

# FETAL ALCOHOL SYNDROME RELATED KNOWLEDGE ASSESSMENT AND COMPARISON IN NEW JERSEY HEALTH PROFESSIONAL GROUPS

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## ABSTRACT

### Background

There is a need to educate health professionals in regard to Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders across many health and allied health fields.

### Objective

Conduct evaluations of educational programs designed to assess knowledge, attitudes and beliefs in relation to Fetal Alcohol Spectrum Disorders (FASD) among health and allied health professionals in the northeastern United States.

### Methods

FASD related educational efforts were carried out and evaluated in New Jersey for various health-related professional groups over a four-month period using a common set of materials. Pre and post-test evaluation comprised 20 questions on FASD recognition, diagnosis, treatment, and prevention. Groups surveyed included nurses, social workers, counselors, therapists, clinicians and allied health professionals comprising physician assistants, dieticians, physical therapists, occupational therapists.

### Results

Results showed that a majority of health care professionals in New Jersey possess basic knowledge related to FASD and the effects of alcohol on a child *in utero*. They also had significant awareness of the importance of early diagnosis and the importance of reducing secondary disabilities. The study did however reveal areas for improvement in some professional groups.

### Conclusions

FASD is the most important preventable cause of mental retardation. Health professionals attending workshops typically had a good basic understanding of FASD, though with some weaknesses specific to their discipline. Educational efforts in regard to FASD should be sensitive to the various health professionals engaged in preventing, diagnosing and treating FASD.

**Key Words:** *Fetal alcohol spectrum disorders, fetal alcohol syndrome, alcohol, pregnancy, in utero*

In the United States, prenatal alcohol exposure is the leading preventable cause of birth defects, developmental disabilities and mental retardation.<sup>1</sup> This exposure to alcohol leads to a range of disorders, collectively known as Fetal Alcohol Spectrum Disorders (FASD) and is a lifelong condition including physical, mental and learning disabilities. One of the important categories of this spectrum is fetal alcohol syndrome

(FAS), which is characterized by facial dysmorphism, growth retardation, and central nervous system (CNS) problems.<sup>2</sup> Problem domains of individuals with prenatal alcohol exposure include cognitive reasoning, memory, learning, motor abilities and executive functioning.<sup>3</sup>

Reports by the Centers for Disease Control and Prevention (CDC) have shown that prevalence rates in the United States range from 0.5 to 2 cases per

1000 live births.<sup>4</sup> Studies have shown that approximately 1 in 33 pregnant women consume alcohol at levels shown to increase the risk of having a baby with FASD and that binge drinking is a serious risk factor<sup>4,5</sup> where binge drinking is defined as consumption of 5 or more drinks on one occasion. The prevalence of alcohol use in women of childbearing age was 52.6%, 54.9% in women who might become pregnant, and 10.1% for pregnant women.<sup>4</sup> Women who might become pregnant were defined as sexually active women of child bearing age not using any form of birth control.

Educational outreach for public health prevention in FASD is of prime importance. In order to decrease the prevalence of prenatal exposure to alcohol, health care professionals can play an important role in recognizing, diagnosing and treating FAS and FASDs in children as early as possible. Physicians, psychiatrists, nurses, allied health professionals, teachers and social workers all play a vital role in disseminating information on the effects of alcohol consumption during pregnancy.<sup>3,6</sup>

The CDC's National Center on Birth Defects and Developmental Disabilities has funded four FASD Regional Training Centers (RTCs). The RTCs, in collaboration with CDC and the National Organization on Fetal Alcohol Syndrome, are developing, implementing, and evaluating educational curricula for medical and allied health students and practitioners and seeking to have the curricula incorporated into the training programs at the grantee's university or college. Training is typically administered in various formats to target groups by teams including a psychologist and physician who are experts in FAS and FASD. The training focuses primarily on practicing physicians and health professionals who can influence the decision making process of their patients and at-risk individuals.<sup>7</sup>

#### **Northeast FAS Regional Training Centers**

The Northeast Center, located in the New Jersey Medical School - UMDNJ, is focused on developing educational programs and presentations reflecting the basic materials comprising the CDC developed curriculum. It has as its primary goal the FAS related education of health professionals in NJ and the Northeast in

multiple training and practice environments. These efforts have the ongoing support of schools and departments within the University of Medicine and Dentistry of New Jersey, the New Jersey State DHSS, and other community based organizations.<sup>8</sup>

Northeast RTC presentations are typically made to reflect the perceived needs of various groups such as physicians, other professionals, teachers, nurses, allied health professionals, counselors, and probation officers. Apart from these presentations and workshops, our trained psychologist provides personalized counseling to mothers of children with FASD. At each educational and 'Train the Trainer' session, informational handouts and references are included. The information presented here was collected over a four month time period during which the materials presented were common to all groups and thus comparable.

