Indiana Fetal Alcohol Spectrum Disorder

Strategic Plan

Draft Four

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Submitted By

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Indiana Fetal Alcohol Syndrome Disorder (FASD) Strategic Plan

Overview

Fetal alcohol syndrome or FAS is the direct result of prenatal exposure to alcohol. Since 1973 much has been learned about alcohol and its effects on the unborn child. Fetal alcohol spectrum disorders (FASD) is the term now used to describe the range of effects, including FAS, occurring in an individual whose mother consumed alcohol during pregnancy. FASD occurs in approximately 1 per 100 live births, or about 40,000 babies per year, outranking Down syndrome (1/800) and autism (1/1,000) in prevalence.

Twenty two counties in Indiana have prevention programs in place for addressing substance abuse through the Prenatal Substance Use in Pregnancy Program (PSUPP) and other prevention programs are in operation in many others. A complete list of counties with substance abuse programs appears in Appendix A. The activities related to alcohol use in Indiana counties were assessed by the Indiana State Department of Health to determine the next steps in the prevention of fetal alcohol spectrum disorders (FASD) in this state. Information gathered confirmed that women of child bearing age and the health care professionals that serve them are aware of the consequences of consuming alcohol while pregnant. The problem of FAS and FASD is more complex than simply understanding the possible negative effects of alcohol on the unborn baby. Many pregnancies are unplanned. Women who are unaware that they are pregnant may continue to drink alcohol, stopping only after their first visit to a physician in their second trimester. Some people are unaware of the range of possible negative effects. In a few cases, family, friends or even medical personnel have informed pregnant women that small amounts of alcohol are safe for them to consume. Compounding the problem is the fact that not every women who consumes alcohol while pregnant will deliver a baby with any obvious effects of that consumption. If the baby looks fine, the mother, as well as others who know her, assumes that there were no negative consequences from drinking while pregnant. Current research only now is finding that there

are more subtle effects physically and neurologically than previously thought. FASD is 100% preventable if no alcohol is consumed by a woman who is pregnant.[1]

Health Status of Children in Indiana

Recognizing the impact of health behaviors during pregnancy on the outcome of a healthy baby's birth, and the impact of those behaviors on long term health and development, data on Indiana births and outcome indicators should be tracked as part of the long term plan related to FASD. These data need to be disaggregated by race because of the health disparity issues that exist in Indiana. Indiana is committed to the appropriate use of data to guide policy and program decisions through the FASD strategic planning process.

In Indiana, conservative estimates indicate nearly 1,000 babies are born each year affected by the mother's use of alcohol during pregnancy. Some experts believe FASD is under-diagnosed both at the state and national level making the prevalence actually higher. According to the data in Table 1 provided by the Indiana State Department of Health Epidemiology Resource Center, most babies are born to women between 18 and 34 years of age. This is the same population who reports using alcohol the most, and who reports consuming alcohol while pregnant the most. Proportionately, a higher percentage of black mothers less than 20 years of age give birth and a higher percentage admit to drinking while pregnant than white mothers.

[1] SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence Fact Sheet, 2004

Table 1

Number and Percent of Mothers Who Used Alcohol During Pregnancy by Age and Race of Mother:
Indiana Residents, 2003

Age of Mother	Births			Used Alcohol During Pregnancy			Percent Used Alcohol During Pregnancy		
	Total	White	Black	Total	White	Black	Total	White	Black
Total	**86,382**	**75,422**	**9,288**	**539**	**437**	**99**	**0.6**	**0.6**	**1.1**
10-14	130	88	41	1	1	0	0.8	1.1	0.0
15-17	2,817	2,182	604	8	7	0	0.3	0.3	0.0
18-19	6,551	5,303	1,192	21	18	3	0.3	0.3	0.3
20-24	25,015	21,379	3,379	134	114	20	0.5	0.5	0.6
25-29	24,872	22,160	2,154	126	105	21	0.5	0.5	1.0
30-34	18,201	16,456	1,251	139	110	28	0.8	0.7	2.2
35-39	7,272	6,508	538	79	59	19	1.1	0.9	3.5
40-44	1,438	1,269	126	28	21	7	1.9	1.7	5.6
45+	74	66	3	3	2	1	4.1	3.0	33.3
Unknown	12	11	0	0	0	0	0.0	0.0	--

SOURCE: Indiana State Department of Health, Epidemiology Resource Center, Data Analysis Team.
Percentages are calculated using total births in each age of mother or age of mother/race category. Please see Table 39 for the number and percentage of missing alcohol use data.

As indicated in Table 2, binge drinking by women 18 to 25 years of age is the highest, increasing steadily with age then decreasing after age 25. More women are reporting they engage in binge drinking during child bearing years which presents a significant risk for fetal alcohol spectrum disorders (FASD). More women engage in binge drinking in the first trimester (10%), which is expected given that the majority of pregnancies in this age group are unplanned and may not be recognized. [2]

[2] James Nocon, MD. Power point presentation for the January 31, 2006 March of Dimes Day, National Pregnancy and Health Survey, National Institute on Drug Abuse, U. S. Department of Health and Human Services, 1997.

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Table 2

Binge Alcohol Use in the Past Month among Females Aged 15 to 44, by Pregnancy Status and Demographic Characteristics: Percentages, Annual Averages Based on 2002-2003 and 2003-2004

Demographic Characteristic	Total[1]		PREGNANCY STATUS			
			Pregnant		Not Pregnant	
	2002-2003	2003-2004	2002-2003	2003-2004	2002-2003	2003-2004
TOTAL	22.4	22.5	4.1	4.5	23.2	23.3
AGE						
15-17	16.6	17.3	7.0	8.8	16.7	17.3
18-25	31.7	32.0	4.8	5.1	33.5	33.7
26-44	19.7	19.4	3.3	3.8	20.3	20.1
HISPANIC ORIGIN AND RACE						
Not Hispanic or Latino	23.3	23.3	4.4	4.7	24.0	24.1
White	25.3	25.5	4.0	4.1	26.1	26.4
Black or African American	18.3	17.2	3.0	5.7	18.7	17.5
American Indian or Alaska Native	34.3	37.7	*	*	35.1	38.3
Native Hawaiian or Other Pacific Islander	*	15.3	*	*	*	15.4
Asian	9.0	9.1	*	*	9.1	9.3
Two or More Races	23.7	26.6	*	*	24.7	27.4
Hispanic or Latino	17.8	18.1	2.9	3.7	18.6	18.8
TRIMESTER[2]						
First	N/A	N/A	10.9	10.6	N/A	N/A
Second	N/A	N/A	1.4	1.9	N/A	N/A
Third	N/A	N/A	0.7	1.1	N/A	N/A

*Low precision; no estimate reported.
N/A: Not applicable.
NOTE: Binge alcohol use is defined as drinking five or more drinks on the same occasion (i.e., at the same time or within a couple of hours of each other) on at least 1 day in the past 30 days.
[a] Difference between estimate and 2003-2004 estimate is statistically significant at the 0.05 level.
[b] Difference between estimate and 2003-2004 estimate is statistically significant at the 0.01 level.
[1] Estimates in the Total column are for all females aged 15 to 44, including those with unknown pregnancy status.
[2] Pregnant females aged 15 to 44 not reporting trimester were excluded.

Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2002, 2003, and 2004.

