Knowledge of Fetal Alcohol Syndrome Among APA Member Practitioners: 2003

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June 2004

In recent years, there has been increased investigation into the effects of alcohol consumption during pregnancy and the potential for subsequent morbidity and mortality among offspring. Since experimental findings have been the main focus and clinical aspects have received less attention, knowledge about what information has reached practitioners, whether it has been useful, and how it could be improved is of great interest to the American Psychological Association (APA).

The survey items focused on the prevention of and diagnosis/treatment of Fetal Alcohol Syndrome (FAS), along with the attitudes, beliefs, practices and skills related to FAS. This information will be used by the APA to develop educational materials and services to benefit psychologists in the changing health care environment.

Methods

In 2003, a proportionate random sample of 1,417 doctoral-level, clinically active APA members was drawn from 6 states: Missouri, Arkansas, Oklahoma, Kansas, Iowa, and Nebraska. The sample was sent a copy of the survey in late August 2003, followed by a postcard reminder about a month later and a final copy of the survey in November. Four hundred and forty-seven members responded for a response rate of 31.5%.

Analyses

Demographics

The respondents were evenly divided by gender. Ninety-four percent of respondents were white. Sixteen (3.6%) did not specify. Two and a half percent were persons of color. Less than 1% was of Hispanic origin.

Almost 37% were located in solo practice settings with 21% in group practices. Thirteen percent worked in a medical school or university while 15% were employed in hospitals or clinics. Almost 5% were employed in community based health centers and just under 10% were located in "other" settings. On average they had been in practice 20.2 years with a SD of 8.4.

Forty-four percent worked in urban settings. Nine percent were located in an inner city area and 30% were in suburban settings. Just under 16% were working in rural settings.

The average age of respondents was 52.1 and the SD was 8.1. Almost 47% (modal "category") were between 50 and 59 years of age.

Hours In Professional Activities

The question asked practitioners to report the number of hours spent weekly in patient care, teaching, research, and administration. Unfortunately a sizeable proportion of respondents did not answer the items. On average the respondents reported working 40.9 hours weekly. The standard deviation was 11.3, with a median of 40. The modal number of hours was 40-49.

Those who provided direct patient care in private practice arrangements (self employed) spent an average of 25.5 hours a week at this. The S.D was 14, and the median was 25. The distribution for time spent in direct care in a private practice self employed arrangement was somewhat flatter than the overall distribution noted earlier. Although the largest single proportion did spend 20-29 hours each week in direct patient care, the second largest proportion spent 0 hours weekly, while the third largest proportion spent between 30 and 39 hours. Sixty-four respondents or 14% did not answer the item.

Respondents reported an average of 20.7 hours weekly in direct patient care in arrangements that did not involve self-employment (e.g., clinic settings, hospitals, nursing homes). The SD was 13.5 and the median was 20. Almost a third said they spent no hours in patient care that was not self-employment and 28% did not answer the item.

Over one third of respondents did not answer an item on hours spent in research while 44% said they spent no hours in research. The largest proportion of those who reported time in research said that they spent less than 5 hours weekly in research. The mean was 7.7 hours, with a SD of 10.7 and a median of 5.

Involvement in administration appeared somewhat more likely – only 18% did not specify and only 14% said zero hours were spent in administration. The mean was

11.5 hours weekly, the SD was 11.1 and the median was 10. The modal category was 10-19 hours each week.

Almost a third of the respondents did not answer the item on time in teaching, and almost 29% said they spent no time in teaching. The mean number of hours weekly in teaching was reported as 9.6 with a SD of 12 and a median of 5. Of those who reported some time in teaching, the modal category was less than 5 hours weekly.

Other activities had a mean of 10.4 hours weekly, with a SD of 8.4 and a median of 8. The modal category was zero hours followed by those who claimed between 10 and 19 hours weekly.

