Educational treatments

One growing area of FASD intervention involves useful educational strategies and teaching curricula, including computer software.

Parents and school staff have long been interested in ideas for effectively educating children with FASD, and both training and research have gathered momentum. Curricula for educators and videos related to school have been produced. Experts have written chapters and books with information for teachers. More recently, educational information has been made available on Web sites. One good example of a Web site useful for educators is the "FASD Toolkit" at <a href="documents-document

Also of interest to educators has been an approach sometimes called "cognitive rehabilitation," (or "cognitive habilitation") in which children are trained in the skills underlying learning (such as attention or organization). This approach has been used in children with other disabilities or learning deficits, such as those that occur after traumatic brain injury or in the presence of ADHD. Strategies drawn from this approach are being used in current FASD intervention research (e.g., Coles et al., 2006). Approaches using a sensory-integration framework are also of interest to educators (and occupational therapists) because techniques based on this framework are thought to help children learn to cope and self-regulate, thereby allowing better classroom performance and adaptive behavior. Intervention ideas based on data gathered from a sensory integration framework have been suggested (e.g., Jirikowic, 2003), incorporated into FASD intervention models (e.g., Carmichael Olson et al., 2004), and drawn from recommendations by multidisciplinary FASD diagnostic clinic teams (e.g., Gelo, personal communication, June, 2006). Anecdotal reports note such intervention ideas are quite useful.

As yet, there is few research data showing whether these promising ideas for learning and behavior management in the classroom would actually work with children prenatally alcohol-exposed or actually diagnosed with FASD. But techniques drawn from these frameworks are just beginning to receive attention in research with children who have FASD, both in terms of direct child-focused intervention (e.g., Adnams et al., 2006; Coles et al., 2005) and as a source of information for creating accommodations in the home and school environments (e.g., Carmichael Olson et al., 2005; Chasnoff et al., 2003). One area of vivid interest is early intervention.

Another area of specific educational interest is computer training for somewhat older children with FASD. One research group has created a fire safety computer-training program, teaching simple but essential fire safety skills, with promising results (e.g., Coles et al., 2006). This is an exciting area because of possibilities seen in computer training of other skills (such as social skills)—or attention training in virtual reality environments or computerized neurobehavioral feedback training.

A final promising area of educational interest lies in FASD intervention that can respond to higher-level language deficits that many believe are common among children with FASD. So far this framework has been used to create accommodations in home and school environments (e.g., Carmichael Olson et al., 2004). But careful step-by-step research in this area is underway. Researchers are carefully describing the social communication, higher-level language, and social skills deficits among children with FASD, especially in "real-life" classroom situations with peers (e.g., Coggins et al., 2003; Svennson, unpublished dissertation; Timler, Olswang & Coggins, 2005). With careful descriptive data,

tailored interventions can eventually be created to respond directly to the social communication and social skill deficits this group of children show.

Some innovative researchers have begun to compare different types of educational strategies used in very high-need school situations. In South Africa, for example, Adnams and her colleagues (2006) are comparing several different school-based programs to see what can make a difference for children drastically affected by prenatal alcohol, poverty, and many environmental risks. Example classrooms have been created that can be thought of as "laboratories" for producing and testing good teaching and classroom management ideas, as detailed at the <u>SAMHSA FAS Center for Excellence</u> site.

What is needed to advance FASD intervention through educational strategies and curricula? Here are some ideas:

- Continue to train educational staff, evaluating the success of training efforts.
- Test some of the most promising educational intervention strategies.
- Expand and evaluate the ways in which computer training can be used with children who have FASD.
- Expand the activity of regional centers and centers providing FASD diagnosis and intervention to provide targeted school consultation.

Fetal Alcohol Syndrome in the Classroom

Children affected by FAS are a challenge in the classroom because they have difficulties with learning. paying attention, memory and problem solving. The term Fetal Alcohol Spectrum Disorders (FASD) is commonly used to cover the range of effects seen in children whose mothers drank alcohol during their pregnancy. FASD can include physical, mental, behavioral and learning disabilities, with developmental delays and possible lifetime implications. Most children with FASD have normal or above normal IQs (only 15% having IQs below 70) and the symptoms that show up in the classroom are first seen as "behavior problems."

The symptoms represent permanent brain damage from alcohol persisting into adulthood and include attention and memory deficits, hyperactivity, difficulty with abstract concepts, poor problem solving skills, immature social behavior, lack of emotional control, poor impulse control and poor judgment. Understanding that these behaviors are not within the child's control and can be made worse by abuse and neglect, teachers may have few strategies for dealing with inappropriate behavior apart from being more forgiving when it happens.

Some experts believe that children with severe FASD cannot be educated but more research is needed before this pessimistic prediction can be confirmed. Children with antisocial behavior are often placed in special education programs but as their symptoms often duplicate other diagnoses such as ADHD they are often undiagnosed and their behavior and learning difficulties remain a puzzle for their teachers.

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The best practices for supporting a child identified as having FASD begin with establishing the child's areas of strength and weakness, reviewing formal reports and assessments from personnel involved in the child's case and talking with the parents to obtain appropriate background information. The FASD child will need much the same support and guidance being given other learning and behavioral disabled children in the classroom. Lesson plans and study skills are not as important as setting up a Behavior Plan for the child, with lots of positive feedback and a reward system. Patience and empathy, a stable environment and consistency with rules and expectations are the basis for working with FASD affected children. The fact that there is no cure makes a teacher's support and understanding even more crucial.

Resources for teachers, information and assistance are readily available online. One very comprehensive resource is the British Columbia Ministry of Education handbook on Teaching Children with Fetal Alcohol Syndrome. It offers a comprehensive series of detailed strategies for helping FASD students develop their own inner resources on the basis of not expecting too little and not demanding too much. Many of the suggestions resonate with other learning or behavior disabilities and reiterate the need for teachers to provide lesson plans which are have a consistent, predictable schedule of activities. The importance is stressed of setting up a classroom environment where a child's self-esteem can be developed through many small successful learning experiences. Teachers are reminded also, that FASD students can bring gifts to the classroom such as creativity, a sense of humor, caring, musical and artistic talent and a desire to please. Because FASD is a lifelong disability, it also calls on the integrated efforts of school, family and community to create a team to follow through on long term goals for the student's future.

More Information On Fetal Alcohol Syndrome

- 1. ABC's of Fetal Alcohol Syndrome- A good introduction.
- 2. <u>Active Learning: Bridging the Gap for Fetal Alcohol Effect Children</u> Article by Debbie Evensen, discussing concerns about the educational implication of teaching prenatally alcohol/drug exposed children.
- 3. Advice for Parents of Children with FAS- By Mercedes Alejandro, Coordinator, Familias Hispanas del Arc.
- 4. Alcohol and Pregnancy Don't Mix A Ohio State University Extension Fact Sheet. What happens when you drink alcohol and how can it affect your baby when you're pregnant.
- 5. <u>Alcohol Related Birth Injury Resource Site</u> A resource for information on FAS, as well as FAE. Providing assistance with research information and pamphlets for school age children to adults.
- 6. <u>Fact Sheet Fetal Alcohol Syndrome</u> A list of causes, and recommendations on how to handle alcohol and pregnancy.
- 7. The Family Village Library Fetal Alcohol Syndrome Test Contact information, chat rooms, forums, and links to resource information.
- 8. FAS Quiz for Professionals- How much do you know?.
- 9. <u>FAS State of Alaska DHSS Fetal Alcohol Syndrome Website</u> Provides screening and assessment, resource materials, and information on support groups in the Alaska area.
- 10. <u>FAS Alaska: Project Facts</u> Information on intervention techniques for educators, family support, and a list of most frequently asked questions.
- 11. FAS Community Resource Center A collection of articles discussing this diagnosis.
- 12. FAS Fetal Alcohol Syndrome The implications of adopting an affected child.
- 13. <u>FASCETS</u> A Consultation, Education and Training Service located in Portland, Oregon.
- 14. FASlink Fetal Alcohol Syndrome Link for Information and Support A comprehensive list of possible damage done by alcohol use, a brain image, and additional statistical information.
- 15. <u>Fetal Alcohol and Drug Unit</u> Research and advocacy unit, headed by Dr. Ann Streissguth. Includes resources such as support groups, an events list, and a publications list.
- 16. Fetal Alcohol Syndrome Resources for information.
- 17. <u>Fetal Alcohol Syndrome</u> Information for the prevention of FAS. Lists possible difficulties an individual with this disease may encounter, as well as prevention activities.
- 18. <u>Fetal Alcohol Syndrome</u> A review of contemporary research, by Anuppa Caleekal, with implications for alcohol and prenatal education.
- 19. <u>Fetal Alcohol Syndrome</u> Statistics and other information on fetal alcohol syndrome and how it can be reduced.
- 20. <u>Fetal alcohol syndrome and Fetal Alcohol Effects</u> How to prevent a child from being exposed to the risks of alcohol related problems.
- 21. <u>Fetal Alcohol Syndrome Diagnostic and Prevention Network</u> Located in Seattle, WA., this organization diagnosis and works with children diagnosed with this disorder.
- 22. Fetal Alcohol Syndrome Movie Online movie regarding this preventable condition.
- 23. Math Skills Checklist- For teaching FAS students.
- 24. <u>National Organization on Fetal Alcohol Syndrome</u>- Offers strategies for working with FAS children.
- 25. <u>NE Consultation</u> A Colorado prevention center, containing training information, facts, support groups, and a chat room.
- 26. Normal Responses of Children with FAS- Helps identify problems FAS children may have in your classroom.
- 27. Preparing to Teach Children-Tips for first-time FAS teachers.
- 28. A Preventable Tragedy Information about FASworld, a world wide self help group dedicated to raising awareness for Fetal Alcohol Syndrome. Links and a support group available.
- 29. Region3 FAS/E Partnership Support and education for families, including links and a message board.
- 30. Science Skills Checklist- For teaching FAS students.

