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Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorder in Indiana

Maternal alcohol use during pregnancy can have deleterious effects. Alcohol in the mother's blood passes through the placenta to the embryo and fetus via the umbilical cord, and may cause numerous problems, including developmental delays, growth impairment, and a variety of behavioral changes [1]. Compared to all other substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus [2].

In 2005, the U.S. Department of Health and Human Services' Office of the Surgeon General released an advisory to warn pregnant women and women who may become pregnant to abstain from drinking alcohol to eliminate the risk of alcohol-related birth defects. The advisory was an update from the 1981 release which initially only suggested that pregnant women limit the amount of alcohol they drink [3]. The update was issued because based on the most current research, no amount of alcohol consumption can be considered safe during pregnancy, and damages to the fetus can occur during any gestational stage. Drinking increases the risk of alcohol-related growth deficiencies and birth defects, including facial abnormalities and central nervous system impairment. In addition, drinking during pregnancy has been linked to behavioral disorders and impaired intellectual development in the child; these cognitive deficits and behavioral problems are lifelong [3, 4]. This has also been substantiated by *Healthy People 2020,* which designated the prevention of alcohol-exposed pregnancies a public health priority, urging women of childbearing age (ages 15 to 44) to abstain from drinking alcoholic beverages [5]. Since there is no safe time to consume alcohol during pregnancy, women should not drink alcohol if they are planning to become pregnant or are sexually active and do not use effective birth control [4].

There is no known safe amount of alcohol to drink while pregnant. There is also no safe time during pregnancy to drink and no safe kind of alcohol. CDC urges pregnant women not to drink alcohol any time during pregnancy. [4]

Consumption of alcohol during pregnancy can cause the infant to be born with a fetal alcohol spectrum disorder (FASD). FASD is not a diagnosis, but an umbrella term that describes a group of conditions associated with prenatal alcohol exposure, including fetal alcohol syndrome (FAS) [6]. FAS is the most severe and widely known type of FASD. Jones et al. (1973) were the first to coin the term "FAS" and systematically describe the pattern of malformations in children of mothers who drank significant amounts of alcohol during pregnancy [7, 8]. In addition to FASD, prenatal alcohol consumption can also lead to other complications such as miscarriages, preterm births, and stillbirths [9, 10]. Since FASD and all other alcohol-related outcomes are the result of maternal drinking during pregnancy, these consequences are completely preventable.

Consequences of Alcohol Use During Pregnancy

Alcohol is a recognized human teratogen[i] that may produce alcohol-related complications in children who have been exposed prenatally [2]. Drinking alcohol during pregnancy can cause numerous problems, including miscarriages, stillbirths, preterm births, and various FASD conditions with lifelong consequences [4, 11, 12]. FASD describes the full range of prenatal alcohol damage, comprising a broad array of physical defects and cognitive, behavioral, and emotional deficits [2, 11, 13]. Children with FASDs might have the following characteristics and behaviors [4, 6]:

a) Abnormal facial features:
This may include midfacial hypoplasia[ii], long smooth philtrum[iii], thin upper lip, small eyes that appear widely spaced and inner epicanthal folds[iv].

i A teratogen is a substance capable of interfering with the development of a fetus, potentially causing birth defects.
ii Hypoplasia refers to a condition in which organs or features are underdeveloped.
iii The ridge between the nose and upper lip is called the philtrum.
iv The epicanthal fold is a skin fold of the upper eyelid, covering the inner corner of the eye; race and certain medical conditions influence whether someone has epicanthic folds.

b) Growth impairment:
This may include microcephaly[v],
shorter-than-average height, and low body weight.

c) Central nervous system and neurodevelopmental abnormalities:
This may include poor coordination; hyperactive behavior and/or difficulty paying attention (ADHD); poor memory; difficulty in school (especially with math); learning disabilities; speech and language delays; intellectual disability or low IQ; poor reasoning and judgment skills; sleep and sucking problems as a baby; vision or hearing problems; and problems with the heart, kidney, or bones.

Prenatal alcohol exposure has been implicated as one of the most common causes of developmental disability and as the leading preventable cause of birth defects in the United States [2, 6].

