

Indiana FASD Needs Assessment Report

September 30, 2022



**INDIANA
ALLIANCE**

On Prenatal Substance Exposure

Educating, Advocating, Supporting Across the Lifespan

Prepared by BVC, LLC for the Indiana Alliance on Prenatal Substance Exposure

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Introduction

The Indiana Alliance on Prenatal Substance Exposure, formerly known as Indiana National Organization on Fetal Alcohol Syndrome (INOFAS), is a prevention program of Mental Health America of Indiana (MHAI). The organization is known in the community as either the Indiana Alliance or IAPSE and works to prevent prenatal exposure to alcohol, drug and other substances known to harm fetal development by educating, advocating, and supporting professionals, policymakers, families, and individuals throughout Indiana (<https://inalliancepse.org/>).

Emerging research has resulted in coining the term Fetal Alcohol Spectrum Disorder or FASD to describe the complex and wide-ranging effects that can occur when a person consumes alcohol during pregnancy. Effects from FASD can include physical disabilities as well as challenges with learning and behavior. These challenges can be life long and have wide ranging impacts on individuals and families.

The Indiana Alliance is charged with conducting a needs assessment to help guide its strategic planning, educational activities, and information dissemination to the public and to service providers about the potentially harmful effects of consuming alcohol during pregnancy.

A comprehensive needs assessment was last completed in 2006 by Emerald Consulting. Two survey documents were developed with input from a variety of stakeholders. One survey was targeted to women of child-bearing age and the other to service providers. The written survey was distributed electronically or via USPS with paper copies returned and analyzed using the Statistical Package for the Social Sciences (SPSS).

2022 Survey Development

The 2022 survey instruments sought to incorporate as many questions as possible from the 2006 survey to facilitate potential comparison of the results. Some questions were modified to reflect current language and increased knowledge about FASD. Additional questions were added to the surveys modeled from the Community Implementation Toolkit developed by the Indiana Department of Child Services (DCS). It was determined that continuing with 2 surveys as was done in 2006 was most appropriate; one survey for people with lived experience (a diagnosis of FASD) and those who are or have been pregnant or caregivers, and another for service providers. The surveys were created using Survey Monkey and made available electronically for ease of distribution and completion.

A link (https://www.surveymonkey.com/r/Indiana_FASD) was provided to a Survey Monkey site that described the needs assessment and invited participants to select the appropriate option to gather their insights. Below is a screen shot of the Indiana FASD needs assessment invitation page.

Indiana FASD Survey

Thank you for helping by taking a survey! **Please click the link below for the correct survey for you. Please complete the survey by Wednesday Sept 7, 2022.**

If you are an **individual** with FAS/FASD or the **parent/caregiver** of an individual with FAS/FASD, please take this survey:

https://www.surveymonkey.com/r/FASD_experience

If you are a **provider**, please take this survey:

https://www.surveymonkey.com/r/FASD_provider

This survey is supported by the Division of Mental Health and Addiction (DMHA) to help the IN Alliance on Prenatal Substance Exposure learn more about the effects of FASD (Fetal Alcohol Spectrum Disorders) in Indiana. By gathering information about the needs of children, families, providers and community agencies we can make recommendations and an action plan for the state of Indiana.

Data Collection

The needs assessment survey invitation was distributed widely through email with an introduction from the Indiana Alliance to encourage participation. Messages were sent multiple times to groups and individuals representing state agencies, training/technical assistance consulting groups, professional societies, individual practitioners, and parent support organizations and other 501(c)3 entities. The Indiana Alliance reached out specifically to identified caregivers and people with lived experience to invite participation in the needs assessment.

Individuals and organizations were provided with sample text targeted to both individuals with FASD and caregivers as well as providers. Sample text was offered for email as well as social media posts.

The survey was open from August 12 to September 9, 2022. Prior to opening the survey email messages were sent to the distribution list. Multiple reminder messages were sent during the open period. The needs assessment was also announced at various statewide training events and meetings to encourage participation. It was also shared in various newsletters and social media.

Data Analyses

Survey Monkey was used to collect and analyze responses. Tableau software and Microsoft Excel were also used to generate some of the visualizations of the data. Descriptive statistics were tabulated for each question from the surveys. Tables representing tabulated responses are included in the Appendices of this report. When possible, tables comparing responses from the 2006 surveys are included.

Demographic data of the respondents as well as cross tabulations for selected questions are presented.

Discussion of Consumer Lived Experience Survey Results

Although the survey invitation was shared broadly and multiple times, only 2 consumers with lived experience completed the entire survey. As such no meaningful results can be concluded from these responses. Respondents to the survey did however endorse a need for support as well as improving access to diagnosis, housing, getting help with education and raising awareness about FASD. One of the respondents did agree to participate in follow-up activities.

The survey was only available in an electronic format which might have been a barrier for this population suggesting future needs assessment activities targeted to consumers be conducted in other formats. Asking individuals affected by FASD how they might most likely participate in a needs assessment may increase involvement of this population.

Discussion of Caregiver Lived Experience Survey Results

There were 47 caregiver respondents to the survey. The majority of respondents were female (94%), married (80%), white (90%), non-Hispanic (90%), completed 4 years of college or more (68%), and were over the age of 40 (84%). 32% have never been pregnant and the other 68% have been pregnant in the past (Question 9). Detailed tables containing demographics and frequencies for responses to all questions for the 2022 survey and the 2006 survey where available are presented in Appendix A – Caregiver Survey Frequency Tables.

Respondents were asked a series of questions about alcohol consumption. Question 10 asked if a doctor has ever told you or your partner that it was safe to drink alcohol during pregnancy. While 12% did not remember, 16% indicated a physician had told them it was safe. The majority (72%) shared a physician did not tell them it was safe to drink alcohol while pregnant. Responses to the 2006 survey on this question were somewhat different with 8% indicating a physician told them it was safe and 89% said no with 3% not recalling. Question 11 asked whether a family member has ever told you or your partner that it was safe to drink alcohol during pregnancy. 31% said “yes” compared to 19% in the 2006 survey. Responding “no” to this question were 69% (2022) and 79% (2006).

Question 12 asks participants how many drinks of alcohol the pregnant person consumed in an average week during the three months before pregnancy. Responses varied from None (31%) to 14 or more (16%). 19% did not remember. Two to three drinks represented 19% of the responses. In comparison with the 2006 survey, 56% of respondents chose None with 1% selecting 14 or more. In 2006, 3% chose 7-13 drinks while in 2022 about 16% indicated as many drinks. Question 13 asked a follow-up question to know how many times the pregnant person drank 5 or more alcoholic drinks in one setting the three months before the pregnancy. 44% responded None in 2022 versus 71% in 2006. Nearly 22% did not remember in the 2022 survey and nearly 19% said 6 or more times versus only 3% in the 2006 survey. Although a small sample, these data seem to reflect evidence regarding increased consumption of alcohol.

Shifting to learning about how respondents get health information, Question 26 asks which sources are believed to be true and accurate. Primary health care provider/doctor was rated at 96% accurate (compared to 91% accurate in the 2006 survey). The next highest rated sources included Internet search engines (43%), websites and webpages (47%), online/support groups (47%), and local support organizations (40%). Social media was selected by 13% of respondents suggesting this is not considered a reliable source of information and resources.

When asked in Question 27 what is necessary for a healthy pregnancy, choices ranged from exercising regularly (79%) to taking prenatal vitamins (96%), not using drugs (96%), and not smoking (81%). All suggested ideas were selected more than 79% of the time suggesting generalized knowledge about activities that support healthy pregnancies. There were slight increases for most of the choices when compared to the 2006 survey, perhaps suggesting success in public awareness initiatives about healthy pregnancies.

Question 28 asks respondents what they think a drink of alcohol means. More than 80% of respondents selected all the choices provided which include a wide range of alcohol drinks and products. The 2022 survey added hard cider and hard seltzer to the list. 98% of respondents agreed that 1 can or bottle of beer is considered a drink of alcohol, and 94% endorsed a glass of wine as meeting these criteria. Responses represent an increase in perception of what a drink of alcohol means compared to the 2006 survey where 72% endorsed 1 can or bottle of beer and 65% agreed with 1 glass of wine.

Question 29 asks how many drinks of alcohol the respondent had in an average week during the last month. 49% indicated None, compared to 63% in the 2006 survey. 26% indicated having 1-3 drinks compared to 13% in the 2006 survey. Question 30 asks how many times the respondent had more than 4 or 5 alcoholic drinks in one sitting during the past month. Responses to this question were more similar between the 2022 and 2006 surveys with 83% indicating no times and 9% one time.

When asked what types of alcohol are safe to drink during pregnancy (Question 31), the clear majority indicated none of the options were appropriate (98%). One respondent selected beer, wine, or a shot of liquor. Results were similar in 2006, however more respondents believed at that time wine was safe to drink during pregnancy (5%). This may indicate success in education initiatives regarding the impact of all types of alcohol consumption on the pregnant person and the developing fetus.

Respondents were asked questions about their knowledge regarding Fetal Alcohol Spectrum Disorders (FASD) first by asking where they have heard, read, or seen information about the condition (Question 32). Most indicated their doctor (60%) or the Internet/websites (61%). The next highest source selected was social media (41%). When asked in Question 33 to choose descriptions of FASD, 90% agreed it is something the baby can get if a person drinks while pregnant and 85% agreed it is entirely preventable if a pregnant person does not drink alcohol. Compared to the 2006 survey, there was a slight increase in selecting these 2 choices (85% and 63% respectively). There was a marked variance between the two surveys with 62% of respondents endorsing the description that FASD is rarely diagnosed although it occurs frequently in 2022 versus 7% in 2006. Additionally, 28% said FASD is a condition that affects 1 in every 1000 babies versus 16% in 2006. This may reflect an understanding of the challenges in identifying and obtaining a diagnosis of FASD.

Question 34 states “FASD can occur if the pregnant person” and offers 4 options. In 2022, 90% of respondents selected “drinks any type of alcohol anytime during their pregnancy” compared to 76% of respondents in 2006. The next highest rated choice, “is an alcoholic” was selected by 64% of respondents in the 2022 survey compared to 57% in 2006. Question 35 asks the respondent which of the proposed statements are true if the pregnant person drinks alcohol while pregnant. 96% of respondents said the baby may be born with problems that will last a lifetime. 94% said the baby may look fine but may still have alcohol related brain damage. 81% said the baby may seem fine at first but may develop problems later. Compared to the 2006 survey, responses were higher for these selections,

however 11% said the baby will be taken away if anyone finds out the mother drank in 2022 versus 15% in the previous survey.

Respondents were asked several questions related to accessing resources in their local community. Question 36 asked where a person could go for help if drinking while pregnant. 90% said a health clinic or hospital, 83% said a substance use treatment facility, 77% said to their doctor, and 49% said to friends and family. These responses were all higher compared to the 2006 survey responses. When asked in Question 37 to select statements that best describe their community, 47% said they did not know the extent to which people drink while they are pregnant. 23% thought some people drink while pregnant and 28% thought many people do so.

Question 38 suggests that communities often have organizations that support families and respondents are asked to identify which organizations they know about, have used, are familiar with FASD and whether they meet the needs of people with FASD and their families. This question was modified from the Community Implementation Toolkit and provides a complex result. A table of responses is presented here (Caregiver Question 38 Table of Results). Generally, respondents are familiar with a wide range of organizations and resources, have used some of them and are less sure whether the resource is familiar with FASD and meeting needs.

Additional questions modified from the Community Implementation Toolkit included Question 39 which asked whether the respondent would know where to get support and help if their family experienced a crisis. The majority responded they would mostly (23%) or all of the time (26%) know where to go. Question 40 asked if, in the past 30 days, the respondent asked a neighbor or friend for some advice or information about raising children.

| | CHECK IF YOU ARE FAMILIAR WITH THE ORGANIZATION | CHECK IF YOU HAVE USED THE ORGANIZATION | CHECK IF YOU BELIEVE THE ORGANIZATION IS FAMILIAR WITH FASD | CHECK IF THE ORGANIZATION IS AVAILABLE, BUT NOT MEETING THE NEEDS OF INDIVIDUALS/FAMILIES |
|--|---|---|---|---|
| Religious or faith organizations | 62.50% 25 | 30.0% 12 | 22.50% 9 | 40.0% 16 |
| Hospital / Urgent care clinics | 63.64% 28 | 31.82% 14 | 31.82% 14 | 27.27% 12 |
| Primary care doctors or pediatricians | 62.22% 28 | 37.78% 17 | 40.0% 18 | 31.11% 14 |
| Parent organizations | 51.35% 19 | 32.43% 12 | 27.03% 10 | 32.43% 12 |
| Sport or recreational programs for children and youth | 60.0% 21 | 28.57% 10 | 8.57% 3 | 48.57% 17 |
| Childcare or preschool programs for children under 5 | 62.16% 23 | 40.54% 15 | 18.92% 7 | 40.54% 15 |
| Before-school, after-school, or summer programs for school-age youth | 67.65% 23 | 32.35% 11 | 11.76% 4 | 41.18% 14 |
| Libraries | 65.71% 23 | 37.14% 13 | 17.14% 6 | 31.43% 11 |

69% indicated they had not, while 12% said once and 19% indicated they had asked for advice more than once.

Recognizing that raising children can be challenging, the final question (number 41) asked the respondent to indicate how often a statement applied to them in thinking about their relationship with their youngest child. The table of responses is provided here (Caregiver Question 41 Table of Results). Overall respondents were able to meet the needs of their youngest child most of the time.

| | RARELY | ON OCCASION | MOST OF THE TIME | N/A |
|--|------------|--------------|------------------|-------------|
| I know how to help my child | 0% 0 | 8.51% 4 | 82.98% 39 | 8.51% 4 |
| I know what to do when my child misbehaves | 0% 0 | 14.89% 7 | 74.47% 35 | 10.64% 5 |
| I praise my child when they behave well | 0% 0 | 4.26% 2 | 87.23% 41 | 8.51% 4 |
| I am able to soothe my child when they are upset | 2.13% 1 | 21.28% 10 | 68.09% 32 | 8.51% 4 |
| I spend time with my child doing what they like to do | 0% 0 | 25.53% 12 | 65.96% 31 | 8.51% 4 |
| I know what to expect from my child as they grow and develop | 4.26% 2 | 17.02% 8 | 70.21% 33 | 8.51% 4 |

Discussion of Provider Survey Results

The invitation to participate in the provider FASD needs assessment survey was shared broadly. Participants received a link to an online survey at Survey Monkey. A total of 333 individuals responded and 279 completed the survey providing usable data for analysis. Detailed tables containing demographics and frequencies for responses to all questions for the 2022 survey and the 2006 survey where available are presented in Appendix B – Provider Survey Frequency Tables.

The majority of respondents were female (87%) and identified as White (87%) and non-Hispanic (94%). The age of participants varied with the largest group identifying at over the age of 50 (30%). Respondents represented a wide range of professions and occupations. Provider responses represented 57 of Indiana’s 92 counties with a larger portion of responses from counties with urban settings. The counties not represented tend to be rural. Demographic data of participants are presented in Appendix B – Provider Survey Frequency Tables.