- 31. Texas Fetal Alcohol Syndrome Consortium Dedicated to prevention, education, and support.
- 32. The Schoolhouse- Examines how FAS/FAE impacts the ability to learn.
- 33. <u>Understanding the Needs of FAS</u>- Unique tips for educating the FAS child.
- 34. Washington State FAS Diagnostic & Prevention Network- Provides information on screening.
- 35. What is Fetal Alcohol Syndrome?- The beginners guide to FAS.

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Teens With FASD: What Makes Them Tick?

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The teen years are difficult for most families, for the teens as well as the parents. Caught between the innocence of childhood and the accountability of responsible adulthood, teens want to be independent and desire to be treated like grown ups but are far from being in control of their behavior, much less their lives. Having raised three teenagers, I can personally attest to the myriad challenges that parents of teens face. Having raised my son John with Fetal Alcohol Syndrome (FAS) through infancy, childhood, and the teenage years, I can proudly say I have earned my "Ph E" (Parent having experience) in FAS. I have witnessed more tantrums, outbursts, impulsivity, hyperactivity, and inappropriate social behaviors than I care to remember, and they were most challenging during John's teen years. I found myself often asking "Why does he do this?" Of course, I constantly reminded myself that he has FAS, but I really wanted to understand the difficult behaviors in an effort to help him and everyone else survive those difficult years.

Parents of teens with Fetal Alcohol Spectrum Disorders (FASD) sometimes feel like they are living with an explosive bundle of emotions that may go off at any moment. Sometimes it is hard to predict their behavior, and even more difficult to understand it. Some describe the teen years as a return to the "terrible twos" and for parents of teens with FASD, the challenges are even greater (Streissguth, 1997). One of the key strategies I have discovered to successfully parenting a teenager with FASD is to understand how the brain functions, both in healthy individuals and in those affected prenatally by alcohol. During the teen years, the brain is undergoing tremendous transformation. Let's look at what research shows us about the development of the teenage brain in general and the function (or dysfunction) of the brains of children and teens with FASD.

There is a pruning of brain cells that takes place during the last trimester of pregnancy, and again during puberty and the teen years. Prenatal alcohol can kill brain cells and may have a significant effect on this pruning process. (Gogtay et al., 2004) In healthy individuals, the pruning process during pregnancy causes a loss of brain cells and during adolescence a loss of brain cell connections that results in 15% less gray matter of the brain (Wallis, 2004).

How do we know this? Scientists use sophisticated electronic instruments to look at the brain and how it works. An MRI (magnetic resonance imaging) is a laboratory tool that shows brain structure. An FMRI (functional magnetic resonance imaging) measures and maps brain function (Wikipedia, 2004). It is helpful to understand the connection between the brain and behavior and to examine recent findings from researchers who use brain imaging and other methods to discover how the brain works.

Executive Functions: The concept of executive functioning refers to deliberate actions that require the ability to hold and manipulate information (working memory) and to focus on one task at a time (attention). The term generally refers to cognitive functions of our brain used in planning ahead and guiding our behavior to efficiently and effective achieve a goal. The prefrontal cortex part of our brain controls these executive functions, which include self-motivation, organization of thoughts, ability to plan ahead, setting priorities, suppression of impulses, decision-making and judgment, and the ability to weigh the consequences of our actions (Chun, 1999). Executive functioning is impacted by the pruning process in adolescence (Wallis, 2004). For teens with FASD, the impact of brain-cell pruning is even greater, as prenatal alcohol exposure causes impairment of the executive functions. In fact, individuals exposed to alcohol prenatally who have mild physical symptoms have similar deficits of executive functioning when compared to children with full Fetal Alcohol Syndrome (Kodituwakku et al., 1995).

Memory: A New York cab driver, who has to remember locations and streets and directions, is likely to have an MRI that shows an unusually large hippocampus, a brain structure involved in memory (Wallis, 2004). The hippocampus is one of the areas of the brain that is affected by prenatal exposure to alcohol. My son John's short term memory is so impaired that he may lose an important thought if he is required to wait to express it for longer than two minutes. This results in constant interruptions when he has the frequent need to tell me something important. And it means that he may forget a task within minutes of a simple assignment. He also forgets rules and the consequences that may result in the infraction of those rules. He requires constant cues to perform daily tasks such as taking medication or saying "excuse me" prior to an interruption.

Social Cues: Being able to read other people's facial expressions is a skill that uses the amygdala and the frontal lobes (Baird et al., 1999), both areas of the brain that are vulnerable to damage from

prenatal alcohol exposure (Mattson & Riley, 2001). Someone with FASD may confuse an expression of fear as anger or hostility. This could lead to inappropriate reactions that could result in negative consequences. If John engages an attractive store clerk in friendly conversation and she responds with a smile, he may misinterpret this as flirtation or romantic interest. Because John is not good at reading social cues, he must have someone responsible with him at all times in social situations.

Risk Taking: A person who is immature or young is likely to engage in risky decision making and high-risk behavior when with other immature or young people. A person whose decision-making skills are already impaired by prenatal alcohol exposure may be even more likely to engage in risky decision making, even in adulthood (Streissguth, 1997). John does not seem to be capable of weighing the pros and cons of making a decision, and frequently miscalculates his odds of having a successful outcome because of thinking "maybe this time I won't get caught" or "maybe this time it will work out okay." John's risky decision-making behavior could result in harm to himself or others, such as injury, assault, arrest, abuse, or death.

Behavioral Difficulties: The behavior problems observed in children who are prenatally exposed to alcohol are related to deficient skills in both the cognitive and emotion-based executive functions (Mattson et al., 1999). It is becoming increasingly apparent through recent research that deficits in social behavior are related to prenatal alcohol exposure (Kelly et al., 2000). Because of difficulties with social behaviors, many families that have children with FASD find they must give up social outings such as family reunions or church picnics because the challenges of monitoring the child or teen take away any pleasure to be derived from attending social functions. Even getting away for an evening or a weekend without the children is difficult, as there is a shortage of respite providers who are trained and willing to care for children or teens with FASD.

Attachment Disorders: Parents of children with FASD report that they have difficulty with healthy bonding and attachment. The children seem to form social attachments quickly, and break them just as easily. They tend to be inappropriately friendly and do not have a good sense of "stranger danger." It has been assumed in the field of social sciences that attachment disorders result primarily from poor parenting and lack of proper bonding in the early months of a child's life outside the womb (Bowlby, 1980; Rutter & O'Connor, 1999). However, deficits in attachment behavior are seen in both alcohol-exposed humans and animals, suggesting that these changes are primarily the result of the prenatal exposure to alcohol rather than maternal behavior (Kelly et al., 2000). It took many years for John and I to form a health parent-child bond, in spite of his growing up from infancy in our nurturing, stable family. John will bond quickly and easily to an interesting stranger, although the attachment is superficial. This places John at risk of becoming involved in unhealthy relationships or being drawn into high-risk groups.

The human brain is not fully mature until age 25 (Wallis, 2004). This is about the age that parents report that they begin to see their adult children with FASD settle down and reach their emotional and social potential. Parents of typical teens are advised to provide structure, help with organizing their time and scheduling, monitor their social relationships, and guide them through decision making. Parents of teens with FASD know that these strategies are even more crucial in helping their children safely make it to adulthood, and throughout their lifetime.

It is critical to understand the neurological aspects of FASD in order to implement effective strategies. Because of the nature of FASD and the brain damage caused by prenatal exposure to alcohol, many affected individuals have such difficulty controlling their impulses and have such poor judgment, that most will require close supervision or at least frequent monitoring well past their teen years. Having come to a reasonable understanding of the behaviors observed in teens with FASD, parents must then come to terms with the possibility of facing a period of never-ending adolescence. The "terrible teens" could last into the "terrible twenties." That prospect would strike terror in the heart of any parent. However, I have discovered, as have other parents of teens with FASD, that sometime before the age of 30 our young adult children seem to mellow out emotionally and socially. Their cognitive abilities may not improve with age, but their emotional behavior and social skills appear to finally become tolerable and this allows them to engage in social and employment relationships with limited success. Their ultimate success will be fragile and will depend on continued guidance and close monitoring that might require a one-on-one mentor or job coach and the presence of an "external brain" in social situations. An "external brain" is a concept coined first by FASD expert Sterling Clarren and later made popular by FASD speaker Susan Doctor.