Fetal Alcohol Spectrum Disorders

In 1996, the Institute of Medicine's (IOM) Committee to Study Fetal Alcohol Syndrome published a set of diagnostic criteria to evaluate and categorize children with FAS and other alcohol-related effects [2]. The IOM study group developed five diagnostic categories:

1.	FAS with confirmed maternal alcohol exposure	Fetal alcohol syndrome
2.	FAS without confirmed maternal alcohol exposure	
3.	Partial FAS (pFAS) with confirmed maternal alcohol exposure	
4.	Alcohol-related birth defects (ARBD)	Alcohol-related effects
5.	Alcohol-related neurodevelopmental disorder (ARND)	

However, there are several problems associated with IOM's diagnostic criteria. Some experts consider them too vague, lacking specific parameters for each category. Additional criticisms include the arguments that family and genetic history of the affected child is not addressed adequately and that ARBD and ARND are not defined in a clinical sense [14]. In 2005, Hoyme et al. proposed a modification of the IOM criteria to improve reliability and validity of FASD diagnoses, "making them more specific and clinically applicable in general pediatric practice" [14]. The revised criteria contain a sixth diagnostic category (pFAS without confirmed maternal alcohol exposure) in addition to the original five, and specify each category's parameters on which to evaluate affected children.

Generally, experts have little difficulty diagnosing FAS, the most severe form on the FASD continuum, in children between 2 and 11 years old. Diagnosis can be more problematic in younger children, because signs of the syndrome might not fully show yet, or in older children, because after puberty, the affected children often catch up on their height and weight [2]. Even cases of full-blown FAS often go undetected at birth [14, 15]. Children with less severe expressions of the FASD spectrum present an even greater diagnostic challenge, since the physical signs are usually more subtle [14]. Yet it is the less severe types of FASD that are much more common, potentially affecting one percent of all children born in the United States [16].

Many genetic and malformation syndromes exhibit some of the clinical FAS characteristics, and children with these syndromes are just as likely to be born to women who drank alcohol during pregnancy as they are to other women in the general population. Therefore, a FASD-related diagnosis should not be assigned solely based on prenatal alcohol consumption and the presence of a child's disability, but should also exclude other (genetic and non-genetic) diagnoses with similar characteristics [14].

Assessment of Prenatal Alcohol Use and FASD in Indiana

Alcohol Use among Pregnant Women and Women of Childbearing Age

FASDs are completely preventable, by avoiding alcohol use during pregnancy. Since nearly half of all pregnancies in the United States are unplanned [17], there is risk of drinking during the early stages of pregnancy before a woman realizes she is expecting [18]. A study found that approximately 60 percent of frequent drinkers were not aware of their pregnancy until the fourth week of gestation and 30 percent still did not know at six weeks [19]. Therefore, assessing the level of risk within the population requires measuring alcohol consumption not only among pregnant women but also among women of childbearing age [18].

According to results from CDC's 2010 Behavioral Risk Factor

v Small head size.

Surveillance System (BRFSS), 12.6 percent (95% CI: 10.7—14.9) of Indiana women of child-bearing age (18 to 44 years) reported they engaged in binge drinking[vi] in the past month (U.S. median: 15.4%) [20]. However, survey results did not indicate if respondents were pregnant, sexually active, or used effective birth control methods.

Findings from the 2006–2007 National Survey on Drug Use and Health (NSDUH) show that nearly 12 percent of pregnant women in the United States drank alcohol in the past month; those who did, consumed an average of 2.4 drinks per day on the days they drank (see Table 1). Additionally, over 42 percent of recent mothers reported past-month alcohol use, consuming an average of 2.5 drinks per day on the days they drank. Even though these women were not pregnant at the time they ingested alcohol, it was not known if they were breastfeeding [21].[vii]

Table 1: Past-Month Alcohol Use and Average Number of Alcoholic Drinks per Day Among Pregnant Women Ages 15 to 44 in the United States, 2006–2007 (National Survey on Drug Use and Health, 2006–2007)

		Past-month alcohol use	Average number of drinks†
Age (years)	15-17	15.8%	3.6
	18-25	9.8%	3.6
	26-44	12.5%	1.7
Race/ Ethnicity*	White	14.5%	1.9
	Black	15.7%	3.1
	Hispanic	4.1%	4.6
Education*	Less than high school	8.9%	4.5
	High school	8.3%	2.6
	Some college	11.7%	2.1
	College graduate	15.8%	1.6
Income*	Less than $20,000	11.7%	3.7
	$20,000-$49,999	9.2%	2.2
	$50,000-$74,999	9.5%	2.3
	$75,000+	16.3%	1.6
Total		**11.6%**	**2.4**

† Average Number of Alcoholic Drinks Consumed per Day on the Days That Alcohol Was Used in the Past Month

* Differences among the groups were significant by race/ethnicity, education, and income.