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Table 3

Alcohol Use in the Past Month among Females Aged 15 to 44, by Pregnancy Status and Demographic Characteristics: Percentages, Annual Averages Based on 2002-2003 and 2003-2004

Demographic Characteristic	Total[1]		PREGNANCY STATUS			
			Pregnant		Not Pregnant	
	2002-2003	2003-2004	2002-2003	2003-2004	2002-2003	2003-2004
TOTAL	51.3	51.1	9.8	11.2	53.0	52.8
AGE						
15-17	28.5	28.4	14.5	14.9	28.7	28.5
18-25	55.7	55.9	10.5	10.6	58.7	58.7
26-44	53.0	52.6	8.9	11.3	54.6	54.3
HISPANIC ORIGIN AND RACE						
Not Hispanic or Latino	53.7	53.5	10.1	11.2	55.3	55.3
White	57.8	58.2	10.8	11.8	59.6	60.2
Black or African American	41.0	39.5	6.4	9.6	42.2	40.6
American Indian or Alaska Native	49.8	49.5	*	*	51.7	50.6
Native Hawaiian or Other Pacific Islander	40.9	*	*	*	42.1	*
Asian	34.9	31.8	*	*	36.0	33.3
Two or More Races	53.3	57.4	*	*	55.6	59.2
Hispanic or Latino	37.9	37.6	8.6	11.0	39.6	39.0
TRIMESTER[2]						
First	N/A	N/A	19.6	22.2	N/A	N/A
Second	N/A	N/A	6.1	7.0	N/A	N/A
Third	N/A	N/A	4.7	4.9	N/A	N/A

*Low precision; no estimate reported.
N/A: Not applicable.
[a] Difference between estimate and 2003-2004 estimate is statistically significant at the 0.05 level.
[b] Difference between estimate and 2003-2004 estimate is statistically significant at the 0.01 level.
[1] Estimates in the Total column are for all females aged 15 to 44, including those with unknown pregnancy status.
[2] Pregnant females aged 15 to 44 not reporting trimester were excluded.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2002, 2003, and 2004.

Considering the information provided in Table 3, Alcohol Use in the Past Month, it is evident that women of child bearing age continue to drink alcohol when they are pregnant, increasing the risk of children born with fetal alcohol spectrum disorders (FASD). While the data indicate that alcohol consumption from 2002 to 2003 decreased overall for women of all ages, there was a statistically significant increase for pregnant women of all ages, all races, in all trimesters of pregnancy. This information illustrates the scope of the problem and the need to educate entire communities of the negative effects of alcohol consumption by pregnant women. The incidence of FASD is a national problem of significance and the effects of prenatal consumption of alcohol are as evident in Indiana as in many other states.

The data related to alcohol consumption by pregnant women described in the Tables 1-3 above should be monitored for Indiana on a routine basis. To ensure any necessary changes in the strategic plan implementation are made in a timely fashion, additional information provided about the state's birth outcomes should be monitored as well. Table 4 illustrates Indiana births and outcomes by race. Negative outcomes for Black mothers are significantly higher in all areas than for White mothers highlighting the severity of health disparities in this state especially for women of child bearing age. There is some concern the data provided through the Indiana birth registry is not as reliable as similar data collected by other means, so caution is advised when viewing this information in isolation.

Table 5 illustrates the percentage of Indiana students between grades six and twelve reporting the use of alcohol. Indiana data and national data are provided as comparisons for grades eight, ten and twelve. Frequency of use increases steadily with age although consumption remains slightly lower than national levels. Combining this information with the number of teenage pregnancies demonstrates that many young women are drinking immediately prior to becoming pregnant and continuing that behavior after finding out they are pregnant. The implications for the number of babies born with some fetal alcohol spectrum disorders require some immediate intervention in public awareness of the possibility of the life long consequences of alcohol consumption while pregnant and the fact that FASD is 100% preventable.

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Table 4

Indiana Births and Outcome Indicators by Race of Mother Indiana 2003			
All Races		**Race**	
Total Births	**Total**	**White**	**Black**
Total Indiana Births	86,382	75,422	9,288
All Races / Ethnicities		**Race**	
Outcomes as a Percent of Births	**Total**	**White**	**Black**
% Low Birth Weight	7.9	7.2	13.3
% Very Low Birth Weight	1.4	1.2	3.3
% Preterm*	9.9	9.0	12.5
% PNC** First Trimester	80.6	82.1	68.2
% Used Alcohol During Pregnancy	0.6	0.6	1.1
% Smoked During Pregnancy	18.5	19.1	15.2
% Unmarried Parents	37.1	32.6	76.3
% Mothers Under 20 Years Old	11.1	10.0	19.7

* Less than 37 weeks gestation
** Prenatal Care
Source:
Indiana State Department of Health, Epidemiology Resource Center, Data Analysis Team.
http://www.in.gov/isdh/dataandstats/natality/2003/tbl35_t.htm

Table 5[3]

Percentage of Indiana Students Reporting the Use of Alcohol 2005					
	Lifetime Use	Annual Use	Monthly Use	Daily Use	Binge
Sixth Grade	26.1	17.6	8.1	.5	4.5
Seventh Grade	34.0	25.7	12.7	.9	6.8
Eighth Grade/National	49.0/52.0	39.0/42.1	21.1/23.5	1.8	11.6/13.4
Ninth Grade	55.2	46.3	26.6	2.4	14.8
Tenth Grade/National	63.5/64.2	54.3/58.2	33.0/35.2	3.6	19.3/22.0
Eleventh Grade	66.6	56.0	34.5	3.6	21.2
Twelfth Grade/National	72.3/76.8	62.2/70.6	41.8/48.0	5.4	25.9/29.2

Needs Assessment

To build on work already accomplished in Indiana and other states, information on existing needs assessment data was gathered from those states with model FASD prevention campaigns and intervention programs, Indiana's FASD Prevention Task Force and representatives across Indiana who participated in two series of Focus Groups conducted in June 05 and January 06 (see Stakeholder Participation). In some cases, the needs assessment information gathered was relevant and consequently was used in the development of the FASD prevention strategic plan.

The activities in these counties related to alcohol use, and those activities in the remaining counties, was assessed to determine the next steps in the prevention of fetal alcohol spectrum disorders (FASD). Information was collected through focus groups held in targeted communities and by written surveys of women of child bearing age and professional health care

[3] Alcohol, Tobacco, and Other Drug Use by Indiana Children and Adolescents, 2004 Prevalence Statistics: Indiana University, Indiana Prevention Resource Center; Monitoring the Future, National Results on Adolescent Drug Use 2004, Institute for Social Research, University of Michigan

providers. In particular, the needs assessment investigated the status of prevention efforts statewide and identified community resources currently being used.

Needs Assessment Instruments.

Prior to the development of the written needs assessment instruments, input was gathered from:

1. Fetal Alcohol Spectrum Disorders (FASD) Prevention Task Force members
2. Health care providers
3. Community representatives
4. Other states with needs assessment measures

The Indiana needs assessment[4] was developed after information from all of the identified sources was reviewed by the FASD Prevention Task Force members and the project coordinator. Two surveys were developed and the final versions approved by the task force and the project coordinator.

Results of Needs Assessment.

Women's Survey. The majority of the 773 women responding (91%) indicated that they obtained health information from their doctor. Family members were the second most frequently reported source of information (34%) and books and magazines cited third (33.8%). Where women are likely to obtain health information they trust has implications for how information is distributed in a public awareness campaign. Women responding indicated that they believe getting prenatal care (94%), not using drugs (92%) and not drinking (90%) were necessary to have a healthy baby. Taking prenatal vitamins and not smoking were reported as necessary by 88% and 87% of the women, respectively. (A full report of the FASD Needs Assessment is available from the Indiana State Department of Health as a separate document.)

It is thought that women are not consistent in their definitions of "a drink of alcohol" and the results of the needs assessment appear to confirm there is some confusion. Between 35 and 38% of the respondents did not believe that a drink of alcohol was synonymous with a glass of wine (35%), a can or bottle of wine cooler (38%), a mixed drink (37%) or a shot of liquor (38%). A can or bottle of beer, suspected as being the drink women would not identify as a "drink of alcohol" was in fact identified as such by the most women (72%). It is important to

[4] The surveys are included in Appendix B

note that 12% of the women did not respond to this question, which may indicate further confusion as to what constitutes “a drink of alcohol”.

Given the variations in the definition of a drink of alcohol as reported by the women responding, the question asking how many drinks a respondent had in the past 30 days may not have yielded accurate results and should be considered with caution. Interestingly enough, when asked about the types of individual drinks that were safe to drink during pregnancy nearly all of the women responding indicated the identified drinks (beer, wine, wine coolers, mixed drinks) were not safe to drink during pregnancy (range 99-95%). Wine was identified as safe by only 5% of the respondents and 3% responded they did not know what was safe. Only 90% of the respondents indicated that “None of the drinks is safe”.