The use of screening tools to identify the need for further assessment and intervention continues to expand. Question 8 asked providers if they routinely screen to identify alcohol use and/or abuse. About 25% of the sample indicated screening was not appropriate to their role/position. Of the remaining group, 42% said they routinely screen and 8% do when warranted. The remaining 25% do not screen. Question 9 targeted those who stated they do not routinely screen to ask why not. The most common responses included screening is not appropriate for the clients served (36%) and screening is not appropriate given their job/position (33%). Of note, 23% indicated that they had never thought about performing screening on alcohol use and/or abuse. Additionally, 10% felt screening takes too much time.

The next set of questions asked about access to health information and alcohol consumption during pregnancy. The ways people access information have changed in the last 15 to 20 years. Respondents

still rely on their primary health care provider (96%) for health information. They rely less on public service announcements, books, magazines, brochures and flyers in the 2022 survey and more on other sources including online groups (33%), local support organizations (36%), but especially on social media (70%).

When asked how much alcohol is safe for a pregnant person to drink in Question 11, 84% indicated None – a slight decrease from the 2006 respondents (90%). There was a slight increase in those who indicated one glass of wine per day is acceptable (2022 - 4% and 2006 - 3%). The 2022 survey added several beverage choices consistent with changes in currently available products including hard cider and hard seltzer. No one indicated these were safe to drink during pregnancy. The 2022 survey also added choices including “one drink per week” (1%), and “an occasional drink at social gathering/special occasions” (4% indicated yes). Positive responses to these added choices might suggest popular beliefs that occasional drinking and drinking only for special occasions is acceptable and would not affect the pregnancy. In the 2022 survey 6% of respondents indicated they do not know how much alcohol is safe for a pregnant person to drink. When asked which types of alcohol are safe to drink during pregnancy, 88% of respondents indicated None. However, 8% indicated wine is safe for consumption. Narrative responses to “other” regarding how much alcohol is safe for a pregnant person to drink include:

“Research varies but generally speaking none.”

“Depending on the history of the woman. A little can be too much for some.”

“The literature is not conclusive on this topic.”

“Alcohol is not recommended, even if in the past the ‘safe’ amount was a drink here or there.”

“There is NO known safe level for pregnant people to drink.”

Question 13 asked respondents which statements they believe are true about drinking alcohol while pregnant. 75% indicated a person should stop drinking as soon as they become pregnant, which is consistent with the 2006 survey (77%). A slight increase from 2006, 5% of respondents believe a person can occasionally drink while pregnant and 22% did not endorse any of the statements perhaps suggesting they believe it is acceptable to consume alcohol at some point during a pregnancy.

The next set of questions sought to obtain respondent ideas about drinking alcohol while pregnant, ways to educate people about drinking while pregnant and resources to help people. Question 14 asked for agreement with a variety of statements about drinking while pregnant. 94% of respondents (compared to 81% in 2006) believe the baby may have mental challenges or intellectual disabilities if a person drinks while pregnant. 25% of respondents (up from 10% in the 2006 survey) believe the baby may be born drunk. 64% believe the baby may be taken away from the mother, an increase from 39% of respondents in 2006. Finally, 16% indicated a belief that the baby may be born with some problems but will outgrow them; an increase from 6% of respondents in 2006.

Question 15 asked which measures respondents use to educate pregnant people who are drinking alcohol. 21% use none of the choices provided in the survey. 62% give verbal explanations (down from 82% in 2006), and 48% provide print materials (down from 70% in 2006). Recommending an internet

website or resource was an added choice to the 2022 survey with 29% endorsing this method of education.

Question 16 regarding available resources indicates a slight increase in the number of respondents unaware of where pregnant people can get help (15% in 2022 versus 9% in 2006). Respondents endorsed substance use counseling (76%), support groups (58%), treatment programs or centers (58%), and use of educational materials (60%). Accessibility to these resources specifically for pregnant people may still be an issue as shown in these narrative responses of note from respondents who listed “other” as a choice:

“If one includes a distance of 30+ miles part of the community, then all of the above are available but one must drive up to Terre Haute for most everything. In the immediate town of Sullivan, there are not a lot of resources available and those that are available need more advertising.”

“Pregnant individuals would have to travel to a neighboring county to access other resources.”

“All available, but I don’t know how accessible they all are for all women.”

“Our small community could use more options.”

“It is not necessarily specific to pregnant people, but these resources exist.”

When asked about perceptions of pregnant people from local communities and their alcohol consumption in Question 17, only 3% stated no people drink while they are pregnant. 40% indicated that some people drink while pregnant and 43% said they do not know the extent to which pregnant people drink.

Since the last survey in 2006, there have been enhancements to how Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) are described and diagnosed. Question 18 sought to measure respondents’ understanding of the criteria that indicate FASD. Responses remained similar to the 2006 survey with 94% noting FASD is something a baby can get if a person drinks while pregnant and 86% believing that FASD is entirely preventable if a pregnant person does not drink alcohol. About 25% of respondents indicated FASD is diagnosed using four specific criteria, is rarely diagnosed although it occurs frequently, and is a condition that affects 1 in every 1,000 babies born.

Responses to Question 19 were very similar in the 2022 and 2006 surveys. Asked if FASD can occur if the pregnant person is an alcoholic, 58% said yes. 38% indicated FASD can occur if the pregnant person drinks during certain times in their pregnancy. Different from the 2006 survey, 24% in 2022 said FASD can occur if the pregnant person drinks certain types of alcohol compared to 14%.

The current data suggests that 50% of pregnancies in Indiana are unplanned (Guttmacher Institute, 2016). New to the 2022 survey Question 20 asked respondents to choose a percentage, however 46% indicated they simply did not know. 25% of respondents accurately identified the current data while 20% thought that the correct response was one quarter of pregnancies are unplanned.

The majority of respondents feel comfortable talking to a person about their alcohol consumption during pregnancy (86%) and talking about the adverse effect of alcohol consumption in pregnancy, including Fetal Alcohol Spectrum Disorders (85%) as indicated in Questions 21 and 22.

Indiana requires a diagnosis of FASD to be reported to the Birth Defects and Problem Registry, however as indicated in Question 23, only 4% of respondents do so. 68% indicated they do not report to the registry because they do not make diagnoses. Yet, 21% indicated they are not familiar with the registry. Selected comments from the choice “other” include:

“This has never occurred in my job.”

“Not in my job scope of duties.” (7)

“I personally do not report.”

“I’m not sure if my agency reports diagnoses to that registry.”

“Our staff report this, but I do not personally report due to role.”

“I work with older adults.” (2)

“Have not identified any.” (3)

Question 24 asks respondents what they do when they know, or strongly suspect, one of their clients has an alcohol problem. About 35% indicate this situation has never come up. The remaining respondents endorsed many of the options presented, however less frequently than respondents to the 2006 survey. The accompanying graphic shows all of the choices with percentage responses for both the 2006 and 2022 survey. The work setting and position of respondents from each survey may influence the differences noted in the responses. The 2022 survey respondents represent a broader and more diverse set of disciplines and job titles compared to the 2006 which included more physicians and nurses.

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| Nothing | 0% | |
| Counsel them on the dangers of using alcohol during pregnancy | 50.18% | 71.9% |
| Encourage them to stop using alcohol during pregnancy | 55.20% | 74.2% |
| Give them educational materials | 51.97% | 65.3% |
| Refer them to counseling | 55.20% | 64.2% |
| Refer them to a support group | 43.01% | 39.0% |
| This situation has never come up | 35.48% | 17.8% |

Provider Question 24 Table of Results

Question 25, the last on the provider survey, seeks to understand which types of services are available in communities and whether they are familiar with FASD and meet needs of families. This question was modified from a sample question in the Community Implementation Toolkit. The complexity and format of this survey question resulted in 235 of the 279 respondents fully completing the question. The complete data are presented here in a table format so the reader can peruse the data. Overall, respondents are familiar with the variety of community organizations, however less likely to have referred clients affected by FASD with even less belief that organizations are familiar with FASD or able to meet the needs of families.

| | CHECK IF YOU ARE FAMILIAR WITH THE ORGANIZATION | CHECK IF YOU HAVE REFERRED TO THE ORGANIZATION | CHECK IF YOU BELIEVE THE ORGANIZATION IS FAMILIAR WITH FASD | CHECK IF THE ORGANIZATION IS AVAILABLE, BUT NOT MEETING THE NEEDS OF FAMILIES |
|--|---|--|---|---|
| Religious or faith organizations | 65.78% 123 | 24.06% 45 | 21.93% 41 | 22.46% 42 |
| Hospital / Urgent care clinics | 65.30% 143 | 29.22% 64 | 53.42% 117 | 12.33% 27 |
| Primary care doctors or pediatricians | 62.10% 136 | 33.79% 74 | 54.34% 119 | 11.42% 25 |
| Parent organizations | 51.80% 72 | 26.62% 37 | 28.78% 40 | 20.86% 29 |
| Sport or recreational programs for children and youth | 63.69% 100 | 21.02% 33 | 14.65% 23 | 26.11% 41 |
| Childcare or preschool programs for children under 5 | 67.22% 121 | 31.11% 56 | 23.33% 42 | 20.56% 37 |
| Before-school, after-school, or summer programs for school-age youth | 64.24% 106 | 26.06% 43 | 18.79% 31 | 23.64% 39 |
| Libraries | 68.82% 117 | 27.65% 47 | 16.47% 28 | 18.82% 32 |
| Parenting education/support programs | 65.34% 115 | 31.25% 55 | 30.68% 54 | 13.07% 23 |
| Family Resource centers | 61.84% 94 | 32.24% 49 | 39.47% 60 | 14.47% 22 |

Provider Question 25 Table of Results

Discussion and Recommendations

The 2022 FASD Needs Assessment provides some useful data to support planning for ongoing education and policy efforts. While there are some limitations with the data, there are several takeaways for consideration. It is important to note that both the caregiver and provider survey respondents represented a largely homogenous group consisting of white, non-Hispanic, woman over the age of 40. The surveys also represented more populous communities. As such the data are not fully representative of the population of Indiana. It continues to be important to explore methods to reach a diverse survey sample for future needs assessment activities.

It is also noted that there was a small number of caregiver participants (47) which limits the ability to generalize to the larger community. Similarly, there were 277 complete survey responses from providers which is more representative, however may also not be generalizable to the state's population.

Where possible, comparison data to the most recent 2006 needs assessment results are provided to help best understand any progress and needs for continued action.

Following are several key data points along with proposed recommendations or action steps for consideration.

1. Input from people with lived experience – Despite efforts to reach out to individuals with lived experience (diagnosis of FASD) there were only 2 responses to the electronic survey. It would be extremely valuable to have input from people who live with the effects of FASD, however it appears that completion of an electronic survey is not the best way to solicit participation.

PROPOSED ACTION STEP: Input from consumers can greatly enhance the efficacy and utilization of programs and services by providing insights about how they are accessed and whether they meet needs. It may be helpful to develop relationships with people with lived experience to learn more about the best ways to include them in future needs assessment activities as well as how to best invite them to be “at the table” to support appropriate policy and program development. Family organizations can provide suggested guidelines for how to meaningfully invite and include consumers and family members in task groups, planning and other types of meetings and activities.

2. Awareness about healthy pregnancies – Survey data suggest improved awareness about healthy behaviors related to pregnancy. Caregivers also demonstrated increased recognition that all types of alcohol can affect the developing fetus. However, some respondents continue to believe wine is not harmful. Furthermore, 24% of providers said FASD can occur if the pregnant person drinks “certain types” of alcohol suggesting an ongoing need for education.

PROPOSED ACTION STEP: Continue public awareness efforts regarding healthy behaviors for pregnant people. Expand public awareness efforts and education about the potential harmful effects of any alcohol consumption by pregnant people.

3. Alcohol consumption during pregnancy – Survey responses seem to indicate an increased consumption of alcohol during pregnancy both the three months before pregnancy and during an average week in the past month. It is noted that alcohol consumption increased during the COVID-19 pandemic, especially among females (Barbosa, 2021). Stay at home orders and eased regulations for access to alcohol impacted both increased purchases and consumption. Barbosa et. al., observed that increases in consumption were consistent across all demographic groups but particularly higher for women. Although relatively small samples were accessed for the 2006 and 2022 needs assessment surveys, there was an apparent increase in alcohol consumption in the latest data. It is not possible to directly link alcohol consumption to the effects of the pandemic, however this may suggest an even greater need for public awareness and education about the potential harmful effects of consuming alcohol while pregnant.

PROPOSED ACTION STEP: There is a need for ongoing education about consuming alcohol during pregnancy. Popular beliefs about occasional drinking and that some types of alcohol (wine and beer for example) are acceptable during pregnancy should be addressed.

Additional research in this area is warranted to better understand alcohol consumption, perceptions of alcohol use and the impacts on pregnant people and the developing fetus.

4. Understanding of FASD – Although there have been ongoing efforts to provide public awareness and education about Fetal Alcohol Spectrum Disorders, the data suggests there remains a continued lack of understanding of the criteria for describing and diagnosing FASD. The 2022 survey participants represented fewer medical practitioners (physician and nurse). Instead, more mental health, early intervention and home visiting providers participated which may suggest a particular need to provide information and education about FASD to professionals across all disciplines and fields.

For further exploration it may be helpful to review a comparison between the caregiver and provider responses across the 2006 and 2022 surveys for 2 specific questions presented below (also provided in

Appendix C – Caregiver-Provider Comparison Tables). The highlighted variances between providers’ and caregivers’ perceptions offer insights where targeted education could be planned.

Q14 (Provider) and Q35 (Caregiver): Which of the following statements do you think are true if a person drinks while pregnant? (Choose all that apply)

| ANSWER CHOICES | Providers % | Providers N | Caregivers % | Caregivers N |
|---|-------------|-------------|--------------|--------------|
| I don't think anything happens to the baby if the person drinks while pregnant. | 0.72% | 2 | 0% | 0 |
| The baby may be born with some problems but will outgrow them | 16.13% | 45 | 2.13% | 1 |
| The baby may be born with problems that will last a lifetime | 93.19% | 260 | 95.74% | 45 |
| The baby may seem fine at first but develop problems later | -- | -- | 80.85% | 38 |
| The baby may have growth deficits | 83.15% | 232 | -- | -- |
| The baby may have mental challenges or intellectual disabilities | 93.19% | 260 | -- | -- |
| The baby may have facial anomalies | 82.44% | 230 | -- | -- |
| The baby may be born drunk | 24.73% | 69 | 8.51% | 4 |
| The baby's central nervous system may be compromised | 87.46% | 244 | -- | -- |
| The baby may look fine but could still have alcohol-related brain damage | 92.11% | 257 | 93.62% | 44 |
| The baby may be taken away from the mother | 64.16% | 179 | 10.64% | 5 |

Q18 (Provider) and Q33 (Caregiver): As I understand it, Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Spectrum Disorders (FASD) is: (choose all that apply)

| ANSWER CHOICES | Provider % | Provider N | Caregiver % | Caregiver N |
|--|------------|------------|-------------|-------------|
| I don't know if FASD is any of these things (professionals) I have not heard or read about FAS/FASD (caregivers) | 1.43% | 4 | 2.13 | 1 |
| A genetic problem that families have no control over | 3.23% | 9 | 2.13% | 1 |
| Something a baby can get if a person drinks while pregnant | 93.19% | 260 | 89.36% | 42 |
| A rare occurrence that few children ever get | 0.36% | 1 | 2.13% | 1 |
| Diagnosed using four specified criteria | 24.01% | 67 | -- | -- |
| Rarely diagnosed although it occurs frequently | 24.73% | 69 | 61.70% | 29 |
| A condition that affects 1 in every 1,000 babies born | 26.52% | 74 | 27.66% | 13 |
| Entirely preventable if a pregnant person does not drink alcohol | 85.66% | 239 | 85.11% | 40 |
| A condition the baby will eventually outgrow | 0.36% | 1 | 2.13% | 1 |

PROPOSED ACTION STEP: Ongoing and expanded public awareness and education about Fetal Alcohol Spectrum Disorder aimed at the broader community is necessary. Information and training should be targeted to both the general population, especially pregnant people, and their families, as well as providers of all backgrounds. Efforts to include rural and diverse community members and providers are recommended.