In adulthood, prenatal alcohol exposure is related to high risk situations such as getting into trouble with the law, exhibiting inappropriate sexual behavior, having clinical depression, suicide ideation and attempt, and inability to properly care for children (Streissguth et al., 1996). These findings suggest

that there may be fundamental problems related to alcohol exposure in the social domain of brain function (Kelly et al., 2000). Because I am acutely aware of these secondary high-risk situations, I have made great efforts to ensure that John is protected from the painful consequences that befall most adults with FASD.

Another key to successfully navigating through the teen years to adulthood for individuals with FASD is *their* having a good understanding of how and why their brain functions as it does and accepting the reality of life with FASD. This has helped my son and many other young adults with FASD to accept the presence of an "external brain" in their lives. This measure will ensure their health and safety in a world that can be full of risks for people who have normal adult appearance and intelligence but have child-level decision-making capacity.

It would be prudent to add a third key of understanding, which is the accepting attitude of others in the community, including extended family members, neighbors, teachers, medical professionals, care providers, and others who might have an opportunity to interact with the teen or young adult who has FASD. As author Dian Smith (1991) wrote, "Parents' accepting attitudes can help children learn to be open and tolerant. Parents can explain unfamiliar behavior or physical handicaps and show children that the appropriate response to differences should be interest rather than revulsion." If those who learn about FASD take an interest in understanding alcohol-affected individuals, and help children and others to understand and accept the unusual and sometimes inappropriate behaviors of those who might be affected by alcohol exposure, the community will become a FASD-friendly environment for John and others like him.

As I take a bow for successfully navigating John from his "terrible twos" through his "terrible teen" years, I realize that I have used well all three of these keys. I educated myself about the neurological aspects of FASD, I helped John understand his own behavior, and I have enlightened every person in John's life who would listen about the nature of his disability. Now that he has emerged from the teen years and is more than halfway through his twenties, he is a mellow, well-mannered, relatively mature young man. In one week he will be moving out of the family home into an apartment he has chosen, to live with a roommate who is a friend of his, to be cared for by agency-hired individuals who will be trained by me in FASD issues. I have finally figured out what makes teenagers with FASD tick, but my task is not done. I will continue to help John survive his adult years by training his new caregivers and I will continue to assist parents and professionals who care for children and adults with FASD through articles, workshops, and web projects.

One project I will pursue is an educational program for teens and young adults with FASD to help them understand themselves in hopes of their finding the same satisfying success that John and I now enjoy. I don't know where the project will end, but I know when it began – with the publication of a chapter I wrote entitled "Broken Beaks and Wobbly Wings" (Kleinfeld, 2000). I'll share my final words from that piece. "We might not be able to strengthen those wings, but we can strengthen the safety nets, and we can encourage our young to fly tandem, with mentors and coaches, who can accompany them as they discover all that life's expansive horizons have to offer."

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Time for the development of effective approaches for the prevention of fetal alcohol spectrum disorder?

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"The brain disorder in fetal alcohol spectrum disorder is by far the most common and serious part of the condition. Animal experimentation shows that alcohol most commonly produces neurochemical, microanatomic changes throughout the brain..."

Fetal alcohol syndrome (FAS) is defined as brain dysfunction, a characteristic set of minor facial features and growth deficiency in the context of alcohol exposure in gestation. It is thought to occur in one-to-three per 1000 births in the USA and Europe. As with most environmental agents that produce birth defects, alcohol produces a wider range of abnormalities than one specific syndrome, such as FAS alone. This larger group, which includes FAS, is called the fetal alcohol spectrum disorder (FASD) and this might occur as frequently as in one per 100 births [1-4]. This is therefore a serious public health problem of epidemic proportion.

The brain is the principal target for FASD teratogenesis

The brain disorder in FASD is by far the most common and serious part of the condition. Animal experimentation shows that alcohol most commonly produces neurochemical, microanatomic changes throughout the brain rather than gross malformations [5]. These changes frequently go undetected for many years, until the affected child reaches an age when normal functions should be maturing but are recognizably impaired. The changes manifest in a wide variety of mild-to-moderate brain dysfunctions in processes, including memory, executive function, social communication and attention, as well as irregular patterns in intelligence test subskills and motor and sensory differences [6-8]. Childhood

depression, anxiety and other mental health conditions are also common and might be other manifestations of the primary brain alterations or may be secondary. The combination of these functional deficits leads to severe adaptive problems at home, at school or work, and in society. Most frequently, individuals who present with maladaptation from this form of diffuse brain dysfunction are either blamed for their failure to take responsibility for their actions or they are treated for some of their specific functional deficits, such as learning disability, attention deficit or depression. If and when this partial treatment is ineffective, the family is usually left to cope without further support. In our experience, FASD is not only devastating to the affected individual whose life choices become narrowed but also for his/her family who are exhausted and feel like failures.

The situation is made more difficult because this form of brain dysfunction is not easily detected. Only the most sophisticated research brain imaging can routinely discern this level of physiologic/anatomic abnormality. At present, diagnosis is made through a comprehensive battery of cognitive and performance testing disclosing the large number of poor scores across many domains of brain function. Professionals in psychiatry, psychology, speech and language pathology, and occupational therapy, who can work as an interdisciplinary group to assemble the entire picture of disability,

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best accomplish this battery of testing. The battery is helpful not only in establishing that brain dysfunction is the basis of the adaptive difficulties faced by the patient but also serves as a template for an individual intervention program [9]. As this capacity for identifying a FASD diffuse form of brain damage is very limited, the condition is largely and tragically unrecognized as the ultimate cause for the behavioral, mental health and cognitive damage that it produces.

Birth mothers of those with FASD are patients themselves

Studies of birth mothers of children diagnosed with FASD show that they are patients too. Most frequently, they have lost custody of their children when the child is brought for diagnosis. In these studies, the birth mothers came from every walk of life but had similar histories of extreme abuse over their lifetimes and mental health disorders, and a significant percentage, perhaps half, were suspected of having FASD themselves; they were socially isolated and had few resources. They often reported that, when they sought mental health treatment, they were redirected to substance-abuse programming first and when they sought substance-abuse treatment they were redirected to mental health. Generally, they were best cared for by health and social service agencies when they were pregnant. The picture that emerged was one of alcohol use as a self-administered drug treatment and pregnancy as a self-induced intervention. These women often had an alcohol-exposed pregnancy, lost custody of the child and had another exposed pregnancy. Rarely, if ever, did these women drink in pregnancy to deliberately harm their unborn [10,11].

Every child diagnosed with FASD is a biomarker for a mother who may have FASD herself, probably has significant health and mental health issues, and is at high risk of producing more children with FASD. Prevention of FASD is urgently needed to save innocent children from a lifetime of suffering and to aid their parents with their own conditions, but this is impeded by a vicious cycle. Without an adequate FASD diagnostic capacity, the fundamental cause of the condition goes unrecognized and resources are not provided to increase capacity. Even so, prevention efforts must be strategically increased.

Dose-response

Alcohol teratogenesis occurs through a complex equation of alcohol dose, timing in gestation, maternal metabolism and fetal resistance [6]. While alcohol is sufficient to damage the embryo/fetus alone, it is often the case in human pregnancies that alcohol exposure occurs with other exposures that might potentiate alcohol's effects. This all produces a relative risk for FASD with no dose-exposure pattern alone predictive of certain embryo/fetal injury and no dose-exposure pattern alone predictive of certain safety. When the Surgeon General of the USA recommended avoiding alcohol in pregnancy altogether [12], it was not because all alcohol exposure was equally dangerous, but because "no drinking equals no risk" and remains the only totally accurate public health statement that could be made.

Need for a comprehensive approach to FASD prevention

It may be helpful to think of FASD prevention as needing to target three groups of women with very different direct approaches and three other groups for help with indirect intervention. First, there is the group of women who are at high risk for having children with FASD. These are women who are addicted to alcohol, drink heavily and frequently, and have the social profiles described previously. These women are unlikely to be capable of changing their habits during a pregnancy by themselves. Studies suggest that they drink because they feel that they need to and hope against hope that the unborn child will be alright [10]. Second, there is a group of women who consume high volumes of alcohol in more of a binge pattern, such as college students or young working women who might party heavily on weekends. These women are often not fully addicted to alcohol and would probably intend to avoid alcohol in pregnancy, but may get pregnant unintentionally and might continue drinking through the first several weeks of pregnancy in this high-risk manner. Finally, there are women who drink smaller volumes of alcohol at lessfrequent intervals, thereby putting their pregnancies at a lower or much lower risk. This group is the more likely to have planned pregnancies and to avoid alcohol even before conception or to stop drinking after minimal exposures. They are the only group of these three who might be able to fully respond positively to direct alcohol cessation messaging campaigns.

"Alcohol teratogenesis occurs through a complex equation of alcohol dose, timing in gestation, maternal metabolism and fetal resistance."