Looking at the numbers responding to the various activities with valid numbers of hours we see that involvement in the activities are from most to least numbers of respondents: self employed patient care, administration, other activities, other direct care, teaching, and research. This order does not reflect the numbers of hours spent in each of the activities.

Level of Knowledge

A series of questions gauged practitioners' level of knowledge about FAS and the effects of alcohol use during pregnancy. The first item asked about prevalence in the United States. The largest proportion (42%) felt that the prevalence was 1 in 1,000. One fourth said that 1 in 10,000 babies was born with FAS and 18% said 1 in 100.

Annually, at least 1 in 750 or 5,000 children are born with full-blown FAS (AMA). Between 35,000 and 50,000 babies are born with alcohol-related neurological disorders (ARND) that will affect their ability to function (March of Dimes, Teratology, November, 1997: 56 (5) 317-26).

Just under 85% of respondents stated that women should abstain completely from alcohol during pregnancy. Eleven percent felt that occasional use of alcohol would not harm the fetus. Only 12% provided an answer identifying a trimester when drinking would be safe, and of these, the largest number said 3rd trimester only and the next largest number replied with the 2nd trimester. When asked to determine what constitutes heavy drinking among pregnant women, respondents provided a range of responses. The lowest answer was one drink per week and the highest were those who proposed that 14 or more drinks weekly constitutes heavy drinking. The mean was 4.7 drinks a week with a SD of 3.1. Estimates of the number of drinks per occasion necessary to be termed binge drinking among pregnant women resulted in a mean of 3.3 drinks per occasion with a SD of 2. The answers were more tightly clustered than in the previous item, with 20% at 2 drinks and 35% at 3 drinks.

When asked at what age FAS is easiest to diagnose, almost 40% were not sure or did not know. Almost 39% said in early childhood, while 14% said as a newborn. Fifty-eight percent disagreed that a diagnosis of FAS stigmatizes the child and family, while almost 38% agreed that such a diagnosis was stigmatizing.

The psychologists were asked if they advised and educated adolescent females on the consequences of alcohol during pregnancy. Twenty-eight percent said always or almost always, a third said sometimes, and 29% said rarely or never. Use of a diagnostic schema for FAS was rare among the respondents with just under 90% saying they did not use a schema. Only 25 or 5% said they did use a schema, most often criteria established by the American Academy of Pediatrics.

The respondents' ratings of any formal training in FAS were discouraging. Almost half did not answer this item, the implication being that almost half the respondents have not received formal training. Thirteen percent maintained that their formal training in FAS was poor, while 31% said it was fair.

Incidence of Fetal Alcohol Syndrome in Practice

Over half of the respondents (62%) said that they had had no patients suspected of FAS in the past year. The 158 respondents who said that they had patients **suspected** of FAS reported an average of 6.8 patients with suspected FAS, and a SD of 9.1. The median or midpoint of the distribution was 4. Over three fourths (78%) responded that they had no patients recognized as FAS, while 88% had no patients diagnosed with FAS. Eighty seven psychologists reported that they had had patients recognized as having FAS, on average they reported 3.6 patients, with a SD of 3.5 and a median or midpoint of 2. The 47 respondents who had patients **diagnosed** with FAS reported 3.6 patients on average in the past year, the SD was 3.7, and the median was 2. The respondents reported **referring** a mean of 3.5 patients in the past year to confirm the diagnosis of FAS, with a SD of 3.6 and a median of 2. In the past year, 61 of the respondents had **provided care** on average for 4.2 clients with FAS, SD of 5.2 and a median of 2.

Beliefs About FAS Scale

Fifty-three percent disagreed that FAS occurs at similar rates across all socioeconomic groups, while a little less than a fourth said that they agreed with this statement. Nineteen percent said they did not know.

There was a somewhat higher rate of disagreement among the respondents to an item that proposed that the rate of FAS is similar across all cultural and ethnic groups (60%). Almost 15% said they agreed and 21% said they did not know.