5. Screening – Results of the needs assessment suggest a general lack of awareness about the purpose, availability, and utility of screening tools.

PROPOSED ACTION STEP: Information and training for providers about available and accessible screening tools should be included in awareness and education efforts. Policymakers may wish to consider ways to encourage use of screening tools to identify pregnant people and children at risk for alcohol exposure.

6. Registry – Results of the needs assessment suggest a lack of knowledge among non-medical providers about the Indiana Birth Defects and Problems Registry (IBDPR).

PROPOSED ACTION STEP: Additional research may be needed to explore the best ways to identify and document prenatal alcohol exposure to support accurate diagnosis across the lifespan (beyond age 5) and to inform necessary and appropriate services for people diagnosed with FASD.

In partnership with the Indiana Department of Health, agency leaders and policymakers may want to consider how data collection can be improved, and how data can support planning for services and programs to meet the needs of people with FASD, their families and their communities.

7. Resource sharing/Education materials – The needs assessment results suggest an ongoing need and demand to provide current resources using preferred information access methods of target audiences.

PROPOSED ACTION STEP: Explore ways to share more information digitally through websites, social media and apps in addition to traditional brochure and print materials.

8. Coordination of efforts around FASD – The results of the 2022 needs assessment echo the findings from 2006 regarding the need for a coordinated approach to the complex issues related to FASD.

PROPOSED ACTION STEP: Establish a statewide FASD Task Force with appointed membership representing people with lived experience, providers, agency leaders, associations, content experts, and policymakers supported by a paid Coordinator to:

- a. Respond to needs identified in the FASD needs assessment.*
- b. Oversee a comprehensive public awareness campaign.*
- c. Collect data to inform education and policy efforts.*
- d. Coordinate with appropriate agency partners, associations, and community leaders.*
- e. Make recommendations about policy, programs, and services.*
- f. Report regularly to policymakers and the community.*

References

Barbosa, C., Cowell, A.J., & Dowd, W.N. (2021). Alcohol Consumption in Response to the COVID-19 Pandemic in the United States. *J Addict Med. Jul-Aug 01;15(4):341-344*. doi: 10.1097/ADM.0000000000000767. PMID: 33105169; PMCID: PMC8327759.

Guttmacher Institute (2016). State facts about unintended pregnancy: Indiana. Retrieved from: https://www.guttmacher.org/sites/default/files/factsheet/in_18.pdf

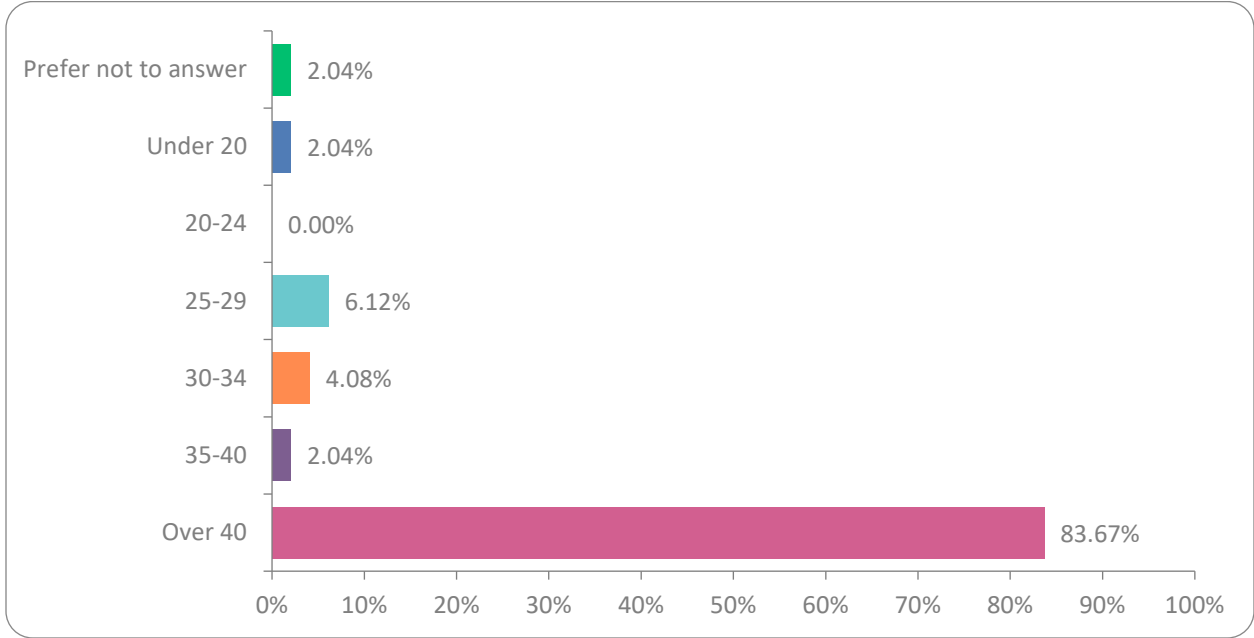
Appendix A – Caregiver Survey Frequency Tables

2022 FASD Needs Assessment

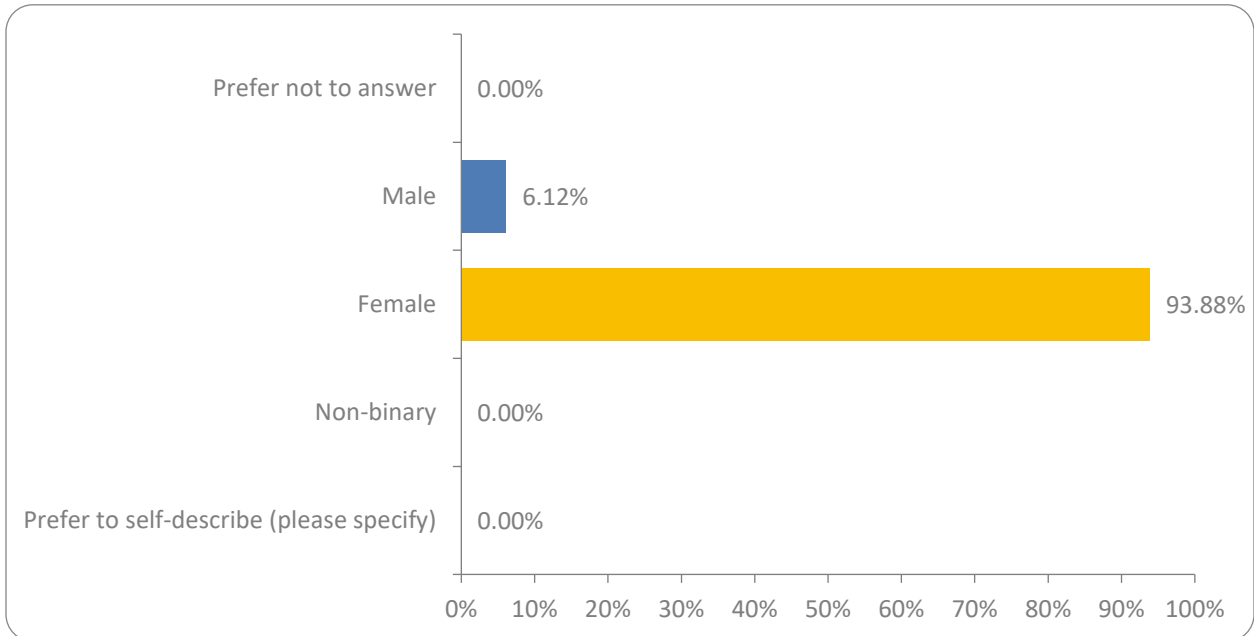
Appendix A – Caregiver Survey Frequency Tables

Caregiver Respondent Demographics

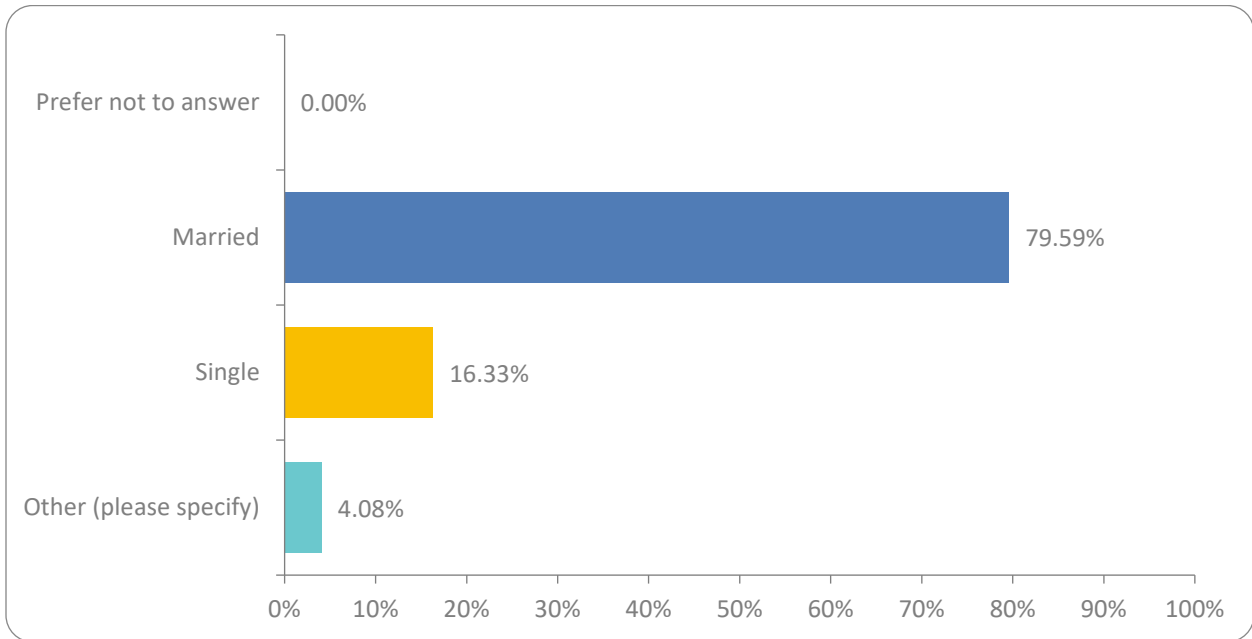
Q1: Age of Caregiver Respondents



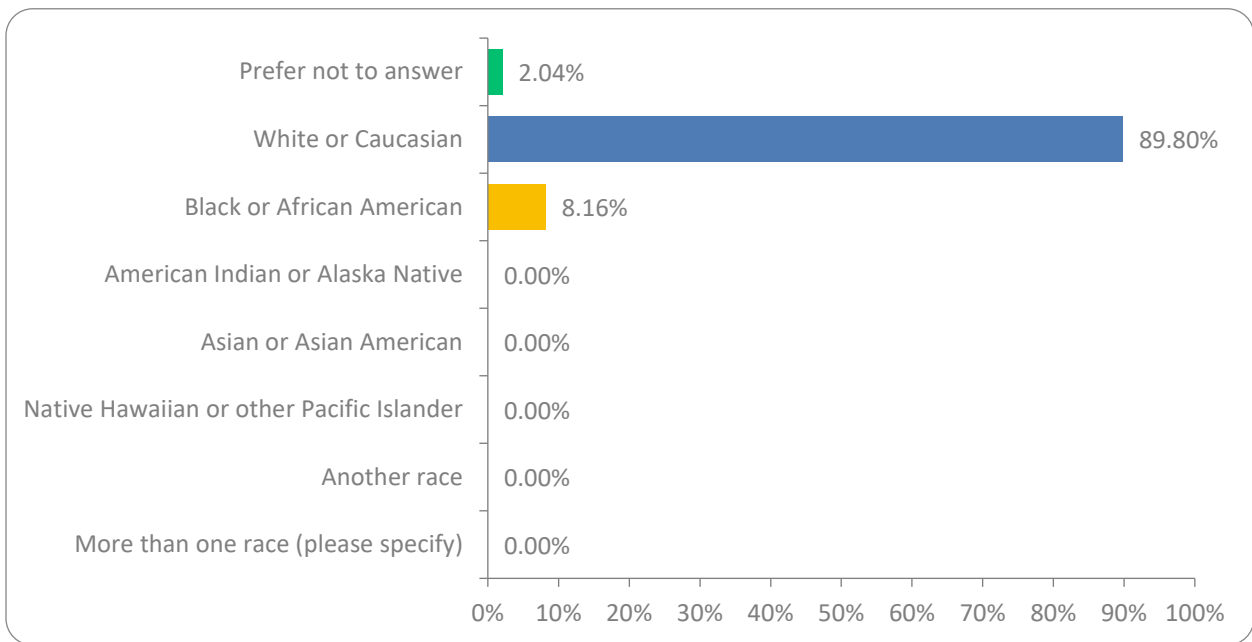
Q2: Gender of Caregiver Respondents



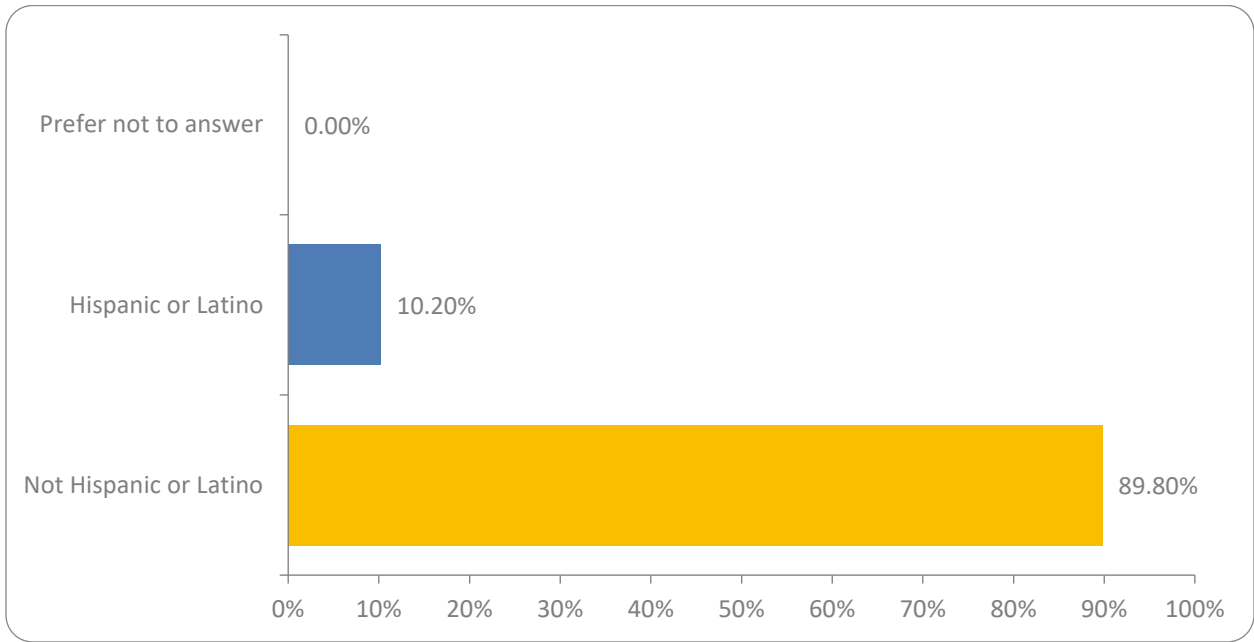
Q3: Marital Status of Caregiver Respondents