The majority of the 773 women who responded that they had heard, read or seen anything about Fetal Alcohol Syndrome indicated that they obtained the information from a doctor (38%) or at school (32%). More women obtained information about fetal alcohol syndrome from newspapers, magazines and television (31%) than from family members, friends or nurses (18%). Only 26% indicated they obtained the information from a clinic. Twenty of the respondents circled “no response” for this item possibly because they were not sure where they obtained the information.

Respondents were allowed to circle more than one response to most questions and they were given the option not to respond to any question. In considering the pattern of responses to Question 9 (As I understand it, FAS is...), it is worth noting that 99% of the women circled “no” to the first option indicating that they did not believe FAS was a genetic problem over which families had no control. It would seem do they believe families have some control over whether or not FAS occurs. As indicated by the 85% who responded that the condition occurs if a mother drinks while pregnant and the 63% who responded that it is entirely preventable if a pregnant woman does not drink, prevention education regarding the consequences may be effective in convincing women not to drink if they suspect, or know, they are pregnant. The remaining respondents do not appear to know what prevents fetal alcohol syndrome but 99% do know that a baby with this condition will not outgrow it. The responses to Questions 10 (behaviors of mother that cause fetal alcohol syndrome) and 11 (what happens if a mother drinks while pregnant) support the idea that women are uncertain as to when fetal alcohol syndrome occurs, however, they are well aware it is a serious and lifelong problem.

Question 10 asked the respondents to identify the situations that caused fetal alcohol syndrome. Some believed the condition results if the mother is an alcoholic (56%) and others that FAS can occur if a mother drinks certain types of alcohol (22%) or drinks at certain times during her pregnancy (32%). Over 75% of the respondents indicated that FAS can occur if the mother drinks any type of alcohol anytime during her pregnancy. Question 11 was designed to determine if the women responding knew what could happen if a mother drinks alcohol while pregnant. Very few (13%) believed the baby may be born with problems that would be outgrown. Significantly more respondents believed that the baby may be born with problems that would last a lifetime (85%) and that while the baby may look fine; he may still have alcohol related brain damage (80%). Fewer than 10% believed the baby would be born drunk and less than 1% indicated they did not believe any of the statements.

Question 12 of the survey asked respondents where a pregnant woman would go for help if she were drinking. The majority cited health clinics (63%), substance abuse clinics (56%) or the woman's doctor (60%). The majority of women responding (62%) did not know the extent to which women drank alcohol while pregnant in their own communities.

Only women who were pregnant or who had been pregnant in the past were to answer questions 14 through 18 and 828 of the respondents completed these items. Only one response was acceptable for each question. Women were asked if they were ever told by a physician that it was okay to drink alcohol while pregnant. Only 6.6% indicated a doctor had told them this. When asked if a family member or friend had ever told them drinking while pregnant was safe, 17% reported yes they had. Given that women believe information provided to them by family and friends, these results would indicate education targeting the broader community would be necessary. In addition, doctors and other health care providers should be informed of strategies for countering any misinformation provided to their pregnant patients.

Women were likely to admit more drinking in the three months prior to their pregnancies than they were to drinking while actually pregnant. Most responded they drank between 1 and 7 drinks in a week during the three months prior to becoming pregnant. Over 16% admitted to binge drinking between 1 and 3 times during the three months prior to their pregnancy. Another 5% admitted to binge drinking between 4 and 6 times during this same period. Over 5% did not remember or did not respond to the question. It is important to note that women responding did not have a consistent definition of what a drink of alcohol meant

therefore these results may not be indicative of actual drinking behavior. Rather they may only reflect what the women responding think they drank given their own definitions of a drink of alcohol. Another complicating factor is that women know drinking while pregnant is not good. This may have also restricted their responses as evidenced by the 80% who report they did not drink at all while pregnant.

Health Professionals Survey. Health care professionals are aware of the potential consequences for a pregnant woman who drinks alcohol. Only 9 of the 349 respondents indicated it was safe to drink alcohol occasionally while pregnant. Two individuals did not respond to the question and all others responded that it was not alright to drink during the last trimester, to drink only beer or wine, or to drink as long as the woman did not get drunk. Asked about specific drinks, almost 3% of the responding health care professionals indicated it was okay for pregnant women to drink a glass of wine per day. Only 77% believed it was necessary for the woman to stop drinking as soon as she knew she was pregnant.

Over 95% of the respondents indicated that the problems a baby might be born with as a result of alcohol consumption by the pregnant mother would last a lifetime and could not be "outgrown". The specific anomalies that the child might have (mental retardation, growth retardation and facial anomalies) were identified by the majority of the respondents (82%, 77% and 79%, respectively). Slightly more than 10% of the respondents indicated the baby would be born drunk if the mother consumed alcohol while pregnant.

Regarding the strategies they have employed when speaking to a woman who was pregnant and drinking, 82% of the respondents indicated they had provided a verbal explanation in an attempt to educate the woman. Print material was provided to the woman by 70% of the respondents and 40% suggested a community resource to the woman. Only 34% recommended a treatment facility and less than 10% recommended a book or an internet site.

Very few health care professionals (8%) were unaware of the resources available in their communities for women who drink while they are pregnant and fewer (1%) indicated their communities did not have any resources. Over half of the respondents indicated there were treatment centers available in their communities and also mentioned support groups as available resources. Over 84% of those responding indicated that substance abuse counseling was available in their communities.

As health care professionals understand FAS, the majority (99%) believe it is not a genetic problem yet 6% responded that they do not believe FAS is caused by a pregnant woman drinking alcohol. Most (98%) did not believe FAS was rare. Only 20% of the respondents knew FAS was diagnosed using four criteria. Almost 80% responded FAS is rarely diagnosed although it occurs frequently, only 89% of the health care professionals responding believe FAS is entirely preventable if a woman does not drink during pregnancy. With the exception of two people who did not respond, all believed that FAS is not something a baby will outgrow.

The relationship between FAS and FASD was not clear to most health care professionals. This is consistent with the results of the women's survey with most understanding the term FAS and not knowing the term FASD. Regarding pregnant women suspected of drinking alcohol, over one quarter of the health care professionals reported they do not counsel them about the dangers of alcohol nor do they encourage them to stop. Even fewer respondents refer women they suspect are drinking while pregnant to counseling or support groups and 18% report this situation has never come up. A total of 64% of the respondents indicate they screen pregnant women for alcohol use and an additional 10% said such screening is not relevant to their job.

Current Substance Use/Abuse Initiatives

Since October, 2004 the Centers for Disease Control and Prevention (CDC) has funded seven cooperative agreements to promote the development of comprehensive, state based fetal alcohol syndrome (FAS) prevention programs. The funded sites are in Colorado, Michigan, Minnesota, Missouri, Oregon, South Dakota and Wisconsin. The purpose is to develop, implement and evaluate programs for FAS prevention and to identify high prevalence geographic areas as well as high risk populations. Additionally, pre-conception intervention programs are to be established or enhanced along with procedures for monitoring the effectiveness of prevention programs.

Many of these states are well on their way to developing model programs. Missouri has developed an outreach program for the rural portion of their state, Michigan has funded a variety of community projects, and Wisconsin has developed the Healthy Choices Project which is a successful campaign and educates young women on preventing FAS by making better choices prior to pregnancy. (Samples of information collected from some of these states are

included in the FASD Prevention Resources Notebook in the Model Programs section available as a separate report from the Indiana State Department of Health).

Of the states funded through the CDC, South Dakota has the most comprehensive system and therefore has been identified as a model state in the area of FAS Prevention. The University of South Dakota, in conjunction with the North Dakota Fetal Alcohol Syndrome Center, has developed a user friendly state system. Prevention, prevalence and evaluation information is readily available. A 75 page handbook entitled " Fetal Alcohol Syndrome Handbook" had been developed and is available to print in PDF format on the Internet.