Source: Substance Abuse and Mental Health Services Administration, 2008 [21]

No significant differences in past-month alcohol use among pregnant women were detected by age group. However, statistically significant differences were observed by race/ethnicity, educational attainment, and annual income:

- white women reported a higher rate of alcohol use than Hispanic women;
- college graduates reported a higher rate of alcohol use than women with less than a high school diploma;
- women with incomes of at least $75,000 reported a higher rate of alcohol use than women with lower incomes; and
- the average number of drinks per day consumed by pregnant women generally declined with greater educational attainment and higher income (see Table 1) [21].

No amount of alcohol has been deemed safe during pregnancy, but larger quantities have been associated with more severe outcomes [1, 4, 6, 22]. The fact that alcohol use is more common among women with higher educational attainment and income, but average per-day consumption is greater among those less privileged, may suggest that women with lower socio-economic status (SES) are disproportionally affected by more severe forms of FASD, such as FAS.

Women in Substance Abuse Treatment

From 2000 through 2009, nearly 100,000 substance abuse treatment admissions in Indiana were attributed to females, making up about one-third of all treatment episodes funded through the Hoosier Assurance Plan (HAP) (see Table 2). Approximately 86 percent of these women were of childbearing age (15 to 44 years). Throughout the decade, about 4 percent of females admitted to treatment were pregnant, with the majority (56%) of pregnant women reporting alcohol use (see Figure 1) [23].

While Figure 1 shows a decrease in the number of pregnant females in treatment, it is important to note that the overall number of treatment episodes decreased from 38,285 in 2000 to 18,004 in 2009 (see Table 2); however, the proportion of pregnant females within the treatment population remained fairly constant at about 4 percent. It is unclear if the decrease in treatment episodes repre

vi Binge drinking for females was defined as having four or more drinks on at least one occasion during the previous 30 days.
vii Information from this NSDUH report was only available for the nation and not provided at the state level.
viii HAP, or Hoosier Assurance Plan, is the main method by which the Indiana Division of Mental Health and Addiction (DMHA) funds substance abuse and mental health services.

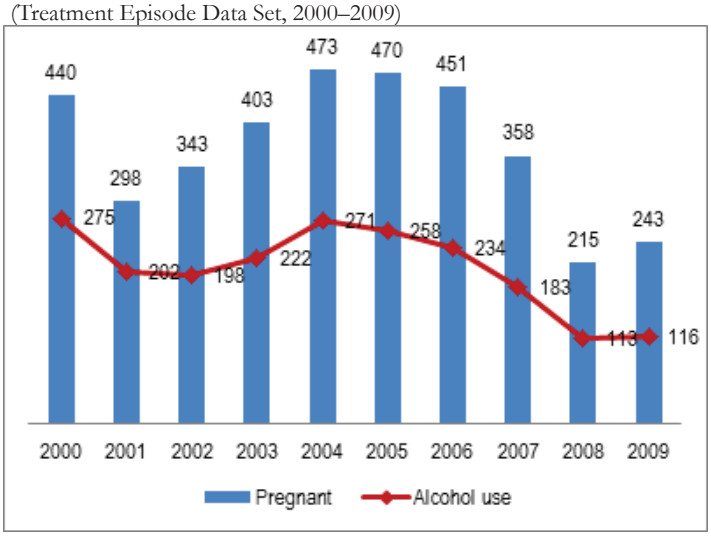
sents a decrease in the need for treatment services, a decrease in the number of individuals eligible for HAP services, or a decrease in available DMHA-funding.

Table 2: Number of Substance Abuse Treatment Episodes in Indana by Gender, 2000–2009 (Treatment Episode Data Set, 2000–2009

Year	Male	Female	Total
2000	25,954	12,331	38,285
	67.8%	32.2%	100.0%
2001	19,560	8,851	28,411
	68.8%	31.2%	100.0%
2002	20,834	9,639	30,473
	68.4%	31.6%	100.0%
2003	21,520	10,173	31,693
	67.9%	32.1%	100.0%
2004	25,079	12,628	37,707
	66.5%	33.5%	100.0%
2005	24,893	12,578	37,471
	66.4%	33.6%	100.0%
2006	23,059	11,634	34,693
	66.5%	33.5%	100.0%
2007	19,312	9,775	29,087
	66.4%	33.6%	100.0%
2008	12,897	6,214	19,111
	67.5%	32.5%	100.0%
2009	11,982	6,022	18,004
	66.6%	33.4%	100.0%
Total	**205,090**	**99,845**	**304,935**
	67.3%	**32.7%**	**100.0%**

Source: Substance Abuse and Mental Health Data Archive, 2009 [23]

Figure 1: Number of Substance Abuse Treatment Episodes in Indiana in Which Pregnant Females Reported Alcohol Use, (Treatment Episode Data Set, 2000–2009)



Source: Substance Abuse and Mental Health Data Archive, 2009 [23]

FASD Prevalence and Incidence Estimates

One of the most detrimental consequences of alcohol use during pregnancy is FAS. The Indiana Birth Defects and Problems Registry (IBDPR) is a data system that collects information on birth defects and birth problems for all Indiana children from birth to 3 years old (5 years old for autism and FAS). According to the registry, the annual number of new cases reported to IBDPR as having a diagnosis of FAS[ix] decreased from 31 in 2003 to 11 in 2007 [24].