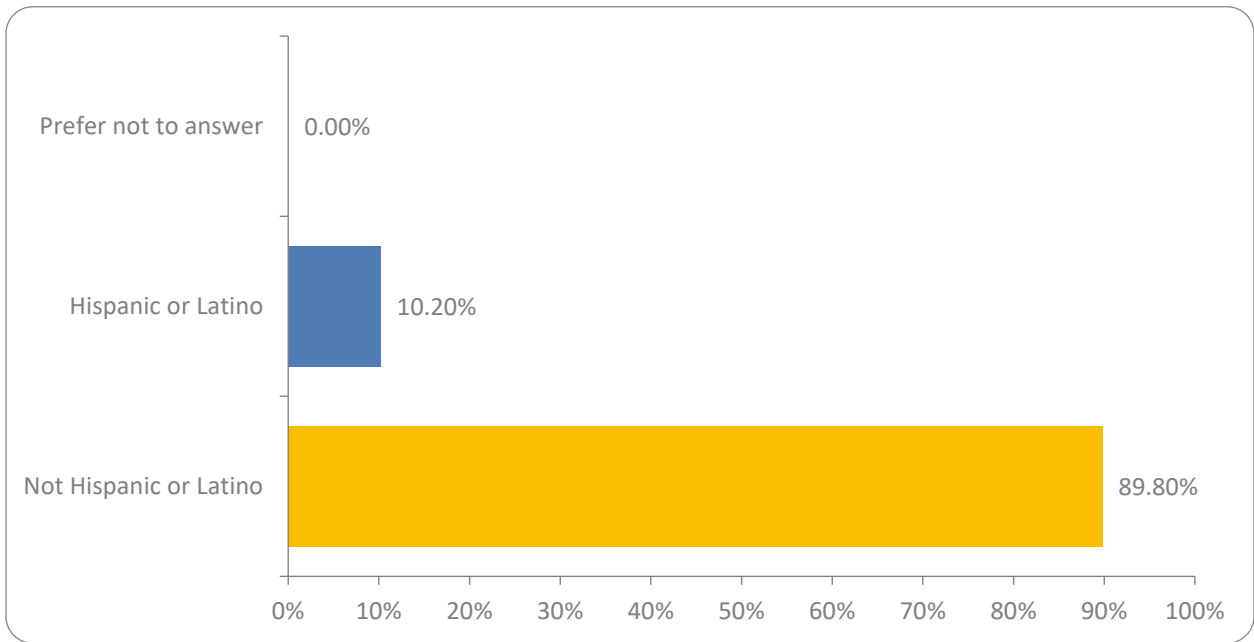
Q4: Race of Caregiver Respondents



Q5: Ethnicity of Caregiver Respondents

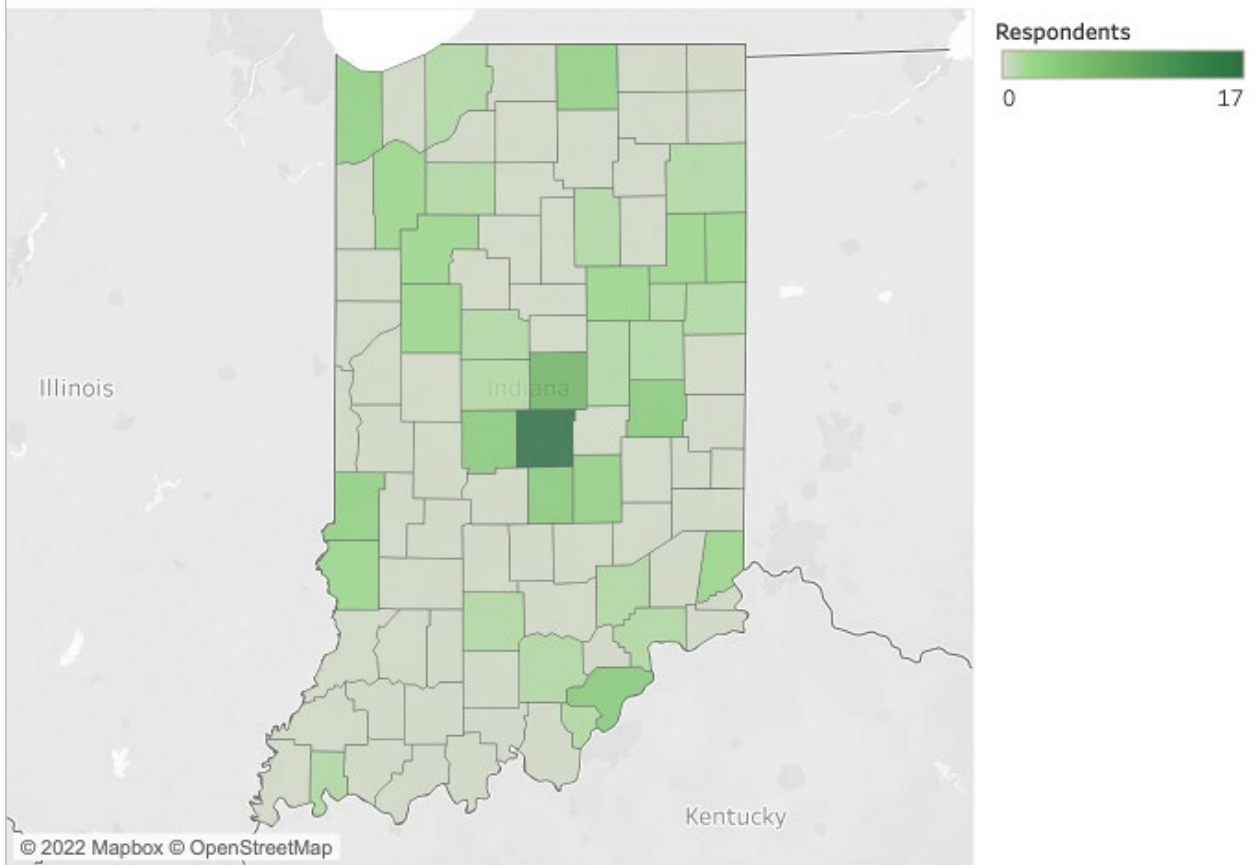


Q6: Education level of Caregiver Respondents



Q7: County of Caregiver Residence

Counties of Residence for Respondents with Lived Experience



Map based on Longitude (generated) and Latitude (generated). Color shows sum of Respondents. Details are shown for County.

Q9: Which statement best describes your pregnancy history (or your partner's pregnancy history)?

| ANSWER CHOICES | 2022 RESPONSES | |
|---|----------------|----|
| Never been pregnant | 31.91% | 15 |
| Currently pregnant for the first time | 0% | 0 |
| Currently pregnant, but not for the first time | 0% | 0 |
| Not pregnant now, but have been pregnant before | 68.09% | 32 |
| TOTAL | | 47 |

Q10: Has a doctor ever told you or your partner that it was safe to drink alcohol during pregnancy?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| Yes | 15.62% ↑ | 7.5% |
| No | 71.88% | 88.6% |
| Don't remember | 12.50% ↑ | 3.0% |
| Prefer not to answer | 0% | 0.8% |

Q11: Has a family member ever told you or your partner that it was safe to drink alcohol during pregnancy?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| Yes | 31.25% ↑ | 19.0% |
| No | 68.75% ↓ | 78.7% |
| Don't remember | 0% | 1.9% |
| Prefer not to answer | 0% | 0.4% |

Q12: During the 3 months before the pregnancy, how many drinks of alcohol did the pregnant person have in an average week?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| None | 31.25%↓ | 57.5% |
| 1 | 3.12% | 13.9% |
| 2-3 | 18.75% | 11.8% |
| 4-6 | 3.12% | 5.2% |
| 7-13 | 9.38% | 3.0% |
| 14 or more | 15.62%↑ | 1.3% |
| Don't remember | 18.75% | 5.2% |
| Prefer not to answer | 0% | 1.9% |

Q13: During the 3 months before the pregnancy, how many times did the pregnant person drink 5 or more alcoholic drinks in one sitting?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| None | 43.75% ↓ | 70.9% |
| 1 | 6.25% | 7.6% |
| 2-3 | 3.12% | 10.5% |
| 4-5 | 6.25% | 1.6% |
| 6 or more | 18.75% ↑ | 3.0% |
| Don't remember | 21.88% | 4.2% |
| Prefer not to answer | 0% | 2.2% |

Q14: During the last 3 months of the pregnancy, how many drinks of alcohol did the pregnant person have in an average week?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| I am/my partner is less than 7 months pregnant | 0% | 1.9% |
| None | 62.50%↓ | 90.2% |
| Less than 1 | 3.12% | 3.6% |
| 1-3 | 0% | 1.2% |
| 4-6 | 0% | 0% |
| 7-13 | 3.12% | 0.1% |
| 14 or more | 9.38%↑ | -- |
| Don't remember | 21.88% | 0.8% |
| Prefer not to answer | 0% | 2.1% |

Q26: Where do you get health information that you believe to be true or accurate? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| None of the above | 2.13% | |
| Primary health care provider / physician / doctor | 95.74% | 91% |
| Family members | 31.91% | 34.2% |
| Friends | 25.53% | 20.1% |
| Advertisements / public service announcements | 8.51% | 12.8% |
| Books / magazines | 34.04% | 33.8% |
| Flyers / pamphlets / brochures | 14.89%↓ | 27.5% |
| Internet search engines (Google, etc.) | 42.55%↑ | 26.9% |
| Internet web pages / web sites | 46.81%↑ | |
| Social Media (Facebook, Instagram, YouTube, TikTok, etc.) | 12.77%↑ | |
| Online groups / Support groups | 46.81%↑ | |
| Local support organizations | 40.43% | |

Q27: There are many ideas about how to have a healthy pregnancy. Which of the following do you believe are necessary to have a healthy pregnancy? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| I don't think any of these are really necessary | 0% | 1.1% |
| Taking prenatal vitamins | 91.49% | 88.4% |
| Getting prenatal care (seeing a doctor or nurse regularly) | 95.74% | 93.9% |
| Not using drugs | 95.74% | 91.7% |
| Not smoking | 95.74%↑ | 87.3% |
| Knowing the warning signs for preterm labor | 80.85% | 79.0% |
| Not drinking | 93.62% | 90.0% |
| Exercising regularly | 78.72% | 71.3% |
| Unknown / Prefer not to answer | 2.13% | 1.1% |
| Other (please specify) | 4.26% | |

Q28: What do you think a drink of alcohol means? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| Prefer not to answer | 2.13% | 12.2% |
| 1 can or bottle of beer | 97.87% | 71.6% |
| 1 glass of wine | 93.62% | 65.0% |
| 1 can or bottle of wine cooler | 91.49% | 61.9% |
| 1 can or bottle or hard cider | 87.23% | -- |
| 1 can of hard seltzer / hard lemonade / hard tea | 85.11% | -- |
| 1 mixed drink or cocktail (including canned) | 87.23% | 62.3% |
| 1 shot of liquor | 80.85% | 62.1% |

Q29: During the past month, how many drinks of alcohol did you have in an average week?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| Prefer not to answer | 0% | 1.1% |
| None | 48.94%↓ | 62.7% |
| Less than 1 | 10.64% | 15.5% |
| 1 - 3 | 25.53%↑ | 13.4% |
| 4 - 6 | 8.51% | 4.4% |
| 7 - 13 | 2.13% | 1.9% |
| 14 or more | 2.13% | .5% |
| Don't remember | 2.13% | .5% |

Q30: During the past month, how many times did you have more than 4 or 5 alcoholic drinks in one sitting? (like during an evening meal or at a party/event)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------------|----------------|----------------|
| Prefer not to answer | 0% | 1.5% |
| None | 82.98% | 86.6% |
| 1 | 8.51% | 6.6% |
| 2 - 3 | 4.26% | 4.0% |
| 4 - 5 | 2.13% | .6% |
| 6 or more | 0% | .2% |
| Don't remember | 2.13% | .3% |

Q31: What types of alcohol are safe to drink during pregnancy? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| None of the above | 95.74% ↑ | 89.9% |
| Beer | 2.13% | 1.1% |
| Wine | 2.13% | 5.3% |
| Wine cooler | 0% | 1.3% |
| Hard cider | 0% | -- |
| Hard seltzer / hard lemonade / hard tea | 0% | -- |
| Mixed drinks or cocktails | 0% | .5% |
| Shot of liquor | 2.13% | -- |
| Don't know | 2.13% | 1.5% |

Q32: Where have you heard, read, or seen information about Fetal Alcohol Spectrum Disorder (FASD)?
(choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | |
|---|----------------|------------|
| I have not heard or read about FAS/FASD | 0% | 0 |
| Family member | 23.40% | 11 |
| Friend | 25.53% | 12 |
| Doctor | 59.57% | 28 |
| Nurse | 27.66% | 13 |
| Health clinic | 34.04% | 16 |
| School | 23.40% | 11 |
| Newspaper / magazine | 21.28% | 10 |
| Television | 14.89% | 7 |
| Internet web page / web site | 61.70% | 29 |
| Social media | 40.43% | 19 |
| Other (please specify) | 23.40% | 11 |
| TOTAL | | 167 |

Q33: As I understand it, Fetal Alcohol Spectrum Disorders (FASD) is: (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| I have not heard or read about FAS/FASD | 2.13% | 7.9% |
| A genetic problem that families have no control over | 2.13% | 1.3% |
| Something a baby can get if a person drinks while pregnant | 89.36% | 85% |
| A rare occurrence that few children ever get | 2.13% | .6% |
| Rarely diagnosed although it occurs frequently | 61.70%↑ | 7.6% |
| A condition that affects 1 in every 1,000 babies born | 27.66% | 15.6% |
| Entirely preventable if a pregnant person does not drink alcohol | 85.11%↑ | 62.9% |
| A condition the baby will eventually outgrow | 2.13% | .9% |

Q34: Fetal Alcohol Spectrum Disorders (FASD) can occur if the pregnant person: (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| Unknown | 4.26% | 6.2% |
| Is an alcoholic | 63.83% | 56.5% |
| Drinks certain types of alcohol | 27.66% | 21.6% |
| Drinks during certain times in their pregnancy | 44.68% | 31.8% |
| Drinks any type of alcohol anytime during their pregnancy | 89.36%↑ | 75.6% |