The Northeast RTC maintains a close relationship to New Jersey state level efforts to diagnose and educate regarding FAS and its linking to numerous other groups across the Northeast. In 2002, the New Jersey Department of Health and Senior Services and Department of Human Services funded state-wide FAS diagnostic centers and these are available to all health and allied health professionals in New Jersey. Each center has a developmental pediatrician, a psychologist, social worker, nurse, speech therapist, and a physical and/or occupational therapist. These centers provide a thorough diagnosis for any child suspected of having FAS. All staff receives training in the diagnostic coding developed by the University of Washington.

Over the past four years, the Northeast FAS RTC has made a large number of presentations before many groups of health related professionals. While we report here a sample of these given within a fixed time frame, educational presentations have been given to physicians, medical and allied health students, allied health professionals as well as groups involved with the repercussions of FASD such as social workers, school personnel, nurses, addiction counselors, probation officers, case managers and foster parents groups. The multi-dimensional aspects of alcohol use, addiction, fetal exposure to alcohol and the limitations of individuals with FASD are

an impetus to provide education on many levels. The programs have been presented in New Jersey, New York, Connecticut, Pennsylvania, Maine, Delaware and Puerto Rico.

### Methods and Materials

Over a four-month period, similar educational presentations were given to all New Jersey groups involved in the Northeast FAS educational program in order to provide an overall comparative assessment of knowledge levels in the different groups and evaluate the basic educational impact of the presentations. Each group in this period received presentations from the same set of presenters and in a similar day-long workshop format. Results were collected in the form of pre/post tests consisting of 20

questions on topics drawn from a cross-section of material (Figure 1).

Topics included the history and foundations of FAS, screening and intervention of women, women and addiction, effects of alcohol on the developing embryo and fetus, diagnostic criteria for FAS, primary and secondary disabilities in individuals with FAS through the lifespan, treatment for individuals with FASD through the lifespan and related issues in FAS. The set of questions comprising the evaluation form is shown in Figure 1. The content of these materials reflect basic materials developed as through the CDC FAS RTC Centers.<sup>1,7</sup> Given the variety of groups and venues, no longer-term follow-up was possible.

**FIG. 1** Pre / Post Test

### **NORTHEAST REGIONAL FAS EDUCATION AND TRAINING CENTER: PRE AND POST TEST ON FETAL ALCOHOL SPECTRUM DISORDERS**

Please check one:    Pre-test\_\_\_\_\_    Post-test\_\_\_\_\_

- 1.    The leading known preventable cause of mental retardations is:**
  - a.    Down Syndrome
  - b.    Fetal Alcohol Syndrome
  - c.    Cerebral Palsy
  - d.    HIV/AIDS
  - e.    Spina Bifida
  
- 2.    Which alcoholic beverage contains the greatest amount of alcohol?**
  - a.    A 12 oz. can of beer
  - b.    A 5 oz. glass of wine
  - c.    A shot of vodka
  - d.    A 12 oz. Wine Cooler
  - e.    They are all equal
  
- 3.    The model of addiction presently accepted is:**
  - a.    Social Learning model
  - b.    Disease model
  - c.    Impaired model
  - d.    Moral model
  
- 4.    Which of the following groups of women are at higher than average risk for drinking during pregnancy?**
  - a.    Women with a college education
  - b.    Unmarried women
  - c.    Female students
  - d.    Women with household incomes greater than \$50,000 annual income
  - e.    All of the above

5. **How much alcohol is safe for a pregnant woman to drink?**
  - a. 1-2 drinks a day
  - b. 1 a week
  - c. any amount in the third trimester
  - d. None
  
6. **Which risk factors can affect the fetus, prenatally?**
  - a. Smoking
  - b. Illness
  - c. Stress
  - d. Poor nutrition
  - e. All of the above
  
7. **All women of childbearing age should be screened for alcohol use**
  - a. Yes
  - b. No
  
8. **What are the characteristics of an individual who has been diagnosed with FAS?**
  - a. Growth retardation
  - b. Facial dysmorphology
  - c. Central Nervous System dysfunction
  - d. All of the above
  