Eighty-three percent of respondents disagreed with a statement that the effects of alcohol on fetal development were unclear, while 92% agreed that prenatal alcohol exposure was a significant risk for brain damage. Eighty-one percent of those answering were convinced that alcohol withdrawal at birth was the worst consequence of prenatal exposure to alcohol.

The psychologists disagreed with the statement that young adults with FAS usually achieve independence successfully at the expected time (82%). Almost 79% of the respondents agreed with a statement that early diagnosis and surveillance of FAS may aid secondary prevention of disabilities.

Factors That Interfere with FAS Diagnosis

It is important to note that the psychologists themselves identified a lack of relevant training in diagnosing FAS most often as a barrier to diagnosis (71%). Thirty-four percent said other factors, 11% said they did not believe that the diagnosis would make a difference. Almost 8% stated that they did not have time to make the diagnosis.

Level of Preparedness to Identify, Diagnose, and Treat

When asked how prepared they were to **identify** children with FAS or other alcohol related disorders, the largest single proportion said very unprepared (39%). Twenty-six percent said somewhat unprepared and 26% said somewhat prepared, while less than 4% said that they were very prepared.

The respondents judged their preparedness to **diagnose** substantially lower than their preparedness to **identify**. Fully half the psychologists responding stated that they were very unprepared to make a diagnosis while another 24% said they were somewhat unprepared. That is, almost three fourths of the psychologists did not feel prepared to make a diagnosis regarding FAS and other alcohol related disorders.

As to managing/coordinating actual treatment of children with FAS or other alcohol related disorders, over 80% said that they were unprepared. Less than 15% felt at all prepared to do this.

Behaviors and Characteristics Associated with FAS

Respondents were asked which of a list of 10 characteristics were associated with FAS. Those chosen by 90% or better of the respondents were delayed development, lowered IQ/retardation, and behavioral problems. Eighty to eighty-nine percent endorsed birth defects/malformations, psychiatric (DSM IV) disorders, and low birth weight. Seventy to seventy-nine percent agreed that infantile withdrawal symptoms, long term emotional disorders, and attention deficit hyperactivity disorders were characteristic of FAS. Fifty-four percent agreed that addictions were characteristic of those with FAS and a little over one third was not sure about the relationship between FAS and addictions.

When asked what specific facial dysmorphia were associated with FAS, almost 31% mentioned a large intercanthal distance, just under 28% mentioned a thin upper lip, and almost 23% said a smooth philtrum. Fourteen percent mentioned flaring nares, only seven percent chose short palpebral fissures, and 4% mentioned full lips. These percentages would appear to be somewhat low in light of the fact that most of these are deemed typical of those diagnosed with FAS (http://www.adopting.org/rwfas.html). Of

447 respondents, the largest number checking any one category was 137 or about 30% which does not appear to indicate a high level of knowledge about FAS.

Usefulness of Supports or Materials

Respondents were presented a list of ten services and were asked to rate how helpful they would be to the respondents' clinical practices.

Concise provider information on the prevention, diagnosis and intervention with respect to FAS was deemed to be a very helpful service by 59% of respondents and as a somewhat helpful service by another 26%.

Patient education materials were perceived as very helpful by 52% and as somewhat helpful by 31%.

Clinical guidelines for best practices for diagnosis of FAS were ruled very helpful by 64% and as somewhat helpful by 21%.

A registry of specialists available for consultation on FAS was deemed very helpful by 42% of respondents and somewhat helpful by 36%.

Listing of community-based resources for children with FAS was rated as a very helpful idea by 49% and as somewhat helpful by 33% of respondents.

Screening and referral checklists, pocket reminders or diagnostic criteria were perceived as very helpful by 54% of respondents and as somewhat helpful by 26%.

Mechanisms for training on FAS such as CE through regional conferences were given somewhat less weight in that only 34% of respondents felt that they would find this very helpful. Subsequent items, such as Internet-based learning opportunities, on-site training, and self study materials such as CD-ROMs or videos also received less positive ratings (only 26%, 23% and 36%, respectively), were willing to rate these as very helpful.