At the same time, indirect intervention efforts need to be directed to include men and women who do not drink (or are not getting pregnant) but who care about the women who are at risk for an alcohol-exposed pregnancy. How can we teach this large group to show appropriate and effective concern and support? Similarly, how do we teach a wide range of professionals to identify and support women in each of the three groups mentioned? Finally, how do we develop FASD knowledge and effective intervention in a wide variety of programs that are seeing women for other purposes – for example, health, mental health, substance abuse, victimization, housing, employment, criminal justice and drunk driving? These programs could and should be doing important simultaneous identification and FASD prevention work.

There is much to be done and some modicum of work has been accomplished with each of these groups and many approaches have shown merit. However, no country, or region within a country, has developed a comprehensive approach to FASD prevention nor maintained any prevention campaign for a long period of time. Little of the prevention work has been evaluated for effectiveness, cost or sustainability. Arguing about whether to advise women not to drink at all or to drink in small amounts during pregnancy is a question that only deals with the lowest risk group of women in the first place. This diverts us from the real problems that must be solved and the real work that needs to be done.

Development of effective approaches for the prevention of fetal alcohol spectrum disorder

Our society is now facing so many enormous problems. However, one of the resources that will help us to solve these problems is the intelligence and skills of our children. We need every one of them. Additionally, we have declining resources for helping disabled people throughout their lives, especially when they could have been fully productive members of society. Let us move the FASD prevention strategies beyond a distracting argument and get to work.

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Secondary Disabilities in FASD

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Based on the Final Report from Research on Secondary Disabilities by Ann Streissguth, presented to the FAS Conference in Seattle in September of 1996

Primary Disabilities refer to the brain damage that results in impaired mental function of persons with Fetal Alcohol Spectrum Disorders (FASD). Primary Disabilities are measured by general intelligence, mastery of reading, spelling, math, and level of adaptive functioning, representing the CNS manifestations of FASD. The sample of 473 individuals in the study included 178 with Fetal Alcohol Syndrome (FAS) and 295 with Fetal Alcohol Effects (FAE). The range of IQ of individuals with FAS was from 29 to 120, with mean IQ of 79. Range of IQ of individuals with FAE was from 42 to 142, with mean IQ of 90. Only 16% of all the individuals with FASD in this study legally qualify as having mental retardation. This means that 86% of the individuals with FASD have an IQ in the "normal" range and do not qualify for services for developmental disabilities. They nevertheless have impaired mental functioning caused by brain damage that is permanent and incurable.

The academic abilities of individuals with FASD are below their IQ level, and their living skills, communication skills and adaptive behavior levels are even further below IQ levels. For example, a person with FAS with an IQ of 80 may have a reading IQ of 78, a spelling IQ of 75, a math IQ of 70, daily living skills IQ of 68, socialization skills IQ of 65, communication IQ of 62 and adaptive behavior IQ of 60. This indicates that when a person with FAS/FAE is evaluated, a battery of tests be done that include a test of level of functional abilities and daily living skills.

Secondary Disabilities are those not present at birth but occur as a result of the primary disabilities. Secondary disabilities can presumably be prevented or lessened by better understanding and appropriate interventions. Secondary disabilities were ascertained from life history interviews of 415 individuals with FASD using 450 questions. Six main categories are defined:

- * **Mental Health Problems**, the most prevalent secondary disability, experienced by 94% of the full sample. During childhood, 60% of children with FASD have ADHD. During adulthood, most adults with FASD have clinical depression. The study revealed that 23% of the adults had attempted suicide, and 43% had threatened to commit suicide.
- * **Disrupted School Experience** (suspension or expulsion or drop out), was experienced by 43% of children of school age. By the time students with FAE reach adulthood, the rate of disrupted school experience peaks at 70%. Common school problems include: not paying attention; incomplete homework; can't get along with peers; disruptive in class; disobeying school rules; talking back to the teacher; fighting; and truancy.
- * Trouble with the Law (involvement with police, charged or convicted of crime), was experienced by 42% of those in the study, and by about 60% of those age 12 and over. The most common first criminal behavior reported was shoplifting. The most common crimes committed (by almost half of individuals with FASD age 12-20) were crimes against persons (theft, burglary, assault, murder, domestic violence, child molestation, running away), followed by property damage; possession/selling; sexual assault; and vehicular crimes.

- * **Confinement** (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime), experienced by 60% of those age 12 and over. Over 40% of adults with FASD had been incarcerated; about 30% of adults with FASD were confined to a mental institution; and about 20% had been confined for substance abuse treatment.
- * Inappropriate Sexual Behavior was reported in 45% of the those age 12 and over, and 65% of adult males with FAE. This includes only sexual behaviors that had been repeatedly problematic or for which the individual had been incarcerated or treated. It is thought that the actual incidence of inappropriate sexual behavior is much higher, and not always reported by the individual or the family due to embarrassment or fear of being reported to authorities. Problem sexual behaviors most common with FASD include: sexual advances; sexual touching; promiscuity; exposure; compulsions; voyeurism; masturbation in public; incest; sex with animals; and obscene phone calls.
- * **Alcohol/Drug Problems** were experienced by 30% of individuals age 12 and over. Of the adults with FAE, 53% of males and 70% of females experienced substance abuse problems. This is more than 5 times that of the general population.

To determine levels of independence in adulthood, two additional categories were identified for individuals 21 years of age and older (median age 26):

- * Dependent Living was the situation for about 80% of adults with FASD.
- * Problems with Employment were indicated in 80% of adults with FASD.

Only 8% of the individuals in the study had no problem with independent living or employment.

Problems With Parenting: Of the 100 females of childbearing age, 30 had given birth; 40% drank during pregnancy, more than half no longer had the child in their care. Of their children, 30% have been diagnosed with or suspected of having FASD.

Risk Factors: The greatest risk factors associated with secondary disabilities in FAS/FAE are shown by the studies to be:

* IQ over 70 (those with lower IQ's are likely to get more services and intervention)

This means that individuals with FAE are at greater risk than those with FAS.

* **Exposure to violence** (sexual and/or physical abuse), which occurs at rate of 72% of individuals with FASD. Those exposed to violence are four times as likely to exhibit inappropriate sexual behavior.

Protective Factors:

* Early diagnosis is a universal protective indicator for all secondary disabilities. Only 11% of individuals with FASD were diagnosed by age 6. Every effort must be made to attain early diagnoses for children with FAS and FAE.

- * **Eligibility for services** from DD division of state is another strong protective factor. These services are needed by most individuals with FASD, yet most do not qualify.
- * Living in stable home with nurturing parents and minimum of changes in household.
- * **Protection from violence**, from witnessing or being victimized by violence.

Recommendations:

- * Develop statewide diagnostic clinic.
- * Parent/citizen education centers re intervention/services for persons with FASD.
- * Agency representative in fields of Mental health, education, criminal justice system, alcohol/drug abuse treatment, health department.
- * Fund further research.
- * Modify eligibility criteria for DD services, and provide adequate services for those with FASD.
- * Fund and implement long-term residential/job training programs for persons with FASD.
- * Promote prevention programs (education, alcohol abuse treatment, advocacy, birth control).

Citation: Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

Read more about Dr. Streissguth's studies on secondary disabilities in her book:

The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.

 $\underline{www.fasstar.com} \sim this article was updated May 31, 2003$

Centers for Disease Control statement on secondary conditions

FAS Community Resource Center

ORIGINAL ARTICLE

Knowledge, attitudes, and behaviors of health, education, and service professionals as related to fetal alcohol spectrum disorders

Mark E. Johnson · Rebecca Volino Robinson · Staci Corey · Sarah L. Dewane · Christiane Brems · L. Diane Casto

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Abstract

Objectives We explored differences in fetal alcohol spectrum disorders (FASD) knowledge, attitudes, and behaviors across six groups of professionals in key position to provide primary and secondary prevention efforts (physicians, educators, correctional staff, social workers, public health nurses, and substance abuse counselors).

Methods Achieving a 60.1% response rate, 2,292 professionals returned surveys, providing data on basic knowledge of FAS, FASD-associated risks and cognitive deficits, and willingness to confront and recommend treatment to alcohol-consuming pregnant women.

Results Across groups, findings revealed ample FASD knowledge and willingness to confront and recommend treatment to alcohol-consuming pregnant women that increases as consumption becomes more frequent and severe. However, results revealed significant betweengroup differences data that provide valuable guidance for targeted future FASD education efforts.

Conclusions Public health initiatives regarding FASD have been effective in increasing knowledge among a broad range of professionals. However, between-group differences indicate the need for targeted, discipline-specific interventions. These differences highlight the need for

all professional groups to provide a consistent public health message regarding maternal alcohol consumption.