Q35: Which of the following statements do you think are true if the pregnant person drinks while pregnant? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| None of the above | 0% | .6% |
| The baby may be born with some problems but will outgrow them | 2.13% | 13.4% |
| The baby may be born with problems that will last a lifetime | 95.74% ↑ | 85.1% |
| The baby may seem fine at first but develops problems later | 80.85% | -- |
| The baby will be born drunk | 8.51% | 9.2% |
| The baby may look fine but may still have alcohol-related brain damage | 93.62% ↑ | 80.1% |
| The baby will be taken away if anyone finds out the mother drank | 10.64% | 15.3% |
| Unknown | 4.26% | 4.2% |

Q36: In your community, where could a person go for help if drinking while pregnant? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| I am not aware of any resources for pregnant people who drink | 6.38% | 11.1% |
| Friends and family | 48.94%↑ | 28.6% |
| Health clinic, hospital, or local health department | 89.36%↑ | 63.2% |
| Substance use treatment facility | 82.98%↑ | 56.2% |
| Doctor | 76.60%↑ | 60.7% |
| Other (please specify) | 4.26% | |

Q37: Which of the following statements best describes drinking in your community?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| No people drink while they are pregnant | 2.13% | |
| Some people drink while they are pregnant | 23.40% | 21.6% |
| Many people drink while they are pregnant | 27.66% | 20.9% |
| I do not know the extent to which people in this community drink while they are pregnant | 46.81% | 61.6% |

Q38: Communities often have organizations that support families. Are you familiar with the following organizations in your community? Have you used these organizations? Are they familiar with FASD? (Please select all that apply)

| | CHECK IF YOU ARE FAMILIAR WITH THE ORGANIZATION | CHECK IF YOU HAVE USED THE ORGANIZATION | CHECK IF YOU BELIEVE THE ORGANIZATION IS FAMILIAR WITH FASD | CHECK IF THE ORGANIZATION IS AVAILABLE, BUT NOT MEETING THE NEEDS OF INDIVIDUALS/ FAMILIES |
|--|---|---|---|--|
| Religious or faith organizations | 62.50% 25 | 30.0% 12 | 22.50% 9 | 40.0% 16 |
| Hospital / Urgent care clinics | 63.64% 28 | 31.82% 14 | 31.82% 14 | 27.27% 12 |
| Primary care doctors or pediatricians | 62.22% 28 | 37.78% 17 | 40.0% 18 | 31.11% 14 |
| Parent organizations | 51.35% 19 | 32.43% 12 | 27.03% 10 | 32.43% 12 |
| Sport or recreational programs for children and youth | 60.0% 21 | 28.57% 10 | 8.57% 3 | 48.57% 17 |
| Childcare or preschool programs for children under 5 | 62.16% 23 | 40.54% 15 | 18.92% 7 | 40.54% 15 |
| Before-school, after-school, or summer programs for school-age youth | 67.65% 23 | 32.35% 11 | 11.76% 4 | 41.18% 14 |
| Libraries | 65.71% 23 | 37.14% 13 | 17.14% 6 | 31.43% 11 |
| Parenting education/support programs | 68.42% 26 | 34.21% 13 | 39.47% 15 | 23.68% 9 |
| Family Resource centers | 59.46% 22 | 24.32% 9 | 40.54% 15 | 29.73% 11 |

Q39: If our family has a crisis we know where to get support and help

| | NOT AT ALL | SOMEWHAT | MOSTLY | ALL OF THE TIME | UNKNOWN |
|--|------------|----------|--------|-----------------|---------|
| | 10.64% | 38.30% | 23.40% | 25.53% | 2.13% |
| | 5 | 18 | 11 | 12 | 1 |

Q40: In the past 30 days, have you asked a neighbor or friend to give you some advice or information about raising your child(ren)?

| | NO | ONCE | MORE THAN ONCE |
|--|--------|--------|----------------|
| | 68.09% | 12.77% | 19.15% |
| | 32 | 6 | 9 |

Q41: Raising children can be challenging. Please indicate how often each statement applies to you in thinking about the relationship with your youngest child living in your home.

| | RARELY | ON OCCASION | MOST OF THE TIME | N/A |
|--|------------|--------------|------------------|-------------|
| I know how to help my child | 0% 0 | 8.51% 4 | 82.98% 39 | 8.51% 4 |
| I know what to do when my child misbehaves | 0% 0 | 14.89% 7 | 74.47% 35 | 10.64% 5 |
| I praise my child when they behave well | 0% 0 | 4.26% 2 | 87.23% 41 | 8.51% 4 |
| I am able to soothe my child when they are upset | 2.13% 1 | 21.28% 10 | 68.09% 32 | 8.51% 4 |
| I spend time with my child doing what they like to do | 0% 0 | 25.53% 12 | 65.96% 31 | 8.51% 4 |
| I know what to expect from my child as they grow and develop | 4.26% 2 | 17.02% 8 | 70.21% 33 | 8.51% 4 |

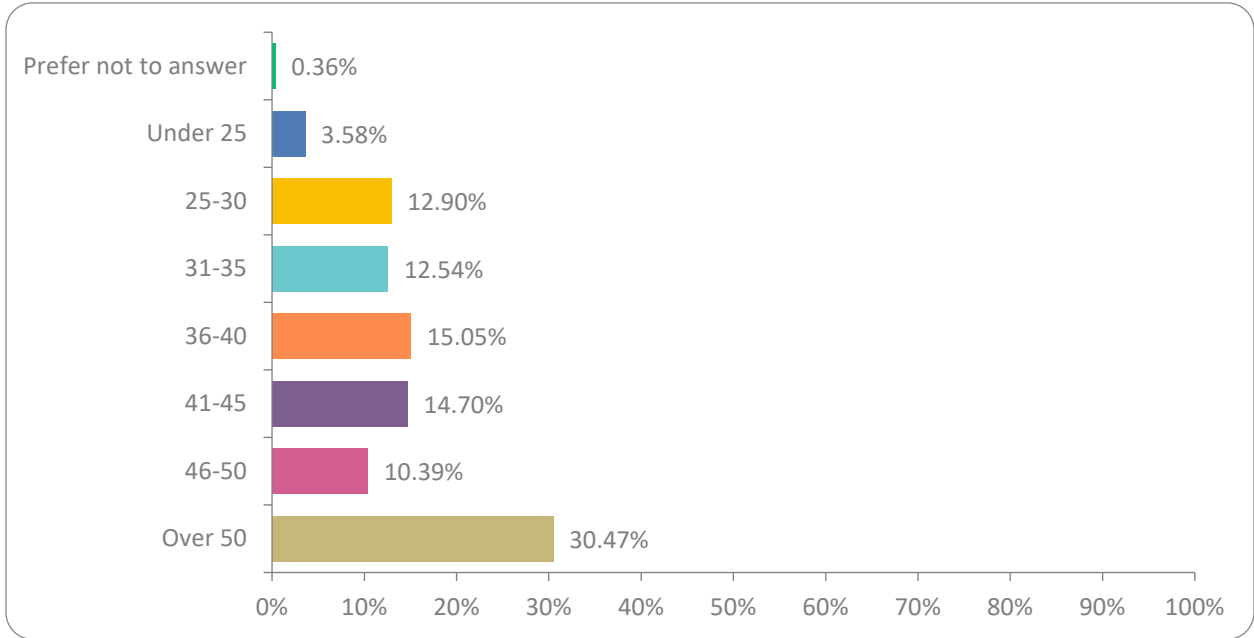
Appendix B – Provider Survey Frequency Tables

2022 FASD Needs Assessment

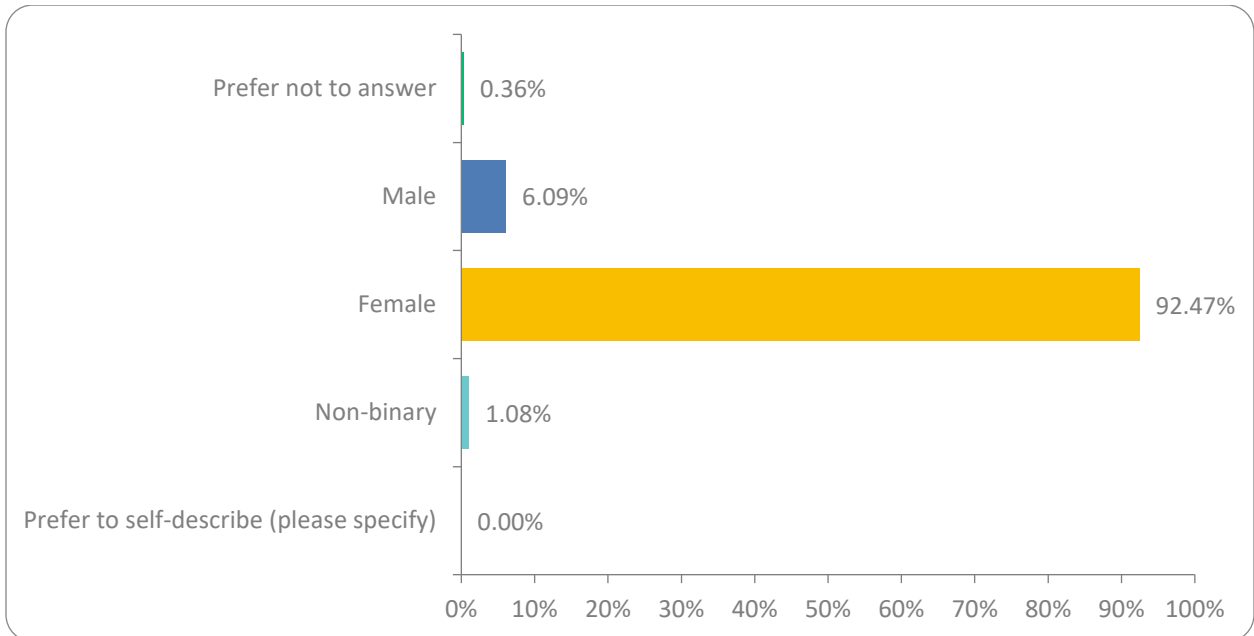
Appendix B – Provider Survey Frequency Tables