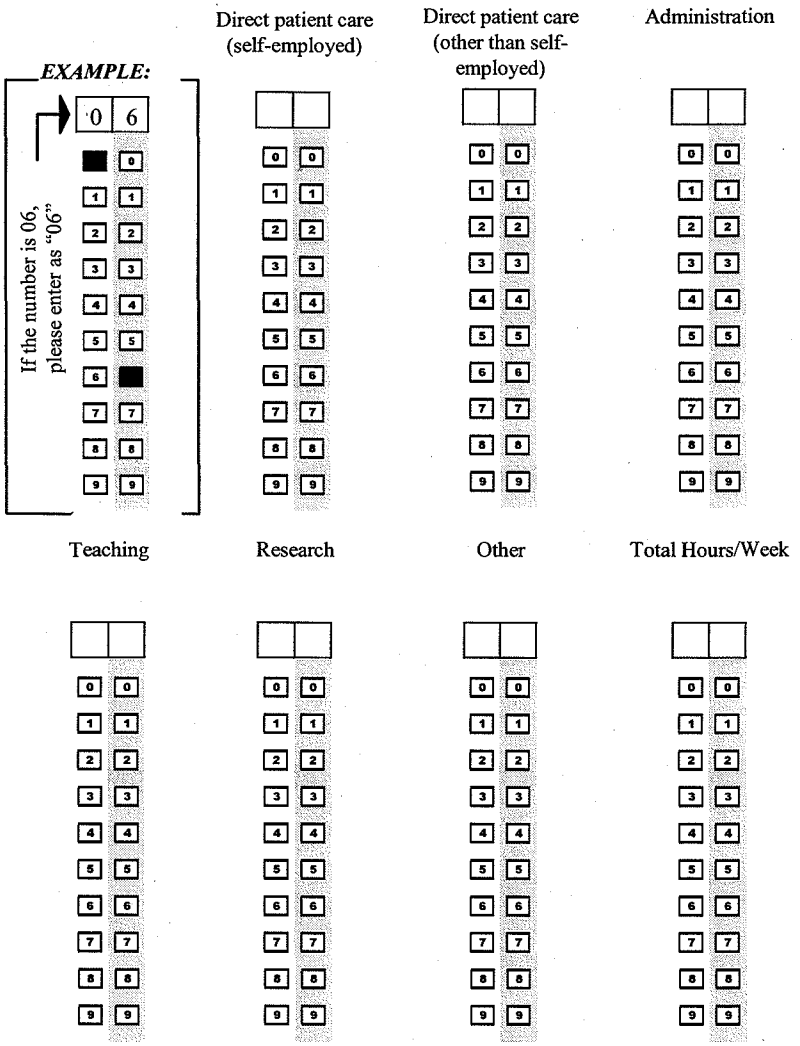
When asked about the **actual availability** of these mechanisms the respondents were more apt to state that they were not available or they failed to respond to the question (leaving it blank). To those who had **experience with** these mechanisms, regional conferences were more apt to be seen as helpful than not and this was true of Internet-based learning opportunities and of self-study materials. It was not as true of on-site training opportunities, which 43% saw as not helpful.

2003 APA Survey on Fetal Alcohol Syndrome

Study_ID# 11417

This survey asks for information on your knowledge, attitudes and beliefs about diagnosis, treatment and prevention of Fetal Alcohol Syndrome (FAS) and other prenatal alcohol-related disorders. Please answer the questions by circling the number of the appropriate response or by filling in the blanks.