Keywords FAS · FASD · Fetal alcohol spectrum disorders · Fetal alcohol syndrome · Prenatal alcohol · Exposure

Introduction

Recognition of the adverse effects of prenatal alcohol consumption on the fetus is by no means a modern phenomenon. Indeed, such adverse effects of prenatal alcohol consumption have been acknowledged throughout much of written history. For example, Plato recommended that newlywed couples avoid alcohol so "...that the child that is begotten may be sprung from the loins of sober parents" and Aristotle stated, "foolish, drunken or hair-brained women, for the most part, bring forth children like unto themselves, morose and languid." However, it was not until 1968 (Lemoine et al. 1968) that fetal alcohol syndrome (FAS) was first described, and 1973 (Jones and Smith 1973) that diagnostic criteria were established for FAS.

Over the 40 years since FAS was first described, knowledge of negative consequences of prenatal alcohol consumption has increased exponentially. It is now recognized that FAS is but the most severe manifestation of such negative consequences and that there is a wide range of adverse effects on the fetus. This wide range of effects has been described as fetal alcohol spectrum disorders (FASD). It is estimated that up to 10 per 1,000 newborns (1%) experience some adverse effects from prenatal alcohol consumption that may be characterized as an FASD (May and Gossage 2001). Lifetime costs of these disorders

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have been estimated to reach as high as \$9.69 million per individual (Harwood and Napolitano 1985; Lupton 2003).

Given that prenatal alcohol consumption is the leading known cause of preventable birth defects in the United States, considerable efforts have been made to prepare healthcare professionals for FASD prevention efforts. One indicator of the success of such efforts is revealed through surveys of physicians over the years. Specifically, earlier surveys revealed a consistent need for physicians to obtain accurate and current FASD information (Abel and Kruger 1998; Diekman et al. 2000; Nanson et al. 1995). However, more recent surveys have indicated that physicians generally have basic knowledge about FASDs (Elliott et al. 2006; Gahangan et al. 2005; Mengel et al. 2006; Tough et al. 2005). Although similar surveys among allied healthcare providers have been sparser, findings indicate that basic FASD knowledge is relatively widespread among professionals who interact with women at risk of an alcohol-effected pregnancy or individuals experiencing FASD (Brimacombe et al. 2008; Sharpe et al. 2004).

To date, the literature is lacking a systematic comparison of knowledge, attitudes, and behavior across various groups of health and allied healthcare providers that would help inform targeted education programs. By better understanding the distinct needs of diverse professional groups, discipline-specific education and training requirements can be determined and curricula and training programs can be tailored to address gaps in knowledge and variations in attitudes and behavior. The purpose of this study was to explore differences in FASD-related knowledge, attitudes, and behavior across six groups of professionals, namely physicians, educators, correctional staff, social workers, public health nurses, and substance abuse counselors, who are in key positions to provide primary and secondary FASD prevention efforts to pregnant women and women of childbearing age.

Methods

Participants

Of the approximate 4,000 professionals across the state of Alaska who were approached to participate in the study, 165 were ineligible, 1,523 were nonrespondents, and 2,292 completed the survey, for an overall participation rate of 60.1%. The professional groups included in the final sample and corresponding response rates were 509 corrections personnel (65.1% response rate), 33 OB/GYNs (48.5% response rate), 61 pediatricians (59.8% response rate), 149 family physicians (48.2% response rate), 105 public health nurses (84.0% response rate), 340 social workers (61.5% response rate), 320 substance abuse

counselors (64.4% response rate), and 775 educators (56.2% response rate).

Instrumentation

Knowledge, attitudes, beliefs, and behavior survey (KABB)

As part of a prevention project funded by the State of Alaska and the Substance Abuse and Mental Health Services Administration, the KABB survey was developed to assess knowledge about FASD, attitudes about primary and secondary prevention, beliefs about alcohol consumption during pregnancy, and behavior related to FASD-related care. Included in the survey are 28 core questions, seven demographic questions tapping similar concepts but specific to each professional group, two open-ended questions, and five to nine additional profession-specific questions. Specific items can be gleaned from Tables 1, 2, and 3. A copy of the survey is available from the first author. For the purposes of this article, we focused on the 28 items common to all groups. These items were organized into the following five subscales:

- Basic knowledge about FAS risk: Four items assessing basic knowledge about FAS risk using different choice formats depending upon question (i.e., yes/no; 0, 1 to 2, 3 to 4, or 5 or more drinks; and never during pregnancy; first trimester; second trimester; and third trimester). Responses were considered correct if the participant endorsed the appropriate answer.
- General FAS knowledge: Eight items assessing general knowledge about prenatal alcohol exposure and associated disorders, scored on a 4-point likert-scale (1 = strongly agree to 4 = strongly disagree). Responses of strongly agree or agree were considered correct.
- 3. Knowledge about FAS-related cognitive deficits: Six items assessing knowledge related to cognitive deficits associated with prenatal alcohol exposure and FAS, scored on a 4-point likert-scale (1 = strongly agree to 4 = strongly disagree). Responses of strongly agree or agree were considered correct.
- 4. Willingness to confront about alcohol consumption: Five items assessing willingness to talk to a pregnant friend or relative about the effect of different levels of alcohol consumption during pregnancy, scored on a 4-point likert-scale (1 = highly likely to 4 = highly unlikely).
- 5. Willingness to recommend alcohol treatment services: Five items assessing willingness to talk to a pregnant friend or relative about getting professional help for different levels of alcohol consumption scored on a 4-point likert-scale (1 = highly likely to 4 = highly unlikely).