Provider Respondent Demographics

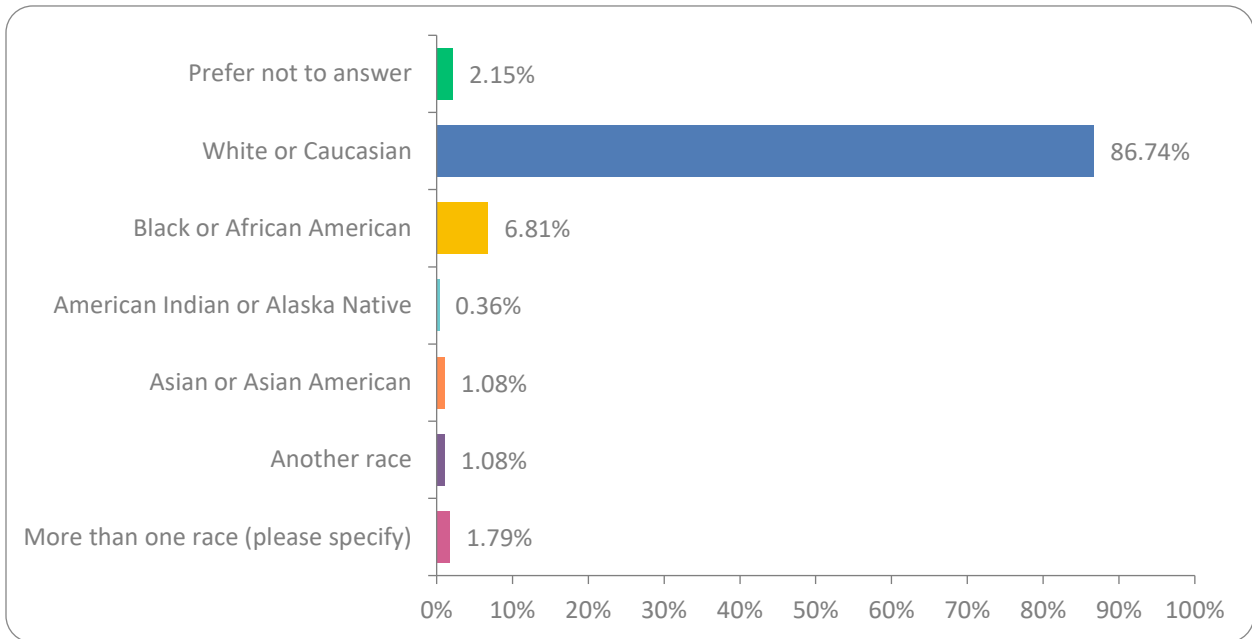
Q1: Age of Respondents



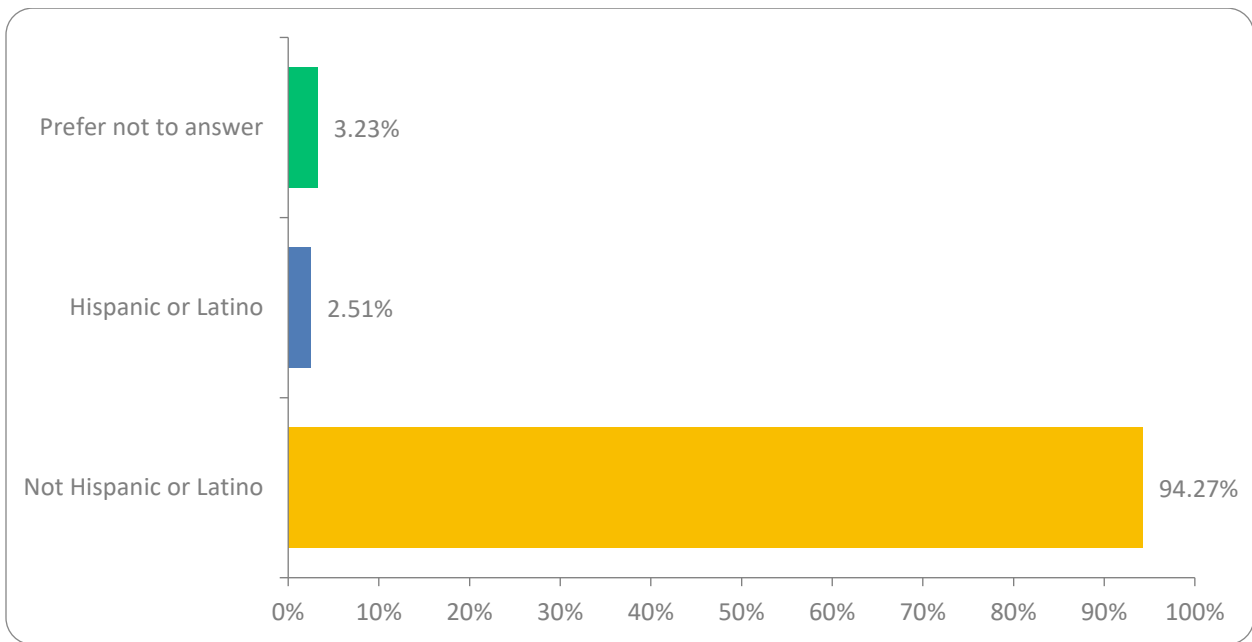
Q2: Gender of Respondents



Q3: Race of Respondents

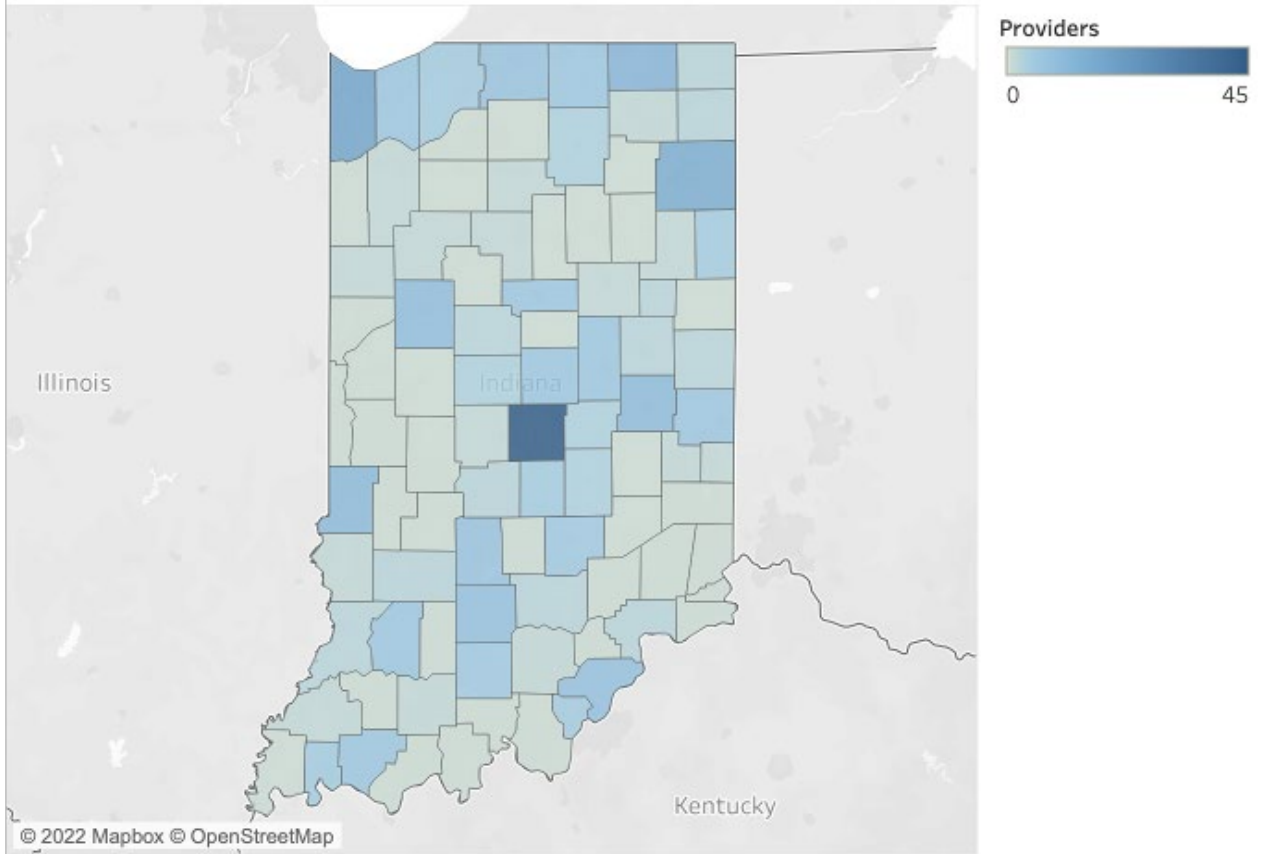


Q4: Ethnicity of Respondents



Q5: Work County of Respondents

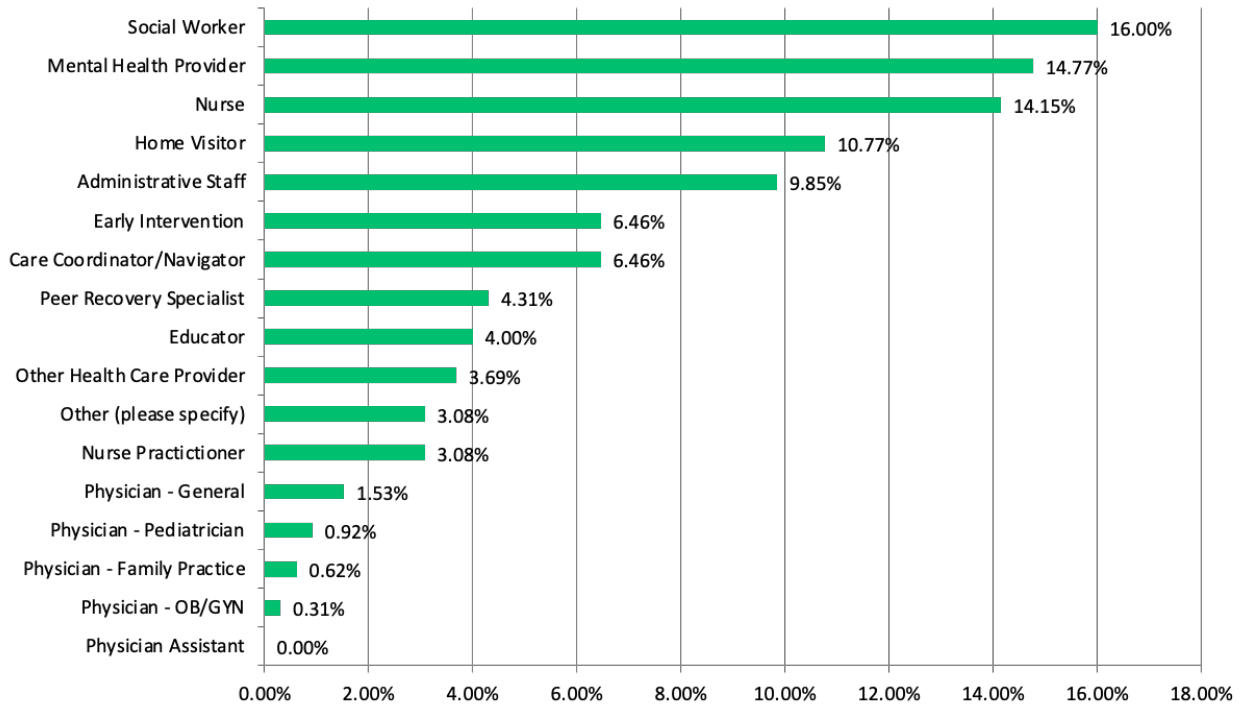
Counties Served by Responding Providers



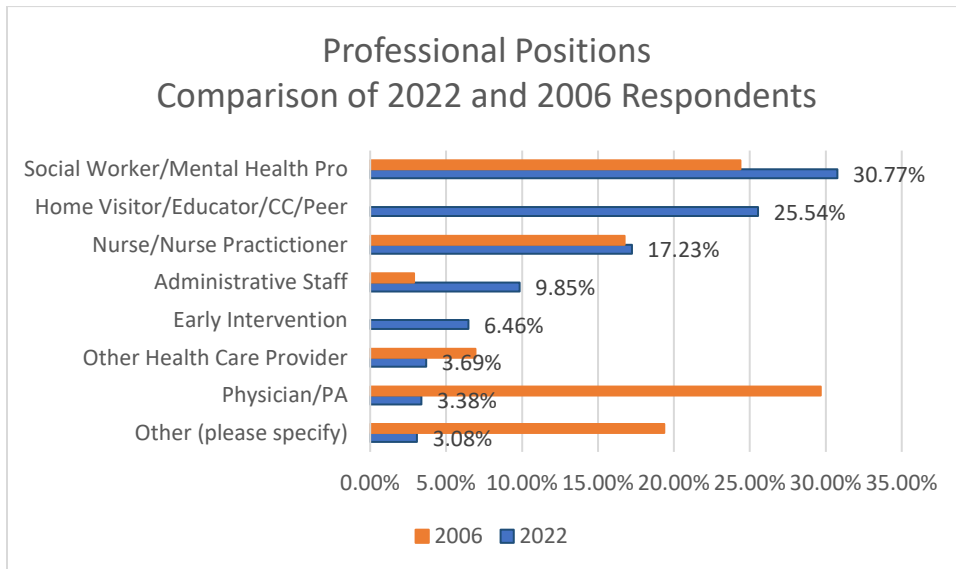
Map based on Longitude (generated) and Latitude (generated). Color shows sum of Providers. Details are shown for County.

Q6: Position of Respondents

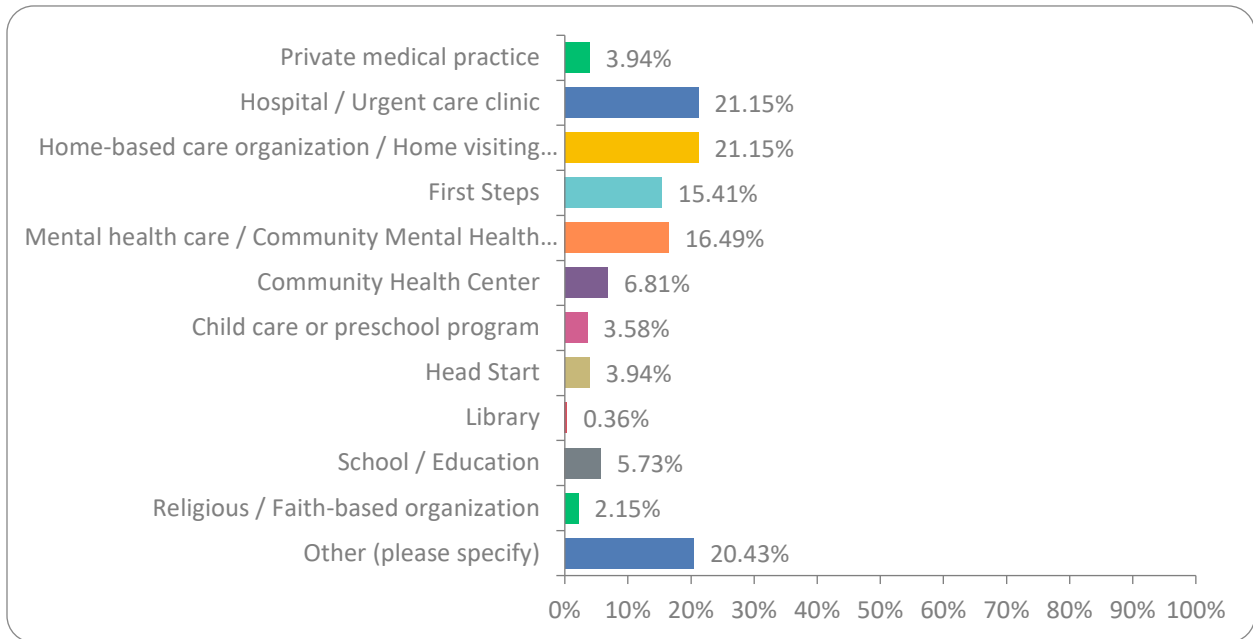
What is your position?



Comparison Tables of Professional Positions from 2006 and 2022 Surveys



Q7: Work Settings of Respondents



Q8: Do you routinely use a screening tool with every patient to identify alcohol use and/or abuse?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---------------------|----------------|----------------|
| Not appropriate | 25.81% ↑ | 8.9% |
| Yes | 41.94% | 63.6% |
| No | 24.01% | 22.9% |
| Only when warranted | 8.24% | 4.0% |

Q8: Do you routinely use a screening tool with every patient to identify alcohol use and/or abuse?
(Broken down by provider age), %(n)

| | < 25 years old (6) | 25 – 30 (22) | 31 – 35 (27) | 36 – 40 (34) | 41 – 45 (33) | 46 – 50 (17) | > 50 (70) | All Ages Total (209) |
|------------------------|--------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|---------------|----------------------------|
| Yes | 50.0% (3) | 50.0% (11) | 59.3% (16) | 61.8% (21) | 57.6% (19) | 47.1% (8) | 57.1% (40) | 56.5% (118) |
| No | 33.3% (2) | 36.4% (8) | 25.9% (7) | 29.4% (10) | 33.3% (11) | 41.2% (7) | 32.9% (23) | 32.5% (68) |
| Only when warranted | 16.7% (1) | 13.6% (3) | 14.8% (4) | 8.82% (3) | 9.1% (3) | 11.8% (2) | 10.0% (7) | 11.0% (23) |

Q9: [For those respondents who did not answer 'Yes' to Q8] Why don't you use a screening tool with every patient to identify alcohol use and/or abuse? (Choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| It takes too much time | 9.89% | 20.0% |
| It's not something that can be billed for | 5.49% | 6.0% |
| There are no treatment facilities available for the person, if identified | 0% | 6.0% |
| The purpose of a screening tool is not clear | 12.09% | 11.0% |
| I lack information about prevention and intervention | 6.59% | 16.0% |
| It is not appropriate for the patients I see | 36.26% ↑ | 25.0% |
| I have never thought about it (therefore I haven't done it) | 23.08% | 30.0% |
| It is not appropriate given my job/position | 32.97% | 49.0% |

Q10: Where do women in your community obtain health information? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| None of the above | 0.36% | |
| Primary health care provider / physician / doctor | 96.42% | 93.7% |
| Family members | 78.14% | 86.5% |
| Friends | 74.55% | 83.3% |
| Advertisements / public service announcements | 35.48% | 46.4% |
| Books / magazines | 16.13%↓ | 55.9% |
| Flyers / pamphlets / brochures | 37.63%↓ | 70.9% |
| Internet search engines (Google, etc.) | 69.89% | 60.2% |
| Internet web pages / web sites | 47.31% | -- |
| Social Media (Facebook, Instagram, YouTube, TikTok, etc.) | 69.53%↑ | -- |
| Online groups / Support groups | 32.62% | -- |
| Local support organizations | 36.20% | -- |

Q11: How much alcohol is safe for a pregnant person to drink? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| No alcohol is safe for pregnant people to drink | 83.87% | 89.7% |
| 1 can or bottle of beer per day | 0% | 0.6% |
| 1 glass of wine per day | 4.30% | 2.6% |
| 1 can or bottle of wine cooler per day | 0% | 0.6% |
| 1 can or bottle of hard cider per day | 0% | -- |
| 1 can of hard seltzer / hard lemonade / hard tea per day | 0% | -- |
| 1 mixed drink or cocktail (including canned) per day | 0% | 0.3% |
| 1 shot of liquor per day | 0% | 0.3% |
| One drink per week | 1.08% | -- |
| An occasional drink at social gatherings/special occasions | 3.94% | -- |
| I do not know how much alcohol is safe for pregnant person to drink | 5.73% | 2.6% |
| Other (please specify) | 2.87% | 6.9% |

Q12: What types of alcohol are safe to drink during pregnancy? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES |
|---|----------------|
| None of the above | 87.81% |
| Beer | 1.79% |
| Wine | 7.89% |
| Wine cooler | 1.79% |
| Hard cider | 1.43% |
| Hard seltzer / hard lemonade / hard tea | 1.79% |
| Mixed drinks or cocktails | 0.72% |
| Shot of liquor | 0.36% |
| Don't know | 4.66% |