9. **FASD:**
  - a. Is a lifespan disability
  - b. Is a genetic disability
  
10. **FASD is the result of:**
  - a. A woman drinking during pregnancy
  - b. A birth father drinking when the woman conceives
  - c. Only when an alcoholic mother drinks during pregnancy
  - d. None of the above
  
11. **FAS/FASDs can be passed on genetically**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
12. **The placenta protects the developing fetus from prenatal alcohol exposure**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
13. **Alcohol can effect the developing embryo at a cellular level**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
14. **IQ is a good indicator of an individual who has FAS/FASD**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
15. **Genetic syndromes, such as PKU and Noonan Syndromes are similar in presentation to FAS**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
16. **Secondary disabilities are common in individuals diagnosed with FASD**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
  
17. **Protective factors have been found which lower the rate of secondary disabilities in individuals diagnosed with FAS/FASD**  
TRUE \_\_\_\_\_ FALSE \_\_\_\_\_

18. **A team approach is the best way to assess and manage an individual suspected of having prenatal alcohol exposure**  
 TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
19. **Traditional medicines, such as Ritalin, usually work well with children diagnosed with FASD and ADHD**  
 TRUE \_\_\_\_\_ FALSE \_\_\_\_\_
20. **Advocacy and education is very important for communities and states to understand the devastation of prenatal alcohol use and the effect on the fetus**  
 TRUE \_\_\_\_\_ FALSE \_\_\_\_\_

Discipline/Profession: \_\_\_\_\_

Practitioner/Clinician \_\_\_\_\_ Teacher \_\_\_\_\_ Student \_\_\_\_\_

Other (Please explain) \_\_\_\_\_

## RESULTS

Pre-and-post question based evaluations were obtained for each group. Overall average pre/post test scores are shown in Table 1. Improvements were observed both in terms of overall range, mean and median scores, though these were not

statistically significant. Minimum overall test scores were increased by 22% among allied health professionals, 20% among nurses, 5% among social workers and 25% among counselors/therapists.

**TABLE 1** Overall Average Results (Mean (std dev), range, median)

	<b>Nurses (n = 126)</b>	<b>Social Workers (n = 11)</b>	<b>Counselors/Therapists (n = 31)</b>	<b>Allied Health (n = 45)</b>
<b>Pre-test</b>	.85 (.08) [.52, 1.0] .88	.89 (.08) [.71, 1.0] .89	.86 (.10) [.50, 1.0] .88	.87 (.10) [.38, 1.0] .88
<b>Post-test</b>	.93 (.06) [.76, 1.0] .94	.92 (.08) [.76, 1.0] .94	.90 (.09) [.63, 1.0] .94	.92 (.07) [.75, 1.0] .94

Table 2 reports results for nurses (n = 124). Pretest scores for individual questions were in the range of 57% to 99% with a post-test range of 75% to 100%. Significant increases in knowledge were observed on several questions including; safe amount of alcohol, whether screening women of child bearing age for alcohol consumption

should be mandatory, FAS related disability, genetic syndromes similar in presentation to FAS, issues related to secondary disabilities and the importance of a team approach as the best way to assess and manage an individual suspected of having prenatal alcohol exposure.

**TABLE 2** Nurses and Nursing Students (Correct scores/Total, (%))

Questions	Pre-test	Post-test	P values
1. Preventable cause of MR	120/124, (96.8)	122/124, (98.4)	0.408
2. Most amount of alcohol	99/123, (80.5)	120/124, (96.8)	0.001
3. Amount safe	116/124, (93.6)	122/124, (98.4)	0.051
4. Alcohol screening necessary	82/124, (66.1)	101/122, (82.8)	0.002
5. Characteristics	119/122, (97.5)	123/124, (99.2)	0.306
6. FAS Disability	117/124, (94.4)	123/124, (99.2)	0.029
7. Causes of FAS	118/123, (95.9)	121/122, (99.2)	0.098
8. Genetically transferred	117/123, (95.1)	119/122, (97.5)	0.313
9. Placenta Protects	123/124, (99.2)	122/124, (98.4)	0.561
10. Developing embryo	120/123, (97.6)	119/121, (98.4)	0.664
11. IQ	71/124, (57.3)	94/122, (77.1)	0.001
12. Genetic syndromes	86/120, (71.7)	101/116, (87.1)	0.003
13. Secondary Disabilities	120/124, (96.8)	122/123, (99.2)	0.176
14. Factors lowering Sec disability	73/120, (60.8)	91/121, (75.2)	0.016
15. Team Approach	116/124, (93.6)	124/124, (100)	0.003
16. Advocacy /Education	117/120, (97.5)	122/123, (99.2)	0.303