1. During a typical work week, how many hours per week do you spend in the following professional activities? *If you do not spend any time in a particular activity, please indicate this by entering zero (00) hours in the appropriate space and filling in the corresponding rectangles.*



The following questions are for psychologists who provide some DIRECT PATIENT CARE. If you do NOT provide direct patient care, please check this box ☐ and go to Q# 22

GENERAL KNOWLEDGE

2. What would you estimate the overall prevalence of Fetal Alcohol Syndrome in the United States to be?

☐ 1 in 10 ☐ 1 in 100 ☐ 1 in 1,000 ☐ 1 in 10,000 ☐ 1 in 100,000

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3. Please check which of the two statements below corresponds most closely with your personal viewpoint. Please pick only ONE box.

☐ Pregnant women or women planning to become pregnant should completely abstain from consuming alcohol.

☐ Occasional consumption of alcohol (one drink per day or less) during pregnancy is not harmful to the mother or fetus

→ I believe that occasional alcohol consumption (one drink per day or less) is safe during the following trimesters of pregnancy, (check all that apply):

☐ 1st trimester ☐ 2nd trimester ☐ 3rd trimester

4. In your opinion, how many drinks per week would constitute heavy drinking for pregnant women? (Fill in your answer)

(1) (2) (3) (4) (5) (6) (7) (8) (9) (10) (11) (12) (13) (14+)

5. In your opinion, how many drinks per occasion would constitute binge drinking for pregnant women? (Fill in your answer)

(1) (2) (3) (4) (5) (6) (7) (8) (9) (10) (11) (12) (13) (14+)

6. Please indicate whether you agree or disagree with the following statements:

	Agree	Disagree	Don't Know
FAS occurs at similar rates in all socioeconomic groups of society	☐	☐	☐
FAS occurs at similar rates among all cultures and ethnic groups	☐	☐	☐

7. Please indicate whether you agree or disagree with the following statements:

	Agree	Disagree	Don't Know
Alcohol's effect on fetal development remains unclear	☐	☐	☐
Prenatal alcohol exposure is a significant risk factor for permanent brain damage	☐	☐	☐
Alcohol withdrawal in a baby at birth is the worst outcome of prenatal alcohol exposure	☐	☐	☐
Young adults with FAS usually achieve successful independence at the expected time (18 to 21 years)	☐	☐	☐
Early diagnosis and ongoing surveillance of FAS may lead to implementation of secondary prevention of disabilities	☐	☐	☐

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8. Do you consider any of the following problems to be associated with Fetal Alcohol Syndrome?

	Yes	No	Don't Know
Infantile withdrawal symptoms	☐	☐	☐
Delayed development	☐	☐	☐
Birth defects/malformations	☐	☐	☐
Psychiatric (DSM IV) disorders	☐	☐	☐
Lowered IQ/retardation	☐	☐	☐
Behavioral problems	☐	☐	☐
Low birth weight	☐	☐	☐
Long term emotional disorders	☐	☐	☐
Addictions	☐	☐	☐
Attention deficit hyperactivity disorder	☐	☐	☐

9. Which of the following are included in the facial dysmorphia associated with Fetal Alcohol Syndrome? (Check all that apply)

☐ Large intercanthal distance
☐ Short palpebral fissures
☐ Full lips
☐ Smooth philtrum
☐ Thin upper lip
☐ Flaring nares
☐ Don't Know/Unsure

10. It is easiest to diagnose FAS at what age?

☐ Newborn
☐ Early Childhood
☐ Adolescence
☐ Adulthood
☐ Don't Know/Unsure

11. Please indicate whether you agree or disagree with the following statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Making a diagnosis of FAS stigmatizes the child and family	☐	☐	☐	☐

Please consider your own practice over the past 5 years when answering the following questions.