Table 1 Fetal alcohol syndrome knowledge, by professional groups in Alaska, 2006

Percent providing correct response to the following questions about FAS risks Standard Everyal Percentage and Percentage a		Corrections $(n = 480)$ $(\%)$	Physicians $(n = 237)$ (%)	Public health nurses $(n = 105)$ $(\%)$	Social workers $(n = 329)$ $(\%)$	Substance abuse counselors $(n = 308)$	Educators $(n = 743)$ $(\%)$	χ2
easional 91.4 82.7 97.1 94.7 94.1 94.1 94.1 94.1 94.1 94.1 94.1 94.1		nt FAS risks						
astional 80.4 36.2 53.3 71.8 87.5 9	Is it okay for a pregnant woman to have an occasional alcoholic beverage? (percentage answering no)	91.4	82.7	1.76	94.7	94.1	7.16	36.36**
vorman could artificial by the safe during her range of drinks) 85.4 87.2 87.6 88.2 93.4 about 85.5 64.5 81.7 86.3 91.8 r) 85.5 64.5 81.7 86.3 91.8 r) about 85.7 85.3 91.8 sbott 94.2 97.1 92.1 94.7 sbott 94.2 97.1 92.1 94.7 sbott 94.2 92.4 77.9 88.4 spott 94.2 92.4 77.9 88.4 spott 94.2 92.3 92.6 90.0 spott 94.3 90.9 90.9 91.9 spott 94.3 92.0 92.3 92.3 spott 95.1 96.7 92.0	Is it okay for a nursing mother to have an occasional alcoholic beverage? (percentage answering no)	80.4	36.2	53.3	71.8	87.5	71.2	223.11**
during her from the form of the following her states the following states the following states the following states the following states and states the following states the following states and states states and states states are states as following states and states are states as following states are states as following states as following states as following states are states as following states as following states are states a	What do you think is the most alcohol that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering 0 drinks)	83.9	299	87.6	88.2	93.4	82.3	81.24**
about 85.5 81.7 86.3 91.8 82.5 87.2 85.7 85.9 89.7 92.1 94.2 97.1 92.1 94.7 85.1 94.2 97.1 92.1 94.7 10th od 92.3 93.4 98.1 95.0 90.0 10th od 92.3 93.4 98.1 95.3 91.6 10th od 92.4 100.0 98.8 90.9 91.6 10th od 78.4 100.0 98.8 90.9 91.9 10th od 98.4 100.0 98.8 90.9 91.9 10th od 98.4 100.0 99.7 91.9 92.2 10th od 98.4 100.0 92.7 92.8 92.8 10th od 98.2 94.3 92.1 92.8 92.8 10th od 98.1 96.2 93.2 92.8 93.8 10th od 98.1 96.2 94.3 94.3 95	When do you think that a woman could drink during her pregnancy that would probably be safe for her developing baby? (percentage answering never)	86.4	72.4	9.88	90.6	92.2	84.5	54.73**
82.5 87.2 85.7 85.9 89.7 92.1 94.2 97.1 92.1 94.7 85.1 94.2 92.4 77.9 88.4 93.1 99.2 93.3 95.0 90.0 inth defects 96.7 98.4 100.0 98.8 91.6 guancy 96.7 98.4 100.0 98.8 99.7 ohol 78.4 91.4 94.3 90.9 91.9 wledge items 89.7 94.6 95.1 92.0 93.2 wledge items 89.7 94.3 96.7 99.1 97.1 98.4 wledge items 95.1 96.2 93.2 95.8 95.0 95.0 92.5 93.7 96.3 99.1 96.3 95.1 96.5 95.0 92.9	Average % correct across all basic knowledge about FAS risk items	85.5	64.5	81.7	86.3	8:16	82.5	
82.5 87.2 85.7 86.9 89.7 92.1 94.2 97.1 92.1 94.7 85.1 94.2 92.4 77.9 88.4 93.1 99.2 93.3 95.0 90.0 intl defects 96.7 98.4 100.0 98.8 91.6 intl defects 96.7 98.1 96.9 91.6 intl defects 96.7 98.8 90.9 91.9 ignancy 97.1 98.4 100.0 92.7 91.9 wledge items 89.7 94.6 95.1 92.0 93.2 wledge items 89.7 94.6 95.1 92.0 93.2 87.6 89.3 94.3 87.1 92.8 92.8 92.5 91.8 96.2 93.2 92.8 92.8 93.7 96.3 99.1 96.3 93.8 93.8 92.9 92.9 94.3 94.3 95.3 95.0	General FAS knowledge							
92.1 94.2 97.1 92.1 94.7 85.1 94.2 92.4 77.9 88.4 93.1 99.2 93.3 95.0 90.0 builthood 92.3 98.1 95.3 90.0 sirth defects 96.7 98.4 100.0 98.8 99.7 shold 98.4 100.0 98.8 99.7 shold 98.4 100.0 99.7 99.7 wledge items 89.7 94.3 87.1 92.8 wledge items 89.7 94.3 87.1 92.8 syl 96.2 95.1 92.0 92.8 syl 96.2 93.2 95.3 95.8 syl 96.7 99.1 96.5 95.0 syl 96.7 99.1 96.5 95.0 syl 96.3 99.1 96.3 95.0 syl 92.9 94.3 96.3 96.3 syl 92.9	People with FAS have a set of birth defects	82.5	87.2	85.7	85.9	89.7	86.2	9.03
85.1 94.2 92.4 77.9 88.4 93.1 99.2 93.3 95.0 90.0 birth defects 96.7 98.4 100.0 98.8 90.0 birth defects 96.7 98.4 100.0 98.8 90.7 bohol 78.4 91.4 94.3 90.9 91.9 shancy 97.1 98.4 100.0 99.7 92.7 wledge items 89.7 94.6 95.1 92.0 93.2 wledge items 89.7 94.3 87.1 92.8 95.3 wledge items 89.7 94.3 87.1 92.8 95.3 wledge items 89.3 94.3 87.1 92.8 95.3 syl 95.1 96.2 93.2 95.3 95.3 syl 96.7 99.1 96.8 97.8 95.0 syl 92.9 94.3 96.3 95.3 95.8 syl 92.9 94.3 <td>People with FAS have brain damage</td> <td>92.1</td> <td>94.2</td> <td>97.1</td> <td>92.1</td> <td>94.7</td> <td>92.7</td> <td>5.97</td>	People with FAS have brain damage	92.1	94.2	97.1	92.1	94.7	92.7	5.97
untthood 93.1 99.2 93.3 95.0 90.0 pirth defects 96.7 98.4 98.1 95.3 90.0 gianacy 78.4 91.4 94.3 90.9 91.6 gianacy 97.1 98.4 100.0 98.7 91.9 wledge items 89.7 94.6 95.1 92.0 92.7 wledge items 89.7 94.5 92.0 93.2 93.2 wledge items 89.7 94.3 87.1 92.8 93.2 wledge items 89.7 94.3 87.1 92.8 93.2 wledge items 89.7 94.3 87.1 92.8 93.2 wledge items 89.3 94.3 87.1 92.8 93.2 93.2 wledge items 93.7 96.7 99.1 96.5 95.0 95.0 95.0 wledge items 93.7 96.3 99.1 96.3 95.3 95.3 wledge items 94.3	People with FAS are affected physically	85.1	94.2	92.4	9.77	88.4	88.3	41.57**
birth bodd 92.3 93.4 98.1 95.3 91.6 sirth defects 96.7 98.4 100.0 98.8 99.7 guancy 78.4 91.4 94.3 90.9 91.9 sprancy 97.1 98.4 100.0 99.7 99.7 wledge items 89.7 94.6 95.1 92.0 93.2 wledge items 89.7 94.3 87.1 92.8 grad of the street items 89.3 94.3 87.1 92.8 grad of the street items 96.2 93.2 93.2 93.2 grad of the street items 96.7 96.1 97.8 97.8 grad of the street items 96.7 96.7 96.3 95.0 grad of the street items 96.3 96.1 96.3 96.3 grad of the street items 96.3 96.1 96.3 96.3 grad of the street items 96.3 96.3 96.3 96.3 grad of the street items 96.3	People with FAS will outgrow these effects	93.1	99.2	93.3	95.0	0.09	95.2	24.91**
ohol defects 96.7 98.4 100.0 98.8 99.7 ohol guancy 97.1 98.4 100.0 99.7 91.9 97.1 98.4 100.0 99.7 99.7 99.7 99.7 92.8 87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.8 93.7 96.7 99.1 97.1 98.4 97.8 93.1 96.8 97.8 99.1 96.5 95.0 95.0 99.1 96.5 95.0 99.1 96.5 95.0 99.1 96.5 95.0 99.1 96.5 95.0 99.1 97.8 99.1 96.5 95.0 99.1 97.8 99.1 96.5 95.0 99.1 97.8 99.1 97.8 99.1 97.8 99.1 97.8 99.1 97.8 99.1 97.8 99.1 97.8 99.3 99.3 99.3 99.3 99.3 99.3 99.3 99	People with FAS have these effects through adulthood	92.3	93.4	98.1	95.3	91.6	91.6	10.24
ohol 78.4 91.4 94.3 90.9 91.9 guancy 97.1 98.4 100.0 99.7 99.7 wledge items 89.7 94.6 95.1 95.2 93.2 87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.8 97.8 92.9 97.1 96.5 95.0 95.0 92.9 97.1 96.3 95.0 95.0 92.9 97.1 96.3 95.0 95.0 92.9 97.1 96.3 95.0 95.0 92.9 97.7 97.1 96.3 95.3 92.9 97.7 97.3 95.3 95.3	Drinking alcohol during pregnancy can cause birth defects	2.96	98.4	100.0	8.86	2.66	7.86	16.00*
wledge items 99.1 98.4 100.0 99.7 99.7 wledge items 89.7 94.6 95.1 93.2 87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.8 97.8 93.7 96.3 99.1 96.5 95.0 92.9 94.7 97.6 94.3 95.3 92.6 94.7 97.6 94.3 95.5	Currently, the only known cause of FAS is alcohol consumption by a birth mother during her pregnancy	78.4	91.4	94.3	6.06	616	83.1	56.93**
wledge items 89.7 94.6 95.1 92.0 93.2 87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.8 97.8 93.7 96.3 99.1 96.5 95.0 92.9 97.1 99.1 96.3 93.8 92.9 94.7 97.6 94.3 95.5	Fetal alcohol syndrome is preventable	97.1	98.4	0.001	1.66	7.66	7.86	16.77*
87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.1 98.4 93.7 96.7 98.1 96.8 97.8 93.7 96.3 99.1 96.5 95.0 92.9 97.1 99.1 95.3 93.8 92.6 94.7 97.6 94.3 95.5	Average % correct across all general FAS knowledge items	89.7	94.6	95.1	92.0	93.2	8.16	
87.6 89.3 94.3 87.1 92.8 92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.1 98.4 93.7 96.3 99.1 96.5 97.8 92.9 97.1 99.1 96.5 95.0 92.9 97.1 97.6 94.3 95.5	Knowledge about FAS-related cognitive deficits							
92.5 91.8 96.2 93.2 95.3 95.1 96.7 99.1 97.1 98.4 93.7 96.3 99.1 96.5 97.8 92.9 97.1 99.1 96.5 95.0 92.9 97.1 97.6 94.3 95.5	FAS affects a person's motor skills	87.6	89.3	94.3	87.1	92.8	92.8	18.37*
95.1 96.7 99.1 97.1 98.4 93.7 96.7 98.1 96.8 97.8 93.7 96.3 99.1 96.5 95.0 92.9 97.1 99.1 95.3 93.8 92.6 94.7 97.6 94.3 95.5	FAS affects a person's memory	92.5	8.16	96.2	93.2	95.3	97.2	20.34**
93.7 96.7 98.1 96.8 97.8 93.7 96.3 99.1 96.5 95.0 92.9 97.1 99.1 95.3 93.8 92.6 94.7 97.6 94.3 95.5	FAS affects a person's judgment	95.1	1.96	99.1	97.1	98.4	8.96	9.29
93.7 96.3 99.1 96.5 95.0 92.9 97.1 99.1 95.3 93.8 92.6 94.7 97.6 94.3 95.5	FAS affects a person's ability to plan	93.7	2.96	98.1	8.96	97.8	97.4	16.21*
92.9 97.1 99.1 95.3 93.8 92.6 94.7 97.6 94.3 95.5	FAS affects a person's ability to reason	93.7	96.3	1.66	96.5	95.0	8.76	*91.71
92.6 94.7 97.6 94.3 95.5	FAS affects a person's ability to learn	92.9	97.1	99.1	95.3	93.8	98.3	30.95**
	Average % correct across all knowledge about cognitive deficit Items	92.6	94.7	9.76	94.3	95.5	2.96	

FAS fetal alcohol syndrome * p < 0.01; ** p < 0.001

Table 2 Willingness to confront about alcohol consumption, by professional groups in Alaska, 2006