Information gathered from a number of other states with FAS prevention programs indicated each had some qualities that may be useful to adapt in Indiana. Washington and Alaska in particular have very comprehensive programs and were identified as having model FAS prevention programs. Both states, together with South Dakota, have readily available information on prevalence, treatment, and prevention as well as evaluation information that illustrates the success of their prevention programs. All three states identified as models have utilized existing resources and formed community based prevention programs that have been coordinated statewide. Although these states have special challenges due to their high risk populations, they are demonstrating success in the area of FAS Prevention. Washington State for example, has documented through the Pregnancy Risk Assessment Monitoring System (PRAMS) a decrease in maternal drinking during pregnancy as well as a decrease in the prevalence of drinking alcohol 3 months prior to pregnancy. (For more information the states with model FAS Prevention Programs visit their websites or the see the Model Programs section of the FAS Prevention Resources Notebook).

A total of 275 substance abuse clinics were identified throughout the state with more of them located in more densely populated areas (Indianapolis, Gary, Ft. Wayne, and Evansville) and areas with large college campuses (Lafayette and Bloomington). Approximately 75 - 80% of the clinics identified accept Medicaid in addition to self pay and private insurance and less than 10% of all clinics offer only the self payment option.

Of the Indiana clinics identified, approximately 10% list special programs related specifically to women among the other services they provide. Special services for adolescents are provided by 25% of the clinics and 5% of the clinics have special programs that relate to

women who are pregnant. These programs related to women primarily exist in highly populated areas and areas with large college student populations.

Stakeholder Participation

As a beginning step in the development of the strategic plan, Emerald Consulting staff attended two meetings of the FASD Prevention Task Force[5] to discuss the needs assessment and its anticipated outcomes. According to the members of the FASD Prevention Task Force, both health care providers and the general public had a limited awareness of Fetal Alcohol Spectrum Disorders (FASD) and a limited awareness of the negative consequences of consuming alcohol when pregnant.

Members of the task force were interested in determining the type and amount of information provided to pregnant women by the health care community. In addition, they were interested in determining what women of child bearing age knew about fetal alcohol spectrum disorders, how they obtained this information about FASD, and finally, what level of alcohol consumption during their pregnancies the women reported. Specific needs assessment questions were developed to address these areas of interest.

To determine what information would be of interest to health care providers and other community representatives, and to determine the most appropriate phrasing of some questions, focus groups were conducted in June 2005 in four Indiana communities: Gary, South Bend, Indianapolis and Madison. Forty five individuals participated across the four sites. Reports of the results of these focus groups were submitted to ISDH and were used to determine the questions used in the final versions of both needs assessment surveys.

The data collection plan included the administration of a written survey distributed electronically or by post to approximately 5,000 people representing the identified target groups. One thousand professional surveys were distributed using mailing lists from Indiana State Department of Health (ISDH), Healthy Families and the National Association of Social Workers. Approximately 50 of the professional surveys were returned as undeliverable and 349 (33%) were returned completed.

Approximately 4500 women's surveys were distributed throughout the state using mailing labels from the March of Dimes, Healthy Families, and ISDH. Of the 4500 distributed,

[5] Membership roster is included in Appendix C

approximately 215 were returned as undeliverable and 936 (22%) were returned completed. According to the demographics reported on the returned surveys, 60 different Indiana counties were represented for both professional health care providers and women of child bearing age. Some respondents did not identify their county of residence.

Follow up focus groups were conducted following the preliminary analyses of the needs assessment data. Four Indiana cities were selected to participate: Richmond, Ft. Wayne, Terre Haute and Jasper. Sites were selected based on size, urban or rural location, and were not located in the same geographical regions as the first focus groups. Invitations to the focus groups were extended to those in the host county who provided some health care service to women of child bearing age and the general public. Attendance at three of the four sites was limited and at one site there were no participants.

Vision

The FASD Prevention Task Force has adopted the vision and mission statement of the Maternal and Children's Special Health Care Services. The vision statement is:

"To improve the health status of families in the State of Indiana and to ensure that all children within the context of their family and culture will achieve and maintain the highest level of physical, mental, and emotional health in order to realize their human potential to the fullest."

The Mission of the Maternal and Children's Special Health Care Services is to:

1. Promote the delivery of high quality, comprehensive, family-centered health services for women, infants, children, and adolescents.
2. Identify and assess the health factors and conditions of families that adversely affect their social, economic, and health status.
3. Monitor relevant health status indicators to identify, assess, and pro-actively plan for current and future areas of need, including proposals for regulatory change.
4. Promote early prenatal care, treatment for substance abuse, breastfeeding, provision of nutritious food, health education and referrals in preventative and primary health care services to improve pregnancy outcome and child health.

5. Develop and promote effective outreach and identification, including the provision of culturally sensitive and competent care coordination and management.
6. Establish policy and standards of care, and promote quality preventative health care services that emphasize early evaluation, prevention of regression of health status and promotion of maximum function.
7. Strengthen outreach, educational and marketing efforts including communications to target high-risk populations, local agencies, and community organizations.
8. Provide technical assistance to local communities to assure the development of systems of health, nutrition education and special health care services.
9. Develop standards for health and nutrition services to evaluate the quality and outcomes of initiatives and to evaluate local project operations and management.
10. Procure and appropriately utilize funds and other resources to improve the health of families, with emphasis on women, infants, children, adolescents and children with special health care needs.

The overall outcome of the FASD strategic planning initiative is that ***"No baby shall be born in Indiana with fetal alcohol spectrum disorders".*** The goals of the prevention campaign are:

Goal 1: To increase public awareness of the consequences of alcohol consumption by pregnant women through a direct marketing campaign throughout the state.

Objective 1: Identify a marketing company to design an attractive name, succinct message and look (brand) for the FASD Prevention Campaign.

Objective 2: Coordinate public awareness efforts with any existing marketing campaigns to reduce drug and tobacco use in Indiana.

Objective 3: Distribute FASD Prevention Campaign materials throughout the state (physicians' offices, clinics, schools, health fairs book stores, groceries, and other venues).

Objective 4: Form an ad hoc committee to develop guidelines to standardize the follow up procedures for babies who test positive for alcohol and other illegal substances (cocaine, methamphetamines, marijuana)

Goal 2: To educate Indiana communities about fetal alcohol spectrum disorders and how to prevent them.

Objective 1: Develop or adapt educational materials (print and media) for use with health care providers, educators, and the general public.

Objective 2: Continue to monitor national organizations for resources and information useful in the Indiana FASD Prevention campaign including National Organization on Fetal Alcohol Syndrome (NOFAS) and Substance Abuse and Mental Health Services Administration (SAMHSA).

Objective 3: Collaborate with existing state organizations, agencies and ISDH programs to distribute FASD educational materials at regularly scheduled events throughout the state including INshape Indiana, Indiana Perinatal Network, Indiana Mental Health Association, Indiana Coalition to Reduce Underage Drinking, March of Dimes and others.

Objective 4: Present information about FASD at conferences and events where ISDH staff are already scheduled.

Goal 3: To support the efforts of up to four local communities to plan and implement an FASD Prevention Campaign.

Objective 1: Develop a request for proposals that provides direction to local communities to apply to the state for a planning grant of up to $25,000 to:

a) form (or build on an existing) coalition of local representatives interested in improving the health of mothers and babies; b) identify community priorities with respect to FASD including a target audience; c) to plan and implement a FASD prevention campaign and d) evaluate their campaign's cost and effectiveness.

Objective 2: Support the local communities selected by providing access to the state's marketing and educational materials.

Objective 3: Using information gathered from the local communities implementing prevention campaigns; submit requests for additional funding to replicate those campaigns that are most cost effective and efficient.

Goal 4: Replicate FASD Prevention Campaigns in additional communities.

Objective 1: Using the PSUPP model and based on the results of the initial local prevention campaigns developed with state support, request proposals from additional communities to implement prevention campaigns.

Objective 2: Provide support to local communities by providing access to the state's marketing and educational materials.

Objective 3: Monitor the pilot sites performance comparing state data to that gathered from the individual sites.

Objective 4: Using information gathered from the local communities implementing the prevention campaigns; submit requests for additional funding to replicate those campaigns that are most cost effective and efficient.