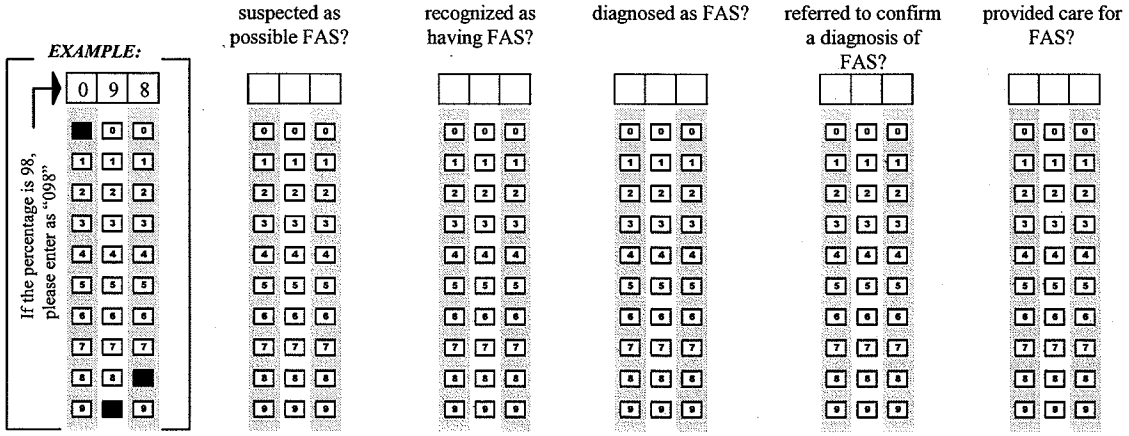
DIAGNOSIS & TREATMENT

12. Do you provide advice and education on the consequences of alcohol use during pregnancy to your adolescent female patients? (Check ONE box)

☐ Always/almost always
☐ Sometimes
☐ Rarely/never

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13. During the past 12 months, how many patients have you… (if none, enter "000")



14. Do you make use of a diagnostic schema for FAS in your practice?

☐ Yes

☐ No

If yes, which one of the following do you use?

☐ Institute of Medicine criteria

☐ American Academy of Pediatrics criteria

☐ Seattle 4 digit diagnostic criteria

☐ Other (please specify) _____

15. Many providers do not make the diagnosis of FAS in their practice. Please indicate which of the following factors may contribute to this situation. (Please select all that apply)

☐ Lack of time needed to make diagnosis

☐ Lack of specific training to make the diagnosis

☐ Belief that making the diagnosis will not make a difference to the individual

☐ Other (please specify _____

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TRAINING/PERCEIVED COMPETENCE/PERCEIVED NEEDS

16. Do you recall receiving any formal training in the following FAS competencies and if so, indicate where you received this training: (Check all that apply)

		YES			
	NO	Graduate School	Internship	CE (received credit)	Other
Ability to recognize the constellation of features associated with FAS and other alcohol-related effects	☐	☐	☐	☐	☐
Understanding of the basic biomedical mechanisms that result in FAS	☐	☐	☐	☐	☐
Ability to select valid and reliable assessment instruments to screen for/diagnose FAS and other alcohol-related disorders	☐	☐	☐	☐	☐
Ability to identify risk factors and interventions for secondary FAS disabilities	☐	☐	☐	☐	☐
Ability to plan and perform clinically relevant treatment and management plans to assist and aid both the patient with FAS and their families	☐	☐	☐	☐	☐
When appropriate, be able to make a referral for further workup in a child with FAS	☐	☐	☐	☐	☐
Appreciation and ability to use interdisciplinary team evaluations for individuals with FAS	☐	☐	☐	☐	☐
Ability to assist clients in accessing local FAS-related resources, including family support	☐	☐	☐	☐	☐
Utilization of techniques for effectively communicating information to individuals with FAS, their family members, and care providers	☐	☐	☐	☐	☐
Demonstration of the ability to provide ethical protections to the patient with FAS regarding confidentiality and autonomy	☐	☐	☐	☐	☐
Ability to educate pregnant women about the effects of alcohol on their babies	☐	☐	☐	☐	☐
Ability to screen women for risky or hazardous drinking	☐	☐	☐	☐	☐
Ability to conduct alcohol cessation brief interventions	☐	☐	☐	☐	☐

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17. If you have received any formal training on FAS in any venue (graduate school, internship, CE), overall, would you say that training was:

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

18. In general, how prepared do you feel to (Check one box in each row):

	Very Prepared	Somewhat Prepared	Somewhat Unprepared	Very Unprepared
Identify children with possible FAS or other alcohol-related disorders	☐	☐	☐	☐
Diagnose children with FAS and other alcohol-related disorders	☐	☐	☐	☐
Manage/coordinate the treatment of children with FAS and other alcohol-related disorders	☐	☐	☐	☐

19. Please rate how helpful the following kinds of materials or supports would be to you in your clinical practice (Check one box in each row).