Willingness to confront about alcohol consumption	Corrections $(n = 480)$ $(\%)$	Physicians (n = 237) (%)	Public health nurses (n = 105) (%)	Social workers (n = 329) (%)	Substance abuse counselors $(n = 308)$ (%)	Educators (n = 743) (%)
Percent responding likely or highly likely to the following	lowing question	ons				
Your friend or relative drank 1 or 2 alcoholic beverages during her entire pregnancy	63.4	44.8	74.2	67.8	80.0	54.4
Your friend or relative drank 1 or 2 alcoholic beverages a month during her pregnancy	81.9	79.9	97.1	89.0	90.6	83.1
Your friend or relative drank 1 or 2 alcoholic beverages a week during her pregnancy	89.7	94.2	99.0	96.1	95.0	94.1
Your friend or relative drank 5 or more alcoholic beverages on any one occasion during her pregnancy	92.3	98.5	99.0	97.3	95.6	96.6
Your friend or relative drank 1 or 2 alcoholic beverages a day during her pregnancy	91.9	99.8	99.0	97.9	95.9	96.6

Table 3 Willingness to recommend alcohol treatment services, by professional groups in Alaska, 2006

Willingness to recommend alcohol treatment services	Corrections $(n = 480)$ $(\%)$	Physicians (n = 237) (%)	Public health nurses (n = 105) (%)	Social workers (n = 329) (%)	Substance abuse counselors $(n = 308)$ (%)	Educators (n = 743) (%)
Percent responding likely or highly likely to the followin	g questions				**************************************	
Your friend or relative drank 1 or 2 alcoholic beverages during her entire pregnancy	33.3	14.8	32.3	29.5	46.8	25.4
Your friend or relative drank 1 or 2 alcoholic beverages a month during her pregnancy	60.6	40.8	67.6	58.4	74.6	56.4
Your friend or relative drank 1 or 2 alcoholic beverages a week during her pregnancy	85.4	79.2	97.1	87.8	91.8	85.5
Your friend or relative drank 5 or more alcoholic beverages on any one occasion during her pregnancy	91.9	93.8	96.1	94.9	95.3	92.8
Your friend or relative drank 1 or 2 alcoholic beverages a day during her pregnancy	92.3	97.9	100	98.2	97.1	94.5

Procedures

Potential participants were identified through publicly available lists of corrections personnel, physicians (OB/GYN, family practitioners, and pediatricians), public health nurses, social workers, substance abuse counselors, and educators. A sample of 50% of all front-line staff from each Alaskan correctional institution was approached for participation. All educators were coded based on school location into urban or rural, and a random sample of 1,400 educators (50% urban, 50% rural) was approached for participation. For the other groups, all members were invited to participate.

Survey procedures followed recommendations by Dillman (2000). Specifically, the survey process began with a preletter notifying potential participants that they would soon receive a survey. The preletter was followed 2 weeks

later by the survey packet, including a cover letter, informed consent, survey, and postage-paid envelope. Reminder postcards were sent 2 weeks later to non-participants, followed by a second survey packet mailed 2 weeks later, then by a reminder postcard 2 weeks later, and a final survey 2 weeks later.

Data analyses

Primary data analyses involved comparing responses from targeted professional groups. For all analyses, general physicians, pediatricians, and OB/GYNs were combined, resulting in six groups of Professional Disciplines (i.e., correctional personnel, physicians, public health nurses, social workers, substance abuse counselors, and educators). Separate Chi-square analyses were conducted for each of the knowledge items. Analyses compared proportions of

individuals within the professional groups who answered items correctly. Separate one-way MANOVAs were conducted for two subscales assessing willingness to confront a pregnant friend or relative about the effects of alcohol consumption and willingness to recommend alcohol treatment services to a pregnant friend or relative. For each MANOVA, the independent variable was Professional Discipline; dependent variables were the five items that comprised each subscale. Significant multivariate findings were explored using ANOVA and Duncan's Multiple Range tests.

Results

Of the 2,292 participants, 861 were men and 1,402 were women, and 29 did not provide their gender. Participants' mean age was 46.5 years (SD 10.3) and the average length of time since participants completed their highest degree or certification was 15 years (SD 10.3). Participants reported an average of 14 years of experience in their profession (SD 9.3), with an average of 11 years of this experience (SD 7.9) in Alaska.

Basic knowledge about FAS risk

Table 1 presents the percentage of participants who answered each FAS risk item correctly, by professional group. Overall, the majority of professionals responded correctly to these questions assessing knowledge of when and how much alcohol pregnant and nursing women can safely drink. However, significant between-group differences were revealed on all items (see Table 1 for Chisquare results). For all items, substance abuse counselors had the highest percentage correct, whereas physicians had the lowest. The most discrepant items were the appropriateness of nursing mothers having an occasional alcoholic beverage with 36.2% of physicians answering "no" and 87.5% of substance abuse counselors saying "no".

General FAS knowledge

Table 1 presents the percentage of participants who answered each general FAS knowledge item correctly, by professional group. Correct responses were determined based on clinical guidelines for physicians that state there is no known safe amount of alcohol consumption during pregnancy or breastfeeding (American Academy of Pediatrics 2005; American College of Obstetricians and Gynecologists 2006). The vast majority of professionals in all groups correctly answered each of these items. Indeed, the average percentage of correct answers across all items ranged from 89.7% for corrections personnel to 95.1% for

public health nurses. Significant between-group differences were revealed for five of the eight knowledge items (see Table 2 for Chi-square results). Most of these differences are accounted for by corrections personnel having a lower percentage or physicians and public nurses having higher percentages.

Knowledge about FAS-related cognitive deficits

Table 1 presents the percentage of participants who answered each knowledge item about FAS-related cognitive deficits item correctly, by professional group. Overall, the vast majority of professionals in all groups correctly answered each of these items. The average percentage correct across all items ranged from 92.6% for corrections personnel to 97.6% for public health nurses. Significant between-group differences were revealed for five of the six items (see Table 3 for chi-square results). Most of these differences were accounted for by corrections personnel having a lower percentage correct or public health nurses having a higher percentage correct.

Willingness to confront about alcohol consumption

As illustrated by Fig. 1, across all groups, professionals become increasingly willing to confront a pregnant friend or relative about the effects of alcohol as consumption becomes more frequent and severe. In other words, when consumption is 1 or 2 alcoholic beverages during the entire pregnancy, most professionals are somewhat likely to confront. However, when consumption is 5 or more beverages on one occasion or 1 or 2 beverages daily, most professionals are highly likely to confront.

Results of a one-way MANOVA revealed significant between-group differences, F(25, 8048) = 5.81, p < 0.001. Univariate differences were revealed on four of five items, with binge drinking being the exception. Post hoc tests revealed that for 1-2 beverages throughout entire pregnancy, physicians and educators were less likely to confront than all other groups; and corrections personnel and social workers were less likely to confront than substance abuse counselors. For 1-2 beverages per month, physicians were less likely to confront than all other groups; and educators and corrections personnel were less likely to confront than substance abuse counselors and public health nurse. For 1-2 beverages per week, corrections personnel were less likely to confront than substance abuse counselors and public health nurses. For 1-2 beverages per day, corrections personnel were less likely than physicians and public health nurses. Table 2 provides the percentage of participants in each professional group who were likely or highly likely to confront about alcohol consumption.

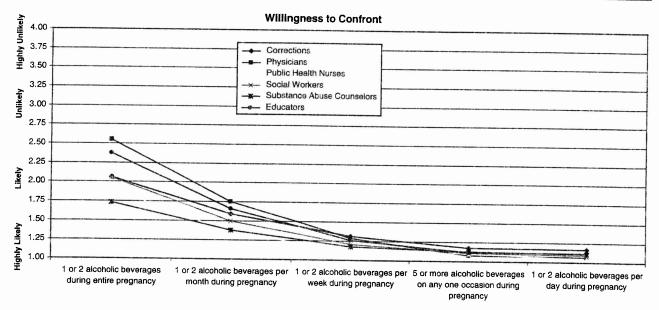


Fig. 1 Willingness to confront a pregnant friend or relative about their alcohol consumption, by different levels of consumption and professional groups in Alaska, 2006. Scale ranges from 1 (highly likely to confront) to 4 (highly unlikely to confront)

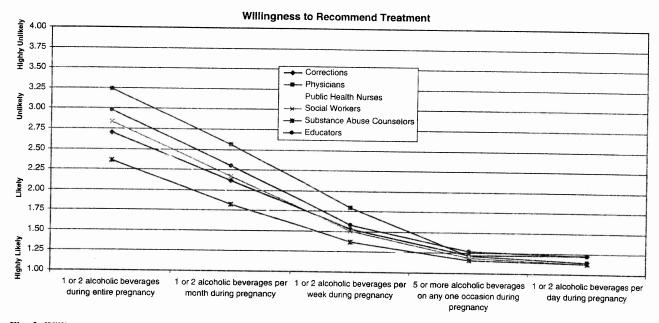


Fig. 2 Willingness to recommend that a pregnant friend or relative seek professional help for their alcohol consumption, by different levels of consumption and professional groups in Alaska, 2006. Scale ranges from 1 (highly likely to recommend) to 4 (highly unlikely to recommend)

Willingness to recommend alcohol treatment

As illustrated by Fig. 2, across all groups, professionals become increasingly willing to recommend alcohol treatment to a pregnant friend or relative as consumption becomes more frequent and severe. In other words, when the consumption is 1 or 2 alcoholic beverages during entire pregnancy, most professionals are unlikely to recommend treatment. When consumption is 5 or more beverages on

one occasion or 1 or 2 beverages daily, most are highly likely to recommend treatment.