Goal 5: Evaluate the FASD Prevention Campaign efforts throughout the state.

Objective 1: Determine indicators of effective FASD Prevention Campaigns including cost.

Objective 2: Gather data on the indicators.

Objective 3: Analyze data.

Objective 4: Present findings and recommendations.

Workplan

Strategic Implementation Plan

The following charts provide the work plan for implementation strategies that have been identified to support the achievement of the Priority Objectives. The detailed activities and timeline are included as Appendix F.

Goal 1.0: To increase public awareness of the consequences of alcohol consumption by pregnant women through a direct marketing campaign throughout the state**.**		
Objectives	Collaborative Partners	Measurement
1.1 Identify a marketing company to design an attractive name, succinct message and look (brand) for the FASD Prevention Campaign.	•	•
1.2 Coordinate public awareness efforts with any existing marketing campaigns to reduce drug and tobacco use in Indiana.		•
1.3 Distribute FASD Prevention materials throughout the state (physicians' offices, clinics, schools, health fairs, book stores, groceries, and other venues).		•
1.4 Form an ad hoc committee to explore the feasibility of developing guidelines to standardize follow up procedures for babies who test positive for alcohol and other illegal substances.		•
Goal 2.0: To educate Indiana communities about Fetal Alcohol Spectrum Disorders and how to prevent them.		
Objectives	Collaborative Partners	Measurement
2.1 Develop or adapt educational materials print and media) for use with health care providers, educators, and the general public.	•	•
2.2 Continue to monitor national organizations for resources and information useful in the Indiana FASD Prevention campaign including National Organization on Fetal Alcohol Syndrome (NOFAS) and Substance Abuse and Mental Health Association (SAMHSA).	•	•
2.3 Collaborate with existing organizations, agencies and ISDH programs to distribute FASD	•	•

educational materials at naturally occurring events throughout the state including INshape Indiana, Indiana Perinatal Network, Indiana Association for the Education of Young Children, Indiana Coalition to Reduce Underage Drinking, Indiana Mental Health Association, March of Dimes and others.		
2.4 Present information about FASD at conferences and events where ISDH staff is already scheduled.	•	•
2.5 Distribute FASD Prevention materials throughout the state (Physicians' offices, clinics, schools, health fairs and other places	•	•
Goal 3.0: To support the efforts of up to four local communities to plan and implement an FASD Prevention Campaign.		
Objectives	Collaborative Partners	Measurement
3.1 Develop a request for proposals that provides direction to local communities to apply to the state for a planning grant of up to $25,000 to: a) form (or build on an existing) coalition of local representatives interested in improving the health of mothers and babies; b) identify community priorities with respect to FASD including a target audience; c) to plan and implement a FASD prevention campaign and d) evaluate their campaign's cost and effectiveness.	•	•
3.2 Support the local communities selected by providing access to the state's marketing and educational materials.	•	•
3.3 Using information gathered from the local communities implementing prevention campaigns, submit requests for additional funding to replicate those campaigns that are most cost effective and efficient.	•	•
Goal 4: Replicate FASD Prevention Campaigns in additional communities		
Objectives	Collaborative Partners	Measurement
4.1 Using the PSUPP model and based on the results of the initial local prevention campaigns	•	•
4.2 Provide support to local communities by providing access to the state's marketing and	•	•

educational materials.		
4.3 Using information gathered from the local communities implementing the FASD prevention campaigns, submit requests for additional funding to replicate those campaigns that are most cost effective and efficient.	•	•
4.4 Using information gathered from the local communities, implement the prevention campaigns that are most cost effective, efficient and produce positive outcomes	•	•
Goal 5: Evaluate the FASD Prevention Campaign efforts throughout the state.		
Objectives	Collaborative Partners	Measurement
5.1 Determine indicators of effective FASD prevention campaigns including cost.	•	•
5.2 Gather data on the indicators 5.3 Analyze data.	•	•
5.4 Present findings and recommendations.	•	•

Appendix A
County Listing of Substance Abuse Programs

Program Key:

1= Afternoons Rock

2= Prenatal Substance Use Prevention Program

3= Indiana Reduces Early Sex and Pregnancy by Educating Children and Teens (RESPECT)

4= Students Against Destructive Decisions (SADD) In 225 Indiana High Schools and 50 Middle Schools (*Program information available by school district only therefore participating counties are not identified here)

5= Checkmate Drugs (National Guard Drug Demand Reduction Program)

6= Drug Abuse Resistance Education Project (DARE)

County	Programs
Adams	1, 3, 6
Allen	1, 2, 3, 6
Bartholomew	1, 3, 6
Benton	1, 3, 6
Blackford	1, 3, 6
Boone	1, 3, 6
Brown	1, 3, 6
Carroll	1, 3, 6
Cass	1, 3, 6
Clark	1, 2, 3, 6
Clay	1, 3, 6
Clinton	1, 3, 6
Crawford	1, 3, 6
Daviess	1, 3, 6
Dearborn	1, 2, 3, 6
Decatur	1, 3, 6

De Kalb	**1, 3, 6**
Delaware	**1, 2, 3, 6**
Dubois	**1, 2, 3, 6**
Elkhart	**1, 2, 3, 6**
Fayette	**1, 3, 6**
Floyd	**1, 3, 6**
Fountain	**1, 3, 6**
Franklin	**1, 2, 3, 6**
Fulton	**1 , 3, 6**
Gibson	**1, 3, 6**
Grant	**1, 3, 6**
Greene	**1, 3, 6**
Hamilton	**1, 3, 6**
Hancock	**1, 3, 6**
Harrison	**1, 3, 6**
Hendricks	**1, 3, 6**
Henry	**1, 3, 6**
Howard	**1, 3, 6**
Huntington	**1, 3, 6**
Jackson	**1, 3, 6**
Jasper	**1, 3, 6**
Jay	**1, 3, 6**
Jefferson	**1, 3, 6**
Jennings	**1, 2, 3, 6**
Johnson	**1, 3, 6**
Knox	**1, 3, 6**
Kosciusko	**1, 3, 6**
Lagrange	**1, 3, 6**
Lake	**1, 2, 3, 6, 5**

La Porte	**1, 2, 3, 6**
Lawrence	**1, 3, 6**
Madison	**1, 2, 3, 6**
Marion	**1, 2, 3, 6**
Marshall	**1, 3,**
Martin	**1, 3, 6**
Miami	**1, 3, 6**
Monroe	**1, 3, 6**
Montgomery	**1, 3, 6**
Morgan	**1, 3, 6**
Newton	**1, 3, 6**
Noble	**1, 3, 6**
Ohio	**1, 2, 3, 6**
Orange	**1, 3, 6**
Owen	**1, 2, 3, 6**
Parke	**1, 3, 6**
Perry	**1, 3, 6**
Pike	**1, 3, 6**
Porter	**1, 3, 5, 6**
Posey	**1, 3, 6**
Pulaski	**1, 3, 6**
Putnam	**1, 2, 3, 6**
Randolph	**1, 3, 6**
Ripley	**1, 2, 3, 6**
Rush	**1, 3, 6**
St Joseph	**1, 3, 6**
Scott	**1, 3, 6**
Shelby	**1, 3, 6**
Spencer	**1, 2, 3, 6**

Starke	**1, 3, 6**
Steuben	**1, 3, 6**
Sullivan	**1, 3, 6**
Switzerland	**1, 2, 3, 6**
Tippecanoe	**1, 2, 3, 6**
Tipton	**1, 3, 6**
Union	**1, 3, 6**
Vanderburgh	**1, 2, 3, 6**
Vermillion	**1, 3, 6**
Vigo	**1, 2, 3, 6**
Wabash	**1, 3, 6**
Warren	**1, 3, 6**
Warrick	**1, 2, 3, 6**
Washington	**1, 3, 6**
Wayne	**1, 3, 6**
Wells	**1, 3, 6**
White	**1, 3, 6**
Whitley	**1, 3, 6**

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Appendix B

Survey Instruments

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FASD Prevention Needs Assessment Survey
Physicians/Social Workers/Mental Health/Healthcare Providers

The Indiana State Department of Health is conducting a statewide needs assessment as part of its overall efforts to improve pregnancy outcomes. A variety of audiences are being asked for their impressions of the effects of certain maternal behaviors on pregnancy outcomes as well as their awareness of community resources available for pregnant women. We need your help. Answering this survey will give us information to develop educational materials for women and those who serve them.
There are two parts to the survey.