Results for social workers as a group are shown in Table 3 (n = 11). They had pre-test ranges for individual questions of 55% to 91% and posttest range of 64% to 100%. There was no statistically significant change in the level of understanding among the various questions. Pretest levels showed they were well informed of the characteristics and secondary disabilities of an

individual with FAS, including FAS being a lifelong disability and the leading preventable cause of mental retardation. They were also well aware of the need for a team approach and advocacy & education in communities are ideal in understanding and managing an individual suspected of exposure to alcohol *in utero*.

**TABLE 3** Social Workers and Social Work Students (Correct scores/Total, (%))

Questions	Pre-test	Post-test	P values
1. Preventable cause of MR	24/31, (77.4)	25/31, (80.7)	0.755
2. Most amount of alcohol	22/31, (71.0)	24/31, (77.4)	0.561
3. Amount safe	25/31, (80.7)	25/31, (80.7)	1.0
4. Alcohol screening necessary	20/30, (66.7)	22/31, (71.0)	0.717
5. Characteristics	19/30, (63.3)	24/31, (77.4)	0.223
6. FAS Disability	23/29, (79.3)	30/30, (100)	0.006
7. Causes of FAS	21/30, (70.0)	26/30, (86.7)	0.110
8. Genetically transferred	25/30, (83.3)	30/31, (96.8)	0.073
9. Placenta Protects	23/31, (74.2)	25/31, (80.7)	0.542
10. Developing embryo	27/30, (90.0)	30/31, (96.8)	0.285
11. IQ	18/28, (64.3)	19/28, (67.9)	0.778
12. Genetic syndromes	23/26, (88.5)	25/30, (83.3)	0.579
13. Secondary Disabilities	26/29, (89.7)	28/30, (93.3)	0.612
14. Factors lowering Sec disability	21/28, (75.0)	17/30, (56.7)	0.133
15. Team Approach	25/29, (86.2)	29/30, (96.7)	0.146
16. Advocacy /Education	25/31, (80.7)	25/31, (80.7)	1.0

**TABLE 4** Counselors, Therapists and Clinicians (Correct scores/Total, (%))

Questions	Pre-test	Post-test	P values
1. Preventable cause of MR	9/11, (81.8)	8/11, (72.7)	0.609
2. Most amount of alcohol	6/11, (54.6)	8/11, (72.7)	0.367
3. Amount safe	8/11, (72.7)	8/11, (72.7)	1.0
4. Alcohol screening necessary	7/11, (63.6)	7/11, (63.6)	1.0
5. Characteristics	8/11, (72.7)	8/11, (72.7)	1.0
6. FAS Disability	9/10, (90.0)	11/11, (100)	0.292
7. Causes of FAS	7/11, (63.6)	8/11, (72.7)	0.646
8. Genetically transferred	10/11, (90.9)	10/11, (90.9)	1.0
9. Placenta Protects	8/11, (72.7)	9/11, (81.8)	0.609
10. Developing embryo	8/11, (72.7)	9/11, (81.8)	0.609
11. IQ	9/11, (81.8)	7/10, (70.0)	0.525
12. Genetic syndromes	9/10, (90.0)	8/10, (80.0)	0.527
13. Secondary Disabilities	10/11, (90.9)	9/11, (81.8)	0.531
14. Factors lowering Sec disability	9/11, (81.8)	8/11, (72.7)	0.609
15. Team Approach	10/11, (90.9)	11/11, (100)	0.294
16. Advocacy /Education	8/11, (72.7)	8/11, (72.7)	1.0

Counselors, therapists and clinicians (n = 31), shown in Table 4, had a pre-test range for individual questions in the range of 63% to 90% and posttest range of 71% to 100%. They showed a good understanding of the secondary disabilities related to FAS and the need for team approaches to manage FAS. Issues related to screening and the characteristics related to FAS were not well known. Table 5 shows results from allied healthcare professionals (n = 45) comprising physician assistants, dieticians, physical therapists

and occupational therapists. Among this group the pretest ranges for individual questions were 67% to 100%, with posttest ranges of 78% to 100%. Prior to the workshop there was limited awareness of the importance of mandatory screening of women of child bearing age for alcohol consumption, but on the whole, most pre-test scores were high. Statistically significant improvement was observed in the amount of alcohol that is safe for pregnant women, the necessity of alcohol screening and similar presentation of genetic syndromes.