Results of the one-way MANOVA revealed significant between-group differences, F(25,7929)=7.53, $p<0.001^{1}$. Post hoc tests revealed that for 1–2 beverages throughout the entire pregnancy, physicians were less likely to

Full results, including means and standard deviations are available from the first author.

recommend treatment than all other groups; educators, social workers, and public health nurses were less likely to recommend than substance abuse counselors; and substance abuse counselors were more likely to recommend than all other groups. For 1-2 beverages per month, physicians were less likely to recommend treatment; educators and social workers were less likely to recommend than corrections, public health nurses, and substance abuse counselors; and substance abuse counselors were more likely to recommend treatment than all other groups. For 1-2 beverages per week, physicians were less likely to recommend treatment than all other groups; educators, social workers and corrections personnel were less likely to recommend than substance abuse counselors and public health nurses. For 1-2 beverages per day, educators and corrections personnel were less likely than public health nurses to recommend treatment. Table 3 provides the percentage of participants in each professional group who were likely or highly likely to recommend alcohol treatment.

Discussion

This study represents the first systematic investigation of FASD-related knowledge, attitudes, and behavior among professionals from various disciplines that are likely to encounter women at risk for an alcohol-exposed pregnancy or individuals who experience FASD. Across all groups, the findings revealed ample knowledge about FASD, risks associated with consuming alcohol during pregnancy, and the potential effects of prenatal alcohol exposure. Professional discipline aside, participants' willingness to confront a pregnant friend or relative about alcohol consumption, and willingness to recommend alcohol treatment to a pregnant friend or relative for alcohol consumption, increased as consumption became more frequent and severe. All findings point to the effectiveness of efforts to inform professionals about FASD. However, results revealed significant between-group differences, differences that may provide valuable guidance for future FASD education efforts.

Differences in general FAS knowledge and FAS-related cognitive deficits

Across all groups, general FAS knowledge and knowledge about FAS-related cognitive deficits was ample, with most professional groups evidencing at least an average of 90% correct. Significant between-group differences revealed that correctional personnel had significantly lower knowledge and public health nurses had significantly higher knowledge. Relative to correctional personnel, the impact of this lower level of knowledge may be critical as many

high-risk individuals have contact with the correctional system (Burd et al. 2004; Streissguth et al. 1996) and overall prevalence of FASD is higher in correctional settings than in the general population (Burd et al. 2004). The cognitive deficits associated with FASD, including impaired judgment, memory problems, and difficulty in planning may contribute to individuals' involvement with the correctional system and limit their ability to follow rules and regulations set forth by this complex system. Furthermore, women who are incarcerated experience increased rates of substance use and abuse (Fazel et al. 2006), placing them at a greater risk of having an alcoholexposed pregnancy.

Given their high level of contact with women at risk of alcohol-exposed pregnancies and individuals with FASD, correctional personnel are in an ideal position to educate women on the effects of prenatal alcohol exposure and advocate for prevention and intervention efforts, such as substance abuse treatment services. A recent study on the knowledge and attitudes of criminal justice professionals about FASD revealed that these professionals desire more education and training related to FASD to support their work with alcohol-affected individuals (Cox et al. 2008). Tailored training aimed at increasing knowledge of corrections personnel to support efforts aimed at FASD identification, prevention, and intervention within the criminal justice system.

Knowledge about FAS risk

Relative to differences in knowledge about FAS risk, findings revealed significant between-group differences, with physicians having the lowest scores on four of six items. For example, 17.3% of physicians endorsed occasional alcoholic beverage consumption during pregnancy. These findings represent a discrepancy between physicians' responses and the predominant public health message that states, "A pregnant women should not drink alcohol during pregnancy" (State of Alaska Office of FAS 2005). The findings are also contrary to clinical practice guidelines that state there is no known safe amount of alcohol consumption during pregnancy (American College of Obstetricians and Gynecologists 2006). Further, 63.8% of physicians endorsed occasional use of alcohol by nursing mothers, a stance that is inconsistent with the recommendations of the March of Dimes and the American Academy of Pediatrics (2005). On the other hand, public health nurses and substance abuse counselors' responses were congruent with both these abstinence messages.

Findings regarding physician's incongruence with predominant public health messages about FASD are particularly important given that physicians are uniquely positioned to educate women of childbearing age about

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alcohol consumption during pregnancy. Inconsistent messages regarding prenatal alcohol use may thwart prevention efforts, especially when the message comes from physicians who are typically considered the pre-eminent authorities on health-related issues. It should be noted that the issue of prenatal alcohol exposure is complex and the disorder does not fit into a simple cause-effect model (Maier and West 2001). Physicians' responses may represent more nuanced thinking about the effects of prenatal alcohol exposure than lack of knowledge. However, inadequate instructions regarding the hazards associated with prenatal alcohol exposure may also account for physicians' responses. For example, a recent review of obstetrical textbooks found that only 24% of the texts published since 1990 recommended abstinence from alcohol throughout the course of pregnancy (Loop and Nettleman 2002). According to Mengel and colleagues, FASD-related training in medical schools tends to focus on identification of clinical features of FASD, with limited guidelines related to primary and secondary prevention (Mengel et al. 2006). Further, only 28% of postgraduate physicians reported being trained on FASD-screening and diagnosis and only 50% received training about screening for risky drinking behavior (Gahangan et al. 2005).

Willingness to confront and to recommend treatment

Across all professional groups, individuals were more likely to confront a friend or relative about alcohol consumption during pregnancy or to recommend substance abuse treatment as drinking became more frequent and severe. Indeed, for both daily drinking of 1 or 2 and binge drinking of 5 or more alcoholic beverages, professionals across all groups were highly likely to confront and recommend treatment. However, significant between-group differences were revealed. The most consistent finding was that, for lower levels of alcohol consumption, physicians were less likely than other professionals to confront or recommend treatment. These findings are inconsistent with referral guidelines for prenatal alcohol consumption (Bertrand et al. 2004). It is unclear whether this inconsistency represents a more nuanced understanding among physicians of risks associated with prenatal alcohol consumption, an increased likelihood that physicians facilitate brief interventions themselves, or misinformation. Future research is needed to clarify these findings.

Limitations

Some limitations of this study should be considered when interpreting these findings. Regarding instrumentation, the KABB survey asked participants to answer questions based on opinions and asked participants to answer questions

related to behavior with friends and relatives. Therefore, it is possible that results do not accurately represent practice behavior. However, past research on knowledge, attitudes, beliefs, and behavior among specific professional disciplines revealed similar results (Elliott et al. 2006; Sharpe et al. 2004; Tough et al. 2005). It is likely, therefore, that FASD-related attitudes and behavior do cross over into professional practice. Regarding statistical analyses, the large sample size resulted in small between-group mean differences that may demonstrate statistical, but not clinical, significance. Finally, this study only surveyed professionals in Alaska, a state with relatively high FASD rates and a history of considerable statewide education and prevention efforts (State of Alaska Office of FAS 2005). Although findings are consistent with those reported in other surveys, future research is needed in other US regions.

Conclusion

Given that adverse effects of prenatal alcohol consumption have only been recognized in the scientific literature for 40 years, findings indicate that public health initiatives and efforts to publicize information regarding this hazard has reached deeply into the awareness of professionals. However, despite increased knowledge and awareness, data show that 12.2% of women report drinking alcohol during pregnancy and 2% report binge drinking during pregnancy (Denny et al. 2009; Tsai and Floyd 2004). Professional groups surveyed in this study are ideally positioned to implement FASD prevention and intervention strategies to increase awareness of this critical public health issue. The need for targeted, discipline-specific interventions aimed at closing gaps in knowledge and behavior are evident in these data. Such interventions could increase the role of each discipline in FASD prevention and intervention efforts, greatly advancing this important endeavor. Providing a consistent public health message regarding prenatal alcohol consumption across all professional groups is essential for FASD prevention and intervention efforts. Gaining buy-into a consistent public health message across professional groups may prove to be more challenging than disseminating knowledge. One avenue for increasing communication about FASD prevention and intervention may be clinical messaging, an electronic system for securely delivering medical information. Using such emerging technologies may prove to be a powerful adjunct to the existing public health avenues for educating healthcare professionals about the consequences of prenatal alcohol exposure or for prompting professionals to screen for alcohol use with women who may be at risk of an alcohol-exposed pregnancy.

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Conflict of interest The authors declare that they have no competing interests.

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