BASIC INFORMATION: Please respond to each item by circling the answer that best describes you.

1. What is your age?
    a. Less than 25
    b. 25-30
    c. 31-35
    d. 36-40
    e. 41-45
    f. 46-50
    g. Over 50

2. Gender
    a. Male
    b. Female

3. Your position:
    a. Physician
    b. Physician Assistant
    c. Nurse
    d. Social Worker
    e. Mental Health Provider
    f. Other Health Care Provider
    g. Administrative Staff
    h. Other_____

4. What county do you work in? _____

NEEDS ASSESSMENT

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Read each question and then circle the answers you believe are correct. You may circle multiple answers. Please answer each question even if your response is "don't know". This information is confidential and will only be used to develop educational material for Indiana.

1. How do women in your community **obtain health information**?
    a. Physician or health care provider
    b. Family members
    c. Friends
    d. Print materials: Pamphlets/brochures/flyers/posters
    e. Advertisements or Public Service Announcements
    f. Books/Magazines
    g. The Internet
    h. Don't know

2. **How much alcohol is safe** for a pregnant woman to drink?
    a. 1 bottle of beer a day
    b. 1 glass of wine a day
    c. 1 wine cooler a day
    d. 1 mixed drink or cocktail a day
    e. 1 shot of liquor a day
    f. None of the above
    g. Don't know
    h. Other: _____

2. Which of the following statements **do you believe are true** about women drinking alcohol while pregnant?
    a. A woman should stop drinking as soon as she becomes pregnant
    b. A woman can drink occasionally while pregnant
    c. It's okay to drink as long as the woman doesn't get drunk
    d. It's okay as long as the woman only drinks wine or beer
    e. It's okay to drink during the last trimester of pregnancy
    f. I don't believe any of these statements are true

3. Which of the following statements **do you think are true** if a mother drinks while she is pregnant?
    a. The baby may be born with some problems but will outgrow them
    b. The baby may be born with problems that will last a lifetime
    c. The baby may have growth retardation
    d. The baby may have mental retardation
    e. The baby may have facial anomalies
    f. The baby will be born drunk
    g. The baby's central nervous system may be abnormal
    h. The baby may look fine but could still have alcohol related brain damage
    i. The baby may be taken away from the mother.
    j. I don't think anything happens to the baby if the mother drinks while pregnant.

4. Which of the following measures **have you used to educate** a pregnant woman who was drinking alcohol?
    a. Given verbal explanations
    b. Provided print material (booklet, pamphlet)
    c. Recommended a book
    d. Recommended an internet site
    e. Suggested she access a particular community resource
    f. Suggested she talk to a particular person
    g. Referred her to a specific place for treatment
    h. None of the above

5. **In your community**, what resources are available for pregnant women who drink alcohol?
    a. Substance abuse counseling
    b. Support groups
    c. Treatment centers
    d. Church programs
    e. Educational materials
    f. None
    g. Don't know

6. Which statements describe **how things are in your community**?
    a. Some women drink while they are pregnant
    b. Most women do not drink while they are pregnant
    c. More women drink while they are pregnant than do not
    d. I don't know the extent to which women in this community drink

7. **As I understand it**, Fetal Alcohol Syndrome is:
    a. A genetic problem that families have no control over
    b. Something a baby can get if a woman drinks while pregnant
    c. A rare occurrence that few children ever get
    d. Diagnosed using four specified criteria
    e. Rarely diagnosed although it occurs frequently
    f. A condition that affects 1 in every 1,000 babies born
    g. Entirely preventable if a pregnant woman does not drink alcohol
    h. A condition the baby will eventually outgrow
    i. One of the conditions included in Fetal Alcohol Spectrum Disorder
    j. I don't know if Fetal Alcohol Syndrome is any of these things

8. Fetal Alcohol Syndrome can occur **if the mother**:
    a. is an alcoholic
    b. drinks certain types of alcohol
    c. drinks during certain times during her pregnancy
    d. drinks any type of alcohol anytime during her pregnancy
    e. Don't know

9. In Indiana, the reported percentage of **unplanned pregnancies** per year is:

a. 15%
b. 25%
c. 50%
d. 75%
e. Don't know

10. **Do you feel comfortable** talking to a woman about her alcohol consumption during pregnancy?
a. Yes
b. No
c. It depends on the situation
d. Don't know

11. **Do you feel comfortable** talking to a woman about the adverse effects of alcohol consumption in pregnancy, including fetal alcohol syndrome?
a. Yes
b. No
c. It depends on the situation
d. Don't know

12. Do you **routinely use a screening tool** with every patient to identify alcohol use and/or abuse?
a. Yes (Go to question 14)
b. No (Go to question 13)
c. Only with those I think warrant it
d. Not appropriate given my job/position

13. Why don't you use a screening tool with every patient to identify alcohol use and or abuse?
a. Takes too much time
b. Not something that can be billed for
c. No treatment facilities available for person if identified
d. Purpose of screening tool not clear
e. Lack information about prevention and intervention
f. Not appropriate for the patients I see
g. Never thought about it so haven't done it
h. Not appropriate given my job/position

14. When you know, or strongly suspect, one of your clients has an alcohol problem, **which of the following do you do**?

a. Counsel them on the dangers of using alcohol during pregnancy
b. Encourage them to stop using alcohol during pregnancy
c. Give them educational materials
d. Refer them to counseling

e. Refer them to a support group
f. Nothing
g. This situation has never come up

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

Please FAX (to 317 635-9007) or mail the completed survey to:
EMERALD CONSULTING, 225 N. NEW JERSEY UNIT 21, INDIANAPOLIS INDIANA 46204
If you have any questions, contact Darla Cohen at darla.cohen@sbcglobal.net.

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Women's Health Survey

Indiana is working to improve the health of women and babies. Please help us by answering this survey. The information you provide will be used to develop educational materials for both mothers and the health care providers working with them. First we need some information about you.

Please respond to each question by circling the answer that best describes you. **Circle ONE** answer for each question. This information will be kept confidential. It will only be used to describe who responded to this survey.

1. Age
    a. less than 20
    b. 20-25
    c. 25-30
    d. 30-35
    e. 35-40
    f. over 40

2. Marital Status
    a. Married
    b. Single

3. Race
    a. African American
    b. Asian
    c. Caucasian
    d. Native American
    e. Hispanic or Latino
    f. Other

4. What is highest grade you completed in school?
    a. 8th grade or less
    b. 9 or 10th grade
    c. 11th or 12th grade
    d. High School Diploma or GED
    e. 2 year college/trade school
    f. 4 year college degree
    g. Masters Degree

5. Which statement best describes your pregnancy history?
    a. Never been pregnant
    b. Currently pregnant for the first time
    c. Currently pregnant but not for the first time
    d. Not pregnant now but have been pregnant before

6. If you are not pregnant, and are not planning on becoming pregnant now or in the near future, are you using birth control?

    a. Yes
    b. No
    c. Sometimes
    d. No Response

7. What county do you live in? _____

SURVEY QUESTIONS:
Please respond to each question by **circling all of the responses that apply**. If you do not want to respond to a question, please circle "No Response".

