• When asking about use of any substances during pregnancy, frame the question by asking “How much” rather than “Did you…?”
  • That is, asking “How much alcohol did you drink during your pregnancy?” is typically more effective than asking “Did you drink alcohol during your pregnancy?”
    • Asking HOW MUCH gives a woman permission to acknowledge that she did drink during pregnancy
    • Asking in this manner may also be more effective when interviewing others (e.g., spouse/partner, etc.) about the woman’s alcohol use – it gives them permission to acknowledge any possible use during pregnancy.
• Assess prior to pregnancy, prior to pregnancy recognition, and post pregnancy recognition periods separately
  • Women are often more likely to acknowledge alcohol use prior to pregnancy and prior to pregnancy recognition than after pregnancy recognition
    • Drinking patterns from those earlier time periods are predictive of outcome
Assess prenatal alcohol use as part of general interview and in the context of asking about health habits before and during pregnancy (including nutrition, exercise, stress, etc.).

- For example, “Now I’m going to ask you some questions about your health habits during your pregnancy…”

Inquire about more benign substances first, and then ask about alcohol and other drugs

- For example, ask about consumption of tea, coffee, and caffeinated sodas first

Ask about different types of alcohol

- Consumption of beer, wine, and hard alcohol should be assessed separately
  - Some women may believe that drinking certain types of alcohol is relatively safe (e.g., wine coolers) during pregnancy, and thus may not consider those beverages when asking about prenatal alcohol use
  - If queried about all types of alcohol together, a woman may be more likely to forget or underestimate how much she drank during pregnancy. Asking about consumption of different types of alcohol separately may yield a more accurate estimate.

Assessing pattern of drinking

- Ask about both typical and maximum consumption – that is, a woman may typically drink a certain amount on most occasions (e.g., 2 drinks), but there also may be occasions where a woman drinks much more than her typical amount (e.g., 5 drinks). Because binge drinking is particularly harmful to the developing fetus, it is important to ask both about how much a woman typically drank on most occasions, as well as the most she drank on any one occasion.
  - For example, ask: “Women sometimes drink more than their usual amount on some occasions. Before you knew you were pregnant, what was the most number of drinks you drank on any occasion?
  - It can be helpful to prompt the woman to think about any special occasions on which she might have consumed more alcohol than usual (e.g., a party, a wedding, on vacation, etc.)
Although there is general agreement among these approaches regarding the basic criteria for FAS, there are also some important differences regarding specific thresholds that must be met for the various criteria.

For example, these approaches may differ regarding what specific criteria to use as thresholds for growth deficiency or facial dysmorphology. Despite such challenges, these approaches offer clinicians and researchers better methods for evaluating individuals with prenatal alcohol exposure that will lead to increased validity and reliability in their diagnostic decisions.
In 2004, the CDC’s National Center on Birth Defects and Developmental Disabilities in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the March of Dimes and the National Organization on Fetal Alcohol Syndrome published guidelines for referral and diagnosis of FAS:
(http://www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf)

**Growth**
- There has been some debate regarding whether to use below the 10th percentile or below the 3rd percentile as the severity cut-off for growth deficiency.
- The Scientific Working Group that developed these guidelines decided for the public health reason of identifying the most individuals who might need services to prioritize minimizing the number of false negatives, and thus utilized the criteria of below the 10th percentile.
- Growth deficiency should not be due to nutritional deprivation

**Facial Dysmorphology**
- There are numerous physical anomalies that are associated with prenatal alcohol exposure. However, the three facial features that are most discriminating with regards to identifying FAS are a smooth philtrum, a thin upper lip and short palpebral fissures.
- Note that facial features can change with age or development, and that it may become more difficult to identify FAS in older individuals, particularly after puberty.