Studies to determine the prevalence of FASD conditions are limited in number and vary widely in their methodology, resulting in differential patterns and frequency of occurrence of these disorders [13, 16]. According to most reports, the overall prevalence of

ix The ICD-9-CM code for fetal alcohol syndrome (FAS) is 760.71.

FAS alone is likely to be between 0.5 and 2.0 per 1,000 births in the United States. However, the various FASD conditions combined may affect 10.0 per 1,000 births (or 1 percent) or more, depending on the specific diagnostic methods and criteria used [16].

The current knowledge of the incidence of FASD is limited and provides only estimates, since no large-scale national incidence studies have been undertaken [6]. Several experts in the field consider these estimates conservative, because they have been generally based on passive rather than active surveillance [12]. Researchers have primarily used three approaches to assess patterns of occurrence, including passive surveillance and record review systems, clinic-based studies, and active case ascertainment methods. All these strategies have certain advantages and disadvantages, and the resulting prevalence estimates vary widely based on the design. For example, passive surveillance, which is the least aggressive method, provides the lowest estimates; while active case ascertainment, the most aggressive approach, offers the highest estimates (see Table 3) [13].

Table 3: Prevalence Rates of Fetal Alcohol Spectrum Disorders (FASDs) by Method

Method	Rate of FAS* per 1,000	Rate of FASD per 1,000
Passive surveillance/ Record review systems	Median = 0.265 Mean = 0.845	N/A
Clinic-based studies	Median = 1.900 Mean = 1.830	Median = 4.800 Mean = 6.200
Active case ascertainment	Median = 8.500 Mean = 15.610	Median = 19.000 Mean = 38.200

* FAS (fetal alcohol syndrome) is a category within FASD, and therefore included in the total FASD estimate.

Source: May, et al., 2009 [13]

Based on in-school studies on FASD prevalence, May et al. (2009) concluded that FASDs are more prevalent in school populations, and therefore in the general population, than previously estimated, and that the prevalence rates in the "typical, mixed-racial, and mixed-socioeconomic" U.S. population is at least 0.2 to 0.7 percent for FAS and 2 to 5 percent for total FASD [13].

Applying the more conservative but also more frequently used and cited incidence[xi] rates of 2.0 per 1,000 live births for FAS and 10.0 per 1,000 live births for FASD to Indiana's population, an estimated 896 infants were born with FASD in 2007, of which 179 infants had the more severe form, FAS[xii]. Overall prevalence[xiii] was estimated at 63,452 for FASD, including 12,690 FAS cases in Indiana in 2007 (see Table 4) [25, 26].

Table 4: Estimated Impact (Number of Cases) of Fetal Alcohol Spectrum Disorders (FASDs) in Indiana, 2007 (Prevalence & Cost Calculator)

	FAS*	FASD
Incidence (cases in annual birth cohort)	179	896
Mortality (cases in annual birth cohort)	9	62
Prevalence (cases in total population)	12,690	63,452
Mental retardation (cases in total population)	5,076	9,136
Congenital heart defects (cases in total population)	5,888	29,441
.Epilepsy (cases in total population)	761	3,806
ADHD (cases in total population)	5,076	25,380
Speech and language disorders (cases in total population)	10,533	52,665
Sensorineural hearing loss (cases in total population)	3,553	17,766
Cerebral palsy (cases in total population)	190	951
Autism or other Pervasive Developmental Disorder (cases in total population)	215	1,077
Mental illness (cases in total population)	8,883	44,416

* FAS (fetal alcohol syndrome) is a category within FASD, and therefore included in the total FASD estimate.