1. Where do you **get health information** that you believe to be true or accurate?
    a. Primary health care provider/physician
    b. Family members
    c. Friends
    d. Advertisements/public service announcements
    e. Books/magazines
    f. Flyers/pamphlets/brochures
    g. Internet
    h. Library
    i. No response

3. Which of the following do **you believe are necessary** to have a healthy pregnancy?
    a. Taking prenatal vitamins
    b. Getting prenatal care
    c. Not using drugs
    d. Not smoking
    e. Knowing the warning signs for preterm labor
    f. Not drinking
    g. Exercising regularly
    h. I don't think any of these are really necessary
    i. No response

4. What do you think a drink of alcohol means?
    a. 1 can or bottle of beer
    b. 1 glass of wine
    c. 1 can or bottle of wine cooler
    d. 1 mixed drink or cocktail
    e. 1 shot of liquor
    f. No response

5. During the past 30 days how many drinks of alcohol did you have in an average week?
    a. 14 or more
    b. 7-13
    c. 4-6
    d. 1-3
    e. Less than one
    f. None
    g. Don't remember
    h. No response

6. During the past 30 days how many times did you have more than five alcoholic drinks in one sitting?
    a. 6 or more
    b. 4-5
    c. 2-3
    d. 1
    e. None
    f. Don't remember
    g. No response

7. What types of alcohol are safe to drink during pregnancy?
    a. Beer
    b. Wine
    c. Wine Coolers
    d. Mixed drinks or cocktails
    e. None of the above
    f. Don't know
    g. No response

8. Have you heard, read, or seen anything about Fetal Alcohol Syndrome?
    a. Yes (answer question 8)
    b. No (Skip question 8)
    c. No response

9. Where did you hear, read or see information about Fetal Alcohol Syndrome?
    a. Family member
    b. Friend
    c. Doctor
    d. Nurse
    e. Health clinic
    f. School
    g. Newspaper/magazine
    h. Television
    i. Other
    j. No response

10. As I understand it, Fetal Alcohol Syndrome is:
    a. A genetic problem that families have no control over
    b. Something a baby can get if a woman drinks while pregnant
    c. A rare occurrence that few children ever get
    d. Rarely diagnosed although it occurs frequently
    e. A condition that affects 1 in every 1,000 babies born
    f. Entirely preventable if a pregnant woman does not drink alcohol
    g. A condition the baby will eventually outgrow
    h. One of the conditions included in Fetal Alcohol Spectrum Disorder
    i. No response

11. Fetal Alcohol Syndrome can occur if the mother:
    a. Is an alcoholic
    b. Drinks certain types of alcohol
    c. Drinks during certain times in her pregnancy
    d. Drinks any type of alcohol anytime during her pregnancy
    e. No response

12. Which of the following statements **do you think are true** if the mother drinks while she is pregnant?
    a. The baby may be born with some problems but will outgrow them
    b. The baby may be born with problems that will last a lifetime
    c. The baby will be born drunk
    d. The baby may look fine but may still have alcohol related brain damage
    e. The baby will be taken away if anyone finds out the mother drank
    f. I don't believe any of the statements
    g. No response

13. **In your community**, where could a woman go for help if she drank while she was pregnant?
    a. I don't know
    b. Her friends and family
    c. Health clinic or local health department
    d. Substance abuse clinic
    e. Her doctor
    f. I am not aware of any resources for pregnant women who drink
    g. No response

14. Which of the following statements **describes how things are** in your community?
    a. Some women drink while they are pregnant
    b. Most women do not drink while they are pregnant
    c. I do not know the extent to which women in this community drink while they are pregnant
    d. No response

If you have been pregnant in the past or are pregnant now, please continue on to the remaining questions. If you have never been pregnant, stop here. Thank you.

15. Has your doctor ever told you it was safe to drink alcohol during pregnancy?
    a. Yes
    b. No
    c. Don't remember
    d. No response

16. Has a family member ever told you it was safe to drink alcohol during pregnancy?
    a. Yes
    b. No
    c. Don't remember
    d. No response

17. During the 3 months BEFORE your pregnancy, how many drinks of alcohol did you have in an average week?
    a. 14 or more
    b. 7-13
    c. 4-6
    d. 2-3
    e. 1
    f. None
    g. Don't remember
    h. No response

18. During the 3 months BEFORE you got pregnant, how many times did you drink 5 or more alcoholic drinks in one sitting?
    a. 6 or more
    b. 4-5
    c. 2-3
    d. 1
    e. None
    f. Don't remember
    g. No response

19. During the last three months of your pregnancy, how many drinks of alcohol did you have in an average week?
    a. 14 or more
    b. 7-13
    c. 4-6
    d. 1-3
    e. Less than one
    f. None
    g. Don't remember
    h. I am less than 7 months pregnant
    i. No Response

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

Please FAX (to: 317 635-9007) or mail the completed survey to:
EMERALD CONSULTING, 225 N. NEW JERSEY UNIT 21, INDIANAPOLIS INDIANA 46204
If you have any questions, contact Darla Cohen at darla.cohen@sbcglobal.net

Appendix C

FASD Prevention Task Force Membership

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TASK FORCE MEMBERS

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Appendix D

Executive Summary of Survey Results

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FETAL ALCOHOL SPECTRUM DISORDERS
NEEDS ASSESSMENT EXECUTIVE SUMMARY

The Indiana State Department of Health Genomics division contracted with Emerald Consulting, LLC to conduct a statewide needs assessment to identify the issues in Indiana related to the public's awareness and prevention of the effects of prenatal exposure to alcohol. Using written surveys, focus groups and state and national data sources, information was collected on the community's awareness of FAS, the use of alcohol by women of child bearing age, the effects of prenatal exposure to alcohol and existing community resources for the prevention and treatment of substance use and abuse. Data were analyzed and used to develop a five year strategic plan for the prevention of Fetal Alcohol Spectrum Disorders in Indiana.

Results of the needs assessment indicated that women obtain health care information they trust primarily from physicians, family and friends. The majority of both women of child bearing age and health care professionals knows the term Fetal Alcohol Syndrome (FAS) but is not familiar with the term Fetal Alcohol Spectrum Disorders (FASD). Definitions of "a drink of alcohol" vary greatly across groups and individuals. Both women and health care professionals responded that a baby who is prenatally exposed to alcohol may have lifelong problems yet 22% of the health care professionals responded it was not necessary for a woman to stop drinking as soon as she learns she is pregnant. Comparisons of information from the statewide needs assessment and national data collection efforts indicate that women of child bearing age self report consumption of alcohol while pregnant to varying degrees according to age and race. Discussions in the statewide focus groups revealed many believed women do not report the actual extent to which they drink alcohol while pregnant because they know it is not recommended for a healthy pregnancy.

The overall outcome of the five year strategic plan is that "no child shall be born in Indiana with Fetal Alcohol Spectrum Disorders". The plan focuses on five overall goals to achieve this outcome:

1. To increase awareness of the consequences of alcohol consumption by pregnant women through a direct marketing campaign throughout the state**;**
2. To educate Indiana communities about Fetal Alcohol Spectrum Disorders and how to prevent them;
3. To support the efforts of up to four local communities to plan and implement an FASD Prevention Campaign;
4. Replicate FASD Prevention Campaigns in additional communities and
5. Evaluate the FASD Prevention Campaign efforts throughout the state.

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Appendix E

Focus Group Results

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Summary of Focus Groups

In January 2006 four focus groups were scheduled in the Indiana cities of Richmond, Ft. Wayne, Jasper and Terre Haute. Participants were informed of the purpose of the Fetal Alcohol Spectrum Disorders (FASD) Prevention initiative, the recent statewide needs assessment and the state's plan to write a five year strategic plan for implementing a FASD Prevention Campaign. Each site followed the same agenda and those attending were asked some specific questions about their awareness of FAS, FASD and the extent to which alcohol consumption by pregnant women was an issue in their communities. Information gathered from the 17 participants was tabulated into a separate report presented to the members of the task force.

According to the focus group participants, there is a lack of understanding of the terms FAS and FASD and the problem of prenatal alcohol exposure in general. Nearly all believed the negative consequences of women drinking alcohol while pregnant are not immediately evident at birth leading to the misconception that there are no effects. This belief is further supported by other women who drink while pregnant and who appear to have healthy children.
Most of the participants believe women do not accurately report the amount or the frequency alcohol is consumed when they are pregnant. It was further reported that there are probably more cases of FAS and FASD than are diagnosed by the medical community. All participants with the exception of one believed FAS (and FASD) to be 100% preventable if a woman refrains from consuming alcohol while pregnant.