**CNS Abnormalities**
- Structural anomalies may include a diminished head circumference or abnormalities evident in imaging studies (e.g., thinning or agenesis of the corpus callosum, etc.)
- Neurological abnormalities might include seizures that are not attributable to some type of postnatal insult or fever, or other soft signs of impaired neurological functioning (e.g., motor problems, etc.)
- Functional deficits might include global cognitive impairment or developmental delay, or impairments in 3 specific domains, including specific learning disabilities, or deficits in executive functioning, motor functioning, speech and language, social functioning, adaptive functioning, attentional problems, etc.

**Maternal Alcohol Use**
- Note that maternal alcohol use during pregnancy can be confirmed or unknown. A significant number of individuals may present with multiple signs of FAS, but there may be an unknown history regarding the mother’s use of alcohol during pregnancy. This commonly occurs among children in foster care or who are adopted.
- The diagnosis of FAS or another alcohol related disorder can be made in the case of a unknown history of maternal alcohol use during pregnancy, as long as the other criteria are met and other differential diagnoses had been ruled out.
- It is important to note that there are other disorders that can present similarly to FAS (e.g., some genetic syndromes, Fetal Hydantoin Syndrome), and these disorders should be ruled out before making a diagnosis of FAS.
Measuring Palpebral Fissure Length
From:  http://depts.washington.edu/fasdpn

Photograph reprinted with permission from Susan Astley, University of Washington: www.fasdpn.org

• This photograph depicts how to measure palpebral fissure length
  • Short palpebral fissures are one of the three essential facial anomalies considered when making a diagnosis of FAS.
Photograph reprinted with permission from Susan Astley, University of Washington: www.fasd pn.org

• The photograph on the left depicts the other two essential facial anomalies considered when making a diagnosis of FAS:
  • Smooth philtrum
  • Thin upper lip

• In contrast, note in the photograph on the right the distinct philtrum and normal upper lip of a child without prenatal alcohol exposure
Partial FAS: Diagnostic Criteria

- Confirmed alcohol exposure **AND**

- Evidence of some components of the pattern of characteristic facial features, **AND**

- Evidence of:
  - Some growth retardation, **OR**
  - CNS abnormalities, **OR**
  - A complex pattern of behavioral or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone

General criteria for other alcohol related disorders, including Partial FAS, Alcohol Related Neurodevelopmental Disorder (ARND) and Alcohol Related Birth Defects (ARBD) were published by the Institute of Medicine (IOM; 1996).

- However, at this time, more specific criteria for these other disorders are still being developed.
- This slide and the following two slides outline the IOM criteria for Partial FAS, ARND, and ARBD, respectively.
Alcohol Related Neurodevelopmental Disorder (ARND): Diagnostic Criteria

• Confirmed alcohol exposure **AND**

• Evidence of
  – CNS abnormalities **OR**
  – A complex pattern of behavioral or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone
Alcohol Related Birth Defects (ARBD): Diagnostic Criteria

- Confirmed alcohol exposure AND

- One or more congenital defects
  - Cardiac
  - Skeletal
  - Kidney
  - Vision
  - Hearing
• It remains a common misperception that individuals who have been affected by prenatal alcohol exposure will be readily identifiable by their physical features.
  • It is important for families, health care professionals, educators, legal professionals, and social service professionals to recognize that many individuals who do not present with the classic “face” of FAS will still have profound impairments and will be in need of services and support.
• Many individuals with FASDs do not receive any services because testing indicates they have IQs in the “normal” range. These individuals often have the poorest outcomes because they slip through the cracks.
  • Individuals who are suspected of having or have been diagnosed with FAS or another alcohol related condition should receive a comprehensive evaluation that assesses multiple domains of functioning.
    • A comprehensive evaluation is more likely to reveal areas of deficit (e.g., such as executive or adaptive functioning) that may be interfering with the individual’s daily functioning--areas that would not otherwise be detected by a general IQ test.
• The long-term prognosis for individuals with FASDs has historically been quite poor.
  • However, with early diagnosis and intervention, and life-long support that both addresses areas of deficit and capitalizes on areas of strength, these individuals can have the potential to lead productive lives.