Q13: Which of the following statements do you believe are true about drinking alcohol while pregnant?
(choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| I don't believe any of these statements are true | 22.22% | -- |
| A person should stop drinking as soon as they become pregnant | 74.55% | 77.2% |
| A person can drink occasionally while pregnant | 5.02% | 2.6% |
| It's okay to drink while pregnant, as long as they don't get drunk | 0% | 0.6% |
| It's okay to drink while pregnant, as long as they only drink wine or beer | 0.36% | 0.6% |
| It's okay to drink during the last trimester of pregnancy | 0.72% | 0.3% |

Q14: Which of the following statements do you think are true if a person drinks while pregnant? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| I don't think anything happens to the baby if the person drinks while pregnant. | 0.72% | |
| The baby may be born with some problems but will outgrow them | 16.13% | 5.7% |
| The baby may be born with problems that will last a lifetime | 93.19% | 94.6% |
| The baby may have growth deficits | 83.15% | 77.1% |
| The baby may have mental challenges or intellectual disabilities | 93.19% | 81.7% |
| The baby may have facial anomalies | 82.44% | 79.4% |
| The baby may be born drunk | 24.73% | 10.3% |
| The baby's central nervous system may be compromised | 87.46% | 80.8% |
| The baby may look fine but could still have alcohol-related brain damage | 92.11% | 88.8% |
| The baby may be taken away from the mother | 64.16%↑ | 38.9% |

Q15: Which of the following measures have you used to educate pregnant people who were drinking alcohol? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| None of the above | 21.15% | -- |
| Given verbal explanations | 62.37% | 81.9% |
| Provided print material (booklet, pamphlet) | 48.03%↓ | 70.2% |
| Recommended a book | 10.04% | 7.4% |
| Recommended an internet website, app or online resource | 29.03% | -- |
| Suggested they access a particular community resource | 42.29% | 39.8% |
| Suggested they talk to a particular person | 31.18% | 32.1% |
| Referred them to a specific place for treatment | 42.65% | 34.4% |

Q16: In your community, what resources are available for pregnant people who are drinking while pregnant? (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| I am not aware of any resources for pregnant people who drink in my community | 15.05% | 8.6% |
| Substance use counseling | 75.63% | 84.2% |
| Support groups | 57.71% | 63.0% |
| Treatment programs or centers | 58.42% | 51.6% |
| Church programs | 40.86% | 38.4% |
| Educational materials | 59.50%↓ | 75.1% |
| Other (please specify) | 3.23% | |

Q17: Which of the following statements best describes drinking in your community?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| No people drink while they are pregnant | 2.87% | -- |
| Some people drink while they are pregnant | 39.43% | 48.1% |
| Many people drink while they are pregnant | 14.70% | -- |
| Don't know | 43.01% | 32.0% |

Q18: As I understand it, Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Spectrum Disorders (FASD) is:
(choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|--|----------------|----------------|
| I don't know if FASD is any of these things | 1.43% | -- |
| A genetic problem that families have no control over | 3.23% | .3% |
| Something a baby can get if a person drinks while pregnant | 93.19% | 93.1% |
| A rare occurrence that few children ever get | 0.36% | 1.4% |
| Diagnosed using four specified criteria | 24.01% | 18.6% |
| Rarely diagnosed although it occurs frequently | 24.73% | 19.8% |
| A condition that affects 1 in every 1,000 babies born | 26.52% | 17.5% |
| Entirely preventable if a pregnant person does not drink alcohol | 85.66% | 89.1% |
| A condition the baby will eventually outgrow | 0.36% | 0.6% |

Q19: Fetal Alcohol Spectrum Disorders (FASD) can occur if the pregnant person: (choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| I do not know | 7.53% | 4.3% |
| Is an alcoholic | 58.06% | 58.7% |
| Drinks certain types of alcohol | 23.66% | 13.8% |
| Drinks during certain times in their pregnancy | 38.35% | 33.5% |
| Drinks any type of alcohol anytime during their pregnancy | 74.19% | 73.9% |

Q20: In Indiana, the reported percentage of unplanned pregnancies per year is:

| ANSWER CHOICES | 2022 RESPONSES |
|----------------|----------------|
| I do not know | 46.24% |
| 15% | 4.30% |
| 25% | 19.71% |
| 50% | 25.45% |
| 75% | 4.30% |

Q21: Do you feel comfortable talking to a person about their alcohol consumption during pregnancy?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES | |
|----------------|----------------|----------------|--|
| Yes | 86.02%↑ | 76.5% | 2006 survey offered additional choices including: Depends on situation (18.9%) Don't know (1.7%) |
| No | 13.98% | 2.0% | |

Q21: Do you feel comfortable talking to a person about their alcohol consumption during pregnancy?
(Broken down by provider age group, %(n))

| | < 25 (11) | 25 – 30 (36) | 31 – 35 (35) | 36 – 40 (42) | 41 – 45 (41) | 46 – 50 (29) | > 50 (86) | No age given (1) | All Ages Total (281) |
|-----|--------------|-----------------|-----------------|-----------------|-----------------|-----------------|---------------|------------------------|-------------------------------|
| Yes | 72.7% (8) | 83.3% (30) | 82.9% (29) | 90.5% (38) | 90.2% (37) | 86.2% (25) | 87.2% (75) | 0% (0) | 86.1% (242) |
| No | 27.3% (3) | 16.7% (6) | 17.1% (6) | 9.5% (4) | 9.8% (4) | 13.8% (4) | 12.8% (11) | 100 % (1) | 13.9% (39) |

Q22: Do you feel comfortable talking to a person about the adverse effect of alcohol consumption in pregnancy, including Fetal Alcohol Spectrum Disorders?

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|----------------|----------------|----------------|
| Yes | 84.95% | 80.8% |
| No | 15.05% | 2.0% |

2006 survey offered additional choices including:

Depends on situation (15.2%)

Don't know (1.4%)

Q22. Do you feel comfortable talking to a person about the adverse effect of alcohol consumption in pregnancy, including Fetal Alcohol Spectrum Disorders? (Broken down by provider age, %(n))

| | < 25 (11) | 25 – 30 (36) | 31 – 35 (35) | 36 – 40 (42) | 41 – 45 (41) | 46 – 50 (29) | > 50 (86) | No age given (1) | All Ages Total (281) |
|-----|---------------|-----------------|-----------------|-----------------|-----------------|-----------------|---------------|------------------------|-------------------------------|
| Yes | 90.9% (10) | 77.8% (28) | 82.9% (29) | 95.2% (40) | 80.5% (33) | 75.9% (22) | 89.5% (77) | 0% (0) | 85.1% (239) |
| No | 9.1% (1) | 22.2% (8) | 17.1% (6) | 4.8% (2) | 19.5% (8) | 24.1% (7) | 10.5% (9) | 100 % (1) | 14.9% (42) |

Q23: Do you report diagnoses of FASD to the Indiana Birth Defects and Problem Registry?

| ANSWER CHOICES | 2022 RESPONSES | N |
|---|----------------|-----|
| Yes | 3.94% | 11 |
| No, because I don't make diagnoses | 68.10% | 190 |
| No, because I'm not familiar with this registry | 20.79% | 58 |
| No, for any other reasons (please specify) | 7.17% | 20 |
| TOTAL | | 279 |

Q24: When you know, or strongly suspect, one of your clients has an alcohol problem, which of the following do you do? (Choose all that apply)

| ANSWER CHOICES | 2022 RESPONSES | 2006 RESPONSES |
|---|----------------|----------------|
| Nothing | 0% | |
| Counsel them on the dangers of using alcohol during pregnancy | 50.18% | 71.9% |
| Encourage them to stop using alcohol during pregnancy | 55.20% | 74.2% |
| Give them educational materials | 51.97% | 65.3% |
| Refer them to counseling | 55.20% | 64.2% |
| Refer them to a support group | 43.01% | 39.0% |
| This situation has never come up | 35.48% ↑ | 17.8% |

Q25: Do families in your community have access to support from the following organizations? Are they familiar with FASD? (Please select all that apply)

| | CHECK IF YOU ARE FAMILIAR WITH THE ORGANIZATION | CHECK IF YOU HAVE REFERRED TO THE ORGANIZATION | CHECK IF YOU BELIEVE THE ORGANIZATION IS FAMILIAR WITH FASD | CHECK IF THE ORGANIZATION IS AVAILABLE, BUT NOT MEETING THE NEEDS OF FAMILIES |
|--|---|--|---|---|
| Religious or faith organizations | 65.78% 123 | 24.06% 45 | 21.93% 41 | 22.46% 42 |
| Hospital / Urgent care clinics | 65.30% 143 | 29.22% 64 | 53.42% 117 | 12.33% 27 |
| Primary care doctors or pediatricians | 62.10% 136 | 33.79% 74 | 54.34% 119 | 11.42% 25 |
| Parent organizations | 51.80% 72 | 26.62% 37 | 28.78% 40 | 20.86% 29 |
| Sport or recreational programs for children and youth | 63.69% 100 | 21.02% 33 | 14.65% 23 | 26.11% 41 |
| Childcare or preschool programs for children under 5 | 67.22% 121 | 31.11% 56 | 23.33% 42 | 20.56% 37 |
| Before-school, after-school, or summer programs for school-age youth | 64.24% 106 | 26.06% 43 | 18.79% 31 | 23.64% 39 |
| Libraries | 68.82% 117 | 27.65% 47 | 16.47% 28 | 18.82% 32 |
| Parenting education/support programs | 65.34% 115 | 31.25% 55 | 30.68% 54 | 13.07% 23 |
| Family Resource centers | 61.84% 94 | 32.24% 49 | 39.47% 60 | 14.47% 22 |

Appendix C – Caregiver-Provider Comparison Tables

2022 FASD Needs Assessment

Q14 (Provider) and Q35 (Caregiver): Which of the following statements do you think are true if a person drinks while pregnant? (Choose all that apply)

| ANSWER CHOICES | Providers % | Providers N | Caregivers % | Caregivers N |
|---|-------------|-------------|--------------|--------------|
| I don't think anything happens to the baby if the person drinks while pregnant. | 0.72% | 2 | 0% | 0 |
| The baby may be born with some problems but will outgrow them | 16.13% | 45 | 2.13% | 1 |
| The baby may be born with problems that will last a lifetime | 93.19% | 260 | 95.74% | 45 |
| The baby may seem fine at first but develop problems later | -- | -- | 80.85% | 38 |
| The baby may have growth deficits | 83.15% | 232 | -- | -- |
| The baby may have mental challenges or intellectual disabilities | 93.19% | 260 | -- | -- |
| The baby may have facial anomalies | 82.44% | 230 | -- | -- |
| The baby may be born drunk | 24.73% | 69 | 8.51% | 4 |
| The baby's central nervous system may be compromised | 87.46% | 244 | -- | -- |
| The baby may look fine but could still have alcohol-related brain damage | 92.11% | 257 | 93.62% | 44 |
| The baby may be taken away from the mother | 64.16% | 179 | 10.64% | 5 |

Q18 (Provider) and Q33 (Caregiver): As I understand it, Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Spectrum Disorders (FASD) is: (choose all that apply)

| ANSWER CHOICES | Provider % | Provider N | Caregiver % | Caregiver N |
|---|------------|------------|-------------|-------------|
| I don't know if FASD is any of these things (professionals) I have not heard or read about FAS/FASD (caregivers) | 1.43% | 4 | 2.13 | 1 |
| A genetic problem that families have no control over | 3.23% | 9 | 2.13% | 1 |
| Something a baby can get if a person drinks while pregnant | 93.19% | 260 | 89.36% | 42 |
| A rare occurrence that few children ever get | 0.36% | 1 | 2.13% | 1 |
| Diagnosed using four specified criteria | 24.01% | 67 | -- | -- |
| Rarely diagnosed although it occurs frequently | 24.73% | 69 | 61.70% | 29 |
| A condition that affects 1 in every 1,000 babies born | 26.52% | 74 | 27.66% | 13 |
| Entirely preventable if a pregnant person does not drink alcohol | 85.66% | 239 | 85.11% | 40 |
| A condition the baby will eventually outgrow | 0.36% | 1 | 2.13% | 1 |

Appendix D – Lived Experience and
Professional Survey Questions
2022 FASD Needs Assessment

FASD Experience Survey

Indiana is working to understand the health needs of pregnant people and babies. You can help by completing this survey. The information you provide will be used to develop a plan and educational materials for birthing parents and the health care providers who work with them.

First, we need some information about you. This information will be kept confidential and will only be used to describe who responded to the survey, as a whole.

*** 1. What is your age?**

- Under 20
- 20-24
- 25-29
- 30-34
- 35-40
- Over 40
- Prefer not to answer

*** 2. What is your gender?**

- Male
- Female
- Non-binary
- Prefer to self-describe (please specify)

- Prefer not to answer

*** 3. What is your marital status?**

- Married
- Single
- Other (please specify)

- Prefer not to answer

* 4. What is your race?

- White or Caucasian
- Black or African American
- American Indian or Alaska Native
- Asian or Asian American
- Native Hawaiian or other Pacific Islander
- Another race
- More than one race (please specify)

- Prefer not to answer

* 5. What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to answer

* 6. What is the highest grade you completed in school?

- 8th grade or less
- 9th or 10th grade
- 11th or 12th grade
- High school diploma or GED
- 2-year college or trade school
- 4-year college degree
- Graduate degree from college (masters, doctorate, etc)
- Prefer not to answer

* 7. What county do you live in?

* 8. Which best describes you? *(we are asking this so that we can ask you different questions based on your answer)*

- I am a person with FAS/FASD
- I am the parent or caregiver of someone with FASD

Please click the Next button below to move to the next page of questions.

FASD Experience Survey

* 9. Which statement best describes your pregnancy history (or your partner's pregnancy history)?

- Never been pregnant
- Currently pregnant for the first time
- Currently pregnant, but not for the first time
- Not pregnant now, but have been pregnant before

Please click the Next button below to move to the next page of questions.

FASD Experience Survey

* 10. Has a **doctor** ever told you or your partner that it was safe to drink alcohol during pregnancy?

- Yes
- No
- Don't remember
- Prefer not to answer

* 11. Has a **family member** ever told you or your partner that it was safe to drink alcohol during pregnancy?

- Yes
- No
- Don't remember
- Prefer not to answer

* 12. During the 3 months **before** the pregnancy, how many drinks of alcohol did the pregnant person have *in an average week*?

- None
- 1
- 2-3
- 4-6
- 7-13
- 14 or more
- Don't remember
- Prefer not to answer

* 13. During the 3 months **before** the pregnancy, how many times did the pregnant person drink 5 or more alcoholic drinks in one sitting?

- None
- 1
- 2-3
- 4-5
- 6 or more
- Don't remember
- Prefer not to answer

* 14. During the **last 3 months of the pregnancy**, how many drinks of alcohol did the pregnant person have in an average week?

- I am/my partner is less than 7 months pregnant
- None
- Less than 1
- 1-3
- 4-6
- 7-13
- 14 or more
- Don't remember
- Prefer not to answer

Please click the Next button below to move to the next page of questions.

FASD Experience Survey

* 15. When did you get diagnosed with FAS/FASD?