Participation in the four focus groups was poor considering the topic, the level of community interest expressed by local contacts and the evening scheduling to accommodate more people, however, information gathered was consistent with both the Indiana needs assessment data and national and state sources of
Information related to FASD prevention.

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Appendix F

Strategic Plan Implementation Timeline

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Fetal Alcohol Spectrum Disorders Prevention Strategic Plan Implementation Timeline

Goal 1.0: To increase public awareness of the consequences of alcohol consumption by pregnant women through a direct marketing campaign throughout the state.					
	Year One	**Year Two**	**Year Three**	**Year Four**	**Year Five**
1.1 Identify a marketing company to design an attractive name, succinct message and look for the campaign					
1.1.1 Prepare request for proposals for brand design					
1.1.2 Review proposals submitted					
1.1.3 Select vendor to design brand for FASD					
1.2 Coordinate public awareness efforts with any existing marketing campaigns to reduce drug and tobacco use in Indiana.					
1.2.1 Identify existing initiatives within ISDH that could promote FASD prevention					
1.2.2 Meet regularly with identified initiative coordinators to plan collaborative marketing and educational techniques					
1.2.3 Implement collaborative marketing and educational activities					
1.3 Distribute FASD prevention materials throughout the state (physicians' offices, clinics, schools, health fairs, book stores, groceries, and other venues).					
1.3.1 Identify and prioritize appropriate distribution points throughout the state for FASD prevention materials					
1.3.2 Distribute marketing materials to priority locations					
1.3.3 Monitor distribution of FASD prevention materials					
1.3.4 Expand distribution of FASD prevention materials					
1.4 Form an ad hoc committee to explore the feasibility of developing guidelines to standardize follow up procedures for babies who test positive for alcohol and other illegal substances.					
1.4.1 Identify those FASD Prevention partners who work with pregnant women interested in serving on					

the committee and invite them to participate					
1.4.2 Support the committee as they meet to determine the feasibility of developing guidelines.					
Goal 2.0: To educate Indiana communities about Fetal Alcohol Spectrum Disorders and how to prevent them.					
	Year One	**Year Two**	**Year Three**	**Year Four**	**Year Five**
2.1 Develop or adapt educational materials (print and media) for use with health care providers, educators, and the general public.					
2.1.1 Using CDC guidelines for FASD prevention, develop or adapt print educational material					
2.1.2 Using CDC guidelines for FASD prevention, develop or adapt media-based educational material					
2.1.3 Identify state and local agencies to serve as distribution points of educational materials					
2.1.4 Provide print and media educational materials to identified distribution points					
2.1.5 Monitor distribution and use of educational materials					
2.2 Continue to monitor national organizations for resources and information useful in the Indiana FASD Prevention campaign including National Organization on Fetal Alcohol Syndrome (NOFAS) and Substance Abuse and Mental Health Association (SAMHSA).					
2.2.1 As new resources or prevention material becomes available review it for its applicability to Indiana's FASD prevention campaign.					
2.2.2 Inform the FASD prevention task force and those participating local communities of the new resources as they are identified.					
2.3 Collaborate with existing organizations, agencies and ISDH programs to distribute FASD educational materials at naturally occurring events including INshape Indiana, Indiana Perinatal Network, Indiana Association for the Education of Young Children, Indiana Coalition to Reduce Underage Drinking, Indiana Mental Health Association, March of Dimes and others.					

	Year One	Year Two	Year Three	Year Four	Year Five
2.3.1 Expand FASD Prevention task force membership to include representatives from existing organizations working with women and children					
2.3.2 Convene expanded task force at least four times per year					
2.3.3 Determine how members of the task force can collaborate and consolidate their efforts to educate women and the public at large about healthy pregnancy outcomes					
2.3.4 Work together with expanded task force to distribute educational and marketing materials					
2.3.5 Monitor distribution and use of educational and marketing materials by members of the task force					
2.4 Present information about FASD at conferences and events where ISDH staff are scheduled to work, exhibit or present.					
2.4.1 Using available calendars of events provided by agencies and organizations represented on the FASD task force and others, identify conferences and events appropriate for the distribution of FASD prevention information					
2.4.2 Prepare or adapt a variety of presentations in a variety of formats for distribution at scheduled conferences and events					
2.4.3 Contact conference and event planners to confirm ISDH participation					
2.4.4 Present FASD prevention material at conferences and events					
2.4.5 Record locations and dates of presentations and types of information distributed at conferences and events					
Goal 3.0: To support the efforts of up to four local communities to plan and implement an FASD Prevention Campaign.					
	Year One	**Year Two**	**Year Three**	**Year Four**	**Year Five**
3.1. Develop a request for proposals that provides direction to local communities to apply to the state for a planning grant of up to $25,000.					
3.1.1 Develop a Request for Proposals to identify up to four pilot communities					

	Year One	Year Two	Year Three	Year Four	Year Five
3.1.2 Identify a review committee to review the proposals submitted and select up to 4 pilot sites					
3.1.3 Conduct an evaluation to identify what works for future replication communities					
3.1.4 Establish an advisory committee across the communities to support replication efforts.					
3.2 Support the local communities selected by providing access to the state's marketing and educational materials.					
3.2.1 Provide resources to the local communities.					
3.2.2 Provide technical support as needed/					
3.3 Using information gathered from the local communities implementing prevention campaigns, submit requests for additional funding to replicate those campaigns that are most cost effective, efficient and produce positive outcomes .					
3.3.1 Identify potential fund sources.					
3.3.2 Submit applications for funding.					
Goal 4.0: Replicate FASD Prevention Campaigns in additional communities					
	Year One	**Year Two**	**Year Three**	**Year Four**	**Year Five**
4.1 Using the PSUPP model and based on the results of the initial local prevention campaigns developed with state support, request proposals from additional communities to implement prevention campaigns					
4.1.1 Develop a Request for Proposals to identify up to four pilot communities.					
4.1.2 Provide resources and technical assistance to support the successful applicants.					
4.1.3 Conduct an evaluation to identify what works for future replication communities					
4.1.4 Establish an advisory committee across the communities to support additional replication efforts.					
4.2 Provide support to local communities by providing access to the state's marketing and educational materials.					

	Year One	Year Two	Year Three	Year Four	Year Five
4.2.1 Ensure each of the sites has access to the FASD prevention materials.					
4.2.2 Convene the advisory committee up to three times per year to identify technical assistance needs of the participating communities					
4.3 Monitor pilot sites performance comparing state data to that gathered from the individual sites					
4.4 Using information gathered from the local communities, implement the prevention campaigns that are most cost effective, efficient and produce positive outcomes.					

Goal 5.0: Evaluate the FASD Prevention Campaign efforts throughout the state.					
	Year One	**Year Two**	**Year Three**	**Year Four**	**Year Five**
5.1 Determine indicators of effective FASD Prevention Campaigns including cost.					
5.1.1 Convene advisory committee of four selected sites					
5.1.2 Determine common indicators across the four selected sites					
5.1.3 Present the common indicators to the FASD Task Force					
5.1.4 Review common indicators and determine whether they provide all of the required information					
5.1.4 Determine whether there are other sources of data pertinent to the indicators					
5.2 Gather data on the indicators.					
5.2.1 Identify data collection methods and instruments for the identified indicators					
5.2.2 Review existing data collection methods and instruments for the state					
5.2.3 Develop data collection procedures and instruments as needed					
5.2.4 Collect data from FASD Prevention Campaign sites					
5.2.5 Tabulate the data collected					
5.3 Analyze data.					
5.3.1 Identify questions of interest to FASD Task Force					
5.3.2 Identify questions of interest to communities participating in the FASD Prevention campaign					

	Year One	Year Two	Year Three	Year Four	Year Five
5.3.3 Determine analyses appropriate to answer the identified questions					
5.3.4 Conduct the analyses					
5.4 Present findings and recommendations.					
5.4.1 Prepare preliminary report of findings					
5.4.2 Discuss findings with FASD Prevention Task Force					
5.4.3 Determine if additional analyses are necessary and if so conduct them					
5.4.4 Prepare final report and recommendations					
5.4.5 Present findings and recommendations to the FASD Prevention Task Force					