**TABLE 5** Allied Health: Physician Assistants, Dieticians, Ultrasound and Physical Therapy (Correct scores/ Total, (%))

Questions	Pre-test	Post-test	P values
1. Preventable cause of MR	44/45, (97.8)	43/45, (95.6)	0.556
2. Most amount of alcohol	42/44, (95.4)	44/45, (97.8)	0.554
3. Amount safe	40/45, (88.4)	45/45, (100)	0.018
4. Alcohol screening necessary	32/45, (71.1)	45/45, (100)	0.001
5. Characteristics	44/45, (97.8)	45/45, (100)	0.312
6. FAS Disability	43/45, (95.6)	44/45, (97.8)	0.556
7. Causes of FAS	43/45, (95.6)	44/44, (100)	0.148
8. Genetically transferred	43/45, (95.6)	40/42, (95.2)	0.944
9. Placenta Protects	45/45, (100)	45/45, (100)	*
10. Developing embryo	43/45, (95.6)	45/45, (100)	0.148
11. IQ	30/45, (66.7)	35/45, (77.8)	0.236
12. Genetic syndromes	26/44, (59.1)	39/45, (86.7)	0.009
13. Secondary Disabilities	42/45, (93.3)	45/45, (100)	0.073
14. Factors lowering Sec disability	32/44, (72.7)	34/39, (87.2)	0.040
15. Team Approach	44/45, (97.8)	45/45, (100)	0.312
16. Advocacy /Education	45/45, (100)	43/43, (100)	*

## DISCUSSION

The results reported here indicate that many health care professionals in New Jersey possess acceptable levels of basic knowledge related to FAS and the effects of alcohol on a child *in utero*. In all groups there was significant awareness of the importance of early diagnosis and reducing secondary disabilities. The study also revealed some deficiencies in knowledge regarding core issues fundamental to the appropriate diagnosis and treatment of FAS. The use of a limited time frame, standardized educational materials and a focus on New Jersey alone allowed for comparison of knowledge levels across various health professional groups.

In New Jersey efforts to educate and raise awareness have been ongoing for several years. Pre-test levels of awareness reflect this sustained educational effort. The workshops covered professionals from diverse groups across the health care system. These groups included nurses, social workers, counselors, therapists, clinicians, administrators and allied health professionals comprising of physician assistants, dieticians, physical therapists and occupational therapists.

Nurses benefited most from training in topics such as; whether the screening of women of child bearing age for alcohol consumption should be mandatory, which alcoholic beverage contained most amount of alcohol, IQ as an indicator for FAS diagnosis, various genetic syndromes similar in presentation to FAS and if a team approach is the best way to assess and manage an individual suspected of having prenatal alcohol exposure. Allied health personnel demonstrated understanding of concepts similar to nurses and showed a lower awareness of factors that lower the rate of secondary disabilities in individuals diagnosed with FAS. The highly heterogeneous nature of both these groups was not controlled for in this study.

Social workers demonstrated a high level of understanding in both pre and post tests. This is reflective of their ongoing exposure to the presence and effects of FAS, especially in the context of the educational and juvenile justice systems. Counselors, therapists and clinicians also possessed sound knowledge base in FAS, likely for similar reasons. The presence of a system of FASD specific referral centers in New Jersey may

have played a role in this high awareness level. While pre-test assessment showed higher levels of knowledge amongst the various groups in FAS, the educational presentations were able to address weaknesses where they existed, thus raising levels of awareness regarding the various dimensions of FASD.

## Limitations

The knowledge assessment was carried out in a standardized manner, over a fixed time period, which limited sample size. The training sessions, while offered in numerous institutional settings where attendance was often mandated, are often voluntary in nature, allowing for possible self-selection bias.

## SUMMARY

FAS is the single largest and most important non-genetic preventable cause of mental retardation. If left undiagnosed at an early stage could lead to irreversible damage for a lifetime in affected individuals. The personnel who attended these workshops were mostly health and health related professionals who came in contact with individuals affected by FAS in their everyday lives and had good basic understanding regarding FAS. The survey was designed in such a manner that it addressed diverse groups with varied understanding of the subject of FAS. As shown by the evaluation results, health related professionals have a relatively high awareness of FAS and FASD issues.

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