- 0 to 5 years old
- 6 to 12 years old
- 13 to 19 years old
- 20 to 30 years old
- 31 years old or later

* 16. Who gave you this diagnosis?

- Primary Care Physician
- School evaluation
- Specialist doctor
- Counselor (psychologist or social worker)
- Self-diagnosed
- Other (please specify)

* 17. What do you think are the **top 3 FASD needs** in our state? (*choose up to 3 answers*)

- Getting a diagnosis
- Finding services
- Getting housing
- Getting support
- Getting help at school
- Raising awareness of FAS/FASD
- Other (please specify)

* 18. What is hard for you?

* 19. Who or what helps you?

* 20. What was/is school like for you?

* 21. What do you want people to know about FASD?

* 22. Would you be willing to share your story?

Yes

No

* 23. Would you like to/be willing to meet with other individuals with FASD?

Yes, virtually

Yes, in person

No

* 24. Would you be willing to serve on the [Indiana FASD Coalition?](#) *(more information about the coalition available by following the link)*

Yes

No

Please click the Next button below to move to the next page of questions.

FASD Experience Survey

Because you answered that you were interested in sharing your story, connecting with others, or serving on the coalition, we will need to collect your contact information so that we can follow up with you. This information will be kept separate from your other survey answers and will only be shared with the coordinators for the IN Alliance on Prenatal Substance Exposure.

* 25. Contact Information

Name

Email Address

Phone Number

Please click the Next button below to submit your survey. Thank you!

If you have any questions, contact Jan Bledsoe at bvcinc@sbcglobal.net

For further information on FASD, please visit the website: <https://inalliancepse.org>

FASD Experience Survey

* 26. Where do you get **health information** that you believe to be true or accurate? (*choose all that apply*)

- Primary health care provider / physician / doctor
- Family members
- Friends
- Advertisements / public service announcements
- Books / magazines
- Flyers / pamphlets / brochures
- Internet search engines (Google, etc.)
- Internet web pages / web sites
- Social Media (Facebook, Instagram, YouTube, TikTok, etc.)
- Online groups / Support groups
- Local support organizations
- None of the above

* 27. There are many ideas about how to have a healthy pregnancy. Which of the following do **you believe are necessary** to have a healthy pregnancy? (*choose all that apply*)

- Taking prenatal vitamins
- Getting prenatal care (seeing a doctor or nurse regularly)
- Not using drugs
- Not smoking
- Knowing the warning signs for preterm labor
- Not drinking
- Exercising regularly
- Unknown / Prefer not to answer
- Other (please specify)

- I don't think any of these are really necessary

* 28. What do you think a drink of alcohol means? (*choose all that apply*)

- 1 can or bottle of beer
- 1 glass of wine
- 1 can or bottle of wine cooler
- 1 can or bottle of hard cider
- 1 can of hard seltzer / hard lemonade / hard tea
- 1 mixed drink or cocktail (including canned)
- 1 shot of liquor
- Prefer not to answer

* 29. **During the past month**, how many drinks of alcohol did you have *in an average week*?

- None
- Less than 1
- 1 - 3
- 4 - 6
- 7 - 13
- 14 or more
- Don't remember
- Prefer not to answer

* 30. **During the past month**, how many times did you have **more than 4 or 5** alcoholic drinks *in one sitting*? (like during an evening meal or at a party/event)

- None
- 1
- 2 - 3
- 4 - 5
- 6 or more
- Don't remember
- Prefer not to answer

* 31. What types of alcohol are safe to drink during pregnancy? (choose all that apply)

- Beer
- Wine
- Wine cooler
- Hard cider
- Hard seltzer / hard lemonade / hard tea
- Mixed drinks or cocktails
- Shot of liquor
- Don't know
- None of the above

* 32. Where have you heard, read, or seen information about Fetal Alcohol Spectrum Disorder (FASD)? (choose all that apply)

- Family member
- Friend
- Doctor
- Nurse
- Health clinic
- School
- Newspaper / magazine
- Television
- Internet web page / web site
- Social media
- Other (please specify)

- I have not heard or read about FAS/FASD

* 33. As I understand it, Fetal Alcohol Spectrum Disorders (FASD) is: (choose all that apply)

- A genetic problem that families have no control over
- Something a baby can get if a person drinks while pregnant
- A rare occurrence that few children ever get
- Rarely diagnosed although it occurs frequently
- A condition that affects 1 in every 1,000 babies born
- Entirely preventable if a pregnant person does not drink alcohol
- A condition the baby will eventually outgrow
- I have not heard or read about FAS/FASD

* 34. Fetal Alcohol Spectrum Disorders (FASD) can occur if the pregnant person: *(choose all that apply)*

- Is an alcoholic
- Drinks certain types of alcohol
- Drinks during certain times in their pregnancy
- Drinks any type of alcohol anytime during their pregnancy
- Unknown

* 35. Which of the following statements do you think are true if the pregnant person drinks while pregnant? *(choose all that apply)*

- The baby may be born with some problems but will outgrow them
- The baby may be born with problems that will last a lifetime
- The baby may seem fine at first but develops problems later
- The baby will be born drunk
- The baby may look fine but may still have alcohol-related brain damage
- The baby will be taken away if anyone finds out the mother drank
- Unknown
- None of the above

* 36. In your community, where could a person go for help if drinking while pregnant? *(choose all that apply)*

- Friends and family
- Health clinic, hospital, or local health department
- Substance use treatment facility
- Doctor
- Other (please specify)

- I am not aware of any resources for pregnant people who drink

* 37. Which of the following statements best describes drinking **in your community**?

- No people drink while they are pregnant
- Some people drink while they are pregnant
- Many people drink while they are pregnant
- I do not know the extent to which people in this community drink while they are pregnant

* 38. Communities often have organizations that support families. Are you familiar with the following organizations in your community? Have you used these organizations? Are they familiar with FASD? (Please select all that apply)

| | Check if you are familiar with the organization | Check if you have used the organization | Check if you believe the organization is familiar with FASD | Check if the organization is available, but not meeting the needs of individuals/families |
|--|---|---|---|---|
| Religious or faith organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hospital / Urgent care clinics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Primary care doctors or pediatricians | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Parent organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sport or recreational programs for children and youth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Childcare or preschool programs for children under 5 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before-school, after-school, or summer programs for school-age youth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Libraries | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Parenting education/support programs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Family Resource centers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

* 39. If our family has a crisis we know where to get support and help

| Not at all | Somewhat | Mostly | All of the time | Unknown |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

* 40. In the past 30 days, have you asked a neighbor or friend to give you some advice or information about raising your child(ren)?

| No | Once | More than once |
|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

* 41. Raising children can be challenging. Please indicate how often each statement applies to you in thinking about the relationship with your youngest child living in your home.

| | Rarely | On Occasion | Most of the time | N/A |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| I know how to help my child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I know what to do when my child misbehaves | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I praise my child when they behave well | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to soothe my child when they are upset | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I spend time with my child doing what they like to do | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I know what to expect from my child as they grow and develop | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Thank you so much for taking the time to complete this survey. **Please be sure to click the Done button below.**

If you have any questions, contact Jan Bledsoe at bvcinc@sbcglobal.net

For further information on FASD, please visit the website: <https://inalliancepse.org>

FASD Provider Survey

The Indiana Alliance on Prenatal Substance Exposure, a program of Mental Health America of Indiana, 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 people. We need your help. Answering this survey will give us information to develop educational materials for birthing parents and those who serve them.

First, we need some information about you. This information is considered confidential and will only be used in aggregate to describe survey respondent demographics.

*** 1. What is your age?**

- Under 25
- 25-30
- 31-35
- 36-40
- 41-45
- 46-50
- Over 50
- Prefer not to answer

*** 2. What is your gender?**

- Male
- Female
- Non-binary
- Prefer to self-describe (please specify)

- Prefer not to answer

* 3. What is your race?

- White or Caucasian
- Black or African American
- American Indian or Alaska Native
- Asian or Asian American
- Native Hawaiian or other Pacific Islander
- Another race
- More than one race (please specify)

- Prefer not to answer

* 4. What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to answer

* 5. What county do you work in? (choose primary county, if you serve multiples)

* 6. What is your position?

- Physician - OB/GYN
- Physician - Family Practice
- Physician - Pediatrician
- Physician - General
- Physician Assistant
- Nurse Practitioner
- Nurse
- Social Worker
- Mental Health Provider
- Home Visitor
- Educator
- Peer Recovery Specialist
- Care Coordinator/Navigator
- Other Health Care Provider
- Administrative Staff
- Other (please specify)

* 7. What setting(s) do you work in? (Choose all that apply)

- Private medical practice
- Hospital / Urgent care clinic
- Home-based care organization / Home visiting program
- First Steps
- Mental health care / Community Mental Health Center
- Community Health Center
- Child care or preschool program
- Head Start
- Library
- School / Education
- Religious / Faith-based organization
- Other (please specify)

FASD Provider Survey

NEEDS ASSESSMENT

Read each question and select the answers you believe are correct. This information is considered confidential and will only be used to develop educational material for Indiana.

* 8. Do you **routinely use a screening tool** with every patient to identify alcohol use and/or abuse?

- Yes
- No
- Only with those I think warrant it
- Not appropriate given my job/position

FASD Provider Survey

* 9. **Why don't you** use a screening tool **with every patient** to identify alcohol use and/or abuse? *(Choose all that apply)*

- It takes too much time
- It's not something that can be billed for
- There are no treatment facilities available for the person, if identified
- The purpose of a screening tool is not clear
- I lack information about prevention and intervention
- It is not appropriate for the patients I see
- I have never thought about it (therefore I haven't done it)
- It is not appropriate given my job/position

FASD Provider Survey

* 10. Where do women in your community obtain **health information**? (choose all that apply)

- Primary health care provider / physician / doctor
- Family members
- Friends
- Advertisements / public service announcements
- Books / magazines
- Flyers / pamphlets / brochures
- Internet search engines (Google, etc.)
- Internet web pages / web sites
- Social Media (Facebook, Instagram, YouTube, TikTok, etc.)
- Online groups / Support groups
- Local support organizations
- None of the above

* 11. **How much alcohol is safe** for a pregnant person to drink? (choose all that apply)

- 1 can or bottle of beer per day
- 1 glass of wine per day
- 1 can or bottle of wine cooler per day
- 1 can or bottle of hard cider per day
- 1 can of hard seltzer / hard lemonade / hard tea per day
- 1 mixed drink or cocktail (including canned) per day
- 1 shot of liquor per day
- One drink per week
- An occasional drink at social gatherings/special occasions
- I do not know how much alcohol is safe for pregnant person to drink
- Other (please specify)
- No alcohol is safe for pregnant people to drink

* 12. What types of alcohol are safe to drink during pregnancy? *(choose all that apply)*

- Beer
- Wine
- Wine cooler
- Hard cider
- Hard seltzer / hard lemonade / hard tea
- Mixed drinks or cocktails
- Shot of liquor
- Don't know
- None of the above

* 13. Which of the following statements **do you believe are true** about drinking alcohol while pregnant? *(choose all that apply)*

- A person should stop drinking as soon as they become pregnant
- A person can drink occasionally while pregnant
- It's okay to drink while pregnant, as long as they don't get drunk
- It's okay to drink while pregnant, as long as they only drink wine or beer
- It's okay to drink during the last trimester of pregnancy
- I don't believe any of these statements are true

* 14. Which of the following statements **do you think are true** if a person drinks while pregnant? *(choose all that apply)*

- The baby may be born with some problems but will outgrow them
- The baby may be born with problems that will last a lifetime
- The baby may have growth deficits
- The baby may have mental challenges or intellectual disabilities
- The baby may have facial anomalies
- The baby may be born drunk
- The baby's central nervous system may be compromised
- The baby may look fine but could still have alcohol-related brain damage
- The baby may be taken away from the mother
- I don't think anything happens to the baby if the person drinks while pregnant.

* 15. Which of the following measures **have you used to educate** pregnant people who were drinking alcohol? *(choose all that apply)*

- Given verbal explanations
- Provided print material (booklet, pamphlet)
- Recommended a book
- Recommended an internet website, app or online resource
- Suggested they access a particular community resource
- Suggested they talk to a particular person
- Referred them to a specific place for treatment
- None of the above

* 16. **In your community**, what resources are available for pregnant people who are drinking while pregnant? *(choose all that apply)*

- Substance use counseling
- Support groups
- Treatment programs or centers
- Church programs
- Educational materials
- Other (please specify)

- I am not aware of any resources for pregnant people who drink in my community

* 17. Which of the following statements best describes drinking **in your community**?

- No people drink while they are pregnant
- Some people drink while they are pregnant
- Many people drink while they are pregnant
- I do not know the extent to which people in this community drink while they are pregnant

* 18. As I understand it, Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Spectrum Disorders (FASD) is: *(choose all that apply)*

- A genetic problem that families have no control over
- Something a baby can get if a person drinks while pregnant
- A rare occurrence that few children ever get
- Diagnosed using four specified criteria
- Rarely diagnosed although it occurs frequently
- A condition that affects 1 in every 1,000 babies born
- Entirely preventable if a pregnant person does not drink alcohol
- A condition the baby will eventually outgrow
- I don't know if FASD is any of these things

* 19. Fetal Alcohol Spectrum Disorders (FASD) can occur **if the pregnant person:** *(choose all that apply)*

- Is an alcoholic
- Drinks certain types of alcohol
- Drinks during certain times in their pregnancy
- Drinks any type of alcohol anytime during their pregnancy
- I do not know

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

- 15%
- 25%
- 50%
- 75%
- I do not know

* 21. **Do you feel comfortable** talking to a person about their alcohol consumption during pregnancy?

- Yes
- No

* 22. **Do you feel comfortable** talking to a person about the adverse effect of alcohol consumption in pregnancy, including Fetal Alcohol Spectrum Disorders?

- Yes
- No

* 23. Do you report diagnoses of FASD to the Indiana Birth Defects and Problem Registry?

- Yes
- No, because I don't make diagnoses
- No, because I'm not familiar with this registry
- No, for any other reasons (please specify)

* 24. When you know, or strongly suspect, one of your clients has an alcohol problem, which of the following do you do? (Choose all that apply)

- Counsel them on the dangers of using alcohol during pregnancy
- Encourage them to stop using alcohol during pregnancy
- Give them educational materials
- Refer them to counseling
- Refer them to a support group
- This situation has never come up
- Nothing

25. Do families in your community have access to support from the following organizations? Are they familiar with FASD? (Please select all that apply)

| | Check if you are familiar with the organization | Check if you have referred to the organization | Check if you believe the organization is familiar with FASD | Check if the organization is available, but not meeting the needs of families |
|--|---|--|---|---|
| Religious or faith organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hospital / Urgent care clinics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Primary care doctors or pediatricians | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Parent organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sport or recreational programs for children and youth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Childcare or preschool programs for children under 5 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before-school, after-school, or summer programs for school-age youth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Libraries | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Parenting education/support programs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Family Resource centers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Thank you so much for taking the time to complete this survey. **Please be sure to click the Done button below.**

If you have any questions, contact Jan Bledsoe at bvcinc@sbcglobal.net

For further information on FASD, please visit the website: <https://inalliancepse.org>