	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Concise provider and staff information on prevention, diagnosis, and intervention on FAS and other alcohol-related disorders	☐	☐	☐	☐
Patient education materials on the impact of alcohol use during pregnancy on children	☐	☐	☐	☐
Clinical guidelines for best practices for diagnosis of FAS and other alcohol-related disorders	☐	☐	☐	☐
Registry of specialists available for consultation about FAS and other alcohol-related disorders	☐	☐	☐	☐
Listing of community-based resources for children with FAS	☐	☐	☐	☐
Materials for office practice including FAS screening and referral checklists and pocket reminders of diagnostic criteria	☐	☐	☐	☐

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20. How helpful would the following mechanisms be to you for receiving training on FAS prevention, diagnosis, and intervention? (Check one box in each row)

	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Regional Conferences (CE)	☐	☐	☐	☐
Internet-based learning opportunities	☐	☐	☐	☐
On-site training for myself and colleagues	☐	☐	☐	☐
Self-study materials (eg, CD-ROM, videos)	☐	☐	☐	☐

21. Please indicate whether the following types of FAS-related training and educational materials are available in the community where you practice, and whether these resources are helpful, or would be helpful if they became available. (Check all that apply)

	Available	Not Available	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Regional Conferences (CME)	☐	☐	☐	☐	☐	☐
Internet-based learning opportunities	☐	☐	☐	☐	☐	☐
On-site training for myself and colleagues	☐	☐	☐	☐	☐	☐
Self-study materials (eg, CD-ROM, Videos)	☐	☐	☐	☐	☐	☐

BACKGROUND INFORMATION

22. What is your gender?

☐ Male

☐ Female

24. Are you: (Mark all that apply)

☐ African-American/Black

☐ American Indian/Alaskan Native

☐ Asian

☐ Native Hawaiian/Pacific Islander

☐ White

☐ Other (please specify)

25. Is your ethnic heritage Hispanic?

☐ Yes → **If yes, is it:**

☐ No

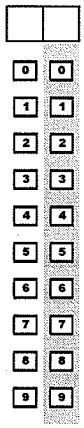
☐ Mexican American

☐ Puerto Rican

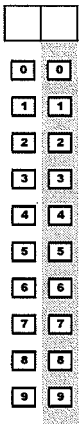
☐ Other Hispanic (please specify)

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26. What is your age?



27. Years in practice:



28. What is your primary employment setting? (Please select only one)

- ☐ Solo practice
- ☐ Group practice
- ☐ Medical School or University
- ☐ Hospital or clinic
- ☐ Community-based health center
- ☐ Other (please specify)

29. Do you consider your primary employment location to be: *Circle ONE response*

- ☐ Urban inner city
- ☐ Urban not inner city
- ☐ Rural
- ☐ Suburban

Thank you. Please return in the enclosed envelope to:

Attn: Research Office-2003 APA FAS Survey
American Psychological Association
750 First Street NE
Washington, DC 20002

Some questions from this survey were taken from:

Clarke M, Tough SC. A National Survey Regarding Knowledge and Attitudes of Health Professionals About Fetal Alcohol Syndrome. Health Canada Final Report, January 2003.

Shane T. Diekman, et al. A Survey of Obstetrician-Gynecologists on Their Patient's Alcohol Use During Pregnancy. ACOG. Vol 95, Number 5, May 2000.

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