Source: Online Clinic, 2011 [25]

The large difference between the *reported* number of new FAS cases (IBDPR) and the *estimated* number of new FAS cases (Table 3) may be a function of the difficulty assessing the disorder, since cases of even full-blown FAS often go undetected at birth and later in life [14, 15], as well as the type of methodology used (IBDPR is a form of passive surveillance; whereas prevalence estimates are based on various methodologies) [13].

x Prevalence estimates of birth defects, including FASD and FAS, can vary considerably due to differences in case definition, method of case ascertainment, and the types of data sources used. Passive surveillance (or passive case ascertainment) is the most conservative approach, receiving its information from data sources; active surveillance is the "intensive level of case identification that involves staff finding cases at strategic data sources. Ascertainment is usually very complete, and each diagnosis in the database is confirmed" (definition from the National Birth Defects Prevention Network website at http://www.nbdpn.org/current/resources/sgm/Ch_6_Case_Ascertainment_Methods6-04%20no%20app.pdf).

xi Incidence refers to the number of new cases of a disease in a population in a given time period.

xii This was calculated by multiplying the number of live births by the estimated prevalence rate. For example: (89,719 * 2.0) / 1,000 = 179 FAS cases per 1,000 live births. (Number of live births is available from the 2007 Indiana Natality Report [http://www.in.gov/isdh/reports/natality/2007/index.htm).])

xiii Prevalence refers to the number of total cases of a disease ni a population in a given time period.

Economic Burden

Empirical data on FASD's economic burden are scarce. A study by Bouchery, et al. (2011) estimates that the total economic cost of excessive drinking in the United States was $223.5 billion in 2006; of this amount, $2.9 billion were attributable to FAS [27]. A systematic literature review by Popova et al. (2011) on the financial impact of the disorder yielded 13 well-documented studies with comprehensive methodologies: 10 studies from the United States and three studies from Canada. No cost studies from any other countries were found. Based on the ten U.S. studies, the adjusted[xiv] annual cost for all persons with FAS ranged from $156.7 million to $8.5 billion in 2010 dollars. These vast differences in cost estimates among the studies reflect the fact that the researchers utilized different methodologies and assumptions, including different prevalence/incidence rates, different cost components, and different age categories [28].

Some experts consider even the higher estimates of the total costs related to FASD an underestimate because some components (e.g., law enforcement costs, child welfare costs) were not included in the analyses; also, underlying prevalence/incidence rates only reflected FAS rates and not all FASD conditions [12, 28].

According to the *Prevalence & Cost Calculator,* the total annual costs for FASD (including costs for special education and juvenile justice for children ages 5 to 18) in Indiana were estimated to be $167.2 million in 2011. Since comprehensive data on many of the costs are not available, this estimate is best considered a minimum [25].

Thoughts for Policymakers

FASD continues to be a significant public health problem, affecting an estimated one percent of all live births in the United States [16]. Several environmental and genetic predisposing variables have been identified; however, maternal alcohol consumption during pregnancy remains the ultimate risk factor for these conditions. Prenatal alcohol exposure has been implicated as one of the most common causes of developmental disability and the leading preventable cause of birth defects in the United States [2]. Unfortunately, drinking during pregnancy and its adverse consequences continue to be under-identified [6].

The implementation of evidence-based strategies will be crucial to reducing the consequences of prenatal alcohol exposure in Indiana. To improve detection and outcomes of FASD, consider the following policy recommendations:

1. Reduce prenatal alcohol exposure by providing:
   - Routine screenings of at-risk women (pregnant or of childbearing age/preconceptional) in clinical settings, using a validated instrument (e.g., T-ACE, TWEAK, AUDIT-C) [29]
   - Evidence-based brief interventions for women who screened positive for high-risk drinking [29]
   - Training for healthcare and social service professionals in the areas of screening and intervention for high-risk drinking among pregnant or preconceptional women [6, 29]
   - Access to alcohol treatment services for pregnant women [29]
2. Meet the needs of FASD individuals and their families by:
   - Providing FASD training for healthcare and social service professionals [30]
   - Developing a comprehensive system of care for individuals with FASD, including cost-effective prevention and treatment programs [30]
   - Developing standard diagnostic criteria and terminology across the FASD spectrum [30]
   - Promoting inclusion of FASD in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental disorders* and the World Health Organization's *International Classification of Diseases and Related Health Problems* [30]
3. Assess risk of FASD in the community by providing surveillance of alcohol use among high-risk pregnant women (e.g., Pregnancy Risk Assessment Monitoring System/PRAMS)

In conclusion, FASDs are completely preventable. Implementation of strategies to reduce alcohol consumption during pregnancy, especially binge drinking, will help prevent new FASD cases, and reduce the considerable costs (human and financial) of these disorders.

xiv Adjusted for inflation (June 2010) [29]

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The Center for Health Policy

The Indiana University Center for Health Policy (CHP) is a nonpartisan applied research organization within the Department of Public Health, Indiana University School of Medicine. CHP researchers work on critical public health policy issues and subjects that affect access to and quality of health care services. The mission of CHP is to collaborate with state and local government, as well as public and private healthcare organizations, in health policy and program development and to conduct high quality program evaluation and applied research on critical health policy-related issues.

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